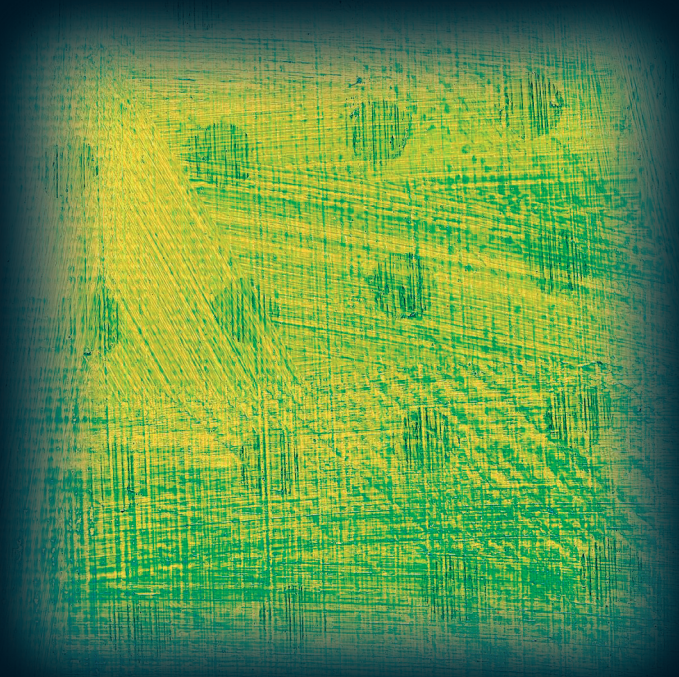




Wiley Series in Clinical Psychology



Clinical Psychology and People with Intellectual Disabilities

Second Edition

Eric Emerson, Chris Hatton, Kate Dickson, Rupa
Gone, Amanda Caine and Jo Bromley

 WILEY-BLACKWELL



CLINICAL PSYCHOLOGY AND
PEOPLE WITH INTELLECTUAL
DISABILITIES



Wiley Series in CLINICAL PSYCHOLOGY

Adrian Wells *School of Psychological Sciences, University of Manchester, UK*
(Series Advisor)

For other titles in this series please visit www.wiley.com/go/cs



CLINICAL PSYCHOLOGY AND PEOPLE WITH INTELLECTUAL DISABILITIES

Second Edition

Edited by

Eric Emerson (Lancaster University
and University of Sydney)

Chris Hatton (Lancaster University)

Kate Dickson (Betsi Cadwaladr University Health Board)

Rupa Gone (Enfield Integrated Learning Disabilities
Service)

Amanda Caine (Pennine Care NHS Foundation Trust)

Jo Bromley (Central Manchester University Hospitals
NHS Foundation Trust)



WILEY-BLACKWELL

A John Wiley & Sons, Ltd., Publication

This edition first published 2012
© 2012 John Wiley & Sons, Ltd

Wiley-Blackwell is an imprint of John Wiley & Sons, formed by the merger of Wiley's global Scientific, Technical and Medical business with Blackwell Publishing.

Registered Office

John Wiley & Sons Ltd, The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

Editorial Offices

350 Main Street, Malden, MA 02148-5020, USA

9600 Garsington Road, Oxford, OX4 2DQ, UK

The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

For details of our global editorial offices, for customer services, and for information about how to apply for permission to reuse the copyright material in this book please see our website at www.wiley.com/wiley-blackwell.

The right of Eric Emerson, Kate Dickson, Rupa Gone, Chris Hatton, Jo Bromley and Amanda Caine to be identified as the authors of the editorial material in this work has been asserted in accordance with the UK 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.

Wiley also publishes its books in a variety of electronic formats. Some content that appears in print may not be available in electronic books.

Designations used by companies to distinguish their products are often claimed as trademarks. All brand names and product names used in this book are trade names, service marks, trademarks or registered trademarks of their respective owners. The publisher is not associated with any product or vendor mentioned in this book. This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. It is sold on the understanding that the publisher is not engaged in rendering professional services. If professional advice or other expert assistance is required, the services of a competent professional should be sought.

Library of Congress Cataloging-in-Publication Data

Clinical psychology and people with intellectual disabilities / edited by Eric Emerson ... [et al.]. – 2nd ed.

p. ; cm.

Includes bibliographical references and index.

ISBN 978-0-470-02971-8 (cloth) – ISBN 978-0-470-02972-5 (pbk.)

