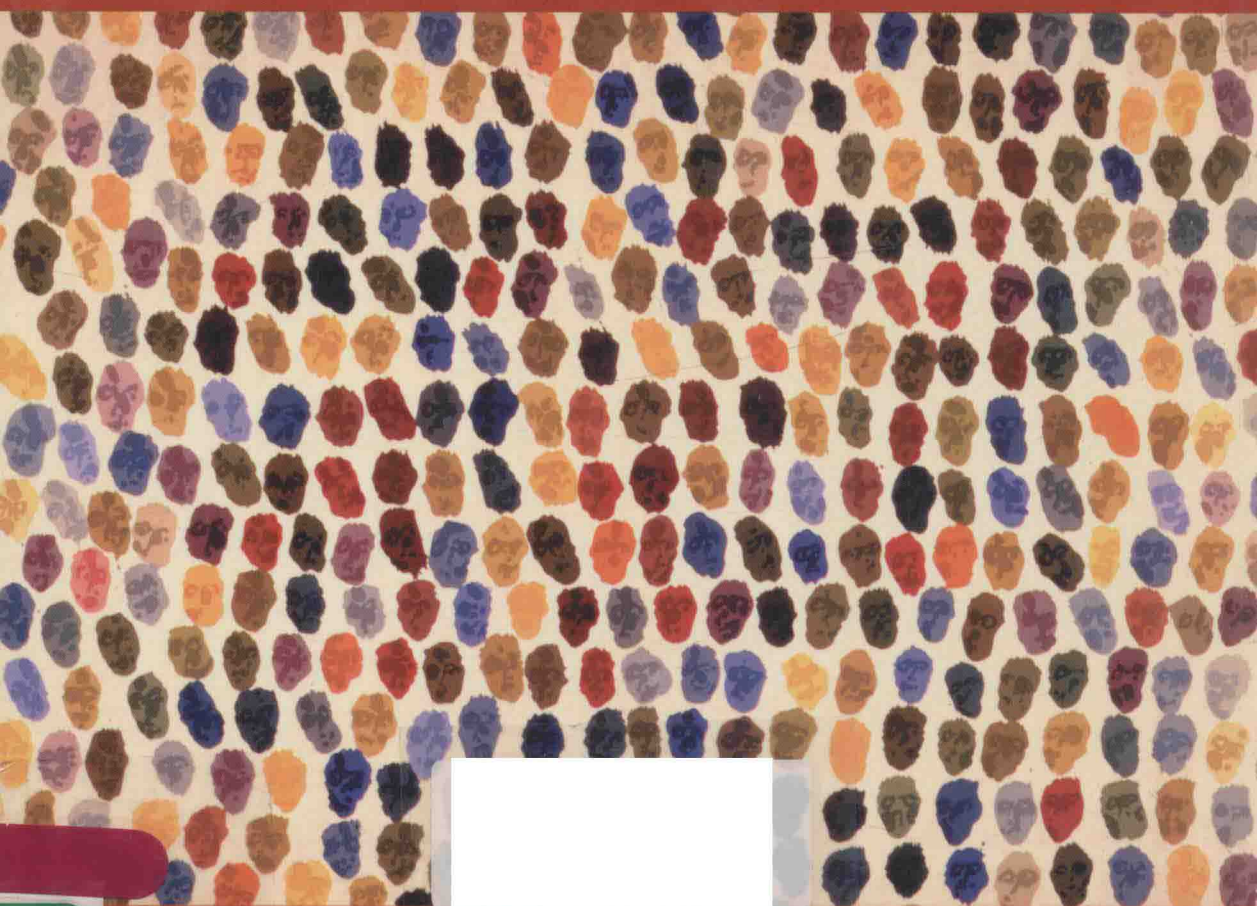


Health of Women with Intellectual Disabilities

EDITED BY

Patricia Noonan Walsh & Tamar Heller



书馆



Blackwell
Publishing



Health of Women with Intellectual Disabilities

Edited by

Patricia Noonan Walsh

National University of Ireland, Dublin

and

Tamar Heller

University of Illinois at Chicago

Blackwell
Science

© 2002 by Blackwell Publishing Company
Editorial Offices:

