**Introduction**

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To appear in Emerson, E., McGill, P. and Mansell, J. (eds) *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services,* Chapman and Hall, London (expected Autumn 1993).

In this chapter we will outline the development of community care for people with severe learning disabilities, pointing to the limited progress made with people with challenging behaviour. We will emphasise the importance of comprehensive, high quality services by describing the frequent, extremely adverse consequences of challenging behaviours for individuals and their carers. Finally we will provide a brief overview of the rest of the book.

THE DEVELOPMENT OF COMMUNITY CARE

The last three decades have witnessed the growth of a veritable catalogue of criticisms of institutional forms of care for people with learning disabilities. Long stay institutions have been criticised for their excessive size, the segregation of their residents from the outside world, the separation of residents from their family and friends and from the general life of the community, the poverty of their material and social environments, their low staffing levels, the absence of stimulation and of meaningful pursuits for residents, for the development of abnormal systems of care or, in sum, for the degrading and, at times, abusive patterns of relationship characteristic of an institutional culture.

Over the same period, concerns regarding the predicted costs associated with continued institutional provision provided a window of opportunity for planners, managers, professionals and advocates to translate emerging ideas about alternatives into actual practice. As the values and objectives which help shape services have moved away from custodial care to ones which emphasise habilitation, quality of life and normalisation, alternative models of community‑based provision have begun to be articulated. These alternatives have been broadly defined by the reduced size of their settings, their location within ordinary communities, higher levels of staffing and a redefinition of staff roles to replace the emphasis on health care with aims based upon social care, enabling and support. Community‑based services have sought to enable users to experience the patterns of living, learning, working and enjoying their leisure time typical for people of their age in the wider community.

Within the UK, initial reforms centred around the provision of alternative kinds of residential care. Early developments, such as those in Wessex (Felce *et al.*, 1980), sought to provide an intermediate model of domestic community‑based provision. However, towards the end of the 1970's, a consensus began to develop that reform needed to be more fundamental. Specifically, it was suggested that ordinary housing should be available for all people who required residential support, an idea which found expression in the King's Fund `An Ordinary Life' paper (King's Fund, 1980). These ideas were already being put into practice in the second generation of community‑based housing projects which sought to provide residential care for all people with severe learning disabilities in ordinary, domestic style housing (e.g., Felce and Toogood, 1988; Humphreys *et al.,* 1987; Mansell *et al.,* 1987).

These fundamental changes in residential provision served to highlight the institutional nature of not only hospital, but also community‑based **day care**. Existing `community‑based' services were criticised on the basis of the segregation of users from the surrounding community, the unstimulating and demeaning nature of many of the activities provided and the failure of services to support users to move on to better things. Changing values again helped shape alternative forms of service provision which emphasised the importance of meaningful integration, the provision of support when and where it was needed, and recognised the importance of work in the community at large (King's Fund, 1984).

While the rhetoric accompanying such values now appears well accepted (e.g., Departments of Health and Social Security, Welsh Office, Scottish Office, 1989), the viability of extending the opportunities provided by these alternative models of service provision to **all** people with severe learning disabilities remains contentious. In particular, progress towards providing high quality community‑based care for people with severe learning disabilities who also show challenging behaviour has been particularly slow. There appear to be several reasons for this.

As deinstitutionalization and the growth of community‑based provision have progressed, people with less severe handicaps and without behavioural difficulties have typically been the first to move, often for financial reasons (e.g., Department of Health, 1989). As a result, the remaining institutional provision is coming to serve an increasingly disabled population. This apparent reluctance of local services to gain experience in serving those with more serious disabilities has itself been used to support arguments for the continuing need to provide institutional services for people with serious disabilities since either the community itself or local services are perceived as being `not ready' to support people who challenge services.