I. Emerson, Eric, 1953–

[DNLM: 1. Mental Retardation–complications. 2. Mentally Disabled Persons–psychology. 3. Mental Disorders–therapy. 4. Psychology, Clinical–methods. WM 300] 616.89–dc23

2011043016

A catalogue record for this book is available from the British Library.

Wiley also publishes its books in a variety of electronic formats. Some content that appears in print may not be available in electronic books.

Set in 10/12pt Palatino by SPi Publisher Services, Pondicherry, India

*In memory of our colleague
and friend Amanda Caine (1954–2011)*

CONTENTS

About the Editors	ix
List of Contributors	xi
Preface	xiii
Part 1: Setting the Scene	1
Chapter 1 Intellectual Disabilities – Classification, Epidemiology and Causes	3
<i>Chris Hatton</i>	
Chapter 2 Service Provision	23
<i>Rupa Gone, Chris Hatton and Amanda Caine</i>	
Chapter 3 Social Context	51
<i>Eric Emerson and Rupa Gone</i>	
Chapter 4 Cognitive Assessment	63
<i>Isobel Lamb</i>	
Chapter 5 Common Legal Issues in Clinical Practice	83
<i>A.J. Holland</i>	
Part 2: General Clinical Issues.....	105
Chapter 6 Interviewing People with Intellectual Disabilities	107
<i>Helen Prosser and Jo Bromley</i>	
Chapter 7 Working with People: Direct Interventions	121
<i>Nigel Beail and Andrew Jahoda</i>	
Chapter 8 Working with Families.....	141
<i>Jo Bromley and Christine Mellor</i>	
Chapter 9 Working with Organisations or: Why Won't They Follow My Advice?.....	161
<i>Judith McBrien and Sue Candy</i>	
Chapter 10 Reflections on 25 Years Working in the NHS	181
<i>Ian Fleming</i>	

Part 3: Working with...	203
Chapter 11 Working with People Whose Behaviour Challenges Services	205
<i>Alick Bush</i>	
Chapter 12 Working with Offenders or Alleged Offenders with Intellectual Disabilities	235
<i>Glynis H. Murphy and Isabel C.H. Clare</i>	
Chapter 13 Sexual Exploitation of People with Intellectual Disabilities	273
<i>Paul Withers and Jennifer Morris</i>	
Chapter 14 Working with Parents Who Happen to Have Intellectual Disabilities.....	293
<i>Sue McGaw</i>	
Chapter 15 People with Intellectual Disabilities and Mental Ill-Health.....	313
<i>D. Dagnan and W.R. Lindsay</i>	
Chapter 16 Working with People with Autism	339
<i>Jo Bromley, Elizabeth Crabtree, Christine Mellor and Mary Delaney</i>	
Chapter 17 Older Adults with Intellectual Disabilities: Issues in Ageing and Dementia	359
<i>Sunny Kalsy-Lillico, Dawn Adams and Chris Oliver</i>	
Index.....	393



ABOUT THE EDITORS

Eric Emerson is Professor of Disability and Health Research at the Division for Health Research, Lancaster University (UK) and Professor of Disability and Population Health in the Faculty of Health Sciences at the University of Sydney (Australia). His research addresses the health and social inequalities faced by people with disabilities and, in particular, people with intellectual and developmental disabilities.

Chris Hatton is currently Professor of Psychology, Health and Social Care at the Centre for Disability Research at Lancaster University, where he has worked since 2000. His research has principally involved people with intellectual disabilities, focusing on documenting the nature and scale of inequalities experienced by people with intellectual disabilities and their families and evaluating policy and practice innovations to reduce/eliminate these inequalities.

Kate Dickson is a Clinical Psychologist working for the Betsi Cadwaladr University Health Board in North Wales. She specialises in work with children with intellectual and developmental disabilities and their families.

Rupa Gone qualified as a Chartered Clinical Psychologist in 2002. She is currently working with adults with intellectual disabilities as head of psychology in an Integrated Learning Disabilities Service in Enfield. Previously she has worked as a clinical psychologist with children who have intellectual disabilities and/ or autistic spectrum disorders for Hertfordshire Community NHS Trust; and with people with intellectual disabilities in Bury and in Rochdale, for Pennine Care NHS Foundation Trust.

Amanda Caine was Consultant Clinical Psychologist in the Psychological Therapies Service Pennine Care NHS Foundation Trust. She had always worked in the NHS with several different client groups including adults with learning disabilities.

