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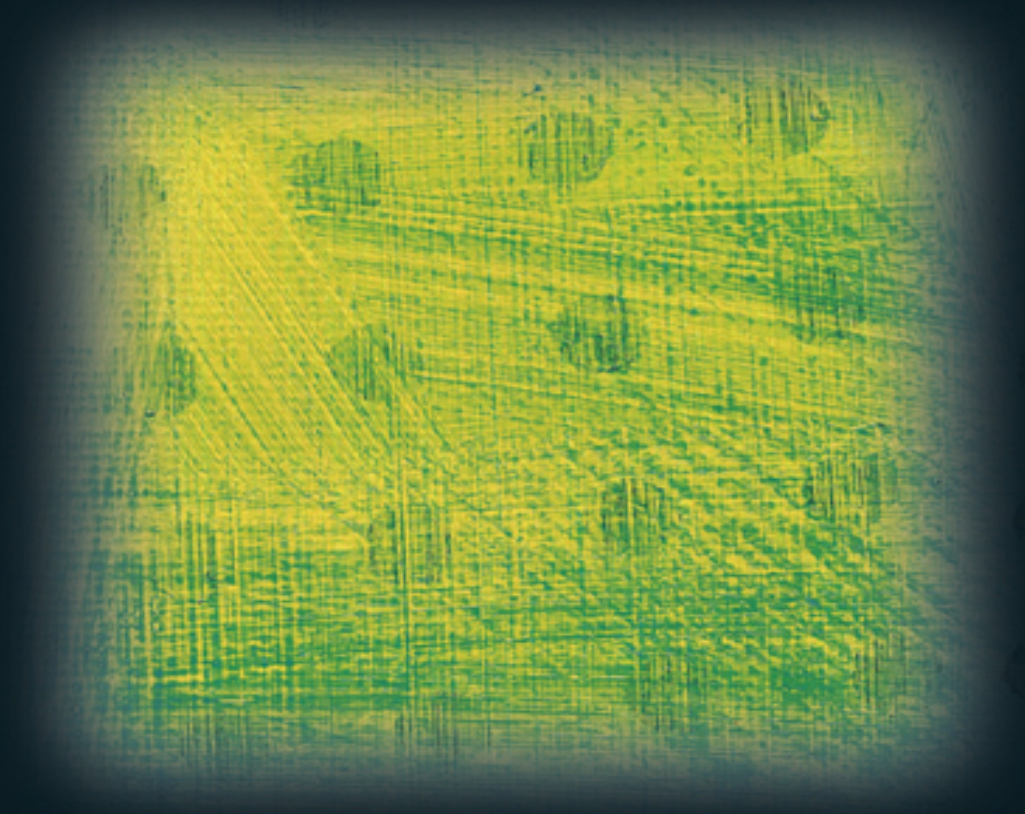

Clinical Psychology and People with Intellectual Disabilities

Second Edition

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

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CLINICAL PSYCHOLOGY AND PEOPLE WITH INTELLECTUAL DISABILITIES

Second Edition

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

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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.

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.

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.

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.