

Reviews

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Jabeer Butt and Alex O'Neil, *'Let's Move On': Black and Minority Ethnic Older People's Views on Research Findings*, Joseph Rowntree Foundation, York, 2004, 23 pp., pbk £11.95, ISBN 1 85935 175 1.

Although there is a high proportion of younger people in Britain's black and minority ethnic (BME) communities, the older population is growing. The authors of this report identify a six-fold increase in the number of older people from BME communities over the last two decades: it is therefore important to improve our understanding of their specific needs and experiences. The authors acknowledge a plethora of studies in the field and the report aims to assess their relevance by bringing together a comprehensive range of research findings on BME elders, including those relating to household composition, health and social care needs, and poverty and housing and service uptake, and, in a series of consultations with older people, to discuss the relevance of the findings and to suggest issues that need to be addressed.

In total, 105 older people from various BME communities were involved in three meetings held in London, Bristol and Leeds. Participants were recruited mainly through community organisations and some unidentified 'statutory providers'. The authors express their surprise that 'many of the older people in the different areas were already familiar with the experience of being researched over many years' (p. 1). However, given the mode of contacting individuals (primarily through community groups), it is hardly surprising that many had experience of being researched. Community organisations are the easiest way of targeting individuals from different sections of the community and offer a quick and effective method of recruitment. But this method is subject to a sampling bias in that those who do not use services are unlikely to have their views heard. On a pessimistic note, many of the participants, drawing on their experience of being researched, felt that, despite years of research, not only had the research agenda remained unchanged, with the same questions being asked, but that research had not led to any substantial change.

The consultations found research findings reflective of the personal experiences of the participants. This may be explained by the fact that similar cohorts are repeatedly targeted, as for example the community organisation users. Perhaps different needs would have been identified had they reached older people who were not such users. The report makes the point that older people wanted more information and access to services. These were the opinions of those already accessing some level of services, suggesting that for those who have no access to any services the need to reach and inform is greater still. There were differences in opinion as to who was best placed to provide services to BME communities. Whilst it was agreed that community organisations had provided the best services so far, some felt it was the duty of mainstream providers to respond to the need

and were only too aware of the dependency of community organisations on transient funding programmes.

The report raises a number of important points for consideration including worries about the continuing prevalence of stereotypes, such as the extended nurturing family. Participants felt it was time social services acknowledged changing family structures and made clear what provision would be in place. Respondents also wanted more information on finances; many were aggrieved that they had not had access to support and information on pensions whilst in employment and were now having to rely on state pensions alone. The consultations also confirmed that BME groups were likely to experience the effects of ageing earlier and required care at a younger age, often provided from within the family. Whilst this has been documented in previous studies it seems that services showed little understanding of these issues.

The authors suggest that on top of the issues identified, BME elders also experience the same issues as all older people. This point can be extended to cover the fact that many of the problems identified as specific to the BME older people are relevant across the BME communities in younger generations as well. This was particularly the case for poverty, housing, health and social care, language barriers, lack of access to services and lack of recognition of religious and cultural needs. The report rightly asserts that these are not new issues and that it is time that they were dealt with. The report makes interesting reading and provides a concise summary of research findings on BME elders which will be a useful reference to anyone working in the area. It reminds us of the need to involve BME elders at all stages of research and projects, and to target research to meet the needs of older people.

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Katy Gardner, *Age, Narrative and Migration: The Life Course and Life Histories of Bengali Elders in London*, Berg, Oxford, 2002, 254 pp., hbk £45.00, ISBN 1 85973 313 1.

There is a growing focus in the migration literature on the phenomenon of transnationalism which has been described by Basch, Schiller and Blanc-Szanton (1994: 6) as, 'The process by which immigrants forge and sustain multi-stranded social relations that link together their societies of origin and settlement'. In this book, Gardner explores narratives of age and migration within that context. The book focuses on Bangladeshis who attend a day centre for older people in Tower Hamlets. Gardner examines shifting notions of identity and belonging and the changing constructions of *desh-bidesh* (home and abroad) over the lifecourse. Informants were drawn from 23 households all of which had a family member who used the day centre. Eleven men and 16 women were interviewed. Most of the male respondents suffered ill health, whilst the majority of the female users of the centre attended in their capacity as carers.

The author rightly points out that, in studying ageing amongst Bangladeshis, chronological age is of little significance: age is not measured in years amassed but rather in terms of social or physical events. Gardner lists the ways in which one can reach the status of being a *Murubbi*, a respected elder, a position which has no definitive age but is marked more so by life achievements, as for example going on *Hajj*, or the birth of grandchildren, and is tied to religiosity.

Migration is characterised by a series of costs and benefits, and these are especially relevant for the older members of the Bangladeshi community. Living in Britain has meant that many family ideals have undergone change. Some have been enforced by council regulations, with its housing targeted at nuclear rather than extended families, but others simply by being a part of change within families where children are less likely to take on traditional care roles. Respondents often bemoaned the fact that, had they lived in Bangladesh, they would have received the unquestioning care and respect that they had right to as a *Murubbi*. Amongst the benefits, access to health and social services were the most pertinent.

Gardner explores the changing constructions of identity among this group and makes the important point that fluid identities are not the sole preserve of recent generations of migrants, albeit their greater exposure and active engagement with the host community. She describes the ways in which older people's identities are subject to just as much contestation as younger people's. Men's narratives of their younger days relied on metaphors of work and money, and stressed their efforts in providing for their family (in both the UK and Bangladesh). These were important markers of identity and success in their youth. With age, it was more important to be identified as pious and devout, and many took on that identity by dressing in traditional attire including prayer cap, and by attending the mosque regularly and engaging in religious discussions.

Gardner's detailed exploration of identity in the narratives highlights the crucial role of gender in migration both as experienced and narrated. Men's narratives reflected their migration purposes, primarily surrounding work, but many of the women had arrived with the sole purpose of family reunification or to care for their spouses. Consequently, much of their narrative was constructed around care and nurturing roles. For the women, one of the costs of migration has been that in modern British society there is less certainty that they will receive the same care from their daughters-in-law as they had so fervently provided to their mothers-in-law in their youth.

The narratives provide a fascinating insight into the changing identities and roles that individuals adopt. Gardner makes the interesting and highly relevant point that 'Women carers are far from passive in Britain; indeed it is their children and husbands who tend to be dependent upon them rather than vice versa' (p. 190), which strongly contradicts commonly held stereotypes about Bangladeshi women. Thus there is a transition from the man to woman as the person depended on until, in late life, roles are transformed once again and it becomes the turn of the children to be depended upon by both parents for material, physical and emotional support.

