COMMONWEALTH of VIRGINIA

Department for the Aging

Jay W. DeBoer, J.D., Commissioner

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COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: Ellen Nau, Human Services Program Coordinator

DATE: June 2, 2003

SUBJECT: **Key Policy Issues in Long-Term Care** – World Health Organization, Geneva

The concern over long-term care is not limited to the United States. The World Health Organization is producing a series of publications addressing the following topics: long-term care in developing countries: ten country case-studies; long-term care strategies in industrialized countries: case-studies of countries with and without national LTC legislation; framework for guiding the development of long-term care policies in developing countries; ethical choices in long-term care: what does justice require and, a long-term care "Futures tool kit".

Key Policy Issues in Long-Term Care is the first document in the WHO series. It reviews the experiences of certain industrialized nations with long-term care policy issues. The 292 page document is now available on the WHO web site:

http://www.who.int/ncd/long_term_care/index.htm

http://www.who.int/chronic_conditions/en/ The Adobe PDF of the document is attached.

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The key policy issues which confront the theory and the practice of long-term care are diverse and complex. As the numbers of persons needing such care continue to increase, these issues become critical.

This volume, another in the World Health Organization Collection on Long-Term Care, addresses many of these issues. Included are the role of and support to the family, integration with health and social systems, case management, human resources,quality assurance, and choosing strategies for designing LTC systems. Recognized experts provide a comprehensive overview of these and related topics.

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LONG-TERM CARE *KEY POLICY ISSUES* WORLD HEALTH ORGANIZATION

World Health Organization
Collection on Long-Term Care

KEY POLICY ISSUES IN LONG-TERM CARE

Editors: J. Brodsky, J. Habib, and M. Hirschfeld

**The Cross-Cluster Initiative on Long-Term Care
World Health Organization
Geneva**

and

**The WHO Collaborating Centre for Research on Health of the Elderly
JDC-Brookdale Institute**

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This publication can be found on the WHO web site:

http://www.who.int/ncd/long_term_care/index.htm

http://www.who.int/chronic_conditions/en/

i Preface

Demographic and epidemiological transitions will result in dramatic changes in the health needs of the world's populations. Everywhere, there is a steep increase in the need for long-term care (LTC).

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 growing need for LTC policies is generally associated with industrialized countries. What is less widely acknowledged is that long-term care needs are increasing in the developing world at a rate that far exceeds that experienced by industrialized countries. 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.

Therefore, the search for effective LTC policies is one of the most pressing challenges facing modern society. Recognizing that such trends greatly increase the need for well coordinated and cost-effective LTC, the World Health Organization (WHO) launched a global initiative, with the JDC-Brookdale Institute leading this effort.

The goal of the project is to prepare a practical framework for guiding the development of long-term care policies in developing countries. This framework will address the major issues and alternatives in designing LTC systems. 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.

This process is based on a number of major premises:

- Previous efforts have not been successful in identifying meaningful policy guidelines that are appropriate to the unique situations of developing and middle-income countries.
- A key resource in formulating LTC policies for developing countries is their own existing experience.
- LTC policies in the developing world need to reflect each country's unique conditions, which have to be understood in much more depth and complexity.
- 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.
- 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 course of the project, a number of steps have been taken to promote exchange of experience. 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 and 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 LTC policies that address the needs of policy-makers.

In December 1999, a meeting of a group of LTC 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), and ratified by the 54th World Health Assembly in May, 2001.

One lesson from this workshop was 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 with these experts 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 ten developing countries were written by local health care experts (People's Republic of China, Costa Rica, Indonesia, Lebanon, Lithuania, Mexico, Republic of Korea, Sri Lanka, 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. These include:

- The role of the family and informal care, and mechanisms to support the family.
- Issues of coordination among various LTC services, and of LTC with the health and social service systems.
- Human resource strategies in delivering LTC.

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, *Bridging the Limousine – Train – Bicycle Divide*, 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 report from the meeting, entitled *Lessons for Long-Term Care Policy* (WHO/NMH/CCL/02.1), gives 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.

In parallel, work proceeded on developing estimates of current and future LTC global needs. R. H. Harwood and A. A. Sayer analysed the 1990 WHO Global Burden of Disease data and prepared estimates for all WHO Member States. These estimates are published on the WHO web site http://www.who.int/ncd/long_term_care/index.htm and summarized in a report, *Current and future long-term care needs* (WHO/NMH/CCL/02.2).

Another complementary area of work relates to family caregiving in countries with high HIV/AIDS prevalence. E. Lindsey conducted several qualitative studies, focusing on Community Home-Based Care and its effects on young girls and older women. She summarized the findings from studies in Botswana, Cambodia, Haiti, Kenya, Thailand and South Africa in a guideline entitled *Community Home-Based Care in Resource-Limited Settings: A Framework for Action* (ISBN 92 4 156213 7, WHO, Geneva, 2002). The theoretical framework for this guideline had been developed by JDC-Brookdale for the analysis of LTC laws in five industrialized countries. One additional area of work relates to ethical responsibilities in LTC and the ethical discussion countries need to initiate as input into the determination of the priority of LTC and the considerations in designing fair and just policies.

This volume is the first in a series of publications addressing the following topics:

- Key policy issues in the design of long-term care: a review based on the experience of industrialized countries (this volume).
- Long-term care in developing countries: ten country case-studies.
- Long-term care strategies in industrialized countries: case-studies of countries with and without national LTC legislation.
- Framework for guiding the development of long-term care policies in developing countries.
- Ethical choices in long-term care: what does justice require?
- A long-term care ‘Futures tool kit’.

In order to consider this volume within the broader context, we paraphrase from the Director-General's *World Health Report 2000*,*

> Health care (and long-term care) can be catastrophically costly. Much of the need for care is unpredictable, so it is vital for people to be protected from having to choose between financial ruin and loss of health . . . . The other peculiarity of health is that illness itself . . . can threaten people's dignity and their ability to control what happens to them . . . .
>
> Health systems have a responsibility not just to improve people's health, but to protect them against the financial cost of illness . . . reducing the damage to one's dignity and autonomy, and the fear and shame that sickness often brings with it – and to treat them with dignity . . . .

In accordance with these goals, countries need to address long-term care as they further develop and reform their health and welfare systems.

*WHO (2000), *The World Health Report 2000 Health Systems: Improving Performance*, pages 8, 24. Geneva, World Health Organization.

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iii Abbreviations

ADL	Activities of daily living
AWBZ	Exceptional Medical Expenses Act (The Netherlands) (in Dutch, *Algemene Wet Bijzondere Ziektekosten*)
IADL	Instrumental activities of daily living
IPA	Independent Practice Association, a type of HMO
ICF	International Classification of Functioning, Disability and Health
CSHSC	Center for the Study of Health System Change
GBD	The Global Burden of Disease
GNP	Geriatric Nurse Practitioner
GP	General practitioner
HIV	Human Immunodeficiency Virus
HMO	Health Maintenance Organization
MDS	Minimum Data Set
MRC	Medical Research Council (United Kingdom)
MSHO	Minnesota Senior Health Options programme
NRV	National Public Health Council (The Netherlands) (in Dutch, *Nationale Raad voor de Volksgezondheld*)
PAC	Post Acute Care
PACE	Program for All-inclusive Care of the Elderly
RAI	Resident Assessment Instrument

RAPs	The Resident Assessment Protocols
RIO	Regional Assessment Organization (The Netherlands) (in Dutch, *Regionaal Indicatie Orgaan*)
RUG	Resource Utilization Groups
SDI	Social Dependency Insurance (Germany)
SHMO	Social Health Maintenance Organization
SWO	Welfare Services for Older People (The Netherlands) (in Dutch, *Stichting Welzijn Ouderen*)
UNDP	United Nations Development Programme
WPP	Wisconsin Partnership Program

iv Acknowledgements

The World Health Organization gratefully acknowledges the crucial scientific and technical leadership of the JDC-Brookdale Institute, Jerusalem, a WHO Collaborating Centre, in guiding the WHO Long-Term Care Policy Initiative and in preparing this volume. The special contributions of Jack Habib, Jenny Brodsky, and Ben Siegel are most appreciated.

WHO also gratefully acknowledges the authors of the chapters included in this volume: Joshua Wiener of The Urban Institute in Washington, DC, USA; Marja Pijl, an independent researcher in The Hague, The Netherlands; Robert L. Kane of the University of Minnesota School of Public Health in Minneapolis, USA; Dennis L. Kodner, of the Wagner Graduate School of Public Service at New York University, USA; David Challis of Manchester University in the United Kingdom; Rosalie A. Kane of the University of Minnesota School of Public Health in Minneapolis; Itziar Larizgoitia of the Department of Health Services Provision at the World Health Organization in Geneva, Switzerland; Jenny Brodsky, Jack Habib, Ben Siegel, and Yael Rockoff of the JDC-Brookdale Institute in Jerusalem, Israel; and Miriam J. Hirschfeld, Director of the Cross-Cluster Initiative on Long-Term Care at the World Health Organization in Geneva, Switzerland.

Another in the ***WHO Collection on Long-Term Care***, this document was produced and edited under the direction of Miriam J. Hirschfeld. The manuscripts in this volume were language edited and formatted, and the WHO Collection on Long-Term Care was designed, by Anne Bailey and Ross Hempstead of Creative Publications.

V Introduction

This volume focuses on selected major issues in designing long-term care. These issues represent significant opportunities for learning from the experience of industrialized countries. It was prepared by leading experts in long-term care to promote a more systematic effort to learn from the experience of the industrialized world in the framework of the WHO Long-Term Care Initiative, described in the Preface to this volume.

There are a large number of design issues that need to be addressed when developing a LTC system. Within the framework of this project, J. Habib and J. Brodsky developed a classification of these key issues to analyse available policy alternatives and identify factors relevant to the choice among them. Some major design issues include: the relative priority of LTC among other needs; which LTC services should be prioritized; state vs. family responsibility; service delivery strategies; nature of entitlements, targeting and financing; strategies for achieving integrated or coordinated care; human resource strategies; provision of LTC by government, nongovernmental organizations and for-profit organizations; role of voluntarism and community organizations.

The resolution of this set of issues adds up to an overall LTC policy, and determines the degree to which LTC needs are addressed. There is a need to analyse each of these design elements separately, and to better understand the interaction between them.

This volume focuses on five issues.

- The role of the family and informal care, and mechanisms to support the family (Chapters 1–2).
- Issues of coordination among various LTC services, and of LTC with the health and social service systems (Chapters 3–5).
- Human resource strategies in delivering LTC (Chapter 6).
- Approaches to evaluating LTC systems (Chapter 7).
- Approaches to designing overall LTC strategies (Chapter 8).

The first three deal with specific design issues, and the final two address the LTC system as a whole. On each issue, the authors present a conceptual framework for understanding the issue, reflect on the major considerations for its resolution, and provide selected examples from the experience in industrialized countries.

1. The role of the family and informal care, and mechanisms to support the family. Chapters 1 and 2, written by Joshua Wiener and Marja Pijl, respectively, discuss the role of the family in providing LTC and mechanisms to support the family in this role. The papers in these chapters complement each other in their focus and also in the range of experience presented from industrialized countries.

According to Joshua Wiener, despite the development of formal services, care by the family and other informal carers is by far the dominant form of care throughout the world. However, there are many questions regarding the possibility and desirability of informal care maintaining such a large share of caregiving responsibilities as LTC needs rapidly increase.

Thus, a particularly critical issue is the balance of responsibility between society and the family. Many long-term care policy issues revolve around whether the individual, the family, or society, should be responsible for providing and caring for persons with disabilities. Does the primary responsibility for care belong with individuals and their families, and should governments act only as a payer of last resort for those unable to provide for themselves? Or – on the contrary – is long-term care primarily a societal responsibility and therefore public support should play a larger role? The resolution of this issue determines who should receive assistance and how much.

Some additional policy issues raised in these papers include 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.

The papers also discuss the types of assistance that various governments have provided to aid informal caregivers, such as education, training, and counselling of families; respite care; laws guaranteeing unpaid leave if they have to care for sick relatives; and various forms of direct financial support.

2. Issues of coordination among various LTC services, and of LTC with the health and social service systems. Chapters 3, 4, and 5, written by Robert Kane, Dennis Kodner, and David Challis, respectively, address the complex issues of coordination/integration among various LTC services, and of LTC with the health and social service systems.

The paper by Robert Kane particularly focuses on the possibility of integrating long-term care with preventive, acute, and chronic health care, and is based on the North American experience. Kane emphasizes the fact that integrating funding streams is necessary but not sufficient to achieve integrated care.

Successful integration requires a major reorganization of the programmatic infrastructure, which can then be reinforced by funding approaches. One of the major obstacles raised by Kane is that health systems are built upon an acute disease model that is not appropriate to addressing long-term care needs. Kane provides a review of the experience in the United States with programmes aimed at providing integrated care.

Dennis Kodner's paper describes and analyses the fragmentation that exists in most LTC systems, classifies the major integrating/coordinating strategies, and provides a review of the experience of several European countries in addressing this issue.

The paper prepared by David Challis provides a comprehensive review of case management, one of the principal coordinating strategies developed in the past two decades in industrialized countries. According to Challis, case management has a central role as the mechanism designed to achieve a shift from institutional provision to home-based care.

3. Human resource strategies in delivering LTC. Chapter 6, written by Rosalie Kane, analyses some of the major decisions related to human resource policy. Kane discusses the types of human resources that a country requires to provide long-term care based on the experience of industrialized countries. She presents principles for deciding on the various types of personnel needed in particular care settings based on the kind of skill and abilities required.

Some major issues discussed include the level of formal requirements and training for different tasks; the need for a specialized versus 'generic' staff to provide LTC (i.e. those providing general health and social services); and appropriate working conditions for the development of a LTC workforce.

4. Approaches to evaluating LTC systems. Chapter 7, written by Itziar Larizgoitia, provides a conceptual framework to analyse the performance of LTC systems in meeting their goals. Using the WHO framework for assessing the performance of health systems, Larizgoitia argues that in order to isolate the contribution of long-term care, it is necessary to identify the specific subset of health and responsiveness outcomes which are a direct consequence of, or directly attributable to, the long-term care received. The paper explores some specific LTC outcomes and examines the implications for quality assurance mechanisms.

5. Approaches to designing overall LTC strategies. Chapter 8, an overview written by JDC-Brookdale staff, represents an effort to go beyond the discussion of specific design issues to present broad paradigms of alternative systems that combine in various ways the resolution of these specific issues. It attempts to address the complexities of the policy-making process by considering the following broad questions. Is it possible to reduce the broad range of LTC policy design issues to a smaller number of major overall policy strategies? Is it possible to suggest key starting points in developing an overall strategy? What are the key interdependences in the resolution of LTC issues and how do they play a role in defining alternative overall strategies?

The paper argues that in specifying alternative strategies it is necessary to distinguish between design issues that are more primary, and those that are more derivative in defining overall policy strategies. It discusses principles of eligibility, service integration, and the interaction between these two aspects of LTC policy design.

We hope that the richness of the material presented in this volume will be useful for the development of LTC policy in both industrialized and developing countries alike.

Part one

THE ROLE OF AND SUPPORT TO THE FAMILY

CHAPTER 1

THE ROLE OF INFORMAL SUPPORT IN LONG-TERM CARE

Joshua M. Wiener

CHAPTER 2

THE SUPPORT OF CARERS AND THEIR ORGANIZATIONS IN SOME NORTHERN AND WESTERN EUROPEAN COUNTRIES

Marja Pijl

1 THE ROLE OF INFORMAL SUPPORT IN LONG-TERM CARE, *Joshua Wiener*

1 Introduction

Informal care – unpaid care by relatives and friends – is the dominant form of care of disabled persons throughout the world, despite the considerable burdens that it places on those who do it. Paid services, either at home or in institutions, play a relatively small role, except in a few countries. 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. Modern society – especially with its trend towards smaller families, greater longevity, separate and more independent living situations for older people, greater freedom for women, and workplaces that are separate from home – places strain on the traditional mechanisms of providing unpaid care.

Thus, 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. This paper presents background information on informal care, describes the services and other support that governments and private agencies provide to family caregivers, analyses issues raised by public support of informal caregivers, and discusses some of the implications of these issues.

2 Background

While there is a widespread belief that modern families in industrialized countries have abandoned their disabled relatives, informal care is by far the most prevalent form of long-term care and dwarfs the provision of care in nursing homes and by paid home care workers. In fact, because of increased longevity, the lifetime risk of having to care for a disabled parent is much higher now than it was fifty years ago.

In a review of the data on the non-institutional population in ten developed countries, Sundstrom (1994) found the vast majority of primary caregivers to be family members in Australia, Finland, Germany, Japan, the Netherlands, New Zealand, Sweden, the United Kingdom, and the United States. Only in Denmark were paid home care workers a major source of primary caregivers, and even there the family was the primary caregiver in a majority of cases. In the United States in 1994, 94% of all disabled elderly in the community received at least some informal care (Spillman & Pezzin, 2000).

Spouses and adult children, especially daughters and daughters-in-law, are the most common informal caregivers. In the United States in 1994, a spouse or adult child provided some care to 80% of the disabled elderly persons in the community receiving informal care (Spillman & Pezzin, 2000). Among disabled older people with spouses or adult children, almost half of primary informal caregivers were spouses and almost half were children; other relatives and non-relatives played a very small role in providing informal care. Daughters were over twice as likely as sons to be primary caregivers; overall, almost two-thirds of primary caregivers were women.

In England, most caregivers are women, as in the United States; however, caregivers appear more likely to be under the age of 65 than in the United States (United Kingdom Department of Health, 2000). Most elderly in Japan live with their sons (if possible) and care of elderly disabled persons is traditionally the responsibility of the daughter-in-law (Campbell & Ikegami, 2000).

Caregiving is difficult, but when it is required families almost always do what is necessary to care for their disabled relatives, resorting to institutions mostly when the burden becomes too great. Lack of family and informal care are major predictors to use of nursing home care. In many countries, home care is increasingly helping to meet the needs of community-based disabled persons.

Informal caregivers take on these caregiving tasks for many different reasons:

- There is a sense of family obligation, that families take care of each other and that blood relationships are the most important ties that exist.
- In many societies, there is a tradition of care for parents and other relatives when they are older. Informal care is the way that care for the disabled elderly has always been handled.
- In some societies, the principal alternative to informal care is primarily institutional care, especially nursing homes, which have a reputation of poor quality care. Families continue to provide care because they do not want to place their relatives in these facilities.
- Caregiving may provide a number of personal satisfactions, such as feeling useful and needed, feeling a sense of accomplishment, having the opportunity to express love for the disabled relative, experiencing satisfaction that one has fulfilled one's responsibilities, feeling appreciated by family members and the disabled relative, and altruistic feelings that one has done all one can (Toseland & Smith, 2001).

Again, despite these positive aspects, much research and public policy emphasize the burden it imposes. Prolonged caregiving has negative effects on the emotional health and perhaps physical health of caregivers, even when it is voluntarily undertaken and a source of personal satisfaction (Whitlatch & Noelker, 1996; Zarit, Reever & Bach-Peterson, 1980). The physical health of family caregivers to the frail elderly may deteriorate, with such changes as interrupted sleep, chronic fatigue, muscle aches, and irregular eating (Toseland, Smith & McCallion, 2001).

In a study in the United Kingdom, about half of caregivers had suffered a physical injury, such as a strained back, since they began to care. About half had been treated for a stress-related illness since becoming caregivers (Henwood, 1998). Despite the widespread perception that the strains and burdens of caregiving result in increased health problems, the evidence as to whether caregivers suffer proportionately more physical problems than other people of the same age is not conclusive (Neundorfer, 1991; Schulz, 1995; United Kingdom Department of Health, 2000).

Psychological health appears to be the aspect of the informal caregiver's life that is most affected by caring. As compared to the general population, primary caregivers are frequently depressed and anxious, are more likely to use psychotropic medications, and have more symptoms of psychological distress (Neundorfer, 1991; Schulz et al., 1995; Schulz & Williamson, 1994; Schulz, 2000; Toseland & Smith, 2001). Depression appears to be the most common disorder, with 20 to 50% of caregivers reporting depressive disorders or symptoms (Butler, 1992; Schulz et al., 1995; Schulz, 2000).

3 Supports for informal caregivers

Public and private programmes provide a number of supports for informal caregivers, although few countries focus on the caregiver in their long-term care policies. These supports include information and training, respite care, tax benefits and payments, and regulation of businesses and initiatives by private organizations.

An underlying premise of many of these programmes is that the provision of such services or cash payments to informal caregivers will enable them to do a better job, that they will experience less stress, and that they will be able to provide care for a longer period of time.

3.1 Education and training, counselling and support

Informal caregivers typically come to this role without knowing a great deal about:

- how care should be provided;
- how to navigate an often-complicated financing and delivery system;
- the likely course of disability and illnesses;
- how to cope emotionally with the strains of caring for a highly disabled individual.

To aid informal caregivers, many countries provide some sort of education and training. This support can provide very concrete skills, such as information on how to lift a disabled individual without creating back strain. On the other hand, emotional counselling may be provided through support groups in which caregivers come together to share emotional and practical concerns. A goal of many of these groups is to have caregivers recognize that there are others who have the same emotions and problems and that their experience and feelings are 'normal' (Toseland & Smith, 2001). Individual counselling may also be provided.

3.2 Respite care

One of the burdens of providing informal care is that care is often needed day after day after day, many hours a day, without end. Some tasks, such as the need to use the toilet, are hard to schedule and require constant attendance. In addition, and specifically among people with dementias and other cognitive impairments, disabled persons often cannot be left on their own without being a danger to themselves and perhaps others. The constant nature of a great deal of caregiving imposes heavy burdens and strain.

To address this problem, many countries provide some form of respite care to provide temporary relief to family caregivers. Time off from the unrelenting demands of caregiving is believed to be directly therapeutic for the caregiver and indirectly therapeutic for the care receiver (Lawton, Brody & Saperstein, 1989).

Formal respite care includes temporary inpatient placement in residential facilities, nursing facilities, or hospitals; in-home respite by paid caregivers; and adult day care (also known as adult day health care) (Toseland, Smith & McCallion, 2001). At a practical level, however, there is not much difference between respite care and most long-term care services; almost any long-term care service in which another individual temporarily takes over care responsibilities can be viewed as providing respite to the informal caregiver.

Among the countries providing formal respite services are Australia, Germany, the United Kingdom, and the United States. As part of the German social insurance programme for long-term care, informal caregivers who provide a substantial amount of informal care are entitled to up to four weeks of respite care (Cuellar & Wiener, 2000). In Australia, short-term stays for respite care are estimated to make up 40% of all residential care admissions (Merlis, 2000).

Respite care is a central component of the *National Family Caregiver Support Program*, which was enacted in 2000 in the United States, and many states provide some respite care, especially for families of people with Alzheimer Disease. The United Kingdom *Carers and Disabled Children Act* 2000 is another example of a recent initiative focusing on respite care as a way of providing relief to informal caregivers. While these initiatives in the United Kingdom and the United States have substantially increased funding for respite care, they comprise a small part of the long-term care delivery system.

3.3 Regulation of business/business initiatives

Informal caregivers often find that caregiving conflicts with the requirements of their jobs. To facilitate caregiving, some governments have mandated that businesses make medical leave available to allow family members to care for disabled or sick relatives, and some businesses, on their own initiative, have sought ways to help informal caregivers.

For example, in 1990 Sweden introduced a programme of paid leave to care for people who are terminally ill (Sundstrom, 1994). In the United States, all public agencies and private-sector employers who employ 50 or more workers must provide up to 12 weeks a year of unpaid leave for employees to care for an immediate family member with a serious medical condition or to take medical leave to care for themselves (Employment Standards Administration). Upon return from leave, the worker must be restored to the original job or to an equivalent job.

Several American states have more generous standards than the federal law in terms of covering more employees or requiring longer leave (Coleman, 2000). The United Kingdom is exploring these types of requirements (United Kingdom DOH, 2000). Beyond government mandates, some businesses (usually large corporations) have adopted initiatives to aid their employees combine work and caregiving (United Kingdom DOH, 2000; Washington Business Group on Health, 1991). These initiatives can involve flexible work time (in terms of hours and scheduling of time off), paid and unpaid medical leave, information and referral for services, and counselling.

The business argument for making these changes is the claim that they will lower staff turnover, reduce absenteeism and sickness, improve labour flexibility (by increasing the size of the labour pool and making the business more attractive to older workers), and improve employee morale and staff loyalty (United Kingdom DOH, 2000).

3.4 Tax benefits and payments to informal caregivers

Another form of support for informal caregivers involves money, which may be provided as a tax benefit, supplemental income, or payments to the disabled person or directly to the caregiver. For example, in the United States, President Bush has proposed modest tax benefits for informal caregivers who live with severely disabled relatives.[1] In the United Kingdom, an income supplement, the Invalid Care Allowance, is available to caregivers of working age who supply more than 35 hours per week of care and who are wholly or mostly out of the labour force (Twigg, 1996).

Cash payments to disabled individuals and the ability to hire family members as care providers is part of a movement towards consumer-directed long-term care, in which individuals rather than agencies are given the power to hire, train, direct, and fire the people who provide care (Tilly & Wiener, 2000; Tilly, Wiener & Cuellar, 2000). These programmes aim to empower disabled persons to take control over their own lives and decide what is best for them. In most cases, disabled individuals receive vouchers that they can use to purchase a variety of services. However, cash payments to disabled persons in lieu of services are provided in Austria, France and Germany (Cuellar & Wiener, 2000; Tilly, Wiener & Cuellar, 2000). In Austria and Germany, there are no significant restrictions on the use of cash benefits and the national governments do not monitor how beneficiaries spend their money (Tilly, Wiener & Cuellar, 2000). The United States is conducting a large-scale research and demonstration project to test the concept of cash payments.

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[1] This proposal is a variant of an earlier proposal by President Clinton.

Although the consumer-directed care movement has a large market component to its ideology, it is widely believed that cash benefits in Austria and Germany are passed along to informal caregivers or are contributed to household budgets rather than used to purchase formal services. Germany's cash payments are designed to support informal caregivers and to facilitate the withdrawal of women caregivers from the labour force (Cuellar & Wiener, 2000). France gives beneficiaries a cash allowance, most of which must be used to pay workers. A French demonstration project of cash payments found that 30% of workers were family members (Simon & Martin, 1996).

Finally, consumer-directed home care programmes in some parts of the United States and in the Netherlands, allow direct public payment of family members to provide care to disabled family members, although family members who are legally responsible for the care of the individual (i.e. spouses and parents of minor children) are usually excluded. The underlying philosophy is that the public sector should not pay a spouse or parent for services that they would normally be required to provide without charge.

From the government's perspective, paid family members are simply another formal provider, although various requirements may be relaxed. In California's *In-Home Supportive Services (IHSS) Program*, for example, 40% of consumer-hired personal attendants are related to the beneficiary and an additional 30% are friends, neighbours, or other individuals the beneficiary already knows (Benjamin et al., 1998). In the Netherlands, 60% of workers in the consumer-directed option are family, friends, or acquaintances of beneficiaries (Baarveld et al., 1998).

3.5 Pension credits

Informal caregiving can result in reduction in labour force participation because of the difficulty or impossibility of combining caregiving and holding a job. This is particularly a burden for women, who perform the vast majority of informal caregiving. Withdrawing from the world of paid work can have a long-lasting negative financial impact on the caregiver, not only in terms of lost income but also in terms of reduced pensions, since most pensions are related to years of paid work. To partially compensate caregivers for their efforts, a few countries, such as Germany, provide pension credits to caregivers who provide a substantial amount of care (Cuellar & Wiener, 2000). Fully 93% of persons receiving credits in Germany are women, with about 55% of them aged 50–65.

The Blair administration in the United Kingdom has announced its intention to provide a second pension to informal caregivers, but this has not yet been enacted (United Kingdom DOH, 2000).

4 Issues

Informal caregiving and public programmes to support it raise a number of important public policy issues. These include the balance of responsibility between society and the family, 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.

4.1 Who is responsible: family or society?

Many long-term care policy issues revolve around the issue of whether the individual and family, or society as a whole should be responsible for providing and caring for persons with disabilities (Wiener, Hanley & Illston, 1994). Some people believe that the primary responsibility for care of people with disabilities belongs with individuals and their families and that government 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 and tend to oppose aid to caregivers as unnecessary and likely to undesirably monetize family caring relationships. This view predominates in the United Kingdom and the United States. At its extreme, many industrialized countries, including Germany, the United Kingdom, and the United States, used to have so-called 'family responsibility' policies that held relatives financially responsible for care of disabled relatives; these requirements are no longer in force.

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, societally-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. According to this view, the fact that one has a disabled relative should not result in an undue financial or care burden to the family.

Proponents of this view favour programmes that provide universal coverage and are not means tested. This perspective is characteristic of the long-term care systems in Germany, Scandinavia, and recently in Japan. Indeed, the enactment of the new social insurance programme in Japan was a deliberate decision to shift the burden of long-term care from the family to society as a whole (Campbell & Ikegami, 2000).

One way in which the issue of who is responsible for care of people with disabilities is played out is through the allocation of paid home care resources among the eligible population. In some countries, such as the United Kingdom and the United States, the availability of informal care is an important determinant of whether and how many paid services will be provided by public programmes (Wiener & Cuellar, 1999; Smith et al., 2000). This is especially likely where home care resources are perceived to be limited and where public programmes are means tested.

By taking informal care into account, public resources are stretched further and more people are able to receive at least some services. In these countries, the governmental response has been driven by beliefs that public support should only occur after family resources are exhausted, or the family is not able to meet basic standards of care.

In these situations, services have been focused on the care recipient rather than the family (Toseland, Smith & McCallion, 2001). In the United States Medicaid programme at least, this means that services cannot be provided if they principally benefit the family rather than the disabled person's particular needs (Smith et al., 2000).

In other countries, such as Denmark, Germany and Japan, the availability of informal care is not taken into account in determining how many services will be provided (Cuellar & Wiener, 2000; Campbell & Ikegami, 2000).[2] This is usually the practice where the expansion of home and community-based services is being actively promoted and where programmes are not means tested. This is especially the case where services are provided on an insurance basis, since taking informal care into account is often thought to be inconsistent with insurance principles and to violate the principle of horizontal equity in which all persons having a similar level of disability should be eligible for the same amount of services.

4.2 Conflict between work and caregiving

Over the past generation, the participation of women in the labour force in industrialized countries has increased dramatically, creating a potential conflict between working outside the home and providing informal care. In the United States, only 26% of married women ages 45–64 were employed in 1960, compared to 65% in 1997 (US Census Bureau, 1998). In the United States in 1994, 27% of primary caregivers and 59% of secondary caregivers worked 30 or more hours a week (Spillman & Pezzin, 2000).

[2] In Denmark, public programmes consider the presence of the spouse, but not the availability of help from children (Merlis, 2000).

Similarly, in the United Kingdom, nearly half of all caregivers are working, either full- or part-time (United Kingdom Department of Health, 2000). Of the caregivers who are working full-time, nearly 20% provide more than 20 hours a week of care.

Paid work can be a legitimate reason for being unavailable to provide care; however, many women combine working and caring, taking on both burdens. In addition, the so-called 'women in the middle' find themselves responsible for caring for young children as well as elderly relatives at the same time.

Work may affect caregiving and vice versa. On the one hand, working may reduce the ability to provide care; on the other hand, providing care may also reduce the ability to work. In both cases, the conflict reflects the physical separation of work and family in industrialized countries, making it harder to combine the two activities.

Although conventional wisdom predicts that individuals will generally reduce hours of paid work when they devote time to helping their parents and other relatives, research evidence in the United States on the relationship between caregiving and labour supply is mixed. Whereas some researchers have concluded that hours of paid work reduce hours of caregiver assistance or that hours of assistance reduce hours of employment (Muurinen, 1986; Brody & Schoonover, 1986; Boaz, 1996; Soldo & Hill, 1995; Johnson & Lo Sasso, 2000), others have been unable to find a relationship between caregiving and labour supply (Stone & Short, 1990; Ettner, 1996; Wolf & Soldo, 1994; Stern, 1995; Dentinger & Clarkberg, 1999; Pezzin & Schone, 1999).

In studies where researchers found no relationship, working women coped primarily by reducing their own free time. In some of the cases where working women reduced their caregiving time, secondary caregivers, including paid home care providers or other relatives, made up the reduced time. Even when working women did reduce their caregiving hours, they almost never completely withdrew from the caregiving activity.

4.3 Substitution of formal for informal services

One of the main barriers to the expansion of home and community-based services is the fear on the part of policy-makers that paid home care will cause friends and relatives to stop providing informal care (Hanley, Wiener & Harris, 1991). Policy-makers do not want the public paying the bill for services that would otherwise be provided free. Should the vast volume of informal care disappear and be substituted with paid care, the costs could be enormous.

Although the fiscal implications of a widespread shift from unpaid to paid care are abundantly clear, there is little research evidence in the United States to suggest such a result is likely to happen on a large scale (Weissert et al., 1988; Christianson, 1986; Smith-Barusch & Miller, 1985; Edelman and Hughes, 1990; Hanley, Wiener & Harris, 1991). Indeed, as noted above in the background section, in virtually all countries the family is the dominant source of care, even where substantial paid home care is provided (Sundstrom, 1994).

If formal care does not cause a decline in informal care, this suggests a certain dilemma regarding home care policy (Hanley, Wiener & Harris, 1991). On the one hand, if paid home care can be expanded without eroding the amount of informal care, that would suggest that formal care (i.e. paid care) increases the overall amount of care provided and thus should result in fewer unmet needs among the disabled elderly.

On the other hand, one of the main rationales for expansion of home care is to relieve caregiver burden. At least in terms of quantity of services provided, providing paid home care may not dramatically reduce caregiver burden because most caregivers will continue to provide roughly the same amount of care. This may help explain the perplexingly small impact that prior paid home care demonstrations have had on perceived caregiver burden.

This does not mean that informal caregivers are ungrateful or do not want paid home care, but rather that caring for a disabled relative is so large a task that modest amounts of paid services cannot radically change the global perception of burden. What paid home care can do for caregivers is to give them a needed break and allow them to arrange their hours and tasks more efficiently. Families welcome the relief, but their burden will remain great.

4.4 Cash vs. services

A number of policy issues are raised by the provision of cash benefits directly to informal caregivers through:

- tax benefits;
- income supplements;
- permitting the hiring of relatives to be service providers;

or indirectly through:

- cash payments to disabled individuals which is then turned over to family members.

First, evaluation of cash payments as a policy depends on the purpose of the payments. Cash payments to informal caregivers raise the classic economic conflict between equity and efficiency (Wiener, 2000). In many instances, the level of the payment to informal caregivers is extremely low, or highly discounted against the cost of comparable formal services, and cannot be seen as real 'market compensation' for the amount of effort by the informal caregiver. For example, the tax benefit proposed by President Bush for most people would be only several hundred dollars a year, a very small fraction of what formal care costs would be.

In the German social insurance programme, disabled persons choosing the cash benefit receive somewhat less than half the amount of funds available for agency services, making it difficult to use the money to buy formal care (Cuellar & Wiener, 2000). Indeed, in Germany, most stakeholders view the cash payments as a mechanism to support informal caregivers rather than a means to purchase services. Payment levels are often kept low in order to control total expenditures since so many people qualify for benefits; even small benefits multiplied by a large number of beneficiaries can result in substantial costs.

A general income supplement for people with disabilities and their families may be a good idea, but it does not constitute a programme to pay for long-term care services. Although almost everyone would like more money and the funds surely help to defray some of the incremental costs of caring for a disabled relative, many of these payments are best seen as a social recognition of the 'good works' that informal caregivers do. In this view, these payments are a kind of societal 'gold star' and the case for them is based on concepts of social equity. Because of their good works, informal caregivers should be better off financially than those who do not provide such care, or at the very least, they should not be worse off.

On the other hand, if the goal of these payments is to change behaviour by reducing nursing home use or increasing the amount of informal care provided, it is not clear how effective these cash payments are. It seems unlikely that very many people would decide whether or not to put their mother in an institution based on receipt of a relatively small cash payment for informal care.

Research in the United States suggests that the decision to place disabled elderly persons in nursing homes occurs when the amount of care becomes overwhelming and unsustainable (e.g. requiring 24-hour a day care) (Boaz & Muller, 1991), or when the type of care needed is more medical than the personal care that families can provide. Similarly, although the rationale for paying informal caregivers is to expand the pool of potential workers, the payment levels, at least in the United States, are not high enough to entice very many persons out of other jobs and into full-time caregiving.

With receipt of cash payments by disabled relatives, only ten per cent of Austrian caregivers reduced hours worked at their place of employment and nine per cent left their jobs to provide help to disabled relatives (Badelt et al., 1997).[3] In a study in the United States of a programme that allowed disabled workers to hire family members, 80% of family members chosen were already providing informal care prior to being hired (Benjamin et al., 1998).

For lower-income relatives, however, receipt of the cash payment may make a big difference in their financial status and may make caregiving less of a burden. For policy-makers, the crux of the problem is that the enormous amount of informal caregiving being provided means that cash benefits end up paying for a lot of care that is already being provided at no public cost. It is also extremely difficult to increase the volume of informal care, because such a large volume is already being provided.

In addition, consumer-directed home care raises a number of ***other public policy issues:***

- ***Do people with disabilities want to take on the management responsibilities inherent in a consumer-directed model?***

  Several surveys in the United States suggest a moderate level of interest by older persons, although substantially less than among younger people with disabilities (Glickman, Stocker & Caro, 1997; Desmond et al., 1998; Mahoney et al., 1998; Simon-Rusinowitz et al., 1998). Data from Germany and the Netherlands suggest that younger people are more likely to choose consumer direction than older persons (Woldringh & Ramakers, 1998; Tilly, Wiener & Cuellar, 2000).

- ***Are people with disabilities capable of managing their own services?***

  Little is known about the extent to which people with disabilities have the individual management capabilities necessary to handle the responsibilities of consumer-directed services (Tilly & Wiener, 2001). People with disabilities are often very sick, frail and cognitively impaired; their informal caregivers generally do not have expertise in long-term care financing and service delivery. Nonetheless, this is not always the case and many of the services required are of a non-technical nature, such as personal care and housekeeping, that disabled people and their relatives should be capable of managing.

[3] On the other hand, half of the Austrian caregivers reported that the cash payment permitted them to coordinate their relative's care better, and 60% said the money was sufficient to cover most of their caregiving costs.

Other public policy issues (continued):

■ *Is quality of care adequate in consumer-directed home care?*

The quality of consumer-directed services is probably the most highly contested issue facing policy-makers. Traditional home care programmes attempt to assure quality by relying heavily on government regulation that mandates provision of services by professionals, training requirements for paraprofessional staff, and agency supervision of paid caregivers. Almost all of these mechanisms are lacking in consumer-directed care, where the ultimate quality assurance mechanism is to fire the worker, which is difficult when relatives are involved. Limited research suggests that consumer-directed services provide quality of care and life that is at least comparable to agency-directed care (Benjamin et al., 1998; Taylor, Leitman & Barnett, 1991; Tilly, Wiener & Cuellar, 2000). However, these results generally relate to measures of consumer satisfaction and not to objective measures, such as delay of functional decline or absence of avoidable hospitalizations, that may be important indicators of quality. The choice of family and friends to provide care may improve the quality of care because of the emotional bonds that exist. However, public agencies and disabled individuals have great difficulty disciplining poor-performing relatives. It is difficult for government officials to insist that a daughter be fired.

■ *How do workers fare in consumer-directed service programmes?*

Workers in traditional home care programmes receive their salaries from agencies, work under agency rules, and are not directly answerable to beneficiaries, whereas consumer-directed workers are. Consumer direction most likely improves individual workers' relationships with beneficiaries, but leaves workers at somewhat of an economic disadvantage compared to their agency counterparts in terms of wages and benefits (Benjamin, 1998; Tilly, Wiener & Cuellar, 2000).

5 Conclusions

Informal care is the dominant mode of helping people with disabilities with their long-term care needs. Throughout the world, policy-makers are concerned about social and economic forces that may undermine the provision of unpaid care and seek ways to shore it up. A major premise of this support is that the disabled individual is usually not alone, but is embedded in a web of family and other relations. (Where disabled individuals are truly alone, their long-term care needs are likely to be especially great.)

Services and other initiatives aimed primarily at informal caregivers rather than the disabled individual include:

- education and training;
- respite care;
- regulation of business to make it easier for family members to combine work and caregiving;
- tax benefits and payments to informal caregivers; and
- provision of pension credits for informal caregiving.

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.

Provision of aid to informal caregivers raises a number of ***difficult issues***.

- ***First, should public policy focus on individual persons with disabilities or on the family of people with disabilities?***

  Despite the fact that most long-term care is provided by informal caregivers, almost all public long-term care programmes in industrialized countries consider only the needs of individuals with disabilities and not those of the family in which the individual is situated. In the United States, for example, services that principally benefit the family and not the disabled individual cannot be reimbursed.

Thus, help with the care of the children of disabled adults is not covered. In part this reflects the individualistic character of industrialized countries; in part it reflects the historical underfunding of long-term care services. It is also a cost containment mechanism since many long-term care services (e.g. housekeeping) have an inherent desirability to people who are not disabled as well as to those who are. The one area where many countries take the family into account is in deciding how much service to provide, with additional informal support leading to reduced formal services. All of this ignores the fact that individuals live within families and that the informal care provided imposes a substantial burden on caregivers.

- ***Second, how can public policy support informal caregivers without monetizing family relationships?***

Almost all informal care is provided voluntarily independent of any public policy interventions. This is done for a wide variety of reasons, of which a sense of family duty and love are important factors. A key issue for policy-makers is how to support informal caregivers without converting this non-monetary relationship into one dominated by market characteristics where services are only provided if money changes hands. While fear that monetizing family relationships would destroy informal caregiving, there is no evidence that supporting family caregivers will adversely affect how family members relate to one another. Where family caregivers are paid, however, there are questions about whether relatives will be fired if they perform inadequately.

- ***Third, can support for informal caregivers be increased without costs exploding?***

The great strength of informal caregiving is that there is so much of it; it is the overwhelming source of care in the industrialized world and virtually the only source of care for people with disabilities in the developing world. But that means that the families of virtually all disabled persons in the community might qualify for benefits if provided (subject to financial and income eligibility standards).

Thus, even small benefits provided to large numbers of people (as is being proposed in the United States with tax benefits) will result in substantial expenditures; substantial benefits provided to large numbers of people will result in even larger expenditures. Public spending (or tax loss) can be controlled by making the benefits part of an appropriated programme without an entitlement to benefits, but doing that violates horizontal equity. That is, fairness demands that similarly-situated individuals be eligible for the same benefits, a criterion that is not met if some persons are denied benefits because the money has run out.

- ***Fourth, what does support for informal care mean for the role of women in developing societies?***

In virtually every way, long-term care is a women's issue. Because of greater longevity, long-term care is primarily needed by elderly women, and women are overwhelmingly the main providers of both informal and formal care. The fact that women are the primary providers of informal care has led some critics to oppose support for informal caregivers because they see it as a way of forcing women to stay home and out of the workforce. Indeed, Japan consciously chose not to provide for cash payments as part of its social insurance programme for long-term care out of fear that doing so would more tightly tie women to the task of providing informal care (Campbell & Ikegami, 2000). Supporters of aid to informal caregivers counter that the goal is to create more options for people with disabilities and their caregivers. Moreover, they argue that the reality is that most disabled people receive their care from women relatives and those caregivers need help.

In sum, as developing countries address the ageing of the population, a major issue is how to balance the provision of paid services with support for informal caregivers. Given limited resources, trade-offs between the two will likely be necessary, but a long-term care policy that ignores informal caregivers neglects the elephant in the room.

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2 THE SUPPORT OF CARERS AND THEIR ORGANIZATIONS IN SOME NORTHERN AND WESTERN EUROPEAN COUNTRIES, *Marja Pijl*

1 Introduction

Carers are the pedestrians in the long-term care traffic. Like pedestrians, carers have no specific vehicle or tool – as do professional drivers, cyclists, or train engineers.[1] Even less do they have any specific licence or diploma, which qualifies them for the job.

One does not give much thought to being a pedestrian; and yet, everyone is a pedestrian at times. One does not feel inadequate because of not having had any training to be a pedestrian. Walking comes naturally.

Increasingly, however, it becomes necessary – even as a pedestrian – to have some basic notions about traffic rules and regulations. Similar observations can be made about carers.

Everyone may, at some point in life, be called upon to provide long-term care for someone in their circle of relatives and friends. When this happens, the offer of help is usually spontaneous.

Carers do not stop and worry about a lack of qualifications. Their help is needed, and they give it. Learning comes on the job. Those who have become carers will find themselves increasingly in situations in which they will come to realize that they need more insight, knowledge, skills, and support.

The discussion in the initial section of this volume concerns support of carers and their organizations in certain countries in northern and western Europe. It is largely based on a research project commissioned by the Netherlands' Ministry of Health, Well-being, and Sports, in cooperation with two advisory boards: the Council for Health and Social Service, and the Council for Social Development in the Netherlands (Tjadens & Pijl, 2000).

[1] References to these terms are derived from the subtitle of the Meeting on Long-Term Care Policy, "Bridging the Limousine–Train–Bicycle Divide", convened in Annecy, France in 2001. That subtitle refers to a continuum of diverse long-term care systems, characterized by a range from the extremes of the industrialized countries ('limousines') to the developing countries ('bicycles'). In between are the 'trains', those countries with established systems which are now confronted with diminished resources.

The main purpose of the research was to ascertain support that is given in comparable countries in Europe, with a view to the development of new policy initiatives *vis-à-vis* carers in the Netherlands. Included in the study were Belgium (Flanders), Denmark, Finland, Germany, Ireland, the Netherlands, and the United Kingdom. The data were collected in 1998.

Since that time, there have been many new policy developments in the countries concerned. It has been possible to follow up what has happened in some – but not in all – of these countries.

2 Carers: what and who?

2.1 Definitions of the concept of carer

It is important to define the concept of 'carer' at the outset. The research project (Tjadens & Pijl, 2000) adopted a definition which is more or less generally accepted in the Netherlands. It reads:

> *Carers are persons who provide care, not in the context of a care profession, to someone in need of care in their direct circle of family and friends. The provision of care stems directly from the social relationship.*

The Government of the United Kingdom, on its web site for carers (http://www.carers.gov.uk/), gives a more simple definition:

> *By carers we mean people who look after a relative or friend who need support because of age, physical or learning disability, or illness, including mental illness.*

The word 'carer' in itself may lead to confusion. A home help is also a carer. In order to prevent confusion, two specifications are often used to designate non-professional carers. These are 'informal carers' and 'family carers'.

Both terms, however, are inadequate. Carers themselves regard the term 'informal' as not doing justice to the importance and the actual burden of their work. The prefix 'family' is inadequate, because not only family members but also neighbours and friends can be carers.

It is true that at present the majority of carers are family members, but it is not unlikely that in the future their share may diminish. It is to be expected that neighbours and friends will fill some of the gaps.

This section shall use the simple term 'carer', without the prefix 'informal' or 'family', when referring to carers who do not perform their work in the context of a profession. It concerns long-term care provided in the home where the dependent person lives. The carer may or may not live in the same household.

The foregoing definitions say nothing about the minimum time input per week, or the length of time during which care should be provided before one is considered to be a carer. If someone does the shopping for frail elderly parents and devotes between one and two hours a week to it, is that person considered a carer? Hardly. There is no generally accepted 'bottom line', which makes it difficult to estimate the number of carers.

However, the number of hours spent caring can still be a criterion for eligibility for a benefit. The English Invalid Care Allowance is an example. In order to qualify, the carer has to meet a range of rather strict criteria, one of which is that the carer must spend more than 35 hours a week on care activities.

Likewise, there is no agreement on how long one has to be involved in care work before one is considered to be a carer. If one's partner is ill during one or more weeks, obviously this creates problems. Usually, with some improvisation, these problems can be solved. How long can one go on, however, without structural adaptations?

Again, the research found that there are some provisions where a minimum duration of the need for care is required before one becomes eligible for a benefit. The German Pflegeversicherung – an insurance for long-term care which offers the person in need of care either services or a cash payment with which the carer can be paid – can only be obtained in those cases where care is needed for more than six months.

Also, the definitions say nothing about the tasks which are performed by carers. These include many simple but time-consuming activities. Regularly, however, carers are required – out of necessity – to undertake complicated medical tasks which professional home helps or nurses' aides would not be allowed to perform. Accordingly, the definition of a carer leaves much to be guessed.

2.2 Numbers and characteristics of carers

It is not surprising that the researchers found few precise figures about the number of carers. Moreover, most figures are estimates. For instance, in the Netherlands one can read in almost any publication on the subject that 11% of the adult population, or 1.3 million persons, are carers. However, these figures are ten years old. Furthermore, they come from a survey that was designed for other purposes than the study of carers (de Boer et al., 1994). In Finland, it is estimated (by the Carers' Association) that 6.3% of the population are carers. In Ireland, an estimate was found of between 2.8% and 10% of the population.

The United Kingdom has some more recent figures. In *Caring about Carers. A National Strategy for Carers* (United Kingdom Department of Health, 1999), figures from 1998 are quoted, but even this report refers to an estimate of 5.7 million persons. The percentages of the population vary per region between 11% and 17%. It may be assumed that in most countries of northern and western Europe, the percentage of adults who have some structural caring responsibilities is not too far from 10%.

What else do we know about carers? The UK National Strategy states:

- 3.3 million are women;
- 2.4 million are men;
- carers are most likely aged 45–64;
- 9 out of 10 care for a relative;
- 2 out of 10 care for a partner or spouse;
- 4 out of 10 care for parents;
- half of all carers look after someone aged over 75; and
- 18% of carers look after more than one person.

From various research projects in the Netherlands, it is known that carers are primarily women between the ages of 35 and 64, frequently with lower educational and gross individual income levels (Tjadens & Pijl, 2000). The present research has not focused on quantitative data in the various countries.

2.3 On becoming a carer

Among carers in the Netherlands, one can often hear remarks such as “I did not choose to become a carer, it just happened to me”. This is very true. One becomes a carer because of an event in the life of someone else, who then becomes a person in need of care. This event has not been planned. It is something like the onset of a chronic illness, the birth of a child with a disability, or an accident.

