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Abstract

While the concept of "challenging behaviour" is socially defined, it often involves persistent behaviour with serious physical and social consequences for the person and others. Challenging behaviour is relatively common amongst people with learning disabilities and often poorly dealt with. Models for understanding such behaviour have developed over time and can now provide a relatively sophisticated account. Such models are of immense use in understanding the behaviour of individuals and have clear implications for the development of individualised interventions. They also have implications for the design and organisation of services which will more competently support people with challenging behaviour and, as far as possible, prevent its emergence in those at risk.

Introduction

This paper presents a cognitive-behavioural approach to understanding and working with challenging behaviour in people with learning disabilities. We will argue that research has increased our understanding of the nature and causes of challenging behaviour to the point where a real difference can be made in the behaviour and lifestyle of the people concerned. We will describe the strategy that can be used to address challenging behaviour in an individual and illustrate this with an example. Finally, we will consider what needs to happen to apply this approach in a much more widespread way and its implications for the design and organisation of services.

The nature of challenging behaviour

Challenging behaviour is a label - another label in a field where we already have too many. Carers and services often use the label in circumstances where a person is behaving in unusual, indeed dangerous ways. Such behaviours include self-injury, aggression, destruction of the environment, sexually inappropriate acts, fire-setting, faecal smearing and many others. In such circumstances challenging behaviour is very real. The labelling process, however, should also be considered in terms of the consequences for the people applying the label. If complaining about challenging behaviour gets help or entry to another service then carers may use the label primarily to get access to the service. Similarly, since the label may lead to exclusion or other undesirable sanction, it is open to being used in a discriminatory way i.e. it may be differentially applied to people having certain characteristics as a way of excluding or discriminating against them for reasons unconnected to their behaviour

If we focus on the extent to which the label is correctly applied and refers directly to the person's behaviour then severely challenging behaviour can be defined as

"behaviour of such an intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities" [Emerson, 1987 #192].

This widely used definition is useful principally because it does not just refer to the person's behaviour but also to the impact which that behaviour has on their lifestyle. Serious challenging behaviour is not easy to overcome and the task is sometimes as much about managing it in a way which allows the person to lead a more ordinary lifestyle [Mansell, 1994 #808].

Challenging behaviour is both relatively common and relatively persistent amongst people with learning disabilities. Recent British studies [Qureshi, 1992 #885; Oliver, 1987 #536; Harris, 1993 #2324] have suggested rates between 7 and 18%. While these rates are not directly comparable (because of the different behaviours considered and definitions used) they show the extent of the problem. Qureshi's study suggests that in an area with a population of 220,000 we can expect between 31 and 56 people to present significant challenging behaviour. These studies (amongst others) have also suggested that challenging behaviour is more common amongst people with certain characteristics including more severe disabilities, additional sensory impairments and deficits in social and expressive language skills.

Understanding challenging behaviour

Frameworks for understanding challenging behaviour have become more sophisticated over time with important implications for assessment and intervention practices. We will illustrate these frameworks, consider their implications and then provide an example of the assessment and intervention planning process.

It is well recognised that "demands" (amongst other things) often set off challenging behaviour. We might ask someone to wash the dishes and they become aggressive. This often results in action to calm the person down or prevent injury to themselves or others. They may be moved to another room or restrained or given medication etc. In any event they end up not doing the dishes. One of the earliest sensible conceptions of challenging behaviour cf. [Bijou, 1968 #61] depicted exactly this pattern:

Antecedent ® Behaviour ® Consequence

demand ® aggression ® escape from demand

The demand "sets off" aggression which results in escape from the demand. From the perspective of the carer the person's aggression "sets off" their removing the demand and (with luck) the aggression stops:

Antecedent ® Behaviour ® Consequence

aggression ® remove demand ® aggression stops

The outcome of this process can be readily seen. The person is more likely to become aggressive when presented with demands and the carer is more likely to remove demands when the person becomes aggressive. Similar models have also been developed around other

important outcomes such as the gaining or avoidance of social contact, gaining sensory stimulation and getting access to materials or activities [Carr, 1994 #2588].

