AGEING WITH A LIFELONG DISABILITY

A Guide to Practice, Program and Policy Issues for Human Services Professionals

Christine Bigby

Foreword by Gordon Grant
Ageing with a Lifelong Disability
of related interest

**Care Services for Later Life**
Transformations and Critiques
*Edited by Tony Warnes, Mike Nolan and Lorna Warren*
ISBN 1 85302 852 5

**Choosing Assistive Devices**
A Guide for Users and Professionals
*Helen Pain, Lindsay McLellan and Sally Gore*
ISBN 1 85302 985 8

**Quality of Life and Disability**
An Approach for Community Practitioners
*Ivan Brown and Roy I. Brown*
*Foreword by Ann Turnbull and Rud Turnbull*
ISBN 1 84310 005 3

**The Psychology of Ageing**
An Introduction, 3rd Edition
*Ian Stuart-Hamilton*
ISBN 1 85302 771 5

**Spiritual Growth and Care in the Fourth Age of Life**
*Elizabeth MacKinlay*
ISBN 1 84310 231 5

**Manual Handling in Health and Social Care**
An A-Z of Law and Practice
*Michael Mandelstam*
ISBN 1 84310 041 X
Contents

LIST OF FIGURES AND TABLES 7
FOREWORD 9
ACKNOWLEDGEMENTS 13

Part 1 Perspectives on Ageing
1 Successful Ageing: Continuity and Adaptation 17
2 Older People with Lifelong Disability: Strategies to Counter Age Discrimination 36
   Part 1 Vignettes 60

Part 2 Physical and Psychological Needs
3 Healthy Ageing 71
4 Psychological Ageing and Emotional Well-being 87
   Part 2 Vignettes 107

Part 3 Social Dimensions of Ageing
5 A Sense of Belonging: Informal Support from Family, Friends and Acquaintances 115
6 Achieving a Sense of Purpose: Retirement or Supporting Lifestyle Choices 130
7 Achieving a Sense of Continuity and Security: Housing and Support Options to Enable Ageing in Place 158
   Part 3 Vignettes 183
Part 4  Older Parental Carers of Adults with a Lifelong Disability

8  Issues Confronting Older Parents Living with their Adult Children  193
9  Working with Older Parents  209
Part 4 Vignettes  231

Part 5  Service Developments and Policies for Successful Ageing

10  Policies and Programs for Successful Ageing  241

APPENDIX: AGE-RELATED BIOLOGICAL CHANGES AND HEALTH RISKS  273
REFERENCES  286
SUBJECT INDEX  308
AUTHOR INDEX  316
List of Figures and Tables

Figures
1.1 Social contextual layers in which individuals are embedded 22
2.1 Projected number of people with intellectual disability aged 55 years and over in Australia 44

Tables
2.1 Projected number of people with intellectual disability aged 55 years in each Australian state from 2000 to 2020 and percentage change for five-year periods 45
4.1 Summary of characteristics and responses at the three stages of Alzheimer's disease 103
6.1 Aims and outcomes of day support services for older people with intellectual disabilities 137
6.2 Suggested service or program characteristics 140
6.3 Strengths and weaknesses of different approaches to day programs 143
7.1 Existing housing and support options for people ageing with intellectual disability 165
10.1 Policy directions for ageing with a disability 255
This book addresses an important and often overlooked subject, ageing with a lifelong disability. It deals with an area of major tension for policy, namely how best to plan for the lives of people whose needs and circumstances commonly fall into the interstices separating disability services and services for older citizens. It is a dilemma that has not yet been satisfactorily resolved, not least because the challenges involved have been far from adequately deconstructed. This book makes a commendable contribution in tackling this problem through introducing theoretical perspectives that may help in uniting thinking and strategic planning, and also through providing empirical evidence to illustrate ways forward that have meaning for older people with disabilities, their families and front-line professionals. The book’s virtues are strengthened by the author’s ability to draw upon experiences in countries at the forefront of development work and research in this field, particularly the USA, the UK and Australia, but also other European countries like the Netherlands. Christine Bigby has spent many years researching the lives of older people with intellectual disabilities and their families so she is uniquely placed to produce a volume of this kind.

A book on the subject of ageing with a lifelong disability is also very timely for reasons beyond important questions about the coordinating responsibilities of services. In developed countries people with lifelong disabilities are living much longer, and therefore able to experience the joys and tribulations of all the life cycle demands like everyone else. This therefore puts a premium on supports being available to help people to anticipate and plan to realize their hopes and dreams throughout the life span. Besides having considerable resource implications, it also suggests the importance of understanding ways in which the expertise of informal as well as formal support can be harnessed in ways that serve people’s interests as they age. Experience also demonstrates that people with lifelong disabilities aspire like everyone else to be contributing members of society so that they can realize their talents, confirm their status as citizens and
receive proper acknowledgements of their efforts. This book contributes evidence about how such issues can be addressed, yet it also details how social, economic and institutional barriers created by society can still impede progress. In so doing it throws down the gauntlet to all of us.

The book is organized in five sections dealing with, in turn, theoretical perspectives, physical and psychological needs for older people, social dimensions of ageing, older family carers, and finally policy directions. The first four sections are complemented by a series of vignettes about the lives of older people and their families that help to ‘bring to life’ the more abstract and conceptual issues introduced elsewhere. The over-arching theoretical issues serve well their intended function in bringing some synthesis to diverse literatures and experiences. Readers will therefore find *Ageing with a Lifelong Disability* engaging for the way it seeks to anchor grand theorizing with biographical and life history material about the everyday lives of individuals and their families.

