LONG-TERM CARE FOR THE ELDERLY

A Comparative View of Layers of Care

Betty H. Landsberger

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to the memory of Hugh B. Hatch and Margaret Macdonell Hatch and

Ernst Landsberger and Annie Winter Landsberger who gave long-term care to hope and human values throughout their long lives

FOREWORD

The development of services for old people in one country can derive great benefit by drawing upon similar experiences in others, as long as cultural, economic and structural differences are properly understood and taken into account.

In the field of ageing, we have had relatively slender resources on which to base inter-country comparisons and the literature in this field is still very scant. An International Congress of Gerontology with a limited social science element every third year, the quarterly Bulletin of the International Federation on Ageing, material from the World Health Organization and a few research agencies together with the United Nations World Assembly on Ageing have provided the principal mechanisms for exchanges between policy-makers and practitioners, apart from Conferences on special issues. However, the high cost of international travel and the need to spend time in a visited country limits participation at even these useful events.

This means that, at a personal level, books continue to provide the principal resource for the majority of people; but reliable texts which combine information and analysis in different national settings are still few and far between. If they are written by a single author they may lack sensitivity to national differences; if written by a team from different countries and disciplines, they may lack comparability. For this reason, I welcome the publication of Betty Landsberger's valuable contribution to the literature on long-term care for old people. She describes the settings, the people involved and the strategies being developed in the United States, Great Britain and Germany with additional references to Scandinavian countries in a thoughtful and incisive way. This helps our understanding of the policies and their implication for practice during a period of rapid change in which long-held beliefs about the place of institutional care within the scheme of things are being challenged on both economic and ideological grounds.

Long-Term Care for the Elderly is a useful book in its own right, as well as being a model for a comparative study dealing with practical realities within a conceptual framework. It draws out some of the current arguments about the relative merits of differing

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systems of delivery, the sectors through which it is organised and about the critical role of co-ordination and liaison when a range of agencies and disciplines may be involved in the networks of care supporting old people on a long-term basis.

Betty Landsberger's study should certainly be of value to those working in the countries she has studied; but its lessons have much wider implications. It also appears at an opportune moment in relation to far-reaching discussions in many countries about the nature and scope of the welfare society itself. 'Is it to be extended or dismantled?' and 'What are the key elements, as far as older people are concerned?' are serious questions for all of us with their best interests at heart.

David Hobman CBE
President, International Federation on Ageing
Director, Age Concern England

PREFACE

This book arose from the author's share of the intense and widespread concerns about how to improve the life of the many very elderly people who need help in handling long periods of disability and infirmity.

Knowing these concerns at first hand in the United States, the author took advantage of an opportunity to visit Britain and West Germany in 1984 to become acquainted with the thoughts and actions of those and other European countries. The 1982 World Assembly on Aging, convened by the United Nations, had stimulated many nations and international study groups to produce descriptions and updates regarding the condition of and provisions for older people. These always included attention to long-term care. The reports were not only useful to her, but the author feels that they constitute a literature which should be more widely known than is usual amongst gerontologists, health professionals and the public at large. Consequently, some of these documents are quoted frequently and sometimes extensively herein. Studies and writings from within individual countries were also helpful sources of information about particular topics.

The literature led to making first hand visits to several kinds of sites and programs which both Britain and West Germany have developed for their infirm elderly citizens. These visits ranged from training programs for *altenpflegen* (old people's nurses) in the Ruhr to geriatric day hospitals in London, and from the head-quarters of the German Gray Panthers in Wuppertal to an aftercare program attached to a hospital in the upper reaches of England's Lake District. The author is greatly indebted to all of the many people who made reading materials and visits possible and has included references to this help under Acknowledgements.

It is clear that no matter how rich the literature and how helpful the hosts, any foreign visitor on a single visit must emerge with a very inadequate view of each part of the picture. In spite of this inevitable limitation, a responsible effort to look at the same social phenomenon in various countries does produce valuable insights and new ideas about approaches and techniques, and because of this the project was undertaken. However, the author wishes to

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offer an apology for any inadequacies and inaccuracies still present in her account, though the reviews of the original text made by many knowledgeable people will have picked up most of the errors originally there.