Jo Bromley is Service Lead for the Clinical Psychology Service for Children with Disabilities in Manchester (Central Manchester Foundation Hospitals NHS Trust). She has a particular interest in making Child and Adolescent Mental Health Services accessible to children with disabilities and their families.



LIST OF CONTRIBUTORS

Dawn Adams

School of Psychology, University of Birmingham, UK

Nigel Beail

Professor and Clinical Lecturer, Department of Psychology, University of Sheffield; Professional Head of Psychology Services, Barnsley NHS, UK

Alick Bush

Psychological Services, Sheffield Health and Social Care NHS Foundation Trust

Sue Candy

Consultant Clinical Psychologist and Managing Director Psychology Associates, Saltash Cornwall.

Isabel C.H. Clare

Consultant Clinical and Forensic Psychologist, Cambridgeshire and Peterborough NHS Foundation Trust and Cambridge Intellectual and Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge

Elizabeth Crabtree

Consultant Clinical Psychologist, Alder Hey Children's NHS Foundation Trust

D. Dagnan

Honorary Professor, Lancaster University; Clinical Director, Cumbria Partnership NHS Trust

Mary Delaney

Specialist Clinical Psychologist, Oldham Community Stroke Team, Pennine Care NHS Foundation Trust, Integrated Care Centre, New Radcliffe Street, Oldham, OL1 1NL

Ian Fleming

Consultant Clinical Psychologist PennineCare NHS Trust, Lancashire, UK

A.J. Holland

Health Foundation Chair in Learning Disabilities, CIDDRG, Section of Developmental Psychiatry, University of Cambridge

Andrew Jahoda

Professor (Learning Disabilities), Glasgow University Centre for Excellence in Disabilities Development, University of Glasgow; Honorary Consultant Clinical Psychologist, Glasgow Learning Disability Partnership

Dr Sunny Kalsy-Lillico

Consultant Clinical Psychologist, Birmingham Learning Disabilities Service, Birmingham Community Healthcare NHS Trust, UK

Dr Isobel Lamb

Consultant Clinical Psychologist, Head of Learning Disability Speciality Blackburn with Darwen and Hyndburn Ribble Valley, Lancashire Care NHS Foundation Trust, UK

W.R. Lindsay

Consultant Clinical Psychologist, Lead Clinician in Scotland and Head of Research, Castlebeck Care; Chair of Learning Disabilities and Forensic Psychology, University of Abertay, Dundee

Judith McBrien

Consultant Clinical Psychologist, Cornwall Foundation NHS Trust.

Sue McGaw

Consultant Clinical Psychologist, PAMS Training Ltd, Cornwall

Christine Mellor

Clinical Psychologist, Central Manchester Foundation NHS Trust

Jennifer Morris

Clinical Psychologist, Mersey Care NHS Trust

Glynis H. Murphy

Professor of Clinical Psychology & Learning Disabilities, Tizard Centre, University of Kent

Chris Oliver

School of Psychology, University of Birmingham, UK

Helen Prosser

School of Health Sciences, University of Salford

Paul Withers

Head of Psychological Treatment Services, Calderstones Partnership NHS Foundation Trust



PREFACE

In compiling the second edition of our book *Clinical Psychology and People with Intellectual Disabilities* we have attempted to provide a resource that will support the training of clinical psychologists and other professionals to work with people with intellectual disabilities. Our aim was to produce a text that covered the middle ground between a 'how to do it' manual and an academic review of the relevant literature.

The book consists of three sections. In the first section (creatively called Part 1: Setting the Scene) we have attempted to cover a range of issues that are likely to (or should) underpin the provision of clinical psychology (and other) services for people with intellectual disabilities. These include summaries of what is known about the number of people who have intellectual disabilities, the needs of people with intellectual disabilities, trends in service provision for people with intellectual disabilities and the legal framework within which services are provided.

In Part 2, we address a range of issues pertinent to clinical practice. These include general issues related to interviewing people with intellectual disabilities, structuring interventions and building rapport, working with families and with (and within) organisations.

In Part 3, we focus more specifically on issues related to clinical practice when working with some particular client groups; people with challenging behaviours or mental health problems, older people, parents who themselves have learning disabilities, people at risk of (or who have experienced) sexual exploitation and people with autism spectrum disorders. This list was not meant to be (and could not be) exhaustive. Instead our aim was to address clinical issues pertinent to supporting some of the more common reasons for intervention.

