Reviews

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Mary M. Marshall (ed.), *Perspectives on Rehabilitation and Dementia*, Jessica Kingsley, London, 2005, 256 pp., pbk £19.95, ISBN 1843102862.

Anthea Innes, Carole Archibald and Charlie Murphy (eds), Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice, Jessica Kingsley, London, 2004, 288 pp., pbk £18.95, ISBN 1 84310 174 2.

People with dementia and their families have never received so much attention and, one could argue, this has arisen partly from the work of Professor Mary Marshall, who until 2005 directed the Dementia Services Development Centre at the University of Stirling. Under her leadership, Stirling became synonymous with a concern for human rights and optimal support and services for people with dementia. These two volumes, concerned respectively with rehabilitation and social inclusion, further these agenda. Together they offer a contemporary overview of the potential for people to live a good life with dementia, and of the need to tackle 'dementism' in society at large and in the health-care and social-care systems (Brooker 2004).

Mary Marshall's book has two principal aims: to develop thinking and practice in dementia care, and to generate interest and excitement about dementia-care among mainstream health and social-care practitioners. She believes that many recent developments in thinking and practice have been articulated in a language that means little to those outside the field. Her hope is that by using mainstream terms, such as *rehabilitation*, a wider audience will be influenced. She set the contributors the task of writing about what rehabilitation means to them. It may surprise mainstream health and social care professionals that few of the contributions are concerned with what many regard as rehabilitation, i.e. 'the restoration to previous or optimal levels of functioning', but rather are concerned with any intervention that promotes quality of life and wellbeing for people with dementia. These include efforts to assist the person to adjust and adapt to their changed abilities and circumstances. Given this broad conception, not surprisingly many contributors draw links to Kitwood's (1997) person-centred approach to dementia care, and argue that a broad ethos of rehabilitation is at the heart of effective care and support.

The editor's introduction identifies four categories of rehabilitation: after an acute physical episode; after an acute behavioural episode; cognitive rehabilitation; and the general approach. The book has 30 chapters in seven unequal parts: named as (I) perspectives on the field as a whole; (2) perspectives of people with dementia and their carers; (3) specific professional perspectives; (4) specific settings; (5) specific interventions; (6) specific difficulties; and (7) conclusions. While the sevenfold structure does not mirror Marshall's four themes, it is apparent that most of the book is concerned with rehabilitation as a general

strategy. The volume has ambitious scope and covers almost all potential supports and services. Most of the chapters have been written by professionals who work with people with dementia and their families, and most are British social workers and professionals allied-to-medicine (occupational therapy, physiotherapy and speech and language therapy): some recently completed postgraduate study at Stirling. The academic contributions are predominantly from a social work perspective. One part of the book is devoted to contributions from people with dementia and their carers.

The volume, edited by Anthea Innes, Carole Archibald and Charlie Murphy (also from Stirling University), is concerned with promoting social inclusion and combating the marginalisation of people with dementia and their families, and aims both to outline and to challenge the barriers that lead to their social exclusion. The editors' intention is that the book brings currently marginalised areas of research and practice into the mainstream, and they argue that key challenges for the future are social inclusion, citizenship and identifying and exerting rights for people with dementia. The collection has 16 chapters in five parts. They offer interesting discussions of neglected areas of research and practice in dementia care and repay close reading.

Part I illustrates the neglected potential of community and has chapters on: the nature and potential of 'communities' in the lives of people with dementia (Bell), the experience of people with dementia living in rural communities (Innes and Sherlock), and the relative isolation of domiciliary-care staff (Cobban). Part 2 addresses the marginalised socio-cultural issues of spirituality and religion (Dilworth-Anderson), death and dying (Cox and Watchman), and sexuality (Archibald). Part 3 tackles marginalised issues in care, including faecal incontinence (Muller-Hergl), social exclusion in care homes (Bruce), and risk taking (Manthorpe). Part 4 is concerned with the capacity of people with dementia to communicate their experience of living with the condition, and is creatively dealt with by Cheston, McColgan and Craig. The last section examines future directions from medical perspectives (Bradbury et al.) and social science perspectives (Bond et al., Hulko, and Cantley and Bowes). The focus throughout is on the circumstances of people with dementia and their families in Britain. The contributors are predominantly academics, many with a background in sociology and social work. Some contributions are empirical research reports, while others engage with the theoretical complexity. The papers were first presented at a conference, so invariably breadth eclipses depth and the sustained development of ideas is not a strong feature. Nevertheless, while we wait for a textbook on the sociology of dementia, several of this volume's contributions provide valuable introductions.

