A review of Some Important Issues in Research and Services for People with Learning Disabilities and Challenging Behaviour

Chris Cullen

Professor in the Psychology of Learning Disabilities
Keele University

and

Clinical Director for Psychological Therapies
North Staffordshire Combined Healthcare NHS Trust

Address for correspondence:

Professor Chris Cullen
Psychological & Behavioural Service
North Staffs Combined Healthcare NHS Trust
Stallington Hall
Stallington Road
BLYTHE BRIDGE
Stoke-on-Trent
Staffs
ST11 9QL

1. Introduction

1.1 In June 1999 I was asked by the Social Work Services Inspectorate of the Scottish Office (Home Department) to help with their ongoing review of services to people with a learning disability by reviewing some of the issues in services to people with challenging behaviour. This paper is the result of my review. The views and opinions here are mine alone, and do not necessarily represent those of any other organisation.

1.2 I was asked to provide information on incidence, prevalence and type of challenging behaviour; to summarise evidence on service configuration; to outline treatment options and their relative merits; to comment on staff training and organisational issues, and; to describe the effect particular environmental structures have on challenging behaviour.

1.3 In responding to this brief I have relied on recently published work, wherever possible, as well as drawing on my own experience as a clinical practitioner during the past 25 years. Nevertheless, what follows is necessarily my personal interpretation, and should be read with that in mind.

1.4 I have not attempted to be exhaustive in the literature I have cited, since to do so would have resulted in an unnecessarily long and unwieldy document. Rather I have tried to identify seminal or clear examples to support the points I have made. I have been as objective as I could, and I do not believe that the points I have made are contradicted by important sources I have ignored.

2. Prevalence and type

2.1 There is often confusion between the term ‘incidence’ and ‘prevalence’, and many people use them interchangeably. In this

report I will take prevalence to be the number of people in a population who have the condition at a given point in time, whereas incidence is the number of new cases of a condition identified in a population over a period of time. Accordingly I shall summarise the literature on prevalence.

2.2 Different interpretations of the term *challenging behaviour* will have a major impact on prevalence figures. It is not possible or sensible to search for the holy grail of an operational definition of challenging behaviour which would be acceptable across the country. What behaviours challenge some services clearly appear to be accepted by others. It has often been argued, for example, that the old long-stay hospitals were able to ‘cope with’ much difficult behaviour which then becomes an issue once the client had been transferred to community based services. Often what happened in these large hospitals was that the person would be ignored and their stereotypy, aimless wandering, severe withdrawal, minor self-injuries, etc were simply not noticed.

2.3 The term *challenging behaviour* has become very common in the past decade. It was originally adopted from the Association for Persons with Severe Handicaps (TASH), a North American organisation, and given prominence in this country in the King’s Fund Centre Project Paper *Facing the Challenge : An Ordinary Life for People with Learning Difficulties and Challenging Behaviour,* edited by Roger Blunden and David Allen in 1987. It is usually defined by reference to the relative intensity, frequency and duration of a problematic behaviour, and by the likelihood of that behaviour leading to harm or exclusion of services. Cullen et at (1999) have pointed out that such behaviours, like other behaviours, are usually a function of the persons environment, and in this sense challenging behaviour is one behaviour within the person’s whole repertoire. It can be dangerous to concentrate on only one part of what the person does. My own preference would be to use the term *interactional challenge*, which makes the point that behaviour is the result of the individual interacting

with their environment. Labelling a behaviour as challenging adds little to our understanding of how that behaviour functions in the person adapting to their world. Referring to interactional challenges alerts us to the necessity of looking beyond the person, often to others in their immediate environment.

2.4 Chung et al (1996) found that the prevalence rate of challenging behaviour in reported studies usually fell between 8 per cent and 38 per cent of the surveyed population of people with learning disabilities. In their own study, in one English health district, they found that 39 per cent of their 98 subjects had one or more severe challenging behaviours, although they point out that further work needed to be carried out to determine the prevalence in different settings, such as institutional and non-institutional services.

2.5 Bruininks et al (1994) found a higher prevalence in institutions than in family homes, group homes, foster homes and semi-independent residences. This picture is one which is now relatively well accepted, although it leads to an important question. Is the challenging behaviour in institutional settings a function of the setting? This seems unlikely to be the only major factor, for some challenging behaviour at least, since most studies examining what happens when people move from institutions to the community do not demonstrate a dramatic decrease in challenging behaviour. It is more likely that those people who are the most difficult have tended to live in institutions. However, there are undoubtedly many aspects of institutional life which will increase the likelihood of challenging behaviour, such as overcrowding, noise, lack of stimulation, absence of opportunity, and so on (cf. The Royal College of Psychiatrists, 1998).

