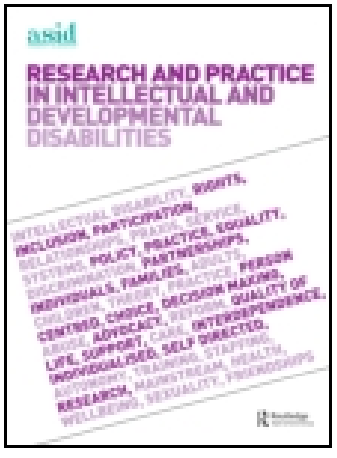

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John Ockenden[a], Bev Ashman[a] & Julie Beadle-Brown[b]
[a] United Response, London, United Kingdom
[b] Tizard Centre, University of Kent, United Kingdom; and La Trobe University, Victoria, Australia
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Active Support – Fundamental to Positive Behaviour Support

John Ockenden[a]*, Bev Ashman[a] & Julie Beadle-Brown[b]

[a]*United Response, London, United Kingdom;* [b]*Tizard Centre, University of Kent, United Kingdom; and La Trobe University, Victoria, Australia*

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Support for people with intellectual disabilities and challenging behaviour in the United Kingdom is currently under much scrutiny. Positive behaviour support has been put forward as the key approach for improving services for this group of people. Drawing on both the literature and on the practice experience of organisations, arguments are made that implementing active support can reduce the need for positive behaviour support and also support the implementation of positive behaviour support where this is needed. Key features of both active support and positive behaviour support are outlined and the fit between the two explained at both a general level and for the different stages of developing and implementing positive behaviour support interventions. It is suggested that implementing active support not only provides conditions in which challenging behaviour is likely to decrease, thereby reducing the need for the implementation of positive behaviour support, but, where such implementation is necessary, it can provide a valuable foundation upon which positive behaviour support can be built. Appreciating the extent to which active support complements and in fact sets the context for successful implementation of positive behaviour support will help practitioners in this field develop a successful approach to challenging behaviour.

Keywords: active support; positive behaviour support; challenging behaviour

Emerson and Einfield (2011) suggested that 0.1% of the general population have a severe intellectual disability and engage in "challenging behaviours". Research across a number of countries has found wide variations in the prevalence of challenging behaviour but it appears that somewhere between 5% and 20% of people with intellectual disabilities show behaviour that challenges (Campbell, 2010; Emerson et al., 2011; Totsika, Toogood, Hastings, & Lewis, 2008). Figures are substantially higher for people who live in more restrictive settings, those who have more severe disabilities, those who are aged between 15 and 34 years, those who have additional impairments such as autism, communication difficulties, hearing and visual impairments, and those who have mental health impairments or specific syndromes (Emerson & Einfield, 2011). Without appropriate intervention, challenging behaviour is a chronic issue (e.g. Murphy et al., 2005; Totsika et al., 2008), which has substantial impact not only on the individuals themselves, but on those who support them and their families (Emerson & Einfield, 2011; Wodehouse & McGill, 2009).

In the United Kingdom the sector-wide response to the abuse of adults with intellectual disabilities, specifically those in private hospitals for people with challenging behaviour as documented at Winterbourne View (Department of Health, 2012), has included a

*Correspondence to: John Ockenden, United Response, Vantage House 1 Weir Road, Wimbledon Park, London SW19 8UX, United Kingdom. Email: john.ockenden@unitedresponse.org.uk

