Capable Environments

Introduction

Challenging behaviour remains a significant problem in family and supported accommodation settings for people with intellectual and developmental disabilities (cf Department of Health, 2007). Almost half of residential care services report the use of restrictive responses such as physical intervention (Deveau & McGill, 2009). Challenging behaviour is associated with placement breakdown (Phillips & Rose, 2010) and the subsequent, costly removal of individuals to more restrictive, out-of-area settings (Goodman et al, 2006). Furthermore, it is associated with high rates of injury to care staff (National Task Force on Violence against Social Care Staff, 2001).

Generally, challenging behaviour is treated as an individual, health-related problem requiring treatment by psychologists, psychiatrists or other behaviour support professionals (Royal College of Psychiatrists et al, 2007). But many such professionals now adopt positive behaviour support (PBS) (Carr et al, 2002), an approach which inevitably leads to a focus on the context in which challenging behaviour is occurring – “the central independent variable in PBS is systems change” (Carr, 2007, p.4). Such change is not easily obtained with regular reports of difficulties implementing the proposed treatments (e.g., Ager & O'May, 2001; Bambara et al, 2009). These problems are not unique to intellectual and developmental disability. For example, the problems of difficult behaviour presented in mainstream schools have been recognised as requiring a broader approach, more focused on prevention (Sugai & Horner, 2002). The development of school wide positive behaviour support in the USA reflects this (Horner et al, 2009). As yet, there has been little attention to the potential for a similar approach in social or family care settings though Freeman et al (2005) outline what might be required to embed positive behaviour support in human service organisations.

Such an approach is also consistent with theoretical developments in our understanding of the causes of challenging behaviour. Once seen as an almost inevitable concomitant of intellectual disability, it is now regarded as a result of the complex interaction of biological, developmental and environmental factors (Langthorne et al, 2007). Of particular relevance to this chapter, it has become clear that certain characteristics of the social environment (such as social distance and aversive stimulation) may underpin the motivation of challenging behaviour (McGill, 1999). Altering such “motivating operations” then becomes a theoretically viable approach to preventing or reducing the occurrence of challenging behaviour in those at increased biological or developmental risk (cf Emerson & Einfeld, 2011).

The current chapter will discuss this systemic, theoretically-driven approach in which the focus is on improving the quality of care and support arrangements especially in those areas known to be associated with challenging behaviour. The chapter will stress the development of more capable environments in which the support strategies emphasised are, as much as possible, those known to be associated with the reduced occurrence of challenging behaviour. Such an approach promises substantial quality of life improvements for individuals, better work environments for staff and a reduction in the costs associated with specialist care and out-of-area placements.

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Background

The revised Mansell Report (Department of Health, 2007) identified three central problems faced by people with learning disabilities whose behaviour presents challenges:

- Community placements break down;
- Out-of-area placements are increasingly used;
- Poor quality institutional solutions persist.

These problems are, of course, closely linked. Placements competent to meet the needs of people who present a challenge are often not available in peoples’ local areas despite continued guidance that they should be (Department of Health, 2004). Over 1/3rd of people with learning disabilities supported by local authorities are placed out-of-area and there was a slight rise in the percentage between 2006 and 2008 (Whelton, 2009). While there is no definitive evidence concerning the comparative quality of out-of-area placements, it is clear that they are inadequately monitored (Beadle-Brown et al, 2006; Emerson & Robertson, 2008), may cause stress and family dislocation (McGill et al, 2006) and that the quality of at least some is dubious (Beadle-Brown et al, 2006; Becker, 2006; Emerson & Robertson, 2008). Winterbourne View provided a tragic example of very inadequately monitored, very poor quality, out-of-area, institutional placements.