2.6 In 1993 the Department of Health commissioned Professor Jim Mansell to summarise what was then known about challenging behaviour, and his team suggested that the point prevalence of behaviours that present a significant challenge (as opposed to all

challenging behaviours) is probably in the order of 20 adults with a learning disability per 100,000 of the whole population. This proportion increases with the severity of impairment. This is in line with the figure which was produced by the late Dr Albert Kuslick for the Wessex survey in 1967. It also matches the figure suggested by Qureshi (1993). She suggested that the total number of adults and children with challenging behaviour in a typical health district of 220,000 is likely to be between 31 and 56. The figure will be affected by factors such as the socio-economic and demographic characteristics of the area, and their residential location will vary dependent on whether there was a hospital in the locality.

2.7 The experience of learning disability service commissioners and providers appears to be that, regardless of national estimates of prevalence, the number of people with interactional challenges usually seems to be just more than the capacity of local services to cope! So, for example, where there are specialist Assessment and Treatment Units, they are invariably filled, regardless of the number of beds, and usually have great difficult in discharging people, since there are not sufficient services in the locality to receive people back (cf. Newman and Emerson, 1991). Similarly, special teams, usually composed of clinical psychologists and nurses, find that their referrals are almost always for people with challenging behaviour, and in almost all areas, teams have waiting lists.

2.8 It is clear that comprehensive service provision should always include a significant element of staff and facilities able to deal with people who have difficulties to a greater or lesser degree. There must always be some expertise (see below) in dealing with challenging behaviour. How much service is difficult to determine. The view of many experienced clinicians is that there is a need for inpatient facilities, which should be sensitively designed to be relatively small, together with specialist staff able to support people in their own homes (see Section 6).

3. Medication and Challenging Behaviour

3.1 There is a substantive body of literature which tells us that people with severe disabilities and challenging behaviour are more likely to receive anti-psychotic medication than most other people in our society (Kiernan, Reeves and Alborz, 1995). There has long been a vigorous debate on ethics and efficacy (Anderson and Reeves, 1991; Singh, Guernsey and Ellis, 1992) with an emerging consensus in the literature which appears to have had surprisingly little effect on the behaviour of many prescribers.

3.2 Using psychotropic medication to reduce challenging behaviour was a follow-on from earlier discoveries that phenothiazines could reduce symptoms associated with some forms of schizophrenia (Kennedy Meyer, 1998). In conjunction with the discovery of decreases in delusional speech and repetitive behaviours brought about by antipsychotic medication was the absence of psychological or other environment procedures for managing behaviours, and it was not long before these medications were tried with people with severe disabilities who emitted challenging behaviour. Kennedy and Meyer (1998) point out that

> *It is important to note that this extrapolation of psychotropic medication was not based on an etiological or theoretical basis linking behaviour problems and medical illness in these two groups, but on an immediate need to reduce challenging behaviour.*
>
> *(Page Pp 83-84)*

The continued use of medication in learning disability services is not usually associated with formal diagnoses of mental illness (Kiernan, Reeves & Alborz, 1995).

3.3 The main categories of psychotropic medication used are antipsychotics, anti-epileptics, anxiolytics and others such as anti-manics, anti-depressants, stimulants and opiate antagonists. Elsewhere in this document I have referred to the importance of understanding behavioural function as a necessary condition for addressing the problem of challenging behaviour in the longer-term. It is notable that, of the different types of medication in common usage, it is only the opiate antagonists whose use is directly linked to inferred behavioural function. They work by blocking the analgesic and euphoric effects of endogenous opiates which, it has been suggested, may be involved in some cases of persistent self-injury (cf. Smith, Gupta and Smith, 1995).

3.4 Nearly all reviews of the literature express serious concerns about the continued use of most psychotropic drugs used for challenging behaviours.

The concerns include:

1. The relatively high rates of prescribing
2. The common incidence of polypharmacy
3. Detrimental side-effects from some drugs that are often not closely monitored
4. Lack of an evidence base
5. Absence of data to determine whether or not drugs are having an effect.

3.5 It is important to consider why, in the absence of a strong evidence base, medication continues to be prescribed for challenging behaviour. Cullen (1991) reported that one of the reasons why medication is often used in learning disability settings is because staff have to be seen to be doing something, and in the absence of other strategies changing or implementing a medication regime is relatively easy. Literature on staff perceptions of challenging behaviour, referred to in Section 5, demonstrates clearly that how staff perceive challenging behaviour is a

major determinant of their reactions to it. It is not be too far-fetched to suggest that staff perception, rather than evidence on effectiveness, is what lies behind much medication use. To put this in an overly extreme way, doctors have to be seen to be doing something, and if prescribing were not an option what else could they do? Similarly, administering medication, especially PRN medication, leads nurses to feel that they are responding in a professionally unique way to challenging behaviour. It is probably no coincidence that it is outward directed challenging behaviour which is usually the subject of medication, rather than other forms of challenging behaviour, such as extreme withdrawal (Keirnan, Reeves & Alborz 1995).