We hope that this comprehensive revision of *Clinical Psychology and People with Intellectual Disabilities* provides clinical psychologists and other professionals with the context, evidence and expert guidance required for effective clinical practice.

Eric Emerson
Chris Hatton
Kate Dickson
Rupa Gone
Amanda Caine
Jo Bromley



Part 1

SETTING THE SCENE

Chapter 1

INTELLECTUAL DISABILITIES – CLASSIFICATION, EPIDEMIOLOGY AND CAUSES

Chris Hatton

INTRODUCTION

Epidemiology has been defined as ‘the study of the distribution and determinants of health, disease, and disorder in human populations’ (Fryers 1993). Although intellectual disability can be argued to be neither a disease nor a disorder, understanding the epidemiology of intellectual disability is of fundamental importance for service planning. Quite simply, to provide a needs-led service you have to know how many people with intellectual disabilities there are, what services they are likely to need, and whether there will be any changes in the need for services in the future.

However, determining the epidemiology and causes of intellectual disabilities is at best an inexact science. As ‘intellectual disability’ is socially constructed, what it means, how it is measured, and therefore who counts as having an ‘intellectual disability’ has varied over time (Trent 1995; Wright and Digby 1996) and across cultures and countries (Emerson *et al.* 2007; Jenkins 1998). Current professionally driven conceptualisations of ‘intellectual disability’ as largely a deficit in intelligence (Wright and Digby 1996) often have little resonance for people labelled with intellectual disability or their families (Finlay and Lyons 2005; Jenkins 1998). Therefore, before looking more closely at the literature concerning epidemiology and causes, we must first look at how people are currently classified as having an ‘intellectual disability’.

CLASSIFICATION

As mentioned above, 'intellectual disability' is socially constructed. The classification system used will determine who counts as having an 'intellectual disability', with obvious consequences when considering epidemiology and causes. In high-income English speaking countries, over the last 100 years classification systems have largely located intellectual disability as a series of deficits within the individual; typically in terms of deficits in intelligence and 'adaptive behaviour' (the behaviours necessary to function within society) that become apparent before cultural norms of adulthood (Emerson *et al.* 2007) – the so-called 'medical model'. In more recent times, the social model of disability (where it isn't a person's 'impairment' that disables them, but the oppressive organisation of society that acts to create disability) has presented a fundamental challenge to traditional classification systems (Thomas 2007).

Classification systems have changed in different ways to meet the challenge laid down by the social model of disability. For example, the American Association on Mental Retardation (AAMR), now renamed the American Association on Intellectual and Developmental Disabilities (AAIDD), produced the most recent revision of their classification system in 2010 (AAIDD 2010), presented in Box 1.1; similar (although less precise) definitions are used by the Department of Health (Department of Health 2001). This revision still locates intellectual disability as largely a function of individual deficits, although in their guidance they do state that adaptive skills are a result of the 'fit' between a person's capacities and their environment. In a supportive environment a person may be able to function perfectly well (thus not meeting the criteria for intellectual disability) – in a less supportive environment the same person may have problems and meet criteria for intellectual disability.

A more thoroughgoing attempt to incorporate social model ideas into medical model classification systems has come from the World Health Organization's International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001). This classification system attempts to describe intellectual disability in terms of interactions between the person's impairment (i.e. intellectual ability), their potential capacity and their actual performance across a range of activities, taking into account the person's environmental, cultural and personal context.

Whichever classification system is used, there are a number of issues regarding classification which are likely to arise when working in services for people with intellectual disabilities.

Box 1.1 AAIDD 2010 Definition of ‘Intellectual Disability’

‘Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.’

OPERATIONAL DEFINITIONS:

‘Intellectual functioning: an IQ score that is approximately two standard deviations below the mean, considering the standard error of measurement for the specific assessment instruments used and the instruments’ strengths and limitations.’

‘Adaptive behavior: performance on a standardized measure of adaptive behavior that is normed on the general population including people with and without ID that is approximately two standard deviations below the mean of either (a) one of the following three types of adaptive behavior; conceptual, social, and practical or (b) an overall score on a standardized measure of conceptual, social, and practical skills.’

Important elements of the definition:

...significant limitations ...

Intellectual disability is defined as a fundamental difficulty in learning and performing certain daily life skills. There must be significant limitations in conceptual, social and practical adaptive skills, which are specifically affected. Other areas (e.g. health, temperament) may not be.

...in intellectual functioning...