It is hoped that this study in a modest way demonstrates the values of comparative study for gerontology. The larger hope is that learning of other nations' experiences and approaches regarding long-term care for the elderly will be of some help as each nation attempts to develop better forms of care.

ACKNOWLEDGEMENTS

Special kinds of help are needed for a study which must be carried out away from home. These include support from home in the form of arrangements for taking over tasks during one's absence as well as financial support. Away from home, beyond the comfort of their hospitality, one requires of the hosts a great deal of time and effort to collaborate with the project in order to make suggestions and offer introductions and explanations.

This American's study of long-term care for elderly people in several European countries was made possible and enriched by generous assistance at home and abroad. The School of Nursing and the University of North Carolina at Chapel Hill made possible a six-month stay in Great Britain to learn about the care of elderly people there and in different parts of Europe.

People as individuals and people in various organizations offered essential orientation and suggestions about the British scene. Dr Robin Huws Jones, CBE, from the world of social work, Miss Marjorie Simpson, OBE, from the world of nursing and Professor Brian Abel-Smith of the London School of Economics. who has a special acquaintance with social policy in the European Economic Community, were among the persons who made suggestions and opened doors at the outset. Persons at the King Edward's Hospital Fund for London provided a warm and helpful home in London, and Professor Pinker and the London School of Economics gave a very supportive academic home to my husband and I. Dr Sheila Peace and her associates at the North London Polytechnic, Mrs Sally Greengross at Age Concern, Ms Alison Norman at the Centre for Policy on Ageing, and Mrs Linda Thomas at the Royal College of Nursing were sources of good ideas about where to go and what and whom to see. The libraries of the Centre for Policy on Ageing, the King's Fund and the Royal College of Nursing were great resources. Elderly patients themselves, nurses, social workers, health visitors and physicians — all of them on the front line of long-term care — were most generous in introducing me to people and sites at first hand.

In West Germany, many persons made the special effort to explain to me in English the nature of work and care for the

elderly in that country. Among them were Dr Margret Dieck at the German Center for Gerontology in West Berlin; Dr Willie Rückert at the German Foundation for Care of the Elderly in Cologne; Herr Hen Tröost of the German Workers' Welfare Organization and Herr Brandt of the Bundesarbeitsgemeinschaft der Frein Wohlfahrtpflege, located in Bonn. Frau Christa Romberg and Schwester Anagret Taake, both of whom work in Duisburg with the Christophorus Werk of the Diakonisches Werk der Evangelischen Kirche in Deutschland, provided information about training people for work with the elderly. Several officers of the Senioren Schutz Bund at their headquarters in Wuppertal gave a stimulating introduction to their organization, also known as the German Gray Panthers.

Persons from Denmark, Sweden and Norway communicated by letter and sent books and booklets by mail. The same is true for the WHO Office for Europe at Copenhagen, the International Federation on Ageing, EURAG, the United Nations Office for Aging in Vienna, and the Centre de Liason d'Etude, d'Information et de Recherche sur les Problèmes des Personnes Agées at the Commission of the European Communities in Brussels.

Indebtedness is expressed to many authors and teams of persons whose writings have been quoted in the book, often at some length. Many of these materials — the Country Reports prepared for the World Assembly on Aging are an example — are not copyrighted, while copyrights are held by authors, publishers or both on other works cited extensively here. Appreciation is expressed to all whose work has seemed so appropriate that excerpts have been included. Copyright holders who have generously given permission to use materials include the following: Alison Norman, author, and the National Corporation for the Care of Old People (now, the Centre for Policy on Ageing), publisher of the book Rights and Risk; the Writers and Readers Publishing Co-operative, publishers of The Alienated, by the late Gladys Elder; Ellen Newton, author of This Bed My Centre; Dr Philip Selby, holder of the copyright for the following work: Selby, P. and Schechter, M., 1982. Aging 2000 - A challenge for society. Lancaster, England: MTP (published for the Sandoz Institute for health and socio-economic studies), a book quoted throughout this volume. Others are the authors, Dr E.M. Goldberg and Ms N. Connelly, and the Policy Studies Institute, holders of the copyright for Effectiveness of Social Care of the Elderly, published by Heinemann; the Centre

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for Policy on Ageing, publishers of New Literature on Old Age 44 (March-April 1984) and Organising Aftercare, from which excerpts are reprinted here; Age Concern England, publishers of the Age Concern England Handbook, from which a section has been reprinted; Dr Malcolm Johnson, author of 'Involvement of Patients and Relatives in Discharge and Aftercare'.