3.6 Is it possible therefore, to reduce antipsychotic medication for people with a learning disability? Work recently carried out at the Welsh Centre for Learning Disabilities at the University of Wales College of Medicine (1996) had somewhat mixed results. 36 randomly chosen subjects and 20 controls on anti-psychotic medication for behaviour disturbance in Wales and the north west of England were screened to exclude a mental illness, and their Consultants agreed to a progressive 25 per cent reduction in anti-psychotic medication dosage. The effects were evaluated by direct behavioural measurement and a range of checklists. After 6 months, 48 per cent of the active group had medication reinstated to full dose; 33 per cent had been successfully withdrawn from their anti-psychotic medication, and 19 per cent were taking 50 per cent or less of their original dose. What is interesting is that in the group who ‘failed’ (i.e. were reinstated to their baseline dose after only 25 per cent reduction) there was no evidence to indicate that their behaviour had changed. They had not improved, but, importantly, had not deteriorated either. For the other groups, where there was a success in managing to remove or reduce the medication, there was a significant increase in the number of stereotypy and movement disorders when drug reduction reached minimum levels or was stopped. The increase in stereotypy returned to baseline level at the end of the study period, although the level of movement disorder

remained elevated. The researchers pointed out that staff anxieties and attributions were an important factor in influencing the outcome of the drug reduction, rather than behavioural change. There were some indications in the research that environmental variables were also important, such as the ability of other residents living with the subject (those in the failed group were more likely to come from settings where there were few other residents who could speak in sentences) and staff characteristics (the failed group had less senior staff to resident ratios). This work is due to be reported in the *British Journal of Psychiatry,* hopefully in January, 2000.

3.7 Although not a strong effect in the Welsh study, other research has found that there is an association between the kind of service a person receives and their psychotropic medication. In general, there is more drug usage in hospitals, less in community residential facilities, and least in family homes (Clarke et al 1990; Kiernan, Reeves and Alborz 1995). Kiernan et al (1995) found that there was a difference in prescribing practice in different parts of the country, and they hypothesised that this may be due to different organisation in psychiatric services for people with learning disabilities. It is probable that different psychiatrists will have different opinions on the efficacy of medication and this will influence their prescribing practices.

3.8 Given that it is highly unlikely that there will be dramatic changes in the use of psychotropic medication, efforts have been made to influence how decisions are made about which drug to use and what dosage. For example, Sturmey (1995) suggested first using a formal system such as DSM-IV to determine the precise diagnosis for a behavioural disorder before prescribing medication. The rationale for this is that psychiatric disorders respond differentially to different classes of treatment.

3.9 In 1998 the Royal College of Psychiatrists *Management of Imminent Violence Clinical Practice Guidelines: Quick reference Guide* warned

against the inappropriate use of medication and pointed out that environmental solutions are often helpful in preventing behavioural disorders. They pointed out that, in a situation of imminent violence, "medication is often given as a sedative rather than as a treatment for a patient's underlying psychiatric condition" (p.12).

4. Therapeutic approaches

4.1 Given issues raised elsewhere in this Report, especially around the role of staff and service organisation, it is important to say that there is no single set of therapeutic approaches which can simply be implemented with the hope of achieving huge changes for people with difficult behaviour. This makes our task quite different from that in other areas, such as acute interventions in medical services. Exhibiting an interactional challenge is qualitatively different from having a physical illness.

4.2 Challenging behaviour is a function of the interaction between the person (involving their physiological, emotional and cognitive state as well as their public behaviour) and their current environment (which includes the physical setting and other persons). This means that successful and enduring therapeutic interventions will be those that avoid addressing only the specific problem behaviour. (Cullen, et al 1999).

4.3 To some extent this is a matter which first surfaced in the 1970's. Holland (1978) discussed the application of 'behaviour modification' and argued that we tend to attempt to 'fix' the problem by resorting to special environments and therapeutic procedures, and avoid addressing the wider issues (often societal contingencies) which lead to the problem. Cullen (1999), discussing the question of 'choice' by people with learning disabilities, raised the same point; it is all well and good devising procedures to help people to make choices, but these may be

futile if clients do not live under circumstances where real and meaningful choices are possible.

4.4 The necessity of using evidence-based interventions needs no justification. What do we know of the evidence base for interventions in challenging behaviour? In 1996 I summarised some of the literature on assessment, analysis and treatment for the British Psychological Society (Division of Clinical Psychology) Reference Library on Clinical Practice (Cullen, 1998). Ball and Bush (1998) more recently have produced clinical practice guidelines for psychological interventions for severely challenging behaviour. In identifying the strength of the evidence they categorised each guideline according to 3 levels:

Level 1 : evidence from well-designed, randomised controlled trials, meta-analyses or systematic reviews

Level 2 : evidence from well-designed cohort or case controlled studies

Level 3 : evidence from uncontrolled studies or clinical consensus

They identified 51 guidelines, of which only 7 were supported by level 1 evidence, and 8 were supported by level 2 evidence. Following extensive consultation with clinicians, they also categorised the guidelines into those which are ‘good practice’, which means they ought to be followed unless there are extenuating circumstances, and those which are ‘essential practice’ and must be followed. Failure to adhere to the essential practice guidelines would constitute bad practice. Of the 51 guidelines, 16 were considered ‘essential’. Only 4 of the essential practice guidelines were at level 1, and one was at level 2. This tells us that the research base for therapeutic interventions is not as firm as it ought to be.