Osney Mead, Oxford OX2 0EL, UK

Tel: +44 (0)1865 206206

108 Cowley Road, Oxford OX4 1JF, UK

Tel: +44 (0) 1865 791100

Blackwell Publishing USA, 350 Main Street,

Malden, MA 02148-5018, USA

Tel: +1 781 388 8250

Iowa State Press, a Blackwell Publishing Company,
2121 State Avenue, Ames, Iowa 50014-8300, USA

Tel: +1 515 292 0140

Blackwell Munksgaard, Nørre Søgade

35, PO Box 2148, Copenhagen, DK-1016, Denmark

Tel: +45 77 33 33 33

Blackwell Publishing Asia, 54

University Street, Carlton, Victoria 3053, Australia

Tel: +61 (0)3 9347 0300

Blackwell Verlag, Kurfürstendamm 57, 10707

Berlin, Germany

Tel: +49 (0)30 32 79 060

First published 2002

A catalogue record for this title is available from the
British Library

ISBN 1-4051-0103-2

Library of Congress
Cataloging-in-Publication Data
is available

Set in 10/13 Palatino
by DP Photosetting, Aylesbury, Bucks
Printed and bound in Great Britain by
MPG Books Ltd, Bodmin, Cornwall

For further information on
Blackwell Publishing, visit our website:
www.blackwellpublishing.com

The right of the Author to be identified as
the Author of this Work has been asserted
in accordance with the Copyright, Designs and
Patents Act 1988.

All rights reserved. No part of this publication may
be reproduced, stored
in a retrieval system, or transmitted,
in any form or by any means,
electronic, mechanical, photocopying,
recording or otherwise, except as
permitted by the UK Copyright, Designs
and Patents Act 1988, without the
prior permission of the publisher.

Dedication

To
Brendan, Colm, Nessa and Ben
and
Uri, Talya and Natalie

Contributors

Deborah J. Anderson PhD

Institute on Community Integration, University of Minnesota, Minneapolis, USA

Christine Bigby BA (Hons), MSocWk, PhD

Senior Lecturer, School of Social Work and Social Policy, LaTrobe University, Melbourne, Australia

Pamela Block PhD

Centre for Alcohol and Addiction Studies, Brown University, Providence, Rhode Island, USA

Allison A. Brown BA

Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, USA

Margaret Flynn BA (Hons), CQSW, PhD

Senior Lecturer, Department of Psychiatry of Disability, St George's Hospital Medical School, London, UK

Carol J. Gill PhD

Department of Disability and Human Development, University of Illinois at Chicago, USA

Susan M. Havercamp PhD, Licensed Clinical Psychologist

Clinical Assistant Professor, Center for Development and Learning, University of North Carolina at Chapel Hill, USA

Tamar Heller PhD

Professor and Interim Head, Department of Disability and Human Development, University of Illinois at Chicago, USA

Sheila Hollins MBBS, FRCPsych, FRCPC

Professor and Head of Department of Psychiatry of Disability, St George's Hospital Medical School, London, UK; Consultant Psychiatrist in Learning Disabilities and Senior Policy Advisor, Department of Health (England)

Mike Kerr MBChB, MSc, MRCPsych

Senior Lecturer in Neuropsychiatry, Welsh Centre for Learning Disabilities, University of Wales College of Medicine, Cardiff, UK

Henny M.J. Van Schrojenstein Lantman-de Valk MD, PhD

Physician for people with learning disabilities, Echt, Netherlands;
Researcher, Department of General Practice, Maastricht, Netherlands

Yona Lunsky PhD

Assistant Professor, Department of Psychiatry, University of Toronto,
Canada; Psychologist, Centre for Addiction and Mental Health, Toronto,
Canada

Beth Marks RN, PhD

Assistant Director, Rehabilitation Research and Training Center on Aging
with Developmental Disabilities, University of Illinois at Chicago, USA

Mary McCarron RNMH, RGN, BNS (Hons)

PhD student in the School of Nursing and Midwifery Studies, University
of Dublin, Trinity College, Ireland

Michelle McCarthy BA (Hons), BPhil/CQSW, MA, PhD

Senior Lecturer in Learning Disability, Tizard Centre, University of Kent,
Canterbury, UK

