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Introduction

Around 0.1% of people have a severe intellectual disability and also engage in 'challenging' behaviours such as aggression, self-injury and destructiveness. This combination of severe intellectual and behavioural disabilities can significantly limit the life experiences of the person themselves and can place the health, safety and welfare of those who support them in jeopardy. They also represent a significant challenge to organizations involved in providing educational, health and welfare supports for people with intellectual disabilities.

Over the past four decades we have learned much about the nature of challenging behaviours and have developed approaches to support and intervention that have been shown to be effective, for some people, in bringing about rapid and socially significant reductions in challenging behaviour. The primary aim of this book is to provide a concise overview of this body of knowledge. This is not, however, a 'how-to-do-it' book. Instead, it will focus on describing developments in knowledge that have important implications for practice. A range of alternative texts are available for those seeking detailed instructions for carrying out intervention programmes (Ball *et al.*, 2004; Clements and Zarkowska, 2000; Luiselli, 2006; McLean and Grey, 2007; Sigafoos *et al.*, 2003; Thompson, 2008; Woodward *et al.*, 2007).

Virtually all of the studies mentioned in this book have been undertaken in one of the world's richer countries, and more often than not in one of the world's richer English-speaking countries. This bias reflects the existing pattern of inequalities in investment in health and social research related to people with intellectual disability (Emerson *et al.*, 2007a). However, we believe that many of the basic processes that underlie challenging behaviours are likely to be relatively universal and, as such, transcend cultural boundaries. What is culturally specific, however, is knowledge that relates to the organization and effectiveness of services designed to support people with intellectual disabilities and challenging behaviours. As such, the latter chapters of this book may be more relevant in some countries than others.

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Terms and definitions

Intellectual disability

The terms used to refer to people with intellectual disabilities have undergone numerous changes over the last century. As terms used to describe socially devalued groups enter the common vocabulary, they quickly acquire disparaging connotations. Today's scientific terminology quickly becomes tomorrow's terms of abuse. 'Idiots', 'imbeciles', 'morons', 'subnormals' and 'retards' are nowadays nothing more than terms of denigration. In this chapter we use the term intellectual disability in preference to the synonymous terms 'mental retardation', still used in the main psychiatric classificatory systems and in many countries around the world (American Psychiatric Association, 2000; World Health Organization, 1992, 1996, 2007), and 'learning disability' (often used in health and social care systems in the UK).

This choice reflects the emergence of intellectual disability as the preferred terminology within the international scientific community (cf., the International Association for the Scientific Study of Intellectual Disability, the American Association on Intellectual and Developmental Disabilities) (Harris, 2005). It also avoids the confusion arising from terms which have very different meanings in different countries (e.g. 'learning disability' has very different meanings in the UK and USA) and avoids the use of terms which in many countries have acquired disparaging connotations (e.g. mental handicap, mental retardation).

The definition of intellectual disability involves two core components: a general deficit in cognitive functioning, which emerges during childhood (American Psychiatric Association, 2000; Harris, 2005; World Health Organization, 1992, 1996). A 'general deficit in cognitive functioning' is usually taken as a score of less than two standard deviations below the mean on a standardized IQ test. Given that most IQ tests are constructed to have a mean of 100 and a standard deviation of 15, this is ordinarily equivalent to a score below 70. This aspect of the definition is important in discriminating between people with significant deficits in multiple areas of cognitive functioning and people with very specific cognitive deficits (or specific learning difficulties such as dyslexia). The second component of the definition (emergence during childhood, typically before the age of 18) is important in distinguishing people with intellectual disability from people with cognitive deficits acquired in later life; in particular, deficits associated with dementias.

A third component, that the person also shows deficits in adaptive behaviours or social functioning, is sometimes added to the definition. However, classificatory systems differ in the extent to which such deficits are seen as an inherent characteristic of the deficit in cognitive functioning or as an independent characteristic whose presence needs to be determined for the classification to apply. For example, the World Health Organization's ICD-10 guidance suggests that 'adaptive behaviour is *always impaired*, but in protected social

environments where support is available this impairment may not be at all obvious in subjects with mild mental retardation' (World Health Organization, 1996). In contrast, adaptive behaviour is considered as an independent criteria in the commonly used definition advocated by the American Association on Intellectual and Developmental Disabilities (AIDD, formerly the American Association on Mental Retardation; AAMR) (Luckasson *et al*., 2002; Schalock *et al*., 2007).

