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A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities

Richard P Hastings, David Allen, Peter Baker, Nick J Gore, J Carl Hughes, Peter McGill, Stephen J Noone and Sandy Toogood

Abstract

Background: To be able to define positive behavioural support (PBS), describe PBS interventions and clarify the individual and organisational competencies needed to support PBS, a clear underlying conceptual framework is needed to identify why challenging behaviours occur.

Method and materials: Non-systematic review and discussion of the state of research and theoretical evidence focusing on vulnerability factors for challenging behaviours, maintaining processes, and the social impact of challenging behaviour.

Results: Understanding challenging behaviour is related most strongly to context. First, challenging behaviours are defined in terms of their social effects. Second, vulnerability factors for challenging behaviour include some biological factors, but mainly psycho-social risks relating to the life situation and inequalities experienced by people with developmental disabilities. Third, social contextual processes are primarily responsible for maintaining challenging behaviours.

Conclusions: PBS is a broad approach to understanding and intervention referring to multiple contributing factors and processes. To describe PBS without reference to an underlying theoretically grounded conceptual framework would lead to an impoverished version of the approach.

Keywords: Challenging behaviour, positive behavioural support, causation, conceptual framework

Introduction

Interventions designed to ameliorate problems faced by individuals with developmental disabilities¹ need to be informed by a model or framework that describes an understanding of the problem (Hastings, 2013). Positive behavioural support (PBS) is no exception. To learn about PBS without understanding what the intervention approach is designed to do, or why PBS exists in the form that it does, would represent an incomplete and impoverished picture.

The need to elucidate the assumptions about the origins of a clinical problem to inform an intervention approach should not be a surprise to anyone reading this paper. In individual clinical practice, especially when applying

psychological interventions, a professional will develop a formulation of the problem and use that formulation to inform the focus of therapeutic intervention (see chapters in Taylor et al, 2013). Within PBS, formulation may be given a different name (generation of causal hypotheses, hypotheses about the function of a challenging behaviour) but it is a similar process. For example, any PBS intervention should be informed by functional assessment data (O'Neill et al, 1990). Indeed, there is evidence that including a functional analysis as a part of intervention for challenging behaviour significantly improves outcomes (e.g. Scotti et al, 1991).

¹ Developmental disability will be used as a term including children and adults with intellectual disability (ID) and those with autism, following international terminological conventions. Where evidence cited refers specifically to individuals with ID or with autism, this will be made explicit.

What may be less well understood is that for any intervention approach to be considered evidence-based, a necessary criterion is considered to be clarity about the theory underpinning the intervention approach. Thornicroft et al (2011) describe theory development/understanding of a problem as the first phase in developing evidence for complex psychological interventions such as PBS. This knowledge can then inform what processes are targeted by an intervention. The focus is on how an intervention is intended to work. Thus, it is clear that interventions do not materialise from thin air – they are informed by theory.

The purpose of the present paper is to describe what might be the underlying conceptual framework upon which PBS should be based. We will draw on research evidence about why challenging behaviours occur in people with developmental disabilities. We do not intend to carry out a systematic review of the research evidence in relation to challenging behaviour, or to be exhaustive. Rather, we want to describe a general formulation of the ‘problem’ of challenging behaviour. Beginning this special issue with a conceptual framework is appropriate because everything else then follows: it provides the context for what PBS is, and also what skills or competencies are needed in individuals or teams delivering PBS and within the organisations in which they work.

Challenging behaviour as a social construction

Perhaps the most widely used definition of challenging behaviour, certainly in the UK, derives from Emerson and colleagues’ work from the 1980s in the south east of England (Emerson et al, 1994). Emerson’s latest definition (Emerson and Einfeld, 2011), very clearly emphasises that challenging behaviour is defined socially. This social definition is at two levels. First, behaviours that might meet a definition of ‘challenging’ are culturally inappropriate – they stand outside of the social norm. It is important to bear this first level of social context in mind. However, more significant for our understanding of challenging behaviour is that these are actions that occur so frequently, at a high enough level of severity, or for a long enough time, that they begin to have clear social consequences. These consequences have been defined in terms of harm to the person, harm to other people (or the risk of harm in either case), or exclusion from typical community life in some way. The fact that challenging behaviours are defined primarily in terms of the impacts that they have is illustrated simply in *Figure 1*. As will be seen later, a focus on the impacts of challenging behaviour has profound implications for our understanding of why these behaviours tend to occur.