requirement to implement positive behaviour support in any settings where challenging behaviour is presented. Failure to develop suitably skilled local services is one of the key reasons hospital and assessment and treatment units continue to exist (Department of Health, 1993, 2007). A recent review of a range of services for people with learning disabilities by the Care Quality Commission in England found that just under half of services were non-compliant with the care and welfare standards and the safeguarding standards, with 58% of people living in services that were non-compliant (Care Quality Commission, 2012). Research in the United Kingdom and Australia has shown that quality of life of people with intellectual disabilities is not equal to that of the general population on a number of domains (e.g. Bigby, Cooper, & Reid, 2012; Emerson, Malam, Davies, & Spencer, 2005). In addition, people living in services generally tend to spend a large proportion of their time disengaged and isolated (Mansell & Beadle-Brown, 2012; Mansell, Beadle-Brown, & Bigby, 2013). This is primarily because they do not receive the facilitative support they need to engage in activities and interactions. On average, less than one-third of people living in services receive consistently good active support and in the absence of active support people receive assistance less than three minutes in every hour. People who do receive good active support tend to be more able than those who do not, meaning that those who need the most support tend to get the least (Mansell & Beadle-Brown, 2012; Mansell et al., 2013; Beadle-Brown, Leigh, Whelton, Richardson, & Bradshaw, 2014).

Over the many years since some of the early descriptions by Carr, Horner, et al. (1999) and Koegel, Koegel, and Dunlap (1996), there have been varying definitions and attempts to conceptualise positive behaviour support. Carr, Dunlap, Horner, et al. (2002) attempted to bring together some of the earlier work, outlining the primary goal of positive behaviour support as "assisting individuals to achieve comprehensive lifestyle change with a view to improving quality of life not only for persons with disabilities but also for those who support them" (p. 6). They described the reduction of challenging behaviour as an important secondary goal that is of "value principally because of its facilitative effect on producing meaningful lifestyle and cultural changes that are stable and enduring" (p. 6).

More recently, at least partly in response to the rising profile of positive behaviour support in the United Kingdom, a number of clinicians and academics sought to clarify the definition and scope of positive behaviour support (Gore et al., 2013). They stressed its ideological and empirical elements, together with its emphasis on understanding the context within which challenging behaviour occurs and on promoting outcomes that enhance quality of life delivered through individualised and long-term improvements in support.

Positive behaviour support, as conceived for this paper, is both a general approach to support and a collection of technical elements and skills. The focus is on enhancing the quality of life of an individual by developing a well-informed intervention that enhances the environment and improves the skills of the individual first and foremost. Reducing the challenging behaviour is emphasised as a way of further enhancing the quality of life of individuals and those who support them rather than as an end in itself. Active support focuses on enabling people with intellectual disabilities to make the most of the opportunities available to them at home and in the community, so that people spend their time engaged in meaningful activities and relationships, growing in skills and independence, experiencing choice and control, and being seen as valued members of their community, irrespective of the degree of intellectual disabilities or the presence of additional difficulties such as autism or challenging behaviour (Mansell , Beadle-Brown, Ashman,

& Ockenden, 2005; Mansell & Beadle-Brown, 2012). Both positive behaviour support and active support have their foundation in the science of applied behaviour analysis (Gore et al., 2013; Mansell & Beadle-Brown, 2012). In some iterations of positive behaviour support, this is more strongly emphasised than others. For example, Lavigna's conceptualisation is much more strongly based on applied behaviour analysis and focuses first and foremost on reducing challenging behaviour (LaVigna & Donellan, 1986; LaVigna, Willis, & Donnellan, 1989). It does not generally include any active support as a concept but talks about "positive programming" (i.e. teaching people new skills and behaviours to replace the challenging behaviour). In some cases, training on positive behaviour support does include active support as an element in that training (e.g. the Advanced Certificate in Positive Behaviour Support provided by NHS Wales (Learning@NHSWales, n.d.) and research over many years indicates that active support should be a vital component in the support of people with challenging behaviour (Jones et al., 2013; McGill & Toogood, 1994).