People placed out-of-area are by no means exclusively people presenting challenging behaviour but are more likely to be so (Emerson & Robertson, 2008). It is important to note that the process of exclusion underlying these problems often starts in childhood. Children whose behaviour presents a challenge are frequently excluded both from school (including from special school) and from other local services such as short breaks. As a result, out-of-area residential placement is relatively common (McGill, 2008). Such placements are, from the point of view of the commissioners of adult services, literally ‘out of sight and out of mind’. As a result, substantial numbers of those placed in residential schools continue in out-of-area placements. Others, having remained with their families throughout childhood, leave their local areas at 18 or 19 when it becomes apparent that there is no local college at which they can continue their education and no local process for developing the personalised, supported accommodation and employment opportunities that they need. Others, either during childhood or adulthood, in the wake of a mental health crisis and their exclusion from local mental health services, go off to an out-of-area private psychiatric hospital. Once out-of-area, a return to a local community placement is relatively difficult. Typical transition protocols are challenged by the difficulty of including people now living some distance away (Heslop & Abbott, 2007). The whole process of developing a local service, relying as it does on a good understanding of the person’s needs and wishes, is made more difficult. Families, experienced in the failures of local services and used to the apparent safety of the out-of-area provider, may oppose any move. Providers, often relying on economies of scale and based in areas of the country where property and land are cheaper, have a vested interest in maintaining the status quo.

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2 This section is adapted from McGill et al (2010).
3 In a recent evaluation by Peter McGill of a residential care provider, more than 2/3rds of the 70 residents (average age 24 years, almost all in out-of-area placements) had previously been placed in a residential school, many in schools run by the same care provider.
Many out-of-area placements are relatively institutional, e.g. in “village” or “campus” or “hospital” settings. Concern about their quality inevitably arises given the increased difficulty for local authorities of monitoring outcomes for individuals. The very nature of the settings often reinforces the view (amongst commissioners, providers and/or families) that the individual could not succeed in a local, more inclusive placement. But there is considerable evidence that this is not true. First, studies of the resettlement of people from the long-stay hospitals demonstrate very clearly that individuals whose behaviour is very challenging are able, when supports are tailored to their needs, to live in ordinary, local community settings (Mansell et al, 2001). Second, there are practice examples of individuals returning successfully from out-of-area residential school placements as children to local life (Emerson & Robertson, 2008) and the Association for Supported Living (2011) has provided examples of similar transitions made by adults. Third, there is considerable variation in the use of out-of-area placements suggesting that some areas are much more successful than others at including people in local service developments (Whelton, 2009).

Evidence

As can be inferred from the above, the lack of capability in local services to respond appropriately and inclusively to challenging behaviour can be seen in both the immediate environment (e.g. a supported accommodation setting) and in the broader professional environment (e.g. the local community team). This section of the chapter will focus particularly on three issues:

- What we know about the characteristics of capable environments
- How we help environments become more capable
- What professionals need to do to provide capable support

Characteristics of capable environments

It is not possible here to provide a comprehensive review of all that we know about capable environments. Accordingly, Table 1 provides a summary of many of their characteristics. These characteristics share two defining features. First, they produce positive outcomes for individuals and their supporters such as enhanced quality of life. Second, they prevent many instances of challenging behaviour. They will not, it should be noted, prevent all instances of challenging behaviour. But, at the very least, they will ensure that the individual (in some cases, despite persistent challenging behaviour) is living as good a life as is currently possible.

Helping environments become more capable

Unfortunately, many of the environments where individuals at risk of displaying challenging behaviour are supported are not nearly as capable as they could be. The literature on helping such environments change remains limited. Mansell et al (1994) described the use of “whole environment training” to improve the quality of support by staff teams in supported accommodation settings. The approach had a number of components:

- 12 days hands-on training in each house delivered by external trainers in collaboration with the organisation’s middle managers
<table>
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<td>Positive social interactions</td>
<td>Carers like the person and interact (speak, sign, physically etc) frequently with them in ways that the person enjoys and understands.</td>
<td>In situations where the person receives unconditional, positive social interactions they are less likely to display challenging behaviour to obtain social interaction; carers who establish good relationships with individuals can embed any necessary less positive interactions (e.g. physical care that may be uncomfortable or distressing). Most people (with and without learning disabilities) want to receive positive social interactions from those around them.</td>
<td>Non-contingent social interaction reduces challenging behaviour maintained by attention (Carr et al, 2009).</td>
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<td>Support for communication</td>
<td>Carers communicate in ways the person understands and are able to notice, interpret and respond to the person’s own communications whether indicated by speech, sign, gesture, behaviour or other. This support for communication is seen across all areas of the person’s life and people are supported in rich communication environments. This knowledge of communication is shared across environments and with unfamiliar communication partners (e.g. through the use of</td>
<td>Challenging behaviour is less likely when the person understands and is understood by those around them. Most people (with and without learning disabilities) want to communicate with those around them, especially those they are close to.</td>
<td>Both receptive and expressive communication are strongly associated with severity of challenging behaviour in children with developmental disabilities (Sigafoos, 2000).</td>
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<td>Support for participation in meaningful activity</td>
<td>Carers provide tailored assistance for the individual to engage meaningfully in preferred domestic, leisure, work activities and social interactions. Assistance meaningfully employs speech, manual signs, symbols or objects of reference as appropriate.</td>
<td>Challenging behaviour is less likely when the person is meaningfully occupied. Skilled support ensures that they can participate at least partially even in relatively complex activities so that they learn to cope with demands and difficulties that might otherwise provoke challenging behaviour. Most people (with and without learning disabilities) like to be busy.</td>
<td>Person-centred active support reduces the severity of challenging behaviour (Beadle-Brown, Hutchinson, &amp; Whelton, 2012).</td>
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<td>Provision of consistent and predictable environments which honour personalised routines and activities</td>
<td>Carers support the person consistently so that the person’s experience is similar no matter who is providing the support. Carers use a range of communication and other approaches tailored to the individual (e.g. visual timetables, regular routines) to ensure that the person understands as much as possible about what is happening and about to happen.</td>
<td>Challenging behaviour is more likely when the person is supported inconsistently or when in transition between one activity/environment and another activity/environment. Most people (with and without learning disabilities) value consistent and predictable support.</td>
<td>Activity schedules decrease challenging behaviour in children and young people with autism spectrum disorders (Lequia et al., 2012).</td>
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<td>Support to establish and/or maintain relationships with family and friends</td>
<td>Carers understand the lifelong importance to most people of their family, and the significance of relationships with others (partners, friends, acquaintances etc). Carers actively support all such relationships while being aware of the risks that sometimes arise in close or intimate relationships.</td>
<td>Challenging behaviour is less likely when the person is with family members or others with whom they have positive relationships. For most people (with and without learning disabilities), relationships with family and friends are a central part of their life.</td>
<td>Challenging behaviour is less likely where there is good rapport between individuals and their carers (Magito-McLaughlin &amp; Carr, 2005).</td>
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<td>Provision of opportunities for choice</td>
<td>Carers ensure that the individual is involved as much as possible in deciding how to spend their time and the nature of the support they receive from the relatively mundane (e.g. choice of breakfast cereal) to the rather more serious (e.g. who supports them).</td>
<td>Challenging behaviour is less likely when the person is doing things that they have chosen to do or with people that they have chosen to be with. Most people (with and without learning disabilities) value the opportunity to decide things for themselves.</td>
<td>Offering choices between activities reduces challenging behaviour of children with autism spectrum disorders (Rispoli, et al., 2013).</td>
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<td>Encouragement of more independent functioning</td>
<td>Carers support the individual to learn new skills, to try new experiences and to take more responsibility for their own occupation, care and safety.</td>
<td>The development of new skills and independent functioning enables the individual to have more control over their life. Most people (with and without learning disabilities) like to be independent.</td>
<td>Teaching individuals functional communication skills reduces the occurrence of challenging behaviour (Kurtz et al, 2011).</td>
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<td>Personal care and health support</td>
<td>Carers are attentive to the individual’s personal and healthcare needs, identifying pain/discomfort, enabling access to professional healthcare support where necessary and tactfully supporting compliance with healthcare treatments.</td>
<td>Challenging behaviour is less likely when the individual is healthy and not in pain or discomfort. Most people (with and without learning disabilities) attach the highest possible value to “good health” and want to receive personal support in dignified ways.</td>
<td>Challenging behaviour is more likely when individuals are in pain or suffering from a number of different health conditions (Kennedy &amp; O'Reilly, 2006).</td>
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<td>Provision of acceptable physical environment</td>
<td>Carers support the individual to access and maintain environments which meet the individual’s needs/preferences in respect of space, aesthetics (including sensory preferences), noise, lighting, state of repair and safety.</td>
<td>Challenging behaviour is less likely in the absence of environmental “pollutants” (e.g. excessive noise). Most people (with and without learning disabilities) want to live and work in safe, attractive environments where they feel at home.</td>
<td>Exposure to poverty increases the risk of conduct problems in children with intellectual disabilities (Emerson et al, 2010).</td>
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<td>Mindful, skilled carers</td>
<td>Carers understand both the general causes of challenging behaviour and</td>
<td>Challenging behaviour is less likely when carers understand its causes</td>
<td>Training family carers in mindfulness leads to reductions in the challenging</td>
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<td><strong>Effective management and support</strong></td>
<td>Carers are managed and/or supported by individuals with administrative competence and the skills to lead all aspects of capable practice.</td>
<td>Challenging behaviour is less likely when carers are well-managed, led and supported. Most people (with and without learning disabilities) want to be confident that their carers (if they need them) are, themselves, well supported and can get help when they need it.</td>
<td>A combination of extended short breaks and intensive positive behaviour support reduces challenging behaviour in children and young people with intellectual disabilities (Reid et al, in press)</td>
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<td><strong>Effective organisational context</strong></td>
<td>Support provided by carers is delivered and arranged within a broader understanding of challenging behaviour that recognises (among other things) the need to ensure safety and quality of care for both individuals and carers.</td>
<td>Challenging behaviour is less likely when positive behaviour support informs the culture of families, service providers and service commissioners. Most people (with and without learning disabilities) want to receive evidence-based, well governed supports.</td>
<td>School-wide positive behaviour support integrates interventions at organisational and individual level to reduce challenging behaviour of both typically developing and disabled children (Horner et al, 2010)</td>
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• Collaboration with first line managers during the training to strengthen their competence and role in providing practice leadership
• Addressing administrative and organisational issues with more senior managers (e.g. to ensure staff recruited appropriately or that policies don’t get in the way of good practice)
• Developing a management information system to gather and monitor information about staff performance and client outcomes in each house.