In the two former cases, the consequences of the illness or the disability become apparent only gradually – as for example in the case of caring for an ageing parent. First, one will help with the shopping and an occasional odd job around the house. Then, it will be the laundry or some cleaning of the house. Eventually, as the loss of functions progresses, more and more tasks are taken over by the carer: domestic work, personal care, paperwork, intimate care, and possibly nursing. At some point in this process, the carer will stop and ask "What am I doing?" When the carer has arrived at this point, it is usually too late.

People from carers' organizations report that this question arises only after the carer has been overburdened for a certain length of time. The process, from the moment when the carer begins to realize that something is wrong to the point where adequate measures can be taken to reduce the burden, can be quite long.

Because many caring processes start so gradually, carers do not realize what they are getting into. Performing some caring jobs comes so naturally, that most people (especially women) do not even think about it: they just go and do whatever they think needs to be done.

The comparison with the pedestrian, mentioned at the outset, is a very appropriate one. Does anyone ever think about walking, as long as one is physically fit, and does not have to overexert oneself? Precisely because caring is such a natural thing to do, many people who are carers do not consider themselves as such. The mother of a handicapped child would define herself rather as a 'mother' than as a 'carer'. Daughters who provide much care to elderly parents will often say that they only lend a hand, and that they are happy to be able to do so.

If carers do not consider themselves as such, it is hard to reach them and even harder to establish effective policies. Awareness-raising is among the first requirements of an effective policy to support carers. The media can be very helpful in this respect.

3 An increased interest in carers

The reason the research was commissioned involved a concern by the Netherlands' Government and two of its Advisory Councils, that the volume of informal care might shrink unless better conditions were created for carers to stimulate them to continue providing care. Although it is known that carers provide the bulk of care, reliable and precise figures are not available. A recent White Paper of the Netherlands' Ministry of Health, Well-being, and Sports (VWS, 2001) states that three-quarters of all care is provided by carers.

Johansson (2001), in his paper *Recent developments in caregivers' support in Sweden,* estimates that two-thirds of all care to the elderly outside institutions is being provided by carers.

In most European countries, there were considerable cutbacks in publicly-financed social and health services during the nineties. What happens in those cases where expected care is not provided can only be guessed. Persons in need of care may have to lower their standards. They may also resort to their informal network which may or may not come to their rescue.

It seems that governments have come to realize that it would be a disaster if carers in great numbers gave up their work. That is why more and more governments are seen to be making an effort to develop a carers' policy. Finland, Ireland, the Netherlands, Sweden, and the United Kingdom are active in this respect, as is the Flemish part of Belgium. In other countries, new policies are being developed that, while not aimed directly at carers, may ease the burden for them, for instance through the introduction of care allowances payable to the dependent person. France, Germany, and Italy provide examples of this approach.

One of the conclusions of the research has been that policy measures do not really stimulate carers, because carers who see the need and are in a position to do so, will care anyway. There is no need for a stimulus.

In most countries in the research project, however, carers said they wanted some kind of recognition. Increasingly, carers develop the insight that they save their governments a lot of money. Therefore, they feel they deserve some kind of a reward. Their first demand is recognition, and not payment for their work. Paying the carer is a touchy issue, which will be addressed below. Carers in most countries in the study feel that the government owes them some sort of concrete resource, which would make their caring job lighter. Such provisions would reduce tensions and increase their well-being.

The growing interest in carers does not come only from the care sector. Policy-makers responsible for labour market policies begin to see the relevance of reconciling paid employment and family life, if they are to stimulate women to participate more fully in the labour market. It is obvious that policies are contradictory if, on the one hand, women are expected to take part in the labour market – which is the current policy in the European Union (EU) – while, on the other hand, care policies rely heavily on non-professional carers.

The Scandinavian countries have solved this problem with regard to caring for healthy children. The state has taken over the responsibility and is providing sufficient facilities for child care to enable both parents to participate in the labour market.

In some Scandinavian countries, like Denmark, the long-term care policy is such that it takes into account the labour-market participation of the carer. Formal services are made available when the carer goes to work. But this is not (yet) the case in all Scandinavian countries. In an interview with the Finnish Carers' Association, it was made clear that caring for a child with a disability while holding a job is quite a different story. There are no sufficient provisions to care for such a child, and the parents have to be most imaginative to compose a package of help that will allow them to remain in the labour market. In almost all European countries, long-term care services are at a lower level than in Scandinavia, so that in these countries it is even more difficult to reconcile caring with paid employment.

The European Union seems to have become aware of this problem and may well take a lead in trying to confront this rather complicated issue. In line with its open method of coordination, the European Commission may stimulate exchange of good practices. (See also Den Dulk et al., 1999).

4 Some results of the research project

4.1 The research questions

The Ministry of Health, Well-being and Sports and the two Advisory Councils wanted answers to certain questions. In large part, these questions overlapped. Obviously, some of them were inspired by problems that were encountered in the Netherlands; others served to compare initiatives in the Netherlands with their European counterparts. The countries selected for the study were neighbouring countries where interesting developments were expected to be found.

The study employed topic lists rather than questionnaires, because the situations varied considerably among countries. The questions revolved around the following themes:

- the relation between family and state concerning provision of care;
- legislation and other formal arrangements which have an impact on the (financial) situation of carers;
- carers' organizations, their aims, activities and funding; their relationship with other organizations having to do with carers (e.g. organizations of persons with certain diseases, or associations of parents of children with learning disabilities, etc.);
- vision of policy-makers concerning the position of carers; and
- support for carers at the local level.

4.2 Selected issues from the findings

The study found very diverse patterns in the seven countries, some of which are discussed here. Basically, the interest of the Ministry was mostly directed at concrete measures, such as the (financial) support of carers' organizations, or the (financial) support of volunteer organizations that play a role in respite care.

The questions of the Advisory Boards tended more in the direction of a policy for carers. Also emerging from the findings were the activities of carers' organizations and of other organizations that have played an important role in supporting carers.

Since the research was mostly aimed at policy questions, the study did not enquire into the contents of specific programmes for carers, although some respondents gave some information about them. Described here, mostly on the basis of the research, are:

- Who is responsible for social care: family or state? (4.2.1)
- The health care – social care divide (4.2.2)
- Financial support for carers (4.2.3)
- The role of carers' organizations (4.2.4)
- Respite care (4.2.5)
- Awareness raising, counselling, training and education (4.2.6).

4.2.1 Who is responsible for social care: family or state?

This is an important question when looking at the position of carers. In those countries where the state is responsible, e.g. the Scandinavian countries, the person who needs care is entitled to services which are available at no cost or low user fees. Where sufficient publicly-financed services are provided, the life of the carer is a lot easier than in countries where such services are not available.

Denmark is a good example of a country where the state has taken on the responsibility for long-term care. The municipalities are responsible for the provision of care. This does not mean that carers do not play a role, but they know that they can always fall back on the municipality in case of need.

Carers provide the care they want to give. If a carer wants to work, the municipality has to help find a solution. The same is true when the carer wants to go on vacation. The policy intends to enable carers to continue with their own life and not to let caring interfere with normal activities.

The question arises, has this eroded the willingness of the Danes to provide care? Rostgaard (1995) has made a comparison between spouses and daughters as carers in Denmark and the United Kingdom. She has found that:

> *Spouses are no less important a source of support in Denmark than in the UK. The difference in informal provision of care arises with the help which children offer in personal care.*[2]
> *It is much more likely that children are involved in personal care in the United Kingdom, whereas it is the home help in Denmark who helps with personal care. The help of friends and neighbours is limited to domestic tasks in Denmark. Children are likely to provide material and psychological support.*

Rostgaard (in: Tjadens & Pijl, 2000) concludes:

> *Formal care has to some extent replaced informal care but only as regards personal care from children.*
> *Spouses are involved in personal and material care and even to a higher degree than in the United Kingdom.*

The situation in Finland is comparable to that in Denmark – with one important difference: Finland has suffered from a severe economic recession. This situation has resulted in drastic cutbacks in the social sector.

When the research was conducted in Finland, municipalities were having difficulties in meeting the demand for care. In the particular local situation described in the study, the municipal social services – knowing that they were obliged to provide services – entered into a process of negotiation with the person in need of care and his or her informal network. Efforts were also made to share some responsibilities with the voluntary sector. It was the function of the municipality to find a solution agreeable to all parties.

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[2] Rostgaard defines personal care as “the intimate and physical tendering involving feeding, washing, protecting and comforting the care recipient”. Material support is defined as “household tasks such as hoovering, shopping, managing finances and contributing financially to living costs”. Psychological support is defined as “caring for by visiting, calling or providing a feeling of safety”.

The situation in the Netherlands is similar to that in Scandinavian countries. The major difference is that the Government is responsible for providing the finances for long-term care, while care delivery is in the hands of private organizations, which receive public money and are heavily regulated.

Still, the question of how far the responsibility of carers goes has been a point of debate. This has manifested itself around the issue of assessment for long-term care. With the introduction of independent assessment boards, standards had to be developed, and one of the questions that arose involved how to consider the work of carers.

Many boards started from the assumption that carers could continue to give the care they were providing at the time of the assessment. While making their decision about the amount of formal care to be provided they did not take account of the needs that were being met by carers. This practically forced carers to continue with their activities, even if they were more than overburdened.

Formally, this situation has now been redressed. A policy document by the Deputy Minister of Health, Well-being and Sports, dated June 2001 (VWS, 2001), reads (translation by this author):

> *Neither the state nor a professional organization can extort (informal) care. Anyone faced with someone else's need of long-term care has to answer the question whether or not to provide it, and if yes, to what extent he or she wants to meet this demand. The government should not and cannot make this choice for them.*

The letter accompanying this document states that the Government takes as a point of departure the consideration that carers must be able to participate normally in society. In theory, carers in the Netherlands can themselves decide how much care they are willing to give. In practice, it is difficult for them to realize this right due to enormous shortages in the care sector. Recent research by Dautzenberg (2000) has shown that women in the Netherlands are still quite ready to take care of their elderly parents.

The situation in Belgium and Germany is different, in that the family is held responsible for financing care. If the person who needs care cannot pay for it himself, then there is a legal obligation for relatives to pay. Only if relatives are also unable to pay, can social assistance be provided. The obligation of the family is somewhat mitigated in Germany by the long-term care insurance (Pflegeversicherung), which pays for part of the care (see also Section 4.2.3). The remaining part must be provided by the family.

In Flanders (the Northern part of Belgium), a new care insurance scheme has been introduced on 1 October 2001. Small amounts of money can be paid to persons in need of care. This scheme is intended to compensate some of the costs of professional and/or informal care. Apart from that, however, relatives are still responsible for the costs of care. Still, the Flemish carers' organization appreciates this provision, since it represents recognition of carers.

The consequence of the financial obligation of family members, as in Germany or Belgium, is that financial considerations place extra pressures on carers. This can easily lead to disputes, as for example among the children of elderly persons, about who must provide how much care.

Formal obligations to pay for the costs of care of relatives do not exist in Ireland and the United Kingdom. Persons in need of social care must make income dependent co-payments for their care. Local authorities target social care at the most vulnerable, and those with low incomes. Others have to fend for themselves, using their assets or mortgaging their houses in order to pay for social care.

In the case of the United Kingdom, relatives of older people may find themselves discussing the question of which is the financially more advantageous option: providing informal care (mostly a woman's job) and leaving the assets for the inheritors – or buying professional care and losing the inheritance (see also Ungerson, 2000). Apart from financial considerations, the moral obligation is felt in the United Kingdom as in other countries.

In Ireland, the Constitution refers to the duties of women in the home. In this country, the family – and especially its female members – is held responsible for care. It would appear that this principle is so firmly entrenched in the Irish value system that it does not meet with much opposition. Social services are scarce in Ireland, so pressure on (female) carers is higher than in any other country in the study.

4.2.2 The health care – social care divide

Packages of care for dependent persons living at home are usually made up of quite a number of different services. A major part is played by home care services, which comprise nursing, personal care, and domestic care.

In some countries, all these services are financed and supervised by just one authority. This is the case in the Scandinavian countries, where municipalities are responsible for both the finances and the delivery of the full range of care services. In most other countries, there is a sharp divide between medical services on the one hand and social services on the other.

Medical services are insured or a state responsibility and are free or almost free at the point of delivery, but social services come under a different regime. They may differ from place to place, and require co-payments of the user.

Nursing is usually part of the medical services, but personal and domestic care are mostly considered as social services. (The Netherlands is an exception in this respect: nursing, personal care, and domestic care are all covered by the Exceptional Medical Expenses Act (AWBZ) – the Act which covers most long-term care services. Other social services are the responsibility of municipalities.) For the carer, this means – apart from the financial consequences – that negotiations with more agencies are necessary and that the arrangement of sufficient services becomes more complicated.

Sometimes there are disputes between the agencies about boundaries. A well-known example is the debate in the United Kingdom about bathing a dependent person. The medical services prefer to see it as a social service, the social services say it should be a medical provision. The background of this question is who will pay for it (Weekers & Pijl, 1998). Such disputes only make the lives of carers more difficult. Fragmentation of the care system is a major obstacle for carers.

4.2.3 Financial support for carers

Carers are likely to be financially less well off than those who do not have to care for a dependent family member. There is usually a loss of earning capacity. Dependent persons are unlikely to be in paid employment, and the carer may have to reduce working hours or give up a job altogether. If the carer and the dependent person live in the same household this may mean that there is a double loss of income. Dependency can entail other costs as well, such as house adaptations, higher costs for heating, dietary costs, costs of assistive devices, equipment, or special clothing or shoes.

In the countries studied, different forms of financial compensation were found. These will be described under four headings:

- Income replacement or substitution payments.
- Compensation for extra costs incurred by care.
- Other financial arrangements.
- Career break option.

Income replacement or substitution payments

Under this heading are three different approaches:

- income support;
- compensation for loss of income; and
- payment for work performed.

Income support

This means that carers who have no income – or only limited income because of their care activities – receive an allowance. Examples include the Invalid Care Allowance and the Carer Premium in the United Kingdom and the Carer's Allowance in Ireland. In the case of income support, allowances are income-dependent. If a certain income level is exceeded, the allowance is forfeited.

In the Irish case, not only is the carer's own income taken into account, but the partner's as well. A married woman, caring for her mother, may lose her entitlement to the allowance if her husband's income is raised and exceeds the stated limit. Irish carers were quite angry about this. Both in Ireland and in the UK, pension rights may be accumulated while receiving the allowance.

Compensation for loss of income

This kind of allowance was found only in Denmark, where a parent who cares for a seriously ill or disabled child receives an allowance equivalent to the lost income, plus any additional expenses. The minimum duration is one year.

There are two additional allowances in Denmark, the amount of which is based on the forfeited income. They are an allowance for parents of a sick child under 14 years, and an allowance for persons caring for a terminally ill relative. These benefits are linked to the sickness benefit and have a time limit.

Payment for work performed

Examples of this approach were found in Denmark, Finland, Germany, and the Netherlands. Since the study, this possibility has also been introduced in the United Kingdom. In Denmark and Finland, the municipality can enter into an agreement with the carer that he or she will perform a certain amount of work and will be paid by the municipality.

In Germany, the long-term care insurance may either provide services or a cash payment. The cash payment equals roughly half the amount that would be paid if one opted for services.

There are three levels of dependency and corresponding amounts of money. The monthly payments in 1998 were:

	Services	*Cash*
Level 1	€ 383.40	€ 204.51
Level 2	€ 920.32	€ 409.00
Level 3	€ 1431.62	€ 664.68

In extreme cases the maximum for services can be raised to € 1917.34 per month. The cash payments are intended to serve as payment for the carer.

Additional benefits accrue to carers who spend at least 14 hours a week caring and work less than 30 hours a week in paid employment. These include:

- contributions towards the old age pension;
- accident insurance; and
- an allowance when caring has come to an end.

Carers who have worked twelve months can obtain substitute care for a period of four weeks in order to take a vacation. There are also some provisions for temporary substitute care in cases of crisis. Obviously, the payments to carers of heavily dependent persons are far from enough to cover all costs or to be considered as a real wage for the work they do.

In the Netherlands, persons in need of care can apply for cash instead of services. If they choose the cash option they can hire and fire their own helpers. They must make formal contracts with them, for which there are strict rules. Contracts must meet the requirements of the labour market (e.g. wages cannot be lower than the minimum wage, paid holidays must be provided, etc.).

Gradually the scheme is being improved in the sense that fringe benefits, such as those provided to workers in the formal services, can also be given to carers. Recipients of the care allowance can make a contract with spouses or other members of the family.

This scheme is appreciated by those who opt for it because it allows for more flexible care arrangements. Moreover, the relatives (if they are hired) are happy with the payment.

The payment of carers is a touchy issue. This emerged most clearly in Ireland. The fact that the carer's allowance is a social assistance payment – solely intended to assure that the carer has a minimum income and not at all related to the efforts made by the carer – is considered most unfair.

While conducting the interviews in Ireland, this researcher discussed with quite a few persons, among them carers and former carers, the question of whether they would prefer wages, comparable to those in the care sector. This idea was totally rejected. The moral obligation of caring was felt very strongly and it seemed inconceivable that caring for relatives could be considered as a paid job.

At the same time, carers asked very urgently for more recognition and for a review of the carer's allowance. In a way, it seems illogical on the one hand to claim a better payment – related to the efforts of the carer – and on the other hand to oppose the idea of a waged job for persons who care for a family member.

Other sources also report that carers like to receive recognition and appreciate something (not necessarily money) in return for their services (e.g. Luijkx, 2001). Care allowance schemes, in which the care recipient has the possibility to choose either services or cash with which the carer can be paid, seems a reasonable solution.

Compensation for extra costs incurred by care

In Belgium and Denmark, the study found this kind of compensation for carers.

Other financial arrangements

Quite a few other ways in which the financial situation of the carer can be improved were found by the study. Belgium, Ireland, and the Netherlands have certain tax relief measures. These are not described in great detail, because they presuppose some knowledge of the tax system.

Other provisions encountered include:

- increased children's allowance for a disabled child;
- supplementary payment on social security benefit;
- accommodation adaptation or contribution towards this;
- reduction on television and radio licences;
- co-payment ceilings;
- VAT exemption on car purchase; and
- reduced or free public transportation fares.

As a rule, these provisions are aimed at very specific target groups.

Career break option

Employed carers may want to temporarily reduce working hours or take leave. In Belgium, employees have the option of taking leave of absence on five occasions, up to a maximum of a year, during their entire career. During this time, they receive a monthly sum of € 270. This scheme was introduced in 1985 as a job-creation instrument.

The career break was introduced in the Netherlands in 1998. Employees have the option of a full-time or part-time leave for a maximum duration of 18 months. In the case of full-time leave, a maximum allowance of € 434 may be paid. An unemployed person must be taken on by the employer in the place of a carer who leaves his or her job. This scheme has not proved very successful as it is too complicated for employers.

Recently, the possibility of a ten-day paid leave was introduced as care leave. This can be used when someone must care for a sick member of the household or for sick parents. Discussion concerning long-term care leave is under way. So far, it seems as though politicians are not ready to embrace this idea.

Eurolink Age (1999) conducted a project on carers in paid employment and demonstrated that there are corporations which have carer-friendly policies. Career breaks are among the options.

4.2.4 The role of carers' organizations

In Finland, Flanders (Belgium), Ireland, the Netherlands and the UK, there are national organizations of carers, which are open to anyone who is a carer. In Denmark and Germany, such organizations did not exist at the time of this research. The gap within these two countries was filled by organizations such as the Alzheimer Association and organizations of older persons. In four of the five other countries, the carers' organization is a membership group, i.e. carers can join and the organization speaks on their behalf.

In 1998, the Dutch organization was the odd one out. However, at the end of 2001 this group changed its constitution and became a membership organization as well. These organizations work in network structures, with local and regional organizations and with other national organizations which deal in some other capacity with caring issues. All organizations were confronted with the problem that it was difficult to reach carers and therefore not easy to attract new members. In 1998, the largest of all of these organizations was the one in the United Kingdom, with 14 000 members. In Ireland, the membership numbered about 2000; in Finland, about 3000.

There are many similarities in the way carers' interests are advocated in the various countries. Their methods include:

- increasing awareness – aimed at carers, care professionals and others (including politicians);
- providing information and advice;
- legal support;
- practical help; and
- influencing the political agenda.

There is a noticeable direct link in Finland and the United Kingdom between the carers' organization and the political arena. Conversely, in Flanders the organization is trying to maintain its independence and to avoid affiliation with any particular political stream.

Finances are a problem for all organizations. All are financed from different sources. These include annual subsidies from one or more government bodies, or other official agencies (such as, in Finland, the Slot Machine Association) and finances for specific projects from foundations.

Money is also raised from publications, membership fees, and consultancy work. In Ireland and the United Kingdom, sponsorship from the commercial sector also enters the picture.

Carers' organizations fulfil a significant role, both in awareness-raising and in providing peer and other kinds of support. They also serve an important function in making the voice of carers heard, and can become critical partners of policy-makers.

4.2.5 Respite care

Respite care is care given to the dependent person with the aim of giving the carer a break. Respite care can take various forms. It can be provided in the home of the dependent person; but alternatively the dependent person may go to a residential home, a nursing home, or some other place where that person can receive the necessary care.

Such care can be provided for a period of a few hours, a day or several days, or weeks. In many cases, it will be provided by the formal system, but there are also schemes where trained volunteers provide the respite care.

Respite programmes for carers usually entail a weekend or a slightly longer stay away from home. At the same time, care will be provided to the person in need of care. There are also programmes where carers and care recipients can go together and where there is a programme for both groups.

Respite care is extremely important because caring is a continuous job with few possibilities for carers to have time of their own. Time pressure and a lack of free time are among the strongest felt problems of carers. If they know there is respite and that it is accessible, this reduces tension.

Forms of respite care were found by the study in all countries. In Denmark, however, it is not provided under this name. It is considered normal that the carer can go off for a break and the municipality will help to make the necessary care available. In addition to the regular services, voluntary organizations may arrange programmes. Described in the study was the example of a programme organized by Daneage, in which volunteers are trained to give substitute care to persons with dementia.

The volunteer is carefully introduced to the family where he or she will work. Once the patient is used to the volunteer, the carer can leave him or her in charge and take some time off. The volunteers are organized in small groups and supervised by professionals from the care sector.

Ireland has very many facilities for respite care, which are offered by voluntary organizations. It is not unlikely that this has to do with the fact that there is a low level of formal services. The voluntary sector has realized how restricted most carers are and many organizations have set up programmes for carers. A directory of respite care for the year 1997 mentions projects of no fewer than 229 agencies at the national, regional, or local level.

Two special projects deserve to be mentioned here. First, the activities of Soroptimist International (SI), a women's organization, which has played a key role in drawing attention to the position of carers and which has been instrumental in initiatives for research, programmes for carers, and action towards policy-makers. SI has a network of members all over the country and these have been involved in setting up activities for carers, among them respite programmes.

Secondly, the FAS programme is an employment programme supported by the European Commission, through which large numbers of jobs have been created. FAS workers up to age 35 can remain one year in a FAS job; older workers can remain three years. The jobs are for 19.5 hours a week.

The Irish Carers Organization has set up a programme in which they employ some 100 FAS workers, who are trained and can then give care in the home in order to give the carer a break.

In Finland, research has been conducted on respite care. Carers were given vouchers with which they could get respite from a variety of providers. Respite programmes varied in duration. Research showed that care recipients preferred day care, whereas carers preferred breaks of four to six days.

It was also found that carers of very dependent persons were reluctant to leave them in the hands of others. For the carers of dementia patients, respite care was a delicate issue. Respite makes the demented person often more confused, so that there is more work for the carer after the break. For these patients respite care in their own home may be better.

Also in Finland, the study found an initiative in which volunteers participated. This involved a service bank where participants could register and offer voluntary care. They receive a guaranteed return when they themselves need help.

In the United Kingdom, respite care has become a fairly well-integrated element of the services offered by Social Services. There are both sitting services and possibilities for short residential stays. Voluntary organizations such as Crossroads or Age Concern provide substitute care in the home.

Also in the United Kingdom, a discussion has arisen concerning the concept of respite care. Patients' organizations have made clear that the term respite may be felt to imply that the carer wants to get away from the care recipient. In the United Kingdom, the term respite care is therefore increasingly being replaced by the terms 'short stays' or 'short-term breaks'.

The respite care included in the German long-term care insurance has already been described.

In the Netherlands, the Carers' Organization will soon launch a large-scale programme of respite weekends for carers. This initiative is intended to establish balanced programmes with relaxation, recreation, and exchange between carers, in combination with some educational or cultural activities. Advice from carers is being sought about the contents of the programmes.

There will be some weekends during which carers and care recipients can participate together. However, in the majority of cases substitute care for the dependent person will be arranged in the home.

4.2.6 Awareness-raising, counselling, training, and education

The study was not intended to collect information on specific programmes and their contents for carers or professionals. Although these have been mentioned occasionally, they have not been elaborated upon because that was not the assigned purpose of the study.

However, the Limousine–Train–Bicycle Meeting addressed the subjects of counselling, training, and education. Accordingly, these subjects will also be discussed on the basis of materials from the study and other sources.

It is evident that in most countries in the study and elsewhere, programmes targeting these areas are being developed. Some of them have been researched, and it is probable that a great deal could be learned from a more concerted effort to investigate such programmes and their evaluations.

Moreover, to the three issues counselling, training and education, can be added a fourth: awareness-raising. It has been explained under point 2.3 of this section, that many carers are not aware of the fact that they perform this role. By the same token, others – who deal with them as relatives, friends, or in a professional capacity – may not be aware of them being a carer and the consequences thereof for their lives.

Before policies for carers can be implemented effectively, both the population and, more specifically, carers themselves must know about the role of carers. They must also know that they are entitled, not only to recognition, but increasingly also to concrete services.

It is not only carers themselves who need information, training, and education. There are other target groups as well. The researchers distinguish:

- the general public;
- carers themselves;
- those who have to do with carers in another capacity than as carers (e.g. in their capacity of employee); and
- those who work with carers professionally or as volunteers.

Programmes encountered in the study, for each of these target groups, include the following.

The general public

The general public should be made aware and be informed. Everyone may become a carer at some point in life. In addition, most people will know someone who is a carer. It is helpful if the public understands what it means to be a carer and if they have some idea what services are available, so that they themselves – or people they know – can use them when appropriate.

The use of the media can be very helpful in this respect. When advertisements are used, one has the right to decide on the contents. By contrast, if one tries to interest journalists or managers of radio or television programmes, one is dependent on what they want to publish or broadcast.

In the Netherlands, a publicly-funded campaign is currently being prepared, in order to direct radio listeners to the web site of the carers' organization. Another approach involves organizing events which will attract the attention of journalists or broadcasters. The Irish Carers' Organization has been quite skilful in this respect. They have a 'Carer of the Year Award', with the principal goal of creating opportunities to draw public attention to the work of carers.

Another event proudly mentioned by the Irish Carers' Organization involved an opportunity for a carers' group to meet the President of the Republic at her residence. This event yielded very good publicity.

Carers

Awareness-raising

Carers will be reached by awareness-raising programmes for the general public, but special efforts can also be made to reach carers with campaigns aimed directly at them. Flyers or packages of information can be distributed in places where one might expect to find carers (e.g. in offices of general practitioners and in pharmacies, in supermarkets, and the information markets which are held on many occasions). Women's organizations and organizations of older people are other channels that can be used for this purpose.

Counselling

It is well known by all carers' organizations that carers need someone who listens to them. They want to speak about their experiences and their emotions, and sharing these feelings with others can bring some degree of relief. They may have good friends who are ready to listen, but generally exchange with other carers or former carers is especially effective. This helps them realize that most carers experience similar problems. They need not explain their concerns to the others in the group: the others know from experience. Groups for carers may be organized around themes familiar to them, and they may take the form of educational programmes. The Flemish Carers' Organization offers a series of meetings under the following headings:

- Home care is total care, a vision on care, and those who are partners in care.
- Bottlenecks in home care: seeking a balance.
- Do children remain the children of their parents? Loyalty between adult children and their parents.
- Clear-cut agreements in home care are necessary.
- Getting lost. What families should know about dementia.
- The importance of tailored information.
- Demand-led care: are the patient and his network heard?
- Home care: you don't think about it, you do it.

Meetings of this kind are generally offered at the local level, in cooperation with, for example, a social work agency or a community centre. Other organizations, such as patients' organizations, home care agencies, women's organizations and the like, may also offer such programmes.

Carers may need professional counselling when they have emotional problems with the changed perspectives in their own lives, or with changes in the relationship with the cared-for person. Such a provision was offered in the experiment in Denmark, which sought to determine and meet all the needs of carers. A psychologist worked with couples of which one partner was disabled because of brain damage.

Learning new skills

Carers go into caring without any training for it. Yet, they must perform many tasks for which particular skills are needed. An example which is frequently given involves lifting a person without causing injury to one's back. Needed skills will, to a large extent, depend on the disability of the person receiving care.

Professional organizations, such as home care agencies, can provide this kind of training. Such courses exist in the Netherlands. In Finland, rehabilitation courses for carers, free of charge and lasting from eight to seventeen days, are offered to carers who are suffering from some illness or disability.

Increasingly, information and communication technology (ICT) will play a role in caring. Carers must learn to work with new instruments when these will facilitate their task. They can use computers not only to obtain information and for communicating with professional staff, but also to maintain social contacts. An EU-funded programme in this connection is called Assisting Carers using Telematics Interventions to meet Older person's Needs (ACTION). Information can be found on its web site: http://www.hb.se/action/.

Acquiring information and knowledge

Carers will be looking for many kinds of information. Medical information is an important subject for them. Carers want to know about the illness or disability of the person they care for and the possibilities for treatment.

Patients' organizations (which in fact are often the organizations of their carers, such as the Alzheimer Association or the organizations of parents with an intellectually handicapped child), usually avail themselves of much information. They can therefore be of great help to carers.

Carers will also want to know about services which are available for the person receiving care. Some of this information relates to national structures, but most services will actually be local. They may be organized differently from place to place. In the countries studied, it was learned that it is increasingly difficult to know what services exist and how they can be accessed.

An Information Bureau in the city of Münster, Germany is described in the study. It is a municipal bureau, but is considered to be independent because the municipality itself does not provide any care services. Its motto is to shed light 'on the jungle of care supply'.

The Dutch Support Centres for Carers fulfil a similar function. Many of them publish a local carers' guide. Their tasks, however, are broader. They also provide counselling and organize support groups. Providing information is a good way of getting in touch with carers.

Many countries have telephone helplines, where carers can ask practical questions. Callers can also find someone who listens to them.

As the social systems in which carers operate become more and more complicated, carers may need legal advice. For instance, they may need advice about the allocation of care, allowances, tax concessions, their rights as carers, facilities at work to help them reconcile paid employment with their caring jobs, and so on.

The Finnish carers' organization provides such services. These services, as well as a telephone helpline, demonstrate where the most important bottlenecks for carers are to be found. As such, they can be used simultaneously as an important input to the advocacy work of carers' organizations.

Professionals who meet carers in another capacity

It is clear that caring has a profound influence on people's lives. It restricts their use of time, and may cause them to become tired, distracted or depressed. This may negatively influence their performance in other sectors, or it may affect their health.

Professionals who deal with them (for example, teachers in school or bosses at work) may not realize why carers suddenly begin to underachieve. Professionals who meet large numbers of people are likely to meet some carers among them. Therefore, it is desirable to inform these professionals about the consequences of being a carer, and to advise them where to refer carers if they cannot themselves provide help.

A concrete example involves the special case of young carers. Even among children in school, there are some who care for a disabled parent or sibling. In Ireland, the Netherlands, and the United Kingdom, there are projects for young carers. In this special case, teachers need to be reached as well.

Another example is the personnel department in labour market organizations. Personnel officers should be aware of the fact that some of their employees are carers. These personnel officers should be made sensitive to the special facilities that carers may need if wanting to continue their job.

It would be desirable to give some attention to the position of carers in the training of both teachers and personnel officers. The study did not encounter such programmes.

Those who work with carers professionally or as a volunteer

Included in this case are professionals such as medical doctors, nurses, home helps, physiotherapists, social workers, community workers, and the like. Their professional training should contain at least a module about carers.

Recently, the Flemish Carers' Organization developed an information kit for teachers of professional workers in home care. It consists of a video, a guide about home care which lists all services and facilities, and a book which helps the teacher to prepare lessons on caring. Similar initiatives may have been undertaken elsewhere.

If no module on caring is included in the initial training of these workers, it may be worthwhile to attempt to organize programmes of recurrent training, which are available for most professionals, to include at least a session about carers. Some carers' organizations maintain lists of carers who are prepared to speak in such courses.

As mentioned above, volunteers play a rather important role in supporting carers, especially by sitting with persons receiving care. Several such initiatives were encountered in the study. As a rule, volunteers who wish to perform this kind of work are carefully selected, trained, matched with a family, and supervised.

Also described above was a Danish project in which relatives of Alzheimer patients received support from volunteers. Another Danish project was developed within the context of the Lutheran Church. This project was initiated by a nurse who had worked abroad, in developing countries and in the USA, and who had become interested in the hospice movement. She adapted this idea to the Danish situation and began to work with relatives of dying persons. She extended her target group to relatives of chronically ill or demented persons, and the bereaved.

The nurse, who was still the project leader in 1998, reported that she interviews potential volunteers and asks them about their motivation, their experience, and whether they have some back-up at home. As she expressed it, they must have clarified the major questions of life.

It was also required of volunteers that they be able to provide three hours at a time, although they could themselves decide how often they chose to do this. Volunteers in the Copenhagen area get together once every five weeks. Twice a year, there is a one-day course for all volunteers in the entire country. This course provides an opportunity for them to exchange experiences and to obtain information on new developments from outside teachers.

When a family asks for help, the project leader visits them and tries to find a volunteer to go there the day after the interview. Basically, the volunteer listens. In some cases, the carer wants to go out. In other cases, the carer is so tired that he or she only wants to sleep. In these cases, the volunteer stays with the patient.

In other cases, the relatives simply want to talk and the volunteer uses the time to listen. Quite often, the fact that there is someone with whom they can talk is a relief to the family. The volunteers themselves, of whom quite a few are former professionals from the health care sector, find this work extremely meaningful.

This seemed a well-conceived project. During the course of the investigation, the study found several other examples of projects run by voluntary organizations that are similar to the one described above.

5 Some more recent policies for carers

When the data were collected in 1998, new initiatives targeted directly or indirectly at carers were being prepared in almost all of the countries studied.

In Denmark, a three-year experiment was in progress. It was financed by the Disability Unit of the Ministry of Social Affairs. The principal aim of the experiment was to follow twenty couples under 60 years of age, of whom one of the partners had a chronic illness, or a disability due to brain damage. The experiment sought to determine the help that was available, and that which was wanted by the couples. In those cases in which the couples wanted something that was not available, the experiment could provide it. On the basis of the outcomes, the project staff advised the Government concerning legislation. Another function of the experiment involved assessment of the economic value of the work performed by carers. Unfortunately, the outcomes were not yet available at the time of this research.

In Ireland, the Carer's Allowance was under revision and an interdepartmental group was examining the possibilities of tax relief for carers.

In Belgium, a discussion on establishing a long-term care insurance programme was in progress at the time of the study. This discussion resulted in the introduction of such insurance in Flanders on 1 October 2001. This programme provides far less generous insurance coverage than its German counterpart.

In Finland, a carers' policy was also being debated at the time of the study. In fact, Government plans were more far-reaching than those which were realized at the time. Due to the economic recession, only small steps forward have been taken.

Additional information about policies developed after 1998 is available for only two countries included in the study, the United Kingdom and the Netherlands. Sweden, which was not included in the study, is also active in developing a carers' policy.

5.1 A national strategy for carers in the UK

In February 1999, the British government published *Caring about Carers. A National Strategy for Carers*. In the foreword, the Prime Minister states:

> *The national strategy for carers – the first ever by a Government in Britain – sets out what we have been doing, and what we are going to do. It offers practical help in ways which are needed, and which will work. Carers will have better information. They will be better supported. They will be cared for better themselves.*
>
> *This makes a decisive change from what has gone before. While we will continue to make sure that help goes directly to people who need it, we will now ensure that help is offered to carers themselves as well – because helping carers is often a good way of helping those they're caring for. Caring for carers is a vital element in caring for those who need care.*

The Strategy pleads for carer-friendly employment policies, and states that the Government takes action by offering unpaid leave for family emergencies for employees. All organizations involved with carers must now focus not just on the client, patient, or user – but must include the carer.

Under the heading of "information", the following initiatives are mentioned:

- a new charter on what people can expect from long-term care services: setting new standards;
- improvement of the consistency of charging for services;
- good health information;
- NHS direct helpline for carer information; and
- government information on the internet.

Under the heading of "support" can be read:

- carers need to be involved in planning and providing services;
- local caring organizations should be consulted; and
- comment cards, advice surgeries, and carers' weeks are good ways to involve carers.

Under the heading of "care" can be found:

- carers' rights to have their own health needs met;
- new powers for local authorities to provide services for carers;
- helping carers take a break, for which an amount of £140 million for three years is targeted; and
- review of financial support for working carers.

In addition, measures will be taken to entitle carers to a second pension. There will be support for neighbourhood centres, including carers' centres. Extending help to carers to return to work will be considered. A new question about carers is to be inserted in the census. There will be support for young carers, including help at school.

The first commentaries were favourable, although several spokespersons said it was not enough by far. The Association of Directors of Social Services stated that many councils had to cut back on social services, and that this new policy should not founder because there is simply not enough money in social services' mainstream budget.

Approximately one month after the appearance of the National Strategy, another report was published, which also discusses the position of carers. This report is entitled *With respect to Old Age*, and was published by the Royal Commission on Long Term Care (1999).

Among the recommendations of this report is found the statement:

> *Better services should be offered to those people who currently have a carer.*

The Royal Commission found that large numbers of older people being cared for by informal carers receive no services at all. They propose that older persons living with a carer should get the same amount of help as older persons living alone. They ask the assessment process to be 'carer blind'.

The different approaches of the two documents are discussed by Linda Prickard in an article in *Social Policy and Administration* (September 2001). The Royal Commission stresses the importance of providing sufficient services to the dependent person, as if there were no carer. The Strategy wants to improve services for carers, but with the aim of providing better services for those in need of care. Prickard comes to the conclusion that neither of the two approaches to social policy for carers seems on its own to be sufficient:

> *A focus on the interests of carers may mean that the interests of the people they care for are neglected. This is a problem particularly associated with respite care, a major component of both Caring about Carers and the note of dissent by two members of the Royal Commission. Equally, a focus on the interests of the people cared for may mean that the separate interests of carers are neglected. This seems to have happened in the case of the Royal Commission's recommendations for carers. These limitations seem to have arisen partly from the purposes for which the policy documents were developed.*

Prickard recommends a comprehensive approach to policy for carers in which the interests of both carers and cared-for are considered together.

5.2 "Care nearby" – a paper about the support of carers in the Netherlands

This paper (Ministry of VWS, 2001) is not a government paper as is the one in the UK, but rather one which sets out the intended policies of the Ministry of Health, Well-being and Sports. It does not introduce new visions, but promises an amount of more than € 11 million yearly for the support of carers. Compared with funding available to date, this represents a very significant amount.

The following actions are proposed:

- Strengthening the support of carers by ensuring that the entire country will be covered with a network of support centres for carers. Additional funding for the Carers' Association and two other national agencies working in the interest of carers.
- In the assessment of persons applying for long-term care, it should be taken into account that carers must be able to participate in society.
- The infrastructure of volunteer organizations will be strengthened.
- Acute care should be made available in cases of crisis. There should be better cooperation between professionals and carers. Respite care needs to be made available, but it will be necessary to first define the needs more clearly and to look at the conditions concerning organization and finances. An experiment will be conducted with respite weekends.
- A centre of expertise on caring will be set up.
- The effect of caring will be monitored. The central question is to what extent 'informal' substitutes for 'professional' care.
- Research will be conducted on the financial situation of carers.
- With the employers who receive funding from the Ministry and with municipalities, agreements will be made about measures which facilitate the reconciliation of paid employment and care.
- Professional organizations in the social and health-care sectors will be made more aware of the position of carers.
- The Ministry will initiate, with the Carers' Organization, an information campaign targeted at (potential) carers.

5.3 Support policy in Sweden

Johannson, in a paper presented at the Conference of the International Association of Gerontology (Vancouver, 2001), describes the growing interest in Sweden in the work done by carers. There are three main types of support available in Sweden:

- economic support, in the form of allowances for the cared-for person or for the carer and the possibility to take time off work to care for relatives with compensation from the social insurance system;
- respite care, both as residential and day care; and
- counselling and personal support, largely consisting of support groups arranged by voluntary organizations.

Since 1998, the revised Social Service Act includes a new paragraph, which states that:

> *the local authorities should support families and next of kin, when caring for elderly, sick and dependent family members.*

During the period 1999–2001, an extra financial input has been provided, in the amount of 300 million Swedish Kroners for 3 years (± € 11 million per year). Respite services are now available in practically all municipalities and the number of support groups has increased considerably.

6 Conclusions

It would appear that carers are beginning to reach the national political agenda in the countries studied. This is mainly due to two developments:

- An increasing demand for care, whereas in most countries there have been considerable cutbacks in services. This means that the demands made on carers are more pressing. Governments are concerned that carers will opt out.
- Increasing participation of women in the labour market. Labour market policy-makers begin to be aware that there will be growing numbers of employees with caring responsibilities. Policy documents recognize that paid employment and family life must be reconciled.

In some countries, a carers' policy is being developed. The most notable example is the United Kingdom, where a National Strategy for Carers has been adopted. With reference to the British example, we have briefly discussed the question as to whether a policy needs to be developed for carers or whether a good care policy aimed at persons in need of care should be sufficient. In fact, both will be needed. Even if sufficient care for the dependent person can be made available, the special position of carers demands that some specific services be provided for them.

There are no grounds to conclude that people in the countries studied would no longer be willing to care. They do care, without even realizing they are carers. Therefore, awareness-raising is necessary, so that policies aimed at carers will actually reach them. Carers do not need to be stimulated, but they need to be recognized and supported.

The study found different forms of support in the various countries. The following categories can be distinguished:

- emotional support and counselling;
- information, advice, training and education;
- respite care;
- financial support; and
- newer, and not yet well developed, measures to help carers reconcile paid employment and family life.

Carers' organizations can play an important role in the formation of carers' policy. They help to make carers visible and can speak on the latter's behalf. Carers and their organizations should be actively involved in the development policy which concerns them.

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ISSUES OF INTEGRATION AND COORDINATION

CHAPTER 3

THE INTERFACE OF LTC AND OTHER COMPONENTS OF THE HEALTH AND SOCIAL SERVICES SYSTEMS IN NORTH AMERICA

Robert L. Kane

CHAPTER 4

LTC INTEGRATION IN FOUR EUROPEAN COUNTRIES: A REVIEW

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CHAPTER 5

ACHIEVING COORDINATED AND INTEGRATED CARE AMONG LTC SERVICES: THE ROLE OF CARE MANAGEMENT

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Part two

3 THE INTERFACE OF LTC AND OTHER COMPONENTS OF THE HEALTH AND SOCIAL SERVICES SYSTEMS IN NORTH AMERICA, *Robert L. Kane*

1 Introduction

The provision of health care is shaped by several forces:

- the concept of disease;
- design of the health care system; and
- the payment system.

Although it is customary these days to expect that economics drives all behaviour, the solution to the problems of better coordinating the acute and long-term care sectors will require more than a change in payment policies; it demands a revamping of the fundamental care infrastructure. Exclusive reliance on payment-based solutions threatens to address the cost of everything and the value of nothing.

2 Integrating medical and long-term care

A basic first question should be the extent to which we really want to see an integration of medical and long-term care. Many fear that such an integration would mean too great a loss of autonomy for one sector; few think it would be health care. There are already concerns expressed about the dominance of the 'medical' model and the inherent losses in quality of life that it implies. Is it feasible to seek the best of both worlds?

There are certainly differences in the goals and perhaps the underlying values represented by the prototypical health and social service providers. The former are driven by a desire to cure, whereas the latter are more reconciled to cope with extant situations. In the medical context problems are interesting to the extent they are deemed treatable. It is hard to sustain enthusiasm for managing clients who are perceived not to benefit. Medical care is less accustomed to resource restrictions or to thinking in terms of cost–benefit.

One can outline a spectrum of integration that includes the following levels:

- Incorporation
- Integration
- Coordination
- Cooperation
- Tolerance
- Truce

Incorporation – and even integration – implies more surrender of autonomy than either side would likely find acceptable. Tolerance seems too weak a commitment. Perhaps cooperation is a more realistic goal than true integration.

A further caveat for this exploration is the recognition that the priorities in developing countries may differ from those in industrialized countries. Countries still operating in a survival mode may view talk of integration as a luxury.

When integration occurs, it must be on a very basic level. The integration may actually occur more naturally. For example, indigenous health workers may have more rapport with social issues than do highly trained physicians. Indeed, one might argue that training cadres of sophisticatedly educated physicians may widen the gap between health and social care.

From a policy perspective, there are several different opportunities to redistribute effort and resources. Within a sector – such as the health sector – one might decide, for example, to place more emphasis on palliative care in exchange for less intensive acute care; or more efforts might be directed towards better primary care for chronic disease instead of emphasizing technologically complex intensive care.

Alternatively, one might seek to actually shift resources across sectors, using former health dollars. Examples include the purchase of food or housing.

3 The North American experience

In the United States (and to a lesser degree in Canada) the integration of acute and long-term care has depended on integrating the medical and social care funding streams. There is a fundamental belief that such integrated funding is the basis for programme integration. More accurately, it is necessary but 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.

Bringing about this level of integration is difficult. The predominant vehicle has been some variant of managed care, by which is meant a pooling of funds to support an organized approach to providing care. Managed care supersedes traditional health insurance to the extent that it takes direct responsibility for the way care is actually delivered, rather than simply paying for it. Unfortunately, much of what has been launched under the banner of managed care has been primarily minimally modified health insurance with little active intervention (Robinson, 2001; Kane, 1998).

Although there are examples of managed care staff model group practices, like Kaiser, the modal approach has typically featured some variant of subcapitation or hiring a large number of vendors (physicians and medical groups), none of which serve enough of any given target group to make it efficient to change their approach to care to accommodate to the needs of this subpopulation. In essence, each practitioner is only marginally engaged and hence is not motivated to change practice patterns. There is little accountability or direction. Without this investment in infrastructure reform, altering financial arrangements is unlikely to have a substantial impact.

In theory, managed care should be a great facilitator of better integrated acute and long-term care. Its capitated basis should offer incentives more closely aligned with the goals of good chronic care than those under fee-for-service. Specifically, managed care should support an investment philosophy. Better primary care, including comprehensive assessments where warranted, are means to achieve this. It can achieve ultimate savings by reducing the subsequent use of expensive services. Indeed, the success of comprehensive geriatric assessment has been demonstrated in both medical and financial terms (Stuck et al., 1993).

Managed care can also provide a vehicle for the effective use of geriatric services. Whereas such care does not generate substantial income under fee-for-service arrangements, it can be used in a leadership capacity under managed care to provide both referral and consultation services and to provide overall guidance in terms of guidelines or other clinical management assistance. Managed care can afford the management information infrastructure that can help practitioners to take a more extended temporal approach to their care.

Information systems can demonstrate change in patients' status over time and compare their actual to expected clinical courses.

Managed care can provide the oversight to assure that appropriate care is being rendered. It can encourage and assist in seeing that patients and their families play an active role in decision-making, by providing structured environments for them to gain relevant information and explore their values about possible outcomes achievable by alternate strategies.

All of these needed shifts in emphasis and care strategy can be supported by a managed care environment to the extent that they also make good business sense. In essence, their costs (in terms of both money and disruption) must be justified by their potential (and demonstrable) benefits.

However, even in the face of growing evidence that such care is cost-effective, Medicare managed care has shown little inclination to undertake the transition to a chronic care model (Kane, 1998). Geriatrics is not actively pursued (Friedman & Kane, 1993). Case management is rudimentary (Pacala et al., 1995).

The reason for this apparent indifference can likely be traced to the shift in sponsorship. When managed care became an investment opportunity, traded on the stock market, its operating premises changed. Like other publicly-traded programmes, the major concern of its management was to increase the support of shareholders – who, in turn, relied on the forecasts of Wall Street analysts.

In essence, quarterly returns became the dominant issue. Changes in operating structures, which require far more than three months to implement and function, were impediments to short-term profits. As a result, the gap between the proprietary and non-profit Medicare managed care operations widened, but even the latter were reluctant to make heavy investments in changing practice styles without some clear promise of quick rewards.

One major disincentive to developing better chronic care models is the lack of adequate risk adjusters. A managed care company that becomes skilful in managing complex chronically ill persons faces the likelihood of attracting such a clientele. An industry that has done well through favourable selection is not anxious to embrace adverse selection. Without some way to appropriately compensate them for the added costs of caring for more difficult and expensive clients, managed care organizations will be reluctant to develop programmes that will attract them.

4 Models of integrated care

Some models of integrated care are available. There is some limited data to suggest that they produce both financial and clinical benefits, but much still remains to be explored.

4.1 Program for All-inclusive Care of the Elderly (PACE)

PACE stands as perhaps the best model of truly integrated care (Kane, 1999; Eleazer & Fretwell, 1999; Eng et al., 1997; Wieland et al., 2000; Pacala et al., 2000). Developed originally to serve an elderly frail Chinese population in San Francisco, PACE has become a federally-certified Medicare managed care programme. It was designed to serve a niche market, persons eligible for both Medicare and Medicaid who were deemed eligible for nursing home care but still lived in the community.

As might be expected, this is a very small target group of high-risk persons whose capitation rate is substantial. About two-thirds of the money comes from Medicaid, but the Medicare rate is a generous multiple (almost two and a half times) of the base rate. This pool of resources allowed for the establishment of an integrated approach to care, which featured physicians working on salary and a clinical base in adult day health care.

A central part of the model was the active inclusion of all those involved in any aspect of the enrollees' care as part of the core team, with regular team meetings and active information sharing. Innovative efforts were made to avoid the use of either acute or long-term care institutions. Creative ways were found to tap all available resources to permit housing support from other means and to integrate care into that housing.