The book highlights important facets of ageing in London's Bangladeshi community and provides a valuable insight into the considerable personal costs of

migration over the lifecourse, namely, poverty, loss of status and displacement, and contrasts these with the benefits of (a degree of) economic certainty provided by the state through health care and a better life for their children. *Age, Narrative and Migration* provides a perspective on older members of the Bangladeshi community and will be highly relevant to practitioners working with older Bangladeshis as well as to those interested in oral histories and trans-national migration.

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Kai Leichsenring and Andy M. Alaszewski (eds), *Providing Integrated Health and Social Care for Older Persons: A European Overview of Issues at Stake*, Ashgate, Aldershot, Hampshire, 2004, 499 pp., pbk £27.50, ISBN 0 7546 4196 1.

This book reports results from the first phase of a European Union (EU) Fifth Framework research project that compared and evaluated different models of integrated health and social care provision for older people. National reports are presented from Austria, Denmark, Finland, France, Germany, Greece, Italy, the Netherlands and the United Kingdom. These are preceded by two chapters that present a general overview and deal with theoretical and conceptual issues. Unfortunately there is no index.

The editors give no theoretical or policy rationale for the choice of national case studies, although they clearly span Europe's different welfare regimes and include some countries that are relatively neglected in the literature. Setting the scene in Chapter 1, Karl Leichsenring makes the odd comment that 'health care expenditure is decreasing across Europe' (p. 11), which is contradicted by the figures in an accompanying table. The key issue, of course, is whether spending is keeping up with the growth of age-associated disease and disability, as well as rising expectations and the impact of social and other demographic trends. Absolutely central to this is the current and future role of family members, and the mix of public and private spending, topics also explored in my and colleagues' cross-national European study of older people's care (Blackman, Brodhurst and Convery 2001). Indeed, it was interesting to compare this book's findings with our own work, which covers very similar ground (but is not cited).

Inevitably, much space in a book that compares different national approaches has to be devoted to the clarification of terms. This is especially the case with care, as the position of social care in relation to health care is very different from

country to country, from being an aspect of universal public care provision, with separate but related services, to a residual role with social care being a family responsibility even at high levels of dependency. Leichsenring's first chapter develops an interesting classification of integrated care across the nine countries using concepts such as degrees of seamlessness, whole system approach, person-centred approach, integration with housing, and admission prevention and guidance. Other important themes are the extent of fragmentation in both provision and assessment, and the nature of partnership working, not just between social and health care services but also with family members. The rising number of non-family 'informal' carers, often immigrants from outside the EU in some countries, is touched on – and is an aspect of the wider critical matter of where the future supply of carers will come from if pay and conditions remain relatively unattractive, and how they will be trained and regulated. In a field of apparently growing complexity, Leichsenring suggests that the new public management may be introducing a common language into integrated care provision.

Chapter 2 turns directly to theory and concepts, and begins with a consideration of earlier 'Fordist' types of welfare organisation, marked by division and problems such as cost shunting, to current 'post-Fordist' approaches based on seamlessness and flexibility. The authors consider the extent of legal obligation on family members to provide care, and the social trends that are attenuating this source of care provision. After considering approaches to integration from structural integration to various types of co-ordination such as information sharing and team decision-making, key concepts are introduced based on the approaches identified from the country reports. In summary, these are achieving continuity of care, a needs-led focus, harm minimisation, person-centredness, social inclusion, and improved wellbeing in old age.

The national reports have a common structure, starting with an introduction, then describing the legal and structural framework, including financing and types of provision, and finally describing model ways of working, followed by a conclusion. Some very interesting initiatives are described in these reports, although many advance generalities rather than clearly identified key points of use to a service planner. A common theme is trying to overcome divisions between health and social care in the different contexts of each country, while seeking to contain costs, especially the use of hospitalisation. The major challenge of maintaining older people with dementia in their own homes is addressed in some of the reports, especially those on Denmark and Finland.

There is a great deal of useful material in this book for students, researchers and practitioners looking for comparative lessons. It is, however, a heavy read and, to be a useful handbook, needed a clearer structure (and an index). Nor does the collection achieve its aim of identifying the most successful and long-lasting innovations in modes of organisation, no doubt partly because many of these are so recent and evaluations are lacking, but also because of the problems of transferring models across different national contexts. Perhaps the next phase of this project will be able to address these issues; if so, we are likely to see some very interesting outputs.

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Albert Jewell (ed.), *Ageing, Spirituality and Well-being*, Jessica Kingsley, London and New York, 2004, 224 pp., pbk £17.95, ISBN 1 84310 167 X.

This collection of 14 essays, the majority written by contributors coming from theological and religious studies, arose from the Second International Conference on Ageing, Spirituality and Well-being held at the University of Durham, England, in 2002. The main purpose of this book is to promote insight into the conceptualisation of, and ways of dealing with, the specific spiritual needs of older people in the context of qualitatively good care and support. The contributors stress that the wellbeing of people should not be related to physical health only – something which evidence-based practice may promote. The themes of ageing, spirituality and wellbeing have been approached from different perspectives. Although it is argued that spirituality should be seen as an integral part of gerontology, these three aspects will be distinguished from one another for the purpose of analysis. It will be clear that not all the contributions can receive the attention they deserve in a short review.

First, the gerontological aspect is represented by, amongst others, the perspectives of creative ageing (Goldsmith), successful ageing (Mowat) and human flourishing (King). The main contours of creative ageing imply the issues of temporality (a time of change), health, scaling down with regard to accommodation, recognition of what has been achieved during life, memories (whether they are beautiful, painful or lost) and the need to reconcile with personal history (p. 39). Mowat offers a very interesting analysis of the cultural and philosophical context of the emergence of spirituality related to sociological aspects influencing gerontological thought. She links the concepts of successful ageing and spiritual journey and concludes that the notions of dependence and independence in gerontology should be reformulated as interdependence and co-dependence (p. 56). King shows that ageing can also be seen as human flourishing. She links this term to the quality of life, meaningful contacts with others, the entire ecosystem and strength (p. 134). As she argues, spirituality can still develop at a time when physical and mental powers decline.