4.5 The four guidelines which have strong research backing, and which are considered essential, are:

4.5.1 the need to carry out thorough and detailed assessments of the person's behaviour, paying particular attention to the validity of the assessment process.

4.5.2 ensuring that the function of the challenging behaviour is understood.

4.5.3 using interventions which replace the challenging behaviour with functionally equivalent and socially acceptable repertoires.

4.5.4 use extreme caution when considering, and if possible avoid completely, the use of punitive procedures. If it is essential to suppress a person's behaviour, perhaps as the only way of avoiding serious injury, then detailed functional analyses must be carried out.

The guideline which was considered essential, but supported only by level 2 evidence was:

4.5.5 always take a baseline measure of challenging behaviour.

Those guidelines which were considered essential by clinicians, but for which there is a less strong evidence base, are:

4.5.6 take into account the person's strengths and needs, and their unique social context.

4.5.7 psychological assessments must consider the three elements of the person, their behaviour, and the environment.

4.5.8 when assessing a person, the psychologist must always meet and interact with the person being assessed.

4.5.9 assessment of the environment should be multi-faceted, and take account of people, the physical setting, and organisational culture.

4.5.10 the person's capacity to give meaningful consent must be evaluated.

4.5.11 interventions must be non-abusive and as risk free as possible

4.5.12 reactive strategies must be in place to protect all involved.

4.5.13 the effectiveness of interventions must be subject to follow-up over time.

4.5.14 feedback must be given to the client and to others involved with the client.

4.5.15 confidentiality must be respected.

4.5.16 the psychologist must make a concerted effort to elicit feedback on their performance.

4.6 Turning now to those guidelines which have a strong research base (level 1), but which are considered good, rather than essential practice, we find:

4.6.1 it is possible to establish new skills which will replace the problem behaviour.

4.6.2 it is important to be sensitive to the ethical issues which surround the use of powerful reinforcement techniques.

4.6.3 all interventions for severe challenging behaviour should be routinely evaluated for their effectiveness.

4.7 It is possible to summarise the essence of the clinical practice guidelines by repeating that approaches to challenging behaviour should be constructional (Cullen et al, 1999). Put simply this approach asks 'what should the person be doing instead of exhibiting the challenging behaviour.' In answering this question staff will have to address the issues of why the problem behaviour is occurring, and how will the person's current or future circumstance allow and support different, socially acceptable behaviour.

4.8 What is missing from these Guidelines is much in the way of suggestions about specific interventions which have been shown to be effective. On the one hand this is an appropriate emphasis. There is a widespread consensus that interventions should be determined by the results of analysis and assessment of why the person is doing what they are doing. However, there is a need for staff to have guidance on therapeutic options. It might not matter precisely which therapeutic approaches are adopted. There is a place for psychotherapy (Waitman

and Conboy-Hill, 1992), cognitive behavioural approaches (Kroese, Dagnan and Loumidis, 1997) and behaviour analysis (O'Reilly, 1997).

4.9 There are 'new' procedures regularly reported in the literature, although it often seems to be the case that direct-care staff and those advising them rarely take them up in any systematic and concerted manner. Fads and fashions come and go. For example, Gentle Teaching was recently all the rage, and was the topic of many conferences and symposia, but is now rarely mentioned (cf. Cullen and Mappin, 1998).

4.10 Because of the complexity of challenging behaviour we need to encourage the development of sophisticated analyses which will lead to the development of specific interventions, and which will help us to understand why and how some interventions work (cf. Pelios et al, 1999). For example, understanding the role of establishing operations – those environmental circumstances which evoke and establish the motivation for problem behaviour (cf. McGill, 1999) – may help us to understand the importance of living environments and staff attitudes. It might also help us to understand how specific interventions such as "mood-inducing" music (Durand and Mapstone, 1998) or vigorous aerobic exercise (Elliot et al, 1994) have their effects.

5. The role of staff

5.1 There is now a broad consensus (see Section 4) that therapeutic approaches should be non-aversive and constructional. By this what is meant is that procedures such as seclusion and time-out as well as various forms of punishment, should be avoided (cf. Repp and Singh, 1990). Constructional approaches are those which address the behaviour by asking "*If the person were not engaging in this behaviour at this time what should they be doing?*" Asking such a question forces staff to consider (a) why the person is engaging in the challenging behaviour and (b) what more socially acceptable behaviour

could be maintained by the current circumstances. It is important to understand that constructional approaches are not simply about establishing new behaviours, but are concerned with replacing dysfunctional repertoires with functional ones which achieve more for the person. How do we get staff to operate in this way?