Unlike the measurement of cognitive functioning, there is at present no consensus on how 'impairments' or 'deficits' in adaptive behaviour should be operationalized. Indeed, there is a strong scientific case for considering social functioning and adaptive behaviour as a possible outcome of the interaction between impaired cognitive ability and prevailing social arrangements (rather than as a defining characteristic of intellectual disability). Such an approach is consistent with the World Health Organization's International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001; World Health Organization, 2007a). While the ICF recognizes the important association between impairments in 'intellectual functions' and disability, it does not include prescriptive cut-offs for such impairments.

Intellectual disability is often considered to comprise two distinct groups (Einfeld and Emerson, 2008). The first represents the lower end of the normal distribution of intelligence in the population. This group predominantly comprises individuals with mild intellectual disability that is presumed to result from both genetic and environmental influences. The second group comprises people whose 'general deficit in cognitive functioning' is the result of identifiable or apparent disorders, of genetic or environmental origin. In this group, intellectual disability is typically more severe and people are also much more likely to have other neurological problems such as epilepsy, sensory or motor deficits. Among people with severe intellectual disability, language may be absent or limited to individual words or phrases, or a limited range of signs may be used in communication.

Our concern within this book is primarily with people with severe intellectual disability. However, we will, at times, also draw on evidence and knowledge derived from studies of people with a wide range of intellectual disabilities. We will also draw on evidence and knowledge derived from studies of people who do not have intellectual disability.

Challenging behaviour

Over the two decades, the term 'challenging behaviour', initially promoted in North America by *The Association for People with Severe Handicaps*, has come to replace a number of related terms including abnormal, aberrant, disordered, disturbed, dysfunctional, maladaptive and problem behaviours. These terms have previously been used to describe broad classes of behaviours shown by

people with severe intellectual disabilities. They include aggression, destructiveness, self-injury, stereotyped mannerisms and a range of other behaviours, which may be either harmful to the individual (e.g. eating inedible objects), challenging for carers and care staff (e.g. non-compliance, persistent screaming, disturbed sleep patterns, overactivity) and/or objectionable to members of the public (e.g. regurgitation of food, the smearing of faeces over the body).

The term challenging behaviour has been defined as 'culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson, 1995, 2001a) or as 'behaviour . . . of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion' (Royal College of Psychiatrists *et al.*, 2007). There is little meaningful difference between these two definitions.

The term challenging behaviour will be used throughout the remainder of the book for a number of reasons. First, it is free from implicit assumptions regarding the characteristics of the behaviour. A number of alternative terms have unhelpful connotations regarding either the organization of behaviour (e.g. disordered behaviour) or the nature of the relationship between the behaviour and ongoing events (e.g. dysfunctional or maladaptive behaviour). As we shall see, considerable evidence suggests that for some people in some contexts 'challenging' behaviours may be both orderly and adaptive. Indeed, many challenging behaviours can be construed as (at least in the short term) coherently organized adaptive responses to 'challenging' situations.

Second, the term is specific to a socially significant sub-class of abnormal, odd or unusual behaviours. Challenging behaviour only refers to behaviours which involve significant risks to people's physical well-being or act to markedly reduce access to community settings. This consequently excludes behaviours which may be either statistically or culturally infrequent but have a less pronounced physical or social impact.

Culturally abnormal behaviours shown by people with severe intellectual disabilities which are likely to place the physical safety of the person or others in serious jeopardy include serious physical aggression, destructiveness and self-injury as well as such health-threatening behaviours as the smearing of faeces over the body and the eating of inedible objects. Less serious forms of physical and verbal aggression and, perhaps, minor self-injury and stereotypy are included in this definition because they may limit or prevent them gaining access to ordinary community facilities. In the main, however, the focus throughout this book will be on more seriously challenging behaviours.