Both volumes are useful overviews of contemporary thought and practice about contemporary dementia care in the United Kingdom. In their concern with rehabilitation and social inclusion, they provide detailed analysis and development of key elements of the person-centred approach to the care of people with dementia. Such analysis is clearly needed, not only to promote quality of life and wellbeing for people with dementia, but also to promote these ends in society and in its health-care and social-care systems. It is the thesis of the person-centred approach that exclusion and marginalisation, whether at macro or micro levels,

leads to 'suffering', avoidable disability and the diminished quality of life that we have come to associate with living with dementia. These volumes do much to illustrate how such malignant processes operate, and they compel us to challenge them.

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Janet Leece and Joanna Bornat (eds), Developments in Direct Payments, Policy, Bristol, Avon, 2006, 320 pp., pbk £19.99, ISBN 1 86134 653 o.

The meaning of direct-payments is that people dependent on community care are given money instead of services. From a very modest start, with its roots in the advocacy-movement of disabled people, direct-payments have been extended to others, including older people, those with learning difficulties, mental-health services users, and parents with disabled children. Promoting direct-payments is an element of welfare policy in some western countries, and presents an important challenge to traditional formal social-care and the way in which the welfare system is organised. One reason is the double-edged character of directpayments. On the one hand, they arose from the fight by disability campaigners for civil rights and social justice. On the other hand, they demonstrate the market's increasing importance in welfare provision. The agenda of the various actors are not necessarily the same. As pointed out in the book's introduction, 'the (British) government's commitment to new-right or neo-liberal social and economic policies may have greater influence on its decision to change the legislation on direct-payments than its commitment to user empowerment and involvement' (p. 22). The dual objectives challenge both activists and campaigners for the potential users of direct-payments, and policy makers and front-line workers required to implement the schemes.

The intention of the book is to give a broad picture of the development of direct payments. The authors include full-time researchers, campaigners for disabled people's rights, and some who combine these roles. The book has six sections. The first presents the development and implementation of direct-payments in the different welfare systems of England and Wales, Scotland and the United States. The second section discusses the challenges of putting direct-payments into practice. More exactly, the chapters discuss challenges raised when direct payments are to be implemented for people with learning difficulties, older people,

people with mental-health problems, and parents of disabled children. The third section, 'Voices of experience', presents both the experiences of users of direct payments and of people working as personal assistants. The fourth, 'Reporting from the field', has contributions from people who are engaged directly in the implementation and take-up of direct-payments. In the fifth section, 'Working with direct-payments', two chapters focus on the job situations of personal assistants; one applies a cross-national perspective and compares the employment conditions for personal assistants in Austria, France, Italy, The Netherlands and the United Kingdom, with a laudable focus on the circumstances of this neglected group of carers - much previous research has largely been concerned with the situation for users: the other chapter asks if and how intensive support can widen access to direct-payments. The reason for raising this question is that their takeup, by older people, by people with learning difficulties and by mental-health service users, continues to be very low. In the final chapter in this section, the focus is on the views of care-managers, as they have a crucial role if older people are to have more access to direct-payments. The final section considers future developments in direct-payments. Its three chapters raise issues about their settlement in the United Kingdom, and asks what conditions must be met for direct-payments to become the intended tool for liberation and independent living.

The book offers a comprehensive account of the complicated and mixed picture of direct-payments, and therefore is highly recommended. The fundamental approach of the authors is that direct-payments are a 'good thing', and the discussion mainly addresses how to secure the goal of independence. This is an important issue. At the same time, a consequence of this approach is that the appraisal easily becomes restricted, and that some fundamental debates about the ambivalence and dilemmas of direct payments are treated too superficially. One such relates to the dilemmas posed by the extension of direct-payments to people with learning difficulties, older people, and people with mental-health problems. The extension raises fundamental questions, such as: where is the balance between the safety and wellbeing of the individual, and the need to respect the individual's autonomy? Those receiving direct-payments are diverse and have very different abilities for making qualified choices and taking control of their own services. Most of the contributors probably agree that we need to build up good support systems, but this solution raises new questions. If complex support structures are built up and provided by qualified staff (Chapter 7), the boundaries between formal services and arrangements financed by direct-payments could soon be obscure.