This is defined as an IQ standard score of approximately 70 to 75 or below (approximately two standard deviations below the mean), based on assessment that includes one or more individually administered general intelligence tests.

...and in adaptive behavior...

Intellectual functioning alone is insufficient to classify someone as having an intellectual disability. In addition, there must be significant

limitations in adaptive skills (i.e. the skills to cope successfully with the daily tasks of living.

...originates before age 18...

The 18th birthday approximates the age when individuals in this society (i.e. USA) typically assume adult roles. In other societies, a different age criterion might be more appropriate.

Levels of Intellectual Disability

Although some classification systems do not define levels of intellectual disability and regard the labels attached to levels of intellectual disability as misleading (AAIDD 2010), the concept of different degrees of severity of intellectual disability is commonly used in policy and practice in the UK. These classifications are typically based on standardised IQ scores. A typical system is that of the International Classification of Diseases (or ICD), produced by the World Health Organisation:

Mild	50–70
Moderate	35–49
Severe	20–34
Profound	<20

For many purposes (such as epidemiological studies), all people with $IQ < 50$ are classified as people with severe intellectual disabilities. While these labels of levels may assist heuristically in getting a sense of a person's likely capabilities and support needs, they do not map reliably on to capabilities that are potentially important for the clinician, such as capacity to give informed consent or capacity to participate effectively in clinical interventions requiring significant linguistic, memory or other cognitive capabilities. There is no substitute for individual assessment of a person's individual profile of capabilities and support needs.

Cultural and Linguistic Diversity

'Intellectual disability' is socially constructed, and can be regarded as a product of specific English-speaking cultures at a particular point in history (Emerson *et al.* 2007). This is particularly important when considering the reliance of epidemiological research on IQ tests, which can dramatically

over-estimate prevalence rates of intellectual disability amongst minority ethnic communities (Hatton 2002; Leonard and Wen 2002). There are also highly likely to be cultural differences in perceptions of which behaviours are considered to be adaptive (Jenkins 1998).

Present Functioning

'Intellectual disability' is not necessarily a life-long trait or condition, and depending on people's circumstances and responses to them they may not be regarded as having intellectual disabilities throughout their lives. Indeed, many people with 'mild' intellectual disabilities (but see AAIDD 2010) have only intermittent and time-limited contact with services, usually to assist at times of crisis.

Classification in Service Settings

Formal classification systems like the ones outlined above, with their associated assessment tools, are rarely used in existing services to make decisions about whether a person has intellectual disabilities. Also, because such assessments are made by professionals within services, decisions about whether a person has intellectual disabilities are frequently influenced by the availability of services and the professional's judgement of what is in the best interests of the individual. Many factors can impact upon this decision; financial, political, ideological, and administrative.

Consequently, there may be people within intellectual disability services who would not meet systematic classification criteria (e.g. people who were institutionalised many years ago). It is also highly likely that there are people not in contact with intellectual disability services who would meet standard classification criteria. Services are increasingly tightening eligibility criteria to decide who is eligible for intellectual disability services and to 'prioritise' (i.e. ration) service provision. These eligibility criteria vary widely between different services, and use widely different methods of assessment.

EPIDEMIOLOGY

The general epidemiological literature generally has two ways of counting the number of people with a particular disorder in a given population, *prevalence* and *incidence* (see Box 1.2), although as the above discussion will have made clear this is a very inexact science when applied to people with intellectual disabilities.

Box 1.2 Definitions of prevalence and incidence

Prevalence is the number of cases, old and new, existing in a population at a given point in time or over a specified period.

Incidence refers to the number of new cases of a disorder arising in a population in a stated period of time.

(Richardson and Koller 1985)

Prevalence

Epidemiological studies of the prevalence of intellectual disabilities of children and adults across the world's high income countries are becoming more common (see Leonard and Wen 2002; McLaren and Bryson 1987; Murphy *et al.* 1998; Roeleveld *et al.* 1997 for reviews). Prevalence estimates for the world's middle and low income countries are more sparse and varied for a number of reasons, but rates may be higher than those found in high income countries (Durkin *et al.* 2006; Emerson and Hatton 2007; Maulik *et al.* 2011). Much of the variance in prevalence rates reported across studies can be accounted for by methodological factors, including:

- 1) *Sampling method.* Studies which use total population samples, and assess all members of a population for intellectual disability, typically report much higher overall prevalence rates than studies using administratively defined populations (i.e. those currently using services for people with intellectual disabilities or those known to services). This discrepancy is much less for studies of the prevalence of severe intellectual disabilities.
- 2) *Classification criteria.* As discussed earlier, classification systems for deciding whether a person has an intellectual disability vary over time and across different geographical areas, and different researchers have used more or less stringent criteria for classifying people with intellectual disabilities.
- 3) *Assessment method.* Reliance on IQ alone almost inevitably results in higher prevalence rates than those using IQ and adaptive behaviour assessment methods. Other factors, such as the skills of the professional conducting the assessment and the language and culture of people being tested (and those doing the testing) will all influence the prevalence rate reported.