Second, 'spirituality' is identified as a broader concept than 'religion' by most of the main contributors. They argue that while many people express their spirituality within the framework of a particular religion (also related to the search for meaning and religion), it is important to see it as a universal term, which includes approaches or contexts other than that of Christianity. Spirituality

is to be seen as the deepest dimension of all life (Dunn). No common ground, however, exists as far as agreement on or consensus about a definition. On the one hand, it is possible for Hudson to relate spirituality to the Christian doctrine of the Trinity (Barnard even offers a framework for an agnostic theology: p. 180 *ff.*), while, on the other, Mohan explicates in a very informative article the implications of Indian perspectives on spirituality for Western thought. Others relate spirituality to development and growth (King) or to a journey towards wholeness (Mowat).

Third, the only scholars who work out the wellbeing theme explicitly are Jewell and Mohan. Jewell identifies love, hope, joy, creativity and peace (p. 23) as parameters of the dynamic concept 'spiritual wellbeing'. Mohan, by means of cultural analysis, concludes that the eastern understanding of wellbeing (exercising control over the senses, maintenance of balance and moderation in life) might enrich western understanding of wellbeing (satisfying of needs, avoidance of stress and frustration and control of the environment) (p. 173).

Fourth, four scholars look into the relevance of the topic for situations in which people need care. Wilcock explores different ways of helping people suffering from a stroke. Time, respect, a sound view of one's own helplessness, equanimity, acknowledgment of dread, facing danger and humour, are seen as instruments for the helper's toolbox (pp. 64–71). Dunn relates the tools for caring, in the case of people with dementia, to narrative gerontology and the improvement of communication by means of validation therapy (listening with empathy) (p. 155), and Killick identifies emotion as an essential element of the spiritual dimension in dementia (p. 149). Mohan closes ranks by arguing that, when looking into their implications for therapy, religion and spirituality can augment and assist therapy by providing a basis for reframing (p. 179).

By means of critical evaluation, it can be said that despite the distinction between spirituality and religion, the majority of the authors is inclined to equate spirituality with the Christian religion. Jewell even puts Christian spirituality on a different level from the spirituality of other faith traditions (p. 23). Furthermore, at times concepts like 'the strength of spiritual belief' (p. 108) and 'high levels of faith' (p. 168) are used normatively but uncritically. This calls for continuous reflection in order to catch the nuances in meaning.

Contrary to the positive evaluation of variety in the definition of spirituality (Jewell, p. 14), it is worth considering a broader philosophical-anthropological definition of the concept, for example, when applied to health care contexts (against the background of the position of the church in society) or when doing empirical research. It is also important, for future reference, to distinguish between the responsibilities of professionals working in the field of health care or with elderly people. This is because the professional domain of the partaking disciplines must be clear as far as spirituality and religion are concerned, but also because the curricula of initial or supplementary education in this field have yet to be established. To close, suitable modes for research in the field of spirituality have to be considered and implemented. This book offers a valuable contribution to the current debate about the relevance of spirituality for gerontological theory. It is recommended for scholars and practitioners in different disciplines and contexts, but foremost for gerontologists, sociologists, (social) psychologists,

chaplains, theologians and researchers into religion as well as workers in health care and medicine.

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Raphael Wittenberg, Adelina Comas-Herrera, Linda Pickard and Ruth Hancock, *Future Demand for Long-term Care in the UK: A Summary of Projections of Long-term Care Finance for Older People to 2051*, Joseph Rowntree Foundation, York, 2004, 14 pp., pbk £9.95, ISBN 1 85935 203 0.

Caroline Glendinning, Bleddyn Davies, Linda Pickard and Adelina Comas-Herrera, *Funding Long-term Care for Older People: Lessons from Other Countries*, Joseph Rowntree Foundation, York, 2004, 35 pp., pbk £11.95, ISBN 1 85935 205 7.

How best to finance the long-term care of older people is a problem for most developed countries, and a political ‘hot potato’ in the United Kingdom. In 1997, the British government set up a Royal Commission to ‘examine the short and long term options for a sustainable system of funding ... taking account of the number of people likely to require various kinds of long-term care both in the present and through the first half of the next century’ (Royal Warrant and Terms of Reference). The Commission undertook a detailed analysis of the current position and, using a model developed by the Personal Social Services Research Unit (PSSRU) of the London School of Economics, calculated projections. Noting the inadequacy of the available data, however, it stressed that its projections were not predictions or forecasts (and they were limited to the next 20 years). Alongside its main recommendation that the costs of long-term care should be split between living costs, housing costs and personal care costs, with the latter being available after assessment, according to need and paid for from general taxation (free at the point of use), it also recommended the establishment of a National Care Commission which would be responsible for making and publishing projections about the overall cost of long-term care at least every five years. The government rejected both of these recommendations, and five years later a Statement by the Royal Commissioners (Sutherland *et al.* 2003) noted that ‘there is still a live debate. ... Little has been resolved. Governments in most of the United Kingdom decline to act. There is [still] widespread concern’ (p. 2).

The publication of these two papers, both commissioned by the Joseph Rowntree Foundation, is therefore timely, but their juxtaposition is also significant. The UK has clearly not solved its problem, and there are lessons to be learned from the experience of other countries. The first paper, *Future Demand for Long-term Care in the UK: A Summary of Projections of Long-term Care Finance for Older People to 2051*, is written by the same team that undertook the original work for the Royal Commission. It is part of the review of long-term care policy

undertaken by the Institute for Public Policy Research (IPPR) to explore alternative funding structures for long-term care (Brooks, Regan and Robinson 2002), which, significantly, came to exactly the same conclusion as the Royal Commission that both nursing and personal care should be funded from general taxation and provided free-of-charge at the point of use. The model used by the present authors is a refinement of the model used in 1999, and the population projections are based on the most recent data, but otherwise there are no changes. This paper contains only the summary data, but the full methodology is available in Wittenberg *et al.* (2002).

The models use a set of central base-case projections that act as a reference case against which the effect of changes in assumptions can be investigated to create 'low base' and 'high base' projections. Under the central base-case, which takes account of expected demographic changes but assumes no change in dependency rates, patterns of care or funding systems, the numbers of dependent people are expected to grow to approximately 6.4 million in 2051 (an increase of 113 per cent) and long-term care expenditure to £53.9 billion (an increase of 317 per cent). Since the economy is also forecast to expand, the proportion of the GDP represented by these figures would increase from about 1.4 to 1.8 per cent, and the share of long-term care costs met publicly would actually fall from 68 per cent in 2000 to 66 per cent in 2051. The introduction of free personal care in addition to free nursing care would have increased public expenditure on long-term care in 2000 from approximately £8.8 billion to approximately £10.3 billion.