One chapter describes North American approaches to direct-payments, and another compares the situation for personal assistants in some European countries, but most are concerned with direct-payments legislation in the UK and with the British experience. The value of the book would have been raised by a stronger comparative perspective. Both the USA and the UK are among what Esping-Andersen (1990) categorised as 'liberal welfare-state regimes'. The principle of direct-payments has been adopted by many European welfare states, even Nordic countries. With a comparison of direct-payments in different welfare state regimes, it might have been easier to identify their merits and to compare them

with the values that have traditionally characterised the welfare state, namely solidarity, equality and responsibility for the community. Are such values threatened by the strong individualism which direct-payments assume? Perhaps this is the subject of another book.

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Bert Hayslip Jr and Julie Hicks Patrick (eds), *Custodial Grandparenting: Individual, Cultural, and Ethnic Diversity*, Springer Publishing Company, New York, 2006, 334 pp., pbk \$48.95, ISBN 0 8261 1998 0.

In the more than 20 years since sociologist Linda Burton first drew attention to the challenges faced by African-American grandparents raising grandchildren, custodial grandparenting in the United States has been of growing interest to researchers, practitioners and the general public. This has been fuelled by the numbers: the proportion of children living in grandparent-headed households increased from 3.2 per cent in 1970 to over five per cent in 2006, with a particularly rapid growth of 'skipped generation' families, in which not one of the children's biological parents is present. More than one-in-ten American grandparents, and one-in-four African-American grandparents, at some point in their lives have primary responsibility for raising a grandchild for at least six months, and typically for two or more years. The numbers fail to capture either the health and social consequences or the different meanings and contexts, let alone the rewards, of grandparent care-giving.

In this timely volume, the editors Bert Hayslip and Julie Hicks Patrick have explored this diversity and present a nuanced understanding of the meaning and significance of grandparent care-giving in early 21st century America. While placing a heavy emphasis on racial and ethnic diversity, to their credit they have commissioned contributions on less commonly examined factors in the experience of raising grandchildren, such as age, gender, workforce participation and health-status. The book has 19 chapters: it begins with a section on 'Diversity across individuals', which considers issues that have long been studied in relation to carers of frail and disabled elderly people, such as the impact of work disruption, and the roles of both informal and formal social support. In Section 2, the focus moves to age and gender variations, and there is a particularly welcome account of the often-ignored role of grandfathers as care-givers. Sections 3 and 4 examine, respectively, cross-cultural and intra-cultural variations in care-giving and variations by race and ethnicity.

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With the exception of a strong chapter on grandparent care-givers among First Nations' grandparents in Canada, the chapters deal with the United States. In the US, the increase in custodial grandparenting has been shaped partly by historical realities such as: changes in state and federal support for relative (family) care-givers; the world's second highest divorce rate; and a host of problems related to poverty in inner cities, such as drug-abuse, violence, HIV/AIDS, and high rates of incarceration. As the book suggests, however, the nature and genesis of custodial care-givers also varies considerably among and within the various cultural, racial, ethnic and other groups. The customary role of both African-American and native-American grandmothers as care-givers across generations, for example, and the particularly high rates of teenage pregnancy among Latino-Americans, help shape the contours within which an individual experiences custodial grandparenting, and its 'on' or 'off timing'.

Valuable features of the book are the consideration of findings from studies that have used a wide range of research methods, including innovative qualitative approaches, such as grandparents' diaries and critical-incident analysis, quantitative analysis, and sound policy analysis. Two chapters by Hayslip and his colleagues report a particularly informative secondary analysis of the findings of several studies, which they use to strengthen their conclusions on the relationships between variables of interest. Similarly, the chapter by Rosyln Lee and co-authors that examined the 'responsibility continuum' among African-American grandparents addresses a largely-ignored topic using a large longitudinal data set – unfortunately a rare resource in previous research on grandparent-headed households. Finally, many of the empirical chapters have well-presented conceptual frameworks and hypotheses.