Glynis Murphy BA, MSc, PhD, CPsychol, FBPSS

Professor of Clinical Psychology of Learning Disability, Tizard Centre,
University of Kent, Canterbury, UK

Susan L. Parish PhD

Postdoctoral Fellow, Waisman Center, University of Wisconsin, Madison,
USA

Kristiina Patja MD PhD

Tobacco and Health Co-ordinator, Public Health Institute, Helsinki, Fin-
land

Nicole Schupf PhD, MPH, DrPH

Laboratory of Epidemiology, New York State Institute for Basic Research
in Developmental Disabilities, Staten Island, New York, USA; Gertrude
H. Sergievsky Center, Columbia University College of Physicians and
Surgeons, New York, USA

Kathryn Pekala Service MS, RNC/NP, CDDN

Nurse Practitioner, Franklin-Hampshire Area Office, Massachusetts,
USA; Department of Mental Retardation, Northampton, Massachusetts,
USA

Patricia Noonan Walsh PhD

NDA Professor of Disability Studies, National University of Ireland,
Dublin, Ireland

Series Foreword

Health of Women with Intellectual Disabilities introduces a new series of publications associated with the International Association for the Scientific Study of Intellectual Disabilities (IASSID). These publications are designed to address the issue of health, adult development, and aging among persons with intellectual disabilities. Originally a health policy initiative undertaken by the IASSID at the behest of the World Health Organization, this initiative has grown to become a major effort, undertaken by the members of IASSID, to explore a number of topics related to health and aging. It has also evolved into worldwide effort to promote research and practice designed to improve longevity and promote healthy aging of people with lifelong disabilities among the world's nations.

This compilation of chapters from many of the world's leading researchers and practitioners in the area of women's health and disability, is the first in this series. The editors and contributing authors of this text recognized that the inequities in national health policies and services as they affect women with lifelong disabilities seriously impair good health and successful aging. Because of this, they decided to compile a text that would begin to examine a host of issues and facts related to service access and health promotion for women with disabilities. The editors have chosen wisely and the number of topics that are explored show the range of concerns confronting women as they age. It is anticipated that these papers will enable health services administrators and practitioners to become more aware of the barriers faced by women with disabilities, and provide for more accessible and available services.

It is hoped that as the IASSID, as a non-governmental organization, continues to contribute to the worldwide interest and better understanding of the circumstances of people with intellectual disabilities and their conditions, this series will, in part, serve as a catalyst and contributor to the improvement of life conditions and our understanding of adult development and aging as related to lifelong disability.

Matthew P. Janicki, PhD
Series Editor

*University of Illinois at Chicago
Department of Disability and Human Development
College of Health and Human Development Sciences
Chicago, Illinois, USA*

Foreword

The ideal of equality is the touchstone on which the guarantees of international human rights law have been built. Its corollary is the principle of non-discrimination. The story of the international human rights movement, which covers the last half of the twentieth century, has largely been about the struggle to advance the ideal of equality through the elimination of all forms of discrimination. It is neither an easy struggle nor one that produces immediate results.

In the early years discrimination and disability – including the particular vulnerability and needs of persons with intellectual disabilities – was a neglected subject as compared to other forms of discrimination. That neglect has gradually been reversed. The treatment of the disabled has come to be recognised as involving questions of rights rather than exclusively social, humanitarian or welfare considerations.

Change can be dated from the influences that flowed from the UN International Year of Disabled Persons, 1981. From that Year we got the widespread adoption of full participation and equality as the overall goal in the disability field. The World Programme of Action concerning Disabled Persons, adopted by the General Assembly in 1982, spelled out what should happen if that goal was to be realised. Not much did happen, in fact, to change attitudes towards disability.

However, using this foundation, standard rules were elaborated and unanimously adopted by the General Assembly in its resolution 58/96 of 20 December 1993. The standard rules represented progress in that they were more concentrated and concrete in form. They also addressed more directly the issue of member states' responsibility. Most significant was the establishment of an independent and active monitoring mechanism on implementation of the rules – a special rapporteur within the framework of the Commission for Social Development.