There is no reason to challenge the calculations, but there is every reason to challenge some of the paper's assumptions and conclusions. For example, there is no evidence to support the view, which was a key argument of the Royal Commission dissenters, that free personal care would encourage more older people and their children to use residential care (since provision would depend on assessment of need); or that care costs would increase because of higher expectations of users (since the raised expectations would more likely be in hotel standards than in the amount of personal care). Assumptions about residential care use take no account of developments in assisted-living housing or information technology. The demographic projections take no account of risks such as Variant Creutzfeldt-Jakob disease (vCJD) and changes in mortality due to current lifestyles. The conclusion that free personal care would benefit only the rich does not take into account that, since the capital limit is only £20,000, every individual who owns their own home, however modest, is defined as 'rich'. Most seriously, the cost comparisons do not include the enormous transaction costs required by the present system of distinguishing between nursing care and personal care, and assessing eligibility.

Since it is clear that 'affordability' is not about money but about political priorities, the companion paper, *Funding Long-term Care for Older People: Lessons from Other Countries*, is especially interesting. It examines the arrangements for funding long-term care in Australia, Austria, Denmark, France, Germany, Japan, The Netherlands and Scotland. Its criteria for comparison are equity, how far they offer dignity, choice and independence for older people, their efficiency and effectiveness, and their economic and political sustainability. No country has the

whole answer, but there are some common factors that seem to work. None of the countries examined relies on private savings as the basis for funding long-term care. Denmark and Australia fund long-term care provision from general taxation, Germany and Netherlands from compulsory social insurance, and Japan from a mixture of both. None limits benefits to those with low incomes. Austria, Germany, Denmark, Japan and Netherlands have funding regimes that provide benefits to all eligible individuals regardless of income. Denmark and Australia have achieved major resource shifts away from residential provision to community-based services; in Denmark, all people aged over 75 years receive two visits each year by a community nurse to identify risks and offer health-promotion advice.

The authors avoid recommendations; instead they identify 'Issues for debate in the UK', expressed in the form of questions. In particular, they point to the fundamental question of whether public support for long-term care needs is seen as a universal responsibility that embodies and reflects fundamental principles of social solidarity and social justice, or whether public support should be reserved for poorer older people: other countries appear to embody principles of universality in responding to the risks of long-term care. Elements of other countries' approaches to funding long-term care – many not highly costly or difficult to implement – could increase the fairness, effectiveness, efficiency and sustainability of the UK system. The experiences of other countries show that radical system-wide transformations in arrangements for funding long-term care can be accomplished. The present system in the UK is not sustainable quite simply because it is unfair, and is recognised as unfair by the general public. The key to the long-term sustainability of the future funding of long-term care in the UK requires a great deal more political honesty than has been shown by the present government, and, as the authors of this paper suggest, full and open political, economic, social and ethical debates.

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Judith L. Howe (ed.), *Older People and their Caregivers across the Spectrum of Care*, Haworth, New York, 2003, 149 pp., pbk \$19.95, ISBN 0 7890 2284 2.

This book has been co-published simultaneously as the *Journal of Gerontological Social Work*, volume 40 (1/2). The target audience appears to be social workers but there is much to recommend it to health care practitioners and policy makers. It provides a challenging look at the policy framework for care-giving in the United States. The book appears to achieve its purpose, to address the latest research and models of care for an ageing population. It remains, however, a collection of essays which lacks the cohesion one expects in an edited book. Although the policy context is American, the book has resonance for practitioners in Britain, especially the case studies which focus on good practice. The opening contribution by Barbara Berkman and colleagues revisits models of social work assessment. The remainder of the book is an eclectic set of case studies which address the wide-ranging role of carers and care-giver support strategies that foster empowerment both for care-givers and the older people they work with.

Two chapters provide interesting examples of partnership working. That by Susan Kornblatt, Sabrina Cheng and Susana Chan describes the *On Lok Program of All-inclusive Care of the Elderly* (PACE). *On Lok* is Chinese for 'peaceful and happy abode'. It provides an example of a comprehensive model of care based on the concept of 'a one-stop-shop' in which members joining the programme receive all care from acute to long-term care. Once they have joined there is no additional cost for care services. The chapter by Judy Dobrof and colleagues discusses the *Caregivers and Professionals Partnership* (CAPP) programme. This is designed to support care-givers of adults and enhance the responsiveness of the Mount Sinai Medical Centre in New York City. The programme has developed, following a needs assessment, to include a resource centre which co-ordinates centralised information and support services for both English and Spanish-speaking communities, and an education programme aimed at staff and care-givers. It again provides an interesting example of inclusive working and meeting the needs of a diverse community.

The chapter by Charles Emlet and colleagues focuses on some of the challenges for older people living with HIV/AIDS and the support they may need from health and social care practitioners. The authors provide demographic data on the increase of the disease in those aged 50 years and older. They suggest the risk is increased with the rising use of *Viagra* amongst men without the equally important messages of HIV risk. The purpose of the chapter seems to be to alert social workers to this increasingly vulnerable group of older people. They suggest that professionals fail to perceive older people being at risk from HIV/AIDS, and assessment and health promotion in this area is therefore poor.

Beverly Koerin and Marcia Harrigan have written a timely chapter on the experiences of long-distance care-givers, which are defined as those living more than 50 miles from the person they care for. The role of care-giver has many stresses and it is suggested that those living close by are more likely to suffer from

physical exhaustion, while long-distance care-givers are more likely to suffer psychological stress. The authors suggest that we should see long-distance care-givers as an important part of the care network and not discount them. The chapter highlights the limitations in research in this area as the number of long-distance care-givers increases. Patricia Brownell and Agata Wolden explore the question of whether elder abuse can be seen to be caused by care-giver stress or abuser impairment and, therefore, what is the most effective intervention model. They discuss intervention strategies as fitting either a social service or a criminal justice model and evaluate which model has the best outcome when intervening in elder abuse cases. The results suggest that the outcome differs little whichever model is used, although the research did find that for cases of neglect the elder service programme was the most effective and for financial abuse the crime victim's board programme produced the best outcomes.