People with Mild Intellectual Disabilities (i.e. IQ 50 or 55 to 70)

Studies of high income countries (see Leonard and Wen 2002; McLaren and Bryson 1987; Murphy *et al.* 1998; Roeleveld *et al.* 1997) report the following findings (see Durkin *et al.* 2006, for information on low and middle income countries):

- 1) General prevalence rates (i.e. across all ages) of mild intellectual disabilities from 3.7 to 5.9 per 1,000 based on administratively defined populations (i.e. those known to services), with total population studies reporting much higher prevalence rates (based on IQ assessment only) of around 30 per 1,000, although a recent UK study has produced an estimated prevalence rate of 80 per 1,000 (Simonoff *et al.* 2006).
- 2) More males with mild intellectual disabilities than females (ratio approx. 1.6:1, although gender ratios vary widely across studies).
- 3) An increase in the apparent prevalence of mild intellectual disabilities throughout the school years, followed by a sharp drop around the school leaving age.
- 4) A disproportionate number of people with mild intellectual disabilities come from disadvantaged socio-economic backgrounds.

These findings illustrate clearly the complex processes involved in the classification of people as having intellectual disabilities. For example, changes in age-specific prevalence rates (e.g. increasing across school age, then dropping beyond school-leaving age) may simply reflect people's identification by and ongoing contact with services, or they may be a consequence of people on adulthood demonstrating a good adaptive fit to their circumstances, thereby no longer meeting the classification criteria for intellectual disability.

People With Severe Intellectual Disabilities (i.e. IQ < 50 or 55)

Studies of high income countries (see Leonard and Wen 2002; McLaren and Bryson 1987; Murphy *et al.* 1998; Roeleveld *et al.* 1997) report the following findings (see Durkin *et al.* 2006, for information on low and middle income countries, where prevalence rates are likely to be at least double):

- 1) General prevalence rates (i.e. across all ages) of severe intellectual disabilities from 3 to 4 per 1,000, with total population studies reporting higher prevalence rates (e.g. 6.3 per 1,000) than studies using administratively defined populations.

- 2) More males with severe intellectual disabilities than females (ratio approx 1.2:1).
- 3) An increase in the apparent prevalence of severe intellectual disabilities throughout the school years, with little if any reduction at school-leaving age.
- 4) Less association between prevalence and socio-economic background.

For people with severe intellectual disabilities, the classification of intellectual disability is usually made with more confidence and earlier than for people with mild intellectual disabilities. Also, children with severe intellectual disabilities are likely to continue receiving services after leaving school, and are less likely to move out of a classification of intellectual disability due to changes in circumstances.

Incidence

Epidemiological studies of the incidence of intellectual disability are scarcer than studies of prevalence, largely due to their methodological difficulty (Fryers 1993). These studies tend to rely on administratively defined populations of people with intellectual disabilities (typically people identified as such by service systems) rather than independently assessing entire populations, resulting in possible underestimates of incidence for people with mild intellectual disabilities. Studies across the US and Northern Europe have reported similar incidence rates – for example a US study reported a cumulative incidence at age 8 years of 4.9 children with severe intellectual disabilities per 1,000 births and 4.3 children with mild intellectual disabilities per 1,000 births (Katusic *et al.* 1995; see also Rantakallio and von Wendt 1986).

UK Trends – Prevalence and Service Need

It is not possible to estimate the number of number of people with intellectual disabilities in the UK either from information held by central government departments or from large-scale population based surveys. Robust estimates of current and future numbers of people with intellectual disabilities, based on data from registers and general population data, have been recently derived (Emerson and Hatton 2008, 2011). These estimates conclude that:

- 169,000 people aged 20 or more (0.46% of the adult population) were known users of learning disability services in England. Of these, 26,000 were aged 60 or more.