The culmination of these developments came with the Declaration of the Vienna World Conference on Human Rights in 1993. That placed disabled persons, and their active participation in all aspects of society, explicitly in a human rights context: 'all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities'.

It is against this backdrop, of standard setting and inclusion of disability perspectives in the human rights agenda, that this text on health of

women with intellectual disabilities has been produced. I welcome its publication, as indeed I welcome the repeated opportunities I am granted, as UN High Commissioner for Human Rights, to reaffirm the importance of placing the issue of disability, and in particular the issue of intellectual disabilities, in a human rights context. For, in practice, it is unfortunately still the case that many people, and in particular those with intellectual disabilities, are unable to live full lives in equality and free from suffering. Whether such experiences are purposely inflicted or arise from neglect does not matter – we must continue to remind authorities and society that persons with intellectual disabilities are entitled to the same basic human rights as all others, and strive to ensure their attainment.

Persons with intellectual disabilities belong to the most vulnerable sections of society, and as such, are owed special care and attention by governments. It is regrettable that the mentally ill often do not receive that attention. The particular difficulties faced by women, and particularly older women, in this context must also be recognised. This important book will help that recognition. As life expectancy increases, health and quality of life are becoming an ever more pressing concern. The challenge is to ensure that these lives are lived out in the dignity to which we are all equally entitled.

Mary Robinson

United Nations High Commissioner for Human Rights

Acknowledgements

Preparation of the chapters and writings by Anderson, by Gill and Brown and by Heller and Marks was supported in part by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago through the US Department of Education National Institute on Disability and Rehabilitation Research, Grant No. H133B980046. The Heller and Marks chapter was also funded by the Roybal Center on Health Maintenance through a grant from the National Institute on Aging, Grant No. AG15890-12.

In respect of the chapter by McCarron and Pekala Service, Mary McCarron acknowledges the financial support of the Health Research Board, Dublin, Ireland, by way of a Clinical Fellowship in Nursing and Midwifery Studies which was awarded to her.

Partial support for the preparation of the 1999 10th International Roundtable on Aging and Intellectual Disabilities held in Geneva was provided by grant 1R13 AG15754-01 from the National Institute on Aging, Bethesda, Maryland USA to M. Janicki (PI).

Patricia Noonan Walsh thanks her colleagues in the Centre for the Study of Developmental Disabilities, and her fellow psychologists at the National University of Ireland, Dublin – especially Alan Carr – for their instrumental and affective support.

Editorial assistance from Leslie Chapital in Chicago and Richard Molloy in Dublin is gratefully acknowledged.

Contents

<i>Contributors</i>	ix
<i>Series Foreword</i>	xi
<i>Foreword</i>	xii
<i>Acknowledgements</i>	xiv
Introduction – Women’s Health	1
The context of health	2
Health status and trends	3
Promoting health	3
References	4
Part 1 The Context of Health	5
1 Women’s Health: A Contextual Approach	7
<i>Patricia Noonan Walsh</i>	
Introduction	7
Cultural contexts	8
Promoting health: the social context	12
Self-determination	17
Priorities	18
Summary	19
References	19
2 Reproductive and Physical Health	22
<i>Henny M.J. van Schroyen Lantman-de Valk, Nicole Schupf and Kristiina Patja</i>	
Introduction	22
Reproductive and physical health	22
Age-related health problems	28
Summary	35
References	36
3 Women Aging with Intellectual Disabilities: What are the Health Risks?	41
<i>Deborah J. Anderson</i>	
Introduction	41
Analysis of the National Health Interview Survey: comparison of women with and without ID	43

Implications for health care	49
Acknowledgements	52
References	53
Part 2 Health Status and Trends	57
4 Women's Mental Health	59
<i>Yona Lunskey and Susan M. Haverkamp</i>	
Introduction	59
Risk factors	60
Gender differences in prevalence	62
<i>Case study: Tammy</i>	65
Treatment issues	67
Mental health promotion	68
Future areas for research	69
References	70
5 Sterilization and Sexual Control	76
<i>Pamela Block</i>	
Introduction	76
Eugenics and intellectual disability	77
Gender and sexuality	80
References	88
6 Sexuality	90
<i>Michelle McCarthy</i>	
Introduction	90
Taking a life span perspective	90
Taking an equal opportunities/inclusive perspective	92
What we do know about sexuality and women with intellectual disabilities	93
Improving the way women with intellectual disabilities experience their sexuality	98
<i>Case study: Maria</i>	99
Conclusion	100
References	101
7 Parenting	103
<i>Susan L. Parish</i>	
Introduction	103
Parenting in context	103
Research on parenting by women with intellectual disabilities	107
Mothers with intellectual disabilities and the justice system	112