Whole environment training illustrates the key components of an effective change process – organisational support, practical rather than exclusively classroom training and effective mechanisms for communicating and monitoring standards (see also LaVigna et al, 1994). The difficulty of achieving such changes should not be underestimated. Where successfully achieved they have been primarily provider-led and have required a persistent focus on clearly-defined outcomes for individuals. Pressure for change needs also to be exerted by commissioners so that capable environments are a core part of the service specification process.

Professional support

Capable environments require ongoing capable support. In supported accommodation settings much of this should be delivered through providing and commissioning processes but individuals whose needs are particularly complex will require the engagement of specialist professional supporters such as psychologists, psychiatrists and therapists. Where the individual is supported by family carers such professional involvement may be more frequently required. In both contexts professionals will need to work in partnership with carers (e.g., Wodehouse & McGill, 2009). More than this they will often need to acknowledge the limitations of their expertise (Bradshaw & Goldbart, in press) and engage through the kind of multi-partner model described by Carnaby et al (2010) and Bradshaw (in press).

Recommendations

1. Service providers and commissioners should ensure the capability of all environments where people at risk of displaying challenging behaviour are supported.
2. Service commissioners should invest in the development of local, capable environments rather than expensive, out-of-area placements of dubious quality.
3. Both providers and commissioners should state clear expectations for the capability of support environments which should be monitored through both internal provider and service specification processes.
4. Both providers and commissioners should invest in local expertise that supports the development and sustainability of capable environments.
5. Local professionals should engage both in the process of supporting capable environments and, through a multi-partner model, in providing effective support to both family and paid carers.

Standards

People at risk of displaying challenging behaviour should be:

1. liked and frequently interacted with in meaningful ways
2. supported in rich communication environments where their communication skills are consistently recognised and responded to and where communication is considered in all areas of the person’s life
3. supported to participate in meaningful activity, using skilled support, which provides enough support to ensure success
4. supported consistently and be given support to understand and predict events
5. supported to maintain relationships with family and friends
6. offered experiences which lead to meaningful choices which are clearly communicated
7. supported to try new experiences, develop skills and increase independence
8. supported in dignified ways to care for and look after themselves and their health
9. supported in acceptable physical environments
10. supported by skilled and mindful carers who have the skills to lead all aspects of capable practice
11. receiving support that is delivered and arranged within a broader understanding of challenging behaviour that recognises (among other things) the need to ensure safety and quality of care for both individuals and carers.

References

Association for Supported Living (2011) There is an Alternative. ASL.