A further problem is that both the definition and causation of challenging behaviour are unclear and that potential causes may overlap (Baumeister, 1989). Thus, for example, a common belief within hospital based services is that challenging behaviours primarily result from organic factors or psychiatric dysfunction. This has led to an emphasis on the continuing need for hospitals and the professional competencies associated with psychiatrists and psychiatrically trained nurses. Within such a framework, the environment may be seen as only playing a supporting role in the development of psychiatric disorder and the importance of environmental factors, therefore, diminished. One consequence of such a belief system is that adverse comparisons between the social and material environments provided in institution and community‑based provision are seen as less important. Rather, the professional and administrative needs of the staff are considered preeminent, especially the potentially adverse effects of decentralisation on the efficient organisation of treatment and supervision by qualified psychiatric specialists. The importance given to these specialist skills accounts, at least in part, for the continuing call for centralised provision.

In one opposing view, the prevalence of challenging behaviour among people in institutional settings, coupled with analyses of the impoverished nature of life in large institutions, has led some observers to implicate institutional conditions in the causation of challenging behaviour. This has been associated with an expectation or hope that the provision of more normative settings will lead to more usual patterns of activities and interactions which will, in turn, lead to an increase in appropriate behaviour and skills and a concomitant decrease in challenging behaviour. Certainly, the damaging effects of institutionalisation have been amply documented (e.g., Zigler and Balla, 1977). In addition, some research has noted the apparent inverse relationship between adaptive and maladaptive behaviour (e.g., Horner, 1980). It has become increasingly clear, however, that simple changes in location, size and the resources allocated to services have, in themselves, little impact upon the prevalence of challenging behaviour. Rather, it is appropriate to see challenging behaviour as the outcome of complex interactions amongst a range of factors ‑‑ organic, psychiatric, environmental, ecological, historical ‑‑ some of which will be more important than others in individual cases.

Moreover, as the definition of what constitutes severe challenging behaviour is vague, it is difficult to be convincing when generalising from individual examples of successful community‑based care to what might be feasible for an entire `class' of people.

Despite these problems the need for different and better services is clear. Long term institutionalisation, the traditional response to the problem posed by seriously challenging behaviour, is no longer an available option in many localities. In addition, as the replacement of hospital settings continues, more people with seriously challenging behaviour are returning to their communities. As a result, local services are increasingly needing to become `self‑sufficient' and to provide services at a local level for all people with learning disabilities, including those with seriously challenging behaviour.

These same local services are already often struggling to provide for the many people with challenging behaviour who continue to live with their families. Qureshi (1990), in summarising the results of her analysis of services provided to young adults with challenging behaviour living with their parents, concluded that

`perceived service deficiencies include: day services which may be unsuitable, are not flexibly structured and may even exclude the person entirely; a widespread shortage of short‑term and long‑term residential facilities in the community; an incapacity to cope with behaviour problems in many existing facilities; a failure to give parents useful advice on handling behaviour problems at home; insufficient help from social workers and community nurses' (*op.cit.,* p.1).

As a result the needs of the service user remain unmet and carers remain faced with a distressing, stressful and (at times) dangerous situation. The pressure in such circumstances to contain the behaviour by increasingly restrictive means is all too obvious.

Often, however, the only available alternatives consist of attempts to `fix' the individual's challenging behaviour in specialised and geographically remote settings, although access to such specialised treatment facilities is often extremely difficult to arrange. Evidence, albeit largely anecdotal (Newman and Emerson, 1991), also suggests that while such services can be successful in the technical aspects of service provision, for example, the design and implementation of treatment programmes, and as a result achieve marked short‑term reductions in the person's challenging behaviour they also face a number of problems. These include the deleterious effects of congregating together individuals with severe problem behaviour upon user quality of life, staff stress and resulting turnover, and difficulties associated with the person returning to their original setting, a move which is itself extremely difficult to arrange and is often associated with reduced levels of programme implementation, increased use of mechanical restraint, and failure to sustain treatment gains.

The aim of this book is to provide a resource to planners, managers, professionals and those advocating for better services by drawing out some of the key issues and lessons from experience in the field to date. By doing so we hope that future services can avoid some of the problems of the past, for, as we all know, seriously challenging behaviour can blight the lives of service users and those caring for them in a number of ways. They can involve significant risks to the physical well‑being of individuals and can lead to users experiencing unacceptable levels of material and social deprivation.