- 985,000 people in England have an intellectual disability, including people not identified by specialist services (2% of the general population). This included 796,000 people aged 20 or more, of whom 174,000 were people aged 60 or more.
- Overall, there will be sustained growth over the next two decades in both the numbers of people with intellectual disabilities known to learning disability services (11% over the decade 2001–2011, 14% over the two decades 2001–2021) and the estimated ‘true’ number of people with intellectual disabilities in England (15% over the decade 2001–2011, 20% over the two decades 2001–2021).
- Within the 50+ age range there will be very marked increases in both the numbers of people with learning disabilities known to learning disability services (28% over the decade 2001–2011, 48% over the two decades 2001–2021) and in the estimated ‘true’ number of people with intellectual disabilities in England (31% over the decade 2001–2011, 53% over the two decades 2001–2021).

When considering the service needs of people with intellectual disabilities in the UK, three issues stand out:

- 1) In common with other high income countries, the life expectancy of people with intellectual disabilities in the UK is increasing, although still lower than that of the general population (Carter and Jancar 1983; Hollins *et al.* 1998; McGuigan *et al.* 1995). Combined with bulges in prevalence rates for the ‘baby boom’ generation (Fryers 1993) and the increasing survival throughout adulthood of people with more complex and multiple needs, this increased life expectancy suggests a sharp rise in demand for adult services, particularly housing support services.
- 2) There is some tentative evidence (Emerson and Hatton 2004; Emerson *et al.* 1997; Kerr 2001; but see McGrother *et al.* 2002) of higher prevalence rates of severe intellectual disability for children in some South Asian communities in the UK. Combined with the relatively young age structure of minority ethnic communities in the UK, the need for services directed to South Asian people with intellectual disabilities (and possibly other minority ethnic communities, although prevalence data are unavailable) will continue to increase over the next 20 years (Emerson and Hatton 1999).
- 3) There is a consensus among practitioners that increasing numbers of children with intellectual disabilities and very complex medical needs are surviving into adulthood as a result of improved medical care and nutrition (e.g. tube feeding). At present, however, no data are available with which to evaluate this claim.

Disorders and Conditions Associated with Intellectual Disabilities

A range of disorders have been found to be more likely amongst people with intellectual disabilities. While the number of additional disorders a person is likely to have increases with the severity of the intellectual disability, the type of additional disorder reported does not seem to vary significantly across the range of intellectual disabilities (McLaren and Bryson 1987). The wide variation in prevalence rates for associated disorders reflect a wide range of methodological, classification, and assessment differences across studies, and therefore should not be treated as definitive. The most common disorders or conditions associated with intellectual disabilities include:

- 1) *Epilepsy*. Between 15% and 30% of people with intellectual disabilities have been reported to have epilepsy (McLaren and Bryson 1987).
- 2) *Cerebral palsy/other motor impairments*; reported in 20% to 30% of people with intellectual disabilities (McLaren and Bryson 1987).
- 3) *Sensory impairments*; reported in 10% to 33% of people with intellectual disabilities, although studies using clinical criteria for sensory impairments report much higher rates than studies using functional criteria (Hatton and Emerson 1995; McLaren and Bryson 1987).
- 4) *Challenging behaviour*; reported in 6% to 14% of people with intellectual disabilities, although there are widely different criteria for determining and measuring challenging behaviour (Emerson 2001; McLaren and Bryson 1987).
- 5) *Mental health problems*. Due to difficulties in accurately identifying mental health problems in people with intellectual disabilities and differences in definition, the range of prevalence rates reported are particularly wide (10% to 80%), although studies using more stringent criteria tend to report rates of mental health problems among adults (around 20% to 40%) similar to or slightly higher than the general population (Hatton and Taylor 2005). Among children, there is growing evidence of a four to five fold elevation in rates of mental health problems among children with intellectual disabilities (Einfeld and Emerson 2008; Emerson and Hatton 2007).

CAUSES OF INTELLECTUAL DISABILITY

Understanding the causes of a person's intellectual disability can have a potentially crucial impact on prevention, treatment and management programmes for that individual (AAIDD 2010). The 'new genetics' (Dykens *et al.* 2000) is driving much of the research attempting to link genetic

'causes' to treatment and management, although much of this work is the subject of intense ethical debate. For clinical psychologists, the most important issue is that understanding the cause of a person's intellectual disability may have implications for management programmes. One well-known example is phenylketonuria, a deficit in metabolising a particular protein which causes severe intellectual disabilities if untreated. However, such intellectual disabilities can be completely avoided by a diet low in the protein phenylalanine.