Because the medical care is provided by PACE physicians, enrollees must forsake their regular providers in order to join. This provision has proved a deterrent to enrolment. Newer versions have been created that are testing the feasibility of replicating the PACE approach but employing physicians under contract, more akin to independent practice associations and downplaying the role of adult day care. The evaluation of the original PACE demonstration project encountered logistical difficulties, but its results suggest that the programme was able to reduce dramatically institutional use with no diminution in care quality (Chatterji et al., 1998).

A few states have attempted to merge the funding for these so-called dually eligible recipients who are covered by both Medicare and Medicaid. This population is considerably broader and more heterogeneous than the mandate for PACE, which is restricted to those eligible for nursing-home care but living in the community. The dual eligible population includes people living in the community at various levels of disability and those residing in nursing homes.

4.2 State programmes

Minnesota had capitated the care of all its Medicaid population some years ago, covering almost all services except nursing-home care. They then took the next step of merging funding for Medicare and Medicaid. Because all effort to enrol Medicare recipients in a managed care programme must be voluntary, enrolment in this merged entity is voluntary.

In the Minnesota Senior Health Options (MSHO) programme, the care is administered by health plans who subcontract with other programmes to provide care elements. The main advantage of this approach is the potential flexibility obtained to develop necessary solutions unconstrained by payment regulations. To provide more coordination, the plans must employ some degree of case management for all enrollees; the intensity corresponds to the level of impairment (Kane et al., 2001).

Wisconsin has developed a somewhat different approach to addressing the dual eligible population. It has implemented a variation of the PACE model. Under the Wisconsin Partnership Program (WPP), managed care programmes operate PACE-like approaches with one major difference; instead of utilizing a physician hired by the programme to provide primary care, the WPP model allows enrollees to use their regular primary care provider. Active case management is provided by a team of nurse, social worker, and nurse practitioner. The latter is responsible for interacting with the primary care physician to replicate the effects of the team meetings under PACE.

Arizona has operated a prepaid system of care for its Medicaid recipients for some time. Those individuals who need long-term care are cared for by county plans that coordinate the acute care paid under a fee-for-service arrangement with Medicare with the capitated LTC. An evaluation of this approach has suggested it has proved quite effective (McCall, 1997).

Texas has also introduced a managed care programme in Harris County (Houston) for its Medicaid recipients. Here too, Medicare is not formally included, but those dually-eligible recipients who elect to receive their medical care through the same health maintenance organization (HMO) receive a richer set of prescription benefits than would otherwise be available.

In ***Canada,*** the province of Quebec has launched an innovative demonstration programme, the Système Intégré pour Personnes Âgées (SIPA), which creates a simulated capitated pool of funds to cover virtually all the medical and social costs of care (Bergman et al., 1997). The first year's experience with this demonstration project indicates that it has produced great consumer satisfaction, but it has not been able to show a major shift in the utilization of hospitals or emergency rooms (beyond a reduction in bed-blockers), or an improvement in health status.

4.3 The Social Health Maintenance Organization

Another programme that provides at least some coordination between acute and long-term care is the Social Health Maintenance Organization (SHMO). Under this programme, managed care organizations receive the full capitated amount (instead of 95%), with the expectation that the additional 5% will be used to provide at least a modest long-term care benefit. The SHMO is not targeted specifically at dually eligible persons, and only a small number of Medicaid beneficiaries are enrolled.

After the initial evaluation showed little impact (Harrington, Newcomer & Moore, 1988; Manton et al., 1993; Newcomer, Harrington & Friedlob, 1990; Newcomer et al., 1995), a second generation of SHMO projects was launched in the hopes of creating a model of care that emphasized more geriatrics and case management (Kane et al., 1997; Wooldridge et al., 2000).

4.4 EverCare

Another area of innovation in integrated care features coordination more than true integration. Several companies have developed special programmes that offer Medicare managed care to nursing-home residents. The pioneer in this area was EverCare, a programme operated by United Health Care (Kane & Huck, 2000). The inducement for such programmes is the higher capitation rates Medicare pays for nursing-home residents.

Although analyses indicate that nursing-home residence *per se* is not a risk factor for higher Medicare costs (in fact nursing-home residents have lower Medicare costs than persons with the same disease and disability burden living in the community), nursing-home residence has served as a convenient administrative marker for such increases in disability. The higher payment, together with a conviction that better primary care can prevent, or at least reduce, the use of hospital care, serves as the rationale for these programmes.

The basic model is based exclusively in areas of Medicare's responsibility. Payment for nursing-home care is restricted to only that mandated by Medicare (i.e. skilled care after hospitalization) and an inducement payment for extra nursing-home care provided in lieu of a hospital admission.

As noted earlier, the strategy for providing more intensive primary care relies heavily on using nurse practitioners as primary caregivers. These nurses are paid for by EverCare but work under the supervision of private physicians with whom EverCare contracts to provide all needed primary care. An evaluation of this programme is currently under way.

5 The chronic care paradigm

The relationships between acute and long-term care are determined by the very constructs that underlie these terms. The predominant acute disease paradigm is an anachronism. It is shaped on 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. Technology (an inclusive term that ranges from biotechnology to prayer) is used to increase the organism's ability to respond to the insult. 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.

In fact, modern epidemiology shows that the prevalent health problems of today (defined in terms of both cost and health impact) revolve around chronic illness. Most of the money spent on health care, especially among older persons, goes towards the treatment of chronic diseases (Hoffman, Rice & Sung, 1996).

However, medical practice seems to ignore this epidemiological reality. A transformation to a strategy designed to deal effectively with chronic disease would require major changes in the fundamental approach to care, including the end of the artificial distinction between acute and long-term care.

Time

As the name implies, an important difference between acute and chronic care is the role of time. Chronic care operates over time. The definition of treatment is measured less in events than in episodes. The expectation of pay-off likewise includes a broader window. Actions taken at one point may yield important benefits later. In the area of geriatrics, for example, a large body of literature demonstrates the value of comprehensive geriatric evaluation and management in reducing subsequent use of both acute hospitals and nursing homes (Stuck et al., 1993; Rubenstein et al., 1991; Rubenstein, Wieland & Bernabei, 1995).

The extension across time implies a value for continuity of care, although this benefit has rarely been established empirically (Wasson et al., 1984). Nonetheless, the segmentation of care by specialty and site of practice has been understandably decried (Manian, 1999). The emergence of 'hospitalists' in the United States suggests a system more akin to that found in the United Kingdom, but without the strong role of primary care providers.

Goals

Chronic care also redefines the goals of care. Disability displaces disease as the central focus. Because the diseases are not likely to be cured, emphasis shifts to identifying ways to prevent their impact on people's lives.

A World Health Organization classification system emphasizes the relationship between disease and disability in terms of a series of transitions (WHO, 1980). A disease is associated with an impairment at the organ level. This impairment can create a functional problem, or disability. This disability can lead to a handicap if the social demands on the person cannot be met or the environmental supports are inadequate. Efforts to ameliorate the environment to maximize functioning have been dismissed as "halfway technologies" (Thomas, 1979) by adherents to the acute care model.

Chronic care implies a different relationship between client and caregiver (Reiser, 1993). Physicians are just transient figures in the client's life. Observations and reactions to disease occur constantly. Active client involvement is crucial to effective disease management (Lorig et al., 1999). This active role may include compliance with prescribed regimens or adjustments to respond to changes in status. No single strategy for improving compliance works consistently (Roter et al., 1998). Involved clients must also be empowered clients. Decisions cannot be made unilaterally by providers.

Decision-making

To play an active role in decision-making, patients must have good information. They need to know the consequences of alternative actions and the full range of alternatives available. Ironically, this seemingly simple list far exceeds the information base for most chronic illnesses. It points to the limitations of medical knowledge and the inability to practise medicine from an empirical basis.

One encouraging approach has been the development of the programme for 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 communication (Kasper, Mulley & Wennberg, 1992; Barry et al., 1988).

Videotapes are used to offer information at a level and depth that patients can understand. The tapes are endlessly patient. Users can watch them as often as they wish, reviewing elements as needed. Equally important, the entire process takes the decision off-line; it allows more time for more careful consideration of options.

Decisions can be made at various levels. Much attention with regard to frail older persons has been focused on advance directives and end-of-life care (SUPPORT Principal Investigators, 1995; Luptak & Boult, 1994). Part of the rationale for this emphasis has been a concern about preserving the autonomy of persons no longer able to express their wishes, but much of it also seems to be hidden rationing (Emanuel & Emanuel, 1994; Teno et al., 1997). It is ironic that more effort is spent assuring the rights of the comatose than those for persons able to express a preference. When asked, many older patients strongly favour treatment (Tsevat et al., 1998).

Another important and neglected area of decision-making occurs around hospital discharge planning. Ideally, this is a time of careful insight, with important options to be considered. Careful discharge planning can make a substantial difference in patient outcomes (Naylor et al., 1999).

Different levels of consideration should be given separately to the most appropriate modality of post-hospital care and the best vendor of that modality (Potthoff, Kane & Franco, 1998). Different factors are involved in each of these discussion points. In practice, these crucial decisions are made under great time pressure with little opportunity to explore feelings and preferences, let alone options.

In much of long-term care, clients may be substantially limited in their ability to play an active role in their own care. They may rely on others, paid and unpaid, for assistance. However, physical limitations do not necessarily imply a loss of decision-making. Unless they are severely cognitively compromised, frail older persons can still play an active role in determining their care. In some cases, the decision-making responsibilities are shared with family. In these circumstances even more time and effort is needed to achieve a useful level of accord.

A greater consumer role in planning and implementing care implies a shift in responsibility for the outcomes of that care as well. An important question involves the degree of liability professionals retain under this arrangement. Can they be held accountable for poor results? It is hard to see them as totally devoid of responsibility, but it seems equally unfair to blame them for the failures of their clients.

On the other hand, they have an obligation to teach and inform. We would not chastise a teacher for the poor performance of a single student, who may have chosen not to attend the lessons; we would question the prowess of a teacher whose entire class failed the test. Likewise, the chain of accountability for providers of care is best seen in the mean performance of groups of patients, not in single instances.

Managed risk

A new paradigm, termed 'managed risk', has begun to emerge in some of the more innovative aspects of long-term care (e.g. assisted living). Under this arrangement, a specific contract is developed that makes explicit the risks involved in opting for care that may be less safe than the most orthodox approach, for example staying at home or going to a place with less clinical supervision rather than entering a nursing home (Kane & Levin, 1998; Kapp & Wilson, 1995). By signing the document, the client acknowledges the risks and agrees to hold the provider harmless for the consequences of that choice; but the levels of accountability for actual services rendered under that arrangement still need to be refined.

5.1 Primary care

Chronically ill persons, especially those receiving long-term care, require active and aggressive primary care. One of the modern paradoxes is the assumption that such care is wasted on such people. Too often they receive superficial attention under the belief that nothing can be done to change their clinical situation, when just the opposite is true.

Frequently, these people have numerous simultaneous problems, which require close management (Redelmeier, Tan & Booth, 1998). Careful attention can improve their status. At a minimum, iatrogenic complications can be averted, such as overmedication. Evidence of undertreatment can be readily found.

For example, a quarter of nursing-home patients with cancer were found to have inadequate pain medication (Bernabei et al., 1998). Demented patients with unrelieved pain may exhibit behaviours that are falsely attributed to their cognitive state. Early recognition of infection can avoid serious complications and unnecessary hospitalizations. Few physicians have had extensive training in how to manage such patients and react to them with avoidance or indecision (McNamara, Rousseau & Sanders, 1992; Gold & Bergman, 1997).

Most of the medical care delivered to nursing home patients in the United States is provided by physicians with little special training in geriatrics. Geriatrics has never flourished in this country (Reuben & Beck, 1994; Institute of Medicine, 1993). Its role has been ill defined; it is neither a specialty nor a branch of primary care (Burton & Solomon, 1993). Geriatricians represent a very small proportion of practising physicians and their numbers are not growing.

While there is some evidence of better trained and better motivated physicians assuming positions as medical directors of nursing homes, most of the direct care is still in the hands of persons not prepared for this role. Physicians complain that Medicare payment regulations (designed to prevent gang visits and other means of fiscal exploitation) make practice in nursing homes unaffordable. Nonetheless, some physician groups have emerged that make a business out of just such care.

One encouraging response to the need for better primary care in long-term care situations has been the emergence of the geriatric nurse practitioner (GNP). These GNPs combine the basic training of nurses with more advanced training in assessment and disease management. In theory, they would retain the person-centred practice of nursing, with its heavy emphasis on prevention and respect for personal values, with skills that would allow them to manage many of the common problems of long-term care patients and to obtain timely help when they need it.

Early reports of their work in nursing homes suggest that GNPs have had positive effects, working both as nursing-home employees and as part of physician practices (Kane, Garrard, Buchanan et al., 1989; Kane, Garrard, Skay et al., 1989; Garrard et al., 1990; Burl et al., 1998). However, it is not clear whether such personnel can avoid the same environmental pressures for productivity that plague physicians in this role.

A growing model of care, best known in conjunction with the EverCare programme (described above), uses these nurse practitioners as a key part of a strategy to provide better primary care to nursing-home patients whose Medicare coverage is capitated in the expectation that such care will save money by reducing hospital use (Kane & Huck, 2000).

The underlying concept of consolidating care should not be lost. Dedicated teams of physicians and nurse practitioners have been shown successful in improving nursing- home care (Reuben et al., 1999). In the context of managed care, much of the primary care is rendered by physicians who participate in some type of contracted arrangement whereby only a small portion of their total effort is directed to the enrollees and especially to aged enrollees. Such a limited penetration into the physician's practice is unlikely to motivate any major changes in practice styles to accommodate geriatric techniques.

One argument for refocusing attention on chronic care in lieu of ageing is to increase the numbers of primary care patients affected, and thereby to increase the chances that physicians would see the needed changes in practice patterns as more warranted.

5.2 Role of prevention

Another response to the rise of chronic illness has been greater advocacy for prevention. This cause has been taken up in several ways. Building on a thesis of compression of morbidity (Fries, 1983; Vita et al., 1998), some have argued for more direct efforts to change health-related behaviours in an effort to forestall disability.

Some evidence of success in changing such behaviours, even in older persons, has been demonstrated with positive cost–benefit ratios (if modest effect sizes) (Fries et al., 1998). Others have argued that the key role for prevention lies in preventing the onset or worsening of disability.

In this model, care is directed towards maintaining or improving a person's function. It is more akin to rehabilitation. A particular concern focuses on disability acquired through disuse. Indeed, some work shows at least modest functional improvements among very frail nursing-home residents who engaged in minimal structured exercise programmes (Fiatarone et al., 1994).

Traditional primary prevention applied to ageing would include attention to such problems as falls, smoking, osteoporosis, and flu shots. The literature on falls prevention is mixed. A recent Cochrane Collaborative Review suggests that there is some preponderance of evidence favouring interventions, but the case is far from overwhelming (Gillespie et al., 2001). An at least equally promising strategy for high-risk subjects may be wearing hip protectors (Parker, Gillespie & Gillespie, 2001).

The data on smoking suggests that stopping even at advanced ages is associated with health benefits (Jaijich, Ostfeld & Freeman, 1984). New medications, like bisphosphonates, and estrogens have provided new ways to supplement the basic role of calcium (with vitamin D) and exercise (Larson, 1991). Although there is great enthusiasm for the benefits of influenza vaccine and pneumococcal immunization, some data show a paradoxical increase in hospitalization rates for older persons for influenza and pneumonia just as the immunization rates are increasing (Hebert, 2001).

5.3 Iatrogenesis

Discussions about the costs of care have generally failed to appreciate the central role of iatrogenic events. The inappropriate use of services not only adds directly to the costs, it creates a series of potential problems that multiply the overall cost (Fisher & Welch, 1999).

Iatrogenic events can be both overt and covert. Some attention has been paid to the extent of errors associated with hospital care (Leape, 1994; Steel et al., 1981; Kohn, Corrigan & Donaldson, 2000). These add to the costs of such care, but many more problems go unappreciated. Technological imperatives place older people in intensive care units where they can be closely monitored but at the risk of becoming disoriented (Inouye & Charpentier, 1996; Inouye et al., 1999). Aggressive drug therapy can address a variety of physiologic perturbations, but the cumulative negative effects of numerous medications are rarely appreciated.

Data on the wide variation in practice patterns has been cited as evidence of the likelihood of overzealous treatment (Wennberg & Gittelsohn, 1982; Wennberg, Freeman & Culp, 1987; Wennberg & McAndrew, 1996), but no estimates have yet been made of the savings that could be achieved in both costs and quality if unnecessary marginal care was reduced.

However, in the context of chronic care, perhaps the most direct goal for prevention is to avoid catastrophic events, which have both fiscal and health implications. Good chronic care should be able to manage problems in such a way as to allow early detection of changes in patients' status that can serve as a trigger to early interventions. These changes in management can avert costly and dangerous hospitalizations.

5.4 Rehabilitation

The role of rehabilitation in the context of integrated care may raise some issues. The more socially-driven models of care often seem to emphasize compensation over active efforts to improve function. In those situations, care planning involves an assessment of limitations and a plan to provide services to compensate for the areas of functional impairment. Such a compensatory strategy can feasibly promote dependence in the long run. A rehabilitative strategy is more likely to work on improving the patient's ability to function independently. Clearly, a balance is needed.

Rehabilitation in the United States is provided under a variety of venues. Most often, it occurs as a follow-on to an acute hospitalization and is referred to as post-acute care (PAC). PAC can be provided in a formal rehabilitation unit, or in a nursing home. It can be offered at home through a home health agency or it can be given on an outpatient basis. Part of the decision is based on funding coverage and part on availability of resources, but much of it also seems to depend on professional preferences. There is substantial geographic variation in the use of PAC in general and in the type of PAC used (Kane, Lin & Blewett, 2001).

In one study of PAC, it proved difficult to predict what patient characteristics were associated with receiving different venues of PAC (Kane et al., 1996). However, different forms of PAC are associated with better outcomes and with more cost-effective care (Kane et al., 1998; Chen, Kane & Finch, Winter 2000/2001; Kane et al., 2000).

The rapid growth in PAC expenditures under Medicare has prompted changes in the way this care is reimbursed. Prospective payments systems have been introduced for nursing homes and home health care under Medicare, with a third approach planned for rehabilitation. Each of these approaches is self-contained despite the fact that many patients use several different types in the same episode of care (Kane et al., 1996), and that the various approaches in effect compete with each other.

A closely-related subject is the geriatric evaluation and management unit. This has been a well-studied area, but the results of multiple randomized controlled trials (RCTs) do not paint a clear picture. In general, there seems to be a large body of evidence that such an investment can pay dividends (Stuck et al., 1993; Rubenstein et al., 1991), but it is not clear that it will save money (Boult, Kane & Brown, 2000). Moreover, efforts at targeting such care to those most at risk are not necessarily associated with the best results; while seemingly modest efforts with unselected subjects seem to produce quite dramatic effects (Stuck et al., 1995; Hendriksen, Lund & Stromgard, 1984).

5.5 End-of-life care

Beliefs about how to manage the end of a person's life have changed dramatically over the last decades. Much of this transformation can be credited to the hospice movement (Westbrook, 1980; Pickett, Cooley & Gordon, 1998) and the growing interest in thanatology (Kübler-Ross, 1969).

End-of-life care is closely related to rationing in that it offers a way to limit expensive, perhaps futile, care in an ethical context driven by consumer empowerment. Efforts to encourage less aggressive care at the end of life have met with mixed success (SUPPORT Principal Investigators, 1995). To the surprise of some investigators, many older people are not anxious to cede access to potentially life-saving technology, even if the likelihood of benefits is slim (Tsevat et al., 1998). Federal law (the *Patient Self Determination Act* of 1990) now requires that all persons entering a hospital or a nursing home be given an active opportunity to establish their advance directives.

There is an important distinction between advance directives and active decision-making at the end of life. The former may involve making hypothetical choices about feared outcomes that may end up robbing the patient of valuable options.

Indeed, making decisions about situations that have not been experienced may cause the person to weight potential consequences more strongly than would be the case when they were actually confronted (Kane, 1996).

The hospice movement introduced the concepts of modern pain management, where adequate analgesia is provided without false fears of creating drug dependency (Gloth, 2001). Likewise, palliative care is directed towards making patients and their families as comfortable as possible through a combination of symptomatic treatments and emotional support. Hospice patients, once they are assured of responsiveness in times of emergency, are often very anxious to die at home.

Ironically, what began as a counter-cultural movement (hospice) has become a victim of its own bureaucracy. In some communities hospice care is given by home health agencies, which find it easier to operate without a formal hospice licence and all the problems associated with obtaining one.

5.6 Information systems

Chronic care requires an information platform. It is essential to track changes in patients' status over time and to relate outcomes to treatments. Clinicians' observations need to be structured and directed to emphasize salient information in the midst of so much data on so many conditions. Information needs to be shared among the variety of involved parties. Duplicate efforts to collect the same data need to be eliminated and care better coordinated.

Computers and electronic networks provide a promising mechanism to achieve these ends. It is now feasible to introduce information systems that can track clinically relevant parameters and indicate when the patient's course is significantly straying from what is expected (Kane, 2000).

Early indications of deviations from an expected course provide an opportunity for modest mid-course corrections. Patients can actually provide much of the data directly and thus become more actively involved in their own care.

Ironically, a substantial body of research has been devoted to testing innovative approaches to providing better chronic care. The results of many randomized clinical trials are shown in Table 1, which is based on an earlier review (Boult et al., 2000).

The paradoxical observation that follows from this review is that despite often strong evidence of efficacy, very few of these innovations have been widely implemented. At the same time, case management, which is the approach with the least supportive evidence, has been actively embraced as a prerequisite for most efforts to integrate medical and social care.

Table 1. Effectiveness of interventions in chronic conditions, as shown in randomized clinical trials

	Satisfaction	*Function*	*Utilization*	*Costs*	*Mortality*
Geriatric evaluation and management	+	+	-	+	=
Interdisciplinary home care	+	+	+	+	
Self management	+	+	+	+	
Group care	+		+	+	
Home hospital	+		+	+	=
Disease management			+	+	
Professional dyads in nursing home			+		=
Acute care for elderly wards	+	+	=	=	=
Transitional care	=	=	+	+	=
Case management		=	=	=	=

Key:

+ : significant increase or significantly greater
– : significant decrease or significantly less
= : no significant difference

Adapted from Boult et al., 2000

6 Conclusions

Long-term care is basically a social service directed at persons with severe chronic health problems. As such, these people are also likely to require active medical care, which should be closely coordinated with their supportive care. Indeed, nursing-home residents, for example, use on average about three times as much care as non-residents. This difference is due to their disability status rather than their residential location.

If the chronic care model is realized and applied, those providing supportive care – be they paid or unpaid – should do so in conjunction with medical care providers. There should be a shared set of objectives. Each component may emphasize its own particular aspects, but each should be aware of the other's and neither should conflict. Too often, the two groups exhibit philosophically different approaches to care. The long-term care providers appear to work from a premise that their goal is to compensate for their clients' deficiencies (primarily functional). Good care produces services that address these inadequacies without incurring any complications. Thus, the well-tended frail older person who is free of pressure sores and urinary infections may be viewed as a success. Medical care providers tend to assume a more aggressive stance. Although most do not expect to achieve cures, they do aim for a change in the client's clinical trajectory as a result of their efforts. In many cases, the benefit is best expressed as a slowing in the rate of decline.

This same therapeutic orientation can and should become a goal for long-term care. However, demonstrating such success can be difficult. It requires some point of reference, because the only visible evidence is often of decline. The evidence of success lies in comparing the actual course to what can be reasonably expected.

An important component of chronic care is early intervention. Caregivers, both formal and informal, need to be sensitized to detecting early signs of change in status and intervening before a crisis is reached. Such a surveillance system requires systematic collection of information and education of users. At present, substantial effort goes into data collection, especially in nursing homes and home health care, but little of that information is used to direct care. Ironically, while many American nursing-home personnel complain about the burden of data collection from the Resident Assessment Instrument (RAI),[1] others who use the same information system in other countries voluntarily extol it as a great leap forward (Ribbe et al., 1997; Sgadari et al., 1997; Phillips et al., 1997; Fries et al., 1997).

[1] The RAI has two components: the Minimum Data Set (MDS), which is a standardized set of observations, and the Resident Assessment Protocols (RAPs), which are lists of items to consider in evaluating a potential problem suggested by the MDS.

Part of the problem may lie with its mandatory imposition from outside, but another part derives from its lack of clinically-useful information to track disease status. It needs to be translated into a simple tracking system that will allow caregivers to focus on relevant items more frequently without being burdened with a comprehensive measure.

Coordination of acute and long-term care is impeded both culturally and programmatically. We have already noted the differences in philosophy between medical and long-term care providers. Often the long-term care professionals see themselves as protecting their clients from overly-aggressive medical activity. Because the price of failure (an untoward event) is higher than the rewards for success, an aura of therapeutic nihilism sets in. Long-term care, especially nursing-home care, is actively regulated. Most of the regulations penalize mistakes; few reward caring.

A major source of schismatic care is payment. In general, acute care (even if it is for chronic problems) is covered by Medicare, whereas long-term care is predominantly paid for either by Medicaid or out-of-pocket. These different payment sources come with different eligibility rules, different measures of success, and different incentives. In general, long-term care payment is based on the client's level of disability.[2] Medical care is usually paid for on a piece-work basis. Both are increasingly being brought under various forms of prospective payment. Under the long-term care prospective payment models, greater care needs (reflected usually in greater levels of disability) generate greater payments. Hence, the unstated incentive is to create or maintain disability, although everyone vehemently denies that any provider would actually respond to such an enticement.

For both groups, the time horizon is usually short. Prospective payment for nursing homes is calculated on a daily basis. Home care may eventually use episodes as the basis for the calculations but no decisions have yet been made. Neither has built-in incentives to employ some concept of investment, whereby more care at an early stage might produce benefits later.

Coordinating payment is a necessary but not sufficient condition to effect integration of acute and long-term care. Major changes in the infrastructure are required. Before those changes can be even attempted, it is necessary to gain the physicians' attention. As long as physicians view care of older persons as at best only a modest portion of their practice activity, they will not be receptive to considering the sweep of practice changes needed to effectively address chronic disease.

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[2] Medicaid eligibility first requires a stipulated level of poverty, expressed in terms of income and assets.

However, most physicians have been extremely reluctant to embrace geriatrics. In the United States, for example, some physicians who took and passed the certification for added qualifications examination kept that fact a secret, lest they be expected to see a preponderance of geriatric patients. The answer may lie in redefining the issue, away from geriatrics *per se* to the broader purview of chronic care.

6.1 Potential for integrated care

Many observers of contemporary chronic care recognize the disadvantages of uncoordinated care. Beyond the effort that may go into cost shifting and the potential for duplicate billings, there is the promise of greater efficiency. There is considerable interest in seeking ways to integrate such care, especially for the so-called dual eligibles (those covered by both Medicare and Medicaid). Several demonstration projects designed specially to respond to this integrated funding opportunity have been authorized; a few are under way.

Integrating medical and long-term care is not as simple as it at first seems. Each faction views the other as a rich potential source of resources to be redirected its own way. Historically, long-term care has emerged as the junior partner. Medical care is more dramatic and seems to be able to argue for the lion's share of the resource pool.

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4 LONG-TERM CARE INTEGRATION IN FOUR EUROPEAN COUNTRIES: A REVIEW, *Dennis L. Kodner*

1 Introduction

Ageing is a global phenomenon. Whether in the so-called 'developed' or 'developing' world, nations are experiencing, or will ultimately experience, the societal consequences of an ever-increasing elderly population, including the challenges of chronic illness, disability, and long-term care.

The frail elderly, for demographic, economic, and quality reasons, have elevated long-term care to an issue of especial importance in many industrialized countries.[1] It is only a matter of time before developing countries[2] face the very dilemma of how to best finance, organize and deliver long-term care services.

'Long-term care' (LTC) is part health care and part social service. It encompasses a broad array of primarily low-tech services provided by paid professionals and paraprofessionals – as well as unpaid family members and other informal helpers – to individuals with chronic, disabling conditions who need help on a prolonged basis with daily activities of living.

These activites include personal care (e.g. bathing and grooming), household chores (e.g. meal preparation and cleaning), and life management (e.g. shopping, medication management, and transportation) (Feder, Komisar & Niefeld, 2000; WHO & Milbank Memorial Fund, 2000).

[1] The issue of long-term care is important to people with disabilities of all ages. However, since disability increases with age, the group most likely to need services and the preponderance of users will be aged 65 and over (Jacobzone, 1999). This discussion will focus on the elderly population.

[2] More specifically, countries categorized by the United Nations Development Programme (UNDP) as either *Medium Human Development* or *Low Human Development.*

In addition to direct, hands-on personal care and ongoing supervision, long-term care services include the use of skilled nursing and therapies (e.g. physical and occupational therapy) to treat and manage chronic conditions, 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) (Stone, 2000).

This mix of services, whether delivered in home, community-based, or institutional settings, is designed to minimize, restore, or compensate for the loss of independent physical, cognitive, and/or mental functioning.

Industrialized countries, despite differences in health and welfare policies (i.e. social services, income maintenance, and housing), financing arrangements, and programme frameworks, are to varying degrees struggling with issues related to long-term care access, resource allocation, coordination, spending, and the division of responsibility between state, family and private sectors (Tilly & Stucki, 1991; OECD, 1994; Brodsky, Habib & Mizrahi, 2000; Baldock & Evers, 1992).

The fragmentation of long-term care services and the lack of continuity within and between the health and social service sectors have emerged, in particular, as major themes.

This section will:

- first explore the problems of coordinating long-term care at the structural, service delivery, and client levels, and the need for strategies to improve the integration of services;
- then, examine and compare various 'state-of-the-art' approaches to long-term care integration in four industrialized countries – Denmark, Germany, the Netherlands, and Sweden – including their respective policy, financing, and service delivery contexts; and
- finally, conclude with a discussion of the general lessons from this analysis of the experiences of these select countries.

Clearly, in shaping long-term care systems, countries must respond to their own values and resources. Nonetheless, we can learn from each other, despite the various limitations inherent in cross-national comparisons (Kodner, 1999a; Kodner, 1999b). As Kane, Kane & Ladd (1998) state:

> *Developing nations simply cannot afford the patterns of long-term care that have been established by their wealthier counterparts. One hopes they can learn from the experience of those that have already passed through this demographic revolution and avoid some of the mistakes that predecessors have made.*

2 The logic of integration in long-term care

'Integration' of health and social care, especially for the frail elderly, became one of the buzzwords of the 1990s (Kodner & Kay Kyriacou, 2000). Integrated care is receiving increasing attention in the policy and practice arenas of both North America and Western Europe as an important framework for addressing the unique needs of the long-term care population, as well as other groups with chronic conditions.

Like a Rorschach test, the term 'integrated care' has many meanings. For present purposes, this section considers integrated care to be a discrete set of policies, methods, and organizational models designed to create connectivity, alignment, and collaboration within and between the cure and care sectors at the funding, administrative, and/or provider levels.[3]

The main goals of integrated care are to:

- enhance quality of care and quality of life; and
- improve system efficiency for clients whose complex problems cut across multiple systems and providers.

The need for integrated approaches to care is partly a function of the nature of systems *per se*, and partly a reflection of the specific characteristics of target populations and their 'fit' with the existing infrastructure of health and social care. From a general perspective, all systems are comprised of ***interdependent*** parts, which are supposed to play ***complementary*** roles (Scott, 1961; Thompson, 1967).

[3] Adapted from Kodner & Kay Kyriacou (2000).

However, the division, decentralization, and specialization frequently encountered in the architecture of more complex systems often interfere with their efficiency and effectiveness. Therefore, the fulfilment of system aims necessitates cooperation among and between the various parts of the whole (Andersson & Karlberg, 2000). When it comes to the overall health system, the lack of integration means that patients get lost, needed services either fail to be delivered, or are delayed, and there are less than optimal outcomes (Berwick, 1991).

The community-dwelling frail elderly are an especially vulnerable group, and are most likely to benefit from integrated care. They have complicated and ongoing health needs, experience difficulties in everyday living, require a mix of medical services and social supports, and receive care in and out of various institutional settings (Kodner, 2000).

For both clients and family carers, the mostly incurable, unpredictable, and costly nature of the chronic, disabling conditions from which the clients suffer presents difficult challenges in terms of arranging care, preventing, and managing crises, transitioning from one type or level of care to another, and maintaining health and functioning (Kodner, 1995).

The challenges are equally daunting on the provider side. 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, maintenance, rehabilitation, and transition, and performing all of these activities within existing funding constraints (Kodner, Sherlock & Shankman, 2000).

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

Moreover, health and social care distinctly differ in terms of language, clinical roles, responsibilities, and service approaches (Brickner et al., 1987). The end-result is that the delivery of needed long-term care is often fragmented and uncoordinated, and can also create confusion and discomfort for the frail elderly and their families (Brodsky, Habib & Mizrahi, 2000).

An oft-recommended antidote is the creation of a so-called ***continuum of care***. This comprises a connected and coordinated array of services capable of matching, over time and at various stages of disability, the needs and preferences of long-term care clients with the most appropriate settings of care (Evashwick, 1987).[4]

Integration is at the core of this concept, and occurs at various levels of intensity and completeness. According to Leutz (1999), there are three available integrating strategies:

- linkage;
- coordination; and
- full integration.

In 'linkage', health and social service institutions and providers work together as best they can, usually on an ad hoc basis, within the context of existing, fragmented financing and delivery arrangements. This is the minimalist, least-change approach.

'Coordination', on the other hand, is a more formal structure designed to form a bridge between clients and services, by minimizing or, at times, eliminating some of the identified organizational and administrative barriers. Nonetheless, this is also done within existing frameworks.

Finally, 'full integration' represents the complete overhaul and consolidation of all or most responsibilities, resources, and funding for long-term care client management and care. This is most often accomplished through the creation of a single, new, community-based system with broad clinical and financial responsibility and accountability over the entire continuum of health and social care.

[4] Although much of the gerontological literature advances the idea of a 'continuum of care', some experts (for example, Kane et al., 1998; and Stone, 1999) suggest that the paradigm is overly restrictive. Their argument is that there is an essential interchangeability between many services and settings. Therefore, needed care can be provided in any number of ways, depending on a variety of individual, familial, and policy factors (Stone, 2000).

LONG-TERM CARE

A widely held belief, most prevalent in the United States, is that the fully integrated continuum of care model sketched above is best equipped to provide comprehensive services to long-term care clients. This is due to its capacity, at least theoretically, to improve care coordination and continuity; streamline disjointed services and systems; eliminate duplication; reduce administrative and service costs; and promote the more equitable allocation of resources (Kodner & Kay Kyriacou, 2000).

However, as pointed out by both Brodsky, Habib & Mizrahi (2000), and Stone & Katz (1996), three main concerns have been expressed about this approach:

- Long-term care, both needs and services, might receive less priority or be neglected in a system in which they are subsumed by general health care and acute medical needs.
- It is questionable as to whether an appropriate financing mechanism can be developed to adequately compensate for the costs of long-term care, as well as eliminate any disincentives to avoid complex, high-risk, high-cost clients or shift their costs to the medical side of the system.
- There is a general discomfort with applying the same cost-containment principles found in medical care to the provision of long-term care services in such global systems.

In response to these critiques, some proponents have suggested a partial approach to full integration as a first step, namely, the integration of home- and community-based long-term care services (with or without the folding-in of homes for the aged, nursing homes, and special housing).

None of the national models described in the next section fits under the rubric of full integration. However, the section will include examples, though not exhaustive, of various linking and coordination approaches used in the four countries under review.

These models fall into one or more of the following categories:

■ *Administrative consolidation*

When the responsibility for long-term care is fragmented among multiple agencies and levels of government, this affects client responsiveness, as well as quality and care outcomes (GAO, 1994). Therefore, 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.[5]

The reorganization of the above activities can help eliminate complex and overlapping programmes and services, including differences in eligibility criteria, service levels and availability, as well as simplify long-term care access, improve the coordination and continuity of care, and better manage system resources.

■ *Co-location of services*

The fragmented nature of long-term care causes numerous obstacles for both clients and providers. 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 enhance 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.

In addition to these client-centred benefits, 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.

[5] The devolution of administrative responsibility for long-term care services to a single organization or government agency at the local or regional level sometimes involves oversight and/or management of public funds. Clearly, such financial responsibility, especially when located closest to the client population, can be a powerful integrating tool. While this section will include examples of this type, a more detailed discussion of funding for long-term care is found in a WHO report by Brodsky, Habib and Mizrahi (2000).

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 (Scott, 1993). Networking is a major method to improve the way organizations work together (Alter & Hage, 1993), and is increasingly found in health and hospital systems in the United States and other countries (Shortell & Kaluzny, 1994).

Organizational collaboration in these strategic alliances is achieved, both vertically and horizontally,[6] 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 (Evashwick, 2000). A major emphasis is on creating and sustaining an effective, client-centred continuum of care.

Well-designed care networks, operating within the context of committed leadership and firmly established working relationships, offer the potential to improve client care through better coordinated services. Nonetheless, according to CSHSC (2000), only sketchy evidence to date exists (in the American context) on the effectiveness of such networks, particularly with respect to their ability to create the much-hoped-for experience of 'seamless care'. (For more on this concept, see *Chains of care,* opposite.) This probably reflects the considerable challenges involved in meshing different and varying organizations, cultures, resources, and personnel.

Case management

Also known as 'care management', case management is a comprehensive and systematic process of assessing, planning, arranging, coordinating and monitoring multiple long-term care services for the individual client across time, setting and discipline (Kodner, 1993).

[6] 'Vertical' integration means combining two or more organizations that have different positions in the distribution channel, e.g. a hospital and a home care organization. 'Horizontal' integration, on the other hand, means combining two or more organizations that have the same position in the distribution channel, e.g. two home care organizations (Mission: Medical, 2000). Obviously, the former strategy is more geared to building a continuum of care.

The process operates at the administrative, service delivery and clinical levels, and has several goals: to enhance choice and flexibility in service delivery; improve coordination between services; and increase the efficiency and effectiveness of home and community-based care (Davies, 1994).

Case management activities are performed by an individual case manager, or by a team of health and social service professionals. It is also undertaken in a variety of organizational environments (e.g. in a freestanding local or regional entity with formal or informal responsibilities for 'brokering' long-term care services; an insurer or other funding agency; a provider institution like a home care organization, medical clinic or hospital; or supportive housing). Finally, the case management function can stand alone, or can be bundled with other administrative and client management activities as, for example, when it is part of a 'chain of care' (see below).

While case management should not be considered a panacea for what ails the long-term care system, an international review of case management experience by Davies (1992) suggests that this integrating approach can help long-term care clients remain in the community, as well as positively impact effectiveness and efficiency (see Chapter 5 in this volume).

■ *Chains of care*

'Chain of care' means the successive clinical steps (usually guided by clinical guidelines, protocols and care maps) and supporting organizational arrangements necessary to coordinate services, as well as manage client transitions on a longitudinal basis within and between agencies/providers in the health and social service systems (Andersson & Karlberg, 2000). The purpose is to achieve 'seamless care', that is, the smooth and uninterrupted provision of necessary care (Southworth, 1992; Hibberd, 1998; Burda, 1992). One variant of the chain of care idea is 'disease management'.

Disease management is a systematic, population-based approach to patient care and outcomes improvement by coordinating clinical interventions and resources throughout the life cycle of a particular disease or condition and across the entire health care continuum (Kodner, 1998). At the core of both approaches is the use, in one form or another, of multidisciplinary or interdisciplinary teams,[7] and case/care management (see above).

The chain of care approach is applicable to all patient/client groups, but most especially to vulnerable individuals with serious chronic conditions. This group, including the frail elderly, often receives a mix of health and social services, and requires the care of both medical generalists and specialists in various clinical settings. The population also experiences day-to-day problems which, in part, can be ameliorated by lifestyle changes or prevention.

■ *Service-enriched housing*

Housing is the 'where' in long-term care (Kodner, 1996). For the frail elderly, the presence or absence of elderly-friendly and elderly-capable housing arrangements (i.e. physical environments that are flexible, adaptive and supportive of independent living as disability levels change over time) augmented with appropriate services, can make the difference between continued community living or admission to a nursing home (Pynoos & Liebig, 1995; Brink, 1998).

According to Pynoos (1992), housing and long-term care have long been considered as separate domains, each with its own set of programmes, regulations, and funding sources. During the past two decades, however, the notion that housing is solely 'bricks and mortar' has begun to change internationally.

[7] An 'interdisciplinary team' is a highly structured and intensely collaborative group of professionals who are jointly responsible for the coordination and management of a client's care (Williams et al., 1987). The 'multidisciplinary team' is usually a less full-blown approach to communication and cooperation between providers (Kodner & Kay Kyriacou, 2000). However, both terms are sometimes used interchangeably.

More and more, housing is viewed as a viable long-term care resource, despite continuing and unresolved boundary issues on the policy, regulatory, and funding levels. The re-conceptualization of housing as an important element in the continuum of care reflects recognition of the special needs of the frail elderly and growing demands for more quality-of-life-enhancing and cost-effective alternatives to long-term care institutions (Regnier, 1994).[8]

There are two main strategies available to enhance the capacity of housing programmes to support the frail elderly living in the community. One option is to 'bundle' health and social services with housing, thus providing a support system in the particular setting. While this may enhance accessibility and efficiency, it can also limit residential choices.

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 (Pynoos, 1994).

To make the latter idea tenable, however, in-home personal care, the services of a day centre, and transportation must, at a minimum, be affordable and readily accessible. Case management can also be helpful in assisting residents in managing the entire environment, including their housing, health, and human support needs (Heumann & Boldy, 1993).

[8] While the integrating role of housing is the focus of this section of the chapter, another interesting and related approach is the use of nursing homes as the base for community outreach. Nursing homes, which arguably represent a type of housing with the widest and most intensive range of services, can be used to provide a variety of home and community-based services to frail elderly persons living in surrounding neighbourhoods.

3. A review of LTC integration models in four countries

3.1 Denmark

3.1.1 Background

As of 1997, Denmark had a population of 5.3 million, 0.8 million (14.9%) of whom were age 65 and over. Of these, 359 000 (6.8%) were age 75 and over (OECD Health Data, 1999).

Denmark was one of the first industrialized countries to adopt a community care policy which places heavy emphasis on both self-determination and deinstitutionalization, and also gives priority to domiciliary (home) care (Petersen & Rostgaard, 1999). Today, Denmark stands out as having one of the most progressive programmes for the elderly, even among its very generous Nordic neighbours (Kane, Kane & Ladd, 1998).

Health care in Denmark is generally considered to be a public responsibility. Virtually all services (including primary and specialty physician care, hospital care, and pharmaceuticals) are financed, planned and operated by the 16 county (province) level regional authorities within the framework established by the national government through its Ministry of Health.[9] Health care funding derives primarily from general taxation (about 85%), and all residents, regardless of age, employment or socioeconomic status, have free access to nearly all medically-related services under the Public Health Security Act (Friis, 1979; van Kemenade, 1997; Ministry of Health of Denmark, 2001).

In addition to a very limited health care portfolio, the 275 municipalities (in Danish, *Kommune*), are totally responsible for running the local social service system. This includes long-term care and housing services for the elderly and other age groups. For most social services, the main legal basis is the 1998 *Social Service Act*, which the Ministry of Social Welfare oversees at the national level. Another important legal framework is the 1987 *Act on Housing for Older and Disabled Persons*, which governs housing provision. This law is noteworthy for its measures to prohibit the building of new nursing homes, and the support provided for their gradual replacement by different forms of 'special housing' for the frail elderly (Gottschalk, 1995).

[9] The Danish health care system, which is characterized by far-reaching administrative decentralization, gives the responsibility for certain services (home nursing, and preventive programmes such as public health nurses, school health, and child dental care) to the local (municipal) level.

The lion's share of social service costs is financed by local taxes, although the municipalities receive additional reimbursement by means of block grants, equalization grants, and temporary subsidies from the national government to promote the selective expansion of services (Petersen & Rostgaard, 1999). User fees (for home help services) and rents (for institutional and housing services) are levied, but play only a minor role in the social service funding scheme.

3.1.2 Models and examples

■ Administrative consolidation

The municipalities are responsible, under the social service rubric, for the planning, organization, delivery, and financing of care and help at home (both home help services paid for with social service funds and home nursing services paid for with health care funds), and in day homes and centres, nursing homes, and various forms of housing for the elderly. The majority of these services is publicly provided, that is, directly operated and delivered by the municipalities. However, depending on the municipality, some services are outsourced or contracted out to local non-profit organizations. Under this structure, training and staffing by municipal workers is centralized, and human resources are somewhat interchangeable.

■ Co-location of services

In many municipalities, the community centre is the base for home help (and, sometimes, home nursing) services,[10] and also sponsors other activities geared to the community-dwelling elderly (Lindstrom, 1998). The latter can include various health services (e.g. health promotion, and rehabilitation services), information and referral, day care, meals (both congregate and home-delivered), hairdressing and pedicure, transportation, volunteer services, and a variety of social, cultural, and recreational activities. A mix of independent and frail elderly usually attend these neighbourhood-based centres, and intergenerational programming may also be involved.

[10] The terms 'home nursing' and 'home help' are used throughout this section. 'Home nursing' refers to the medically necessary treatments (e.g. injections and wound care) provided by professional nurses at home, usually as prescribed by a physician. 'Home help' refers to the personal care services (i.e. ADL assistance) and domestic tasks (e.g. shopping, meal preparation, and cleaning) provided by a range of paraprofessionals, including personal care workers, homemakers, and housekeepers.

Care networks

For a brief discussion, see the section on *Service-enriched housing* below.

Case management

Denmark has adopted a comprehensive system of assessment and client management for elderly persons living in the community (Petersen & Rostgaard, 2000). According to Merlis (2000) this model entitles everyone age 75 and older to at least two preventive visits annually from a case manager employed by the municipality in order to evaluate individual needs, and assist with planning for independent living. Clients needing formal care are further assessed by a home care manager, and the resulting care plan ends up as a contractual specification for needed services. If the client disagrees with this service allocation, it can be appealed. Home-help workers and home nurses also work closely together to coordinate their services, and ongoing care is regularly monitored by the home care team. Back-up consultation from the medical side of the system is often provided by hospital-based geriatricians or geriatric teams, particularly when home care clients present complex problems or institutional placement is indicated (Nussberg, 1984; Stetvold et al., 1996).

Service-enriched housing

As discussed earlier, nursing homes (and other more institutional types of housing called ***sheltered housing***) are in the process of being phased out. Various forms of service-enriched housing are being developed in their place with the active support of the municipal and national governments. The goal is to create non-institutional, but supportive living arrangements for the elderly with varying levels of functioning. Such housing is often located near, and linked with existing nursing homes, sheltered accommodation, day homes or day centres and/or community centres in order to maximize the use of personnel and facilities, as well as ensure convenient access to home help, home nursing, and other community services (Landsberger, 1985; Gottschalk, 1995; Merlis, 2000). Some of these vertically integrated arrangements are designed to promote ‘ageing in place’, and some are beginning to function as nascent ‘care networks’ (Petersen & Rostgaard, 1999).

3.2 Germany

3.2.1 Background

As of 1997, Germany had a population of 82.2 million, 12.6 million (15.4%) of whom were age 65 and over. Of these, 5 141 000 (6.3%) were age 75 and over (OECD Health Data, 1999). Before 1994, Germany's system of public support for long-term care was institutionally-biased, means-tested, and administered at the provincial level by the states (known as *Länder*) (Scharf, 1998; Hughes, 2001). Three main issues (the increasing fiscal pressures on the states; the growing perception that the then-existing system compromised the German notion of 'social solidarity'; and the belief that the supply and quality of formal services was inadequate) led to the 1994 enactment of legislation creating a universal social insurance programme to cover long-term care (Schneider, 1999; Brodsky, Habib & Mizrahi, 2000; Vollmer, 2000). The programme, known as Social Dependency Insurance (SDI) (in German, *Soziale Pflegeversicherung*), is financed through mandatory, income-related premiums. The system, which gives priority to care in the home over institutional care, became operational between April 1995 (for home care) and July 1996 (for institutional care).

Beneficiaries can receive needed home care benefits in the form of in-kind services, cash, or a combination of both. This major reform put long-term care on equal footing with Germany's enduring, and internationally acclaimed model of acute care (Cuellar & Wiener, 2000). While some of the key features of the new German long-term care insurance system will be sketched below, a full-scale discussion of its organizational principles, eligibility criteria and benefits package is beyond the scope of this chapter.[11]

In Germany, comprehensive health services (i.e. medical, dental, inpatient hospital care, pharmaceuticals, home nursing, rehabilitation, and limited preventive care) are covered through a universal social insurance programme.[12] The system, which was established more than a century ago as part of Bismark's grand design for social security, is administered by approximately 1200 'sickness funds' (in German, *Krankenkassen*), that is, quasi-public, quasi-private health insurance organizations, and overseen by the Federal Government's Ministry of Labour and Social Affairs (Graig, 1999). All elderly pensioners are protected by this system against the financial risks of illness.

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[11] For detailed information, readers should consult Brodsky, Habib & Mizrahi (2000) and Cuellar & Wiener (2000).

[12] The statutory system protects about 89% of the population who have incomes below the government-set limit (US$ 43 000 in 1999) and therefore are mandated to join a sickness fund (van Kamenade, 1997). The remaining 11%, who have incomes above the specified income level, may obtain insurance coverage from private companies. In reality, virtually all Germans are covered through some form of health insurance.

The sickness funds represent patients in their dealings with health care providers, collect income-related premiums, and pay regional provider associations from these revenues. Health care services themselves are delivered through a mixed public–private system. Hospitals are mostly public institutions run by state and local governments, universities or charitable institutions (Lassey, Lassey & Jinks, 1997). Physicians practise in both hospital and ambulatory settings. Ambulatory care physicians, many of whom are focused on primary care, generally serve as gatekeepers to medical specialists and hospital-provided services; they are usually restricted from hospital practice (Busse, 2001).