THE PERSONAL AND SOCIAL CONSEQUENCES OF CHALLENGING BEHAVIOUR

Challenging behaviours can result in direct and indirect threats to the health of service users. Self‑injurious behaviour, by definition, can result in damage to the person's health. Indeed, repeated self‑injury can lead to secondary infections, permanent malformation of the sites of repeated injury through the development of calcified haematomas, loss of sight or hearing, additional neurological impairments and even death (Mikkelsen, 1986).

In addition, the physical well‑being of people with challenging behaviour is often put at risk as a result of the ways in which carers and services respond to them. These unhelpful responses to challenging behaviour can include:

**Physical Abuse.**

Indeed, challenging behaviour is one of the best predictors of who is at risk of being physically abused in institutional settings (Rusch *et al.*, 1986). Maurice and Trudel (1982), for instance, reported that 1 in 40 ward staff in Montreal institutions indicated that their **typical** response to an episode of self‑injury was to hit the client.

**Unnecessary or excess medication.**

Between 40‑‑50% of people who show self‑injurious or aggressive behaviour receive psychoactive medication, of which haloperidol, chlorpromazine, thioridazine are the most common (Altmeyer *et al.*, 1987; Oliver *et al.*, 1987; Stone *et al.*, 1989). They are also significantly more likely to be maintained on such medication over time (Chadsey‑Rusch and Sprague, 1989). The use of such powerful psychopharmacological agents to control challenging behaviour raises a number of questions given that: (1) there is little methodologically sound evidence that such medication has a **specific** effect in reducing challenging behaviour (Gadow and Poling, 1988); (2) prescription practices for people with learning disabilities and a clearly diagnosed psychiatric illness have been judged to be inappropriate in between 40 to 55% of instances (Bates *et al.*, 1986); (3) drug use in facilities can be substantially reduced through peer review processes with no apparent negative effects (Findholt and Emmett, 1990); and (4) neuroleptic medication has a number of serious side effects including sedation, blurred vision, nausea, dizziness, weight gain, opacities of cornea, grand mal seizures and a range of extrapyramidal syndromes including parkinsonian syndrome, akathisia, acute dystonic reaction and tardive dyskinesia (Gadow and Poling, 1988). As Singh and Repp (1989) point out, while the results of drug reduction programmes

`are heartening, they suggest that much of the medication was unnecessary when either originally prescribed or by the time the reduction programme was instituted' (*op.cit.*, pp. 273‑‑4).

**Physical or mechanical restraint**

The use of mechanical restraints and protective devices to manage challenging behaviour, including in up to 50% of cases of self‑injury (Griffin *et al.*, 1986), gives cause for serious concern given that the use of such procedures can lead to muscular atrophy, demineralisation of bones and the shortening of tendons, and result in other injuries during the process of the restraints being applied (Griffin *et al.*, 1986; Richmond *et al.*, 1986; Spreat *et al.*, 1986).

**Deprivation, neglect and abuse**

Aside from being placed in jeopardy of physical harm, people with challenging behaviour are at risk of substantial material and social deprivation through being excluded from everyday activities and settings, having their needs neglected and, as noted above, being subjected to abusive practices. Challenging behaviour is a major cause of stress experienced by carers (Quine and Pahl, 1985) and one of the main predictors of whether parents will seek a residential placement for their son or daughter (Tausig, 1985). Services provided to young adults with challenging behaviour living at home with their parents are often insufficient, especially in the area of providing advice or assistance within the parental home to effectively manage episodes of challenging behaviour (Qureshi, 1990). As noted above, people with challenging behaviour are at significantly increased risk of institutionalisation and exclusion from community‑based services (Lakin *et al.*, 1983; Schalock *et al.*, 1981). Once admitted to institutional care they are likely to spend the bulk of their time in materially deprived surroundings, disengaged from their world and avoided by staff (Emerson *et al.*, 1992; Felce *et al.*, 1985).