It should be noted that challenging behaviour, as defined above, is not synonymous with psychiatric disorder. Not all psychiatric disorders (e.g.

anxiety, mild depression) place the safety of the person or others in jeopardy, or lead to the person being denied access to community settings. Nevertheless, there does exist a significant overlap between challenging behaviours and some categories of psychiatric disorder (e.g. conduct disorders in children). We will return to these issues later in the book.

Finally, the use of the term 'challenge' may help to focus our attention on the process by which social problems are created and defined. That is, it may help to broaden the focus of enquiry by placing individual 'pathology' in the social and interpersonal context in which certain acts are deemed problematic. As was pointed out over 20 years ago, the term challenging behaviour 'emphasizes that such behaviours represent challenges to services rather than problems which individuals with intellectual disabilities in some way carry around with them' (Blunden and Allen, 1987). Indeed, when the term was introduced, it was intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics (Department of Health, 2007). Since then, there has been a drift towards using the term simply as a diagnostic label for people. This is both inappropriate and unhelpful (Department of Health, 2007; Royal College of Psychiatrists *et al.*, 2007). We will use the term in its original meaning in this book.

To construe a situation as a challenge rather than as a problem may encourage more constructive responses. However, it would, of course, be mistaken to believe that minor changes in terminology are capable of bringing about major changes in practice.

An overview

Our book is split into two main sections. The first section focuses on what has been learned to date regarding our understanding of challenging behaviours. In Chapter 2, **The social context of challenging behaviour**, some of the social processes that are involved in defining behaviour as challenging will be highlighted and some of the personal and social consequences that arise from having a severe intellectual disability and challenging behaviour will be examined. Throughout these discussions it will be argued that challenging behaviour must be seen as a social construction. The implications of this perspective will then be explored in relation to approaches to assessing the impact of interventions and supports. In the following chapter, **Epidemiology**, we will look at the available evidence regarding the prevalence, incidence and natural history of challenging behaviours. This information will add to our understanding of the social significance of challenging behaviour. In addition, we will review the results of research that has attempted to identify factors which place people at risk of developing challenging behaviour. Such information may give some insight into the types of processes that may underlie challenging behaviours. It

is also of potential value in targeting approaches to the prevention of challenging behaviour.

The following three chapters summarize the results of three quite distinct approaches to investigating the processes believed to possibly underlie challenging behaviours. In this series of chapters we will move from biological, through behavioural, to consideration of broader social processes. In Chapter 4, **Biological models and behavioural phenotypes**, we will review the burgeoning evidence relating to genetic and biological processes associated with challenging behaviours. In Chapter 5, **Behavioural models**, the models and concepts that underlie modern applied behavioural approaches to analysis and intervention will be discussed. In Chapter 6, **Social determinants**, we will turn to consider some of the wider social determinants of challenging behaviours. In the final chapter in this section, **An integrated approach**, we will explore possible linkages and associations between these very different approaches to understanding challenging behaviours.

The second section of the book focuses on the design and implementation of interventions and supports for people with severe intellectual disability and challenging behaviours. In Chapter 8, **The bases of intervention**, we will consider some of the broad perspectives and issues that should guide all approaches to intervention. In the following chapter, **Assessment and formulation**, we will review current knowledge and practice regarding the assessment of challenging behaviours from both biological and behavioural perspectives. The following two chapters will address current knowledge regarding the efficacy and effectiveness of **Psychopharmacological approaches** and **behavioural approaches** to intervention. Chapter 12, **The situational management of challenging behaviour** (written by David Allen), will address a related issue, approaches to the effective management, containment and diffusion of episodes of challenging behaviours.

The final chapter of the book turns to more general issues. In particular, we argue the case for taking a broader 'public health' approach to the issue of challenging behaviours, an approach that includes a significantly greater investment in preventative interventions.