5.2 Constructional approaches put the emphasis on staff reaction to the challenging behaviour, rather than the behaviour itself, hence my personal preference for the term interactional challenge. With very few exceptions, challenging behaviour is a function of the settings in which the person finds themselves, and the reaction of others to their behaviour. The possible exceptions to this are some very specific forms of self-injurious behaviour, which may be maintained by physiological events. It is, therefore, axiomatic that dealing with challenging behaviour requires appropriate settings and appropriately trained and aware staff.

5.3 Some British research at the moment is concentrating on how staff perceive challenging behaviour, since it is presumed that their attitudes and perceptions will have a significant influence in how they react to challenging behaviour when it occurs, and also how they arrange service settings for clients. For example, Stanley and Standon (in press) presented 6 case studies to 50 care staff working in challenging behaviour day services. They found that the more independent and outer directed the challenging behaviour, the greater the carers attribution of control and negative affect, and the less the propensity to help. The more self-directed and dependent the clients' challenging behaviour, the greater the carers attributions of stability, positive affect and propensity to help.

5.4 Hastings, Reed and Watts (1997) found that experienced care staff rated social and emotional variables, such as boredom and noise, among the likely causes of challenging behaviour more than did inexperienced staff (student nurses). Both groups viewed stereotyped

behaviours as likely to be caused by factors such as boredom, or enjoyment, whereas they thought that aggression was more likely to be caused by frustration or trying to gain attention.

5.5 This field of research, whilst interesting in some ways, also leaves us with problems in knowing how to use it. The work is relatively easy to carry out, involving as it does asking staff to answer questions about what they believe to be the causes of challenging behaviour, usually by completing written questionnaires. However, it is an assumption that how staff actually behave with respect to clients who are exhibiting dysfunctional behaviour is closely related to the attributions they make.

5.6 Stancliffe, Hayden and Lakin (1999) examined predictors of interventions for challenging behaviour in residential settings, and found that externalised behaviour, such as aggression and destructive behaviour, was consistently associated with all types of intervention. Internalised behaviour was much less often associated with formal interventions. This tells us that it is the consequences of behaviour which present a problem to others which probably influence how staff react. These may be associated with particular attributions, but whether the attributions are responsible for staff behaviour or vice versa is an unknown. Organisational theories abound about the relationship between worker behaviour and attitudes but I am unaware of any compelling studies which have attempted to change attitudes and thereby influenced how staff behave. Hatton et al (1999) examined organisational culture variables (such as innovation, staff-orientation and work environment stability) and showed that staff generally rated their organisations as less than ideal in terms of organisational culture. Some organisation theorists have argued that the greater this mismatch the higher the likelihood of stress and alienation, which seems unsurprising. However, the Hatton et al (1999) study did not identify a link between organisational culture and staff performance, and I am not aware of any other studies which throw much light on this issue. This is not to deny the value of research

into attitudes, attributions and organisational culture, but to question whether there is much direct use of it at the moment.

5.7 Perhaps more promising might be research on staff training and management which takes a more direct route to changing staff behaviour. For example, Allen et al (1997) describes the implementation of a non-aversive approach in a small (6 bed) residential behavioural treatment unit. The elements of the approach included understanding aggressive incidents, primary prevention strategies, secondary prevention strategies, reactive strategies and post-incident support. While there were improvements as a result of the introduction of this programme, not many of the changes were significant. What this shows is the difficulty in achieving large scale and enduring change with difficult populations. Staff training (Cullen, 1988, 1992) has not been shown to be sufficiently powerful as a factor, although carefully controlled (and often contrived) staff management strategies seem to work. What is disappointing, though, as the Allen et al study illustrates, is that it is often hard to achieve significant change in real world settings.

5.8 Approaches that work are those which address all the elements of a system. Tinkering with one or two parts of an ecosystem might have short-term effects, but is just as likely to lead to unpredicted impacts on other parts of the system. Staff management is no exception. For example, there is often an assumption that poor staff performance is a result of inadequate training. Consequently, failing organisations often turn to staff training solutions, ignoring a wealth of evidence that staff training hardly ever leads to long-term changes in performance.

5.9 Instead, it might be more useful to return to first principles and find out where the problems really lie. Reid, Parsons and Green (1989) suggest a relatively simple model, shown in Figure 1, for working out where to intervene.