The Beth Johnson Foundation, the Department of Adult Education at the University of Keele and Age Concern England hold the copyright for *Care in the Community: Recent Research and Current Projects*, edited by Frank Glendenning. The author is grateful to those three organizations for permission to quote excerpts from the article by Olive Stevenson, 'Social Trends in Care for the Elderly' and from 'Caring for the Carers' by Sally Greengross.

The article by Dr Johnson mentioned above appeared in a publication not itself copyrighted, entitled *Home from Hospital*—to What? It was issued by the Continuing Care Project under the direction of Mrs G.M. Amos. Her articles and that of P. Thursfield in that volume are gratefully acknowledged. Other individuals and organizations whose non-copyrighted material has been used extensively are Pensioners Link/Task Force, London, publishers, and R. Pearson, author of An Independent Old Age: Provisions for Pensioners in Scandinavia; the Equal Opportunities Commission, the producers of Who Cares for the Carers? Age Concern Greater London, who provided material from the 1984 Health Forum; and Jean Fisher, Maura Hunt, Felicity Watson and Linda Gardner, all of whom generously shared descriptions of their projects for liaison between hospital and home.

The 1981 Final Report of the White House Conference on Aging held in Washington, DC has been cited extensively. Other material regarding the United States was provided by Ambassador John MacDonald of the Department of State. The statement of principles prepared for the Selby and Schechter book, Aging 2000 — A Challenge for Society by Dr Leo Kaprio of the World Health Organization's Office for Europe is reprinted here. The author wishes to acknowledge this excellent contribution to the literature on services for the elderly.

In expressing appreciation for the help from so many persons, the author is of course not attempting to place responsibility for the contents of this book on anyone other than herself. That responsibility rests entirely with the author. The very able

xiv Acknowledgements

assistance of three persons with typing which had to be done very rapidly and well is gratefully acknowledged. They are Norma Dawlings, Sheila Picken and Jean Pilgram, from London and Cambridgeshire.

I owe a special debt to my husband, Dr Henry Landsberger, who took time from his own demanding research tasks to give his expert help with the German language. The German dimension was added to this study because he acted as able interpreter in conversations, as translator of printed material and as locator of organizations and maker of appointments.

I am confident that all who gave their help to make this study possible will join the author in this statement: that our work will have been worthwhile if people in towns and cities, in states and nations, wherever they are, address the needs of their infirm elderly people with some new information, new insights and new determination to provide care they regard with pleasure and with pride.

LONG-TERM CARE IN CONTEMPORARY WESTERN SOCIETY

Introduction

The presence of very old people in large numbers is something altogether new. Persons over 75 and even those over 85, are a growing proportion of the populations of all industrialized countries of the Western world, and this may soon be a phenomenon almost world wide. The topic of the very old was frequently on the agenda when representatives from 124 member states met in Vienna at the United Nations World Assembly on Aging during August of 1982. It has caught us all unprepared, the sudden arrival on the national doorstep of this host of unexpected and unannounced guests.

People everywhere feel that what we have hastily found to provide for the elderly in general, but the very old in particular, is not serving anyone very well. Governments feel the arrangements are too costly, and elderly people say they vary from tolerable to terrible. 'We haven't yet got it right,' is the British way of making this admission. A high priority of our time is to orient ourselves to the reality of the life of very old people in contemporary societies, in order to put it right.

Very large numbers of people in the upper registers of age are as fit as ever they were. Nevertheless, it is recognized and documented that very old people are vulnerable on a number of scores: they are illness-prone, accident-prone, poverty-prone and isolation-prone. Above all, and because of their vulnerabilities, they are disability-prone and thereby many are made dependent on help from others to keep up the essential activities of living, sometimes just as surely as infants and young children are dependent upon others for their survival. But the dependency of older people is made infinitely complex because it represents a demotion from independence. This inevitably leads to psychological and social, as well as physical problems, between the elder person and those who give the needed help. There is cogent meaning behind the assertion, 'I don't want to be a burden.' It is no wonder that the question of how to provide the needed care for long-lasting

disability of their very old populations has baffled societies everywhere.