Parker and colleagues discuss a very interesting project which talks about the adoption and application of a lifecourse model for care-giver support that is currently being used in the US military. It is based on a lifecourse assessment and intervention programme that works with middle-aged women and men to plan proactively for their care-giving roles. A lifecourse perspective emphasises 'the ways in which people's location in the social system, the historical period in which they live, and their unique personal biography shape their experience' (p. 105). It provides a valuable framework for considering the cultural and demographic changes that influence family and work. Researchers are attempting to evaluate its effectiveness with a group of senior female officers to see how these events can be supported by organisational policies and health-promotion programmes. The outcomes from the evaluation should help in the development of strategies which will impact positively on 'retention, performance, and personal and family health' (pp. 117–8). This model could usefully be adapted in Britain as concerns about the balance between work and family commitments are debated.

Lisa M. Goldman discusses the interesting and valuable *Northport Veterans Administration Friendly Companion Program*, which provides a different perspective on care-giving, that of the volunteer. The programme aims to support lonely and isolated older people in nursing care units by introducing them to volunteers who become friendly visiting companions. This scheme was established by social workers in 1999 to enhance the quality of life and social engagement of older people. Outcomes from the project suggest that it offers the opportunity for both volunteers and older people to form meaningful relationships, which in turn, benefit the clinical outcomes and wellbeing of the older residents who engage in the programme. Letha Chadiha and colleagues provide a fascinating conclusion to the book by including the voices of three African-American women talking about their experiences of caring for an older family member. These vignettes provide a good summary for the book, illustrating the diversity and complexity of care-giving and the challenges this poses for the assessment of needs.

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Cathy Stein Greenblat, *Alive with Alzheimer's*, University of Chicago Press, Chicago, 2004, 116 pp., 85 halftones, hbk \$27.50, £19.50, ISBN 0 226 30658 5.

Cathy Stein Greenblat, Professor Emerita at Rutgers University, is both a sociologist and a documentary photographer whose preferred research methods are ethnography and visual sociology. The latter incorporates visual imagery into the research process as a means of presenting findings in more effective ways than conventional writing permits. This book represents the outcomes of many weeks of participant observation, conversations with residents, staff, and family members in Silverado, a senior living facility for people with dementia in Escondido, California. This is one of 12 such facilities in California, Texas and Utah.

In this optimistic and beautiful book, Greenblat uses her considerable literary and photographic talents to present a picture of people who are not just living with dementia but are actually alive, and mostly lively, despite their disabling condition. The book testifies to the intrinsic courage and resilience of the human spirit under threat. It also represents one woman's efforts to understand dementia and face her own inevitable ageing which, given her family history, is likely to include dementia, for as she says: 'My chances of avoiding this fate are not good. A field work project at Silverado, I felt, might help me face my own fears' (p. 3). The photographs are augmented by commentary obtained from photo elicitation interviews with staff and family members. This technique encourages people to talk about their thoughts and feelings as they view large numbers of photographs. Few of the residents were interviewed in the conventional sense because of their advanced dementia but many were capable of warm exchanges, vividly captured in speech and photographs.

The author identifies the key elements of the ethos and care created at Silverado which in many ways resembles another group of American residential care facilities using the Eden approach (Thomas 1996). The major characteristics of both include: enriched sensory environments; respect and affection demonstrated in warm close staff-resident relationships; purposeful individual and group activities; imaginative recreation, stimulation, and occupation; music used widely to provide stimulation, comfort, security and communication. Pets, plants, small children and close involvement with relatives, neighbours and local communities are also essential characteristics. Silverado includes hospice provision and aims to care for people throughout the entire course of their illness. Skilled nursing leadership and valuing and rewarding direct care staff are pivotal.

Generous resourcing is acknowledged and while residents represent an economically advantaged group, the secret of their continuing engagement in life, though eased by money, can only be adequately explained in ideological terms. To resort to old-fashioned terminology, it lies in the consistent application in practice of a horticultural rather than a warehousing model of care (Miller and Gwynne 1972). While offering excellent medical attention, Silverado rejects the medical model as attested in an Afterword written by Enid Rockwell, a geropsychiatrist who succinctly summarises current knowledge about the major

dementias, the diagnosis, care and treatment of people who contract them and types of residential care facilities available in the United States. The images and text illustrate the outcomes of the Silverado ideology. Six chapters explore themes of change, engagement, outings, music, and involvement with staff and family. A short focused bibliography includes references on Alzheimer's, visual sociology and organisations and services.

This book reminds me of *Openings*, a book of poems and photographs by Killick and Cordonnier (2000). Greenblat's book is more cerebral, perhaps more optimistic, often joyful, and equally revealing. The photographs in both publications give tantalising glimpses of people as they now are, captives to a condition not of their choosing and in many ways beyond their control. Both illustrate the essence of person-centred care, which means a person in relationship with another. These are people alive with dementia but people who are not alone. They are held in respectful, warm, affectionate, appreciative relationship with others, including for many, relationships with animals.

The Killick-Cordonnier book conveys more of the bleakness, dread and isolation of dementia yet also conveys humour, playfulness and peacefulness. The Greenblat book is restrained yet full of engagement – a day at the races, music making, parties – but it too illustrates the need to meet people where they are, not where we think they should be, or would like them to be. For it is in that oneness with each other that security is experienced and life-enhancing encounters that sustain both the person with dementia and the staff and family members who nurture them day by day become possible.

Greenblat succeeds in fulfilling her hope that by documenting life at Silverado, the larger personal and policy issues, the universals in dementia care, might be illuminated. She shows that although some characteristics are lost, people can still respond to loving attention. And she demonstrates that such loving attention is possible within an institutional setting. The research reported in this book is far removed from the highly-valued methodology of randomised controlled trials, but nevertheless presents a different kind of incontrovertible, hopeful evidence of effective dementia care. As such it demands attention from policy makers, managers of facilities, care staff, relatives and all concerned with dementia.

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DOI: 10.1017/S0144686X04283143

Stephen Curran and John Wattis (eds), *Practical Management of Dementia: A Multi-professional Approach*, Radcliffe Medical, Oxford, 2004, 237 pp., pbk £27.95, ISBN 1 85775 931 1.

Authenticity is easier to spot than to define, but in clinical disciplines it has something to do with practical wisdom, itself a combination of thoughtfulness and openness to experience. This guide is an example of such authenticity and, in a niche becoming crowded with worthy but sometimes dull works, it offers a broader view and deeper insights than many books aimed at practitioners. Its selling point is the range of contributors who have lots to say, particularly to a medical audience unfamiliar with contributions made to dementia care by nurses, occupational therapists, managers, psychologists, social workers, legal experts and philosophers. Every reader will encounter several new perspectives, I suspect. Mine were Roger Bullock's discussion of the role of old age psychiatry (which I thought I knew), and Ann McPherson's chapter on integrated services. The 'hands on' feel that they bring to the issues is strengthened by short case studies, and more of these would be helpful. Key learning points are included throughout the book, and for once they work without infantilising the reader.