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The social context of challenging behaviour

We have defined challenging behaviour as *culturally abnormal behaviour* of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, *or behaviour that is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities* (Emerson, 1995). This amendment to an earlier definition (Emerson *et al.*, 1988) made explicit the importance of social and cultural expectations and norms in defining behaviour as challenging.

Challenging behaviour is a social construction. Whether a behaviour is defined as challenging in a particular context will be dependent upon such factors as:

- social rules regarding what constitutes appropriate behaviour in that setting;
- the ability of the person to give a plausible account for their behaviour;
- the beliefs held by other participants in the setting about the nature of intellectual disabilities and the causes of the person's 'challenging' behaviour;
- capacity within the setting to manage any social disruption caused by the person's behaviour.

Behaviour in social settings is, at least in part, governed by implicit and explicit rules and expectations regarding what constitute appropriate conduct. The more formal the setting, the more explicit the rules. Indeed, context is essential in giving meaning to any behaviour. Behaviour can only be defined as challenging in particular contexts. For example, loud shouting and the use of 'offensive' language are likely to be tolerated (if not actually condoned) in restaurant kitchens and at football (soccer) matches. The same behaviour would certainly be considered 'challenging' during most religious services. Physical aggression is positively valued in the boxing ring. Severe self-directed aggression, is likely to be seen as challenging when shown by a person with intellectual disabilities, but may be viewed as a mark of religious piety when shown by a flagellant. At a more mundane level, stereotypic rocking is less likely to be tolerated in public places than in an institution for people with intellectual disabilities or in a nightclub.

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Expectations concerning the appropriateness of particular behaviours are also determined by cultural beliefs and general role expectations. Supporting a young man to enjoy a beer in the local pub may be seen as a positive achievement by young white staff in a residential service for people with intellectual disabilities, as unremarkable by other customers in the local pub, and as highly problematic by the young man's devout Muslim family. Similarly, physical aggression may be seen as being more deviant (in terms of involving a greater discrepancy between performance and cultural expectations) when shown by a woman with intellectual disabilities than when shown by a man.

As well as transgressing social conventions, people with disabilities are also likely to be cast in deviant or abnormal social roles. These may serve to modify the operation of contextual rules which ascribe meaning to behaviour. Thus, for example, viewing people with intellectual disabilities as 'eternal children' (Wolfensberger, 1972, 1975) may help absolve the person of personal responsibility for being challenging. In a similar vein, if a person is labelled as having an intellectual disability, observers will tend to ascribe their success on a task to external factors (e.g. the simplicity of the task), while ascribing failure to internal factors such as the person's cognitive impairments (Severence and Gastrom, 1977).

These processes may have a number of consequences, including increased tolerance for odd or deviant behaviour as long as the person is clearly identified as belonging to a defined group for whom personal responsibility is reduced. Indeed, the expectations surrounding group membership may include a positive expectation that the person will behave in unusual or odd ways. So, for example, members of the public may show greater tolerance for stereotypic rocking when shown by a person whom they can clearly label as having an intellectual disability than they would of an 'ordinary' member of the public.

The capacity of a setting to cope with any disruption caused by a person's challenging behaviour is also likely to contribute to determining whether they will be excluded. So, for example, the increased pressure in the UK on mainstream schools to demonstrate academic achievement is likely to increase the pressure to exclude pupils with intellectual disabilities who show challenging behaviour (Mental Health Foundation, 1997). Fluctuations in the levels of experience, competence, stress, stability and fatigue among members of a staff team are likely to determine their capacity to cope with the disruption caused by someone who shows severe self-injury.

Of course, none of these factors is static. The social acceptability of particular behaviours changes over time within and across cultures (e.g. the reduced tolerance of smoking in public places in the UK and North America). Expectations and norms governing behaviour within settings vary over time and across locations. As has been discussed above, the capacity of settings to manage the social disruption caused by challenging behaviour is likely to be

influenced by factors ranging from public policy to local fluctuations in staff sickness.