Although there is substantial literature on both approaches, there is little published research that formally brings together these two approaches. Most of the evaluation of positive behaviour support has focused on outcomes in terms of reduced challenging behaviour and only a few studies have looked at outcomes in terms of improved quality of life following implementation of positive behaviour support (MacDonald & McGill, 2013). Similarly, most active support research has not always included measures of challenging behaviour. However, studies that have explored the impact of successful implementation of active support on challenging behaviour have found reductions in challenging behaviour as well improvements in quality of life (Beadle-Brown, Hutchinson, & Whelton 2012; Koritsas, Iacono, Hamilton, & Leighton, 2008; Stancliffe, McVilly, Radler, Mountford, & Tomaszewski, 2010).

Mansell and Beadle-Brown (2012) and Ashman, Ockenden, Beadle-Brown, & Mansell (2010) briefly described how the different person-centred approaches fit together, including active support and positive behaviour support. The current paper expands this description to illustrate how the two approaches can and should work together, combining theoretical conceptualisation and existing research with the practical experience of a number of different organisations in the process of implementing both active support and positive behaviour support. The paper does not provide detailed description of the two approaches – there are good descriptions available elsewhere (e.g. Gore et al., 2013; Mansell & Beadle-Brown, 2012) – but rather draws out some of the core elements and concepts to illustrate how the two approaches fit together. The premise of the paper is that positive behaviour support relies on (and is not just improved by) active support and that services should focus on providing active support consistently, drawing on positive behaviour support strategies to specifically address challenging behaviour if and when active support is not enough to eliminate the challenging behaviours or at least reduce its impact on quality of life.

Active Support

Active support focuses on the skills and capacity of staff and services in enabling engagement in meaningful activities and relationships. Mansell and Beadle-Brown (2012) talked about the importance of the "enabling relationship" between staff or other supporters and the person they are supporting. There are four core elements to this enabling relationship. Firstly, "every moment has potential" emphasises the fact that everything that goes on around the home and in the community is an opportunity for engagement. Staff should be focusing not just on finding structured activities at home and in the community, but on

supporting people in what is going on in the here and now – in real and age-appropriate activities. "Little and often" is about supporting people to be frequently involved, even if only briefly, going at their pace. The third component, "graded assistance to ensure success", is about providing the right type and amount of support for that person, in that activity, at that time. It is about tailoring the nature and intensity of support to suit the person and ensure successful participation. Finally, "maximising choice and control" focuses on promoting increased autonomy within activities and choice between different activities. Staff are encouraged to think about how they prepare activities and how they present activities; how to ensure success for that person and to think about their style of interaction. They are encouraged to be observant and watch and listen to what people are telling them about how they want to be supported, how they communicate and what they like and dislike.

In addition to staff having the skills and being motivated to provide active support, day-to-day practice leadership from the front-line managers is also important. This includes elements of both organising and improving support. Firstly, support is planned and staff allocated so that people being supported experience as many opportunities as possible and so that staff work together as a team. Secondly, front-line managers demonstrate good practice, and observe and provide feedback on the work of staff, exploiting opportunities to improve the support delivered by their team, and to motivate individuals. Emerging research has shown that practice leadership is important for the implementation of active support and in particular improving active support over time, especially in the context of generally good management (Beadle-Brown, Bigby, & Bould, 2014; Beadle-Brown, Mansell, et al., 2014). Finally, with particular relevance to this paper is the fact that active support is combined with support for communication and autism-friendly practices that enable staff to support people successfully in a range of activities and feed what is learnt into person-centred planning processes to encourage ongoing development over time for that individual.

Positive Behaviour Support

Most conceptualisations of positive behaviour support include the sequence of activity that flows from *assessment and analysis*, through to intervention *planning*, then *implementation* support, and finally *monitoring and review* (Gore et al., 2013). The following section provides an overview of these key components based on Gore et al. (2013).

Assessment and Analysis

In order to effectively support people whose behaviour is challenging, a comprehensive understanding of the relevance of the behaviour for the individual is essential. A range of assessment tools (including direct observation) are used to gather qualitative and quantitative information about person, the environment, and his/her behaviour from a range of people who know the person well. Analysis of the information gathered is then used to produce a summary of the current understanding of the behaviour or what is sometimes called a "hypothesis" about why the behaviour is occurring – this process is often referred to as a "functional assessment."