One reason for the failure to find good solutions has been the very unfortunate timing: the awareness of the numbers of very elderly people in need of care has come just when economies everywhere have been experiencing high rates of inflation, high numbers of unemployed and low rates of economic growth. How to provide the needed long-term care of disabled older people in the present economic conditions remains an unanswered question.

Perhaps one reason it is unanswered is that other questions must be answered first. Just how should we perceive the economics of an aging population? That topic was addressed in a searching article by Robert Butler (1978), the first director of the National Institute on Aging in the United States. He argued for an end to 'narrow gauged' discussions of the costs to society of maintaining its elderly people. Longer life expectancy, he reminded his readers, is a triumph, not a tragedy. This triumph brings with it the need for new forms of social policy making. According to Butler, we must have much more knowledge about aging, of course on the biomedical front, but also in the economics of aging and the social policy issues arising from the connections between health and wealth.

Butler pointed to the lack of prudence when there is little research-based information about services for which a society is making large expenditures. This is very much the case with long-term care services. He noted that the expenditure for research on this kind of enterprise amounts to less than 2 per cent of the billions expended on nursing homes alone. Thus, there is little established fact to enlighten the constant discussions about all of these observations: nursing homes cost too much; there are not enough home care agencies to meet the need; and, even though everyone is now enthusiastic about family members supplying the care (with the possible exception of some family members, and sometimes the patient), many elderly people do not have such an asset: with the high probability of widowhood among them, many live alone and have no relative to serve in the capacity of carer.

'A Comparative View' in the title of this book is intended to signal that various countries have so far responded differently to the needs for long-term care within their elderly populations. There is meant to be an implication that it is worthwhile to look at what other nations are doing. The view of these differences in care

put forward here is that there is more to any nation's provisions for long-term care than appears on the surface: we need to look at them in some depth, both at home and abroad.

These considerations lead to the chief point of the book: finding satisfactory solutions to meet the needs for long-term care is such a large and serious problem that each nation must give it very careful thought. We need to take care not to get stuck with the makeshift solutions which resulted when we threw together something to 'get through today and get by till tomorrow'. None of these is to be accepted uncritically as a starting point, and it is of primary importance that we find the right starting point. Gerontologists from 16 countries who prepared a report entitled Aging 2000 - A Challenge for Society to be used for the 1982 World Assembly on Aging made this statement about the current situation, worldwide:

The report suggests that most countries have not found adequate solutions to the problems caused by the aging of their populations, indeed many do not even have the beginning of adequate social policies for preventing or coping with such problems. There appears to be an urgent need for more information about the elderly and aging societies, as a basis for sound policies and programs. (The Sandoz Institute Study, p. 13)

The fundamental needs and rights, along with the prospects for comfort and recovery of the elderly individual who is disabled and needing the care must be appreciated: that individual is ultimately what it is all about. The interests of his or her family — especially if one or more are to be the care-givers - must be given equally careful consideration. What kinds of care, skills and supports are needed to help the patient regain the ability to function independently must be identified. These are the first questions to address; not, 'How can we cut the costs of nursing home care?' nor, 'What kinds of community services do we have available?' nor, 'What kinds of care are reimbursed by public and private insurance?'. Matters of service delivery and financing must not lead; they must follow after consideration of human rights, national values and ethical standards have shown us the directions we wish to take. We cannot decide upon the qualities needed by the service-delivery personnel nor whether the price is right until we know what it is we want.

4 Long-term Care in Contemporary Western Society

It is certain that many persons upon reading the foregoing paragraph will have thrown up their hands at visions of the expensive, impossible things which that would lead us into. However, for our own sakes as individuals as well as for the public good, it is advisable not to make money the prime consideration at the outset of this inquiry. The experience of disabled elderly persons in modern society is a reality quite likely to confront every one of us as individuals, not once but several times. First it will be through great-grandparents and grandparents; then, with parents and parents-in-law, uncles, aunts and older friends - finally, our own generation, including ourselves; and we may live to see our own children grow old. Some nations are beginning to see two generations beyond retirement. No one needs to have a very broad social conscience to feel some real concern over the issues of aging policy, though in fact many people develop quite a social conscience in the process of facing these issues.