Figure 1 The social effects of challenging behaviour

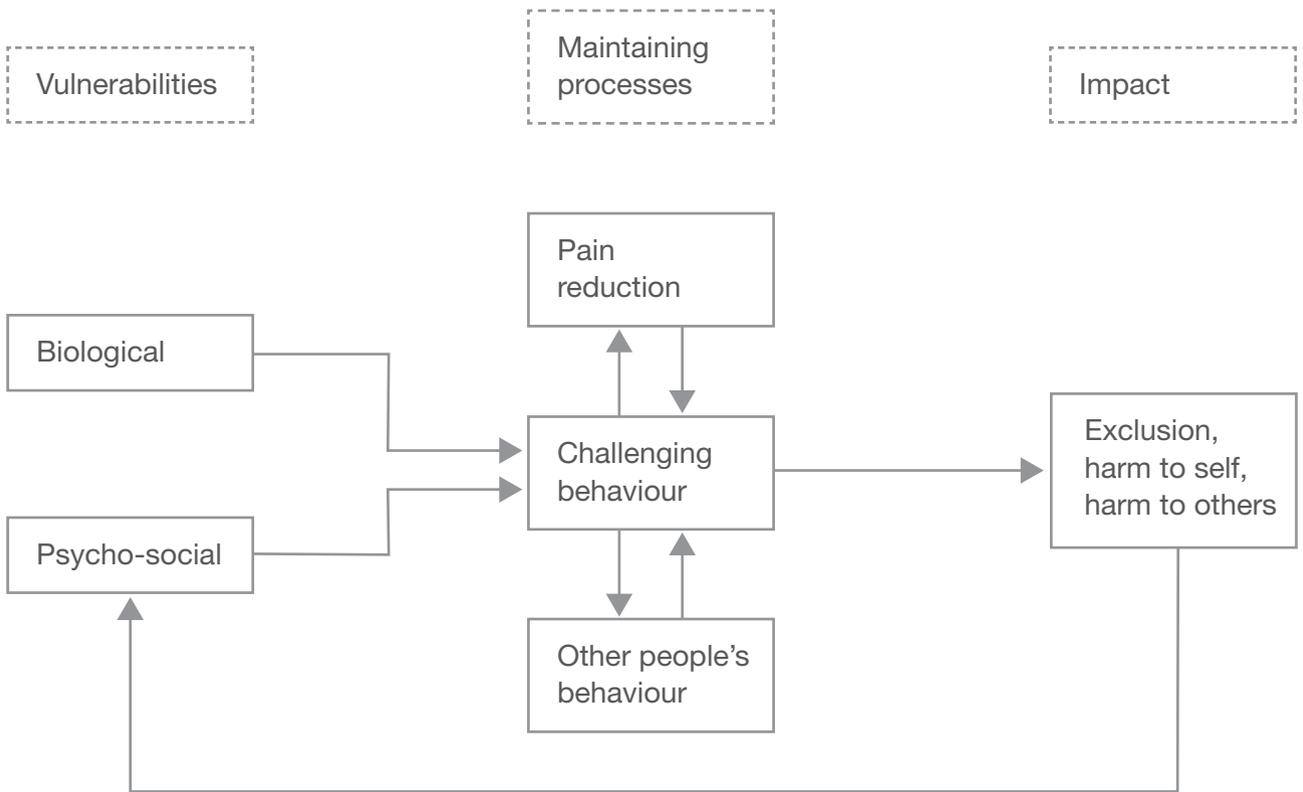


Towards a framework for understanding challenging behaviour

Just as, in definitional terms, the key to challenging behaviour is a social or contextual understanding, context is also central to building a framework that helps to describe why challenging behaviours occur in individuals with developmental disabilities. Our proposed framework is illustrated in *Figure 2*. We have drawn on our understanding of the broad research literature relating to

challenging behaviour/behaviour problems in individuals with developmental disabilities, and brought together the influences on challenging behaviour, we hope, in a parsimonious manner. It is important to explain each part of the framework in turn so that the thinking behind it is clear.

Figure 2 A framework for understanding why challenging behaviours occur



Biological and psycho-social vulnerabilities

A number of both biological and psycho-social factors have been identified through research as vulnerabilities or risk factors for challenging behaviour. These factors are a part of the context in which challenging behaviours emerge.