The 'new genetics' has also introduced the concept of the 'behavioural phenotype' (Dykens *et al.* 2000; Hodapp and Dykens 2004). Prototypically, 'a behavioral phenotype should consist of a distinct behavior that occurs in almost every case of a genetic or chromosomal disorder, and rarely (if at all) in other conditions' (Flynt and Yule 1994, p. 666). This strict definition would limit the study of behavioural phenotypes to a small number of genetic/chromosomal conditions with clear behavioural consequences (e.g. self-mutilation in Lesch-Nyhan syndrome; hyperphagia in Prader-Willi syndrome). This original concept of behavioral phenotypes has been broadened to a more probabilistic definition, for example 'the heightened probability or likelihood that people with a given syndrome will exhibit certain behavioral and developmental sequelae relative to those without the syndrome' (Dykens 1995; p. 523). Clearly, understanding the behavioural phenotype associated with a specific condition is vital when supporting that individual, for example in terms of the person's physical environment, routines, learning style, challenging behaviours, etc. (Dykens *et al.* 2000). However, some caution needs to be expressed regarding the behavioural phenotype approach. Correspondences between genetic syndrome and particular behaviours are rarely perfect; many people with the genetic syndrome do not show the behaviour and many people without the genetic syndrome do show the behaviour. There is also a danger that self-fulfilling prophecies may occur within services (for example, the belief that if a person has a particular genetic syndrome, then particular behaviours are inevitable and not amenable to intervention).

The incidence, prevalence and consequences of different aetiologies are dynamic over time, due to factors such as changes in the age of parents at the child's birth, changes in parental health behaviours such as smoking and alcohol use prenatally, prenatal screening programmes, the survival and treatment of low birthweight babies, and interventions for specific factors associated with intellectual disabilities (Brosco *et al.* 2006; Leonard and Wen 2002), although overall prevalence rates seem relatively stable (Leonard and Wen 2002).

Generally, studies estimate that for people with severe intellectual disabilities, aetiology is unknown for between 20% and 40% of cases, although figures in recent studies are at the lower end of this range

(Leonard and Wen 2002; McLaren and Bryson 1987; Partington *et al.* 2000). For people with mild intellectual disabilities, aetiology is unknown for a somewhat higher 45% to 62% of cases (McLaren and Bryson 1987). For perhaps the majority of people, the determinants of intellectual disability will involve a complex interaction between biomedical, social, behavioural and educational factors. These factors may influence the individual at the prenatal, perinatal, and postnatal stages of life.

Prenatal Causes

Overall, studies estimate that more than 20% of cases of severe intellectual disability can be accounted for by chromosomal disorders, and that a further 20% to 40% of cases accounted for by other prenatal factors, such as single gene disorders, multi-factorial/polygenetic causes and environmental effects (McLaren and Bryson 1987; Partington *et al.* 2000). For people with mild intellectual disabilities, only 4% to 10% of cases are generally accounted for by chromosomal disorders (McLaren and Bryson 1987; Matilainen *et al.* 1995), with a further 11% to 23% of cases assumed to be due to other prenatal causes (McLaren and Bryson 1987; Matilainen *et al.* 1995).

Biomedical Factors

Prenatal biomedical factors potentially determining intellectual disability include chromosomal disorders, single gene disorders and other syndrome disorders (see Connor and Ferguson-Smith 1993; Plomin *et al.* 1997). Advances in medical genetics are being made at a rapid pace, with an increasing number of genetic abnormalities and associated syndromes being identified, although how many cases of currently unknown aetiology will become newly identified is open to debate (McLaren and Bryson 1987).

Chromosomal disorders These account for between 20% and 40% of all live births of people with severe intellectual disabilities. This range of estimates possibly reflects differences across studies in the availability of amniocentesis and genetic screening, and differences in maternal age (McLaren and Bryson 1987). The majority of conceptions with chromosomal disorders spontaneously abort (Connor and Ferguson-Smith 1993).

By far the most common chromosomal disorder associated with intellectual disability is Down syndrome (Trisomy 21, where a person has an extra whole or part chromosome-21). Approximately 1 in 700 live births have Trisomy 21, and almost all people with Down syndrome have an additional intellectual disability to some degree. People with Down syndrome are at risk for congenital heart problems, thyroid problems, epilepsy, immunological deficiencies, vision and hearing loss, and reduced