To look at what other nations are doing in the matter of longterm care is a step toward taking the kind of careful approach and broad perspective needed by any one country as it hunts for and decides upon the solutions it wants to live with.

Theoretical Framework for the Investigation

Taking a close and careful look at the responses which nations are making to the long-term care needs of their very elderly people means that we must look at more than the surface features of institutions and programs. I suggest that it is worthwhile to think of layers beneath, consisting of attitudes, beliefs and values on the social as well as the personal level, brought into play, evoked, by the responses a society makes when people are in need of care. The contents of these layers vary from nation to nation, and any one country needs to look at others to have standards of comparison for evaluating what is found on home ground. At least three of these layers can be distinguished. The description of what the layers are purported to contain makes it clear that they are as much a part of the effect of any program upon elderly lives as money and services.

First, let us be clear that on the surface of our metaphorical sphere are the services, goods, treatments, institutions, information, human interaction and all that make up the visible caring acts and events. Chapters 2 through 6 contain descriptions of the various forms of care. There are not only differences, but many similarities from country to country: some form of home-help service exists in virtually every country in Europe and North America, and there are always nursing homes, whether or not they have just that name.

The layer which lies just beneath this surface is the nature of common beliefs about the proper role of government — both central and local — in relation to the population's needs and the national resources. When we look further into this layer in Chapter 7 we shall note that the country-to-country differences in these beliefs seem to vary like the departments of a bank: the concept in some resembles a beneficent trust officer and in others, a tough loan officer.

Another important layer lies just under this one, and it also reflects attitudes. It consists of the principle of inviolability of the individual against being shaken up, pushed around or overpowered by his or her society. Such rights as respect for privacy and freedom of speech and conscience are backed up by guarantees in constitutions, statutory provisions and legal decisions. In the ways they come to play in matters concerning older people, these vary quite substantially from country to country as we shall see in the material presented in Chapter 8.

Those two layers together constitute the beliefs about how the responsibility for resources to meet particular human needs is divided between the state and the individual; and, beliefs about the necessity for individual freedom to be protected, and to be limited. In matters of elderly care, the two layers become joined because those acting for the state with power over resources may not guard against extending this to power over the individual rights of those persons receiving resources.

Finally, when the outer surface and these layers are peeled away, we are at the center, the heart of the matter: the reactions of this generation of elderly individuals whose needs are to be met by the care. Chapter 9 contains some statements from the center. Ultimately the reason for it all, it seems very strange indeed that it is here that we know very little. A case exists for insisting that evidence must come from older people themselves, that others simply cannot speak for them with authority, and yet there is very little evidence about the experiences of today's older people in their own words. The bureaucracies have warehouses full of paper about regulations for elderly programs and statistics about their operation: think only of Social Security. The philosophers and social scientists have filled libraries on the matter of the proper role of government and, in recent years, about the welfare state. Lawyers and judges have filled other libraries with material about human rights and civil liberties. But much less has been put down for us by older people themselves about their own condition. We have heard enough to know that there are problems of respect, dignity and self esteem, but the evidence as yet is slim. All the more important that efforts be made to get down to this core of whatever program of care we might examine.

Data for the Study

The sources of information used for this study have consisted primarily of reports available in the English language and produced by groups who met together in international meetings and committees to examine the present and future condition of the elderly and recommend the programs needed for older people. The following are prominent examples: reports prepared by the separate countries for the World Assembly on Aging, and the report of the Plan of Action accepted at the Assembly itself in August, 1982. References to that Plan are made as 'WAA'. Reports have been published since then by the International Federation on Aging and the United Nations. Aging 2000 - A Challenge for Society (Selby and Schechter, 1979), is a compilation of survey responses from a small working group of experts from 16 countries about problems of the elderly, carried out by the Sandoz Institute for Health and Socio-economic Studies and the United Nations Centre for Social Development and Human Affairs. This report is referred to throughout as 'The Sandoz Institute Study'. Various reports from the European Economic Community on both aging and poverty in European countries have been helpful, one of them cited extensively as CLEIRPPA (Collot et al., 1982). Reports on aging have also come from the Office for Europe of the World Health Organization. Materials from Britain and West Germany (referred to as UK and FRG, respectively) predominate, but frequent reference is made to Scandinavia and to other countries referred to in the international reports. The Final Report of the White House Conference on Aging held in 1981 has been drawn upon frequently for information about the United States.