The editors hold the collection together well, and have avoided the trap of presenting dementia as homogeneous, or simply divisible into a few subtypes. Complexity is expressed clearly, and the uncertainties and problems of recognising and responding to dementia are recognised (even if this means a few too many clichés of the 'challenging' variety). The medical dominates the book's layout, with pathology, differential diagnosis and epidemiology at the front and disability towards the back, so the multi-disciplinarity of it is clearly doctor-centred. Not surprisingly, then, the focus is more on the 'management' of dementia, as if it were diabetes or an MRSA infection, than on the 'wrap around' tailoring of responses to the disabling impact of cognitive decline that a social perspective might bring.

So be it, the medical model has its advantages and the medical profession has much to learn about dementia. Trainees in old-age medicine and psychiatry should get the book and read the second half – they should know the first. Community mental health nurses and Primary Care Trust managers will get most of what they need outside their own disciplines here, and the growing interest in ageing amongst psychologists will generate a readership that needs the overview this book brings.

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Julia Neuberger, *Caring for Dying People of Different Faiths*, Radcliffe Medical Press, Abingdon, Berkshire, 2004, 104 pp., pbk £19.95, ISBN 1 83775 945 1.

Ethnic and cultural diversity is a feature of British society and health professionals meet people from various cultural backgrounds in the course of their everyday work. The delivery of culturally-appropriate healthcare is fundamental to people's sense of feeling at ease with their carers. Nowhere is this more vital than in the field of end-of-life care. This book offers advice and information on practical and ethical issues involved in caring for dying people of different faiths. Its accessible writing style and uncomplicated approach to the subject make it an invaluable reference book to have at hand in the clinical environment. It outlines the cultures of Judaism, Christianity, Islam, Hinduism, Sikhism, Buddhism, African, Afro-Caribbean, Chinese and Japanese beliefs and customs. Recognising that many people have no specific religion or religious or cultural tradition, and that recent years have witnessed a rise in green (conservationist) and Humanist funerals, this expanded third edition features a new chapter on Humanism.

Aimed at healthcare professionals, particularly nurses in palliative care settings, this book reminds the reader that knowledge of the patient's religious and cultural background is a crucial aspect of care for people who are dying. Palliative care entails looking after the whole person, physically, emotionally and spiritually, hence this guide is an important tool which will assist the busy professional in meeting the individual needs of people from a variety of backgrounds. Educators, researchers and students who need a starting point from which to understand the fundamentals of differing faiths will also find this book a useful addition to their shelves. As Neuberger states, however, this book is just a beginning. It tries to set some of the boundaries and introduce philosophies, religions and ways of life which might be encountered. Readers requiring greater knowledge and depth of the issues raised are directed to titles in the bibliography.

To address the basics of faiths, and the diversity within them, each chapter follows a similar format which briefly outlines: historical background; the significance of religious and cultural symbols; food restrictions; rituals, beliefs and customs surrounding death; and last offices and bereavement. For example, information in respect of people of Muslim faith asserts that, after death, carers have to be aware that many Muslims are particular about who touches the body. Ideally, it should not be touched by non-Muslims, and here advice is offered on how to approach a situation where contact is necessary. Whilst the book's format might sound prescriptive, it encourages a non-judgmental approach and emphasis is placed on treating people as individuals by asking patients and their families about their requirements. Indeed, the importance of enquiring about individual needs is stressed throughout. Neuberger explains that no book can attempt to provide all the information which might be useful and, if approached with sensitivity, talking to patients and families can be a way of showing that staff care about the importance of customs and beliefs. She further comments that nurses should not underestimate how stressful dealing with dying patients and

their families can be, and that the whole process can become easier if the nurse knows something of their expectations.

A limitation of this review is that our personal experience is based in Christian culture. To assess the chapter about Christianity was more straightforward than the others. We found that our familiarity with the subject matter enabled weak points to be identified, which raises questions about how the other chapters might be perceived by those they represent. Nevertheless, this is a comprehensive book that achieves what it intends – it provides basic guidelines to assist health professionals in caring for dying people of different faiths. Neuberger acknowledges that all eventualities cannot be covered in encounters with different cultural and ethnic experience nor every question answered, but she suggests what the questions might be and guides the reader as to when they might occur. Certainly, this third edition of *Caring for Dying People of Different Faiths* offers important practical information and advice and represents a significant contribution to a limited body of literature available to health carers.

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Jan Reed, David Stanley and Charlotte Clark, *Health, Well-Being and Older People*, Policy, Bristol, 2004, 202 pp., pbk £19.99, ISBN 1 86134 421 X.

The tensions between the reality of practice, what older people want, and the aspiration to ensure that practice remains evidence-based is a challenge that the authors of *Health, Well-Being and Older People* readily acknowledge and debate in some depth in their introduction. At a time when user and consumer views and values are regarded as essential to policy and practice, these tensions are real and, as the authors argue, present a dilemma for those wishing to ensure that the needs and wishes of older people are reflected and addressed appropriately. Keen to draw upon their extensive experience of working with older people both in practice, research and policy initiatives, the authors were anxious that the views and concerns of older people would be the main contribution to and component of the book. As the authors explain, however, persuading a publisher of the importance of this was not easy and it took considerable negotiation and many years to produce this book. A second enduring challenge that the authors have addressed is the debate about treating older people as a distinct and different group and the effects that this may have on experience in later life. This debate will probably continue, for it would appear that making this distinction can bring both benefits and disadvantages to the ageing adult.

The format of the book is guided by the issues and concerns that have emerged from work that the authors have undertaken with older people. This work has involved research with older people in focus groups and interviews, involvement with older people in working groups established to address policy issues, and the

experience of working with older people in practice. The authors have extensive experience in all these areas, as reflected by their insightful writing. They draw on three key themes, personhood, empowerment and justice, to inform and shape the contents and approach of the book. Each chapter addresses an issue that has emerged as significant for older people. It is not that any of these areas is new; they have all been addressed in previous publications. What is unique is that they are brought together in one publication to show that these are important for older people. Issues covered include health, housing, sexuality, finance, safety and risk-taking, along with an extensive discussion about user involvement and satisfaction.