A strong emphasis is placed on the role that person-centred planning (PCP) should have in supporting continuity in people’s lives and as a vehicle for integrating support to enable them to age in place as far as possible. This appears to be a central commitment of policy initiatives in many countries. As the author demonstrates, whilst there are many PCP models with good descriptions of their application and how they are experienced, there is as yet little in the way of robust outcome data about their effectiveness from systematic evaluation studies. Evidence is in this way usefully dissected to help the reader to question the status of knowledge and the assumptions upon which policy and practice is based.

One of the strengths of this book is the way it has managed to synthesize diverse literatures on health and social dimensions of ageing. This will make it particularly relevant to those who are responsible for devising ways to help people to age in place, to lead a healthy and socially included life, to be a contributing member of society, to have opportunities to realize dreams, and to maintain control of important domains of their lives. In so doing it reinforces the importance of rights-based discourses and of perspectives that acknowledge the role of (personal) agency and the recognition of individual capacity in enabling people’s visions to be achieved. This prompts some fundamental thinking about changes required of present-day services and how they might work better together in people’s best interests.

Students of social work and social care, nursing, medicine and professions allied to medicine will find something of value and importance in this book; so too will planners and front-line professionals struggling to find useful models about how best to support people with disabilities as they age. Those who shape
policy should also be influenced by what they read in these pages. Let us hope that the result is a more responsive society that values people with lifelong disabilities and makes a proper financial commitment towards helping them to lead an enriched and fulfilling life.

Gordon Grant
Professor of Cognitive Disability
School of Nursing and Midwifery
University of Sheffield
UK
Acknowledgements

This book is based on work I have undertaken over several years. I am indebted to the individuals with intellectual disabilities, their families, the staff and organizations involved in the various studies without whom it would not have been possible. I would also like to thank colleagues involved in this work, in particular, Chris Fyffe, Jeffery McCubbery, Patise Frawley and Elizabeth Ozanne.

Writing the book was made possible by six months study leave from the School of Social Work and Social Policy at LaTrobe University and the generous provision of working space and quiet support from colleagues in the School of Social Work at the University of Melbourne.

I would like to thank Professor Gordon Grant for his critical comments on the manuscript and for his work on the Foreword. Finally, the support and forbearance of my partner John and daughters Jessie and Jacquie, who have lived through this task, must be acknowledged.
PART 1

Perspectives on Ageing
Chapter 1

Successful Ageing

Continuity and Adaptation

A new phenomenon

Ageing with a lifelong disability is a relatively new phenomenon which is illustrated by the dramatic changes in life expectancy for people with intellectual disabilities from about 20 years in 1930 to 70 years in 1993 (Carter and Jancar 1983; Strauss and Eyman 1996). The current cohort of older people with lifelong disabilities is the first sizeable group to have survived into later life. Ageing throws up new opportunities and challenges not for only individuals and their families but also for the helping professions and human service systems. Research on the characteristics, needs and aspirations of older people with a lifelong disability and related policy and service developments are of recent origin. Prior to the 1980s there was little debate about this matter. In the context of ageing populations in Australia, Europe and the USA, people with a lifelong disability are one of the fastest growing but smallest groups of older people.

Responding effectively to ageing with a lifelong disability is very much uncharted territory for human services. Neither Disability nor Aged and Community Care service systems have significant experience, knowledge or expertise around the issues it presents, nor of strategies for tackling these. Evidence suggests that many older people with lifelong disabilities are not ageing successfully. They have high rates of unmet health needs, and, as an extensive UK project concluded, many potential cliffs exist for older people with disabilities to fall from. These include being ‘retired’ from day programs and inappropriately placed in aged care accommodation (Thompson 2002, p.24). A comprehensive policy framework for ageing with a lifelong disability does not exist in either the UK or Australia. While general policies such as Valuing People (DH 2001) in the
UK and the Victorian State Disability Plan (DHS 2002a) can be applied to older people, the translation of these to specific policies and programs is often deficient and leaves grey areas of unclaimed responsibility for service provision.

The ageing of people with a lifelong disability raises two distinct but interrelated sets of issues: those around the inevitable loss of parental support for adults living with elderly parents; and the achievement of successful ageing for all people with lifelong disabilities regardless of where their earlier years have been spent. The first set of issues revolve around the agonizing question asked by the parents who have provided lifelong care for their adult child: ‘What will happen when I die?’ How will the tasks fulfilled by parents be replaced? Associated issues are how best to assist elderly parents to continue care and plan with their adult child for the transition from parental care. Finally, how should middle-aged adults with lifelong disabilities be supported to prepare for the post-parental phase of their lives. The second set of issues is concerned with ensuring that ageing people with lifelong disabilities, wherever they have spent their earlier years, have opportunities to age successfully. Challenges here centre on devising and implementing policies that assemble the most appropriate array of supports to address their needs. A central question often posed is what respective roles should aged care and disability programs play in the provision of support services. The complexity of these issues is magnified by the diversity of the population of people with a lifelong disability in terms of ethnicity, culture, gender, capacity, class and their life experiences.

People with lifelong disabilities include those with a range of physical, cognitive or developmental impairment. Also included are people who acquire a brain injury in early adulthood or suffer from a chronic illness. The largest and most well researched group is people with intellectual disability. Many issues associated with ageing are similar to all groups. However working with people with cognitive limitations has particular challenges: for example, to ensure their voices are heard, wishes respected, and opportunities for choice, engagement and inclusion are maximized. These are complex challenges as, for example, choice for people with intellectual disabilities often requires both the existence of opportunity as well as effective support. The main focus of this book is people with intellectual disability although the issues presented also exemplify those encountered by other groups of people with lifelong disabilities.