Policy recommendations	115
References	117
8 Social Roles and Informal Support Networks in Mid Life and Beyond	121
<i>Christine Bigby</i>	
Introduction	121
Importance of informal support networks	121
Understanding informal networks	123
Network functions	124
Informal support and women with intellectual disability	126
Vulnerability of networks	128
<i>Case study: Ada</i>	129
Summary	132
References	133
Part 3 Promoting Health	137
9 Health and Aging Issues for Women in Their Own Voices	139
<i>Carol J. Gill and Allison A. Brown</i>	
Introduction	139
Salient health issues of older women with intellectual disabilities	139
Promising directions	144
Conclusions and recommendations	147
Note	149
References	149
10 Risk and Vulnerability: Dilemmas for Women	154
<i>Patricia Noonan Walsh and Glynis H. Murphy</i>	
Introduction	154
Rights and risks	155
Abuse and neglect: the evidence	157
Strategies for change	162
Summary	165
References	166
11 Health Promotion and Women	170
<i>Tamar Heller and Beth Marks</i>	
Health promotion and women with intellectual disabilities	170
Health status of women with intellectual disabilities	170
Health risks	172
Key aspects of health promotion programs	180

<i>Case study: Emily</i>	184
Conclusion	185
Acknowledgement	186
References	186
12 Building Health Supports for Women	190
<i>Mary McCarron and Kathryn Pekala Service</i>	
Introduction	190
Background	191
Nutrition and exercise	191
Health screens and examinations	194
Breast health	196
Sexuality and self-image	197
Menstrual matters	198
Menopause: physical and psychological care needs	199
<i>Case study: Beatrice</i>	201
Osteoporosis	201
Uro-gynecology	202
Conclusion	203
References	203
13 Approaches for Health Education and Policies in Health and Social Care	208
<i>Margaret Flynn and Sheila Hollins</i>	
Introduction	208
A chronicle of developing ideas	209
Some inconsistencies	212
Foundations and ideas for progress	214
References	217
14 Men's Health: 'The Female of the Species is More Healthy than the Male'	219
<i>Mike Kerr</i>	
Introduction	219
The differential health status of the male	219
Why the difference? The male picture	221
Meeting the need – delivering health care to the male	223
<i>Case study: 'JD'</i>	225
Conclusion	225
References	226
<i>Epilogue</i>	228
<i>Index</i>	230

Introduction

Women's Health

People alive at the start of the twenty-first century may expect to live longer lives than previous generations. While those born in wealthier, more industrialized countries may live longer, life expectancy is also on the increase in countries still developing. What is less certain is whether more opportunities will translate into richer life accomplishments – health, productivity, self-determination, and satisfying relationships with family members and friends. Health is increasingly viewed as a human right expressed in each society so that all citizens have equal opportunities to healthy living throughout their lives. A vast array of regions and political and cultural environments exerts constraints and presents diverse opportunities for health outcomes. But individuals are not merely silent partners governed by overwhelming environmental forces: they do and must contribute to their own health.

Gender has specific influences on health across the life course, as does the socioeconomic climate of people's lives. Thus, the magnitude and explanations of gender differences in socioeconomic status (SES) inequalities in health are likely to vary according to life stage as well as to the measures used (Matthews *et al.*, 1999). But these lenses of health and socioeconomic status have rarely focused on women with intellectual disability. As a consequence, detail about their lives as young, middle-aged or older adults is blurred. The first aim of this book is to cast light on the place where these domains intersect, to consider the needs and opportunities for women with intellectual disabilities as they emerge over the course of their adult lives in their homes and communities. A further aim is to gather evidence to inform women themselves, their family members and advocates, professional workers and policy-makers so that each can act in concert to promote healthy aging for this distinctive group of women.