This ABC model of behaviour, however, has significant limitations. The chances are that the person does not become aggressive every time (perhaps not even most of the times) a demand is made of them. The model cannot explain this and also has difficulty in explaining why the person "needs" to escape demands. An obvious development would be to include in the model the kinds of factors which we usually take into account in explaining our own and others' behaviour - what people are thinking and feeling. Such thoughts and feelings may be reported directly by the person or (in the case of more severe learning disabilities) be inferred.

We might, for example, establish or infer that the person is thinking and feeling negatively about being asked to wash the dishes. Perhaps they don't know how to (or think they don't know how to) wash the dishes. Whatever the exact nature of the "thought" they are likely to be feeling distressed and wanting to get rid of their distress. Aggressive behaviour then may succeed in removing both the demand and (eventually) their own distress:

Thought "I don't know how to handle this" Antecedent 8 6 Behaviour Consequence 10 demand 8 escape from demand 6 aggression Feeling "I wish this would stop"

The carer may well have similar thoughts and feelings. They may be thinking (negatively) that they don't know how to cope with the person's behaviour and are almost certainly feeling distressed and frightened themselves:

Thought "I don't know how to handle this" Antecedent (8) 6 Behaviour Consequence aggression 6 (8) remove demand aggression stops Feeling "I wish this would stop"

This extension of the model helps us feel that we understand the motivation of the two parties better and shows how negative thoughts and feelings may have maladaptive consequences. Given this depiction it would not be surprising to find that both parties developed failure sets about these kinds of interactions (and therefore avoided them if at all possible) and both parties learned to handle their distress by seeking to escape from the distressing situation. The model does not go very far, however, in explaining the variation in the person's response to demand nor why the person is distressed and needs to escape. To understand more we need to expand the model considerably to take account both of a longer chain of behaviour and of various personal and environmental factors which are likely to influence behaviour cf.[Murphy, 1993 #2594; McGill, 1993 #1546; Clements, 1992 #124; LaVigna, 1989 #403; Murphy, In press #2617; Clare, 1992 #2616; McGill, 1994 #480].

One such expanded model is presented in Figures 1 and 2. The chain of behaviour is expanded to include what the person was doing prior to the presentation of the demand and, from the carer's perspective, to include their presentation of the demand. In addition four kinds of background factors are included - temporary personal (such as feeling tired), persistent personal (such as difficulty understanding speech), temporary environmental (such as a lot of noise) and persistent environmental (such as a climate of social control). The distinctions made here are relatively arbitrary in that some factors (such as chronic pain, acutely exacerbated) may be included in more than one category. Inclusion of these factors adds considerably to our ability to understand the variation in the person's response to demand and the reasons for their distress especially if we consider the kinds of thoughts and feelings with which they might be associated.

Figure 1 about here

Figure 2 about here

The main features of this account of challenging behaviour can be summarised as follows:

- Challenging behaviour often occurs in social encounters between people and their carers.
 Certain sorts of encounters, involving, for example, the presentation of a demand or the withdrawal of attention, appear more likely to "produce" challenging behaviour.
- 2. Challenging behaviour often serves an important function for the individual enabling them to control aspects of their environment and personal state. Typical functions include escape from demand, gaining or avoiding social contact, gaining sensory stimulation and getting access to preferred materials or activities.

- 3. The function which challenging behaviour serves is important for the individual because of the environmental and personal context. From a personal perspective such factors as difficulty in understanding, pain, etc alter the person's needs, making, for example, being left alone or sympathy or many other possible circumstances more important. From an environmental perspective such factors as the frequency of recent demands and their difficulty alter the person's tolerance for current and future demands.
- 4. These personal and environmental factors include factors which are readily understandable to us all ("it's 85 in the shade and you want me to mow the lawn?!") and factors which are harder to understand because they reflect the unusual personal characteristics of people with learning disabilities or the unusual environments which they inhabit. As people with learning disabilities are not always able to tell us their thoughts and feelings we can often only imagine the cognitive and emotional impact of such factors by drawing on our own experience of unusual circumstances.
- 5. We can use the same models to understand the behaviour of carers as of people with learning disabilities. This is important partly because it shows that we don't need to invent new processes to explain challenging behaviour and partly because carer behaviour has been largely ignored in accounts of challenging behaviour (though see [Hastings, 1994 #2539; Carr, 1991 #1263]).