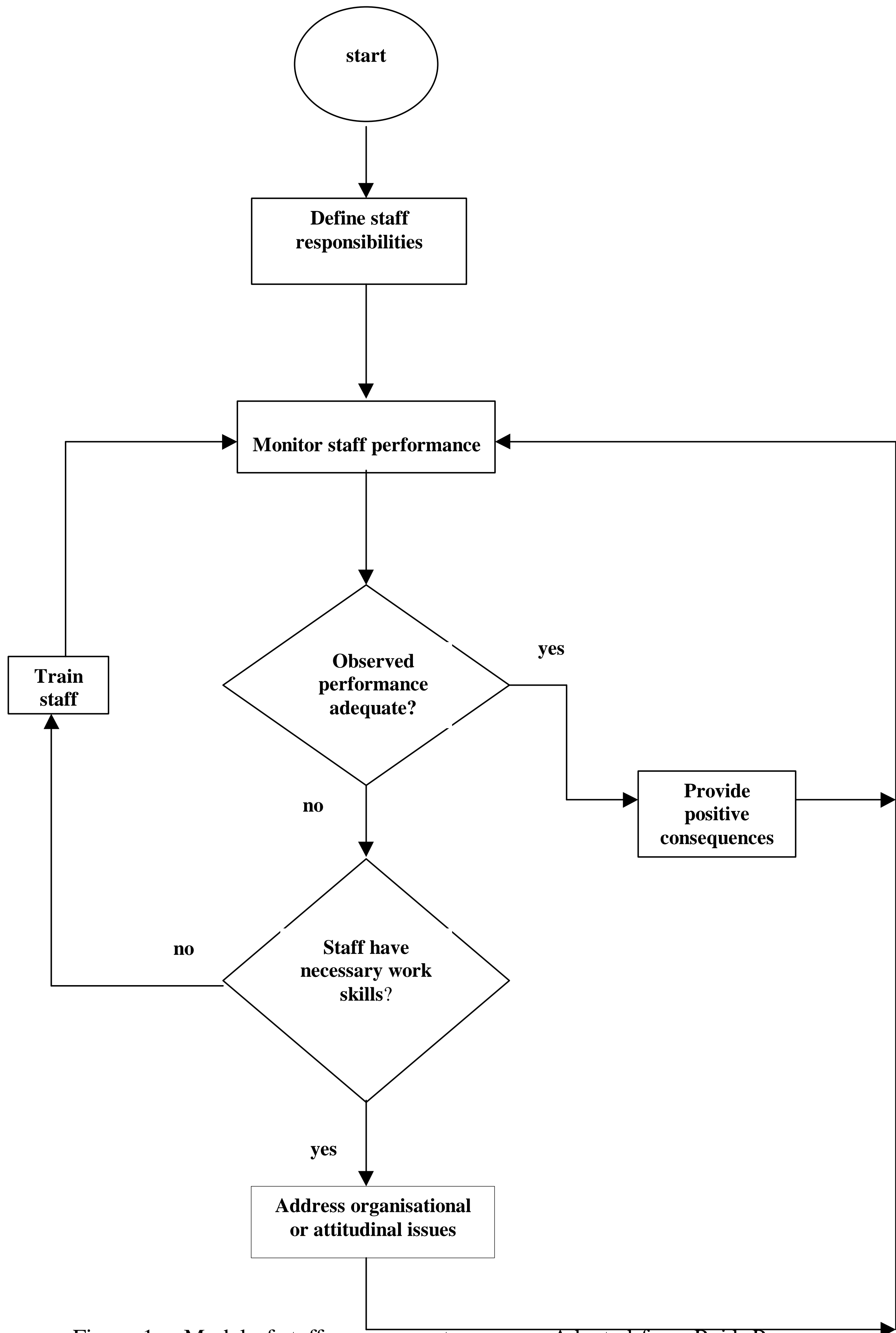

Figure 1. Model of staff management process. Adapted from Reid, Parsons and Green (1989)

First it is essential to have a clear idea of what staff are expected to be doing. In the case of challenging behaviour services this would include therapeutic interventions, assessment processes, ways of valuing clients, and so on. Having set up systems to monitor these repertoires it will then become clear whether or not there is inadequate performance. For good performance it is important to provide positive feedback and other consequences. If there is poor performance, ask whether staff have the necessary skills. If they do not, then institute training programmes. If they do, they address the organisational or attitudinal issues which are preventing appropriate behaviour.

5.10 A word of caution is necessary. There is a real danger of assuming that performance specification, monitoring and emphasising compliance will lead to good services. They do not. What happens is described in Figure 2.

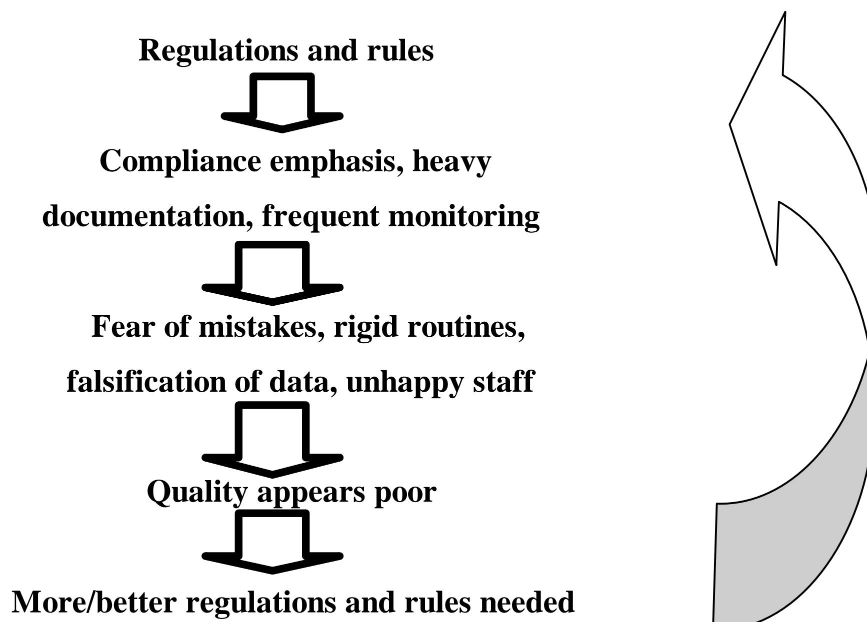

Figure 2. The danger of rules. From Cullen (1998)