While contextual factors are crucial to defining behaviour as challenging, it would be surprising if there were no commonalities between people and settings in their tendency to perceive particular behaviours as more or less challenging. For example, Lowe and Felce summarized the results of two studies that suggested that the level of social disruption caused by a behaviour was integral to its definition as 'challenging' by carers and care staff (Lowe and Felce, 1995a; Lowe and Felce, 1995b). In the first study, analysis of carer and staff ratings collected over a 4-year period on 92 people with intellectual disabilities indicated that behaviours that caused the greatest social disruption (e.g. aggression) or had significant implications for the duty of care exercised by carers or care staff (e.g. running away) were rated as creating the most challenging. In the second study, they reported that the probability of referral to specialized challenging behaviour services was significantly increased if the person showed high levels of behaviours that were likely to be socially disruptive (e.g. aggression, non-compliance).

Similarly, Kiernan and Kiernan employed discriminant function analysis to identify factors which distinguished 'more difficult' from 'less difficult pupils' with severe intellectual disabilities in a survey of segregated special schools in England and Wales (Kiernan and Kiernan, 1994). The first ten factors, in order of significance for pupils without mobility limitations, were: physical aggression involving significant risk to others; persistent interruption of activities of other pupils; social disruption (e.g. screaming); violent temper tantrums occurring weekly; unpredictability of challenging behaviour; breakage of windows, fixtures and fittings; aggression toward other pupils; lack of understanding of emotions of others; non-compliance.

Consideration of the range of social issues involved in defining behaviour as challenging is important for a number of reasons. First, it highlights the importance of explicitly acknowledging the operation of such factors in the definition of challenging behaviour, including operational definitions of challenging behaviour employed in epidemiological research. Unless we acknowledge the importance of social and cultural factors in defining challenging behaviour, we may be tempted to search for ever more refined mechanical and physical definitions of an inherently social process. Such a course of action would, of course, be doomed to failure.

Second, viewing challenging behaviour as a social construction illustrates the complexity of the phenomenon and helps to begin to identify some possible approaches to intervention. Thus, for example, if a person's minor stereotypy has been defined as challenging primarily due to the avoidance behaviours it elicits in others, in some situations intervention may be most appropriately aimed at reducing such avoidance, rather than eliminating stereotypy.

Finally, conceptualizing challenging behaviour as a complex social phenomenon, rather than simply a problem of aberrant behaviour, has considerable

implications for evaluating the social significance of the outcomes of intervention. Prior to discussing this point in more detail, it is useful to examine what is known about the social impact of challenging behaviours.

The impact of challenging behaviours

The social significance of challenging behaviours is determined by the interaction of two factors. First, as we shall see in the next chapter, a significant minority of people with intellectual disabilities show challenging behaviours. Second, such behaviours are often associated with a range of negative personal and social consequences.

By definition, seriously challenging behaviours may significantly impair the health and/or quality of life of the person themselves, those who care for them and those who live or work with them. Self-injurious behaviours can result in damage to the person's health through secondary infections, malformation of the sites of repeated injury through the development of calcified haematomas, loss of sight or hearing, additional neurological impairments and even death. Similarly, serious aggression may result in significant injury to others as well as to the person themselves as a result of the defensive or restraining action of others (Allen *et al.*, 2006; Allen, 2008; Jones *et al.*, 2007; Konarski *et al.*, 1997).

However, the consequences of challenging behaviours go far beyond their immediate physical impact. Indeed, the combined responses of the public, carers, care staff and service agencies to people who show challenging behaviours may prove significantly more detrimental to their quality of life than the immediate physical consequences of the challenging behaviours themselves. These social responses may include abuse, inappropriate treatment, social exclusion, deprivation and systematic neglect.

Abuse

It is, perhaps, not surprising that the difficulties involved in caring for people with challenging behaviours and, in particular, the management of episodes of challenging behaviour, may, at times, lead to inappropriate reactions from carers and care staff. Some of these reactions include physical abuse. Thus, for example, challenging behaviour has been identified as a major predictor of documented instances of abuse in a North American institutional setting (Rusch *et al.*, 1986). Remarkably, 1 in 40 ward staff in Montreal institutions for people with intellectual disabilities indicated that their typical response to an episode of self-injury was to hit the resident (Maurice and Trudel, 1982).