This account of how we can better understand challenging behaviour carries two main practical implications:

 We need to use what we know about the likely causes of challenging behaviour to provide services which target the unusual features of both individuals and environments.
 This issue will be returned to later in the paper.

2. We need to understand the behaviour of individuals in much more detail so as to design interventions which can help overcome entrenched challenging behaviour - this requires much more detailed attention to both the specifics of an individual's personal characteristics and environment and to the processes by which these characteristics have created and maintained challenging behaviour. In the next section we will provide an example of this strategy.

Example of assessment and intervention planning with an individual

John (not his real name) was in his thirties. During the day he had a full programme (mostly paid work-experience) organised by a local resource centre. He lived in a group home.

The model described above was used to develop an understanding of aspects of John's challenging behaviours and his carers' responses. The information presented in Figure 3 was based on interviews with John, his carers and others who knew him, written records, assessments of his skills and difficulties, and observations of his interactions with carers.

Figure 3 about here

John's behaviour typically occurred in the context of demanding (paid) activities which he had requested (and sometimes harassed) carers to be allowed to do. When support was withdrawn, however, he could not cope. He was sometimes able to successfully avoid the demands and try again later but, if put under pressure (as sometimes happened in his group home), or upset by his inability to meet the demands, would respond with verbal abuse which often continued for several hours at a time. Where carers adopted a supportive approach, speaking to him slowly and simply, it was often possible to calm him but, if reprimanded, the situation would escalate and sometimes result in damaging furniture and (occasionally) kicking carers. This was often accompanied by threats to get his carers into trouble or to harm them and their families. These threats carried more weight because of John's history of walking out of the home, setting minor fires and damaging property. In addition, when John had difficulties, his family became upset and would very frequently phone the home, leading staff to feel under extreme pressure.

John's distress was readily understandable. When confronted with a reminder of what he was supposed to be doing (but could not do) he "panicked" (his own word) and blamed others. He either opted out or, if that was not possible, "took out" his anger on others. Some of his carers responded with their own feelings of resentment (at being abused, at being diverted from their other work, at the disruption to the home) rather than an attempt to understand the causes of John's distress.

That such situations arose relatively frequently reflected aspects of John and his situation. While having severe learning disabilities, John had been encouraged to be as independent as possible and appeared more competent than he really was. He saw himself as "an ordinary bloke" who was able to cope with most things but this, coupled with the service's (otherwise appropriate)

philosophy of opportunities and high expectations, resulted in his taking on responsibilities which he could not fulfill without support. Such support was often initially available but withdrawn fairly rapidly because of the incorrect perception of John's competence which existed. The situation was sometimes exacerbated by changes in his routine (e.g. working with a different supervisor) which "phased" John and reduced his ability to cope.

Not surprisingly, carers were somewhat bemused by this situation. They were behaving in ways entirely consistent with the service philosophy and apparently also consistent with John's wishes. Yet events often turned out for the worse and left them reacting inconsistently and, sometimes, inappropriately.

The aims of intervention were to interrupt the sequence leading to John's challenging behaviours as early as possible so that difficulties were prevented, not just reacted to, and to develop John's skills so that he could cope better with the difficulties he was facing. The intervention included:

- 1. making realistic demands based on information about John and his skills (reducing expectations, simplifying tasks with breaks, rewards, support, ensuring he had a better knowledge of what was involved when new responsibilities were negotiated), finding ways to meet his need for development which did not involve taking on responsibilities (e.g. going fishing);
- 2. anticipating difficulties (e.g., by care staff visiting when there was a locum supervisor at his work-experience);
- 3. developing John's skills (coping strategies for dealing with problems, training in recognising and dealing with distress);

4. support for care staff at the residential home (guidance for preventing and managing difficulties, meetings with the whole team to agree approaches).