Like all edited volumes, the collection has limitations, among them the lack of an introductory chapter and bridging sections to provide either an integrative framework or transitions between the four sections. Although the excellent epilogue provides some integration, an earlier presentation of the framework would have been helpful. Several chapters used dated information, when more recent figures are easily accessed through, for example, the US Census Bureau's American Factfinder. A few chapters are based largely on surveys with very small samples and low response rates, which limits their usefulness. Despite these limitations, Custodial Grandparenting is an important new resource for researchers and students interested in the diversity of the experience of the growing number of American grandparent care-givers, and provides valuable guidance on the use of various tools and strategies for studying an important American reality.

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David C. Burdick and Sunkoy Kwon (eds), Gerotechnology: Research and Practice in Technology and Aging: A Textbook and Reference for Multiple Disciplines, Springer Publishing Company, New York, 2004, 288 pp., hbk \$41.61, ISBN 0826125166.

An underlying theme in the public and political debate about an ageing society is that the rapid diffusion of new technologies is transforming the daily life of older people and changing the ageing process. Technology is ascribed the roles of rescuer from escalating demands on formal and informal care-systems, and of good companion to every older person who wants to postpone bodily and mental decline and maintain an active and independent lifestyle. Given the consensually optimistic view of what technological change will bring, paradoxically the material world is seldom observed and analysed in research on ageing and the everyday life of older people. As a result of this 'blind spot', there is a fundamental lack of both empirical knowledge and analytical understanding of how older people use and value new and old artefacts, how new technologies can be of value for different categories (and generations) of people, and how the flood of new artefacts and systems are best designed to meet the demands and needs of older people.

Nevertheless, research in gero(n)technology has been growing for several decades, although to date with marginal impact on the broader gerontological research field and on public debate (Morgan 2005). Change may however be imminent. The first book to discuss 'successful ageing' in relation to new technologies was perhaps Charness and Schaie (2003). This follow-up collection, edited by Burdick and Kwon (which heralds a major series), has a wider perspective and is therefore most welcome. It is a contribution to the research field per se, and will be valuable for social-policy makers, for engineering and design groups, and for students and company staff searching for guidelines on how to develop technology to support the independence of old people. The book has 16 chapters by 27 authors, most of whom work at US universities and institutions. Some chapters provide state-of-the-art descriptions of research questions in specific fields. A limitation is that almost all the perspectives displayed are American, and there has been little effort to compare with research and policies elsewhere. Some contributors were aware of this shortcoming, but the general opinion seems to be that the fundamental aspects of an ageing society areuniversal. Particular weaknesses are that the concept 'old person' is unproblematised, and differences between men and women, social and ethnic groups and generations are ignored.

Most of the chapters evince the customary gerontechnology view, that the major concern is to demonstrate how (not ask if) new technology can meet the needs and abilities of older people. The theoretical perspectives are mainly from human factors, applied psychology and cognitive science. The editors state that a main goal has been to cover material that would stand the test of time. This is, as they recognise, nearly impossible because the driving interest in gerontechnology today is to describe the possible applications of information technologies. The interest focuses on fast-changing technologies: Internet-use and the digital divide,

ubiquitous computing, computer-mediated communication, household and safety monitoring, tele-health and care-systems, and driving simulation.

A few chapters broaden the interest to a wider discussion of how technology influences people's daily lives and shapes the social structure of society. Mollenkopf argues that any study of the usefulness of different artefacts must consider the contextual social organisation. She emphasises that the different cultural and symbolic meanings of artefacts are as essential as their function. Mollenkopf obviously wants to connect gerontechnology to both social-constructivist perspectives and to the phenomenological tradition. Such perspectives raise the question of the double nature of new technologies: they generate both possibilities and obstacles for older people. In a critical contribution, Lessnoff-Caravaglia discusses the ethical dilemmas that are inevitable if one wants to 'solve' individual or societal problems through the application of new technologies. She points out that modern technology redefines the concepts of time and space and makes places and lives amorphous. Combined with a gender perspective, this leads to a short discussion of the marginalisation of older women as new technologies diffuse. Lessnoff-Caravaglia takes, as her point of departure, Heidegger's argument that modern technology transforms everything (natural, material and human) into values that can be exploited. If Heidegger was right, there is no free-zone from new technology for any of us, not even when we are old.

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Alison Clarke and Les Bright, Moving Stories: The Impact of Admission into a Care Home on Residents' Partners, Relatives' and Residents' Association, London, 48 pp., £8, ISBN 9781 900216 067.