Various terms are used to define the target population at the heart of this book. While in the United Kingdom 'learning disabilities' is preferred, this term has an entirely different meaning in the rest of the world, where it refers to individuals who have disorders of memory, auditory or visual perception of language and thinking. Mindful of cross-cultural differences in tradition and usage, the editors of this book have used 'intellectual disability' to express a state of functioning manifested before adulthood characterized by substantial limitations in the individual's

present cognitive and adaptive functioning. While the editors acknowledge the use of 'disabled people' in the advocacy and research communities in some countries, they have adopted 'people first' language throughout the book – 'people with disabilities'. In addition, some contributors refer to the influence of ethnicity on the experiences of women with intellectual disabilities – for example, among those of African heritage.

This book addresses the health of women with intellectual disabilities from multiple disciplinary perspectives – medicine, psychology, education, public health, sociology, anthropology and nursing. It elaborates on and extends a program of collaborative research carried out by the WHO and the Special Interest Research Group on Aging within the International Association on the Scientific Study of Intellectual Disability (IASSID) culminating in a set of reports presented at the 11th World Congress of IASSID in Seattle in August 2000 (WHO, 2001).

Some chapters in this book explore the context of health to identify the cultural, economic and social factors that may thwart or enhance women's health. Others chart the terrain of health status and trends relating to women with intellectual disabilities. Finally, others propose best practices and public policies that promote health – either by changing the environment or by supporting individuals to enhance personal competencies and performance.

The context of health

The widest research lens encompasses the set of controls in the political, cultural and socioeconomic environments helping to determine health outcomes of women with intellectual disabilities. If gender determines health, it does so within the specific environments where women live. In Chapter 1 Walsh adopts a global perspective on the economic, cultural and social contexts of lifelong health for women with intellectual disabilities as they mature into middle and older adulthood.

Women with intellectual disabilities have specific health risks in comparison with men with intellectual disabilities and in comparison with other women. In Chapter 2 van Schrojenstein Lantman-de Valk and her colleagues lay the foundation of the book by documenting what is known about the physical and reproductive health of women with intellectual disability. The comprehensive chapter combines clinical data from experienced clinicians and epidemiological research to provide a look at the unique aspects of health among these women with disabilities.

In Chapter 3 Anderson delineates the health risks for women with intellectual disabilities using data gleaned from a national representative

sample, the US National Health Interview Survey Disabilities Supplement. She examines how age, gender, disability and poverty combine to compound health risks.

Health status and trends

In Chapter 4 Lunsky and Haverkamp critically apply the findings of available research literature related to the mental health of women in general to women with intellectual disabilities, generating a timely and challenging research agenda.

Yesterday's experiences also fuel today's ethical dilemmas. In Chapter 5, Block analyzes cultural historical evidence from Brazil and raises perplexing issues related to contemporary debates about genetics, bioethics and eugenics as these impact on the lives of women with intellectual disabilities.

In Chapter 6, McCarthy explores incisively yet with sensitivity some aspects of women's sexuality – at the core of personal identity and yet often denied to women in this group.

What happens when human rights expressed in personal preferences – to become a parent, for instance – encounter social controls and cultural biases? In Chapter 7 Parish focuses on the sociopolitical context and challenges of parenting among women with intellectual disabilities.

To extend the context of health in terms of social relationships, in Chapter 8 Bigby explores the social realm of women with intellectual disabilities, defining the social roles they play and the various social supports, both personal and instrumental, within their grasp.

Promoting health

Given the complex environmental factors governing their lives, what measures can best promote health among women with intellectual disabilities? A key theme is for women themselves to be personally engaged in efforts to reflect on and to promote their own health throughout their adult lives. In Chapter 9 Gill and Brown give a voice to women with intellectual disabilities by examining their perspectives regarding their health care needs, experiences and concerns. They point to the pressing need for more education of adults with intellectual disabilities, their carers, and health professionals regarding the specific health of women with intellectual disabilities.

Greater self-direction, no matter how desirable, may also expose women with intellectual disabilities to deleterious experiences such as