People with challenging behaviour are also at risk of having their needs neglected. Most episodes of inappropriate client behaviour occurring in institutions are ignored by staff (Felce *et al.*, 1987), and the low levels of attention which **are** provided are likely to be disproportionately negative in character (Grant and Moores, 1977). People with challenging behaviour are likely to be excluded from day services (Qureshi, 1990), even those provided within institutional settings (Oliver *et al.*, 1987). They are also unlikely to receive specific psychological help for their challenging behaviour (Griffin *et al.*, 1987; Oliver *et al.*, 1987) but are, as noted above, likely to be medicated or restrained. Some of the **socially** undesirable effects of medication and restraint procedures include the general sedative effects of neuroleptic medication (Gadow and Poling, 1988), the impact of mechanical restraints in precluding the person's participation in many everyday activities, and their setting the occasion for reduced levels of interaction with carers (Griffin *et al.*, 1986; Richmond *et al.*, 1986; Spreat *et al.*, 1986). The little evidence that is available also suggests that, at least for frequent or severe self‑injury, the psychological interventions which are provided are more than likely to be of a punitive nature. Thus, for example, analysis of the nature of behavioural interventions employed within state institutions in Texas indicates that 30% of treatment programmes implemented for people with frequent self‑injury and 66% of programmes for people with severe self‑injury are reliant on aversive procedures (Altmeyer *et al.*, 1987). Similarly, Griffin *et al.* (1987) reported that only 33% of children exhibiting self‑injurious behaviour in a metropolitan school district had a written formal treatment programme. Of these, 61% contained an aversive component.

THE AIMS OF HIGH QUALITY SERVICES

The personal and social consequences of seriously challenging behaviour stand in stark contrast to the avowed aims of current services for people with learning disabilities. As we have seen, over the past three decades, service aims have come to be explicitly concerned with safeguarding the rights of people with learning disabilities, enhancing their quality of life and providing services that enable users to live as ordinary a life as possible. Normalisation in its many forms (Emerson, 1992) has had a significant impact on shaping service objectives in the UK (e.g., Tyne, 1987), North America (e.g., Marlett *et al.*, 1984), Scandinavia (e.g., Bank‑Mikkelsen, 1980; Grunewald, 1986), and Australasia (e.g., Anninson and Young, 1980). More recently, these ideas have been explicitly incorporated in the aims of services for people with challenging behaviour (Blunden and Allen, 1987; Emerson *et al.*, 1987).

Blunden and Allen (1987), for example, ground their approach in the `Ordinary Life' philosophy (King's Fund, 1980) which takes as its starting point that people with learning disabilities and challenging behaviour:

have the same human value as anyone else;

have a right and a need to live like others in the community;

require services which recognise their individuality.

The same authors go on to consider the implications of these values for service objectives in terms of O'Brien's (1987) five `accomplishments' ‑‑ aspects of life which services should help people to accomplish. They are:

**community presence** ‑‑ people with learning disabilities have the right to live and spend their time in the community, not segregated in residential, day or leisure facilities which keep them apart from other members of society;

**relationships** ‑‑ living in the community is not enough. People with learning disabilities also need help and encouragement to mix with other non‑disabled people in the course of their daily lives;

**choice** ‑‑ people with learning disabilities often have limited power to make choices and look after their own interests. A high quality service will give priority to enhancing the choices available to people and to protecting their human rights generally;

**competence** ‑‑ in order for people with learning disabilities to live a full and rewarding life in their local community, many will require help in experiencing a growing ability to perform useful and meaningful activities with whatever assistance is required;

**respect** ‑‑ people with learning disabilities often have an undeserved bad reputation and are regarded as second‑class citizens. Services can play an important part in helping people to be seen and treated with the same status as other valued members of society.

As we have seen, the reality falls far short of such aims for the vast majority of people with challenging behaviour.