While this intervention was clearly based on the understanding developed of John's behaviour and carer responses, it also drew on research e.g., about how to make demanding tasks less taxing (e.g., [Horner, 1991 #899]). Additionally, in assessing John's behaviour it had become evident that certain approaches worked much better than others so that some features of the intervention were about getting the whole team of carers to do what was already being done by a few people.

Concluding comments

We have outlined above a strategy for understanding and intervening with challenging behaviour in individuals. In summary the strategy involves a detailed assessment based on the model shown in Figures 1 and 2, the collation of information into a formulation of the factors influencing the person's behaviour and the use of this formulation to map out the required package of interventions. The widespread use of such an approach requires attention to a number of issues:

we need people with the skills to conduct this process. As the number of people with such skills is currently rather limited, significant investment in training is required

we need to develop (or identify) model services which can support training and allow the more extensive evaluation and development of the approach we need services which are receptive to the approach. This involves both shared understanding about the nature of challenging behaviour and a willingness to make the sorts of changes to service practices which are required

we need resources to support the often intensive work required.

Getting all of the above in place is likely to make a significant difference to the behaviour and lifestyle of many people with learning disabilities. This is not the whole story, however. We need also to extend our focus from work with people who already present serious challenging behaviour to effective early intervention and prevention. Without such a strategy challenging behaviour will continue to develop relatively frequently in people with learning disabilities and successful interventions will not be maintained over time. While the primary focus of early intervention is likely to be with young children (cf. [Murphy, 1995 #2615]), the emergence (or re-emergence) of challenging behaviour later in life also needs to receive attention. A focus on prevention is required both with young children and in the organisation of all services for people with learning disabilities [Dunlap, 1990 #2595; Mansell, 1994 #809]. Such a focus is likely to involve better meeting of the needs presented by those most at risk of developing challenging behaviour and modifying the environments which all too often contribute to the development or exacerbation of challenging behaviour [McGill, 1993 #1546]. In combination the strategies outlined have the potential to radically improve the lifestyles of people with learning disabilities at risk of challenging behaviour and support their full inclusion in community life.

Acknowledgements

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References

Figure captions

- 1 A more sophisticated model of challenging behaviour
- 2 A more sophisticated model of carer response to challenging behaviour
- 3 Understanding John's challenging behaviours

Key Learning Points

- The term "challenging behaviour" should be reserved for behaviour which is dangerous or significantly interferes with the individual's or others' lifestyles.
- 2 Challenging behaviour occurs in between 7 and 18% of people with learning disabilities and is often relatively persistent.
- It is more common in individuals with certain characteristics such as communication difficulties.
- 4 It often serves one or more functions, helping the individual to control some aspects of their lives more successfully.
- 5 It is often accompanied by emotional distress.
- 6 Challenging behaviour is often accompanied by carer distress and reactions which may help to maintain the behaviour over time.
- Models for understanding challenging behaviour can be used to guide individual assessment.
- Intervention will be more successful if based clearly on the results of assessment and is likely to involve a package of significant changes to the manner in which the individual is supported.

- 9 To attain more widespread use, positive approaches to understanding and intervening with challenging behaviour require investment in training and willingness amongst providers to make significant changes to service practices.
- Approaches to early intervention with and prevention of challenging behaviour should be important service development priorities.

Discussion Points

1	What is "challenging behaviour"?
2	Do you have any challenging behaviours? Do I?
3	How does challenging behaviour affect you?
4	Why do you think some people behave in challenging ways?
5	Imagine you are hitting someone - how are you likely to feel? Imagine you are being hit - how are you likely to feel?
6	How do we/staff/parents/carers usually deal with challenging behaviour?
7	How would you like to be treated if you behaved in a challenging way?
8	Should we include people with challenging behaviour or should we make them live/work/study somewhere else?

The individual	Their circumstances		
teenage and young adulthood	high levels of aversive control and abuse		
more severe disability	unpredictable or unstructured settings		
deficits in social and expressive language	regimes which prevent or limit access to		
skills	preferred objects or activities		
sensory (especially visual) impairment	low levels of social contact		
psychiatric disorder	barrenness, low levels of stimulation		
certain syndromes e.g. autism	material circumstances e.g. heat, crowds, noise		