The underlying emphasis throughout the book is the simple idea, one that still seems difficult to achieve, that older people are adults and individuals with wishes and aspirations just like anyone else and a need to be actively involved in society and in roles where they are able to contribute. Intertwined in every chapter is a debate about what is important for older people in order to achieve a good quality of life: this focuses on the barriers that compromise older people's independence and attitudes about what it is believed older people want, services provided and the development of policy initiatives. Assumptions, for example, about downsizing housing, have guided policy initiatives that have not always reflected what older people want. Rather than promoting the design of facilities and services that will suit older people, it seems that society at times goes out of its way to be unhelpful with inappropriate housing. Likewise, when it comes to addressing issues about health, the emphasis by the Department of Health is on demonstrating improvements, particularly functional improvement, whilst for the older person the emphasis may be achieving a good quality of life. And again, older people may emphasise the value they place on continuity of care when receiving help and services, yet contemporary policy means that services are broken up between different agencies and funding schemes, so that rather than consistency, services are often disparate, involving multiple agencies and people. Furthermore, while the complexity of the pension and benefits systems can be a challenge to everyone, older people can be particularly disadvantaged by lack of information while retaining a need for personal control and pride.

While highlighting many of the challenges faced by older people, the book also includes positive initiatives that have been developed to overcome or address some of these challenges. This provides an uplifting edge and portrays some very rewarding aspects of growing older and the ways in which practice may be influenced. The authors provide a wealth of information that focuses very much on what is important for older people generally while emphasising the importance of diversity. Although the book leans more towards the theoretical than the practical, there is much to interest academics, researchers, policy makers and practitioners alike. Its focus should guide both academics and practitioners into ways of translating theory into more practical approaches to working with older people. This book is a very valuable read.

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Derrel Watkins (ed.), *Practical Theology for Aging*, Haworth Pastoral Press, New York, 2003, 225 pp., pbk \$24.95, ISBN 0 7890 2227 3.

The Christian religion is a universal phenomenon, but the theories and practices that surround Christianity are hugely diverse and shaped by context, culture and experience. So it is interesting to note that while the Christian religion continues to experience significant decline in Europe, it is still a significant force in both North and South America, as indeed in Africa. This edited collection of essays reflects the vibrancy and energy of church life in North America and its commitment to exploring what theologies might best help us to understand the nature of the ageing process and to respond pastorally to older people. The volume strengthens the Haworth Pastoral Press's innovative series of books in this field. This commitment to older people stands in sharp contrast to the present situation in British church life, where older people are largely marginalised or taken for granted.

There are 14 essays, written by educators and practitioners in the field of practical theology. This field covers many specialisations in the United States, such as specific disciplines of pastoral care, pastoral psychology and counselling, and the church's ministry and outreach to particular groups like older people. It is important to note that the lines between these ministries are often blurred and that there is no coherent theoretical foundation that supports the study of the field as a whole. Indeed these 'practical' disciplines depend more upon information derived from non-theological sources than from theology. Watkins hopes to redress this omission by providing essays which are theologically based and, from this base, to offer guidelines for practice.

The first two chapters honour a pioneer in the field of gerontology, Barbara Stancil, who worked hard to encourage churches to esteem the place of older people in congregations and especially in the understanding of the expression of sexuality and intimacy for older people. Chapters 3, 4 and 5 offer some of the basic theological concepts out of which a practical theology might be more thoroughly developed. They examine some of the ultimate questions that older people ask about the meaning and purpose of their lives, especially in relation to pain and suffering. There is a chapter on the biblical foundations for a practical theology of ageing, with particular emphasis on Alzheimer's disease. One of the writers develops a conceptual framework for including persons not generally considered in need of spiritual care. There are chapters on rehabilitation, healing and wholeness, education, preaching and worship. Questions of spiritual formation, human identity, creativity and fulfilment are also explored in the latter part of the book. The final chapter addresses the reality that the older generation can be easily overlooked by church and community planners, and offers a persuasive set of arguments for the inclusion of older people as a source of value and wisdom.

The editor is to be commended for drawing together a stimulating collection of essays which were all thought-provoking and helpful in relation to both theory and practice. The writing is (perhaps inevitably) uneven and the editor might have exercised some measure of influence over some of the expression of thought, repetition and inter-relationships between the essays. The volume lacks

a comprehensive bibliography and would have benefited from an index. Thinking about how these essays might be used, some pointers for further thought and reflection at the end of each of the chapters would have been helpful for students and practitioners alike.

A note of caution is worth articulating at this point. It might have been useful in this theological text to be honest about the ways in which religion might be destructive to human wellbeing. What are the legitimate objections to belief as it shapes an individual's self-image and sense of destiny, especially in old age? Is religion enabling of a fundamental and healthy self-love? Does religion help older people cope with diminishment, change and death? While there is plenty of research to suggest that religion can have a positive contributing influence on wellbeing, it might have been useful for further research to reflect upon a distinction between good religion and bad religion. Might we learn from older people themselves and their experiences of community, faith and pilgrimage, as we gain a greater sense of the limitations and possibilities of religion?

Nonetheless, the achievement of this book lies in its ability to stimulate the reader into further thought and action. For those of us who work in the field of the care of older people, these essays encourage us to consider our understanding of the spiritual and religious dimensions of ageing as key areas for growth and wholeness. Indeed, it may be that these non-physical dimensions of ageing have much more significance than other aspects which are given consideration in this journal and others. Those working with particular theological questions and insights could profitably co-operate with others in a re-visioning of ageing that tackles such fundamental questions as: the significance of life; the valuing of dependence; the nature of time and one's life story; the place of change and loss; the condition of temporality; the acceptance of mortality; and the high value we place upon work and activity for our identity. Is it possible to harvest authentic, shared spiritual experience which enables those engaged in the process of ageing to articulate its questions and impossibilities in a way which is liberating and informative for care? Those wary of religion might look at some of this material to see how it tackles some of this theological work. Despite its decline in Europe, there seems little doubt that theology has a legitimate place in both our understanding of the nature of ageing and our practical responses to it.

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Christine Bigby, *Ageing with a Lifelong Disability: A Guide to Practice, Programme and Policy Issues for Human Services Professionals*, Jessica Kingsley, London, 2004, 320 pp., pbk £19.95, ISBN 1 84310 0770.