Biological vulnerabilities appear to fall into two broad areas. First, challenging behaviours may be related to an underlying sensory problem or a physical health problem, especially those resulting in pain. It is often recommended that a physical health screen is conducted alongside, or more likely before, any assessment of challenging behaviour. Ruling out physical health or sensory causes is important. For example, a person with limited hearing may have problems following instructions or advice in their community living setting and appear stubborn. The situation may escalate as support staff become frustrated with the individual's 'attitude'. Simply solving the hearing problem may be enough to deal with the 'challenging behaviour'. Turning to physical pain, a classic example might be a problem such as an ear infection leading to significant pain in the inner ear. By hitting the ear or side of the head, the pain may be experienced as dulled – due to the release of natural endorphins. Again, there may

be a relatively simple solution through medical treatment and/or pain relief.

The second area of biological vulnerability relates to genetic influence. It has been noted for some time that several genetic syndromes associated with intellectual disability have an increased risk for challenging behaviours. For example, self-injury is a common problem in Cornelia de Lange syndrome (Hyman et al, 2002). This genetic, or likely genetic, vulnerability requires additional investigation so that the implications for understanding challenging behaviour are clear. Individuals with Cornelia de Lange syndrome also appear to be at considerable risk for gastro-intestinal reflux due to biological structural problems associated with their genetic make-up (Hall et al, 2008). At least a proportion of the self-injury in this group appears to be related directly to the pain experienced as a result of reflux. When the reflux is properly treated, self-injury can be reduced (Peebles and Price, 2012).

Psycho-social vulnerabilities relevant to understanding challenging behaviour could be large in number. However, on the basis of existing research evidence, we suggest that there are five main factors: negative life events

(including traumatic experiences and abuse), lack of communication skills, impoverished social networks, lack of meaningful activity, and psychiatric or general mood problems.

Longitudinal data have suggested that cumulative exposure to negative life events predicts increased risk for challenging behaviours over time in individuals with intellectual disability (Hulbert-Williams et al, in press). Such events include repeated changes in staffing support within service settings, and daily bullying in the community as well as negative life events experienced by all members of society (e.g. illness, bereavement). One-off or repeated exposure to serious traumatic events, such as physical or sexual abuse, is also associated with increased risk for challenging behaviour (Hulbert-Williams and Hastings, 2008).

At the core of an understanding of challenging behaviour is the limited communication skill possessed by many individuals with developmental disabilities. This can mean that people resort to other means to get the attention of other people in their environment. Challenging behaviours are very effective ways of getting other people to respond to you (see later). Having limited communication skills is associated with an increased risk for challenging behaviour (Emerson and Einfeld, 2011). Impoverished social networks and lack of meaningful daily activity can also contribute to this vulnerability. In particular, people with developmental disabilities may have fewer opportunities to both develop their communication skills in social contexts and practice them in multiple environments over time.

Having few friends and other members of one's social network is a common experience for people with developmental disabilities (Lunsky and Benson, 1999). This is likely to create multiple associated vulnerabilities. For example, it may be easier for other people to abuse those with developmental disabilities, there may be a reduced protective effect of social support creating vulnerability to depression, and simple loneliness might be experienced. A lack of meaningful activity is also partly related to reduced social networks – having fewer people to do things with socially. However, the lack of meaningful activity is also a broader issue because people with developmental disabilities are much less likely to be in employment and experience access problems when it comes to leisure opportunities (Verdonschot et al, 2009). Lacking meaningful activity again is a risk factor for depressed mood (Lejuez et al, 2011).

At several points in the discussion above, the secondary effect of some vulnerabilities on underlying mental health has been discussed. Research studies have shown *associations* between mental health problems in people with intellectual disability and their challenging behaviours. This association appears to be strongest in those with severe intellectual disability (Felce et al, 2009). Exactly why this is the case, and what mechanisms are in play, is still debated and informed only limited research (Allen, 2008). One possibility is that challenging behaviours may be atypical manifestations of mental health problems especially in a context where communication skills are limited (and thus it is difficult to self-report about mental health symptoms). A further possibility is that mental health problems create increased sensitivity to certain antecedents and consequences for challenging behaviour (see following section).

At this point it is also important to link the impact of challenging behaviour back to vulnerabilities leading to challenging behaviour, since a cyclical relationship is likely to exist. Thus, challenging behaviours are likely to lead to harm to self or others or to community exclusion. These impacts in themselves create additional vulnerability, especially in terms of exposure to negative life events, social isolation, and lack of engagement in meaningful activity.