Patients have free choice of sickness funds and office-based primary care physicians. Hospitals, physicians and other health care providers are paid by the sickness funds (according to regionally negotiated fee schedules or rates), but there are also individual co-payments (subject to a maximum out-of-pocket amount) for certain items such as hospital stays, pharmaceuticals, and rehabilitation services (WHO, 1999).

Before turning to the various examples and models of integrated long-term care below, three key points must be made about the fragmentation traditionally found in both the acute and long-term care systems in Germany. First, hospital and physician care are thought to be poorly integrated, and this is of ongoing concern to policy-makers, providers, and insurance funds for both quality and cost-effectiveness reasons (Kirkman-Liff, 1996). Second, long-term care, and especially home and community-based services, persist in being inadequately coordinated (Enquette-Kommission, 1994; Scharf, 1998). Third, the connections between health and social care (particularly between general practitioners and other community care providers) tend to be weak, and unsystematic (Bundesministerium, 1993).

There are several reasons for this prevailing pattern of care. According to Schunk (2001), Germany's 'entitlement culture' reinforces the influence of regulators, insurers, and providers. As such, it emphasizes the standardization and consolidation of insurance coverage rather than finding ways to shape the delivery of care or make services more responsive and personalized. The delivery system more or less reflects this mindset. Services, although generally available from a wide range of non-profit and for-profit organizations, have long tended to be organized and provided in a relatively inflexible manner. Another impediment is the notable absence of case management. Even under the long-term care insurance programme, no mechanism exists at the client or administrative levels to advocate for clients, assist them in making care choices, target and allocate resources based on need, or provide information and referral to housing, health care, or other community services (Cuellar & Wiener, 2000). Therefore, integration is a major challenge in the German context, particularly as it affects the frail elderly.

3.2.2 Models and examples

■ Administrative consolidation

Under the reformed long-term care financing system, responsibility for administering SDI is incorporated into the sickness fund structure described earlier (GAO, 1994). To simplify administration, individuals must select the same sickness fund (or private insurer, as appropriate) for both acute and long-term care coverage. Physicians and other long-term care professionals, working for the medical office of each such fund or private insurance company, perform requisite client assessments using detailed eligibility criteria specifically written in the law. The entities are also responsible for contracting with and reimbursing long-term care provider organizations, and also play a role, though minimal, in quality assurance.

On the surface, this arrangement would appear to facilitate coordination between the medical and long-term care sides of social insurance. However, the two forms of insurance are legally separate, function with different benefits and rules, and have their own funding streams.

Moreover, there are concerns about possible cost-shifting between the medical and long-term care programmes, especially in the area of rehabilitation services. Consequently, little interaction actually takes place between both programmes, whether at the sickness fund level or in the health and social systems at large (Cuellar & Wiener, 2000). It is clear from the experience to date that the full benefits of administrative consolidation cannot accrue unless the fuzziness between the health and long-term care systems is somehow resolved, at least from a financing perspective.

■ Co-location of services

The ‘social station’ (in German, *Sozialstation*) has played an important role in the organization and delivery of community services for the elderly since the early 1970s, when they were originally established by the individual states to reduce the demand for inpatient hospital care (Diek, 1995; Scharf, 1998).

Social stations are community centres, usually staffed by nurses and social workers, which coordinate a broad range of non-institutional long-term care services, including homemaker and other home help services, counselling, shopping assistance, transportation, equipment loan, meals-on-wheels, day care, and information and referral (Landsberger, 1985; Tilly & Stucki, 1991). They may also arrange home nursing and psycho-geriatric nursing services prescribed by the sickness funds. Such services are either provided directly by centre staff, or by other organizations in the community.

The approximately 4000 social stations are sponsored by six national welfare organizations,[13] and serve catchment areas with 20 000–50 000 inhabitants in cities and 15 000–25 000 inhabitants in rural districts. Their activities are funded by a combination of state and municipal funds, user payments, and reimbursement received from sickness funds under the medical and long-term care insurance schemes (Bauer-Söllner, 1991; Karl, 1994; Scharf, 1998). However, there has been a dramatic decline in state and municipal funding for the kind of community services arranged by the social stations (Cuellar & Wiener, 2000).[14] While some tradition-bound social stations lack a client-centred focus (and continue to fit clients into existing services), many more centres are beginning to provide 'needs-led' services, particularly as a means of addressing the new realities of long-term care insurance (Scharf, 1998). One of these 'new realities' is the emergence of a competitive market for home and community-based services. The SDI programme has removed the long-standing priority given to non-profit providers, and now formally places non-profit and for-profit organizations and institutions on the same level (Backhaus-Maul & Olk, 1991). This measure, coupled with the shift in purchasing power over community care to consumers and the substantial reduction in state and municipal subsidies, has created a difficult environment for social stations. Under these circumstances, they will have to become more customer-driven and market-oriented.

[13] These organizations and their affiliations are: *Caritas* (linked to the Catholic Church); *Diakonie* (linked to the Protestant Charch); *Deutsches Rote Kreuz* (the non-confessional German Red Cross); *Arbeiterwohlfahrt* (linked to the labour movement); *Paritätische* (an 'umbrella' group representing approximately 7000 smaller voluntary organizations); and, *Zentralwohlfahrtsstelle der Juden in Deutschland* (serving the Jewish population).

[14] According to Cuellar & Wiener (2000), there are still a number of persons (primarily nursing-home residents) who are receiving social assistance for the costs of their long-term care under the old system. However, it is believed that this is a transitory issue. The proportion requiring home care is negligible.

Another innovative, but more recent iteration of the co-location model is found in the 'senior citizen cooperative' (in German, *Seniorengenossenschaft*), ten of which are found in the State of Baden-Württemberg. Senior citizen cooperatives represent what Kane, Kane & Ladd (1998) refer to as a "natural community systems" approach. They are organized and run by a combination of local volunteers and staff, and are designed to complement 'informal' and 'formal' care (Scharf, 1998).

These programmes differ from community to community, but include one or more of the following features: mobilization of neighbourhood help to provide simple domestic tasks (e.g. cooking, cleaning, and making beds); home repairs; home visiting; telephone reassurance; self-help groups (e.g. for families taking care of relatives with Alzheimer disease); and, transportation services (e.g. to the doctor's office, and for shopping). Some of the more sophisticated programmes are involved in planning and developing enriched housing programmes and day care centres.

To emphasize the voluntary and cooperative nature of these programmes, most of these senior citizen cooperatives use a form of payment for services based on the receipt and exchange of time credits. Under this scheme (previously introduced in Canada, the United States, and other countries), individuals who provide help are able to earn credits which they can redeem in the future for needed services, either for themselves or for another family member (Cahn, 1992; Kodner & Feldman, 1996).

■ *Service-enriched housing*

In Germany, 'sheltered housing' (in German, *Betreutes Wohnen*) is a form of service-enriched accommodation found on the continuum between independent housing and nursing-home type facilities (Diek, 1995). Such housing consists of purpose-built flats adapted to the needs of the elderly with physical and/or cognitive disabilities. They are usually planned by the municipalities, operated by the municipalities or non-profit groups, and are geared to lower-income individuals. To help with housing costs, elderly tenants (depending on household size and income, as well as housing costs) receive a direct financial subsidy under the national government's system of housing benefits (in German, *Wohngeld*) and/or a combination of housing and social assistance from the states (Altenbericht, 1993).

The service structure of these sheltered housing developments varies. Most of the programmes help tenants to organize needed services. However, the services themselves are provided from the outside, either through the local social station or by a neighbouring home for the elderly or nursing home (run by the same non-profit sponsor) (Diek, 1995).

One other housing model bears mentioning. It is based on the sheltered housing concept, but is oriented to the elderly with higher incomes. Also operated by non-profit organizations (but outside the social housing programme described above), these highly integrated complexes offer a wide range of services, including barrier-free flats, full-fledged hotel services (e.g. meals), entertainment and recreational activities, self-help programmes, and on-site nursing and medical services.

These housing arrangements, which look and operate like an American innovation known as 'continuing care retirement communities', are financed through a combination of monthly maintenance fees and a relatively large, up-front, lump sum payment (a type of insurance) to finance care services over the long term.

According to Diek (1995), there has also been experimentation along the same lines for the elderly with more modest incomes. These so-called 'service houses' attempt to offer a modicum of on-premise services with the goal of enhancing independent living and keeping tenants in the community for as long as possible. Tenants pay rent, an additional monthly service charge (which entitles them to a minimum level of service), and additional fees on a pay-as-you-go basis if more help is required.

These programmes are operated by non-profit groups, but are not connected with long-term care institutional sponsors, as above. Moreover, since the model is less integrated, they tend to obtain the bulk of services from local old-age clubs, day-care centres, respite programmes, and social stations.

3.3 The Netherlands

3.3.1 Background

As of 1997, the Netherlands had a population of 15.7 million, 2.1 million (13.3%) of whom were age 65 and over, of whom 897 000 (5.7%) were age 75 and over (OECD Health Data, 1999).

The Netherlands is widely recognized for its high level of innovation in elderly care (Baldock & Evers, 1992). Three main factors account for this very active profile.

- First, health care in general, and care of the elderly in particular, involves a very wide range of actors in the governmental, non-profit, and commercial sectors, which have been likened to a patch quilt (Ottewill, 1996).
- Second, the elderly population expects a high level of service, and is protected by an extensive, insurance-based entitlement to care (particularly for hospitals and nursing homes).
- Third, because of these characteristics, the costs of care are relatively high.

In this pluralistic, complex, fragmented and costly system, innovation is highly valued, especially initiatives which are designed to achieve 'downward substitution' of services, enhance collaboration within and between health and social care, and achieve 'tailor-made' care (in Dutch, *zorg op maat*). Given the consensus-driven nature of Dutch society, the national government and sickness funds offer grants, subsidies and extra resources to coax, but not pressure, provider organizations to cooperate with one another, as well as to develop and experiment with new approaches.

The need for policy and delivery system reforms in long-term care have received major attention in the Netherlands for over twenty years (Coolen, 1993; Schrijvers et al., 1997). However, the 1994 Government report, *Care for Older People in the Future* (Commissie Modernisering Ouderenzorg, 1994) was instrumental in making the needs of the frail elderly a national priority (Nies, 2001). In the report, the Commission on Modernizing Care of the Elderly called for a better and more coordinated system of care in which more individualized, community-based services would be made available. Many of the group's recommendations were eventually adopted and implemented by the Dutch Government.

Since much of the services that the frail elderly (and the rest of the population) receive in the Netherlands is social insurance based, it is essential to understand the framework within which the health care system operates. Under the Sickness Fund Acts, all Dutch inhabitants under a certain yearly income level (roughly US$24 000) are covered on a compulsory basis for routine, non-catastrophic health care needs through a regional, non-profit 'sickness fund' (in Dutch, *Ziekenfond*) of their choice.

Approximately 64% of the population receive their care under this sickness fund scheme, which provides basic coverage for general practitioner care, specialty medical services, physiotherapy, pharmaceuticals, and inpatient hospitalization (up to one year) (van Kemenade, 1997). Premiums are mainly income-related, and generally deducted from salaries or social security benefits (in the case of pensioners, a reduced rate); employers make a matching contribution. There are also varying co-payments, but after a nominal deductible (lower for pensioners and low-income persons), services are free of charge.

Similar benefits for the remaining 36% of the population who are essentially higher-income employees (with salaries above the legal cut-off) or self-employed individuals, are covered by private insurance companies; such coverage is not required (although most take out insurance). The premiums paid by households in this group are to a certain extent risk-related. According to Kirkman-Liff (1996), the insurance costs for the elderly in the above system are cross-subsidized by younger insured households.

Irrespective of income category or employment status, every resident is protected against catastrophic health risks under the Exceptional Medical Expenses Act (in Dutch, *Algemene Wet Bijzondere Ziektekosten*, or AWBZ), which was originally introduced in 1968. AWBZ is especially important to the frail elderly and other persons with long-term and high-cost conditions.

This universal programme insures against so-called 'exceptional expenses', such as nursing homes and (since 1997) residential homes for the elderly, institutions for disabled persons, home health and (since 1989) home help services, mental health services, and prolonged hospital stays (over one year) (Huijbers & Martin, 1998). The AWBZ premium paid is income-related and fixed (i.e. between 8.85% and 9.6%, depending on monthly income), with a maximum ceiling per wage-earner. Employers pay the majority of this premium for their employees, with the remainder being collected through income tax. The self-employed pay on their own through the income tax system, and pensioners are exempted. Co-payments are also charged, and vary by the recipient's income level. Finally, general tax revenues are also used to fund the ABWZ programme.

A regional assessment system has been in place since 1998 to determine eligibility for in-home and institutional long-term care services covered under AWBZ (Brodsky, Habib & Mizrahi, 2000). Assessments are performed by professional teams employed by a 'Regional Assessment Organization' (in Dutch, *Regionaal Indicatie Orgaan* or RIO) (Schrijvers & Ravelli, 2001).

The provision of health care services is generally regarded as a joint responsibility between the national government and private initiative, although provincial governments also have a role (primarily in the planning area). The Ministry of Public Health, Welfare and Sport sets policy for, regulates, and oversees the entire system, and the Agency for Healthcare Tariffs (in Dutch, *College Tarieven Gezondheidszorg* or CTG) plays a powerful role in rate-setting.

The Netherlands has a well-developed primary care sector, broadly consisting of general practitioners (GPs), home care organizations (providing both home health and home help services), physiotherapists, social workers, and other generalists. Every person is registered with a GP, and is free to select the physician of his or her choice. They serve as gatekeepers to hospital-based specialists, and do not have hospital admitting privileges. GPs are generally self-employed, solo practitioners (although group practice is growing in popularity in urban areas), and have capitation payments for their sickness fund patients and fee-for-service payments for their private patients.

The majority of medical specialists practise in the hospital setting, although there is a new tendency to private practice in the community. About 90% of medical specialists are self-employed, organized in partnership arrangements, and receive fee-for-service reimbursement (van Kemenade, 1997). The rest are salaried employees.

Two other points should be noted specifically with respect to the long-term care aspects of the above system:

- First, individuals are expected to 'join' their local home care organization as members. This covers the home care cost-sharing requirement, and also facilitates a closer connection between community providers and consumers.

- Second, a 'personal budget' programme (in Dutch, *Persoonsgebondenbudget*) was introduced in 1995, which enables certain disabled clients to purchase needed home care from the provider of their choice (i.e. from regular home care organizations, private home care providers, or informal carers) (Weekers, 1998; Schrijvers, 2001).

3.3.2 Models and examples

Administrative consolidation

The AWBZ scheme for long-term, catastrophic care (including home care, nursing-home care, and care in residential homes for the elderly) is administered by the sickness funds (on behalf of their members), and by private health insurers (on behalf of their insured). Sickness funds have pooled this responsibility through regional 'care offices' (in Dutch, *Zorgkantoor* or *Verbindingskantoor*) (Okma, 2001). Their mission is to simplify programme administration at the level closest to care recipients, oversee the regional budget for AWBZ covered services, and ensure appropriate resources to meet regional needs.

While this arrangement appears to enhance coordination between care provided under the basic (largely medical) and catastrophic (largely long-term care) insurance packages described earlier, there is no evidence that this is occurring (Nies, 2001). The integrating potential is widely recognized by the government, sickness funds, and private insurers. However, the two programmes continue to be legally separate and distinct. Furthermore, there are still several grey areas, for example, how care offices and RIOs are supposed to relate to one another. Without a clear mandate, it is unlikely that this potential will ever be fully exploited.

Co-location of services

Community-based organizations known as 'Welfare Services for Older People' (in Dutch, *Stichting Welzijn Ouderen*, or SWO) operate out of neighbourhood centres run, in part, by the local elderly. In addition to recreational, educational, and cultural activities, the SWOs give information and advice (on housing, health and social care, and financial matters); arrange home nursing and home help services (through the local home care organization); and may also provide community services directly. Services include day care, meals-on-wheels, alarm systems, laundry services, pedicures and hairdressing, assistance with bathing and showering, and various forms of volunteer help (Huijsman, 1993; Graveland et al., 1996; Nies, 2001). Centres also supply services to nearby residential homes for the elderly. Funding from the municipalities (with which SWOs closely cooperate) plays a major role in these programmes.

Care network

The changing face of Dutch health care/elderly care includes an increasing tendency towards vertical and horizontal integration within and between the health and social care sectors (Konig, Nies & Timmer, 1996; Fabricotti, 1999; Juch et al., 1999; Nies, 2001).

There are several relatively recent examples of hospitals, nursing homes, residential homes for the elderly, home care organizations, and even housing providers joining together to establish 'umbrella' organizations. More frequently, mergers have taken place between groups of nursing homes, residential homes, and housing programmes.

The integration of home health agencies (the former 'Cross Associations') and home help providers began even earlier, that is, after the merger of their two national organizations over ten years ago (van der Linden & van Dam, 1997). Moreover, between the late 1970s and early 1990s, there were several demonstration projects which attempted to develop a virtually integrated system of care services for the frail elderly.

The Venlo project is, perhaps, the best known (Coolen & de Klerk, 1993). The organizations involved in this project (home care organizations, SWO, and residential homes for the elderly) pooled their resources, and established one central site in the community to centralize intake, assessment, care planning, and service coordination activities. Many of the experiences of these programmes have been incorporated into the more contemporary model of the care network.

There are three major reasons for this emerging trend in the Netherlands. Networking is viewed as an important foundation for building 'chains of care' (see below) in order to better address the fragmentation and continuity problems encountered by the frail elderly and younger persons with complex, chronic conditions.

The model is also increasingly valued as an enhancer of operational efficiency. Finally, it is considered a potentially useful social marketing strategy in a health care environment marked by growing competition.

Case management

Case management was imported to the Netherlands from the United States and the United Kingdom over a decade ago (Kodner, 1991; Koedoot & Hommel, 1993). Health care and social service providers have been using variations of this coordination approach as part of ongoing programmes and demonstration projects ever since (Schrijvers, 2001).[15]

These programmes are too numerous to describe here. Suffice to say that many of today's existing care networks, home care organizations, transmural care programmes and centres (see below under *Chains of care*), and housing providers have integrated case management in their delivery systems as a core function.

Chains of care

'Transmural care' (in Dutch, *transmurale zorg*) is the Netherlands' version of a 'chain of care'. The concept was introduced in the Netherlands at the beginning of the 1990s, and has been a rapidly growing field since then (van der Linden & Rosendal, 2001). By 1999, the majority of hospitals, general practitioners, home care organizations, institutions for the elderly, and care networks have or were in the process of developing transmural care programmes (van der Linden, Spreeuwenberg & Schrijvers, 2001).

The need for the approach was first identified in 1994 by a Government Commission (Commissie Modernisering Curatieve Zorg, 1994). In 1995, the National Advisory Council on Health Care (NRV) defined "transmural care" as:

> *care geared to the needs of the patient, provided on the basis of cooperation and coordination between general and specialized caregivers, with shared responsibility and specification of delegated responsibilities*. (NRV, 1995)

[15] There is an extensive literature on elder care innovation in the Netherlands, including experiments with case management. The reader is referred to the following English-language publications: Coolen, 1993; Romijn & Miltenburg, 1993; and *Home Health Care Services Quarterly*,1995:15(2).

The NRV definition encompasses a wide range of initiatives where home-based and institutional-based providers, traditionally working apart from one another, join together to improve quality and efficiency in care delivery.[16] Demonstration initiatives are now becoming permanent programmes, many of which are operated by newly established so-called 'transmural care centres'.

These centres are partnerships between health and social care providers (especially hospitals and home care organizations) in a particular region. Much of the activity in transmural care targets post-hospitalized patients, such as stroke patients, and elderly patients recovering from total hip replacement surgery (Nies, 2001).

However, there are also more social models for frail elderly patients, and psycho-geriatric patients (Nies, 2000). Typically, clients are followed throughout the course of their disease or disability by an interdisciplinary/multidisciplinary team using case management techniques to coordinate care at various phases of the condition and in various service settings. Needed services are delivered from specially designed 'care packages', and there is often a health education and training component for clients and their family carers.

The development and sophistication of transmural care is expected to increase in the future, particularly with respect to individuals with long-term, chronic, and disabling conditions. However, according to experts, this further evolution will be hampered somewhat by the structural fragmentation inherent in the Netherlands' system, as well as the lack of integrated financing for health care and social services (Nies, 2000).

[16] An excellent English-language summary is found in the recent study by van der Linden (2001).

Service-enriched housing

An unusually large segment of the elderly population in the Netherlands (approximately 10%) resides in institutional settings: residential homes for the elderly and nursing homes (van Vliet, 1995; and van Egdom, 1998). However, since the 1970s, the Netherlands' Government has advocated a policy of 'de-institutionalization'.

This policy was augmented in the 1980s by a call for 'downward substitution'. The idea was to enable the elderly to live in the least restrictive environment, as well as promote more cost-effective alternatives to long-term institutional care (Tunissen & Knapen, 1991). In order to achieve these policy goals, the supply of home and community-based services was greatly expanded, along with the availability of a wide range of so-called 'sheltered housing' arrangements.

'Sheltered housing' is an intermediate form of purpose-built housing for the elderly who need some on-site assistance and support (Nussberg, 1984). These accessible apartments are mostly rental units, although ownership options are also available. The multi-story housing complex is usually developed and managed by a non-profit housing corporation (including sponsorship by various grassroots groups), although commercial operators are entering this market (van Vliet, 1995).

The 'shelter' that is given consists of an apartment, around-the-clock monitoring by a caretaker, extra services such as housekeeping and meals, and a guarantee that any additional care will be organized by the housing provider and be promptly delivered (van Egdom,1998). There are many arrangements for service provision.

For example, there are dwellings that are functionally integrated with residential homes for the elderly. These facilities link housing tenants to a unified alarm system, and offer them a place to go for meals and social activities. Other developments contain a central service centre (sometimes also serving the immediate neighbourhood), which coordinates and arranges a broad range of health and social services (van Vliet, 1995).

The local SWO also plays a service role in these sheltered housing projects. There are, however, limits to service integration in these supportive accommodations, as it is the national government's policy to separate the funding of housing from services (van Egdom, 1998). Nonetheless, the Ministry of Housing subsidizes sheltered housing rents for certain low-income households (van Vliet, 1995).

As indicated above, some residential homes for the elderly reach out to provide supportive services to semi-independent elderly living in their own homes in surrounding neighbourhoods (de Weert-Oene et al., 1997). These institutions provide a package of recreation, meals and other services (e.g. laundry, pedicures and hairdressing), as well as limited home help services. Elderly clients participating in these outreach programmes (many of whom are on facility waiting lists) pay a nominal monthly 'membership fee' for the basic services, and are charged on a fee-for-service basis for any additional services provided (e.g. temporary housing).

Finally, various combined housing and service innovations have attempted to integrate independent living, residential care, and nursing-home care under one roof (Coolen et al., 1993). The flexible concept is known as the 'care house' (in Dutch, *Zorghuis*).

One project, Zorghuis W. Drees, was developed on the site of a former nursing home in The Hague. This care house consists of 119 independent housing units providing accommodation for single individuals or couples. A total of 150 tenants (eligible for admission to a nursing home or residential home for the elderly, or interested in sheltered housing) receive various levels of care, from some help to full nursing care. There are also on-premise nursing units to provide around-the-clock care; these units are reserved for couples who would otherwise be forced to live separately. The project, which is sponsored by the municipality, takes over all of the health and social care tasks, including general medical treatment. An extensive effort is made to integrate neighbourhood services as much as possible into the housing programme (e.g. home care), and a variety of subsidies were provided by the municipal government, Ministry of Housing, and Ministry of Health during the experimental phase. While the project did not achieve the kind of success that planners and policy-makers had expected, it was found that elderly tenants were in greater control of their lives, and fewer applied for institutional admission.

3.4 Sweden

3.4.1 Background

As of 1997, Sweden had a population of 8.8 million, 1.5 million (17%) of whom were age 65 and over. Of these, 730 000 (8.3%) were age 75 and over (OECD Health Data, 1990.[17]

Sweden is recognized throughout the world as a nation with a strong and generous commitment to publicly funded and delivered health and social services for citizens of all ages (Zappolo & Sundström, 1989). A central tenet of the Swedish welfare state is that the elderly are guaranteed financial security, adequate housing, social services and health care according to their needs (Johansson, 2000). Care of the elderly, in particular, is viewed as a 'cradle-to-grave' system of government support (Johansson, 2001).

Two major government policies are particularly relevant to the needs of the frail elderly and the integration of long-term care services. The far-reaching 1992 Elderly Reform (in Swedish, *Ädre-reform*), moved the financing and administration of nursing homes and home nursing from the counties to the municipalities (which already provided social services and housing), and also gave them the financial responsibility for elderly long-term patients in the acute inpatient setting (Johansson, 2000).[18]

This delegation of responsibility was designed to consolidate health and social care for the elderly at the local level, and was aimed at both de-medicalizing elderly care and enhancing the coordination of services (Andersson & Kalberg, 2000). (The implications of this decentralization strategy for both administration and service delivery are discussed later in this section in greater detail.) This was followed in 1998 by a *National Action Plan on Policy for the Elderly*, in which the Parliament identified the need for further structural changes in the Swedish system of elderly welfare.

The plan places major emphasis on ensuring 'good caring services' for the elderly, that is, the elimination of what it calls the 'grey zones' related to poor coordination of care between providers of health and social services (Ministry of Health and Social Affairs of Sweden, 1999).

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[17] Sweden is one of the oldest countries in the world (Johansson, 2000).

[18] The municipalities were given the option of providing home nursing services directly or keeping this service in the county-run health system (Andersson & Karlberg, 2000). In either case, the municipality retains ultimate financial responsibility for the delivery of this service.

One of the main pillars of Swedish elderly care is the health system. Sweden has a national health system for the entire population, which operates within the policy framework mandated by the *Health and Medical Services Act*, 1983. Financing for health care is derived mainly (approximately 87% of the total) from proportional income taxes levied at the county level (the tax rate is about 11.5%).

Other sources include the national insurance system (80% paid by employer contributions, and 20% by central government contributions); and various patient co-payments. Co-payment fees differ by service and by county; are limited by individual ceilings; and certain populations, including persons with chronic illness, are exempted from payment (van Kemenade, 1997).

The central government oversees and evaluates the health care system through the National Board of Health and Welfare (in Swedish, *Socialstyrelsen*). However, it is actually organized and administered at the county (i.e. provincial) level; county populations range from 60 000 to 1.7 million inhabitants. The 21 elected County Councils are each responsible for the financing, administration, and delivery of a comprehensive package of services.

Services include a broad range of ambulatory and inpatient services. Beside primary and specialty medical care and inpatient hospitalization, the national insurance programme also covers preventive services, pharmaceuticals, rehabilitation, dental care, and mental health services (van Kemenade, 1997).

Approximately 80% of county budgets are devoted to such services, and the counties have wide latitude in terms of how they are organized regionally. Health care institutions, including hospitals and health centres, are mostly publicly operated. Private sources of care are minimal, but some counties have begun to encourage their development on a contract basis in order to expand the supply of services, shorten waiting times, and reduce costs (Lassey, Lassey & Jinks, 1997).

For the most part, primary health care services are provided by general practitioners practising in district health centres. These primary care physicians do not act as gatekeepers to specialized care; at the moment, patients are free to go directly to hospital-based specialty clinics.

Hospitals, which are organized hierarchically (i.e. district county hospitals, central county hospitals, and medical-school-affiliated regional hospitals), provide both inpatient and outpatient medical care. Because of the large elderly population, there has been a growing emphasis on geriatric medicine, with hospital-based departments playing an important role in geriatric assessment and rehabilitation (Sundström & Thorslund, 1994).

In this publicly-run system, physicians are mostly salaried. Health care centres operate on a budgeted basis. Hospitals, on the other hand, are reimbursed through a variety of systems: global budgeting; purchases by health centres; or purchases by health districts. The purchaser–provider model (reflected in the latter two approaches) has been available to county councils since 1995, and is meant to reduce referrals to hospital specialty clinics, shorten waiting times for specialist consultations, promote better links between primary and secondary care, and generally enhance patient satisfaction (Jones, 1996; Kirkman-Liff, 1996).

As indicated earlier, social care (including housing and the elderly care services transferred under the Elderly Reform) are the responsibility of the municipalities. This local system operates within the legislative framework created by the 1992 *Social Services Act*, and is supervised nationally by the previously mentioned National Board of Health and Welfare. The 289 local governments finance, organize, deliver, and arrange a wide range of services.

This range includes home care (home nursing and home help services), care in day centres, various forms of 'special housing' (i.e. nursing homes, old-age homes, service houses, group homes, etc.), and assistive devices (e.g. walkers, wheelchairs, security alarms, and housing adaptations) (Johansson, 2001). In addition, the municipalities are liable for the costs of hospitalized long-term care patients. This statutory obligation was designed to encourage the care of so-called 'geriatric bed-blockers' in non-hospital settings, thus reducing the high costs attributable to this population (Johansson, 2001).

Under this scheme, the municipalities are relatively autonomous with respect to how services for the elderly are administered, organized, allocated, and provided. Most of the care is delivered by government workers, although some municipalities contract with the private sector (non-profit or for-profit organizations) to deliver some of the services.

This extensive support system is funded for the most part by local taxes (about 80–85% of the total costs), although the central government provides tax-funded subsidies and grants to cover the remaining 15–20% of the costs. There are also user fees (varying by municipality, and income adjusted and/or subject to out-of-pocket maximums) which, while becoming increasingly popular among local governments, pay only a fraction of these costs.

Before turning to the next topic, it should finally be pointed out that the Swedish system is beginning to move away from its universal model of social care for the elderly (Johansson, 2001). Swedes are living longer, and it is becoming increasingly difficult to shoulder the increasing costs of welfare services through the straining tax base.

In order to address this challenge, greater emphasis is being placed on improving the targeting of services; developing more efficient delivery modes; strengthening the case management function; contracting with private organizations to provide publicly-funded services; and shifting some more of the costs to its citizens (via income-related charges and co-payments). Johansson (2001) speculates that continuing cost containment pressures may ultimately lead to the creation of a government regulated 'quasi-market' in which elderly consumers would use vouchers to obtain needed social services from a mix of competing public and private providers.

3.4.2 Models and examples

■ *Administrative consolidation*

The purpose of the Elderly Reform, summarized above, was to create better 'value' for what are essentially long-term care services through the consolidation of programme administration and public funding at the municipal level (GAO, 1994).
This 1992 mandate gave local government new taxing authority to fund elderly care services; additional staff to deliver them (by transferring county employees to the municipalities); primary responsibility for the planning, delivery and coordination of services; and total control over the supply of services.

It is now possible to identify some of the main effects of this integration strategy.

First, the former problem with 'bed-blocking' has diminished substantially, in some counties by as much as 50% (Andersson & Karlberg, 2000; GAO, 1994). This has been made possible by more appropriate and timely transfers to nursing homes and community care providers.

Second, there has been a considerable increase in the supply of 'special housing' (especially non-nursing home type options), and home care resources.

Third, the municipalities have enhanced the capacity and quality of the home care service. This has been made possible by the transfer of home nursing personnel from the counties to the municipalities, and the legally-mandated special medical nurse's function to monitor quality of care at the local level.

Overall, these accomplishments reflect the impact of fiscal incentives built into the Elderly Reform, as well as improvements in service coordination. In addition to improved communication and collaboration at all levels, the key role of case management has been upgraded and professionalized (Johansson, 1993). (For more on these developments, see *Case management*, below.)

Administrative consolidation, nonetheless, has not solved everything; there are also new problems as a consequence. Coordination at the intersectoral level still remains somewhat of a problem, especially in municipalities which have not assumed direct responsibility from the counties for home nursing (Andersson & Karlberg, 2000).

Moreover, the Elderly Reform left untouched the general fragmentation which has traditionally existed between the acute side of the system (i.e. hospitals and medical providers) and long-term care. In addition, because of growing budgetary pressures and government-imposed limits on the levying of taxes, the municipalities are shifting more of the costs of care to consumers. For example, between 1991 and 1993, out-of-pocket payments increased from 4% to 10% (GAO, 1994).

■ *Co-location of services*

In some communities, home nurses employed by the municipality continue to be out-stationed at, or attached to local health centres, which are operated by the counties (Lassey, Lassey & Jinks, 1997). These so-called 'district nurses' coordinate the home health services they deliver in the home with the care provided at the health centre by the patient's general practitioner (Sundström & Thorslund, 1994).

In addition, they perform 'night patrols' to monitor medically-unstable elderly patients as adjuncts to both the primary care and social service systems (Sundström & Thorslund, 1992).

Case management

Case management has become a core activity in Swedish elderly care, particularly as a means of improving service targeting and coordination, and enhancing the outcomes of in-home support for long-term care clients. Multidisciplinary 'care planning teams' (along with 'hospital discharge planning routines'), which began to appear in virtually every municipality in the 1980s, are now in the process of being re-worked into full-blown 'case management teams' (Johansson, 2000). Operating within the broader Elderly Reform framework, these teams now cover the housing, service, and care needs of their elderly clients, and have wider responsibilities: outreach, case finding, needs assessment, care planning, service coordination, and monitoring. There is also better training for case managers.

In some municipalities, these functions are performed within the context of a purchaser–provider 'split', that is, the local government decides on eligibility and the access to services, but the actual care is delivered by private contractors. While this may be a more cost-effective arrangement, the resulting bifurcated structure presents some logistical challenges from the case management point of view.

Service-enriched housing

The national government and the municipalities have been giving increasing recognition to the importance of housing plus service arrangements as a way of maintaining elderly long-term care clients in the community (Ministry of Health and Social Affairs of Sweden, 2001). A wide range of housing choices (known as 'special accommodation', or *Särskilda Boendeformer* in Swedish), are available to fit the environmental and service needs of physically and cognitively disabled individuals (Swedish Institute, 1999). Various institutions (including nursing homes and old-age homes), as well as service 'blocks'[19] and flats, and group homes (primarily for persons with dementia) fall under this housing category.

[19] A service 'block' is a group of flats or apartments for the elderly that are located in a regular housing development with primarily younger tenants.

The municipalities own and operate this housing stock. However, the supply and types of housing available, and the access to these resources (except the qualification that the elderly person must be in extensive need of care and supervision) vary from municipality to municipality.

Local governments receive some funding from the central government to subsidize new construction, modernize existing buildings, and maintain these facilities (on a very limited basis) (Lundin & Turner, 1995).

Including the above subsidies, the municipalities end up covering about 90% of total housing costs, and the remaining 10% is paid directly by individual tenants. Depending on the kind of accommodation and the municipality in which it is located, these direct payments can include rent and/or other charges for food and services.

Meals, apartment cleaning, recreational services, and local transportation (sometimes) are provided by the housing management. Needed home nursing and home help services are arranged with the municipality, as are other community-based services (e.g. day care). These services are integrated with the housing programme as much as possible (Tilly & Stucki, 1991).

In addition to these traditional housing options, some municipalities have experimented, or are experimenting with alternative forms of living and service. For example, non-profit, cooperatively-owned housing complexes (aimed at higher-income pensioners) are responsible, not only for the maintenance of dwellings and housing estates, but also for on-site home help and medical care (Lundin & Turner, 1995).

This model represents a more comprehensive and customized package than the other programmes sketched above, and is already being adapted by some local governments for low-income inhabitants.

4 Summary and lessons

The 'integration' of health care, social services and housing is considered a major variable in designing and operating efficient and effective long-term care systems, given the complex nature of the frail elderly population and their needs.

Yet, relatively speaking, all industrialized countries face similar problems with respect to integrating the long-term care sector, namely, poor coordination, lack of continuity, less than optimal outcomes, and difficult-to-control costs.

There are a variety of strategies available on the financing, administrative, organizational, service delivery, and clinical levels to address these shortcomings. However, the priority given to solving this dilemma, and the approaches actually taken, depend largely on the nature of a particular country's health and welfare policies, financing and delivery systems, administrative arrangements, funding and resources, and societal expectations and demands.

The four European countries presented in this chapter (Denmark, Germany, the Netherlands, and Sweden) were selected because they have, or are in the process of developing more integrated long-term care systems. Despite the obvious contextual differences between these four countries, they have pursued a number of common directions. A wide range of innovations have been described in this section.

These include various national approaches to administrative consolidation, co-location of services, care networks, case management, chains of care, and service-enriched housing. In addition, we have, in some cases, presented available evidence on the impact of these initiatives.

While the examples described focus on the elderly, it is possible nonetheless, to apply many of these basic concepts to the needs of younger persons with disabilities. However, in doing so, ***policy-makers, planners, and programme managers must be sensitive to the major differences usually found between elderly and younger long-term care populations.***

These differences involve their feelings of dependency, ethos of autonomy and self-direction, sense of consumerism, and disposition to the formal system of 'care' (Kodner, Sherlock & Shankman, 2000).

There are several general lessons that can be drawn from this analysis.

- There is no single solution to the problem of long-term care integration. Because of the various complexities involved, multiple approaches are needed to enhance the quality and cost-effectiveness of care for the frail elderly on both the system and client levels.

- The consolidation (and decentralization) of administrative functions is an important integrating strategy. However, the boundaries between the various sectors comprising the long-term care system (health care, social services, housing, etc.) must be reconciled and aligned in order to obtain optimum results.

- There are various organizational and service delivery models available to bring the long-term care services needed by the frail elderly 'under one roof', as well as to link them in a seamless manner. Whatever the model(s) chosen, most long-term care policy-makers, planners, and providers believe that some form of case management is necessary to effectively target the population-at-risk and coordinate their services.

- Integrated home care is one of the linchpins of a well-organized and effective long-term care system. A critical element is the coordination of home nursing and home help services at both the administrative and client levels. This can be accomplished through a variety of integrating strategies, including the harmonization of home care funding; close collaboration between, or merger of home nursing and home help organizations; joint training of home care workers; and the use of home care teams.

- Purpose-built housing and, to a certain extent, residential care institutions, show promise as the base for organizing more integrated long-term care services for tenants, but also for elderly residents in the surrounding community.

- Volunteers (especially the elderly) represent an important, but largely untapped long-term care resource. In addition to mobilizing the community's natural support network, volunteers can also assist in linking and coordinating 'informal' help with professional services.

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5 ACHIEVING COORDINATED AND INTEGRATED CARE AMONG LTC SERVICES: THE ROLE OF CARE MANAGEMENT, *David Challis*

Preface

The perennial concern of governments has been to identify means of achieving coordinated and integrated long-term care. This may be examined at different levels in the care system: interagency coordination; interprofessional coordination; and case level coordination (Challis et al., 1995). None of these may be separated completely from the others, but the focus of this chapter is upon the third of these.

This chapter, which builds upon commentaries such as Challis (1992a,b; 1993a,b; 1994a,b,c; 1999a,b; 2000), attempts to bring together material about the definition and specification, context and content of care management with a focus upon issues of implementation. Although it necessarily draws from the implementation experience of care management in the United Kingdom, it addresses issues which have a wider resonance.

The chapter is organized as follows:

- an introduction;
- a discussion of the definition of care management;
- a summary of the issues arising from implementation in the United Kingdom;
- a discussion of some extrinsic factors which may shape implementation;
- a discussion of intrinsic factors such as the specific features of care management relevant to implementation; and
- a discussion of issues emerging which are critical to implementation.

1 Introduction

There are major developments in long-term care occurring in many countries and some broadly similar trends can be discerned. In their study of emerging patterns of change in services for elderly people in the Netherlands, Sweden, and the United Kingdom, Kraan et al. (1991) noted three broad trends:

- a move away from institution-based care;
- the enhancement of home-based care; and
- the development of mechanisms of coordination and case management.

In the care of elderly people in many other countries such as Australia, Canada and the USA, a similar trend can also be observed (Challis, 1992a,b). In the mental health services, the reduction of institutional provision and focus upon community-based services is clear (Huxley et al., 1990).

Long-term care policy for other client groups has also taken not dissimilar forms, with the desire to develop community services being stressed (DHSS, 1983; Cm849, 1989). Underlying this is a major debate about the extent to which community services complement or substitute for institutional care.

Concern for coordination has been longstanding and in the United Kingdom took the form principally of attempts to improve interagency coordination, chiefly health and social care, through such initiatives as joint care planning and joint financing. The focus upon coordination at the client level came considerably later – being less evident in a setting where most services were provided by two main agencies, health and social services.

For people with mental handicaps or learning disabilities in the USA, discharge from hospital and developing continuity of care have been key themes, with case management made mandatory to improve coordination of care after discharge (Intagliata, 1982). The rationale for this is cited by Miller (1983) who quotes the conclusion of the US Presidential Commission on Mental Health for case management:

> *Strategies focused solely on organizations are not enough. A human link is required. A case manager can provide this link and assist in assuring continuity of care and a coordinated program of services.* (Miller, 1983, pp.5–6.)

In general, therefore, the origins of case management lie in the "need to coordinate delivery of long-term care services to individual clients" (Austin, 1983, p.16).

Moxley (1989) cites six factors underlying the development of case management:

- de-institutionalization;
- the decentralized nature of community services;
- growing numbers of clients with multiple needs living at home;
- fragmentation of care services;
- a growing awareness of the importance of social supports and carers; and
- the need for cost containment.

Care management and coordination are thus central to the achievement of the goals of community-based care. The United Kingdom White Paper *Caring for People* (Cm849, 1989) described assessment and case management as "the cornerstones of community care" and the Audit Commission has referred to it as "the lynchpin".

Care management is thus in a crucial position in the new care arrangements, being the mechanism designed to achieve both the move away from institutional provision and the strengthening of home-based care. It is the point at which welfare objectives and resource constraints are closest together. Therefore, care management has a pivotal role in the integration of social and economic criteria at the level of service provision, where the balancing of needs and resources, scarcity and choice must take place (Challis, 1992b).

It should not be seen as a panacea (Callahan, 1989) nor a "silver bullet" (Austin, 1992) for the ills of community care, but rather a particular device which, dependent upon the manner of its implementation, offers a means to manage some intractable policy and practice dilemmas. Much is therefore dependent upon the coherence, form, style, and structure of the care management processes to effect community care changes. The debate about the forms and nature of care management which will be appropriate in different environments for different client groups will continue.

Here, an attempt is made to clarify and define the nature of care management and to consider some factors that appear to be associated with more or less effective implementation. In essence, there are four broad areas for consideration:

- the definition of care management and its associated expectations;
- an overview of issues emerging in care management in the United Kingdom from its implementation in the 1990s;
- features of the context within which care management is located, which may be described as extrinsic factors; and
- factors within the system of care management itself, which may be described as intrinsic factors.

The degree of fit between the extrinsic and intrinsic factors of a care management system is an important and valuable area for examination.

2 Defining the nature of case or care management

Beginning with definition is useful, since it helps to identify the types of domain where variations in assumptions about care management may commence. There are a number of high quality reviews of care management (Kodner, 1993; Applebaum & Austin, 1990). However the definition of care management remains far from easy. Definitions abound and even terminology changes.

In the United Kingdom, the Griffiths Report (Griffiths, 1988) talked of ”care management” and the subsequent White Paper (Cm849, 1989) used the term ”case management”. Later, the Department of Health guidelines – published for managers and practitioners (DOH, 1991a,b) – refer to care management, justifying this in terms of the fact that it is the care which is being managed and that the word ”case” may be perceived as demeaning.

A similar point is made in the Care Management Standards of the National Institute on Community Based Long Term Care in the USA (NICBLTC, 1988). The debate about nomenclature also occurs elsewhere. One major organization in the USA, Connecticut Community Care, has used the terms ‘Case Management’ and ‘Care Managers’. Alternatively, the State of Wisconsin is providing a ‘Care Management Program’, but has employed the terms ‘Care Manager’ and ‘Case Manager’ interchangeably. Washington State uses the term ‘Case Management’.

Conversely, in the Canadian Province of Manitoba the term 'Case Coordinator' is employed (Fineman, 1992). In British Columbia, the term 'Assessor' in the Continuing Care Programme was changed to 'Case Manager', reflecting increasing dependency in the needs of the primary client population and the need for continuity of care (BCMH, 1992). What is important is less the precise terms which are used and more the clarity of meaning which is attached to different aspects of the process.

The origins of care management then, lie in the immediate need for coordination of home-based care, albeit with a broader range of objectives including client-centred care and effective use of resources (Challis, 1992b). Six criteria may be identified which together constitute a more precise definition (Challis et al., 1995; Challis, 1994a, 1999a,b):

- the performance of a set of core tasks;
- the function of coordination;
- explicit goals for care management;
- a focus upon long-term care needs;
- particular features which differentiate care management from the activities of other community-based professionals; and
- the dual function of care management at client level and system level.

These criteria are discussed below. They attempt to answer the questions:

- What is undertaken in care management?
- Why is care management employed in the care system?
- How is care management done?
- For whom is care management provided?
- What makes care management different from other community-based work?
- What impact does care management have on the service system?

Each of these would seem to be an important component of the definition.

2.1 The functions of care management

In overall functional terms, Austin (1983) defines case management as:

> *. . . a mechanism for linking and coordinating segments of a service delivery system . . . to ensure the most comprehensive programme for meeting an individual's needs for care.* (p.16)

This involves continuity of involvement and is based upon comprehensive assessment of the individual's needs (Kane, 1990).

Moxley (1989) usefully defines case management as:

> *. . . a dedicated person (or team) who organizes, coordinates and sustains a network of formal and informal supports and activities designed to optimise the functioning and well-being of people with multiple needs.* (p.17)

More generally, Modricin, Rapp & Poertner (1988) describe it as the achievement of a better fit between:

> *. . . the person's needs and the resources available in the community.* (p. 307)

The United Kingdom Department of Health Guidance (DOH, 1991b) defines care management as:

> *. . . the process of tailoring services to individual needs.* (p. 11)

It then refers to specific core tasks.

Similar criteria to these are identified by Rothman (1992), Geron & Chassler (1994), and Rothman & Sager (1998).

2.2 The goals of care management

Moxley (1989) notes three goals of case management:

- improving client utilization of support and services;
- developing the capacity of social networks and services to promote client well-being; and
- promoting service effectiveness and efficiency.

Ten key benefits are listed in the British Government's Social Services Inspectorate Practice Guidance (DOH, 1991a,b, para. 18). These range from client-related benefits such as tailoring services more closely to needs or enhanced choice, to more service-related goals such as improved integration of response both within and between agencies, or greater continuity of care.

These are not dissimilar to those cited by the National Institute for Community Based Long Term Care in the USA (NICBLTC, 1988) which cover both client centred activities such as enhanced service access, coordinated care, independence and community tenure as well as more system-focused goals such as improved service availability, reaching a specified target population, and cost containment through use of appropriate community-based services.

These recognize the potential for goal conflict such as between client and carer or between cost containment and client responsiveness, and specify the need for mechanisms to resolve such conflicts. These include family meetings, advocacy, case manager peer group support, and effective supervision.

Where system-focused goals are important, the issue of service development emerges (Moxley, 1989; Applebaum & Austin, 1990; DOH, 1991a,b; Kendig et al., 1992). This can take the form of 'shaping' – changing the ways in which services operate, rendering them more sensitive to the needs of consumers, such as altering the range of activities undertaken, the way they are undertaken, or the times when they are available.

The Province of British Columbia defines case management as

> *. . . a specific set of client-related functions that include intake and screening for eligibility, assessment of functions and needs, mutual service planning and goal setting, efficient linkage with available resources, quality assurance through ongoing monitoring, review and evaluation, and discharge policy.* (BCMH, 1992, p.26.)

Overall, there would seem to be across the literature a broad general consensus that the core tasks of case management are case-finding and screening, assessment, care planning, implementing, and monitoring the care plan.

2.3 Key differentiating features of care management

Applebaum & Austin (1990) note that many organizations report that they do case management and in fact they do undertake some of the relevant activities. In the United States' context, it has been argued that case management is what most social workers do in most fields of practice most of the time (Roberts-DeGennaro, 1987).

In the United Kingdom, an obvious example of this is the role of the key worker within multidisciplinary teams. However, it is important to discriminate among different roles of different staff for people with different levels of need.

There are important differences between activities such as key worker approaches, which aim to coordinate a ***single service or team*** more appropriately to individual needs often on a ***short-term*** basis, and case management, which aims to coordinate ***multiple services and providers,*** usually on a ***long-term*** basis (Rothman & Sager, 1998).

Applebaum & Austin (1990) identify three factors which differentiate long-term care case management from these key worker approaches:

- intensity of involvement, reflected in relatively small caseloads;
- breadth of services spanned, covering more than one service, team, or agency; and
- length or duration of involvement, being a long-term commitment.

Another key element is that case management is concerned with meeting the needs of people with long-term care problems or multiple needs (Steinberg & Carter, 1983; Moxley, 1989; Geron & Chassler, 1994; Raiff & Shore, 1993; Rothman & Sager, 1998).

The definition of this group is not easy. Davies & Challis (1986) characterize long-term care populations as "those using a high proportion of health and social care expenditure, individuals with multiple and varied needs, recipients of multiple and inflexible services of which social care tends to be the largest component".

Ballew & Mink (1986) describe case management as concerned with people experiencing multiple problems that require multiple sources of help, and who experience difficulty in utilizing that help. The role of care management is thus seen as combining brokerage with interpersonal skills, since it is focused both ". . . on the network of services needed by multi-problem clients and the interaction between members of the network" (p. 8). Therefore, care management is concerned with providing services to a specific target group and need not be seen as the mechanism for providing all forms of care for those who need assistance in coping with everyday living (Kane, 1990).

2.4 The organizational context of care management: a multi-level response

A final but crucial contextual element is identified by Miller (1983) who notes that a focus on client-level activities is insufficient since it does not address the case management system. As Moore (1990) argues, the degree of horizontal integration achieved by case management practice needs a degree of vertical integration at system level in order to be effective. Kane (1990) links case management practice with system-level activities through the use of comprehensive assessments to provide aggregated information for needs-based planning by agencies.

In short, case management is designed not just to influence care at the individual client level, but also at the system level through the aggregate of a myriad of care decisions at the individual client level which exert pressure for change upon patterns of provision themselves. An underlying objective is to render those patterns of services more relevant to individual needs (Austin, 1983; DOH, 1991b; Steinberg & Carter, 1983).

2.5 Towards a composite definition of care management

In the United Kingdom in the 1990s, the context in which care management was practised resulted in it being described as having

> *a pivotal role as the setting where the integration of social and economic criteria must occur at the level of service provision, where the balancing of needs and resources, scarcity and choice must take place.* (Challis, 1992a)

Table 1 describes the characteristics discussed above, which together distinguish care management from other service-related activities.