It is essential to achieve good performance as a result of allowing staff ownership of their own behaviour (Cullen, 1998; Semler, 1993). If this organisation lesson is not heeded, the inevitable result is an increase in staff stress and burnout. For example, Chung, Corbett and Cumella (1996) surveyed 26 staff working with people with challenging behaviour. They found that, whereas burnout was high staff were positive about working with their clients. Their burnout appeared to be more associated with management issues. This is not to deny the multi-faceted nature of staff stress (cf. Hatton, in press), but to warn against simplistic assumptions, such as assuming that working with difficult people is, in itself likely to lead to staff stress and consequent burnout.

6. Service configuration

6.1 The element of effective residential services for people with learning disabilities are now well-understood. In general, services that work are relatively small, avoiding large numbers of people living together. Staff are well trained and managed, providing active support to clients, with an emphasis on meaningful activity, relationships and the acquisition of new behaviours.

6.2 This is not simply 'an ordinary life.' In the worst cases, the misapplication of 'ordinary life' principles in some areas has led to clients placed in poorly staffed and badly organised houses in neighbourhoods where there has been no attempt to involve service users in the community. People may have few real choices over important aspects of their lives, and spend considerable portions of their time waiting for things to happen (Emerson and Hatton, 1994). Staff are unqualified and poorly trained and consequently service users acquire few new skills. In these worst cases life is no better – or even worse – than it was in the old institutions.

6.3 Paradoxically, life in some of the best village communities is of a very high quality (Myles, 1999). Although people usually live in relatively small units, say houses with up to 8 people, the community as a whole may have more than a hundred people in it. Staff may be unqualified and untrained. However people have meaningful day activity which they have chosen, and have fulfilling personal relationships.

6.4 What appears to be common amongst services where people have valued and high quality lifestyles is an approach which actively works at establishing new skills and relationships. It has not been possible to identify discrete structural elements, such as size or location, which are always predictably linked to high quality service provision. There is, however, good evidence for this ‘active support’ model (cf. Mansell, Hughes and McGill, 1994).

6.5 With respect to challenging behaviour there seems to be no good reason why the same emphasis on actively working to establish meaningful relationships should not be essential. There is a strong consensus that services to people with challenging behaviour should not be isolated from generic services. However, over and above this, it is essential to pay attention to the organisation of the service.

6.6 Foxx (1998) described a comprehensive treatment service for adolescents with extreme aggression and/or disruptive behaviour. Although not presented here as a blueprint, a similar combination of elements is almost certainly necessary in an effective service.

6.6.1 The unit was multi-disciplinary, with all staff receiving didactic and on–the-job training in behaviour management techniques. Many of the staff had professional qualifications, often to a high level. Staffing ratios were not generous, with typically five direct-care staff on duty with an average of 44 clients.

6.6.2 Staff duties were clear and specific. A duty card system was in use, in which specific cards detailed each person's programmatic responsibilities at specific times of the day.

6.6.3 Supervision of care staff was carefully scheduled to be available from 8.00 a.m. to 9.30 p.m. each weekday. This scheduling assured the continuity of the behavioural programmes; flexibility in that immediate decisions could be made when necessary; continuous staff training in handling or avoiding crises; continuous contact between direct care staff and experienced supervisors, and; continuous monitoring of the programme's effectiveness. This approach also avoided the 'them and us' attitude which is so common when managers are not themselves clinically skilled, and only occasionally visit the service, spending very little time with clients.

6.6.4 The therapy model was based around a token economy, structured to provide positive consequences for pro-social behaviour. Each client had a thorough assessment, with individualised goal setting. The overall programme rationale was that increased responsibility and appropriate behaviour led to increased opportunities for independence. Verbal and physical aggression, property destruction, window breaking and manipulative self-abuse led to temporary exclusion, or the loss of points.

6.6.5 Psychotropic medication use was kept to a minimum; indeed one of the aims of the approach was to reduce major aggression and disruption so that medication would not be needed. Clients' rights were safeguarded by the involvement of internal and external advocacy agencies and by adhering to statutory guidelines.

6.6.6 The 'experimental' phase of the programme lasted for 6 months, and was then followed by a maintenance phase which lasted 7 months. Table 1 shows the reduction in a number of key measures.

Table 1. Program measures: mean monthly averages and percentage reductions (From Foxx, 1998).