Maintaining processes

Considering vulnerabilities that may lead to the emergence of challenging behaviour is not sufficient for a model of why these behaviours occur. Specifically, because of the nature of the impacts that challenging behaviours have (see *Figure 1*) it is difficult to understand why someone would continue with them when they may well lead to individual harm, harm to others, or lead to exclusion. The point is that challenging behaviours must be 'useful' in some way if they continue to occur. That is, they serve some important *function* for the individual. An understanding of the functions that challenging behaviours may serve is the core part of our framework and essential when it comes to intervention, especially PBS intervention.

For almost four decades, there has been good evidence that the functions relevant to an understanding of probably the vast majority of challenging behaviours are relatively small in number (Carr, 1977): stimulation, attention from others, access to 'tangibles' (things that are tangible, such as food or preferred objects), and avoidance of demands. In more recent times, pain reduction has been added to this list and is examined now in checklists assessing the functions of challenging behaviour (Matson

et al, 2012). Our brief pain-related explanation earlier is a good illustration of the point of function. In the presence of pain, an individual might engage in self-injurious behaviour (e.g. hitting or squeezing hard the body area in pain). This results in the release of natural body endorphins that act as natural painkillers. In the future when pain is experienced, self-injury may occur again because it led to a positive outcome previously. Self-injury is unlikely to occur all of the time (unless pain is constant), but mainly in the presence of pain. Thus, it is important to identify for challenging behaviour the context in which it occurs (what comes before – antecedents) and what results from the behaviour (what comes after – consequences).

The other typical functions for challenging behaviour can be thought of in a similar way. In situations of low attention, if other people (a parent or a support staff member) respond to challenging behaviour by attending (e.g. even with sympathy, or with a rebuke), the behaviour may be more likely to occur in situations of low attention in future. This is an example of social attention in a positive reinforcement relationship with challenging behaviour. Giving the person access to preferred tangibles, such as a favourite toy or other object, would work in the same basic way. In a similar vein, if other people make demands (e.g. ask a person to engage in a task) but then remove the demand when challenging behaviour occurs, challenging behaviour is likely to occur again in future when demands are presented so that they can be avoided. This is an example of a negative reinforcement model – something disliked (e.g. a demand to do something) is removed when the challenging behaviour occurs. The final example of a typical function for challenging behaviour is stimulation in the context of lack of an enriched environment or meaningful activity. Engaging in challenging behaviour can sometimes simply lead to stimulation and if so, may occur again when someone is ‘bored’.

We have just, in very simple terms, outlined typical functions for challenging behaviour – the ‘purpose’ of challenging behaviours. They can effectively increase access to attention or preferred items, reduced demands or otherwise contribute to avoiding less desired situations, they can provide stimulation, and they can help to reduce the experience of pain. Thus, it is important to understand that challenging behaviours occur for a reason, in context, and not in a vacuum. One helpful metaphor that can help in grasping this concept is that of communication – challenging behaviours are a means of communicating something. In colloquial terms, this might be: ‘give me some attention’, ‘give me that’, ‘I don’t want to do that’, ‘I’m bored and need something to do’, or ‘I’m

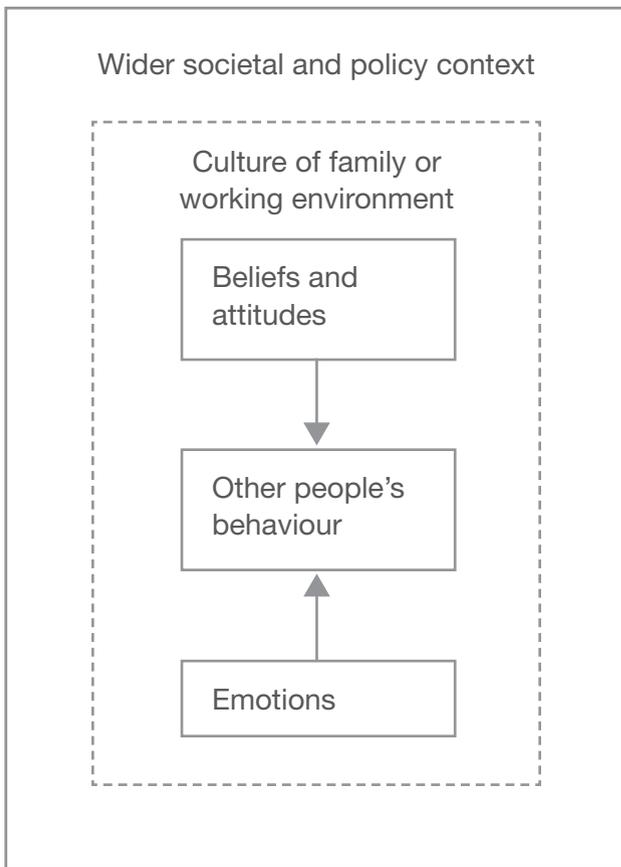
in pain’. Knowing what a person communicates with their challenging behaviour – the function of that behaviour for them – gives us a clear idea of what to do to help them.