Table 1. Defining care management

Key attributes of care management	Distinctive features
Functions	Coordination and linkage of care services; tailoring resources to needs.
Goals	Providing integrated care with continuity; increasing the feasibility of care at home; promoting client well-being; making better use of resources.
Core tasks	Case-finding and screening; assessment; care planning; monitoring and review; case closure.
Target population	Those with long term care needs; multiple service recipients; those at risk of losing community tenure.
Differentiating features	Intensity of involvement; breadth of services spanned; duration of involvement.
Multi-level response	Linking practice level activities with broader resource and agency level activities.

Sources: *Challis et al., 1995; Challis, 1999b.*

From this definition, it is helpful to examine the implementation of care management as part of a new community-care policy in one country, the United Kingdom. In subsequent sections of this chapter, the experience of care management developments is examined to identify factors associated with variation in implementation, both extrinsic and intrinsic to care management.

3 Care management in the United Kingdom: an example of policy implementation and development

3.1 Policy origins and guidance

Service changes in the United Kingdom reflect the common international trends (Challis, 1992a,b; 1994a). In 1989, following a rapid growth of publicly funded residential and nursing-home based care, predominantly for older people, financed through the public sector with no control over eligibility on the basis of need, the British government produced a major policy paper entitled *Caring for People* (Cm 849, 1989). This paper identified six key objectives (para. 1.1.1):

- to promote the development of day, domiciliary and respite services to enable people to live in their own homes where possible;
- to ensure providers give high priority to the needs of caregivers;
- to build upon high quality assessment and case (later care) management as the cornerstone of community care;
- to promote a flourishing independent sector alongside public services;
- to clarify agency responsibilities (principally between health and social care agencies); and
- to achieve better value for money by reducing a funding bias in favour of institutional care.

New levels of funding and responsibilities were given to the Social Services Departments, the main agencies for the provision of social care, which are managed through local government. They were made responsible for undertaking assessments of need, the design and packaging of services tailored to meet such needs, and for the provision of care managers to monitor, review, and act as a single point of contact for those receiving services.

This policy was principally driven by the budgetary pressures of an ageing population and funding anomalies which produced a bias in favour of placement of older people in institutional care, rather than the pursuit of a long standing policy objective to provide home-based care (Challis, 1993a,b). Government guidance about care management was provided in separate documents for managers and practitioners within agencies (DOH, 1991 a,b).

A more recent White Paper, *Modernising Social Services* (Cm 4169, 1998) re-emphasized the role of care management. Policy guidance in this and other documents continues to stress the priority of maintaining independence in older people, including preventing unnecessary admission to homes.

3.2 Funding, providers, and organization

Care management for older people is predominantly the responsibility of publicly-funded local government Social Services Departments. There are currently 150 of these departments in England.

They are the main employers of social workers and care managers, who have the responsibility to assess and arrange packages of care, including residential and nursing-home care, for vulnerable older people. These staff undertaking care management are located in Social Services Department offices, primary care, or hospital settings.

Social Services Departments are both purchasers and providers of a range of home and residential care services. Although care management may be part of a purchased service, in practice there is very little evidence of such developments in older people's services.

3.3 Evidence of care management before implementation of the reforms: the PSSRU studies

Several studies of care management for highly vulnerable groups were undertaken by PSSRU prior to and spanning the community care changes.

These early studies of care management in the United Kingdom were the Kent, Gateshead and Darlington schemes (Challis & Davies, 1986; Challis et al., 1990, 1995, 1997; Davies & Challis, 1986).

The model of care management that was developed in these schemes was designed to ensure that improved performance of the core tasks of care management could contribute towards more effective and efficient long-term care for highly vulnerable people (Challis & Davies, 1986; Challis et al., 1990; Davies & Challis, 1986). The devolution of control of resources to individual care managers, within an overall cost framework, was designed to permit more flexible responses to needs and the integration of fragmented services into a planned pattern of care to provide a realistic alternative to institutional care for highly vulnerable older people.

The first two studies undertaken were focused upon case management in social care. The later initiatives also involved joint health and social care case management interventions, both in primary and secondary care, covering geriatric and old age psychiatry settings.

In the social care studies (Challis & Davies, 1986; Challis et al., 1990), this approach reduced the need for institutional care of vulnerable elderly people significantly. There were marked improvements in the levels of satisfaction and well-being of elderly people and their carers and these were achieved at no greater cost to the social services, the National Health Service (NHS), or society as a whole.

Integrating health and social care at the practice level meant that integrated care management approaches were required. Within the case management service in Gateshead, a pilot health and social care scheme was developed around primary care (Challis et al., 1990), incorporating inputs from a nurse care manager and part-time junior doctor. Outcomes were the same as those noted in the main scheme. A similar approach to care management was also tested in a multidisciplinary scheme for very frail elderly people based alongside a geriatric service (Challis et al., 1989, 1991a, b, 1995). Here, care managers employed by the Social Services Department were members of a geriatric multidisciplinary team, most of the rest of whom were health service employees.

The care managers in this service not only deployed a flexible budget, but also were able to allocate the time of multipurpose care workers who combined the roles of home help, nursing aide, and paramedical aide. Improvements in the well-being of elderly people and a lower level of carer stress were observed for those receiving this new service compared with patients in long-stay hospital care. These gains were achieved at a lower cost than was normally expended upon such patients (Challis et al., 1995) reflecting the higher cost of hospital care compared with other institutional settings.

The Lewisham scheme was established to develop a similar model of care management for older people with a diagnosis of dementia in a community based service for mental health of older people (Challis et al., 1997).

The scheme appeared to have only an effect of improving the probability of remaining at home in the second year of support, compared with existing services. Hence, the community tenure effect appeared more muted than in the other PSSRU care-management studies. However, it was clear that both experimental and comparison group patients were receiving support from a relatively resource-rich community-based old age psychiatry service, by no means typical of that to be found in most of the United Kingdom.

There was evidence of improved well-being for the older people and more markedly so for the carers receiving the intensive care-management support. However, the cost of obtaining these gains in well-being was significantly higher for the experimental group.

Overall, the findings of these PSSRU intensive care-management studies suggest an increased efficiency in the provision of social care with improved outcomes at similar or slightly lower costs. The evidence should not, however, be generalized to a broader application of the care management approach to less vulnerable individuals.

Key elements associated with the outcomes demonstrated included:

- a differentiated type of care management response to need;
- appropriate targeting;
- devolution of budgets;
- continuity of involvement of care manager with service user; and
- appropriate links with specialist health care expertise.

3.4 National policy implementation after 1993

However, the implementation of care management by social service agencies has proved to be more broadly defined and provided for a wider target population than in the PSSRU studies. The official Department of Health Guidance to managers and practitioners on care management (DOH, 1991a,b) was not explicit as to the nature of care management and the types of service user for whom it was an appropriate response. In these documents care management was broadly defined as a process of tailoring services to individual needs, with assessment seen as an integral part of the care management process.

Assessment was identified as one of a set of seven core tasks, which resonate with the care management literature in most countries. These were:

- publishing information;
- determining the level of assessment;
- assessing need;
- care planning;
- implementing the care plan;
- monitoring; and
- review.

It could well be argued that such a definition of care management contains the necessary elements. However, it is not sufficient in itself (Challis et al., 1995), and inevitably risked the over-generalization of care management models designed for intensive support to a wider population of service recipients. This appeared to have occurred.

Assessment remained a problem. The most comprehensive review, which involved analysis of 50 existing comprehensive assessment documents used by social service providers across the United Kingdom, revealed that the majority were generic, and that under a quarter of them were used by both health and social services. The evaluation revealed wide variation in content and quality of the information and no clear linkage between identifying problems and formulating a proper response. Assessment of common features of psychiatric disorder, such as depression and anxiety, was very variable and often neglected. Cognitive impairment and behaviour were assessed in a very variable fashion and specific aspects of physical ill health, such as continence and mobility, were less well specified on generic forms. The only reasonably consistent feature involved activities of daily living, although this was not always recorded in a structured fashion.

It was concluded from this detailed analysis that variability of assessment tools is high and their comparability and capacity to generate standardized information is low (Stewart et al., 1999). There was little integration of health and social care information and marked variability between assessment documents. These ranged from structured to unstructured, generic to specialist, and included documents in which major domains were omitted.

A national survey of care management arrangements in England (Challis et al., 1998a,b, 2001a,b) revealed a number of concerns about care management. Specialist documentation was least likely for older people and most likely in mental health. In terms of care planning, ceilings upon expenditure per case for community services were most common in older people's services (76% of authorities). These ceilings were lower for older people and mental health than for physical disability and learning disability services.

Intensive care management targeted upon individuals requiring high levels of support through staff with small caseloads was very rare. Fewer than 20% of Social Services Departments provided an intensive care-management service, and even fewer purchased one. These services were focused on a number of specific user groups, most commonly people with mental health problems and rarely on older people. Caseloads were likely to be higher in older people's services than for other client groups, particularly mental health services. In mental health care there was confusion over whether health or social care should coordinate care for patients, and over which approach to employ.

Overall, there was relatively little evidence of intensive care management, particularly in older people's services and little evidence of the involvement of health care staff in care management, particularly specialist health care inputs such as geriatric medicine.

It could be concluded that the United Kingdom has focused more upon the development of a more general approach to care management than an intensive approach. Paradoxically however, the model of care to which many agencies have aspired is more appropriate to intensive care management. Hence in many areas there would appear to be a misfit between the ***model*** of care management used and the ***purpose and target group*** of care management.

Government guidance has increasingly taken the form of advising agencies to focus care management upon those most in need and to redefine care management as intensive care management so as to ensure that this costly activity is only provided to those for whom there is a probable benefit. Box 1, on the opposite page, cites recent policy guidance:

Box 1. Recent United Kingdom policy guidance on care management

Social Services Departments should differentiate between the co-ordinating and intensive types of care management. They should ensure that the latter is limited to those people who need it. (DOH, 1997)

While the care of all older people should be managed appropriately and effectively, the most vulnerable older people will often require fuller assessment and more intensive forms of care management. (DOH, 2001, para. 2.39)

Care management to be redefined as 'Intensive Care Management' and reserved for people with complex or frequently changing needs. (Scottish Executive, 2000)

A Government review concluded that no single model suits all levels of need or service user groups and identified three types of care management, each necessary to an integrated and comprehensive approach:

- an administrative type, undertaken by reception and/or customer service staff which provides information and advice;
- a coordinating type, that deals with a large volume of referrals needing either a single service or a range of fairly straightforward services which should be properly planned and administered; and
- an intensive type, where there is a designated care manager who combines the planning and coordination with a therapeutic, supportive role for a much smaller number of users who have complex and frequently changing needs.

The review concluded:

> *. . . the crucial objectives are to ensure that long term care management is devoted to those people who need it and that decisions about the skills of staff to be deployed and about monitoring and reviewing arrangements reflect this.* (Social Services Inspectorate, 1997, p. 30.)

3.5 Linking the health and social care agendas

Although care management in the Unted Kingdom has been associated with assessment as one of the cornerstones of the implementation of community care policy, the precise contribution of health care (and particularly of secondary health care services such as geriatric medicine and old age psychiatry) to this process was not clearly specified and is subject to local arrangements. There is a lack of evidence of the appropriate influence of health care professionals in the assessment process and even less in care management itself. Except in the field of mental health, the PSSRU national study found little evidence of integrated care management arrangements. Care management systems devised in agency isolation and lacking access to appropriate expertise for assessment are unlikely to be fully effective, particularly when dealing with individuals with complex problems.

Integration of health and social care provision on the basis of differentiated care management offers more fruitful possibilities (Challis et al., 1998c). It is fully consistent with recent policy initiatives to develop partnership between health and social care by enabling mechanisms such as pooled budgets and integrated provision (Cm 4818-I, 2000). Vertical integration of systems of health and social care focused upon particular need groups (such as dementia sufferers) may make feasible links between care management, secondary health care and social care, and thereby further the recent emphasis upon improved assessment, rehabilitation, and prevention of inappropriate hospitalization for older people (Cm 4818-I, 2000; Department of Health, 2001). It may also permit the effective pooling of budgets around a common constituency of concern, while avoiding the possible distortions that may arise when health and social care resources are integrated (Challis et al., 1998c). For example, there are possible perverse outcomes from integrating acute and long-term care funding, which might further disadvantage long-term care due to the relative power of the two modes of care.

The structure of the local health service delivery system will offer differing opportunities and settings for the delivery of care management. Factors such as the style and extensiveness of provision of geriatric, psychogeriatric, and community nursing will be relevant. The nature of the district itself, based upon such criteria as the degree of rurality, will also be influential.

The expectations of the local health care providers, patterns of their organization, degree of shared working practices, and perceived shared goals will influence the style and type of location of care management. The history of service development shows us already only too clearly how the opportunity to develop services for a particular client group will be very dependent on the degree of welcome or lack of support from key service providers such as geriatricians and psychiatrists.

As in most other countries, there is an expectation that case management will offer a degree of downward substitution from institution-based to home-based care. The extent to which this goal is pursued is likely to vary among authorities, some hoping to make substantial shifts, some relatively more minor shifts.

In others, the logic of the need for downward substitution would be less evident and care management will be perceived more as a service coordinatory mechanism rather than a mechanism for shifting the pattern of provision.

4 Aspects of variation within care management systems

Surveying many of the currently-published British studies on case management – as well as some major studies from elsewhere – a number of common concerns may be discerned. Seven areas of concern were identified as present in much of the work (Challis, 1993a, 1994a; Stein & Test, 1985; Hoult et al., 1983; Hoult, 1990; Muijen et al., 1992; Mcdowell, Barniskis & Wright, 1990; Kemper, 1988; Weissert, 1988; Challis et al., 1995, 1997, 1998a, 2001a,b). These are:

- targeting;
- caseload size;
- location of case management;
- practice style of case management;
- degree of influence of case managers upon service providers;
- management standards and quality; and
- management information standards and quality, and the logical coherence of the case management arrangements as a whole.

4.1 Targeting

The Audit Commission (1992b) cites four target populations as suitable for care management:

- those at high risk of entry to institutional care (including those with chronic mental health problems);
- those with stressed informal carers;
- those requiring resettlement from long-stay institutions; and
- those requiring intensive short-term support following illness or injury.

Applebaum & Austin (1990), reviewing 20 long-term care projects, noted that the most common client-related eligibility criteria were:

- functional impairment (14);
- risk of nursing home placement (10);
- potential for nursing home discharge (8); and
- hospital discharge (7).

In the Wisconsin Community Options Case Management Programme, the same criteria are used to assess eligibility for the case management programme as for nursing homes (McDowell, Barniskis & Wright, 1990). These criteria include (COP, 1992):

- the presence of a severe unstable medical condition and long-term illness; or
- substantial medical and social needs including the inability to perform activities of daily living; or
- a need for supervision and care, usually for people with dementia.

The lack of reliable, valid, and efficient indicators of need for institutional care suggests the combination of a general eligibility criterion of need for services with the exercise of discretion over which service mode any given individual receives. In the Wisconsin Mental Health Programme (Stein & Test, 1980), where the target population comprised individuals with chronic mental health problems, neither diagnosis nor severity of illness were seen as sufficient indicators, although most patients suffered from schizophrenia. Rather, the focus was upon the specific determinants of service mix. Seven criteria were identified (Stein, Diamond & Factor, 1989):

- willingness to come for services;
- medication compliance;
- need for structured daily activities;
- ability to self-monitor;
- frequency of crises;
- need for professional psychological support; and
- degree of case management.

In some Canadian Provinces, several categories of need have been developed, corresponding to intensity of service provision. However, allocation among categories involves the exercise of professional judgement rather than the use of rigid formulae (Kane & Kane, 1991). Thus, in the Manitoba Home Care Programme three criteria determine eligibility: hospital discharge; risk of entry to hospital care; or risk of entry to nursing-home care (Fineman, 1992).

Similarly, in the United Kingdom some care management schemes used agreed guidelines for referral. However, recognizing the complexity of circumstances which constitute conditions such as need for institutional care, no rigid pre-entry threshold of dependency was specified and accountability for targeting was monitored post-entry.

Clearly such an approach has the advantage of permitting discretion, but it requires careful monitoring and is potentially subject to dispute. Managerial scrutiny of such decision-making processes is particularly necessary and requires the development of improved information systems, including information on client characteristics. The development of mechanisms for achieving effective targeting is thus likely to be linked with debates about assessment.

4.2 Care management and intensive care management

This issue raises almost the obverse of the targeting question which was considered in the discussion of definitions of care management. Most care management services have been intended for those people at risk of admission to institutional care settings, reflecting the policy of 'downward substitution' pursued by a number of different societies. However, if it is accepted that care management by individual workers designated as care managers is relevant only for those individuals with complex or severe needs, then it is important to be clear about how services are to be organized for other less dependent elderly people who require social care services.

Therefore, it is important to discriminate between intensive care management and the more effective organizational procedures for assessment, individual care plans, and regular reviews so that the core tasks are effectively carried out for all other service recipients. Equally important for a rational service system is to avoid the complete separation of services provided for the less dependent from services provided for more vulnerable groups and to permit cross-fertilization. Failure to achieve this runs the risk of establishing new boundary disputes in care, with consequent loss of continuity of care.

However, the practical resolution of this is far from easy. Lack of clarity in this area can lead to a process of definition of care management which might be described as of the 'old wine in new bottles' variety. In the face of organizational change, many front-line service providers, and their managers, may display considerable inertia and attempt to redefine the changes as incorporating (rather than challenging) existing roles and practices. As such, it is unlikely to lead to a reshaping of services or substantial enhancement of home care.

4.3 The location of care management

Care management has been located in a variety of different settings. These settings include Social Service Departments, hospitals, geriatric and psychiatric multidisciplinary teams, primary care, independent agencies, and even independent actors. Effective implementation of care management will need to identify appropriate settings to provide case management for individuals with different kinds of needs.

Primary care may offer improved accessibility, access to the primary health care team in assessment, and home support. On the other hand, the numbers of people requiring intensive care management would be small on any one GP's list or in any PHC clinic.

In these cases, intensive case management might be better located in secondary health care settings such as geriatric services (Challis et al., 1991 a,b). This might facilitate access to health care staff for activities such as assessment and care planning.

Similarly, care for those suffering from schizophrenia may be better provided as part of the community mental health service where care managers are part of a psychiatric service. Similar arguments apply to community mental handicap teams (Audit Commission, 1992b).

There may also be a case for arguing that people whose needs are relatively rare within the catchment area of one local authority may have those needs better met by a specialized service. Perhaps this other service would be located in a non-profit agency covering several local authorities.

An example of care management for physically-disabled people provided by an independent agency is described by Pilling (1992). In the United Kingdom, the development of direct payments to vulnerable people to organize their own care, and of insurance schemes in a number of countries, may lead to further such developments (Ikegami, 1997).

The mid-term review of the Australian Community Care reforms for older people suggested the need to link care management and long-term care services to hospital discharge, to prevent the risk of bed-blocking (Gregory, 1991).

Alternatively, the British experience is one which suggests another risk. The goals of the long-term care system can be distorted if there is too close a linkage with the resolution of the problems faced by the acute sector of hospital discharge (Gostick et al., 1997; Challis, 1999b).

An important link exists between intensive care management and secondary health care services such as psychiatry, old age psychiatry, and geriatric medicine. The development of the Aged Care Assessment Teams as part of the Aged Care Reforms in Australia provided such a context which could facilitate such developments.

Such links and co-location can contribute to effective targeting and to the promotion of a more community-oriented mode of practice in these critically important long-term care specialties (Challis et al., 1995, 1998c, 2001a; Ames & Flynn, 1992; Kendig et al., 1992).

It is noteworthy that the United Kingdom, which was one of the early pioneers of geriatric medicine, has made few such links – with the exception of special studies (Challis et al., 1991a,b, 1995).

4.4 Style of care management: brokerage or more extensive approaches

Some implementations of care management sometimes appear to consider the core tasks more as administrative activities (involving mainly brokerage and service allocation) rather than integrating these with tasks such as support and counselling (requiring staff with human relations skills). This is evident in discussions about the separation of purchaser and provider roles where a rigid distinction considers the provision of human relations skills and emotional support as only a 'provider' role.

However, this is quite inappropriate in good practice (Challis, 1992a,b, 1994a,b,c). Such concerns influenced the planning in several Scottish Local Authorities in the 1990s (Buglass, 1993). An alternative formulation is that of 'clinical' case management (Kanter, 1989; Harris & Bachrach, 1988) which offers a broader combination of roles. It seems that most services fall at some point between these poles (Bachrach, 1992).

Studies consistently indicate that more than brokerage functions are required in practice, even if this were not made explicit in the initial planning or job descriptions (Applebaum & Austin, 1990; Dant & Gearing, 1990; Dant et al., 1989) and that case managers were successful in performing the core tasks through combining practical care with the use of human relations skills, including counselling and support, not only to carers and users but also to direct care staff (Challis & Davies, 1986; Challis et al., 1988, 1990, 1991a,b).

Rothman (1991) notes that case management

> *. . . incorporates two central functions: (a) providing individualised advice, counselling and therapy to clients in the community and (b) linking clients to needed services and supports in community agencies and informal helping networks.* (p.523)

Similarly, the British Columbia case management guide (BCMH, 1992) states:

> *Case managers do both direct services and allocate contracted services on behalf of clients. The direct services are generally counselling, teaching, supporting and crisis intervention.* (p.25)

The US National Standards documents indicate that case managers are expected to assume most or all of the roles of service coordinator, advocate, counsellor, and gatekeeper (NICBLTC, 1988).

Moxley (1989) notes that

> *. . . ignoring the clinical and interpersonal practice dimensions of case management is counterproductive.* (p.144)

He argues that effective case management needs a caring and individualized relationship between client and case manager, the use of interpersonal skills, intervention in crises, and knowledge of the clinical expertise of other disciplines.

In their review of case management programmes for frail elderly people, Steinberg & Carter (1983), reviewing the experience of programmes for the elderly, conclude that:

> *Case managers must be clinically oriented, be skilled in establishing and sustaining personal relationships, like and respect older people, be able to coordinate medical, social and instrumental needs and services, participate in assessment and carry through with implementation.* (p.139)

Although there is considerable debate about the roles required of case managers and the specific skills and training which they require, it would seem that there is a scarcity of appropriately trained personnel. In many settings nurses and social workers are the predominant occupational groups (Raiff & Shore, 1993; Rothman & Sager, 1998).

However, without deliberate planning such scarcity of appropriate staff could well influence the style of care management that develops. An explicit commitment to a clinical model of care management could act as a helpful counter to the risk of over-formalization and insensitivity in the new care arrangements. This is perhaps more likely in some client groups than others. For example, it may be that a pure brokerage model is less readily accepted for people with mental health problems than it is for elderly people, because of the visibility of factors such as relationship difficulties.

4.4.1 Degree of role specificity

The extent to which the role of care manager has become specifically differentiated from other roles varies, probably due to contextual factors such as degree of rurality but also reflecting the form of care management development occurring. Thus some agencies may wish not to differentiate the role of care manager as a specific job, seeing it rather as a role within existing job descriptions (Buglass, 1993).

Another approach has involved some staff defined as having different jobs for different clients, for example as social worker for some and care manager for others. Some studies suggest that such role mixing or part-time care management could lead to a less effective functioning on the part of the case manager (Challis et al., 1990, 1995; Kendig et al., 1992).

4.4.2 Balance of work

In order to maintain continuity of responsibility throughout all the phases of a client's 'career' with the service, care managers could be made responsible for continued monitoring and review after entry to institutional care. While such an approach offers continuity, it could lead to increasing caseloads and a sharper focus upon institution-based work than upon community-based work. For example, in one setting case managers remained responsible for an elderly person after entry into a nursing or residential care home. Since the level of reimbursement to homes is based upon client dependency, there is an incentive for homes to request frequent reviews, with inevitable refocusing of staff time away from home-based care. Unless effectively managed, there is a risk that such pressures could militate against a policy of increased community care.

Another area where balance of work could be of importance, involves hospital-based SSD staff such as social workers. While an important focus of work is upon hospital discharge and nursing-home placement, the hospital setting also confers opportunities for developing community-based work within relevant multidisciplinary teams. This is particularly so in the mental health field but also in geriatric settings (Challis et al., 1991a,b, 1995; Challis, 1998c).

4.4.3 Staff mix

Training has been mentioned as indicative of the expected style of care management. However, staff mix itself could also indicate an important aspect of variation in care-management practice. For example, some Scottish authorities with predominantly rural catchment areas were developing primary assessment teams with staff from both Health Boards and Social Work to undertake assessment and care coordination (Buglass, 1993).

In a number of care-management programmes for older people, staff tend to be mainly from social work and nursing backgrounds. However, patterns of professional employment can cause distortion of effective utilization of staff. For example, staff employed in certain settings where peer group support is unavailable, may experience difficulty in maintaining their continuing professional education (DOH, 1994).

A mixed staff group can permit the targeting of particular staff types with particular client needs within programmes (Rothman, 1992). For example, in one British programme for older people, social workers usually managed cases where mental health and carer problems predominated, whereas nurses tended to manage those where physical health problems predominated (Challis et al., 1990).

4.4.4 Caseload size

Targeting policy will also affect caseload size, which is likely to influence both the quality and style of care management (Rothman & Sager, 1998). Caseloads are likely to be determined by client group, intensity of duration and service, and geographical area (Rothman & Sager, 1998; Challis et al., 1994a).

Indeed, this indicator has been one quality standard used to ensure that sufficient staff time is allocated to each case. A number of factors appear to have influenced decisions about caseload size (NICBLTC, 1988):

- the characteristics of the client group served;
- complexity of care plans, type of area served (urban/rural);
- degree of clerical support;
- availability of community services and responsibiliy; and
- control over funds.

Caseload size in the Thanet, Gateshead and Darlington studies was around 25–30 cases; in some mental health programmes it is much lower, around 12 cases, reflecting the expectation of much greater work in human relationships such as engagement. Washington State had a maximum of 50 cases per worker in the age care programme (Washington State, 1986); and the average in the Wisconsin Community Options Programme was 40 (McDowell, 1990). However, only programme goals and resources can determine caseload size (Massie, 1996; Rothman & Sager, 1998) and thereby the trade-off between scale and quality.

Applebaum & Austin (1990) note the variability in caseload size in long-term care of elderly people, ranging from 35–85 cases per worker. They cite surveys of case managers indicating preferred caseload sizes of 30–50 cases and note the evidence of a decreasing capacity to perform follow-up, monitoring, and review as caseload size increases. Similar variability is evident in the United Kingdom (Challis, 1999a,b).

Clearly, there is a trade-off between caseload size and effective performance of these activities which will concern those implementing programmes. Caseload size is likely to determine the feasible style of case management (Bachrach, 1992), which is discussed later. Caseload size is of course more problematic to define when a team approach to case management is adopted for particularly demanding clients in some mental health programmes (Stein, Diamond & Factor, 1989). Raiff & Shore (1993) have detailed some of the complexities of the team approach.

4.4.5 Continuity

One area of debate is whether the core tasks of case management should be undertaken or coordinated by a single designated worker, or by several people. For example, one of the dangers of separating those who make assessments and prescribe solutions from those who implement and monitor the care plan is the loss of learning through time. In such a model, assessors may fail to receive feedback from the results of their assessments because they do not have continuity of contact with the service user.

Nonetheless, the separation of tasks provides a tempting model for organizations with a limited number of trained and experienced staff. There is an understandable desire to invest the time of the best-trained and experienced staff in the assessment process, because it is perceived as the most critical activity in decision-making. The risk of this approach is the loss of continuity and accountability which may be crucial factors in maintaining a vulnerable person at home (DOH, 1991a,b).

In the mental health field, there are models of shared case management undertaken by all members of a mental health team. These appear to have worked successfully in the context of supporting people with severe impairments, but it is usually not the individual tasks which are shared but rather the overall role of case management (Stein & Test, 1980; Raiff & Shore, 1993). Rothman (1992) suggests that it is inappropriate to argue for one approach being generally superior to the other.

Among the trade-offs is that between continuity and focused responsibility on the one hand, and pressure and risk of staff burnout on the other (Raiff & Shore, 1993). The key question relates to targeting – “for which clients do the additional costs of continuity provide significantly greater benefits?”

4.4.6 Documentation

Although documentation is not frequently discussed as part of care management practice, it is part of the practice environment and can contribute to setting horizons and parameters to activities. The right kind of documentation may facilitate improved practice in areas such as assessment, care planning, and review. In British surveys of assessment study there was little evidence of documentation which could assist staff in moving from the task of information gathering towards activities such as needs formulation and care planning (DOH, 1993; Stewart et al., 1999).

4.5 Degree of influence upon service providers

Crucial to the effective implementation of care management is the degree of influence which care managers have over the form and content of services provided. Arnold (1987) has argued that a brokerage model alone is insufficient to effect influence, and Austin (1992), criticizing pure brokerage, concludes that:

> *Case managers who cannot deliver the services they prescribe in their care plans are not very likely to be very effective.* (p.11)

Dant & Gearing (1990) observe that effective care management requires the care manager to control the supply or availability of services and other resources. A common conclusion is that care management should be separated from the immediate activity of service provision, to render it more client-centred than service-focused.

The evidence would indicate that control over resources is an important factor in enabling case managers to respond more effectively to the varied individual needs of elderly people (Challis & Davies, 1986; Challis et al., 1990; McDowell, Barniskis & Wright, 1990). At worst, in the absence of control of resources, the case manager can merely make requests to the providers of other services but has relatively little power in effecting the kinds of negotiation necessary to ensure that services are sufficiently responsive to meet clients' needs adequately (Hodgson & Quinn, 1980) and consequently effective coordination is not possible (Pijl, 1991).

It is the capacity to influence both the type and content of service available that permits genuine individualization of care. Furthermore, a devolved budget has to cover a substantial proportion of care costs otherwise it is liable to be merely used for 'topping-up' care or for single and unique items of expenditure.

Such 'topping-up' of existing services with individual unique expenditures (McDowell, 1990)

- requires little change in the function of service providers;
- improves individualized care plans only at the margin; and
- diminishes the service user's greater influence in the planning of care.

However, budgetary devolution can raise some difficult questions. Premature devolution of previously centralized budgets without reference to past patterns of expenditure and estimates of need is risky, and the alignment of finance and management responsibility at the same level seems to be crucial (Audit Commission, 1992b). Indeed, sometimes devolution of budgets has been necessary as a means of effective budgetary scrutiny and control which, paradoxically, was not feasible with centralized allocation and control. In terms of practice at the field level however, effective utilization of budgets is likely to be influenced by the level at which decisions can be made and the procedures for accessing funds.

The devolution of budgets to individual case managers would seem to be a crucial element of the development of more responsive patterns of care. It remains to be seen whether organizations can achieve effective decentralization of decision-making and balance this with effective accountability. The challenge of making such changes should not be underestimated, particularly in view of organizational traditions and the bureaucratic hierarchies of public sector organizations.

The separation of purchaser and provider was seen as an important part of the development of services in the United Kingdom, with care management seen as a purchaser role (DOH, 1990, para. 4.5). As such, its role is designed to influence the pattern of provision in more appropriate ways. The distinction between purchaser and provider is deceptively simple and different levels of separation may be discerned.

One aspect involves macropurchasing, the form of purchasing most commonly associated until the present time with health authorities contracting with particular providers to provide services for a district or an area. Such purchasing procedures may be similarly developed by local authorities.

Indeed, care management itself could be purchased on such a basis for particular client groups or for particular areas of the local authority. This process of managing an overall market and purchasing supply to meet the needs of a population within an area should be distinguished from the micropurchasing role whereby care managers individually disperse their budgets (DOH, 1991a, para. 1.18).

However, the separation of purchaser and provider roles at the micro level raises more problems than at the macro level and there are dangers in the pursuit of too rigid a separation. Some roles and activities may span the purchaser/provider divide and blur an apparently clear distinction. An obvious example is that of counselling and support; conceptually it might be possible to define supportive counselling as a provider function. Such confusion appears to have affected the planning of care management in some Scottish authorities (Buglass, 1993).

However, in most settings this process – engaging a person, forming a relationship with him or her, and comprehending the depth of problems so as to establish the right mix of support and services needed – proves to be a purchaser function. Indeed, to make such an activity an exclusive provider function would inevitability push care management towards an administrative or brokerage role. Thus, the needs of effective practice do not always lead to organizationally neat solutions.

Again, in the care of a cognitively impaired elderly person, a hands-on carer (provider) might be used to contribute to assessment and other core tasks such as monitoring well-being, routine, diet, or medication intake because of his or her proximity to the elderly person over a considerable period of time.

Therefore, the nature of these relationships between provider and purchaser needs to be explored carefully so that the process of separation does not lead to new problems of inappropriate care. One helpful way of viewing the separation is to be clear about the different roles of care management (including casework) and service management, traditionally blurred in agencies, which underpin the functions of purchaser and provider. The separation is of less significance in the United Kingdom currently and has been seen to be similarly less so in the United States (Geron, 2000).

The issue of influence is particularly relevant in the context of service development, an often neglected facet in the literature. It is possible to conceive of service development in care management at three levels:

- at the level of an individual service user, to ensure that services are individually tailored to assessed need;
- at an intermediate (team) level, to ensure the development of local services to meet identified needs of a group of service users;
- at an authority-wide level, to achieve an infrastructure of services within a community in order to allow people to live at home as an alternative to residential care or nursing-home admissions.

4.6 Management: standards and quality

Much discussion of care management focuses upon the performance of the core tasks of case management in client-level work and upon styles and types of fieldwork practice. However there are important issues of the management of care management, acknowledged in the separate guidance for practitioners and managers (DOH, 1991a,b). Changes will be required in financial and monitoring systems (Audit Commission 1992a,b; Financial Management Partnership, 1992) and in the ways in which such information is deployed.

For example, the monitoring of eligibility criteria and targeting policy will require imaginative information collation and use of data. Other required areas of change in management practice include style of supervision and the use of peer group review.

Of less visibility in debates is the nature of quality assurance. In a context of greater devolution of authority and possibly flatter organizational hierarchies, there will be a need for managers to focus less upon traditional methods of procedural adherence and more upon outcome-focused approaches – a focus more upon ends and less upon means. The focus is likely to be increasingly upon interagency activities, as well as those at the client/worker and the agency level (Steinberg & Carter, 1983).

Consequently, development of approaches to quality assurance and supervision which differ from much previous practice will be needed at the managerial level.

The Department of Health guidance (DOH, 1991a) states that:

> *Middle managers . . . will also have to develop new skills in the promotion of a more entrepreneurial approach by practitioners . . . important though cost consciousness will be, it should be balanced by an appropriate concern for the quality of care that is being provided.* (para. 3.29)

Where the focus of managers is only upon costs (the most easily measured and recorded indicator) perverse incentives could easily emerge, such as the manipulation of the target group by individual care managers to attract less-costly cases onto their caseloads. The Guidance for Managers (DOH, 1991a) argues that standards should be incorporated into the specifications for all services, and such careful monitoring should also be applied to the care management process itself, as well as to the services organized by case managers. This will require the development of record-keeping systems to monitor process, cost, and outcomes.

Indicators of quality have traditionally been seen as indicators of structure, process, and outcome (Donabedian, 1980). ***Structural*** indicators are concerned with inputs such as staff numbers, qualifications and training, presence or absence of certain services; ***process*** indicators cover such factors as response time and patterns of client/worker interaction; and ***outcome*** indicators refer to the effects of services upon clients and their carers.

It follows, therefore, that while indicators of outcome are the most important for assessing the effectiveness and quality of a service, they are also the most difficult and expensive to obtain. Agencies will therefore tend to use indicators of structure and process with a type of validity which requires that a relationship between these indicators and effective outcomes is either known or reasonably presumed.

Case management agencies have begun to develop standards for practice, which are usually indicators of structure and process, and it is instructive to examine some of these. The case management standards developed by the State of Washington (Washington State, 1986) offer examples of several structural indicators.

These include:

- suitable office accommodation to permit private interviewing;
- administrative minimum standards;
- case management staff possessing a relevant degree with two years experience of providing services; and
- maximum caseload size of 50 cases per worker.

The same document includes process standards such as eligibility criteria for entry, frequency of supervision, ongoing training of 40 hours per year, speed of response to a referral and time taken to commence assessment and develop care plans, review periods, and the maintenance of records. These are similar to the proposed standards developed by the National Institute for Community Based Long Term Care (NICBLTC, 1988).

Additionally in terms of outcomes, the proposed National US standards include questions such as whether care plans are designed to provide adequate and appropriate services in a cost-effective manner and whether services provided meet client needs (NICBLTC, 1988).

Applebaum & Austin (1990) suggest five broad quality assurance questions that can be pursued once standards have been agreed and made explicit:

- How well are eligibility and targeting criteria implemented?
- Are assessments and care plans completed in sufficient time?
- Do service plans meet clients' needs?
- Are service plans actually implemented?
- Are clients satisfied with the care received?

These bear some similarity to the different components of efficiency in Challis & Davies (1986) and cited in the UK Managerial Guidance (DOH, 1991a).

4.7 Logical coherence of care management arrangements

As discussed earlier in this chapter, the managerial, agency, and funding environment within which such practice takes place will tend to determine what are perceived as possible and reasonable solutions to meeting need. Dant & Gearing (1990) note (p. 344) the conclusion of many observers of the US scene:

> *Case management (alone) cannot produce coordinated care, a necessary pre-requisite is the integration of funding sources.*

More broadly, four elements (Aiken et al., 1975) need to be coordinated in a fully coordinated system:

- programmes;
- resources;
- clients; and
- information.

Some programmes attempt to tackle this integration. The Manitoba Continuing Care Programme Policy Guidelines link philosophy, objectives, and principles with detailed features of administration and operation (Manitoba DOH, 1991).

The Madison Mental Health Service illustrates clearly how the practice environment and perceptions of what is possible are influenced by the context of funding. The goals of the service are linked through organizational principles to clinical principles to offer a complete system of care (Stein & Test, 1985; Stein, Diamond & Factor, 1989). Hence, practice ***content*** is likely to be determined by the nature of the practice ***context***, and a tendency to discuss care management at the level of practice content alone (Fisher, 1991) can only provide a partial understanding of the forces at work.

Contextual factors such as degree of managerial support for the development, which agency employs the care managers, their span and degree of budgetary control, where they are located and what choice of target population is made, will again influence the content of what care managers see as realistic and viable choices. The effective implementation of a care management model requires a coherent logic which clarifies the relationship among structure, location, target group, practice model and likely day-to-day pressures and incentives and expected outcomes. As Davies (1992) has noted from case management studies in the United Kingdom and the USA:

> *The experimental inputs of the most successful projects were ideational as well as structural. They were substantially about commitments, values and skills. What the structures (including the resources) were intended to do was to enable and encourage people to apply the commitments, values and skills of the new community care philosophy; that is, provide the incentives and rewards which harness individual motivations to achieve the equity and efficiency goals of public policy. (p.118)*

Several case management studies, either directly or indirectly, raise the issue of internal logical coherence – a relationship between values, desired outcomes or goals, and the practice and managerial incentives arising from structures and resources. The factors discussed earlier are all interlinked – for example, targeting policy influences caseloads which in turn influence feasible styles of the case management process.

The analysis of the logical coherence of care management programmes should therefore be a concern of managers and planners in reviewing the development and performance of care management in their service systems. This includes analysis of practice incentives within service systems, so as to ascertain the extent to which the day-to-day coping behaviour of staff is congruent with, or at variance to, the overall goals of the care management system.

5 Conclusion: developing care management in long-term care

Most evidence arising from evaluation research of care management programmes has been concerned with the intensive support of high-risk or high-need groups in both mental health and ageing. These studies have focused upon populations with high probability of admission or readmission to hospital or nursing-home settings. Despite this diversity and the difficulty of producing reliable and robust definitions of attributes such as severe mental illness or risk of nursing-home placement, there is a considerable degree of consistency in the findings.

From these studies several factors may be identified which appear to be associated with effective outcomes in long-term care management (Challis, 1999b). These are shown in Box 2, below.

As can be seen, these include integrated funding for the programme, clarity and precision of target population, clear service objectives, continuity of involvement, and logical linkages between the model of care management, its objectives, and the incentives which the structures present to the practitioners implementing the programme. At the practice level, this may refer to such factors as appropriate caseload sizes and the means to be able to respond creatively to identified needs, through such mechanisms as devolved budgets.

Box 2. Some factors associated with effective outcomes in care management

- Integrated programme funding.
- Logical linkages between model of care, objectives of programme, and practice-level incentives.
- Clear service objectives.
- Precision and clarity of target population.
- Continuity of involvement.

Integrated funding can avoid some artificial boundaries and perverse incentives arising from organizational pressures to remain within narrow budgetary confines.

Clarity of target population, combined with systems of screening and assessment, can ensure that care management with its inevitably higher overhead costs is provided to those for whom it is most appropriate.

Clear service objectives provide a focus for managing and monitoring care management programmes whether in terms of needs of recipients, service processes such as costs, or outcomes such as hospitalization, community tenure or quality of life.

Continuity of involvement offers the basis of practitioners remaining responsible for assessing, monitoring and reviewing cases and gaining the benefits of feedback from effective and ineffective strategies, whether at the individual case level or more generally.

Logical linkages between programme goals, environment and practice incentives reflect the necessity for congruence between practice environment and overall objectives.

For example, such components as flexible patterns of response, perhaps by means of devolved budgets, need to be available to care managers if a programme goal is for individually-tailored services. In the absence of such flexibility, or where there is marked difficulty in providing other than standard responses, the incentive for practitioners will be to respond in a very standard fashion rather than to individualize care.

Kane (1999) identified related factors associated with more effective long-term care programmes which are also relevant. These include coherent values, a single point of access, flexible and responsive services, available personal care, and acceptance of risk.

Key factors discriminating care management arrangements were identified in a review for the Department of Health in 1994 (Challis, 1994). The issues identified are shown in Box 3. The evidence from findings to date suggests that a number of these issues remain very pertinent.

Box 3. Key features of care management development

- Definition of the nature, structure and goals of care management.
- Influence of external contextual and environmental factors.
- Target population, including user group; targeting methods, including assessment.
- Care management as process and intensive case management; the balance between these two activities
- Location of care management: SSD, NHS, external; access to NHS staff.
- Style of care management; administrative or more extensive?
- Operational aspects of care management; role specificity; balance of activities between assessment and review; caseload size; continuity; documentation.
- Influence over providers; devolution of budgets; range of service mix.
- Management of care management; quality assurance; supervision; peer group review.
- Clarity of organizational arrangements; practice incentives; logical links between values, goals, care management service.

Source: *Challis (1994b)*

The rationale for any society in the implementation of care management as a mechanism to integrate care is also likely to vary. For example, when care management was introduced into the United Kingdom in the late 1980s, community services were nearly all provided by two public sector sources – the National Health Service and Social Services Departments.

The need for coordination was not self-evident, since there appeared to be a simple situation of two providers of care. However, the internal divisions of service providers reflected through various professional and service hierarchies (social work, nursing, home care, day care, day hospital, etc.) caused the experience of service users to be fragmentary. Nonetheless, the environment made the establishment of care management in a lead agency relatively easy.

Conversely, in the USA the presence of a myriad of different service providers made the issue of coordination almost self-evident. In a context where there is very low provision of community services, coordination is of less significance than service development as one of the functions of care management.

However, care management is no panacea (Callahan, 1989; Hunter, 1988), but rather a mechanism which, if effectively implemented, can offer one way to manage the tension between social objectives and economic constraints in long-term care services. This can never be a comfortable process. The elements discussed in this chapter cover some of the critical areas which need to be addressed in implementation, if this approach is to achieve the desired goals for community and long-term care.

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Part three

HUMAN RESOURCES

CHAPTER 6

HUMAN RESOURCES FOR LONG-TERM CARE: LESSONS FROM THE UNITED STATES EXPERIENCE

Rosalie A. Kane

6 HUMAN RESOURCES FOR LONG-TERM CARE: LESSONS FROM THE UNITED STATES EXPERIENCE

Rosalie A. Kane

1 Introduction

Long-term care, in common with most forms of endeavour, depends on the abilities, motivations, and attitudes of those who do the work. Human resources are at the heart of most privately or publicly funded human-services provision, including long-term care. This, in turn, has led to a worldwide understanding that investment in human potential is extraordinarily important.

Such investments begin with child development services such as day care and preschools, and include child health care and basic education at all levels (elementary school, secondary school, colleges, and professional or technical education). Investing in human potential also includes continuing education, and on-the-job staff development, which is particularly important in two circumstances that apply to long-term care: when the knowledge needed to do one's job changes because of advances in technology, and when a person enters employment with minimal education only. Finally, labour practices and general social and family services that support and sustain the workforce are part of an overall strategy to develop and sustain that workforce.

Developing and sustaining a long-term care labour force is particularly challenging because long-term care relies heavily on human labour. Moreover, this human service must be provided in disparate decentralized locations, seven days a week, and at unusual times of the day and night. Sometimes the need for human help cannot even be scheduled: people must simply be on hand in case a need arises for their assistance.

Certainly efficiencies can be achieved in the need for long-term care labour through use of prosthetic equipment, and well-designed buildings, fixtures, and furnishings that increase the capacities for people with disabilities to perform self-care and be independent. Efficiencies can also be achieved by state-of-the-art management information and communication systems that permit information to flow to decision-makers in centralized locations. In the end, however, the need will remain for a large cadre of people to form a long-term care labour force. Long-term care work tends to have less prestige than hospital work for health professionals, and the frontline workers in long-term care enjoy even less prestige.

This chapter discusses the type of human resources that a country might need for long-term care, emphasizing lessons about developing and sustaining a long-term care workforce drawn primarily from the United States experience.

The chapter argues that rigid formulas for human resource needs are a disadvantage because they stifle innovation and prohibit organizations from interchanging personnel with different training, or configuring the labour force in a way that takes advantage of particular strengths in a geographic area and resolves particular problems or challenges.

Labour force characteristics often vary locally. In the United States and Canada, for example, the supply of qualified persons desiring to perform various tasks differs across and within states and provinces. Moreover, labour supply issues are far from static; the supply of nurses, therapists, and frontline nonprofessional workers in ageing and long-term care will fluctuate depending on the labour market in general, leading to periods of relative plenty and relative scarcity.

Developing personnel formulas to be applicable internationally is particularly presumptuous. Each country will have its own demographic imperatives based on the age, gender, and ethnicity structure of the population, the educational and literacy levels of the working-age population, the employment patterns, and the amount of regional variation in all of the above.

Thus, any recommendations must be general. 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 assemble for guiding national and local planning on human resources for long-term care.

When possible, empirical data are offered to support suggestions on human resource development. Unfortunately, most of the wisdom from industrialized countries on labour force issues for long-term care is based on expert opinion rather than driven by data. When data are available, such as for example data that link quality in nursing homes to resident-to-staff ratios of various types of nursing personnel, analyses never take into account the possibilities of substitution of non-nursing personnel for some of the nursing functions. The lack of citations to research in this chapter reflects the absence of helpful research on the topic.

2 Defining the knowledge and skills base

One way to approach the daunting task of deciding what knowledge and skills (and, therefore, what occupations and expertise) are needed in the long-term care labour force is to undertake the somewhat simplistic task of 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 two categories:

- those usually performed by persons with professional degrees;
- those usually performed by persons without advanced or specialized education. When these individuals work directly with older patients, they are sometimes called frontline workers.

3 Professional or specialized human resources

3.1 Tasks to be performed

Below is a list of somewhat specialized tasks with a brief accompanying discussion of the persons typically involved in performing them in industrialized countries.

- ***Diagnosis, treatment, and monitoring of acute illnesses and chronic health conditions of persons receiving LTC***

  Physicians and nurses largely perform these functions, though other personnel can help them with monitoring changes in chronic conditions – for example, home health aides or care personnel in congregate residential settings. Physicians who fulfil these roles may work directly for long-term care programmes, such as nursing homes or home care programmes, or they may be part of a country's general system for delivering primary care and hospital care.

Ordinarily, some physicians with advanced training in geriatric medicine are needed to teach, deliver specialized care on referral, consult with primary care physicians, and the like. In countries where specialized advance-practice nurses, such as geriatric nurse practitioners, are available and permitted to work quasi-independently under the general supervision of a physician, nurses may perform many of the functions otherwise performed by physicians, including prescribing medications.

Monitoring for change in health conditions is particularly important in long-term care. Nurses and physicians may do such monitoring directly, or they may also teach patients, family members or nonprofessional caregivers to notice relevant changes and thus assist in monitoring the health of those needing long-term care.

- ***Rehabilitation services to improve or maintain body functions, including capabilities to swallow and speak, to promote activities and participation, and to prevent development of complications and greater disability***

These functions include an interdisciplinary team approach and some of them are largely performed by physical therapists (for large motor functions), occupational therapists (daily living activities and fine motor functions), and speech therapists (for speech and swallowing). In the United States, certified physical therapy aides (PTAs) and certified occupational therapy aides (COTAs) perform many of the functions of professional therapists, under their supervision. It is also possible for nursing assistants and persons with relatively little training, including friends and relatives, to provide most of those and other similar activities as part of an overall plan. Rehabilitation includes the prescription and provision of assistive devices such as wheelchairs, orthotics and prosthetics, to guarantee mobility and to improve function and quality of life.

The more sophisticated the equipment used to improve mobility and independence of the person with functional disability, the more important it is that a network of individuals is available to repair and service that equipment. Traditionally, not much thought is given to the availability and distribution of personnel who are capable of repairing assistive devices.

- ***Management of or assistance with medication regimens***

  If the older person cannot take his or her own medicines, the task of administering medicines is usually carried out under the supervision of a registered nurse, particularly if the older person receives injectable medicines or medications of the kind that need careful monitoring and titrating (such as sliding scale insulin for persons with diabetes, or anticoagulants). Management of medications is one of the most difficult components of long-term care to put in place because – depending on the legal standards as to who may administer medications, and the complexity of the regimen – expensive nursing personnel may be required to be on hand many times during a day.