		Program (6 months)		*Maintenance (7 months)*	
	Preprogram (3 months)	$\bar{x}$	*Percent reduction from preprogram*	$\bar{x}$	*Percent reduction from preprogram*
Number of broken windows	14	9	36	5	64
Number of clients breaking Windows	10	4.2	58	2.4	76
Number of times emergency Mechanical restraints Implemented	28	6	79	5.4	81
Number of clients restrained	11	4.3	61	3.1	72
PRNs	42	8.7	79	10.6	75
Number of clients receiving PRNs	14	4.2	70	3.8	73
Percent of clients receiving Psychotropic medications	81	67	17	55	32

6.7 My purpose in describing this programme in some detail is not to present it as a model service, or as a blueprint for other services. It so happens that the approach described is explicitly behavioural, but this does not preclude other approaches, such as those with a psychotherapeutic orientation. In fact one of the few controlled studies of Gentle Teaching was conducted in Scotland, showing very little difference between a well-structured behavioural approach and a similarly well-structured Gentle Teaching system (Cullen and Mappin, 1996). The point I want to make is that the essence of an effective service is to structure the activities of well-trained and supportive staff, working towards agreed and clearly specified outcomes for clients. Active support is what is needed to achieve effective services.

6.8 At one time there was a debate over whether it was ‘better’ to have a residential facility for people who challenge, or whether people could

be maintained in their own homes by having a peripatetic team of specialists to provide intensive support. Much was written about the advantages and disadvantages of residential units (e.g. Newman and Emerson, 1991), and about the virtues of specialist teams (e.g. Emerson and McGill, 1993; McBrien, 1994). The literature on these issues has ‘dried up’ somewhat, and most clinicians believe that it is necessary to have both residential and peripatetic services working closely together. Special teams can have a significant impact in helping people to remain in their own homes, but there may come a time when a period in a residential unit is necessary, to undertake specific assessments or to provide a ‘breathing space’ for staff and other residents living with the person who is challenging.

7. Costs

7.1 I was asked to provide information on costs in relation to different service configurations, but I find it not possible to satisfy this aspect of the brief. This is for two principal reasons. The first is that I do not have sufficient background to write with any authority on costing issues. However, more relevant perhaps is that the economic implications of services to people with challenging behaviour are not well understood, and there is not a good evidence base to draw on.

7.2 For example, in 1995-96 I was involved in a two-centre study, funded by the English Department of Health to review the research and census data on residential provision for people with learning disabilities, with particular reference to the debate on whether ‘village communities’ were an appropriate option (cf. Emerson, Cullen, Hatton and Cross, 1996). Since costs were claimed to be an issue, and in particular since there was a strong insistence from RESCARE that ‘village communities’ were less costly than the dispersed housing typically favoured in most hospital resettlement schemes (Cox and Pearson, 1995), the Department of Health funded a parallel study into the costs of village communities. This was carried out by the Economics and

Operational Research Division at the Department of Health with the Personal Social Services Research Unit at the University of Kent.

7.3 Although it was possible to demonstrate that the costs claimed for 'village communities' had not taken into account factors such as capital for building work or revenue for support services provided for people with requirements for intensive support, the author of the report had to point out that it is not appropriate to give a single generic unit costs for the care of people with learning disabilities" (Cronshaw, 1998, p.3). Services to people with learning disabilities are generally financed in complex ways, involving cross-subsidisation and the use of resources from a number of agencies.

7.4 Further work was then commissioned, and Emerson et al (1999) reported again on the quality and costs of residential support for people with learning disabilities. This report did not specifically address the issue of services to people with challenging behaviour, but provided "adjusted" costs which "take into account differences between… approaches with regard to ability, challenging behaviour and age of users" (p.10). These "adjusted costs" were significantly greater in dispersed housing schemes than in residential campuses. Village communities had the lowest adjusted costs, but I doubt very much that there are many services for people with challenging behaviour in village communities. For the purposes of this brief I believe that this option can be safely put to one side.

7.5 In general, what appears to be the case is that the smaller the residential unit, the greater the cost. Table 6 (p.11) of Emerson et al (1999), for example, tells us that the average annual adjusted total costs for supported living schemes, small group homes and larger group homes are £57,076, £53,847 and £50,873 respectively. This is not a surprising finding, and on its own is not particularly helpful to commissioners of challenging behaviour services. What is needed is research which links costs to quality in challenging behaviour services,

and this is not available. Blunden and Allen (1987) pointed out that "very little is known about the relative cost-effectiveness of alternative ways of providing services for people with challenging behaviour" (p.53) and little has changed since they wrote this.

7.6 In 1996 the NHS National Research and Development Programme for People with Physical and Complex Disabilities funded the Hester Adrian Research Centre to carry out research into the quality and costs of community-based services for people with severe challenging behaviour. There were initial delays in starting the work, and then difficulties in recruiting sufficient participant services. The project has now been extended, but is not expected to report before the end of September, 2001. The research was funded precisely because there are few good, existing data on the economics of challenging behaviour services.

8. References

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