This book arises from the author's cumulative research and practice experience over 18 years, and thus incorporates both general themes and specific areas of focus. In this sense, it does not offer a comprehensive or definitive guide to working with disabled people as they grow older but rather a holistic framework, well illustrated with examples relevant to particular groups and situations. The

ten chapters are divided into five sections. Part 1 provides an introduction to perspectives on ageing, with the bulk of the book devoted to a three-fold approach addressing physical and psychological needs, the social dimensions of ageing, and older parental carers of adult children. The final section of one chapter brings together observations on service developments, policies and programmes. Each section of the book includes relevant research studies, examples and a series of individual vignettes that raise questions for learning and professional development. There is thus some scope to use the book directly in teaching and professional development activities.

The main focus of the author's research, and thus the book, concerns older people labelled as having life-long learning difficulties or intellectual impairments. By this, ageing is identified as a relatively recent issue caused by the considerably increased life expectancy of this group in modern societies. There are some useful overviews of relevant themes from the academic literature but these are focused predominantly on examples relating to older adults with learning difficulties from Australia, the United States and the United Kingdom. Although the text refers often to people with physical or sensory impairments as well as to those with learning difficulties, there is more published research on these groups than acknowledged, for example the work of the *Spinal Injuries Association* on older people and direct payments (a topic that is not mentioned).

Key concepts, such as 'successful ageing' and age discrimination, are introduced early in the book and critiqued with reference both to the research literature and to examples. The theme of successful ageing is maintained throughout, and there is an attempt to respond positively to the criticisms levelled from a disability studies perspective (that 'successful' ageing has frequently been equated simply with 'healthy' ageing or an absence of impairment). This framework provides a useful orientation, although a full grasp of these complex debates would require a wider reading.

The focus on particular impairment labels is very useful in providing specificity but the book does not attempt a comprehensive coverage. For example, in the chapter on the physical aspects of healthy ageing, short illustrative sections that outline the implications of specific conditions are limited to Down's Syndrome and Cerebral Palsy (although there is much more in the Appendix). The coverage of intervention strategies is much wider and will be of help to those with professional, therapeutic or policy interests. I applaud the references to both individual and social interventions, such as interventions to change the environment as well as those to treat the person.

There is a strong focus on the value of different circles of support and interdependence, for example, in relation to family, friends, community and services. This is clearly expressed in the frequent focus on the role of ageing parents of disabled adults as carers, and on the need to integrate joined-up service delivery structures with the patterns of people's lives. While these are common themes in the research literature, I felt that there was scope to complement this with more attention to the development of independent living, peer-support and self-advocacy models. That said, the book achieves a certain balance between models of care and models based on disability rights and equality, although the latter receive much less detailed treatment or review. This is perhaps surprising in an

era of such development in the international disability rights agenda, from which older people have so often been excluded. Perhaps it is less surprising given the book's target audience of those involved in more traditional professional interventions. It is primarily a book about working with older disabled people in that context.

This book is likely to interest academics and students in relevant general disciplines as well as practitioners. As a whole, it falls somewhere between an academic research monograph and a practice-oriented guide, with strengths in the latter area as the title suggests. My initial reaction was that it would be of most use as a supporting text on university-based professional training courses for those intending to work in human services with older and disabled people.

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DOI: 10.1017/S0144686X04333143

Bryan J. Kemp and Laura Mosqueda (eds), *Ageing with a Disability: What the Clinician Needs to Know*, Johns Hopkins University Press, Baltimore, 2004, 307 pp., pbk \$24.95, ISBN 0 8019 7817 9, hbk \$55.00, ISBN 0 8018 7816 0.

The main aim of this book is to offer perspectives about what the editors define as a 'new era' in rehabilitation by emphasising what happens to many people with disabilities as they grow older. In fact three eras are depicted: the first is equated with the first half of the 20th century up to the advent of antibiotics, which brought an emphasis on survival; the second is represented by the post-second-world-war years when the emphasis moved towards rehabilitation within society; and the third is viewed as the era of longevity in which long-term survival is increasingly likely for many people. Given the above, it is no surprise that the context of this book is overtly that of developed nations, North America in particular. This is a strength and a weakness. One of the chapters, that concerning the politics of ageing with a disability, does not have a 'read across' facility with its concentration on national demography and specifically United States health care policy. Even in the wider English-speaking world, it cannot be presumed that other countries will replicate US demography or its policy directions. On the other hand, the book does not pretend to take a more global view.

The book has five parts. Part 1 concerns the consumer's perspective, taking in both people with disabilities and family members. Bio-psychosocial issues provide the compass for the second part, with chapters on physiological changes, quality of life and family care respectively. Treatment considerations, important for rehabilitation professionals, are the focus of Part 3, whilst Part 4 examines specific impairments, including spinal cord injury, poliomyelitis, cerebral palsy and developmental (learning) disabilities. Under the rubric of future directions, the final part addresses methodological issues in the study of ageing with a disability and their implications for health policy, with final commentaries from a provider and a consumer of care. As the sub-title suggests, the primary audiences are considered to be practitioners and graduate students, especially those in

rehabilitation professions, including physical and occupational therapy, nursing, medicine, counselling, social work, gerontology and psychology. People with disabilities and families are regarded as a secondary audience. Contributors to the book reflect many of these interests.

The editors argue strongly the need for what some writers call a lifespan or life-cycle approach to ageing with a disability, and in the introduction they posit exemplifying questions. It is curious then that little effort is made to inform this focus by reference to important theories about successful ageing (with the exception of the chapter about people ageing with developmental disabilities) or resilience, or to the wealth of lifecourse research that rehearses creative tensions between biography and environment with turning points that individuals are likely to meet along the way. Similarly, in a book with a focus on disability as well as ageing, it is surprising that there is little mention of disability as a social construct, let alone of the social model of disability. For the most part, the text is informed tacitly by medical-model thinking. The lack of theoretical anchorage is evident in the chapter on quality of life that studiously avoids any discussion of the merits of alternative models and how these might bring different perspectives to bear upon an understanding of ageing with a disability.

The book begins and ends with chapters written by people with disabilities, the former an autobiography by one with cerebral palsy and the latter a commentary by a disability consultant. Both are engaging in different ways, the autobiography because it brings to life the meaning of disability in everyday life, and the commentary because it stresses the importance of listening to, and actively involving, people with disabilities in decision-making about the design of supports they need. As a reader I wished to hear more from such voices to complement the academic and clinically-oriented chapters. This book is strong on coverage but light on theoretical and conceptual content. There is a lot of accessible and usable material but readers will need to weigh carefully its significance.

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