  The difficulty in determining a way to efficiently manage medications in long-term care is ironic because family members typically administer medications when such family is available to do so. Besides a need for personnel to work directly with patients in administering medications, other persons (typically pharmacists) are needed to dispense medications and to inspect the adequacy of prescribing and dispensing practices, including guarding against prescribing incompatible medications.

- ***Testing of hearing, and fitting and monitoring of hearing aids***

  This suggests a need for audiologists and hearing aid specialists who understand how to work with all hearing impaired, and in particular, elderly patients.

- ***Testing visual functions, providing surgical and refractive services and low vision care***

  This requires ophthalmologists and optometrists/opticians able to provide eye care to all vision impaired as appropriate, according to eye care conditions: surgical services for cataracts; refractive devices (spectacles) for uncorrected refractive errors for distance and near vision; low vision services for those with late consequences of glaucoma, age-related macular degeneration, diabetic retinopathy, and/or other retinal degenerative conditions.

- ***Dental care, including fitting of dentures***

  This suggests a need for dentists and dental assistants with expertise in and willingness to work with older people and with often 'difficult patients', as the mentally ill or handicapped.

- ***Diagnosis and treatment of psychiatric conditions, which may be the primary reason for needing long-term care or an additional complicating condition***

  Psychiatrists, psychologists, social workers, and specially qualified psychiatric nurses are all involved in this function. Treatment could include medications, behavioural management, and individual, group, or family therapy.

  Many older people needing long-term care have conditions that result in memory loss and generalized impairment in decision-making. The extent to which care personnel should be specialized or generalists is a matter of some controversy.

- ***Evaluation of fundamental needs and development of care plans***

  This task is often performed by nurses or social workers, and is sometimes performed by an elaborate multidisciplinary team. Sometimes the individuals who do care planning (alternatively called service planning) have the job title 'case manager'.

  It is not clear whether the assessment and care planning task should be done by each organization that provides care (for example, each nursing home and home care provider), or whether greater continuity can be achieved by the establishment of assessment and care planning functions that are freestanding and consider care delivered by all organizations. Decisions for how this function is performed cannot be made in a vacuum, but will be highly dependent on the way services are organized and funded in the country.

Team management

Geriatric assessment and management (GAM) units have been established in many cities in industrialized countries to perform a deluxe assessment on either an inpatient or outpatient basis. Such assessments are often targeted to those older people who have achieved maximum benefit from acute-care hospitalization but who have functional problems and chronic diseases that together make post-hospital planning difficult. Multidisciplinary teams using a variety of techniques (interviews, performance tests, laboratory tests) may be involved, and the assessment can last for a period of many days.

Such teams have been perceived as particularly justified when they have the potential to alter the trajectory of persons who were perceived as management problems or in need of more protected settings. Such freestanding, often one-time, assessment and care management should be distinguished from the ongoing assessment of needs, and planning for services that occur regularly for persons receiving LTC.

Making arrangements for the delivery of care at home or in special congregate settings

This kind of coordinating and allocation function is also often done by persons with the job title of ‘case manager’ or ‘care coordinator’, sometimes in conjunction with assessment and care planning. The most frequent academic preparations for the role are social work or nursing, though often no postgraduate requirements or professional degrees are needed to enter into this occupation.

If personnel who arrange for care are located outside the organizations that provide care, they may also have a quality assurance function. That is, they may judge and try to assure or improve the quality of the help the older person gets, a function even more likely if the case management organization has been involved in purchasing the care.

Providing recreation and stimulation

It is debatable whether this task, which occurs in senior centres, adult day care centres, and various congregate living settings like nursing homes, is really part of LTC. It could be considered more of a general societal function and one that is not necessarily age-specific.

However, adult day care is sometimes prescribed specifically to achieve goals of recreation, socialization, and stimulation, and recommendations for relocation in senior housing or assisted living are often made for the same purpose: to combat isolation in old age. Moreover, when people are encouraged to relocate in nursing homes to meet health and functional needs, they are often cut off from their social moorings and some programmatic help is thought necessary to bring or restore interest to their lives.

The skills needed to perform such tasks are also debatable. Individuals with bachelors or masters degrees in recreational therapy approach this work as an individualized prescriptive therapy. Those less dedicated to a 'medical model' may also perform the functions effectively in a less prescriptive mode.

For example, individuals with skills in music, art, and adult education have worked effectively in offering stimulation and recreation to persons receiving long-term care. It is also probable that generalists without any advanced or specialized education in activity work can fulfil the functions required, although some special skills may be needed to develop programmes, recruit and train volunteers, and the like.

Administering long-term care programmes

Home care agencies, day care centres, senior centres, assisted living programmes, nursing homes, home-delivered meal programmes, and so on, all need to be organized and administered according to sound financial principles and sound principles of managing human resources.

It is unclear how much the knowledge for these tasks is specific to long-term care programmes; for example, those who have administered a school or a hospital, a social service agency, or many other kinds of organizations may have the requisite skills. Furthermore, the kind of personnel needed to manage long-term care programmes will vary according to the complexity of the organizations and the size of the budgets.

Often, people with practical experience in a field, such as nurses and social workers, ascend to management, and these individuals often bring useful particular knowledge and commitment to the tasks. However, they may need additional skills to meet the complicated expectations of a large long-term care programme, including personnel management, budgeting, strategic planning, and quality assurance.

It is certainly possible to develop a system with specific licences to administer programmes such as nursing homes or assisted living settings, and base that licensing on education prerequisites and specific training.

3.2 Issues raised by specialized personnel and their tasks

The various tasks outlined thus far all rely on a somewhat specialized knowledge base or on a set of skills. They have in common the fact that they raise the following issues:

- To what extent should each function be provided within LTC settings versus being organized outside such settings, and be made available to the perons with long-term care needs? The answer to this question will dictate the extent to which primary health care will be the vehicle for some of the specialized services needed by the LTC patient.

Although many industrialized countries have duplicated services for LTC programmes and settings, an argument for both quality and effiency could be made for providing the services at the community level. This is especially true because developing countries may not wish to replicate the high level of institutional arrangements found in industrialized countries.

- To what extent is it necessary to infuse content specific to disability and ageing – and services appropriate for these client groups – into all curricula of health professionals (e.g. physicians, dentists, nurses, therapists, pharmacists, social workers, administrators) for them to be effective in a geriatric and LTC practice?

  Practice wisdom asserts that there are deficits in the extent to which generalists in any professional field understand the challenges of disability and ageing. However, LTC needs are growing rapidly and people with chronic conditions should be able to expect appropriate care in all settings.

- If curricula need to be reoriented to reflect changing needs as the population ages and chronic conditions increase – should this be done separately by each profession, or should this include interdisciplinary teaching/learning?

- To what extent can nurses and other professionals substitute for or augment the work of physicians? If nurse practitioners or physician assistants are to be developed, how can their jobs be structured to maximize their effectiveness?

- To what extent can the work of professionals be replaced by less-qualified non-professional personnel, and what would be the implications for supervision and for assuring quality of care?

4 Nonprofessional workers

Other sets of tasks in long-term care relate very directly to the assistance people need with everyday life because of their disabilities. Although some skill and training to perform these tasks are needed, it is important to remember that family and friends without particular training can perform many tasks, and that many tasks can be performed interchangeably by people with a wide variety of educational backgrounds.

In the rest of this chapter, we use the term 'frontline worker' to refer to those without professional credentials who perform work in long-term care and who work directly with the disabled/older person. It is useful to think of frontline paid personnel as providing services similar to those often provided by family members.

It is widely understood that uncompensated family members provide most of the world's long-term care. The difficult task of frontline workers is to serve as surrogates for family members when the latter are not available.

4.1 Tasks performed by frontline workers

The following LTC tasks can be undertaken by frontline workers:

- assistance with mobility, bathing, dressing, using the toilet, transferring, eating, and positioning in bed as necessitated by the person's condition;
- housekeeping, cooking, and laundry assistance as necessitated by the person's condition;
- shopping for or with a person needing care;
- providing transportation and/or escort for a person needing care;
- supervision of safety and prevention from harm; and
- assisting with financial management (paying bills, reviewing accounts).

The work involved in some of these tasks consists of activities that are widely familiar to many adults (driving a car, cooking, shopping, laundry, bed-making, house-cleaning, handling money or balancing a cheque book); training needed would be minimal and often specific to the particular person being helped (e.g. training on special dietary needs or restrictions). Other skills can be readily taught (dressing, help with using the toilet, transferring, bathing, feeding) with reference to how to perform the tasks so that both the person doing the work and the person receiving the care are comfortable and safe.

Sometimes, the teaching needs to be specific to the special challenges and risks of the specific person being helped or the conditions that necessitate the need for help. For example, a frontline caregiver may need particular knowledge about general issues such as skin care for those who are immobile, or how to assist with mobility for specific conditions such as Parkinson's disease or arthritis. Sometimes, skills are needed in managing special equipment, such as urinary catheters, ventilators, and equipment used for ostomies.

In some societies, many of these kinds of tasks are performed by registered nurses, whereas in many countries less trained assistants with job titles like 'home health aide' or 'nursing assistant' do the bulk of the work.

4.2 Subdivision of tasks of frontline workers

Sometimes direct care work is subdivided. The most common divisions are:

- personal care services, i.e. those that bring the worker into contact with the body of the person receiving care; and
- all other help that these services involve, i.e. homemaking activities and those that involve the person's possessions and physical environment.

Further subdivisions are possible for both the personal care side (e.g. medication technicians), and the homemaking side. The latter is more likely to be subdivided in congregate living situations where it becomes feasible to have waiters, cooks, housekeepers, laundry personnel, and so on, dividing the tasks. For care at home, such specialization may be dysfunctional. The advantages and disadvantages of segmenting the labour force are discussed below.

4.3 Generic attributes required of frontline workers

Although it is apparent that tasks such as cooking, cleaning, laundry and even personal care are not specific to ageing or long-term care, some challenges apply to frontline workers in long-term care settings regardless of whether their tasks are segmented or more general.

First, the individuals performing everyday routine care also form relationships with the person receiving long-term care. The relationships can be positive, affording the disabled/older person a sense of companionship, pleasure, and security. In contrast, the relationships may be impersonal or neutral, or at worst negative – making the individual receiving care fearful, anxious, misunderstood, humiliated, and hesitant to request help. ***Basic human qualities of sensitivity, genuineness, reliability, kindness and practical intelligence are thus of prime importance.***

Second, the persons performing everyday routine care are also in a position to observe changes that are relevant to health status. From this it follows that two rather general skills are needed for frontline long-term care workers: ***communication*** skills and ***observation*** skills. Both of these skills need to be tailored to the clientele and conditions being served. Particular challenges are involved in communicating with people who may have hearing, speech, and cognitive impairments. In addition, changes in all chronic conditions need monitoring.

Third, some degree of ***literacy*** is also needed to perform the tasks of long-term care. Frontline long-term care workers need to be able to read and speak the language in which the work of the programme is conducted. Long-term care work is often a beginning job for new immigrants to a country. It is possible that some of these workers are literate and relatively well educated in their own country yet unable to speak the national language. In the United States, some nursing homes have even begun teaching English as a second language to its caregiving staff; others arrange for such training elsewhere. The more literate and articulate the frontline labour force is, the less dependent the programmes are on supervision by professional personnel.

4.4 Issues raised by tasks of frontline workers

This discussion of the tasks of frontline workers raises the general issues described in the questions raised on the following page.

- How should the frontline jobs in long-term care be constructed in terms of generalist versus specialist expertise?

- Should the frontline jobs in long-term care be constructed differently depending on settings? For example, should the jobs be differently defined and supervised, perhaps with different requirements, for organizations like nursing homes where professional staff are on hand, compared to in-home services?

- Where will the labour force come from for these positions? What general and particular challenges arise in a country, to recruit persons to frontline LTC and retain them in the positions?

- Should frontline long-term care work be viewed as a relatively short-term position (a matter of months and years, rather than decades or entire careers) or should it be possible for persons to have a financially and psychologically rewarding long-term position providing or supervising frontline long-term care? Is some mix of long-term and short-term workers most desirable?

- What kinds of qualifications are needed at entry for frontline long-term care roles?

- What kinds of orientation, staff development, and continuing education would work best? Who should be responsible for offering such ongoing training. Who should pay for it? How particular should it be to the actual circumstances of care settings and current clientele?

- How can communication and observational skills best be taught? How, if at all, can empathic skills be taught, or is that a matter of selection of the right individuals?

- How can adequate literacy levels in frontline personnel be assured? What level of literacy is needed, and is it needed for all personnel? Are there ways to organize jobs and record systems so that they are easier to use by people with less ability to read and write in the language of the country?

5 Specialization

The sections on task-related requirements for professional/technical personnel and for frontline personnel each ended in a list of issues. In this section, a somewhat different set of crosscutting issues is discussed. Most relate to *both* professional or technical personnel and also frontline personnel. Each of the issues in developing human resources discussed in this section is overlapping. The way one is solved will influence other issues on the list. As countries evolve long-term care labour forces, they face most of these problems.

5.1 Professional versus nonprofessional personnel

As stated already, many of the tasks needed for long-term care are familiar to and within the skills of a lay person. Different decisions may be reached about the extent to which professionals, such as qualified physicians, nurses, social workers, mental health personnel, or therapists are needed to perform various tasks. If nonprofessionals serving as frontline workers receive good initial and ongoing training, if they are recruited from people with good basic education, and if a relatively high caliber of personnel is attracted to the jobs because of the salaries and benefits he or she can command, there will be less need for professional supervision and oversight.

In practice, varying standards are developed for the training and supervision of the personnel who perform direct care tasks. Some may be expected to have extensive training (for example, two years of training and a specific credential, such as residential care worker, is common in the United Kingdom) or, by contrast, they may be required to have only 90 hours of training, such as for certified nursing assistants in the United States.

In most countries, certain expectations and prerogatives attach to professional occupations, which are licensed by public bodies and typically monitored by their peers. Professionals are expected to have mastered a body of knowledge, acquired specified skills, and subscribe to a code of ethical behaviour established by the profession.

The argument for requiring a registered nurse to perform certain tasks is related both to his or her presumed ability to perform skilled assessments and also to the confidence placed in the ethical behaviour of members of the nursing profession.

Similarly, qualified social workers (who in some countries are required to have a college degree and often have a master's degree, and in other countries may be prepared through various kinds of technical training) are expected to have mastered some basic skills in working with individuals, families, and groups. Social workers are expected to have a theoretical understanding of human behaviour and of the range of resources available in the society, and to subscribe to a professional code of ethics. Tasks that are performed by nurses and social workers are also performed by people without those qualifications.

Each country is challenged to decide what must be done by which professional, and what can be done by people not licensed in the profession. It is also important to determine what responsibility – if any – the professional has towards others who are performing the tasks on a paid basis, an unpaid basis, or both.

5.2 Specialists versus generalists within a profession

The issue of how specialized or generalized the long-term care labour force should be pertains both to professionals and to frontline workers. In terms of professionals, vigorous debates have been held about the need for geriatric physicians, geriatric nurses, geriatric social workers, and so on.

The answers depend on the role envisaged for the specialist. Will geriatric or rehabilitation specialists care for older/disabled people directly, provide direct care for just a segment of the population (perhaps those who are very old or who have complicated conditions) or will they largely provide consultation to primary care physicians and other specialty physicians?

If geriatric/rehabilitation specialists are to serve largely as consultants and educators, some competence in ageing and rehabilitation needs to be developed in all physicians. Similar issues arise for nursing, social work, psychiatry, and a host of other disciplines. Pragmatism may dictate the answers. In most instances, it will be impossible to provide personnel specialized in geriatrics, rehabilitation and long-term care to work with each disabled or older person.

5.3 Specialists and generalists among frontline workers

As already stated, many societies distinguish between the work that involves contact with a patient's body as opposed to contact with the patient's possessions and environment. 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 frontline 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. Furthermore, ludicrous situations can arise with segmented labour, such as in the example where one category of personnel gives a bath and another cleans the tub.

In congregate living situations, division of labour is more feasible, especially for somewhat large programmes, which may have a personal care staff, a housekeeping staff, a laundry staff, a kitchen staff for cooking and washing up, and a waiter staff for serving meals. Even for congregate settings, however, current thinking is encouraging a more universal worker who assists a small group of residents with a wide range of tasks – from personal care, to serving food, to cleaning rooms, and doing the laundry. The thought is that such generalists are better able to come to know the resident well, form positive relationships, and become better able to communicate and observe, than would occur in the case of a segmented labour force working with a much larger population of residents.

6 Credentials, licensing, and certification

6.1 Professional personnel

Professionals – personnel with technical or professional roles – usually receive their training in post-secondary educational institutions, and these institutions are typically responsible for certifying their beginning competence. This usually entails some combination of review of credentials and/or a qualifying examination.

Beyond that, governments may establish a licensing authority and exact additional requirements such as job experience or periodic refresher training for those who hold the licence. Levels of practice within a job category can also be licensed. Also the professional and technical disciplines themselves may wish to certify or accredit their practitioner, or governments may cede the licensing and policing authority to the professional groups.

Generally, licensing and certifying of personnel is thought to be a way of maintaining quality, though if certain activities can be performed only by those holding special certification, provider organizations have less ability to improvise and innovate. In the United States, there has been recent attention to whether the role of case manager should be licensed or certified, and, if so, what the minimum educational requirements and demonstrated competency should be.

Licensing requirements for various kinds of professional and technical personnel also have a guild-like quality of protecting those already licensed in the occupation from others who wish to do the work, or, in some cases, even to enter the occupation in a given geographic area. In the United States, this issue has arisen particularly with reference to nurse practice statutes and licensing regulations.

These have sometimes been interpreted to mean that only a registered nurse may administer a medication or do various other kinds of nursing procedures that have been performed within families and neighbourhoods for decades. The issue particularly comes to a head when administration of medications or tasks defined as nursing are performed by paid non-family personnel – perhaps those already assisting in the setting with personal care and housekeeping tasks.

In the United States, each state jurisdiction governs professional practices, and some have modified or clarified their laws or their regulations to permit nurses to teach and delegate a variety of tasks to nonprofessional personnel, even when they are not immediately or intensively supervising the tasks (Kane, Baker & O'Connor, 1995; Reinhard, 2001; Wagner, Nadash & Sabatino, 1997). Such 'nurse delegation' is thought to help keep costs low enough for the older person to remain in the community and to promote quality by keeping nurses involved in teaching and monitoring.

An alternative is to formally exempt certain persons or situations from the nurse practice act, such as household servants, attendants for younger people with physical disabilities, and the like. One formal evaluation of a nurse delegation programme in the state of Washington reported positive results (Young et al., 1998).

6.2 Frontline workers

Whether and how frontline workers should be certified is a more vexing problem. Training may occur at centralized locations such as community colleges and technical training academies.

Sometimes, provider organizations themselves become approved to provide entry-level training to their own employees and those of other organizations. Indeed, one strategy for nursing homes to maintain their labour force of nursing assistants is to operate their own training programme. Since frontline workers often have low incomes and scant savings, a pre-employment training requirement for which they pay out-of-pocket may deter them from the field.

Often provider organizations pay for tuition, training, and wages for their employees while they are being trained. Governments may become involved by certifying local training locations (including providers) and mandating a particular curriculum.

Frontline personnel are sometimes required to become certified by a governmental body (usually at a lower than national level) largely so that authorities can develop a registry. Because of concerns about the vulnerability of the people served and the typically low requirements for entry into the occupation, personnel are often required to undergo checks for criminal backgrounds, provide health information, and the like. Personnel who are derelict and terminated from employment for that reason could then be removed from the registries so that they do not recycle to other employers.

Such registries are required for nursing home and home care personnel in the United States, though they are often poorly maintained. Some commentators caution against potential harm from registries and note that personnel must have a way of appealing adverse judgements that affect their ability to work in a field.

7 Retaining a labour force of frontline workers

If unemployment is high, unsatisfying frontline jobs in long-term care may still be filled. In a tight labour market, workers may prefer other relatively unskilled occupations, such as working in hotels, restaurants, and tourist industries, becoming part of a retail sales force, or even working in some unskilled manufacturing jobs. Shortages tend to be cyclical.

In the United States, for example, long-term care providers have reported difficulty in recruiting or retaining frontline personnel, beginning in about 1999 and extending through 2001, with the difficulties being exacerbated in some markets where unemployment is almost nonexistent. When such shortfalls are found, typically there is still variation in the ability of various employers to retain staff.

There is some anecdotal evidence that respect for workers helps to explain which programmes keep their labour force. Recently, various states in the United States have done their own labour force analyses, attesting to shortages and suggesting a range of strategies to improve jobs and job conditions (Faculty Workgroup, 2001; Frank & Dawson, 2000; Leon, Marainen & Marcotte, 2001; North Carolina Division of Facility Services, 1999).

In the face of shortfalls of frontline workers, one strategy is to import workers through a guest worker programme or through relaxed immigration restrictions. Another is to try to improve the nature of the jobs – not only in terms of their pay scales, working conditions, and benefits, but also in terms of making the jobs interesting and respected.

7.1 Respect, rewards, and career ladders for frontline workers

In general, long-term care commands low levels of prestige. Physicians, nurses, social workers and others in long-term care may command less respect and lower salaries than their counterparts in other settings such as hospitals.

The roles do not ordinarily involve working directly with the newest and most exciting diagnostic and treatment technologies. They often take personnel into backwaters of health care provision, in older buildings, and far away from the stimulation of grand rounds, high-profile case conferencing, and the trappings of modern medicine. Nurses and therapists and others employed directly in long-term care settings may have less access to continuing education and less opportunity and eventually motivation to remain up-to-date in their own fields.

Lack of respect from others may lead to lack of self-respect. One way of guarding against this is to make sure that invidious wage distinctions disadvantaging those employed in long-term care do not develop. Of course, if physicians are quasi-independent practitioners whose income is partly a function of the procedures they perform (as is the case in the United States), incomes for those working in long-term care will never ascend to the incomes of those who work, say, as surgeons.

The stock-in-trade of the best geriatric/chronic care personnel is their ability to listen and make judgements, the essential ingredients of which are a prepared mind and time for encounters with patients. Indeed, patients often do better if procedures (such as catheters and tube-feeding) and medications are discontinued rather than initiated.

The prestige issue is exacerbated for nonprofessional employees. The people on the front lines of the long-term care labour force have difficult jobs. At times, their work involves hard physical labour and heavy lifting; and/or disagreeable clean-up tasks. Sometimes they need to adapt to difficult patients and to almost abusive behaviour from clientele, especially if the patients served have lost their inhibitions because of cognitive impairment.

Frontline personnel may have little authority, especially if their jobs are construed as following the plans of nurses and other professionals, but they do have substantial responsibility. They may work in a patient's home far from any professional personnel, or they may be responsible for a group of nursing home residents at night without any professional personnel on hand. It is up to them to decide what problems to communicate to their supervisors, and what constitutes an emergency in which specialized help is needed right away. In a group residential setting, they will be called upon to allocate their time among competing requests and needs of several residents.

A common complaint of frontline workers in industrialized countries is that they get little recognition or respect for their work (Wilner, 1998). Salaries are often low and fringe benefits lacking. Also galling is lack of respect for their opinions. In some nursing homes, frontline workers are prohibited from reading the medical record let alone contributing to it. Aides and housekeepers typically do not participate in care planning even though they may have uniquely accurate information about a patient's needs and preferences based on more sustained interaction.

7.1.1 Career ladders

Closely related to the issue of treating frontline workers with respect is the challenge of providing opportunities for advancement. Many positions in long-term care have little room for the worker to advance to a higher position. To counteract this problem, various jurisdictions in the United States are attempting to develop career ladders for frontline workers to advance to positions of greater authority. Typically, employers bear much of the cost for this effort in terms of paying for tuition and/or offering paid release time to workers in exchange for a commitment of continuing employment. For such a system to work, the additional training must be available at convenient hours to enable the trainee to maintain employment. Also, there needs to be a continuing stream of people willing to perform entry-level jobs.

If frontline workers advance to other jobs, somebody needs to stand on the bottom rung of the career ladder. Immigrants are one likely source of labour. Another possibility might be to attract young people just leaving secondary school and who are uncertain of their career goals. It is even possible to consider some kind of public service commitment for youth, akin to military service, in order to fill entry-level conditions.

7.1.2 Turnover of frontline workers

The subject of career ladders raises the question of its opposite: high turnover. Turnover of personnel is costly to care organizations, and it has become a truism to deplore the high turnover rates often found in long-term care facility staff in industrialized countries. Yet turnover may not be all bad, if there is also a core of personnel who remain for continuity and if the turnover is planned.

For example, if highly motivated people can be attracted to the roles for short periods, perhaps during life transitions, this approach might round out and upgrade the long-term care workforce in a most helpful way. Recent high school graduates, recent college graduates, homemakers with young children, even recent retirees from the labour force, and certainly recent immigrants, might be attracted to long-term care work for a year or so.

If jobs can be fashioned as less than full-time, the likelihood of attracting college students, homemakers, and retirees is higher. There is little research on these issues to help determine the best mix of short-term and long-term frontline workers in long-term care.

7.1.3 Effectiveness of programmes to improve and retain frontline workers

It is easier to be in favour of career ladders for frontline personnel than to determine where the rungs of the ladder might lead. If the career ladder is meant to allow frontline workers to climb into various professional and technical roles, then it will be necessary to develop opportunities for some people to complete their general college and perhaps high school educations, which would often be a prerequisite to getting training as a nurse, a social worker, or an administrator. This kind of career ladder away from the frontlines may respond to the needs and wishes of some frontline workers.

However, it is also possible to design a system with new roles for frontline workers as supervisors, teachers, and mentors so that they remain close to the direct delivery of care. Such positions would need to be properly compensated, of course.

Research on the effectiveness of programmes to promote frontline workers into leadership roles is sparse, though descriptive accounts of innovations are plentiful. Such concepts are just beginning to emerge in isolated examples in the United States.

For example, one nursing home known to the writer has designed a role of 'cluster manager' for selected certified nursing assistants. In this nursing home, the cluster managers are responsible as the primary care coordinator for eight nursing home residents. They have been taught the computer skills to manage the assessment database, and are the ones in the frontline of communication with residents, family members, and others in the health care team. The day-shift cluster manager hands over the mini-unit to the evening cluster manager. These roles can be accessed by people whose training is received 'on-the-job', and do not need to go back to school to complete a college education or to embark on a professional track.

Similarly, in small assisted living programmes, people with experience in building maintenance, personal care, housekeeping, and the like, have been advanced into administrator roles after receiving specialized training, a possibility more likely in a large firm committed to promote from within (as long as governments do not exact requirements for administrators). Other examples like this need to be developed and carefully tested to see what kinds of career ladders are truly feasible for frontline personnel.

8 Personnel ratios

To determine how many personnel with various kinds of training are needed, it is tempting to try to derive a ratio of workers to the number of persons served. This can be done prescriptively with reference to individual organizations, e.g. there could be a requirement for a minimum ratio of nurses to residents or activity personnel to residents in nursing homes. It can also be done to forecast the desired number of professionals needed for a society, e.g. the number of geriatric physicians per 1000 people over age 65.

Used in the second sense, ratios may be useful as crude planning tools or goals. Used in the first sense, that is, requiring minimum staffing ratios for certain types of organizations, staffing ratios are more problematic. They are better if adjusted for the acuity levels of the clientele, but typically they are not based on clear data about the numbers and mixes of personnel needed to perform tasks and achieve results. Moreover, staff ratios usually satisfy the protective instincts of particular professions without considering the extent to which various kinds of personnel are interchangeable. The Institute of Medicine studied the topic of desirable nurse ratios for hospitals and nursing homes and could not reach a sound consensus for the nursing home settings (Wunderlich, Sloan & Davis, 1996).

9 Family members as human resources

Family members provide substantial long-term care services, as discussed in Part one, Chapters 1 and 2 of this volume, by Joshua Wiener and Marja Pijl, respectively. A conscious strategy to encourage, train, and support unpaid family caregiving reduces the need for a paid labour force. Direct payment to family members is also a possibility, and one that is widely used in industrialized countries (Linsk et al., 1992).

If a limited amount of public dollars is available to pay for long-term care services, authorities may be loath to pay family members for what they would otherwise do without compensation. On the other hand, family members may be unable to afford foregone wages to give extensive care.

Direct cash allowances to those needing services find their way into the hands of family members in more than half the cases in most direct payment programmes. In a market with low unemployment rates, family payment may be a solution that increases the labour force, since a variety of kin and neighbours may work on a flexible schedule to meet the need.

Arguably, if wages are at the market rate for frontline workers, opportunity costs will be such that those who can command higher wages will not opt for the positions. Some commentators see payment of family caregivers or direct payment to consumers as a sort of income support to low-income families.

10 Multidisciplinary teams

The multidisciplinary team has almost become a cliché of long-term care. Like most clichés, it emerges from a certain truth. It is true that many different kinds of expertise are needed to plan and manage the care of an older person who is likely to have complex, interacting problems.

It is also true, however, that teamwork is a luxury when human resources are scarce. It is beyond the scope of this chapter to discuss teamwork in detail.

Much has been learned about the skill-building and maintenance activities needed just to have teams function with adequate communication and mutual respect to get their work done towards common goals (Drinka & Clarke, 2000; Mezey et al., 2002). Much has also been learned about the hazards of teamwork, particularly the propensity to forget the main goal and substitute team-member satisfaction rather than consumer outcomes as evidence of success.

A review of the literature suggests the following guidelines as teams are forged:

- Consider ways to get multidisciplinary input, for example in a comprehensive assessment tool, without necessarily having a multidisciplinary group perform the task.
- Develop teams only when they are needed.
- Make sure that core teams are no larger than necessary.
- Recognize that various persons can be interchangeable and avoid orthodoxy about which disciplines are needed and who should lead the team.
- Try to develop effective information systems that cut down the need for, and maximize the effectiveness of, expensive face-to-face meetings of the whole group.
- For ongoing long-term care settings, recall that frontline personnel may have a great deal to contribute to the collective effort.

11 Case Managers

The ideal of 'case management' or 'care coordination' has emerged over the last 20 years in industrialized countries and has engendered some enthusiasm in countries newly articulating a LTC programme. This is somewhat ironic, because industrialized countries have recently been rethinking their views about case management, spurred in part by consumers who are resentful about the intrusiveness of some representative of an official programme managing the details of their lives under the guise of managing their care.

Thus, the role of case manager is being reconsidered in countries such as the United States and Canada. There will always be a need for someone to allocate benefits (if the system has benefits) based on objective criteria, and there will always be a need for those who help older people and their families make complicated decisions and gain access to services. Those LTC consumers with cognitive impairment or extreme physical frailty, and particularly those who lack involved kin or friends, will need more case management on a more sustained basis than those with fewer care needs and/or involved family agents.

Any case management or care management capability needs to be developed in conjunction with the particular system of care in the country, and also developed cautiously (Campbell & Ikegami, 1999). It would, however, be a grave mistake to begin with a care management system at the expense of evolving the services that need to be managed. For a detailed discussion of case management see Chapter 5 of this volume, by David Challis.

12 Culture

Long-term care is intensely personal. The greater the disabilities of the person needing long-term care, the more dependent they are for large aspects of daily functioning on the presence of others. Long-term care workers finish by shaping the day of the long-term care consumer, determining where they go and when, even to details of where and what they eat, and when they get up or go to bed.

Because there is likely to be a great deal of interaction between the person providing frontline care and the consumer, mutual trust is important. Imagine the stress of receiving care in such intimate detail from someone regarded as an enemy. Imagine the difficulty a care consumer might have in asking questions or raising objections to a nurse or physician who is regarded as of much higher prestige based on cultural differences. Imagine the difficulty a care provider might have in raising an issue with either the consumer or members of other disciplines if that care provider speaks a different language, is part of a different culture, and particularly if he or she feels devalued.

Many developing countries are composed of heterogeneous societies with different languages, religious traditions, class structure, and historic animosities. Many countries may be composed of subgroups that differ from each other in their views of the appropriate roles that men and women should play in communicating serious news and delivering personal care to members of the opposite gender.

In industrialized countries, these issues have also plagued the delivery of long-term care. This has given rise to much discussion about the 'culturally competent' organization, in which personnel are prepared to deliver long-term care to all societal groups.

In New York City, in Miami, in San Francisco and in Los Angeles, it is possible to identify large numbers of distinct ethnic and language groups who both give and receive long-term care. A growing literature is appearing on cultural competence in human services in general, and long-term care in particular (Lynch & Hanson, 1998).

Cross-cultural competence can be considered on a variety of levels. Knowledge about dominant patterns within a subculture is necessary for understanding about how health problems and care problems, including discussion of death and illness and dealing with intimate functions, are likely to be understood.

Also necessary are attitudes that recognize that an individual's preferences and quality of life with long-term care are likely to be shaped by their own cultural norms. It may also be necessary, at least in the short run, to try to develop programmes that are staffed and managed particularly to serve heterogeneous groups within a society.

This is particularly true for group residential settings. In turn, this may require special demands for labour force development in terms of recruiting and retaining human resources at various levels that are distributed in particular ways across ethnic groups and gender.

13 Staff development and continuing education

It appears that systematic orientation and on-the-job training, punctuated by more formal continuing education opportunities, will be essential to maintain a labour force for long-term care. Various long-term care organizations have developed their own competency-based training materials and have evolved approaches that include on-the-job mentoring. Some large multi-site nursing home or home care firms retain centralized training personnel.

Nursing homes in the United States are required to have a staff development programme, and a certain content is mandated for repeated sessions. However, great diversity is found in how the staff development role is structured, including the number of staff development hours per resident, the extent to which the training is individualized and is based on diagnosis of need, and the actual programmes themselves.

14 Conclusion and possible lessons for developing countries

Each country will need to assess its own current and future long-term care labour force against its own current and anticipated needs for care. It is possible to conduct such an assessment by considering the range of tasks that must be performed and the variety of personnel available to perform them, and to project both the likely population needs and the likely personnel availability into the future.

One problem in making such forecasts is the difficulty of knowing whether nurses, social workers, and other similar professionals will remain in the labour force in their current occupations. Nursing shortages are difficult to forecast because they, in particular, often migrate to other countries, leave the labour force entirely, or take up different kinds of work.

The age of the workforce in any discipline is also relevant. In the United States, for example, it is often noted that practising nurses are on average a somewhat older group and that retiring nurses are not being replaced in adequate numbers (Aiken et al., 2001).

Countries that are developing long-term care systems have unique opportunities to consider freshly the labour force needed. The content of this chapter suggests that no single formula can be developed that will be applied to all, and that there may be opportunities to avoid developing a system with some of the problems found in industrialized countries like the United States.

WHO has devised a framework for analysing the factors affecting the development and implementation of human resources for health (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 to keep this broader HR context in mind (Egger, Lipson & Adams, 2000).

Some of the issues which countries will need to address are discussed in the recent general HRH literature (Van Lerberghe, Adams & Ferrinho, 2002). These issues include skill mix (Buchan & Dal Poz, 2002), poor working conditions and their effect on the workforce (Van Lerberghe et al., 2002) and, last but not least, the effects of health sector reform for human resource development (Alwan & Hornby, 2002).

For long-term care in particular, the problems to avoid based on lessons from industrialized countries include:

- discrepancies in prestige and wages between long-term care and other health settings;
- a long-term care programme that makes enormous distinctions in wages and prestige between professional/technical personnel and frontline workers;
- dead-end jobs for frontline workers; and
- disregarding the crucial role of families, friends, and communities.

Changing demography, epidemiology, and social realities – such as urbanization, growing poverty, migration, changes in family structures and growing participation of women in the labour force – must all be taken into account when planning human resources for growing long-term care needs.

In general, answering the crucial human resources development questions has a lot 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 overly requiring credentials.

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 to be raised include those listed as questions, on the following page.

- 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?
- What are the possiblities of integating long-term care roles with other roles existing within the health or social services?
- How to support traditional caregiving values?
- How to support families and communities so that they will be able to continue their traditional caregiving roles?
- What is the role of volunteers/semi-volunteers and how do they integrate with paid staff?
- What is the role of traditional healers? 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.

Policy-makers will need to consider all of these issues in planning their future LTC workforce. Resources include the recent WHO publications entitled *Home-based and Long-term Care* (WHO, 2000) and *Lessons for long-term care policy* (WHO, 2002).

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Part four

EVALUATING LONG-TERM CARE

CHAPTER 7

APPROACHES TO EVALUATING LTC SYSTEMS

Itziar Larizgoitia

7 APPROACHES TO EVALUATING LTC SYSTEMS, *Itziar Larizgoitia*

1 The need for long-term care

Coinciding with the United Nations International Year of Older Persons in 1999, the World Health Organization and the Milbank Memorial Fund prepared a Consensus Statement that would initiate the development of a coherent international policy on long-term care (WHO, 2000a). That Consensus Statement established a series of guiding principles for policy, among which the following essential point for shaping long-term care assistance emerged:

> *assurance that long-term care is of high quality and is offered by culturally sensitive providers.*

Traditionally, long-term care has not been among the main concerns of health policy-makers. Cost-containment issues, a perhaps excessive focus on medical specialized care, and the fact that families have always been and remain the major providers of long-term care (WHO, 2000b), have contributed, among other factors, to a slower development of public long-term care services, or to a heavier reliance on private care. Nevertheless, needs and demand for LTC are growing steadily, and the need for increased access to effective long-term care is becoming a pressing issue in practically all societies.

In industrialized societies, the ageing process represents one of the major public health concerns, both for ensuring an adequate level of care to satisfy today's needs as well as for ensuring the system's sustainability in the near future (Sörensen & Pinquart, 2000). According to a forecasting study on the public health status of the Netherlands' population, chronic somatic and psychiatric diseases account for about 80% of the number of unhealthy years. The same forecast reveals that by 2015 the total number of people with chronic diseases will have increased by 20–60% (van den Boss & Triemstra, 1999).

However, needs for long-term care are not restricted to industrialized societies and the ageing process. Technological advances in medicine coupled with the epidemiological transition experienced in many regions of the world have contributed to shift the balance towards care for the chronically ill (Dutton & Levine, 1989), including among these the growing sector of AIDS patients in almost all societies.

Increasingly, all over the world, more people survive diseases that were fatal some decades ago. Furthermore, the burden of disability is aggravated by the persistence of pervasive conflicts and violence which especially affect the developing world. A recent WHO study shows vast increases of need for long-term care over the next decades, in all developing countries (WHO, 2002).

Societal factors, related to changing family roles and caring patterns, as well as the growing expectations of the population for more and better services also increase demand (Jette, Smith & McDermott, 1996). Demand is also increased by reforms in the health system, which tend to restrict acute sector services (e.g. shortened hospital stays) towards the goal of seeking higher efficiency.

The need for reconsidering the role of long-term care is imperative as the burden of disease inexorably evolves towards higher levels of chronic disability and dependency, and as societies demand better and more professional care. Health systems must reorient their services to provide more care for the chronically ill and disabled, expanding the focus of health care from ‘adding years to life’ to ‘adding life to years’. The need to provide effective coverage of long-term care must be among the priorities of policy-makers.

2 The idiosyncrasy of long-term care

Driven by the specificity of long-term care goals, the resources, organization, and processes involved in the delivery of long-term care services adopt in turn distinctive characteristics. Understanding these characteristics is fundamental for the management, planning, or assessment of long-term care services:

> *(The goal of long-term care) is to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity.*

The former is a definition given by a group of experts convened in 1999 by WHO (WHO, 2000b). This panel also described the type of care as follows:

> *(Long-term care) includes activities undertaken for people requiring care by informal caregivers (family, friends and neighbours), by formal caregivers, including professionals and auxiliaries, and by traditional caregivers and volunteers.*

Similar definitions have been given by others (Kane & Kane, 1988). Long-term care addresses many different types of conditions and disabilities, whose common denominator is either physical or mental dependency.

The target groups of long-term care (Clyburn et al., 2000) include:

- people who are chronically ill, including HIV/AIDS patients;
- individuals with disabilities, of whom a numerically important group are the elderly;
- people with sensory limitations;
- mentally ill individuals, including people with dementia;
- substance-dependent individuals; and
- informal caregivers, mostly female family relatives at risk of suffering themselves from limited autonomy and adverse outcomes.

Long-term care is never uniform. It involves a variety of services, both personal care and social services, in response to the multiple needs of patients, and embodies a broad range of activities and providers.

Unlike the acute sector, many of these are unspecialized, labour-intensive, and relatively unskilled. Most long-term care activities are performed by paraprofessionals with a variety of skills (home assistants, housekeepers, nurse assistants, activities staff, or informal caregivers). Skilled workers (nurses, social workers, physical and occupational therapists, administrators, and physicians) are involved to a degree which is significantly less than that in acute care – even though the need for their services is considerable.

Similarly, the level of equipment, medical devices, and support technology is much less sophisticated. Long-term care is considered a low technology type of endeavour.

Many of the core long-term care activities are concerned with helping with basic functioning or with improving patient autonomy in performing the basic or instrumental activities of daily living. The diversity of settings where care is provided (which are usually organized as small facilities, many of which are independent) is another factor to consider.

Long-term care is rendered over a sustained period of time. This prolonged temporal relationship, determined by the persistent nature of dependency, disability, and chronic conditions, is one of the best defining attributes of long-term services. It influences the interpersonal relationships created among patient, families, and providers.

This time factor also determines the physical adaptation of the home or the infrastructure of facilities to accommodate or attend patients on a long-standing basis. Care is more continuous, thus requiring greater coordination between different segments of care and carers.

3 Effective and sensitive care

Optimal care could be expressed as effective care, appropriate to consumer needs, delivered competently and with sensitivity (*Quality in Health Care*,1997). WHO, in its framework for assessing the performance of health systems (WHO, 2000c; Murray & Frenk, 1999*)*, defines the quality of health systems by the achievement of the two main health system goals:

- improvements in health status; and
- responsiveness to the legitimate expectations of populations.

This broad definition is consistent with classical interpretations of quality of care, which identify quality as the care yielding the greatest expected benefits in health, and considers the interpersonal relationships between patient and provider a key factor in the care delivery process (Donabedian, Wheeler & Wyszewianski, 1982).

WHO regards both aspects, health and responsiveness, as desirable outcomes of health systems, thus reinforcing the need for patient-orientated care.

The general WHO framework enables conceptualizing the quality of LTC as the care that achieves gains in health, and is responsive to the legitimate expectations of LTC recipients. It seems necessary to identify the specific subset of outcomes, both in the health and responsiveness domains, which may be directly attributable to the LTC received.

The very nature of long-term care often relates to coping with disability, compassion, and accompaniment on the path to death. LTC attempts to contribute to:

- alleviating suffering;
- maintaining the best possible quality of life;
- reducing discomfort;
- improving the limitations caused by disease and disability; and
- maintaining the best possible levels of functioning.

In this context, improvements in functional ability and in the perceived quality of life (pain, discomfort, other symptoms) can be considered as some of the health dimension outcomes of LTC.

The construct of responsiveness encompasses the domains of dignity, autonomy, confidentiality, prompt attention, quality of basic amenities, access to social support networks, and choice of provider. For the extremely frail and the mentally ill, the assurance of basic civil rights may, however, be one of the most relevant issues to consider. Illustrated below are the principal quality outcomes of LTC.

Health dimension	Functional ability Other health status measures specific to major conditions Health-related quality of life
Responsiveness dimension	Dignity and human rights Autonomy, confidentiality Quality of basic amenities Access to social support networks Choice of provider

4 Ensuring the quality of long-term care

Ensuring quality long-term care implies ensuring an acceptable achievement of the specific outcomes that have been identified previously. The classic conception of structure, process, and outcomes components used for the analysis of health services (Donabedian, 1988) is also useful in understanding the scope of quality improvement measures.

The achievement of quality care will necessarily be defined by achievement of desired outcomes of care, but activities designed to improve the processes or the underlying structure may also contribute to that achievement, if specific direct links with outcomes are established. The underlying notion is that the way in which the structural and process components of care interplay is a key to achieving the desired outcomes of care.

Many mechanisms have been developed to ensure an acceptable level of LTC services. The most basic interventions involve measures which are addressed to establish basic legislation and standards aiming in general at achieving acceptable deployment of resources in institution long-term care:

- minimum staffing ratios and qualifications;
- skill-mix;
- minimum infrastructure and safety conditions;
- minimum content of long-term care services; and
- data collection requirements.

In many countries, compliance with certain regulations is required for licensing (Commonwealth of Australia, 1997). The effectiveness of these regulations in contributing to acceptable quality of care is highly dependent on their enforcement and compliance (Mukamel, 1997), an aspect which is hampered by the atomization of settings and low-skill base of some of the workforce. However, it has been shown that some factors, such as nursing staffing or nursing hours per day, are positively related to better quality (Harrington et al., 2000). The negative relationship between unlicensed facilities and quality of care has also been identified (Fleishman et al., 1999).

Excessive reliance on structural measures such as these, however, may not necessarily be related to better outcomes. It is important to understand that the relationship between the two dimensions, structure and outcomes, needs to be established. Structural criteria are better viewed as minimum standards that need to be in place in order to ensure safe environments and acceptable conditions to satisfy both technical and personal expectations.

Classic Quality Assurance or Total Quality Management are interventions directed to ensure that the chain of processes of care delivery is performed in a satisfactory manner. Quality Assurance interventions provide frameworks for staff to critically assess everyday practice in order to identify gaps, deficiencies, and scope for improvement in order to act accordingly (Challiner, 1997).

These sets of interventions are organization management tools which aim at providing improved services by ensuring that patients' needs and expectations are the focus of most care processes. They involve a set of mechanisms to identify gaps (through epidemiological methods and data collection), processes of verification and the planning of corrective actions, followed by implementation and reassessment (Williamson, 1988).

Completion of the cycle leads to continuous improvements in daily practice. These tools are successful if there is sufficient motivation among the key staff – either self-motivation or stimulated through external incentives – to participate and comply with changes, and if the organization assumes responsibility and leadership for excellence.

A link between current practices or processes of care and the goals of long-term care must be made to ensure that they are oriented in the right direction, and in addition that Quality Assurance activities are well oriented (Evidence-Based Care Resource Group, 1994). Assessment and synthesis of the current evidence, and subsequent standardization of practices, are important mechanisms to identify and implement effective practices (Rosenberg & Donald, 1995).

Practice guidelines are systematization of processes, based on evidence, that attempt to reduce the variability in care provision. They are especially useful when there is wide variability and uncertainty in the processes of care and when there is enough evidence to support one determined path of action; otherwise, they may be problematic. They can then be useful in defining treatment protocols and assessing the effectiveness of care.

There exists a danger if guidelines are only a codification of clinical judgement, and in such cases they should be discarded (Grimshaw et al., 1995). The introduction of guidelines in daily practice is improved by the extent of participation of the workforce, either in their development or adaptation to specific environments.

Specific educational interventions and continuous education of the workforce may also facilitate their effective incorporation (Grimshaw & Russell, 1994). The education of the workforce, with special emphasis on evidence-based practice, is an important step on the path towards quality improvement (Evidence-Based Medicine Working Group, 1992).

5 Outcomes assessment

For many reasons, the above-mentioned interventions, structural regulations, quality assurance activities, continuous education, and the evidence-based movement, may not be successfully implemented, enforced, or adopted. The assessment of the actual outcomes of care remains a necessary instrument to measure the achievement of care, as well as to render providers accountable for their performance. Information on the outcomes of health care is needed in order to understand the extent of goal achievement, so that further corrective action can be adopted on a more empirical basis. Currently, there is an important movement towards outcomes assessment in accordance with a greater emphasis on advancing the empirical evidence for health care policy and planning, management, and clinical decision-making (NHPC, 2001).

Outcomes assessment poses some challenges as well. When outcomes occur with a lag-time after health care interventions, or when other determinants may influence their occurrence, the attribution of specific achievements to specific care processes remains difficult (Lohr, 1988). To avoid this difficulty, many practitioners and researchers propose identifying outcomes that are directly related to health interventions and occur within a reasonably short period after the intervention.

The focus of outcome selection is also important. Since LTC patients tend to present a combination of problems, isolated outcomes concerning specific conditions may not provide a complete picture of the impact of care. Examining functional abilities across a comprehensive series of dimensions may give a more accurate indication of long-term care achievements. Outcome measures aimed at specific aspects of organ function are not as useful as those aimed at overall function across physiological, functional, and cognitive domains (Boston Working Group, 1997).

The most widely-used general functional measures are the ‘activities of daily living’ (ADLs) and ‘instrumental activities of daily living’ (IADLs), which are good approaches to measuring functional level and (over time) variations in functional capacity. Other outcomes of interest in long-term care are the level of pain and discomfort, the level of cognition, as well as social activity, social relationships, and affect (Kane, 1995). There are several instruments which measure those domains and that are available in a number of languages (Landi et al., 2000; Arling et al., 1997).

Expected outcomes are a function of the patient’s condition prior to the intervention. Accordingly, outcomes assessment should be adjusted according to patients’ baseline level of health status or functioning. Thus, one way of assessing outcomes could be by measuring the difference between the observed and the predicted outcome rate for each facility (Mukamel & Brower, 1998).

Outcomes must be adjusted prior to the intervention. Such adjustments must be made according to the patient's characteristics that may affect the occurrence of those outcomes. Otherwise, comparisons are not meaningful.

Those patients' characteristics, or case-mix, encompass a number of factors which modify the individual risk of a patient experiencing specific adverse outcomes. The purpose of the adjustments is to remove the effects of patients' risk from the effects of the intervention. Interfacility differences should also be taken into account, if comparison across settings is intended.

Systems for case-mix adjustment must take into account the main determinant factors of the specific outcomes of interest (Iezzoni, 1997). In long-term care, outcomes should be adjusted by various prognostic factors, including the severity of the condition. Demographic characteristics, such as age and sex, or primary diagnosis as used in acute care, may not be sensitive enough to determine patients' risk of experiencing functional and symptoms outcomes.

The Resource Utilization Groups (RUG) is one of the most highly developed case-mix measurements for long-term care (Stineman, 1997). However, less sophisticated approaches may be used. Measuring baseline functional level through an ADLs type of measure and stratifying patients according to the baseline level of functional limitation may be an easier and useful approach (Cooper et al., 2001). That is, patients can be classified as high- or low-risk and rates calculated within strata.