The preceding discussion could be read too simply – as suggesting that a certain challenging behaviour will have a single clear function. This is absolutely not the case. Even in highly specialised samples, where researchers are reporting the results of functional analyses of challenging behaviour, a significant proportion are identified as potentially serving multiple functions (e.g. Iwata et al, 1994). Day-to-day clinical cases are also usually more complex. Thus, the functions served by one form of challenging behaviour may vary depending on the context (e.g. home versus school for children, in the presence of one staff member versus another), and the same function might be served by multiple challenging behaviours. Thus, it is very important to build an individualised model of a person’s behaviours and how they inter-relate in terms of functions and contexts (Toogood, 2011).

A further issue that is often poorly understood, but has been elucidated for quite some time (Hastings and Remington, 1994; Hastings, 2005), is that the behaviour of other people is what links the reasons why challenging behaviours occur and especially how they are maintained. Other people create the contexts in which individuals with developmental disabilities experience little social contact, aversive (e.g. abusive) interactions, lack of meaningful activity, and have their health needs neglected. Furthermore, other people provide the attention or access to tangibles and remove demands when challenging behaviours do occur. Thus, it is crucial to understand this system of inter-relationships between challenging behaviour and other people’s behaviour to understand fully the maintaining processes for challenging behaviour. In behavioural terms, we need to work out the *functions* of other people’s behaviour in environments in which challenging behaviours occur.

Understanding carers’ behaviour

As with challenging behaviours themselves, if other people’s behaviours are contributing to the maintaining processes for the ‘problem’ of challenging behaviour it is important to work out why this happens. Again, because of the impacts of challenging behaviour on other people (let alone individuals with developmental disabilities themselves) it makes no sense to behave in ways that will lead to its continued occurrence. Drawing on two decades or more of research, we have argued recently that carer behaviour might be understood using the expanded framework shown in *Figure 3* (Hutchinson et al, in press).

Figure 3 Influences on other people's behaviour

The first issue to consider is that perhaps carers respond in ways that are more likely to maintain challenging behaviour than to help reduce it because they do not have an accurate picture of what is going on. This would be perfectly understandable. Take a look at *Figures 1–3* and the number of words it is taking us to explain very basically what these figures are summarising. There are so many possibilities that without good data and analysis of those data, it would be very hard to develop a clear picture of why an individual is engaging in challenging behaviour. Thus, inaccurate or otherwise erroneous beliefs about challenging behaviour may play a role in explaining why other people act as they do in response to challenging behaviour. Beliefs and attitudes might be many and varied. For example, carers might have formed a view that 'he's just doing it to get attention'. If the behaviour is in fact maintained by escape from demands, this is unlikely to be helpful. An equally unhelpful belief might be that 'it just comes "out of the blue", for no reason'. Responses based on this belief would clearly ignore that there likely is a function and might reduce the effort spent trying to find out about that function.

Equally, if not more, important is to understand the emotional impact of challenging behaviours on other people. This can be at two levels. First, there is good evidence that when carers witness challenging behaviours they experience them as aversive (Mossman et al, 2002). In particular, it can be distressing to see someone injure themselves, aggressive behaviours can be frightening, and when carers are the subject of aggressive behaviours it is natural to feel angry. Carer's reactions then to challenging behaviours may serve to reduce these aversive experiences. Thus, if carers respond in ways likely to maintain challenging behaviour (e.g. removing demands from a person whose challenging behaviour functions to reduce demands) the immediate effect is reduction in their aversive experience. However, this will likely ensure the long term survival of the challenging behaviour.