Some materials from a particular country have been cited frequently because of their relevance to one or another of the layers which have been identified in the previous section. One such source helpful in understanding the 'role of government' layer in the Federal Republic of Germany in Flamm's book, Social Welfare Services and Social Work in the Federal Republic of Germany. Alison Norman's book on Rights and Risk has been used extensively for material addressing the situation in the United Kingdom regarding the layer representing human rights' protection as has the Goldberg and Connelly book (1982) for thorough descriptions of programs important for long-term care.

A book comparing elderly care in the United States with Scotland also included a careful and perceptive look at the role of government with respect to nursing home care in the two societies. This book, by anthropologist J.S. Kayser-Jones (1981) is entitled Old, Alone and Neglected: Care of the Aged in Scotland and the United States.

We have indicated earlier that the elderly must themselves inform us about the core of the matter, the experience of today's disabled older person who receives care, and that these sources (at least, published in the English language) are very few and far between. It is true that there are some organizations which truly seem to consist of old people and are run by old people as well as for old people; prominent here are the Gray Panthers of West Germany as well as the US, and in the latter country, the Older Women's League. Their newspapers and meetings appear to contain authentic statements of older people's claims and points of view, but they are not apt to contain as much about long-term care as about Social Security.

As for statements in their own words from individuals, a principal source is a tiny paperback from Britain: the words on the cover say: 'The Alienated: Growing Old Today, by Gladys Elder OAP'. (People outside Britain may need to be told that OAP means 'Old Age Pensioner'.) Another is from a resident of nursing homes in Australia and is entitled, 'This Bed My Centre' (Newton, 1979).

The few available materials of this kind consulted, though not quoted directly are mentioned herewith for the sake of the interested reader. Age Concern England has published Seabrook's compilation of individuals' statements entitled *The Way We Are*.

and there is journalist-emeritus Mary Stott's book entitled Ageing for Beginners. There are some American statements of this kind. with Maggie Kuhn (Hessel, ed., 1977) as always, out in front leading the pack. Carobeth Laird wrote Limbo (1979) as her memoir about the year she spent in a nursing home in the south-west United States. 'Not a tale of horror or of filth and overt cruelty', it is an account of her own day to day experiences and those of the others there with her in what she described as a 'dehumanizing atmosphere' (p. 1). Another book which should be included among these is by Eva Salber, herself retired and a doctor, wellacquainted through her research with many poor elderly persons in a rural area in the southern United States. Dr Salber performed the Herculean tasks of making several visits to each of more than a score of rural residents, taking along her tape recorder to have a verbatim record of the interviews, and then she edited the transcriptions to preserve the original words and thoughts of the speakers.

Printed materials have been supplemented by opportunities to converse with many experts in gerontology and people working in services for elderly people in Great Britain and West Germany, and by correspondence with officials in the Scandinavian countries and international organizations.

It is evident that this study includes very little systematically gathered quantitative data and little presentation of such data from sources who have collected and reported them. There has not been an attempt to include all of the established texts in the references. The reader therefore needs and deserves an explanation of the approach taken by this book to the literature on the subject of long-term care. It is an approach which seems to the author to be suitable given the confusions and dismay in almost all countries over the very unadvanced state of the art. Each nation must at this stage direct some of its attention away from the care-giving activities and the financial problems connected with the present system for long-term care and look toward establishing the goals it wishes to select and attempt to achieve in the years ahead.

The theoretical framework and the descriptive material presented in the pages to follow are designed 'to serve as a guide to further reading rather than as an encyclopedic reference'. That quotation comes from a book edited by Mishler et al. (1981) entitled Social Contexts of Health, Illness and Patient Care. In their statement which follows, the authors express exactly the present

writer's view of what the reader will find, and not find, in this book:

It is selective rather than comprehensive in coverage ... This selective approach reflects, as well, our view that the book should serve as a guide to further reading rather than as an encyclopedic reference. We neither intend nor assume that this is the 'last' book that professionals and students in the health care field may read on these topics. Rather, we hope it will serve as a beginning for the development of their own thought, as a stimulus to further reading and exploration, and as a basis for reflection on their own practice. (p. ix)

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