A problem may arise if risk factors used for adjustment are themselves a function of poor care quality or if they represent problematic care practices, such as faecal impaction or pressure sores. Those risk factors may be considered in themselves outcome indicators of sentinel events (i.e. adverse outcomes, occurrence of which indicates low quality of care) (Porell & Caro, 1998).

Some basic items usually measured in functional and cognitive scales include:

- ADLs – Self-performance in: bed mobility, mobility to/from bed/chair, locomotion, dressing, eating, toilet use, personal hygiene, continence.
- IADLs – Self-performance in: meal preparation, housework, use of phone, use of transportation, shopping, managing basic finances, taking medications.
- Cognitive scales – Orientation, attention, memory, judgement, language, and praxis.

There is an important – and unanswered – debate on whether outcome assessment is sufficient to inform on the quality of care. Many authors proclaim that process measures are needed as well, to better identify gaps in the performance of care practices. Most experts will suggest combining outcome with process, or even structural measures, so as to produce empirical information concerning the different analytical levels of health care organizations, providing that there is a sufficient empirical base to link process or structural measures with outcomes.

Some of the processes of long-term care which have proven such a relationship (i.e. certain preventive immunizations, avoiding unnecessary restraints) illustrate the benefit of their use as quality measures.

Assessment of patients' expectations is the second domain of long-term care goals. WHO conceptualization of responsiveness implies a "service that provides respect for persons and is client-orientated" (Murray & Frenk, 1999).

In considering responsiveness, WHO distinguishes between elements related to the respect for human beings as persons, and more objective elements of how a system meets certain concerns of patients and their families as users of health systems.

These categories are subdivided into seven distinct elements of responsiveness. Respect for persons includes:

- respect for the dignity of the person;
- confidentiality; and
- autonomy to participate in choices about one's health.

Client orientation includes:

- prompt attention;
- amenities of adequate quality;
- access to social support networks; and
- choice of provider.

The sustained relationship between patients and providers that characterizes long-term care, stresses the importance of the responsiveness domains as desired LTC outcomes. Respect for persons – including the basic maintenance of civil rights and confidentiality – acquires special relevance for long-term patients. Also specially relevant for these patients is the quality of the basic amenities with which many of them live for a long time.

Access to support networks is a key outcome for burdened caregivers (Miller & Guo, 2000). Assessment of patients' expectations is sometimes conducted through patient satisfaction questionnaires (Geron et al., 2000), although their use needs to be complemented with other more objective measures.

These objective measures are necessary to compensate for patient's coping mechanisms, their level of accommodation, their personal level of expectations (Branch, 2000), or other factors that may affect the response pattern, such as intimidation. Objective measures may be necessary in the case of cognitive frail patients (observable indicators of well-being, such as absence of agitation, screaming, crying, and the like).

6 Coverage and needs assessment

Effective coverage of effective and responsive health interventions is perhaps the best defining expression of quality of care. The concept of coverage, as opposed to the quality of care which refers to individual patient care, implies a population dimension.

Coverage refers to the proportion of the population which receives a certain service. It also reflects the proportion of those who did not receive that service. Coverage of effective interventions refers to the proportion of the population which receives specific quality services, or services which are effective in improving health.

The extent and distribution of effective coverage also defines the extent of equity within the system. Long-term care is one of the areas of health systems traditionally characterized by lower public coverage.

The mixture of social and health domains, with often different lines of accountability but not always clear boundaries between them, the traditional reliance on families as caregivers, and other factors, contribute to an explanation of lower levels of development of long-term care services and, in some countries, the greater influence of private initiatives. Lack of accessibility and financial barriers hamper the adequate coverage of disabled patients in many countries.

Assessment of the quality of long-term care, from a population viewpoint, must consider the effective coverage of chronically ill and disabled persons. A crucial step involves identifying population needs through instruments for needs assessment, such as population-based health and responsiveness surveys. It is important to recognize that needs assessments must be based on needs of persons with a chronic condition and their family caregivers alike, rather than on the availability of services.

7 Steps forward

There are indications that the quality of long-term care has not been optimal in some countries (Dickinson & Brocklehurst, 1997), with accounts of patients' dignity and autonomy undermined in health care settings (Lothian & Philp, 2001). A recent review undertaken by WHO in selected health care systems based in social insurance schemes concluded that quality of long-term care is the 'weak link' in all countries reviewed (Brodsky, Habib & Mizrahi, 2000).

Some of the key issues that may explain the lower quality of care may relate to a weak 'quality improvement' approach, provider fragmentation, and lack of common standards. Countries may need to examine their long-term care services and move towards a greater quality improvement initiative in order to provide effective and responsive coverage of long-term care.

Recommendations to move forward include the following.

1. Any health system should define the scope and extent of its long-term care coverage.

2. All primary care services need to also address the long-term care needs of people with chronic conditions and disabilities, along with adequately responding to their needs for preventive and curative care.

3. Long-term care coverage should be based on an assessment of needs of the person requiring LTC. However, as the bulk of LTC is provided by informal caregivers and dependent upon their health and well-being, caregiver needs must also be assessed in order to plan resource allocation.

Recommendations *(continued)*

4. Regulatory systems should establish the minimum standards for long-term care facilities, including aspects such as the level and qualifications of staff, the minimum staffing levels and skill-mix, procedural standards, and infrastructure specifications. Some countries may wish to regulate the rights of patients to long-term care, both in terms of technical care and in terms of civil rights. Compliance with standards should be enforced.

5. Standards or Protocols should be established where sufficient evidence is available, and research encouraged to expand the knowledge base necessary for quality LTC.

6. Interventions to improve care, such as Quality Assurance and Continuous Education, need to respond to changing needs and realities.

7. Some measure of outcomes assessment may need to be implemented in order to measure the extent of outcomes achievement and thus to improve care accordingly. Agreement over outcomes definitions should be established. The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980) and The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) may provide a method approved by WHO Member States.

8. The responsiveness to the legitimate expectations of persons with chronic conditions and disabilities, and the responsiveness to the legitimate expectations of their 'informal caregivers', must be translated into the continued improvement of services.

9. Evaluation of the extent of effective coverage across disability groups, and across social determinants that may hinder access to long-term care (such as age or gender, social and economic status, race, ethnic or religious groups, geographical residence, or other criteria) should be performed.

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Part five

CHOOSING OVERALL LTC STRATEGIES

CHAPTER 8

CHOOSING OVERALL LTC STRATEGIES:

A CONCEPTUAL FRAMEWORK FOR POLICY DEVELOPMENT

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1 Introduction

There is a broad range of design issues that arises in developing a LTC system. Some are common to all social service systems and some are specific to long-term care. An algorithm of these key issues was developed to analyse available policy alternatives and identify factors relevant to the choice among them. Some of the major key policy issues identified include:

- the relative priority of LTC among other needs;
- which LTC services should be prioritized;
- state vs. family responsibility;
- service delivery strategies;
- nature of entitlements, targeting and financing;
- strategies for achieving integrated or coordinated care; and
- human resource strategies.

Each design issue may itself be resolved in a number of different ways, as illustrated in the previous chapters in this volume. The numerous issues and ways to resolve them yield a very large number of alternative overall policy strategies.

The resolution of the set of issues defines an overall LTC policy. It is therefore not sufficient to assist policy-makers in understanding each specific issue. They require guidance as to how to deal with the choice of an overall policy.

Furthermore, policy-makers need to take into account the fact that the resolution of the individual issues is not an independent decision. These issues are interdependent, and therefore the choice of a resolution of one issue affects the resolution of others.

Therefore, policy-makers also face the practical question of where to begin: on which issues they should focus first. Given the interdependence among the resolution of the issues, the choice of a beginning point can be of critical importance.

This overview represents an effort to go beyond the discussion of specific design issues to present broad paradigms of alternative systems that combine various ways of resolving these specific issues. We attempt to address the complexities of the policy-making process by considering the following broad questions:

- Is it possible to identify major broad LTC policy strategies and reduce the significant number of alternative strategies?
- Is it possible to suggest key starting points in developing an overall strategy? We shall term these 'primary issues'.
- What are the key interdependencies in the resolution of LTC issues and what role do they play in defining alternative strategies?

We identify two broad primary issues:

- principles of eligibility; and
- integration of LTC services with general health and social services.

After defining the scope of LTC (1.1), we discuss the principles of eligibility in Section 2. We then go on to consider the question of service integration between LTC and the basic health and social services and among components of LTC in Section 3. We conclude by discussing the interaction between these two aspects of LTC policy design and its implications for overall LTC policy strategies.

1.1 Scope of LTC

Long-term care refers to the provision of services for persons of all ages with 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 also 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 or result 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. Just two examples are mobility limitations, which may require services to be brought to the home, and cognitive impairments, which 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 impact on 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 support, 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.

2 Principles of eligibility

In thinking about principles of eligibility, we believe that there are two major underlying decisions that provide useful starting points in developing an overall strategy. In this section, we first define these two basic decisions that we view as primary issues. We then show how in combination they define five basic options. We then examine how the choice between these strategies influences the resolution of a number of significant other design issues.

Two basic strategy decisions involve the following questions:

- Should support be provided only to the poor, or also to the non-poor?
- Should access to services be based on an entitlement?

2.1 Supporting the poor, or the non-poor as well

This issue arises with respect to all areas of social need. Unique to LTC is the additional possibility that the family might meet these needs for many individuals. This is not an option in the same way for many other services such as medical care. Therefore, 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.

This decision is related to the issue of public or individual/family responsibility for financing or providing LTC. Two questions arise. What is the responsibility of the individual or his family to use his own income and assets? What is the responsibility of the spouse and family to provide the care directly? Although not discussed here, its resolution underlies the alternatives (see Chapter 1).

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

- ***Option 1:*** A desire to support the poor, and provide programmes only for the poor.
- ***Option 2:*** A desire to support the poor as a primary goal, but financing through frameworks that include the non-poor.
- ***Option 3:*** A desire to support both the poor and the non-poor, as a primary goal.

The choice among these options is often presented in terms of the choice between selective (or means tested) and universal approaches to social service provision.

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 (option 1). Even if support for the poor is the primary goal, this approach can lead to a strategy that supports the non-poor.

Including them in a more universal programme might be the best way to mobilize support for the poor, and avoid the stigma associated with programmes devoted exclusively to the poor, such as low quality (option 2). Interest in assisting the non-poor as well can be a primary goal (option 3).

Support for the broader population can have several rationales, including:

- ***Social insurance***

  1. There is an interest in the population insuring itself against LTC risks. Thus, some form of compulsory national insurance is adopted to address these risks viewing it a 'normal life risk' on a contributory basis. This rationale is reinforced by the difficulties encountered in developing private insurance.

  2. The potentially catastrophic nature of LTC costs can result in broad segments of the population having difficulty paying for them, becoming impoverished and, once their resources are depleted, becoming a burden on public programmes.

- ***General social philosophy***

  3. The general belief that social needs should be financed through collective tax-based financing mechanisms, rather than on a private pay basis.

- ***Service substitution***

  4. Interest in reducing the utilization of more costly acute care (particularly hospitalization) services by substituting LTC.

- ***Role of family in provision of care***

  5. 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 – with a related interest in preserving family care by providing assistance to help them sustain their caregiving.

  6. Concern for the decline in the availability of family support because of separate living arrangements, fewer children, women's participation in the labour force, changes in values in relation to caring, and breakdown of the traditional family structure as a result of the increase in one-parent families and HIV/AIDS.

Alongside the consideration of all these rationales, it is necessary to also consider the costs involved in serving the greater population in light of the relative priority assigned to LTC versus other health and social needs.

We next consider the decision with respect to entitlements.

2.2 Entitlement or budget-constrained services

A second key question is whether access to LTC services should be based on an entitlement. When examining the importance of providing a LTC programme on an entitlement basis, it is necessary to understand the definition of an entitlement programme.

In this context, we are employing a concept of entitlement that goes beyond simply meeting eligibility requirements. The distinction we are making here relates to whether the ability to receive a service is constrained by available budgets.

Entitlement programmes imply that everyone who fulfils the eligibility criteria (regardless of available budgets) must be granted benefits, and such programmes are almost always established through specific legislation. Costs can be contained only through changes in eligibility criteria, which usually require changes in legislation, and not by denying or delaying service.

Non-entitlement – or budget constrained – programmes imply that the service does not have to be provided once the budget runs out, even for those who meet eligibility requirements. Requests for services within a given budget year can either be denied, or applications put on a waiting list. Costs can be contained through planned budget allocations and not only by adjusting eligibility criteria.

Entitlement approaches are most common in income support programmes, particularly in the context of social security systems, and budget constrained approaches are most common for programmes that provide services. A major exception to this rule lies in health services which are provided in the context of contributory social health insurance.

Yet, the nature of an entitlement is less explicitly defined when it relates to an in-kind service; the more diffuse the service, the more diffuse the entitlement. Health services programmes can define broad types of care guaranteed under an entitlement. But the type, amount, frequency, and timing of the care is subject to discretionary decisions by health providers.

Moreover, some degree of waiting for care is considered reasonable, although not easy to define and monitor. At the same time, failure to provide what is perceived as reasonable access can be legally challenged, and those responsible are under pressure to be responsive.

Many LTC services can be defined explicitly. These include access to a defined number of hours of personal care, number of meals-on-wheels per week, days and hours of weekly attendance at a day care centre, or even access to an institutional placement.

Therefore, entitlements for LTC are more easily implemented. Thus, entitlement programmes fall along a continuum with different levels of restrictions, depending on the nature of the service and the consumer's ability to demand care.

Choosing between entitlement and non-entitlement programmes

One of the considerations in choosing between entitlement and non-entitlement based programmes is ***the broader philosophy*** with respect to social service provision: the preference for rights-based versus budget-constrained service provision.

The rights-based (entitlement) approach grows out of the human rights perspective. It also stems from the practical motivation to protect access to social services in the political process. That is, it arises from the belief that these services should be defined as rights, and protected from the general budgetary process, versus the belief that they should be subject to controls based on budget allocations that can be more flexibly adjusted to fit the budget situation.

A second consideration involves the ability to control costs. This reflects a concern for the degree of controllability of costs, and not only the level of costs. Thus, in entitlement systems the level of cost is not easily predictable or defined, as it is determined by the number of eligible applicants.

Equally significant, however, is the fact that changes in eligibility criteria require changes in legislation rather than administration. This means that these changes are much more subject to public debate and more difficult for governments to bring about if there is a recalcitrant legislature or significant opposition. By definition, these processes take longer.

Table 1 summarizes the alternative strategies for designing long-term care eligibility principles and their implication for seven design issues (i.e. financing, income testing, family support, flexibility, level of benefits, coverage by disability, and cash benefits).

The first and primary design issue is whether to target the poor only, or the poor and non-poor as well. The two approaches to entitlements are consistent with either resolution of the poor/non-poor issue, so that five basic options emerge.

Options 1a and 1b are based on the assumption of supporting the poor, which may be implemented on either an entitlement (1a) or non-entitlement basis (1b).

Options 2a and 2b are based on the assumption of supporting the poor and non-poor – 2a on an entitlement basis, and 2b on a non-entitlement basis.

A fifth (combined) option (2c) provides for a more complex system in which there are two complementary programmes – one based on an entitlement, and the other not.

Table 1. Alternative strategies for designing LTC systems

Other design issues	Primary design issues: 1) Target poor only — a) Non-entitlement	1) Target poor only — b) Entitlement	2) Target poor and non-poor — a) Entitlement	2) Target poor and non-poor — b) Non-entitlement	2) Target poor and non-poor — c) Combined
1. Financing	taxation	taxation	contributory	taxation	combines 1a and 2a
2. Income testing	strict	strict	very rare	liberal	
3. Family support as criterion	common	rare	rare	common	
4. Flexibility of criteria	flexible	flexible	non-flexible	flexible	
5. Level of benefits	high	high	low/medium	medium/high	
6. Coverage by disability	all levels	medium range	narrow range	medium range	
7. Cash benefits	rare	rare	more common	less common	

2.3 The link with seven additional design issues

We now consider how the choices among different approaches to eligibility criteria impact on the resolution of a further set of issues that arise in designing LTC policies. These principles are not iron-clad rules to which we must adhere. Rather, they represent central tendencies behind which are strong rationales. Diverting from these principles is possible, but requires special effort either to justify or to market politically.

2.3.1 Financing (row 1, Table 1)

Entitlement programmes that serve the general population are more generally financed through contributory insurance-type payments, whereas non-entitlement programmes are almost always financed through general taxation.

This is because a pre-paid premium payment is viewed as granting a right to service, while general taxation does not necessarily give the individual the same claim to a right. A second reason is that it may be easier to promote public support and finance for a programme that serves the general population if it is based on direct contributions and principles of compulsory social insurance. 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 aproach.

For this reason as well, there is a concern that entitlement programmes will be less subject to control. The basis for opposition to benefit reductions becomes not only the need for the service and its priority, but 'the fact that the potential recipients have paid' through their contributions, and changes in eligibility criteria are a breach of contract. While this argument does not have legal validity in public insurance schemes, it carries political weight.

Entitlement programmes that focus on serving only the poor will be financed on the basis of taxation rather than contributions.

2.3.2 Income testing of the eligibility for benefits or their amount (row 2, Table 1)

A second implication is with respect to income testing. Programmes that target the poor, whether provided on an entitlement or non-entitlement basis, obviously require income testing. In programmes that include the non-poor, there may still be some degree of income testing to exclude the very high income population or to vary the level of benefits with income. In service programmes, this may take the form of variation with income in co-payments.

When these programmes are financed on a contributory entitlement basis, there should not be any – or at most a very liberal – income test which would exclude from benefits many who had contributed to financing the programme. Somewhat stricter means tests can be included in tax-based programmes.

2.3.3 Family support as eligibility criterion (row 3, Table 1)

As noted, what is unique to LTC is the possibility that the family might meet these needs for many individuals. This is not an option in the same way as for many other services. Thus, the decision whether or not to provide LTC assistance may be based in part on assessments as to whether the family can – or is willing to – provide care.

Family support is usually not taken into account under an insurance framework, so as not to exclude someone who has 'paid for their services', and because it is a very subjective factor implying the use of discretion, which is avoided in insurance frameworks. In non-entitlement programmes, the availability of family support is usually a factor in eligibility for services.

2.3.4 Flexibility of criteria and degree of discretion (row 4, Table 1)

For the same reason, eligibility criteria in an entitlement system will tend to be rigorously defined in terms of precise measures and cut-off points that do not allow for discretion. Generally, a few discrete levels – rather than a full continuum – of support will be defined. By contrast, in non-entitlement systems it is easier to adapt services to each case and use discretion.

2.3.5 Generosity of support (level of benefits) and disability thresholds (coverage by disability) (rows 5 and 6, Table 1)

In entitlement programmes, as income testing and family support are not used to contain costs, there will be a tendency to use other means to achieve this goal. This is often by either restricting the level of benefit per recipient, or by efforts to restrict the number of recipients by setting relatively high disability thresholds as requirements for eligibility. The implication is that recipients without family support may have significant unmet needs and that the less severely disabled will not receive support even though it is needed.

2.3.6 Provision of cash benefits (row 7, Table 1)

Most LTC programmes provide the benefits in the form of direct services or vouchers that enable the individual to purchase services. However in recent years there has been more interest in cash grants that are not restricted to the purchase of services. This approach is more common in insurance-based programmes and is a way of avoiding problems with service availability. It is very common in private insurance programmes.

2.4 Five alternative strategies for designing LTC systems

We can now summarize the strategic options as defined in Table 1.

- Option 1 represents the paradigm of a programme focused on the poor and financed through general taxation on a non-entitlement basis.
- Option 2a represents the opposite approach with support for the broader population on an entitlement basis, and contributory finance.

Options 1 and 2a represent the two extremes and have opposite characteristics in every dimension.

- Option 1 is based on general taxation and will generally be provided on a non-entitlement basis. It includes family support as a criterion and uses more discretion to allocate resources based on need. It tends to provide a potentially high level of benefits to those in high need of public support, and includes a broader range of disability levels. It will generally not adopt a cash approach to benefits.
- Option 2a is a 'universal programme', on a social insurance/ contributory basis. Eligibility criteria will tend to be rigorously defined, which does not allow for discretion based on need. Availability of family support would rarely be used as an eligibility criterion. Because these programmes are targeting the entire population, they tend to include a relatively lower level of benefits per recipient, and set a higher disability threshold. Cash benefits are also common in this type of system.

Option 2b is more between the characteristics of option 1 and option 2a. It supports the broader population but on a non-entitlement basis. Option 2b has tax-based finance and therefore can address all the other design issues more similarly to option 1. It will have stricter income testing for eligibility or level of co-payment than 2a, but still serves a broader population range than option 1.

Option 2b may or may not use family support as a criterion and can be more flexible in its eligibility criteria. Like option 1, it can offer higher benefits because it has budgetary control over costs and may target by availability of family support. But it will be much more costly for the same level of benefits than option 1, and therefore may provide somewhat lower benefits, or be more likely to limit the levels of disability that are eligible for services under the programme.

The difference in the eligibility criteria among the options presented in Table 1 add up cumulatively to basic differences in how support is targeted. Programmes that focus on the poor on a non-entitlement basis and are financed through general taxation will concentrate resources on those most in need as defined by low income and limited family support, but will include a broad range of disability levels.

Programmes that support all groups will, by definition, spread benefits over a larger group, but these programmes will tend to limit more strictly the disability levels that are eligible. This will impact the most on the moderately disabled with low incomes, who will be excluded from eligibility, and the severely disabled with weak family support, who will receive relatively low support despite their extensive needs.

However, despite these differences in the extent of targeting the poor, in the final analysis it is not fully clear under which systems the poor will fare the best. The process of allocating resources in the political system is not a zero-sum game, because the level of total resources also varies with the nature of the system. Sometimes programmes not aimed at the poor will be able to generate more resources per person.

The question is: Will the extra resources mobilized in a system that is less targeted (option 2) be sufficient to yield higher benefits for the poor than in a system that is highly targeted but with less total resources (option 1)? This is an empirical question.

In order to provide resources to the poor and also share in the costs of LTC for the general population, it is possible to adopt a strategy that combines two programmes.

Combining a universal programme with a supplementary, highly-targeted programme (Option 2c)

Option 3 combines options 1 and 2 into a single overall strategy. Thus, we combine a more universal programme, with modest benefits and limited or no income testing, with a supplementary programme that is highly targeted in terms of income and family support but serves all levels of disability and can provide high levels of assistance. These two systems can be implemented under the same or separate auspices, but generally will be implemented under different auspices.

The case for this approach is along the following lines. In option 2, only modest support is available, and therefore supplementary assistance is needed for the two groups that have the greatest needs under this scheme: the poor without family support who need larger amounts of public support; and the more moderately disabled when they have low incomes and limited family support.

This support would be provided by the supplementary programme on the basis of income and family support criteria. The supplementary programme could be more residual. Individuals would first realize their rights under option 2a, and then – if they meet the criteria – receive further support under an option 1a programme (these are combined in option 2c).

Another consideration of systems that combine more than one set of eligibility principles is that different principles may be viewed as desirable for different services. In the discussion up to now we have implicitly assumed that only one principle is applied to the various LTC services. In fact this is often not the case for a number of reasons.

One reason is that health-related services are more likely to be included in systems for the general population and provided on an entitlement basis than in services provided in social systems, which are often budget constrained and based on income testing. The distinction between these two kinds of services is discussed more fully in Section 4.

This reasoning is relevant to the distinction between home health, which is viewed as health related, and the more functionally related LTC services, which are sometimes viewed as of a more social nature. Thus, one often finds that two services are provided by different programmes and subject to different eligibility criteria (see Pacolet et al., 1999).

3 Integration of LTC services

Interest in integration arises out of concern for the quality and efficiency of care. One of the defining characteristics of the challenge of integration is that LTC includes a broad range of services. For the purposes of this discussion, we find it useful to differentiate between three forms of LTC services:

- Home health – health-related care in the home.
- Home care – care provided in the home related to daily functioning such as personal care (eating, bathing) or homemaking, which we shall refer to as daily functioning long-term services.
- Institutional services.

In this discussion, we distinguish between two dimensions of integration.[1]

- ***Integration among the various types of LTC services***

  In LTC systems, it is common to find various forms of fragmentation. Home health is often provided separately from personal care and homemaking services; home care is separated from institutional care; and even the personal care and homemaking services are sometimes separated.

- ***Integration between LTC services and the general health and social service systems***

  LTC services may be independent of these general systems, or may be integrated either as a package or individually in the general health or social services.

[1] Note that there are two potential forms of fragmentation: different service components are provided in separate frameworks; and the same service is provided in more than one framework. Both of these are common.

A further major dimension in discussing integration is that there are a number of programmatic components that can be integrated: finance, administrative responsibility, and organization of care (including gatekeeping, assessment, and direct provision). Integration can imply the unification of one or all of these components. For example, unified administrative responsibility need not imply pooled finance.[2]

There are three broad patterns of integration.

- ***Integrated system***

  Only when the basic health and social systems are themselves unified is it possible to have a fully integrated LTC system. At least partial integration may be achieved through a special budget pooling arrangement between the health and social systems. Another variant is that all LTC services are integrated into one of these two systems, so as to integrate the various components of LTC.

- ***Independent LTC system***

  An independent LTC system can provide an opportunity for integration among the service components of LTC.

- ***Fragmented LTC services, components of which are integrated into different systems***

  Because there are strong health and social systems in industrialized countries, this is the most common pattern. In particular, home health is generally integrated with the health system, homemaking services with the social system, and personal care with either. Moreover, even if there is an independent system for providing LTC, it generally will not include home health services. Furthermore, institutional services are divided between the health and social systems based on the level of care required.

[2] There is also a distinction between integration at the national, regional or local level. We refer here in particular to integration at the local level that can be reinforced and facilitated in various ways at the national or regional level.

The general conclusion is that it is not easy to achieve full integration along all these dimensions and there may be a need to make choices. Thus, there is a need to decide which elements of integration are more important.[3]

3.1 Considerations in determining a policy on integration

The integration of each of these types of LTC services with general health or social care systems can be governed by different considerations. The interest in integration arises out of a number of concerns for the quality and efficiency of care. These include the ability to provide 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-step easily identified sources of provision (see Chapters 3, 4, and 5 of this volume).

Integration also makes it possible to use personnel in more flexible and efficient ways combining roles when appropriate. This can be particularly useful for personnel going into the home for which travel time and travel expenses are an important part of costs.

Links with the health systems can create a continuity of care with general health care and with home health. It makes it possible to take advantage of health providers that will be going into the home for health reasons (see Chapter 6 of this volume). 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 the health care providers can capture the benefits of reduced home and institutional long-term care. On the other hand, when they are in a separate system, health service savings cannot be easily used to finance them, and health providers cannot rely on access to them. (See Chapter 3 of this volume.)

At the same time, there are concerns about linking LTC with primary health care that generate interest in independent models of LTC. For example, there is a concern that long-term care services might be neglected if they were integrated into the general health system, since acute health care would receive greater priority. The incentives to provide adequate LTC in an integrated system are not unequivocal or easily predicted.

[3] In the absence of full integration, there arises the need for some form of coordination mechanisms. These themselves involve a range of options, and in recent years there has been much discussion of the introduction of a case management function (see Chapter 5 of this volume).

Health systems tend to be biased towards addressing acute care needs or more medical-oriented needs, as opposed to those that are more function related. The system may not perceive the potential savings of providing more LTC, or be able to overcome the conflicting interests. In this case, the provision of LTC services might be less than appropriate or efficient. An additional concern is that LTC services could become 'overmedicalized', and as a result more costly. For example, skilled nurses may be paid to provide basic personal care; or LTC that could be provided in a LTC institution might be channelled to more expensive hospital settings.

The question of how to assure the most appropriate level of LTC financing is an important consideration in discussing their integration. The nature of the general political processes in the country by which social budgets get determined will influence the extent to which more funds will be allocated to LTC when financed through separate or integrated budgets. Will the integration with the health or social system enable it to command greater resources even if there are biases in the allocation of resources within these systems? Will more resources be allocated to LTC when it is integrated with health and social care, or will there be a greater tendency to finance and support an independent LTC programme?

Another factor that influences integration of LTC services is the distinction between services that are more social in nature, and those that are more health related. This is part of an unresolved ongoing territorial conflict between health and social systems that is not restricted to LTC. The question is not only where to draw the line, but whether these lines should be drawn at all.

There has been a trend promoted by WHO to view health in broad terms, and to consider the social aspects of health. WHO defines health as

> *a state of complete physical, mental, and social well-being and not merely the absence of disease, or infirmity.*

This definition involves a mandate to include social as well as medical aspects of health. Similarly, various health professions (such as nursing) have expanded their view of their roles to address the social dimensions of care and include emotional support and guidance to caregiving networks. This debate also involves conflict between professions.

A further difficulty in integration of LTC in health systems based on entitlement principles without defined budgetary constraints is the difficulty in predicting the cost of long-term care. This becomes a major issue when the health providers are nongovernmental and financed on a capitation basis.

The implication of full integration of LTC with health systems is of course that health providers would have to attend to the range of LTC services that includes those that tend to be viewed as more of a social nature. While home health is naturally viewed as a direct extension of the general health services, other LTC services are sometimes viewed as more social in nature.

Personal care is often seen as part of health care. By contrast, homemaking services, various forms of day-care, arranging informal care, and various forms of residential care that cater to the less dependent and have a social emphasis, are usually seen as part of social service. Emotional support to families is often seen as part of both health and social services.

As more and more forms of housing arrangements for the disabled emerge, their inclusion would also need to be considered. The willingness of health systems to assume such roles, and the competition with social systems around this professional territory, thus become additional integration issues.

We have discussed a number of considerations relevant to the resolution of the issue of integration. We now consider how the resolution of this issue is also related to eligibility criteria.

4 The link between the principles of service eligibility and principles of integration

Up to now, we have separately discussed principles of eligibility and the issue of service integration. However, the resolution of each issue is mutually interdependent. In this section we discuss the nature of this interdependence and the implications for the policy-making process.

When LTC is integrated with the health or social systems, a link is created between the principles of eligibility, entitlement and finance for LTC and the broader systems. This influences the decision as to whether LTC should be integrated with the health or social systems.

The health or the social systems are often based on different principles. While social service systems are always non-entitlement, budget restricted and targeted towards the lower income populations, health systems are commonly based on insurance principles which target the broader population.

For example when health services are insurance based, then LTC must also be insurance based if finances are pooled. Thus, the question of integration becomes a choice of eligibility principles, and not only one of organizational advantages and provider incentives. If there is an interest to provide LTC on a non-entitlement basis, the option of integration with the social service system becomes more attractive.

In order to choose an overall strategy that combines an approach to eligibility and integration, we need a structured decision-making process that can help deal with the complexity of this decision.

We envision a four-stage process:

- ***Stage 1***

  Decide on desirable principles of eligibility without concern for integration (discussed in Section 2); and decide on desirable principles of integration without concern for eligibility (discussed in Section 3).

- ***Stage 2***

  Determine whether desired principles of eligibility are consistent with current systems of health and social service provision.

- ***Stage 3***

  Examine the compatibility between desired principles of eligibility and desired principles for integration.

- ***Stage 4***

  If the desired principles are not consistent, consider which principle has the higher priority.

Stage 1 was discussed in the previous sections of this chapter. We now proceed to elaborate on the other three stages. To simplify the example, we focus on the integration with the health system.

In analyses of compatibility, it is also necessary to take into account the fact that health systems may include several different public programmes (and of course additional private ones) that may operate under various financial and entitlement principles. There may be a particular interest in integration of LTC with the system that has a dominant role among the poor.

Stage 2 requires an examination of the desired principles for LTC that were decided upon in Stage 1, and a comparison with the actual principles of eligibility that characterize the existing health system within the country.

Stage 3 presents several possibilities depending upon the interaction between desired principles of eligibility in LTC and the existing eligibility principles in the health system.

When there is complete ***consistency*** between the desire to integrate into the health system, and the health system is based on the desired eligibility principles for LTC, the decision to integrate is easier.

When there is a conflict between the desired resolution of the two design issues, it is necessary to ***decide which is more important.*** If integration with the health system is the highest priority, it may be optimal to compromise on the desired principles of eligibility. Otherwise, the integration of LTC into the social system, or the creation of an independent system needs to be explored.

Thus one can ***compromise*** on eligibility principles to achieve the goals of service integration, or compromise on service integration to achieve the desired principles of eligibility. The final outcome represents a system, which can be considered optimal in the sense of the most reasonable compromise (sub-optimization under constraint).

In Table 1 (option 2c), we also pointed to hybrid strategies that combine different eligibility principles. This can allow for an approach that would integrate LTC services into both the health and social systems. This can arise when, as illustrated earlier, there is interest in supplementing the services provided in insurance systems on an entitlement basis with services provided on the basis of non-entitlement budget constraints.

Up to now, we have presumed there is a common view of the desired eligibility principles for all components of LTC. However, this is not necessarily the case for a variety of reasons. Moreover, the concept of ***the desired integration of LTC services can also differ by type of service***.

Therefore, there can also be a case for integrating various components of LTC into the health and into the social systems separately. This can explain some of the existing fragmentation in service integration to which we referred in the previous section.

In addition, with respect to ***home health***, the issue of family as an alternative provider does not arise as it does with function-related services. Therefore, there is more willingness to provide home health on an entitlement basis within health care systems, although this is at the expense of fragmenting LTC.

In summary, there may be a ***trade-off*** between the desire to integrate fully LTC services with the general health and social services, and the desired principles of eligibility for LTC services. It would seem that an important reason that LTC services are not generally integrated into general health services is a result of this trade-off.

5 Examples from industrialized countries

In this section we illustrate how various industrialized countries have resolved the two primary issues of eligibility and integration against the background of the alternative strategies identified in this paper.

There are a number of examples of countries that focus support for LTC on the lower income groups (option 1a in Table 1). The United Kingdom and Australia are examples of option 1a, as they target support on the lower income groups and provide LTC on a non-entitlement budget restricted basis. The Medicaid programme in the United States is an interesting example of a system that focuses on the poorer groups, financed by general revenues, but recipients have a legally recognized entitlement (1b).

These programmes have taken different approaches to integration. In Australia, LTC is provided in a system that is independent of the health and social services, but integrates a broad range of LTC health and function-related services. In the United States, there is also an independent system for the elderly, but it provides a narrower range of services. In the United Kingdom, LTC services are divided between the health and social service systems.

The Scandinavian countries provide support to the broader population financed through general taxation, and therefore represent option 2b. Although there is not an entitlement in the same sense that exists in the contributory programmes, they do have a strong commitment to adequately budgeting these programmes so as to meet the needs. The LTC services are integrated partly within the health system, and partly within the social service system, although the general health and social services are sometimes more closely coordinated at the local level than in other countries.

In recent years, a number of countries have adopted LTC legislation. Germany, Israel, and Japan provide LTC services to both the poor and the non-poor through a legally recognized entitlement that is financed on a contributory basis (option 2a). Germany and Japan provide a broad range of LTC services within the law, and in Japan it even extends to health-related LTC services. In Israel, the law only provides for community-based services and does not include institutional care or health-related services. In all three countries the programme is independent of the general health and social service systems. In Israel, it is part of the social security system.

Germany and Israel, however, have combined this entitlement programme with a second complementary programme that targets the low-income groups, and is financed through general taxation. They thus represent option 2c. This programme is integrated into the social service system.

In all the above-mentioned countries the pattern of interrelationships among the eligibility issues is consistent with that presented in Table 1.

The eligibility principles of the Austrian system for LTC do not exactly fit into the models presented in Table 1. It provides support to both the poor and the non-poor on an entitlement basis, but is financed through general taxation. It provides an unrestricted cash benefit that can be used to finance any type of LTC needs. This system is independent of the general health and social service systems.

The Netherlands is also an interesting exception. It provides service on an entitlement basis to the broader population financed through contributions, as in 2a. However, it has adopted additional eligibility criteria that characterize non-contributory tax-based programmes. It allows for significant discretion in determining the level of support, and includes availability of family support as one of the criteria for determining the amount of service. The Netherlands is also an interesting variant in its approach to integration. The LTC services are integrated administratively within the health system, but have a separate budget and designated financial base.

In examining together the way the principles of eligibility and integration have been resolved, we can make the following broader observations.

Countries that have adopted more of an entitlement approach serving the broader population have clearly preferred more separation into an independent system. This is exemplified by Austria, Germany, Israel and Japan. As mentioned, it is even partially true of the Netherlands, which while integrating LTC into the health system maintains a separate budget and designated financing scheme.

We also see that most LTC services have generally been fragmented between the health and social services systems. Home health – integrated within the health system and sometimes health-related institutional care – is based on the same eligibility principles as the health system. Function-related services are commonly integrated into the social service system, based on its eligibility principles.

It would seem that principles of eligibility also play a role in decisions about integration; however this works in multiple ways. On the one hand, systems that want to provide LTC services on the basis of a strong entitlement refrain from linking LTC with the social, or even the health system, and have created independent systems. On the other hand, systems that prefer to provide the function related services on a non-entitlement basis are not inclined to link them with the health system. They adopt a more fragmented approach by dividing LTC services between the health and social services.

Among the only countries that have really integrated the more health- and function-related services are Australia, Japan, and the Netherlands.

It is important to also emphasize that countries with a more fragmented approach to LTC make various efforts to coordinate services, as discussed in previous chapters of this volume.

6 Conclusion

The papers in this volume illustrate ***the complexity of the design of a LTC system,*** and the many issues that need to be addressed. This chapter has tried to address one central dilemma: ***how can we help policy-makers deal more effectively with this complexity?*** In the process, we also illustrate how different countries have addressed some of the major strategy issues. Our analysis has demonstrated a number of general lessons that may be useful in designing a policy framework.

- It is possible to identify a smaller number of overall strategies to narrow the range of choice.
- There are important interactions between major design issues that must be addressed in resolving them. In particular, the issues of eligibility and service integration cannot be separated.
- The issues on which you decide to begin the design process can make an important difference in finding your way through the maze of issues. It is possible to identify useful starting points.
- The basic principles of the general health and social service systems and the degree of coordination between them will have an important impact on the design of an LTC service system.

We should emphasize that this analysis relies primarily on the experience of industrialized countries. The conditions in the developing world and their initial experience in developing LTC systems are quite different. Thus, not only the resolution of the basic LTC design issues, but even the strategy for defining and analysing these strategies needs to be different. These issues are explored more fully in three companion volumes that have been described in the Preface.

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COMMONWEALTH of VIRGINIA

Department for the Aging

Jay W. DeBoer, J.D., Commissioner

NOTICE OF INTENT TO AWARD

Virginia Respite Care Grant Program
RFP #163-03-02

June 3, 2003

Agency	Amount
Alzheimer's Family Day Center Falls Church	$100,000
Jefferson Area Board for Aging Charlottesville	100,000
Bedford Memorial Hospital Bedford	100,000
County of Loudoun Area Agency on Aging Leesburg	72,106
Total Funding	$372,106

Records for this procurement are now available for inspection by any Offeror on this RFP.

Tim M. Catherman
Deputy Commissioner, Support Services

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COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: Ellen Nau, Human Services Program Coordinator

DATE: June 3, 2003

SUBJECT: **National Conference – "Computer-Based Technology and Caregiving for Older Adults"**

The **Spry Foundation, Setting Priorities for Retirement Years**, together with the Federal Government and private organizations, is sponsoring a national conference on "Computer-Based Technology and Caregiving for Older Adults" from October 2-3, 2003 at the National Institutes of Health, Hatcher Conference Center, Bethesda, MD. The conference will focus on the use of computer-based technologies in the areas of disease prevention and medical and personal care support services. To read further about conference goals, rationale and participants consult the Spry Foundation's wesite: **http://www.spry.org/special_events/special_events.html**. Through the website, you can be placed on a mailing list for registration information and a preliminary program agenda.

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COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging
AAA Transportation Managers
Case Managers

FROM: Faye D. Cates, MSSW, Human Services Program Coordinator

DATE: June 3, 2003

SUBJECT: QUESTIONS AND ANSWERS CONCERNING COMMON WHEELCHAIRS AND PUBLIC TRANSIT

The American with Disabilities Act of 1990 has specific public transit regulations related to transporting wheelchair riders and other mobility devices such as electric scooters. Attached are some common questions and answers.

Department of Justice offers technical assistance on the ADA Standards for Accessible Design and other ADA provisions applying to businesses, non-profit service agencies, and state and local government programs; it also provides information on how to file ADA complaints.

ADA Information Line for publications, questions, and referrals

800-514-0301 (voice)
800-514-0383 (TTY)

Internet address (ADA Home Page)

ada.gov or www.usdoj.gov/crt/ada/adahom1.htm

At this web site you will find a list of telephone numbers and Internet addresses of federal agencies and other organizations that provide information about the **Americans with**

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Disabilities Act (ADA) and informal guidance in understanding and complying with different provisions of the ADA.

Federal Transit Administration ADA Information

Published by the Office of Civil Rights, Volume 1:

Questions and Answers Concerning Common Wheelchairs and Public Transit

What is a "common wheelchair?"

Section 37.3 of the DOT's regulations implementing the American with Disabilities Act of 1990 (ADA) (49 CFR Parts 27, 37, and 38) defines a "common wheelchair" as a mobility aid belonging to any class of three or four wheeled devices, usable indoors, designed for and used by individuals with mobility; impairments, whether operated manually or powered. A "common wheelchair" does not exceed 30 inches in width and 48 inches in length measured two inches above the ground, and does not weigh more than 600 pounds when occupied.

Is an electric scooter or other mobility device a common wheelchair?

If an electric scooter or other mobility device meets the physical specifications of a common wheelchair as defined by the DOT's ADA regulations, it must be treated as a common wheelchair.

May transit operator require common wheelchairs be secured to the vehicle?

Yes, provided that the transit operator has established such a policy. Section 37.165(c) (3) of the DOT's ADA regulations allows a transit operator to establish a policy that requires all riders to have their common wheelchairs secured while aboard a transit vehicle.

Therefore, the operator may decline to provide service to a rider who refuses to allow his or her common wheelchair to be secured.

Alternatively, transit operators may adopt a policy that allows common wheelchairs to ride unsecured. If the rider wishes his or her wheelchair to be secured, however, the operator's personnel must provide the requested assistance.

What kinds of securement equipment must be provided?

Section 38.23(d) of the DOT's ADA- regulations requires all ADA compliant vehicles to have a two-part securement system, one to secure the common wheelchair, and a seatbelt and shoulder harness for the wheelchair user. Section 38.23(a) requires vehicles over 22 feet in length to have

enough securement locations and devices to secure two common wheelchairs, while vehicles 22 feet and under must be able to accommodate at least one common wheelchair.

May transit operator deny boarding to a rider whose common wheelchair is difficult to secure?

No. If the transit operator has a policy that requires securement, or if a rider asks that the wheelchair be secured, Section 37.165(f) of the DOT's ADA regulations requires transit personnel to use their best efforts to secure any mobility device that meets the regulatory definition of a common wheelchair. Section 37.165{d) states that transit operators cannot refuse to accommodate a common wheelchair including a scooter or other specialized mobility device that complies with the ADA regulation's specifications -- because the wheelchair cannot be secured to the driver's satisfaction. Given the diversity of "common" wheelchairs, transit operators should consult with the manufacturers of securement devices and wheelchairs, as well as the owner of the wheelchair, to determine the best means of securement.

Does a wheelchair user have to use the seatbelt and shoulder harness?

Under the broad non-discrimination provisions in Section 37.5 of the DOT's ADA regulations, a transit operator is not permitted to mandate the use by wheelchair users of seatbelts and shoulder harnesses, unless the operator mandates the use of these devices by all passengers; including those sitting in vehicle seats. For example, on fixed route buses, if none of the other passengers are required to wear shoulder belts then neither can the person in the mobility device be required to do so.

Transit operators may establish a policy that requires the seatbelt and shoulder harness to be used by all riders, including those who use wheelchairs as well as those who use vehicle seats, if seatbelts and shoulder harnesses are provided at all seating locations. In some cases, state law could require an operator to adopt such a policy.

What kind of services must transit personnel provide?

Because safe and nondiscriminatory transportation is the responsibility of the transit operator, Section 37.173 of the DOT's ADA regulations requires transit operators to train their personnel to properly assist and treat individuals with disabilities with sensitivity, and to operate vehicles and equipment safely. This includes training personnel to use the accessibility equipment and to accommodate the different types of common wheelchairs.

Attendant-type services (e.g., carrying passengers, personal baggage, or suitcases) are not required, but assistance with boarding and disembarking, including pushing a manual wheelchair up a particularly steep ramp, is required.

What if the accessibility equipment is missing or not working?

Section 37.161 of the DOT's ADA regulations requires transit operators to maintain and repair the accessibility equipment. Section 37.163 requires public transit operators to establish a schedule or system to ensure regular and frequent maintenance checks and to take a vehicle out of service to repair or replace any broken or missing equipment before returning the vehicle to service. In some instances, a transit operator must provide alternative accessible transportation if the accessibility equipment is not present or not working.

Does a common wheelchair need brakes in order to use public transit?

No. The DOT ADA regulations' definition of a common wheelchair does not include a requirement for brakes or any other equipment. A transit operator may not deny transportation to a wheelchair user because the wheelchair does not have brakes or the user does not choose to set the brakes.

Can an operator refuse to carry a person with a disability, especially a person using an electric scooter that meets the definition of a "common wheelchair," because of higher insurance rates or liability concerns?

No. Section 37.5(g) of the DOT's ADA regulations prohibits an operator from denying service to an individual with a disability because its insurance company conditions coverage or rates on the absence of individuals with disabilities or persons who use common wheelchairs.

Can a transit operator require a person to transfer from a wheelchair to a vehicle seat?

No. Section 37.l65(e) of the DOT's ADA regulations allows persons who use wheelchairs to transfer to a vehicle seat, if one is available. Such a move is the rider's decision and the transit operator cannot force a rider to transfer to a vehicle seat, although the transit operator can suggest a transfer in a non-coercive way.
For more information on this and other topics related to the ADA and public transit, contact:

Federal Transit Administration Office of Civil Rights
400 7th Street NW, Room 9102
Washington DC 20590
ADA Assistance E-mail: ada.assistance@fta.dot.gov

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging
Case Managers

FROM: Faye D. Cates, MSSW, Human Services Program Coordinator

DATE: June 3, 2003

SUBJECT: **MEDICARE PUBLICATIONS FROM THE KAISER FAMILY FOUNDATION**

The Kaiser Family Foundation recently updated three fact sheets on the Medicare program that you may find useful:

1. Medicare and Prescription Drugs Fact Sheet profiles current sources of prescription drug coverage among the Medicare population, the characteristics of beneficiaries who lack drug coverage, the implications of being without such coverage, and current data on prescription drug use and spending (Publication #1583-05).

2. Medicare + Choice Fact Sheet provides an overview of the program, state variations in enrollment and participation, trends in supplemental benefits and premiums, and recent changes in payments to plans (Publication #2052-05).

3. Medicare at a Glance Fact Sheet provides a basic overview of the Medicare program, including financing, eligibility, covered benefits, supplemental sources of coverage, and data on current and future program spending (Publication #1066-05).

The fact sheets are available on the Kaiser Family Foundation website at <http://www.kff.org/medicare> or by calling 800-656-4533.

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COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: Ellen Nau, Human Services Program Coordinator

DATE: June 3, 2003

SUBJECT: **National Family Caregivers Support Program**

The Administration on Aging (AoA) 2002 Annual Report is now available on the AoA website: http://www.aoa.gov/about/annual_report/annual_report.asp. One section of the report discusses the National Family Caregiver Support Program (NFCSP) and its various initiatives. I have attached the PDF of this section of the Annual Report.

Please find attached a press release about the May 20, 2003 testimony of Josefina Carbonell, Assistant Secretary for Aging, before the Senate Special Committee on Aging. Secretary Carbonell announced a new AoA public service campaign, "Who Cares about the Caregivers". Public service announcements providing information to caregivers on assistance in their communities were distributed to radio and television stations throughout the United States.

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Thursday, May 20, 2003

For Immediate Release Contact: AoA Press Office
May 20, 2003 (202) 401-4541

Baby Boomers Alerted to Caregiving Issues and Other Aging Initiatives

Washington, DC---- Assistant Secretary for Aging, Josefina G. Carbonell, appeared before the Senate Special Committee on Aging and announced the release of a new public service campaign, "Who Cares for the Caregivers?" This campaign is designed to inform baby boomers and other caregivers – individuals providing ongoing care for family members, neighbors or friends in their homes - that assistance is available in their communities, and how to access them. The television and radio PSAs, in English and Spanish, were sent today to television and radio stations throughout the country.

With many baby boomers about to turn 60 years old – the age that will qualify them for services under the Older Americans Act, caregiving and other aging issues are becoming increasingly important to this growing segment of the U.S. population.

AoA, in preparation for the aging baby boomers, is working in partnership with communities and families to support longevity and productive aging. AoA's three main priorities are:

- To support families in their efforts to care for their loved ones at home and in their communities.
- To make it easier for older people to access an integrated array of health and social supports by re-balancing the long-term care system from an over-reliance on institutional care to providing more home- and community-based assistance;
- To help older people stay active and healthy through health promotion and disease prevention activities; and Ms. Carbonell's full testimony and the Caregiver PSA's will be posted on www.aoa.gov.

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supporting caregivers

supporting families in their efforts to care for their loved ones at home and in t

One in three Americans or 22 million people are providing compassionate assistance to a family member, neighbor, or friend. Caregivers include grandparents raising grandchildren as well as those who help older Americans. In many cases, both the caregivers and care recipients are aging adults. The National Family Caregiver Support Program (NFCSP) was established in 2000 to provide supportive services for family caregivers. Since the enactment of the NFCSP, AoA and our National Aging Services Network have demonstrated creativity in implementing family-directed services to caregivers of the elderly and persons with disabilities.

The NFCSP is already producing results. Preliminary data from state agencies indicate that we have exceeded statutory expectations to serve 250,000 caregivers by serving over 325,000 caregivers during the first years of implementation. The same preliminary data reflect that the states and area agencies on aging are providing a solid mix of services to caregivers, including information, assistance, counseling, respite, and supplemental services. Early data from AoA's first national survey of caregivers indicate that caregivers value the services provided by the Network to older clients. Eighty-eight percent reported that services enabled them to care longer than would otherwise have been possible, and 72% reported that the services "helped a lot."