The second level at which carers' emotional experience is important to our framework is their general experience of levels of stress in the work setting or in the home (for parents). Both parents (Totsika et al, 2011) and support staff in services (Devereux et al., 2009) report increased stress associated with caring for children or adults with developmental disabilities. Furthermore, both parental (Hastings, 2002b) and support staff (Hastings, 2002a) stress is related to their ongoing exposure to challenging behaviour. Carers in a state of heightened stress are likely to respond very differently to the individuals in their care and especially to their challenging behaviours. For example, carers under stress may be additionally vigilant for any aversive experiences or may uncharacteristically show lowered patience in dealing with challenging behaviours.

Carer's beliefs and emotional life also need to be considered within a wider context (*Figure 3*). The first level is the culture of the family or the informal working culture of services. Within a family, there will be various accepted practices including how a single parent or a couple approach parenting, the extent to which they have access to outside support and advice, and the extent of willingness to accept external help and advice. In a service setting, support staff cultures are also likely to be powerful. Again, there will be accepted ways of doing things, certain individuals who are seen as leaders and whose advice is followed, and the competing demands of the context (e.g. the need to ensure a safe and clean physical environment as well as the social and emotional needs of people with developmental disabilities).

These more informal cultures, and the individual carers embedded within them, are set in a broader societal context. Thus, the layer of policy and practice as well

as general societal attitudes will have some influence on what carers do when they respond to challenging behaviours. In services, for example, there will be policies about risk to consider. Not only will these apply to the individuals with developmental disability, but also to the support staff (i.e. health and safety at work issues). In terms of families, there may be considerable social attitudinal (e.g. families are the best place to care for people) and policy/economic (e.g. reluctance to spend money on out-of-home placements) pressures for them to continue to care for a very challenging relative at home.

Conclusions

There is a great deal more detail that we could have provided both to evidence our outline framework and also to describe its dimensions. However, our intention was to present an overview that would provide a broad context for the remainder of this special issue. Rather than detail all of the possible implications of this framework for PBS, we will make a few observations to reinforce the need for a conceptual model of challenging behaviour when working in this field:

- Medical management is likely to play only a minor, although important and specific (in relation to underlying health conditions), role in intervention for challenging behaviour. The overwhelming focus is on social environmental and psychological factors, especially the behaviour of other people.
- Context is crucial to an understanding of all of the elements of our framework – how challenging behaviour is defined, the vulnerabilities for challenging behaviour, and other people's behaviour. Thus, intervention is clearly not just about the challenging behaviour itself.
- Vulnerability factors can be tackled directly to reduce the chances of challenging behaviour occurring. Thus, lifestyle and other preventative interventions are an important part of PBS. For example, teaching social and communication skills or increasing engagement in meaningful activity will be important PBS intervention components.
- When challenging behaviours are established, learning theories informing applied behavioural analysis (ABA) assessment and intervention methods are especially needed to ensure maintaining processes are tackled. Because of the inter-relatedness of the components of our framework, ABA models, competencies and methods are not an optional extra for PBS. PBS lives or dies with ABA.
- Although it is important always to have interventions and service models that will ensure the best support for individuals whose challenging behaviour has developed to a concerning level, early proactive intervention is needed. Certainly this applies to preventative models for working with children with developmental disabilities (informed by our conceptual framework), but also to adolescents and adults who may be vulnerable to the development of challenging behaviour.

Finally, it is important to be clear that PBS can be broadly defined by focusing our conceptual framework. In fact, PBS must be rooted in a clear and agreed underlying conceptual model. The first broad implication of this is that PBS will address multiple factors and levels within the systems outlined in *Figures 1–3*. Our framework shows why PBS is broad and systems-based. A second implication is that any approach focusing on only one area of these systems is not synonymous with PBS but might be a part of a PBS intervention approach. For example, not all challenging behaviour is trauma-related and to treat it as such misses completely the conceptual underpinnings of our understanding of challenging behaviour. We might learn from aspects of care informed by trauma models, but trauma-focused care is not an alternative to PBS. The third broad implications are in terms of measurement of the success of PBS interventions. Certainly, one would be interested in whether challenging behaviours reduce in intensity, frequency, or duration (because this is likely to reduce their impacts). However, a range of other outcomes must also be measured and indeed be targeted by PBS intervention. The implication is that reductions in challenging behaviour alone are perhaps necessary but certainly not sufficient for PBS.

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