ABOUT THIS BOOK

As we noted above, the present book represents an attempt to draw out some of the key lessons from experience gained to date in the provision of community‑based services for people with severe learning disabilities and challenging behaviour. This is not, however, a `how to do it' book. To undertake such a venture at our present state of knowledge would be remarkably presumptuous. Rather, we have attempted to bring together a range of contributions which, we hope, will highlight some of the more important issues facing those involved in the development, support, management and purchase of services for people with challenging behaviour.

The book is organised into three sections. The first section contains three further chapters which attempt to set the scene for later analysis and discussion. In Chapter 2, **The size of the problem**, Hazel Qureshi discusses the definition of the term `challenging behaviour' and draws upon the results of a large epidemiological study and other literature to address some of the important questions relating to the prevalence and persistence of challenging behaviour in people with severe learning disabilities. In the following chapter, **Understanding challenging behaviour**, Glynis Murphy provides an overview of current knowledge concerning the complex interaction of biological, behavioural and ecological factors which underlie the phenomena of challenging behaviour. In the final chapter in this section, **Conceptualising service provision**, Jim Mansell, Peter McGill and Eric Emerson discuss some of the organisational and contextual factors determining patterns of service provision and provide a framework within which the complex array of services required to meet the needs of people with challenging behaviour can be identified.

The middle section of the book draws upon descriptions of innovative services which have gained invaluable experience in attempting to put the values embodied in the `ordinary life' approach into practice for people with challenging behaviour. In Chapter 5, **Ordinary housing for people with severe learning disabilities and challenging behaviours**, David Felce, Kathy Lowe and Siobhan de Paiva review the experience of the early attempts in Wessex and Cardiff to provide residential accommodation in ordinary houses for all people with severe learning disabilities, including people with challenging behaviour. In the following chapter, **Individually designed residential provision for people with seriously challenging behaviours**, Peter McGill, Eric Emerson and Jim Mansell discuss the experience gained by the South East Thames Regional Health Authority's Special Development Team, a project which built on some of the lessons gained in the earlier Wessex projects and attempted to extend them to those people perceived as representing the most serious challenge to services. Residential care is not, of course, the only aspect of service provision relevant to people with challenging behaviour. The final two chapters in this section review some of the lessons learned from recent approaches to day care and intervention services. In Chapter 7, **Towards meaningful daytime activity**, David Allen describes some of the more innovative approaches to vocational and recreational provision for people with challenging behaviour. Following on from this, Judith McBrien discusses the experiences of **The Behavioural Services Team for people with learning disabilities**, a peripatetic community‑based support and intervention team for people with challenging behaviour.

The final section of the book contains 5 chapters which discuss in more detail some of the key issues arising from these, and other, examples of service provision. In particular, these final chapters attempt to identify critical issues for those involved with designing, managing or supporting community‑based services for people with challenging behaviour. The first two chapters focus upon issues central to the efficient and effective organisation of staff support to people with seriously challenging behaviour. In Chapter 9, **Values, attitudes and service ideology**, Eric Emerson, Richard Hastings and Peter McGill attempt to unpack the complex interrelationships between personal, social and agency values involved in the translation of service ideology into practice. Following on from this in Chapter 10, **Organising community placements**, Peter McGill and Sandy Toogood provide an organisational framework for considering staff support and client activity within community‑based settings. Chapters 11 and 12 address a number of issues at a wider organisational level. In Chapter 11, **Maintaining local residential placements**, Jim Mansell, Heather Hughes and Peter McGill draw upon examples of placement breakdown and other problems in community‑based services to identify some of the key organisational tasks important in maintaining and assuring quality. In Chapter 12, **Assessing costs and benefits**, Martin Knapp and Jim Mansell provide a framework for the comprehensive costing of service provision and discuss the relationships between costs and benefits in community care. The section, and the book, is rounded off in Chapter 13, **Policy and policy implications**, in which Jim Mansell reviews the recent development and nature of current English policy drawing on the themes emerging in earlier chapters.

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