This short report explores some of the views and experiences of people who have partners in care homes in the United Kingdom. While not fitting the usual definition of a carer, they nonetheless have physical, emotional and financial caring responsibilities. Obviously there are many kinds of difficulties when a partner has to move into a care home, but this study focuses on the emotional and financial issues raised by the particular British admission and social-services funding arrangements.

Inevitably, given the difficulties of locating and recruiting care-home residents' partners, eclectic methods were employed, including an analysis of calls made to

the Relatives' and Residents' Association. A postal questionnaire with follow-up interviews and two focus groups with spouses were also used. Although the 'spouse liability rule' has been superseded (whereby the spouse remaining at home could be assessed for contributions towards the other person's care-home fees), there are still financial implications for the partner at home. These include topping-up the fees paid by the local authority for a care-home place, and paying extra for a single room or for haircuts, outings and chiropody. As the study points out, moving into long-term care is a life-changing event. Because there is a need for advice about the alternatives to long-term care as well as appropriate care homes, decisions should be taken carefully and with a great deal of professional help. Unfortunately, some local authorities in England and Wales accept a responsibility to do no more than provide a list of care homes if the person concerned has savings above the statutory level for social-services funding. This monograph concludes with a list of specific recommendations for key stakeholders, including local authorities – they are encouraged to fulfil their statutory obligations both to carry out assessments of older people considering care-home admission, regardless of the level of their savings, and to offer a Carer's Assessment to the spouse or partner. This is a timely and important reminder of the emotional and practical difficulties experienced by partners and spouses when the problem of care-home admission presents.

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Karen Croucher, Leslie Hicks and Karen Jackson, *Housing with Care for Later Life: A Literature Review*, Joseph Rowntree Foundation, York, 2006, 142 pp., £9.95, ISBN 978 1 85935 437 7.

There is rising interest in, and growing investment by both the private and public sectors, in housing schemes for older people that allow independent living to be combined with relatively high levels of care. This review of the research evidence published since 1999 on housing-with-care schemes in the United Kingdom was conducted by the Centre for Housing Policy at the University of York. It is an important contribution to the debate about their merits. The report makes it clear that there are serious limitations to the current evidence on the efficacy of the housing-with-care model. To date, only 11 British studies have sought to evaluate, rather than describe, such schemes. An intrinsic difficulty lies in the terminological diversity for these facilities: very-sheltered housing, housing-withcare, extra-care housing, supported housing, close-care, flexi-care and retirement community. A particularly useful aspect of the review is that it draws together key themes from the international research and evaluation literature. It was found that, although research has provided relatively detailed accounts of both the reasons why older people move into retirement communities and the social life of the communities, there is surprisingly little about the cost-effectiveness of the services or the levels of service provision.

The review found that: residents value independence and security; the schemes provide opportunities for social interaction and companionship;

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the schemes could be an alternative to residential care; and such housing may have a positive impact on health and wellbeing. Whether or not housing-with-care has a cost advantage compared with residential care remains an open question. This is, of course, a key question for those who advocate more housing-with-care schemes. One of the contentious issues is whether such housing provides a 'home for life'. None of the studies reviewed actually addressed this question, even though the notion is an important selling point for prospective residents of extra-care or very-sheltered housing schemes. The diversity of housing-with-care schemes, even among the few that were evaluated, makes generalisation problematic. The available evidence supports the idea that housing-with-care promotes independence and generates high levels of resident satisfaction. There are, however, more ambivalent messages regarding the social isolation of tenants who are very frail, or for those with severe cognitive disorders.

Although the research appears to show that the schemes provide an alternative to residential care, the reviewed studies report several instances of people moving out of housing-with-care into care-homes. The studies provided little if any evidence about the role, or lack of role, for assistive technologies, the suitability of the schemes for ethnic-minority older people, or of end-of-life care. The important question remains unanswered: who is best served by housing-with-care schemes: the fit and the frail or just the frail? The evidence-base will shortly expand with the results from two evaluations: by the University of Kent Personal Social Services Research Unit of extra-care housing schemes, and by the Institute of Gerontology, King's College London and the Bartlett School of Graduate Studies, University College London, of extra-care schemes remodelled from sheltered housing or residential care homes.

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