We have provided leadership, guidance, and technical assistance to the Network in implementing and maintaining the NFCSP. The Network focused on developing support systems and expanding the range of services to meet the diverse needs of caregivers. These efforts have resulted in the formation of new local partnerships, improved access to services, outreach to special populations and caregivers who may not be connected to our service delivery networks, and provision of services to respond to the unique needs of families.

Providing Leadership and Technical Assistance

Since the establishment of the NFCSP, AoA has identified and disseminated state-of-the-art knowledge, information, and technical assistance on models and techniques that can be used by states, tribes, and communities to design and implement programs and services that support family caregivers.

In 2002, we developed a *Resource Guide to the National Family Caregiver Support Program.* The guide provides research-based implementation strategies and approaches that network staff may consider in carrying out the NFCSP. AoA also launched a web page, http://www.aoa.gov/ to provide guid-

ance in implementing the NFCSP as well as information on the characteristics and needs of family caregivers.

Promoting Consumer Awareness

Caregivers often are not aware they are caregivers or that services exist which can support them. All too often caregivers seek assistance only when a crisis occurs with their loved ones. To educate family and other informal caregivers about the services available to support them in their caregiving role, we created the following:

- A NFCSP brochure that contains information on eligible populations, services provided through the program, and highlights innovative state caregiving programs;
- A 10-step approach called "Caregiver Survival Tips" for family caregivers to use to identify areas where they may need support and information on how to locate and access this support; and
- A Public Service Announcement entitled "Who Are The Caregivers" which was shown on public television stations reached over 4.6 million people. This five minute segment talked about the NFCSP and was aimed at caregivers who may need support services.

NFCSP 2002 Funding

$128 million allocated to states

$5.5 million distributed to 187 Indian Tribal and Native Hawaiian Organizations

$7 million was awarded to 39 innovative projects

"I provide financial, emotional, and hands-on care everyday as the primary caregi

Supporting Innovation Through the NFCSP

Through the NFCSP, AoA is supporting 39 innovative projects to assist families and informal caregivers at a national and community-based level. These competitive grants focus on systems development, service components, linkages to special populations and communities, field-initiated demonstrations to develop and test new approaches to support caregivers, and national projects that enhance the development of caregiver programs. Projects funded in 2002 include the following:

- The Caring Workplace Project is recruiting and establishing ongoing support from eleven major corporations in St. Louis. Individualized action plans for each business were created based on employee and organizational information. Eldercare services and direct services including one-on-one assessments, consultations, home and safety assessments, and follow-up visits are provided at each company.

- The Elder Caregivers of Adults with Disabilities project is implementing a support system in Pennsylvania for elderly primary caregivers of adult children with mental retardation and developmental disabilities. This consumer-driven project emphasizes supporting the caregiver and family in ways that are specific to his or her needs. The project reimburses these individuals for expenditures related to caregiving and provides resources for all caregiving needs. The strength of the program lies in its flexibility to allow the caregiver to decide how to use the reimbursement.

- The CARE-Pro project uses newer technologies to educate a significant number of health practitioners about how to meet the needs of family caregivers. The Care-Pro project conducted five one-hour Web and teleconference seminars that reached 850–1,000 nurses, occupational therapists, and social workers.

- The Multi-State Family Caregiver Mediation Project, in Michigan, uses mediation to assist frail older persons and their family caregivers to address and resolve problems and disputes which arise when families face the physical, emotional, and financial demands of providing long-term care to an older family member. The goal is to use mediation to protect the autonomy and dignity of older persons while assisting and enabling family caregivers to resolve problems, which if left unresolved, could destroy the family and caregiver support system and could result in institutionalization, financial exploitation, neglect, or abuse.

iver for my mother. I am not an "informal" caregiver."

— a family caregiver

Supporting the President's Agenda

AoA is active in implementing President Bush's New Freedom Initiative, a comprehensive plan to remove barriers to community living for people with disabilities by working to ensure that all Americans have the opportunity to learn and develop skills, engage in work, make choices about their daily lives, and participate fully in community life.

We convened the New Freedom Initiative Caregiver Support Workgroup, an interdepartmental workgroup, to identify opportunities for collaboration and coordination in the area of family caregiver support. The Caregiver Support Workgroup developed a *Compendium of HHS Caregiver Support Activities*. To view the Compendium, visit http://www.aoa.gov/. The Compendium, a first at HHS, catalogues the existing efforts by HHS agencies to support family and informal caregivers.

Caregivers Are Receiving Services Through the NFCSP

States and AAAs Reach Out with Well-Rounded Service Programs in 2002

- 1.3 million caregivers reached by states
- 325,000 received access to help
- 150,000 received counseling and training
- 60,000+ received respite help
- 45,000+ received supplemental services

ensuring elder rights

ensuring the rights of older people and preventing their exploitation, abuse, and

Ensuring Elder Rights

Protecting the rights of older people and preventing their exploitation, abuse, and neglect continues to be one of our most important goals and that of the National Aging Services Network. Predatory lending, home repair scams, and other types of financial exploitation undermine our efforts to promote autonomy and independence. AoA provides critical consumer information, training, technical assistance, and funding for programs that protect the rights of vulnerable, at-risk older persons.

Programs are in place to assist older persons and their families if they are in trouble. If older persons or their family members are having a problem with a nursing home or long-term care facility, the long-term care ombudsman program can help. Long-term care ombudsmen are trained to solve problems and provide information. Similarly, if someone has been the victim of fraud or abuse and needs legal assistance, AoA's legal services may be able to provide support. Additionally, AoA's Senior Medicare Patrol projects train people to detect and stop Medicare and Medicaid fraud and abuse.

Preventing abuse through education is also critical. We have produced consumer education materials and public service announcements to help older persons help protect themselves. We have also provided training to caregivers and elder abuse programs.

Long-Term Care Ombudsman Program

The commitment of AoA and the Network to protect older Americans is reflected in the tireless efforts of the long-term care ombudsman program. Long-term care ombudsman programs in every state and almost 600 regions of the country provide information to residents of long-term care facilities and those in need of long-term care, help residents and their families resolve problems, and advocate for systemic changes to improve care and protect residents' rights.

In 2002, long-term care ombudsmen had the opportunity to use quality data about nursing home programs to assist families in making informed decisions about choosing a nursing home. The quality data is from a pilot project and is based on nine measures of nursing home quality. The six-state pilot project, involving nursing homes serving Medicare and Medicaid beneficiaries in Colorado, Florida, Maryland, Ohio, Rhode Island, and Washington, is part of HHS' Nursing Home Quality Initiative to further improve the quality of care received by the 2.9 million Americans who live in nursing homes.

The success of our nation's ombudsman programs is evident. Ombudsman programs around the country investigate over 260,000 complaints each year, ranging from abuse to inadequate staff to involuntary transfers. They resolve or partially resolve over 70% of the complaints. One thousand paid and 14,000 volunteer staff (8,000 certified) provide information to more than 280,000 people on a myriad of top-

ics including how to select and pay for a long-term care facility, residents' rights, and state and federal rules for facilities. Additionally, the AoA-funded Ombudsman Resource Center provides national and regional training and technical assistance to enhance the skills and knowledge of state and local ombudsmen.

Senior Legal Services

The OAA is one of the top funding sources for low-income senior legal services. There are approximately 1,000 OAA legal services providers nationwide supplying over one million hours of legal assistance per year. The following are two examples of how AoA's legal services help seniors:

- In Michigan, a 73 year-old woman was contacted by a telemarketer and invited to join a discount buyers club. She told the company she wasn't interested. However, when her checks began bouncing, she contacted her bank and found that an electronic transfer to the buyers club had been made. Intervention by senior legal services led to a refund of all her money plus additional expenses.

- In Georgia, an elderly couple was charged nearly $11,000 for minor home repairs that were never completed. Legal services assisted the couple in canceling the contract.

Preventing Elder Abuse

"I'm really glad to know you're available for this kind of help. Seems like people start trying to take advantage of you as you get older. Sometimes I just need legal advice or a little help. Thank you for being there for me."

— Comment given to a West Virginia Senior Legal Aid

"For 30 years, the nation's volunteer ombudsmen have worked to protect nursing h

Preventing Elder Abuse

Financial and material exploitation of older persons continues to be a major problem. To get a better understanding of this phenomenon, AoA is working in partnership with the HHS Office of the Assistant Secretary for Planning and Evaluation to carry out a national study on elder financial exploitation. In an effort to foster information exchange and collaboration, we also co-chair the Elder Justice Interagency Working Group, a group of officials responsible for carrying out elder justice activities in the Federal government.

In 2002, we supported the development of consumer education materials and consumer alerts, including the National Consumer Law Center fact sheet, *Protect Your Investment: Don't Let Predatory Lenders Take Your Home.* The fact sheet can be found at http://www.consumerlaw.org/initiatives/seniors_initiative/protect_invest.shtml. Similarly, we are supporting a Pennsylvania Department of Aging project to provide financial literacy training to minority seniors, raise awareness about predatory investment scams, and train adult protective services staff in how to investigate and resolve exploitation cases.

Additionally, AoA's National Center on Elder Abuse worked to carry out the National Elder Abuse Action Agenda 2002. Educating the public, training professionals, and increasing prosecutions are some of the critical areas the agenda addresses.

We are working in partnership with the HHS Office of Women's Health to support an effort by the Wisconsin Coalition Against Domestic Violence/National Clearinghouse on Abuse in Later Life and the AARP Foundation to promote collaboration and information sharing between domestic violence and elder abuse prevention advocates and practitioners.

OAA funding also supports state and local elder abuse prevention public awareness campaigns, training programs, and multidisciplinary teams. Examples of such abuse prevention efforts from 2002 include the following:

- Orange County, California's Fiduciary Abuse Specialist Team met monthly to discuss cases; the program coordinator offered 38 community and law enforcement education sessions to nearly 1,800 people.
- In Broward County, Florida, caregivers were taught how to handle difficult behaviors and defuse stressful situations. Over 400 individuals received in-home training and approximately 700 others attended information sessions about elder abuse.
- Arkansas' Adult Protective Services and the State Long-Term Care Ombudsman programs jointly sponsored regional trainings on elder abuse that included participation by law enforcement and EMT personnel, prosecuting attorneys, hospital and nursing home administrators, social workers, and clergy.

home residents and improve the quality of care."

— HHS Secretary Tommy G. Thompson

Senior Medicare Patrol Projects

AoA supports 51 Senior Medicare Patrol (SMP) projects in 45 states, the District of Columbia, and Puerto Rico for the purpose of recruiting retired nurses, doctors, accountants, and other professionals to train other older persons and to serve as expert resources to detect and stop Medicare and Medicaid fraud, error, waste, and abuse.

In 2002, AoA launched a website and convened a national conference designed to promote consumer awareness and facilitate the sharing of information and best practices between Medicare and Medicaid beneficiaries; the SMP projects; and federal, state, and local partners. The website also links seniors to information about how to become a volunteer. For more information, please visit the website at http://www.aoa.gov/smp/index.asp.

Since their inception in 1998, SMP projects have resulted in the recovery of $3,008,937 in Medicare funds and $76,621,601 to the Medicaid program and other payers.

Making an Impact in 2002

Senior Medicare Patrols

- 9,000 new volunteers were trained
- 400,000 beneficiaries were directly educated by the retired volunteers

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Volunteer Coordinators
Area Agencies on Aging

FROM: Faye D. Cates, MSSW, Human Services Program Coordinator

DATE: June 3, 2003

SUBJECT: VIRGINIA CORPS STATISTICS AS OF MAY 30, 2003

Virginia Corps IS governor Mark Warner's new effort to capture the renewed spirit of volunteer service and community preparedness which has emerged since September 11, 2001. Virginia Corps serves as a central clearinghouse for volunteer opportunities across Virginia, linking citizens with a wide variety of volunteer efforts.

Attached are the latest statistics on Virginia Corps efforts in Virginia. To explain the acronyms in this document: CCC is for Citizens Corps Council and CERT is for Community Emergency Response Team program.

Janet Clements, Director of Virginia Corps is eager to get more seniors involved. She would like to attend a V4A meeting to solicit the assistance of the AAAs in doing so. Ms. Clements works out of the Office of the Governor and can be reached at (804) 786-2211, ext. 2334. Her e-mail address is: jclements@gov.state.va.us.

Website for Virginia Corps is www.VirginiaCorps.org and its telephone number is 1-866-239-4868 toll free.

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Virginia Corps Statistics as of 05/30/03

Citizen Corps Federal Funding

- All jurisdictions that applied for 2002 funding for CERT and Citizen Corps Councils received their funding. Total award $353,135.
- More than 50 localities were represented in the applications (see attached).

CERT

- Pat Saunders -the state CERT Coordinator - assumed duties April 14th.
- Our regionally located Train-the-Trainer classes have been scheduled and posted to the VDEM Web site (with a direct link from the Virginia Corps Web site.)
- These classes will be held in Roanoke in June, Richmond in July, Hampton Roads in August, Fairfax in September and Charlottesville in October. Over 70 people have signed up. Ten people from Virginia are attending a FEMA-sponsored class in Harrisburg, Pennsylvania in June.
- Nine localities have active CERT training programs in place. They include: Albemarle/Charlottesville, Arlington County, Chesapeake, Hampton, Henrico County, Loudoun County, Suffolk and York County.
- We have over 700 CERT -trained citizens with more than 500 in the pipeline. VMI graduated a 200-cadet CERT class April 8, 2003 - CERT training will now be a requirement for all future fourth-class cadets.
- VDOT has expressed an interest in CERT training for all its employees.

Citizen Corps Councils

- There are now 30 councils in Virginia covering more than 50 localities (counties and cities). These councils are providing support and promotion for volunteerism and community preparedness for more than 1/3 of the state's population.
- Councils include: Albemarle County, Alexandria, Amherst County, Amelia County, Arlington County, Brunswick County, Central Shenandoah Valley, Charles City County, Chesapeake, Chesterfield County, Danville, Fairfax County, Goochland County, Hampton, Hanover County, Henrico County, Henry County, Highland County, James City County, King George County, Nottoway County, Page County, Pittsylvania County, Portsmouth, Richmond, Roanoke Valley, Suffolk, Virginia Beach, Williamsburg and the Virginia Corps State Council.
- One of our local councils -Arlington -has been chosen as a model at the national level.
- Botetourt County just joined the Roanoke Valley (Regional) Council as a participating member.

The Governor

- Recognized Red Cross and fire volunteers in Arlington
- Recognized CERT team members in Arlington
- Recognized VMI CERT effort during commencement address at the school.

Media

- Coverage of VMI CERT training on Roanoke and Lynchburg stations April 8th.
- Coverage of CERT training in Arlington aired on D.C. area stations April 5th.
- Washington Post articles on CERT training mentioned Virginia Corps on March 30th and April 10th.

Events/Meetings

- Pat Saunders attended several CERT graduations -She hopes to visit at least one in each jurisdiction.
- Suzanne Simmons (Corps staff) and Pat helped kick-off the first meeting of the Fairfax Citizen Corps Council.
- Suzanne, Janet and Pat attended the Arlington recognition events with the Governor.
- Suzanne and Virginia Commission member B.J. Northington participated in Department of Homeland Security, Office of National Capital Region Coordination, Citizen's Preparedness planning meeting on May 1st.
- Suzanne gave Virginia Corps presentations to local citizen corps councils and the VDEM community at events in Richmond and Abington.

Virginia Corps Web Site

- The Web site has been updated. Be sure to check out the volunteer profiles and encourage your community to send information for posting to the Best Practices section.
- Coming soon - a list serve for the volunteer community where ideas can be exchanged.

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: Tim M. Catherman
Deputy Commissioner, Support Services

DATE: June 3, 2003

SUBJECT: AAA Internet Capabilities – A Reality Check

In Virginia, the aging network has been placing more reliance on the Internet. Beginning October 1, 2003, the Internet will no longer be a luxury, but a necessity for our network to perform its work.

For the past several years, you have been using the Internet to send the AMR to VDA and to upgrade the AIM software. The size of these files continues to grow.

In April, VDA began electronic transmission of the Tuesday Mailing. Although we have encountered some difficulties that we continue to work through, communicating information this way has been well received. VDA will limit the size of any Tuesday Mailing attachment to 4 MG. If a Tuesday Mailing file should exceed that size, we will subdivide the file into smaller attachments.

Beginning October 2003, AAAs will be using several new online websites. These websites will require some AAA program staff to have constant access to the Internet.

- The AAA VICAP Coordinator will be accessing two systems simultaneously. SHIPTALK.ORG – to access Medicare training material and submitting summary data. The VICAP/SHIP National Performance Report and Medigap Enforcement System is being developed by VDA to enter client counseling data.
- The AAA Ombudsman will be reporting client information using OmbudsManager by the Synergy Corporation.

1600 Forest Avenue, Suite 102, Richmond, Virginia 23229
Telephone (804) 662-9333 (V/TTY) Fax (804) 662-9354 Toll-Free (800) 552-3402 (V/TTY)

In preparation for the changes that are about to occur this fall, it is important to review your Internet capabilities now. You need to make sure you have quality-fast access to the Internet. Many options exist that were not previously available.

Please review your access and discuss your options with your information system administrator or IT contractor. If you are currently using a 56 kb dial-up modem, please explore other economical connection options such as ISDN, DSL, cable, or satellite. Once you have identified your options, please feel free to discuss them with Leonard Eshmont. He will be happy to review your proposed plans as an additional resource.

VDA will be providing training on these new systems as deployment becomes closer. If you have any questions, please call me at (804) 662-9309.

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: Tim M. Catherman
Deputy Commissioner, Support Services

DATE: June 3, 2003

SUBJECT: Federal NAPIS–SPR Public Comment

On Monday, June 2, 2003, the Administration on Aging (AoA) placed notice in the Federal Register to solicit comments on the revised NAPIS-SPR report. A copy of the report is attached. AoA is accepting comments through August 1, 2003. Send comment to:

Attention SPR Comments
Administration on Aging
Office of Evaluation
Washington, DC 20201

The four areas they are seeking comments on are:

1) Whether the proposed data collection is necessary for the proper performance of AoA's functions, including having practical utility;
2) The accuracy of AoA's estimate of burden of reporting (2,606 hours system wide);
3) Ways to enhance the quality, utility, and clarity of the information; and
4) Ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques when appropriate, and other forms of information technology.

The Department will be making public comment. We invite you to make public comment also. Should you choose to comment, please send a copy of your comments to me.

If you have any questions, please call me at (804) 662-9309.

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Reporting Requirements
For Title III and VII

Of the Older Americans Act
(Not including LTC Ombudsman Program)
For FY '04 and Subsequent Years

Title III and VII State Program Report Data Elements
State Program Report Transmittal Requirements
State Program Report Definitions

Administration on Aging
U.S. Department of Health and Human Services
June 2, 2003

Overview of Title III and VII State Performance Reporting Requirements

In the 2000 reauthorization of the Older Americans Act, the Administration on Aging (AoA) was instructed to use, to the maximum extent possible, the data collected by State agencies, area agencies on aging, and service providers through the National Aging Program Information System (NAPIS) and other applicable sources of information in the development of performance measures, and in compliance with the Government Performance and Results Act of 1993.

The Assistant Secretary for Aging was also instructed to annually report to the President and to the Congress on the activities carried out under the Older Americans Act. This report includes (section 207 (3)) *statistical data and an analysis of information regarding the effectiveness of the State agency and area agencies on aging in targeting services to older individuals with greatest economic need and older individuals with greatest social need, with particular attention to low-income minority individuals, older individuals residing in rural areas, low-income individuals, and frail individuals (including individuals with any physical or mental functional impairments).*

As a response to these mandates, AoA is issuing revised reporting guidelines for Titles III and VII. These OMB approved reporting requirements are a revision of those which are currently in effect. The factors which influenced the revision of the SPR, include: 1) the need to develop more permanent information requirements for the National Family Caregiver Support Program; 2) the need to comply with revised OMB standards for gathering information regarding race and ethnicity; 3) the need to reduce the burden of the SPR/NAPIS requirements on States, area agencies and service providers; and 4) the need to consider the collection of alternative data elements to reflect Network performance.

This document summarizes the requirements for the State Program Performance Report (SPR) for Titles III and VII for fiscal year 2004 (FY04) and subsequent years by all State units on aging. The sections of the SPR include:

Section I. Elderly Clients and Caregivers

A. Elderly Client Counts
B. General Characteristics of Elderly Clients Receiving Registered Services and those Receiving Cluster 2 Registered Services (FY05 Implementation)
C. Detailed ADL Characteristics of Elderly Clients Receiving Cluster 1 Services (FY05 Implementation)
D. Detailed IADL Characteristics of Elderly Clients Receiving Cluster 1 Services (FY05 Implementation)
E. Summary Characteristics of Caregivers Serving Elderly Individuals (National Family Caregiver Support Program – Title III-E) (FY05 Implementation)
F. Summary Characteristics of Grandparents and Other Elderly Caregivers Serving Children (National Family Caregiver Support Program – Title III-E III-E) (FY05 Implementation)

Section II. Utilization and Expenditure Profiles

A. Title III Utilization and Expenditure Profile (except Title III-E)
B. Title III-E Utilization and Expenditure Profile For Caregivers Serving Elderly Individuals
C. Title III-E Utilization and Expenditure Profile For Grandparents and Other Elderly Caregivers Serving Children
D. Title VII Expenditures by Chapter (Except Chapter 2. Ombudsman and Chapter 5. Benefits Access Counseling)
E. Other Services Profile *(Optional)*

Section III. Network Profiles

A. State Unit on Aging Staffing Profile
B. Area Agency on Aging Staffing Profile
C. Provider Profile (excluding AAAs providing direct services)
D. Profile of Community Focal Points and Senior Centers

Section IV. Developmental Accomplishments

A. For Home and Community Based Programs
B. For A System of Elder Rights

On the following pages, the SPR format is exhibited through a series of data tables corresponding with the sections of the SPR listed above. The tables are for presentation purposes only. AoA will continue to require electronic transmittal of the annual SPR data. The feasibility of internet based reporting is also being considered.

SECTION I. Elderly Clients and Caregivers

A. Elderly Client Counts

State ID: ____

Fiscal Year: ____

	Total
1. Unduplicated Count of Persons Served For Registered Services Supported by the OAA Title III	
2. Estimated* Unduplicated Count of Persons Served For Unregistered Services Supported by the OAA Title III	
3. Total Estimated Unduplicated Count of Persons Served Through Services Supported by OAA Title III	

* There is no prescribed method for developing this estimate.

SECTION I. Elderly Clients and Caregivers

B. General Characteristics of Elderly Clients Receiving Registered Services and Those Receiving Cluster 2 Registered Services (FY05 Implementation)

State ID: ____ Fiscal Year: ____

___ Total Registered Clients ___ Congregate Meals ___ Nutrition Counseling ___ Assisted Transportation

	Clients Receiving Registered Services*				
	Total	With Income Below Poverty	Age of Client		
			60-74	75-84	85+
Total Clients					
Total with Age Reported					
Age Missing					
Female					
Male					
Gender Missing					
Rural Clients					
Rural Missing					
Poverty Missing					
Live Alone					
Live Alone Missing					
Clients By Ethnicity					
Hispanic or Latino					
Not Hispanic or Latino					
Ethnicity Missing					
Clients By Race					
American Indian or Alaska Native (Alone)**					
Asian (Alone)					
Black or African American (Alone)					
Native Hawaiian or Other Pacific Islander (Alone)					
White (Alone)					
White (Alone) - Hispanic					
Persons Reporting Some Other Race					
Persons Reporting 2 or More Races					
Race Missing					

NOTE: States are no longer required to report Unduplicated Client Counts By Characteristic for Unregistered Services.
States are required to report unduplicated client counts by characteristic for all registered services.

Registered services include: Personal Care, Homemaker, Chore, Home Delivered Meals, Adult Day Care/Health, Case Management, Assisted Transportation, Congregate Meals, and Nutrition Counseling.
*** Total clients includes OAA specified eligible meal participants under age 60.**
****"(Alone)" means that the individual only designated one race category.**

SECTION I. Elderly Clients and Caregivers

C. Detailed ADL Characteristics of Elderly Clients Receiving Cluster 1 Services (FY05 Implementation)

(Report information for all Cluster 1 services combined and each service separately.)

_____ Total Cluster 1 Clients **_____ Personal Care** **_____ Homemaker**

_____ Chore **_____ Home Delivered Meals** **_____ Adult Day Care/Health**

_____ Case Management

ADL SUMMARY FOR _____	Total – All Ages*					Total Age 60-74					Total Age 75-84					Total Age 85+				
	Total	0 ADL	1 ADL	2 ADL	3+ ADL	Total	0 ADL	1 ADL	2 ADL	3+ ADL	Total	0 ADL	1 ADL	2 ADL	3+ ADL	Total	0 ADL	1 ADL	2 ADL	3+ ADL
Total Clients																				
Clients with Age Data																				
Age Missing																				
ADLs Missing																				
Female																				
Male																				
Gender Missing																				
Rural																				
Rural Missing																				
Income below Poverty Level																				
Poverty Missing																				
Clients by Ethnicity																				
Hispanic / Latino																				
Not Hispanic or Latino																				
Ethnicity Missing																				
Clients by Race																				
American Indian or Alaskan Native (Alone)																				
Asian (Alone)																				
Black / African American (Alone)																				
Native Hawaiian or Pacific Islander (Alone)																				
White (Alone)																				
White (Alone) – Hispanic																				
Persons Reporting Some Other Race																				
Persons Reporting 2 or More Races																				
Race Missing																				

*** Total includes OAA specified eligible meal participants under age 60.**

SECTION I. Elderly Clients and Caregivers

D. Detailed IADL Characteristics of Elderly Clients Receiving Cluster 1 Services (FY05 Implementation)

(Report information for all Cluster 1 services combined and each service separately.)

_____ Total Cluster 1 Clients **_____ Personal Care** **_____ Homemaker**

_____ Chore **_____ Home Delivered Meals** **_____ Adult Day Care/Health**

_____ Case Management

ADL SUMMARY FOR _____	Total – All Ages*					Total Age 60-74					Total Age 75-84					Total Age 85+				
	Total	0 IADL	1 IADL	2 IADL	3+ IADL	Total	0 IADL	1 IADL	2 IADL	3+ IADL	Total	0 IADL	1 IADL	2 IADL	3+ IADL	Total	0 IADL	1 IADL	2 IADL	3+ IADL
Total Clients																				
Clients with Age Data																				
Age Missing																				
IADLs Missing																				
Female																				
Male																				
Gender Missing																				
Rural																				
Rural Missing																				
Income below Poverty Level																				
Poverty Missing																				
Clients by Ethnicity																				
Hispanic / Latino																				
Not Hispanic or Latino																				
Ethnicity Missing																				
Clients by Race																				
American Indian or Alaskan Native (Alone)*																				
Asian (Alone)																				
Black / African American (Alone)																				
Native Hawaiian or Pacific Islander (Alone)																				
White (Alone)																				
White (Alone) - Hispanic																				
Persons Reporting Some Other Race																				
Persons Reporting 2 or More Races																				
Race Missing																				

*** Total includes OAA specified eligible meal participants under age 60.**

Section I. Elderly Clients and Caregivers

E. Summary Characteristics of Caregivers Serving Elderly Individuals (National Family Caregiver Support Program - Title III-E)

Note: Data is for Title III-E Cluster 1 Services only – See Section II-C for specifics. (FY05 Implementation)

State ID: ____ Fiscal Year: ____

Caregiver Characteristics	All Caregivers	Age of the Caregiver			
		Under 60	Age 60-74	Age 75-84	Age 85 +
Total Caregivers					
Caregivers with Age Data					
Age Missing					
Female					
Male					
Gender Missing					
Rural					
Rural Missing					
Caregivers by Ethnicity					
Hispanic or Latino					
Not Hispanic or Latino					
Ethnicity Missing					
Caregivers by Race					
Asian (Alone)					
Am. Ind./Alaska Native (Alone)					
Black or African American (alone)					
Native Hawaiian or Other Pacific Islander (Alone)					
White (Alone)					
White (Alone) - Hispanic					
Persons Reporting Some Other Race					
Persons Reporting 2 or More Races					
Race Missing					
Caregivers by Relationship					
Husband					
Wife					
Son					
Daughter					
Other Relative					
Non-Relative					
Relationship Missing					
Care Recipients					
Total Care Recipients					
Care Recipients Below Poverty Level					

SECTION I. Elderly Clients and Caregivers

F. Summary Characteristics of Grandparents and Other Elderly Caregivers Children

(National Family Caregiver Support Program - Title III-E) (FY05 Implementation)

Note: Data is for Title III-E Cluster 1 Services only – See Section II-C for specifics.

Grandparent/Relative Caregiver Characteristics	All Caregivers			
		Age of the Caregiver		
		60-74	75-84	85+
Total Caregivers				
Caregivers with Age				
Age Missing				
Female				
Male				
Gender Missing				
Rural				
Rural Missing				
Caregivers by Ethnicity				
Hispanic or Latino				
Not Hispanic or Latino				
Ethnicity Missing				
Caregivers by Race				
Asian (Alone)				
American Indian/Alaska Native (Alone)				
Black or African American (Alone)				
Native Hawaiian or Other Pacific Islander (Alone)				
White (Alone)				
White (Alone) - Hispanic				
Persons Reporting Some Other Race				
Persons Reporting Two or More Races				
Race Missing				
Caregivers By Relationship				
Grandparents				
Other Elderly Relative				
Other Elderly Non-Relative				
Relationship Missing				
Total Individuals Receiving Care (children under 18)				

SECTION II. Utilization and Expenditure Profiles

A. Title III Utilization and Expenditure Profile (Except Title III-E)

State ID____ Fiscal Year: _____

A. Title III Utilization and Expenditure Profile (Except Title III-E)									OAA Title III Expenditures ($) by Part			
For Selected Services	Number of Providers	# of AAAs Direct Services Provision	Unduplicated Persons Served	# of Persons Served at High Nutrition Risk	Service Units	Title III Expenditure	Total Service Expenditure	Program Income	B	C1	C2	D
Cluster 1: Registered Services - Requiring Detailed Client Profile												
1. Personal Care												
2. Homemaker												
3. Chore												
4. Home Delivered Meals												
4a. NSIP Home Delivered Meals*												
5. Adult Day Care/Health												
6. Case Management												
Cluster 2: Registered Services - Requiring Summary Client Profile												
7. Assisted Transportation												
8. Congregate Meals												
8a. NSIP Congregate Meals*												
9. Nutrition Counseling												
Cluster 3: Non-Registered Services – No Client Profile Required												
10. Transportation												
11. Legal Assistance												
12. Nutrition Education												
13. Information and Assistance												
14. Outreach												
15. Other Services												
Total (Unduplicated)												

Note: States are to report Title III-E in the next table: Section II. B-Title III-E Caregiver Utilization and Expenditure Profile

*** See definition in the Appendix.**

Section II. Utilization and Expenditure Profiles

B. Title III-E Utilization and Expenditure Profile for Caregivers Serving Elderly Individuals

Caregiver Support Categories:	Title III-E Expenditures	Total Service Expenditures	Program Income	# Caregivers Served (Cluster 1: unduplicated/ Cluster 2 estimated unduplicated)	Units of Service	# of Providers (unduplicated)
Cluster 1						
1. Counseling						
Individual Counseling						
Support Groups						
Caregiver Training						
Other						
2. Respite Care						
In-home respite (includes Personal Care, Homemaker, and other in-home respite)						
Adult Day Care/Senior Center respite						
Institutional Respite						
Direct Payments for respite (if not included elsewhere)						
Other respite						
3. Supplemental Services (specify:)						
Cluster 2				**Estimated Audience size:**		
4. Information Services						
				Estimated Unduplicated:		
5. Access Assistance						
Information & Assistance						
Case Management						
Outreach						
Transportation						
Assisted Transportation						
Other						
Totals (unduplicated)						

Section II. Utilization and Expenditure Profiles

C. Title III-E Utilization and Expenditure Profile For Grandparents and Other Elderly Caregivers Serving Children

Caregiver Support Areas:	Title III-E Expenditures	Total Service Expenditures	Program Income	# of Caregivers Served (Cluster 1: unduplicated/ Cluster 2 estimated unduplicated)	Units of Service	# of Providers (unduplicated)
Cluster 1						
1. Counseling						
Individual Counseling						
Support Groups						
Caregiver Training						
2. Respite Care						
3. Supplemental Services (specify:)						
Cluster 2						
				Estimated Audience size:		
4. Information Services						
				Estimated Unduplicated:		
5. Access Assistance						
Information & Assistance						
Case Management						
Outreach						
Transportation						
Assisted Transportation						
Other						
Totals (unduplicated)						

SECTION II. Utilization and Expenditure Profiles

D. Title VII Expenditures by Chapter

C. Title VII Expenditures By Chapter	Title VII Expenditure	Total Service Expenditure
Chapter 3: Elder Abuse Prevention		
Chapter 4: Legal Assistance Development		

Note: OAA Title VII, Chapter 2, Ombudsman expenditures are reported separately in the National Ombudsman Reporting System (NORS).

SECTION II. Utilization and Expenditures Profiles

E. Other Services Profile *(Optional)*

State ID: ____ Fiscal Year: ____

Service Name (Up to 30 Characters)	Service Unit Name (Up to 15 characters)	Mission/ Purpose Category	OAA Service Expenditure Amount	Total Service Expenditure Amount	Estimated Unduplicated Persons Served	Estimated Service Units
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						
11.						
12.						
13.						
14.						
15.						
16.						
17.						
18.						
19.						
20.						
21.						
22.						
23.						
24.						
25.						

Mission/Purpose Codes:
A. Services which address functional limitations
B. Services which maintain health
C. Services which protect elder rights
D. Services which promote socialization/participation
E. Services which assure access and coordination
F. Services which support other goals/outcomes

There are no restrictions on the number of “other” services that may be reported.

For each “other” service being reported, please provide all the data elements—name, unit name, mission code, expenditure data, persons served, and service units.

SECTION III. Network Profiles

A. State Unit on Aging Staffing Profile

State ID: ____ **Fiscal Year: ____**

SUA Personnel Categories	Total FTEs	Minority FTEs
1. Agency Executive/ Management Staff		
2. Other Paid Professional Staff (By Functional Responsibility)		
A. Planning		
B. Development		
C. Administration		
D. Service Delivery		
E. Access/Care Coordination		
F. Other		
3. Clerical/Support Staff		
4. Total SUA Staff		

Functional Responsibilities:
A. Planning—Includes needs assessment, plan development, budgeting/resource analysis, service inventories, standards development and policy analysis.
B. Development—Includes public education, resource development, training and education, research and development and legislative activities.
C. Administration—Includes bidding, contract negotiation, reporting, reimbursement, accounting, auditing, monitoring and quality assurance.
D. Access/Care Coordination—Include outreach, screening, assessment, case management and I&R.
E. Service Delivery—Includes those activities associated with the direct provision of a service which meets the needs of an individual older person and/or caregiver.

SECTION III. Network Profiles

B. Area Agency on Aging Staffing Profile

State ID: ____ Fiscal Year: ____ Total # of AAA's _____

AAA Personnel Categories	Total FTEs	Minority FTEs
1. Agency Executive/ Management Staff		
2. Other Paid Professional Staff (By Functional Responsibility)		
A. Planning		
B. Development		
C. Administration		
D. Service Delivery		
E. Access/Care Coordination		
F. Other		
3. Clerical/Support Staff		
4. Volunteers		
5. Total AAA Staff		

Functional Responsibilities:
A. Planning—Includes needs assessment, plan development, budgeting/resource analysis, service inventories, standards development and policy analysis.
B. Development—Includes public education, resource development, training and education, research and development and legislative activities.
C. Administration—Includes bidding, contract negotiation, reporting, reimbursement, accounting, auditing, monitoring and quality assurance.
D. Access/Care Coordination—Include outreach, screening, assessment, case management and I&R.
E. Service Delivery—Includes those activities associated with the direct provision of a service which meets the needs of an individual older person and/or caregiver.

Section III. Network Profiles
C. Provider Profile (Excluding Area Agencies on Aging providing direct services)

	Total # of Providers	Total # of Volunteers
Total		
Minority		
Rural		

SECTION III Network Profiles
D. Profile of Community Focal Points and Senior Centers

State ID: ____ Fiscal Year: ____

	Number
1. Total Number of Focal Points Designated Under Section 306(a)(3) of the Act in Operation in the Past Year.	
2. Of the Total Number of Focal Points in Item 1., the Number That Were Senior Centers.	
3. Total Number of Senior Centers in the State in the Past Fiscal Year.	
4. Total Number of Senior Centers in Item 3. That Received OAA Funds During the Past Fiscal Year.	

SECTION IV. DEVELOPMENTAL ACCOMPLISHMENTS
a. FOR HOME AND COMMUNITY BASED PROGRAMS*

State ID: ____ Fiscal Year: ____

Identification Of Three Top Accomplishments		
1.		
Type of Development	**TYPE_CODE**	**Enter Code(s)**
2.		
Type of Development		**Enter Code(s)**
3.		
Type of Development		**Enter Code(s)**

Development Type Codes:			
1. Public education/awareness	**3. Training/education**	**5. Policy development**	**7. Other**
2. Resource development	**4. Research and development**	**6. Legislative development**	

*** includes Title III-E NFCSP**

SECTION IV. DEVELOPMENTAL ACCOMPLISHMENTS
B. FOR A SYSTEM OF ELDER RIGHTS
State ID: ____ Fiscal Year: ____

Identification Of Three Top Accomplishments		
1.		
Type of Development	**TYPE_CODE**	**Enter Code(s)**
2.		
Type of Development		**Enter Code(s)**
3.		
Type of Development		**Enter Code(s)**

Development Type Codes:			
1. Public education/awareness	3. Training/education	5. Policy development	7. Other
2. Resource development	4. Research and development	6. Legislative development	

Appendix -- Definitions

The following definitions should be used when completing the SPR:

A. Characteristics of Elderly Clients

Race/Ethnicity Status – The following reflects the requirements of the Office of Management and Budget (OMB) for obtaining information from individuals regarding race and ethnicity. It constitutes what OMB classifies as the "two-question format." When questions on race and ethnicity are administered, respondents should ideally be given the opportunity for self-identification, and are to be allowed to designate all categories that apply to them. Consistent with OMB requirements, the following are the race and ethnicity categories to be used for information collection purposes:

Ethnicity:

- Hispanic or Latino
- Not Hispanic or Latino

Race:

- American Indian or Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

American Indian or Alaskan Native—A person having origins in any of the original peoples of North America (including Central America), and who maintains tribal affiliation or community attachment.

Asian –A person having origins in any of the original peoples of the Far East, Southeast Asia or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam

Black or African American—A person having origins in any of the black racial groups of Africa.

Hispanic or Latino—A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.

Native Hawaiian or Other Pacific Islander—A person having origins in any of the original peoples of Hawaii, Guam, Samoa or other Pacific Islands.

White – A person having origins in any of the peoples of Europe, the Middle East, or North Africa.

Impairment in Activities of Daily Living (ADL) --The inability to perform one or more of the following six activities of daily living without personal assistance, stand-by assistance, supervision or cues: eating, dressing, bathing, toileting, transferring in and out of bed/chair, and walking.

Impairment in Instrumental Activities of Daily Living (IADL) -- The inability to perform one or more of the following eight instrumental activities of daily living without personal assistance, or stand-by assistance, supervision or cues: preparing meals, shopping for personal items, medication management, managing money, using telephone, doing heavy housework, doing light housework, and transportation ability (transportation ability refers to the individual's ability to make use of available transportation without assistance).

Poverty—Persons considered to be in poverty are those whose income is below the official poverty guideline (as defined each year by the Office of Management and Budget, and adjusted by the Secretary, DHHS) in accordance with subsection 673 (2) of the Community Services Block Grant Act (42 U.S.C. 9902 (2)). The annual HHS Poverty Guidelines provide dollar thresholds representing poverty levels for households of various sizes.

Living alone—A one person household (using the Census definition of household) where the householder lives by his or herself in an owned or rented place of residence in a non-institutional setting, including board and care facilities, assisted living units and group homes.

B. Characteristics of Individuals Associated with the National Family Caregiver Support Program (Title III-E. NFCSP)

Child—An individual who is not more than 18 years of age.

Caregiver—An adult family member or another individual, who is an "informal" provider of in-home and community care to an older individual. "Informal" means that the care is not provided as part of a public or private formal service program.

Grandparent or other older relative caregiver of a child –A grandparent, step grandparent or other relative of a child by blood or marriage, who is 60 years of age or older and—

(A) lives with the child;
(B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and
(C) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally.

Elderly Client – An eligible (60 years of age or older) elderly individual who receives OAA services.

C. Standardized names, definitions and service units are provided for the services that are singled out in the SPR for reporting

Personal Care (1 Hour) -- Personal assistance, stand-by assistance, supervision or cues for a person with an ADL impairment.

Homemaker (1 Hour) -- Assistance such as preparing meals, shopping for personal items, managing money, using the telephone or doing light housework for a person with an IADL impairment.

Chore (1 Hour) -- Assistance such as heavy housework, yard work or sidewalk maintenance for a person with an IADL impairment.

Home-Delivered Meal (1 Meal)**--** A meal provided to a qualified individual in his/her place of residence. The meal is served in a program administered by SUAs and/or AAAs and meets all of the requirements of the Older Americans Act and State/Local laws. As noted in Section IIA, meals provided to individuals through means-tested programs such as Medicaid Title XIX waiver meals or other programs such as state-funded means-tested programs are excluded from the NSIP meals figure in line 4a; they are included in the meal total reported on line 4 of Section IIA. Certain Title III-E funded home delivered meals may also be included – see the definition of NSIP meals below.

Adult Day Care/Adult Day Health (1 hour) – Personal care for dependent elders in a supervised, protective, and congregate setting during some portion of a day. Services offered in conjunction with adult day care/adult day health typically include social and recreational activities, training, counseling, and services such as rehabilitation, medications assistance and home health aide services for adult day health**.**

Case Management (1 Hour) -- Assistance either in the form of access or care coordination in circumstances where the older person is experiencing diminished functioning capacities, personal conditions or other characteristics which require the provision of services by formal service providers or family caregivers. Activities of case management include such practices as assessing needs, developing care plans, authorizing and coordinating services among providers, and providing follow-up and reassessment, as required.

Congregate Meal (1 Meal) – A meal provided to a qualified individual in a congregate or group setting. The meal as served meets all of the requirements of the Older Americans Act and State/Local laws. As noted in Section IIA, meals provided to individuals through means-tested programs such as Medicaid Title XIX waiver meals or other programs such as state-funded means-tested programs are excluded from the NSIP meals figure in line 8a; they are included in the meal total reported on line 8 of Section IIA.

Nutrition Education (1 session per participant) -- A program to promote better health by providing accurate and culturally sensitive nutrition, physical fitness, or health (as it relates to nutrition) information and instruction to participants, caregivers, or participants and caregivers in a group or individual setting overseen by a dietician or individual of comparable expertise.

Nutrition Counseling (1 session per participant) -- Individualized guidance to individuals who are at nutritional risk because of their health or nutrition history, dietary intake, chronic illnesses, or medications use, or to caregivers. Counseling is provided one-on-one by a registered dietician, and addresses the options and methods for improving nutrition status.

High Nutritional Risk (persons) – An individual who scores higher than a six (6) on the DETERMINE Your Nutritional Risk checklist published by the Nutrition Screening Initiative.

NSIP Meals (1 meal) -- A Nutrition Services Incentive Program (NSIP) Meal is a meal served in compliance with all the requirements of the OAA, which means at a minimum that: 1) it has been served to a participant who is eligible under the OAA and has NOT been means-tested for participation; 2) it is compliant with the nutrition requirements; 3) it is served by an eligible agency; and 4) it is served to an individual who has an opportunity to contribute. Meal counts in 4, 4a, 8, 8a, include all OAA eligible meals including those served to persons under age 60 where authorized by the OAA. NSIP Meals also include home delivered meals provided as Supplemental Services under the National Family Caregiver Support Program (Title III-E) to persons aged 60 and over who are either care recipients (as well as their spouses of any age) or caregivers.

Assisted Transportation (1 One Way Trip) -- Assistance and transportation, including escort, to a person who has difficulties (physical or cognitive) using regular vehicular transportation.

Transportation (1 One Way Trip) – Transportation from one location to another. Does not include any other activity.

Legal Assistance (1 hour) -- Legal advice, counseling and representation by an attorney or other person acting under the supervision of an attorney.

Information and Assistance (1 Contact) -- A service that: (A) provides individuals with information on services available within the communities; (B) links individuals to the services and opportunities that are available within the communities; (C) to the maximum extent practicable, establishes adequate follow-up procedures. Internet web site "hits" are to be counted only if information is requested and supplied.

Outreach (1 Contact) – Intervention with individuals initiated by an agency or organization for the purpose of identifying potential clients (or their care givers) and encouraging their use of existing services and benefits.

Note: The service units for information and assistance and for outreach are individual, one-on-one contacts between a service provider and an elderly client or caregiver. An activity that involves contact with multiple current or potential clients or caregivers (e.g., publications, publicity campaigns, and other mass media activities) should not be counted as a unit of service. Such services might be termed public information and reported on the public information category. They may also be reported in "Section II.E. – Utilization and Expenditures Profiles, Other Services Profile (Optional)."

Other Services – A service provided using OAA funds that do not fall into the previously defined service categories. States have the option of reporting such services in "Section II.E. – Utilization and Expenditures Profiles, Other Services Profile (Optional)." Expenditures on "Other Services" in Section II.A. Line 15 is required.

D. Services to Caregivers

Counseling --(1 session) Counseling to caregivers to assist them in making decisions and solving problems relating to their caregiver roles. This includes counseling to individuals, support groups, and caregiver training (of individual caregivers and families).

Respite Care --(1 hour) Services which offer temporary, substitute supports or living arrangements for older persons in order to provide a brief period of relief or rest for caregivers. Respite Care includes: (1) In-home respite (personal care, homemaker, and other in-home respite); (2) respite provided by attendance of the care recipient at a senior center or other nonresidential program; and 3) institutional respite provided by placing the care recipient in an institutional setting such as a nursing home for a short period of time as a respite service to the caregiver. If the specific service units purchased via a direct payment (cash or voucher) can be tracked or estimated, report those service unit hours. If not, a unit of service in a direct payment is one payment.

Supplemental services –Services provided on a limited basis to complement the care provided by caregivers.

Information Services (1 activity) -- A service for caregivers that provides the public and individuals with information on resources and services available to the individuals within their communities. [Note: service units for information services are for activities directed to large audiences of current or potential caregivers such as disseminating publications, conducting media campaigns, and other similar activities.]

Access Assistance (1 contact) -- A service that assists caregivers in obtaining access to the services and resources that are available within their communities. To the maximum extent practicable, it ensures that the individuals receive the services needed by establishing adequate follow-up procedures. [Note: Information and assistance to caregivers is an access service, i.e., a service that: (A) provides individuals with information on services available within the communities; (B) links individuals to the services and opportunities that are available within the communities; (C) to the maximum extent practicable, establishes adequate follow-up procedures. Internet web site "hits" are to be counted only if information is requested and supplied.]

E. Other Definitions

A variety of other terms are used in the SPR. Definitions for these terms are as follows:

Legal Assistance Development - Activities carried out by the state "Legal Assistance Developer" that are designed to coordinate and enhance state and local legal services and elder rights programs.

Volunteer—An uncompensated individual who provides services or support on behalf of older individuals. Only staff working under the AAA, not the AAA contractors, shall be included.

Agency Executive/Management Staff—Personnel such as SUA director, deputy directors, directors of key divisions and other positions which provide overall leadership and direction for the state or area agency on aging.

Other Paid Professional Staff—Personnel who are considered professional staff who are not responsible for overall agency management or direction setting but carry out key responsibilities or tasks associated with the state or area agency the following areas:

Planning—Includes such responsibilities as needs assessment, plan development, budgeting/resource analysis, inventory, standards development and policy analysis.

Development—Includes such responsibilities as public education, resource development, training and education, research and development and legislative activities.

Administration—Includes such responsibilities as bidding, contract negotiation, reporting, reimbursement, accounting, auditing, monitoring, and quality assurance.

Access/Care Coordination—Includes such responsibilities as outreach, screening, assessment, case management, information and referral.

Service Delivery—Includes those activities associated with the direct provision of a service that meets the needs of an individual older person and/or caregiver.

Clerical/Support Staff—All paid personnel who provide support to the management and professional staff.

Provider – An organization or person which provides services to clients under a formal contractual arrangement with an AAA or SUA. Under Title III-E, in cases where direct cash payment is made to a caregiver and the ultimate provider is unknown, the number of providers may be omitted.

Minority Provider – A provider of services to clients which meets any one of the following criteria: 1) A not for profit organization with a controlling board comprised at least 51% of individuals in the racial and ethnic categories listed below. 2) A private business concern that is at least 51 percent owned by individuals in the racial and ethnic categories listed below. 3) A publicly owned business having at least 51 percent of its stock owned by one or more individuals and having its management and daily business controlled by one or more individuals in the racial and ethnic categories listed below. The applicable racial and ethnic categories include: American Indian or Alaskan Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, or Hispanic.

Rural Provider – Providers of services to clients who live in rural areas. Rural providers are not necessarily providers of services only to rural clients. They may also be providers of services to clients in urban areas. [See definition of rural].

Total OAA Expenditures—Outlays/payments made by the SUA and/or AAA's using OAA federal funds to provide an allowable service.

Total Service Expenditure – OAA expenditures plus all other funds administered by the SUA and/or AAA's on behalf of elderly individuals and caregivers for services meeting the definition of OAA services – both services which are means tested and those which are not. SUAs are encouraged to report expenditures in these service categories whether or not AoA funds were utilized for that purpose. This is not intended for financial accountability but for statistical purposes such as computing accurate service unit costs based on total service expenditures.

Program Income—Gross income received by the grantee and all sub grantees such as voluntary contributions or income earned only as a result of the grant project during the grant period.

Rural—A rural area is: any area that is not defined as urban. Urban areas comprise (1) urbanized areas (a central place and its adjacent densely settled territories with a combined minimum population of 50,000) and (2) an incorporated place or a census designated place with 20,000 or more inhabitants.