Planning

Following assessment and analysis, positive behaviour support requires the development of an intervention plan. This process promotes careful selection from a range of

possible components and again serves to ensure that all possible least restrictive options are considered. Indeed, for people with intellectual disabilities, long-standing challenging behaviour is likely – at least in part – to be maintained by chronic quality of life deficiencies, and therefore positive behaviour support plans must specifically address unhelpful lifestyle and environmental issues. This is done regardless of the degree to which it seems that such issues are connected to the incidence of challenging behaviour.

Intervention plans should primarily focus on changing the circumstances of the individual so that occurrences of challenging behaviour become less frequent. *Proactive strategies* focus on modifying the environment to be as supportive as possible for the individual, reducing difficult sensory stimuli, promoting engagement in more positive behaviours and enhancing the skills of the individual supported, so that challenging behaviour is not required to bring about a change in the immediate environment. The plans should include using augmentative and alternative communication methods and other ways of allowing people to express their needs and preferences. *Reactive strategies* focus predominantly on bringing about a rapid return to calm normality when challenging behaviour does occur – what is sometimes called de-escalation. Such reactive strategies can involve early stage intervention strategies such as distraction or redirection, reassurance, or time out from an activity. Any reactive strategies should be the least restrictive possible but for some people a behavioural plan might include how and when more restrictive practices such as seclusion, mechanical restraint, chemical restraint, or social restraint, might be used (Gore et al., 2013).

Implementation

Positive behaviour support recognises that intervention plans must take account of the capacity of the individual's support network to implement change successfully: plans that expect too much will typically fail and result not only in continuing damage to the person and others, but also in disillusionment with the whole approach. Consideration of the "contextual fit" (the extent to which the intervention plan is suited to the circumstances in which it is to be implemented) is therefore vital. A whole environment- or organisation-wide approach is usually required to promote successful implementation (Allen et al., 2013). Positive behaviour support plans and guidance need to be both physically accessible and easy to read and understand

Monitoring and Review

To establish the effectiveness of intervention, positive behaviour support requires objective and comprehensive monitoring and review. Such evaluation must track a range of pertinent issues in addition to the relevant aspects of the focal person's target behaviour because of the broader intervention aims, notably data concerning the quality of life targets addressed by the plan. In addition, attention paid to the fidelity of implementation promotes early identification of poor or inconsistent execution, potential deterioration, or relapse. Ongoing consultation with the focal person and his/her supporters enhances authentic and relevant appraisal of intervention effectiveness.

Positive behaviour support plans are always expected to change to reflect changes in the person's life, variation in the capacity of his/her support network, and to build on developing success of implementation. Established and thorough instruments that assist monitoring and review of intervention outcomes are commonly in use.

Explaining the Fit between Active Support and Positive Behaviour Support

The remainder of the paper will focus on describing how the two approaches fit together both at a general, overarching level, and at the level of each of the four stages of positive behaviour support. At a general level, the overall purpose of active support, as already mentioned, is to promote engagement both because of its positive relationship with quality of life and because it is a necessary platform for all other lifestyle aspirations and accomplishments (Mansell & Beadle-Brown, 2012). Effective implementation of active support therefore enables increased levels of engagement, skill development, and choice making, all of which are also common features of successful positive behaviour support interventions. At a similarly general level, active support requires services to work in particular ways: for example, with objectivity and effective teamwork, and through practice leadership. Again, such features are highly useful to the implementation of positive behaviour support interventions at an individual level, at a service level, and at an organisational level.

Active Support Contributes to Each Stage of Positive Behaviour Support

Assessment and Analysis

Active support techniques are designed to enable rapid identification of a range of personal preferences and individual strengths and needs (including those related to communication), regardless of the degree of disability experienced by the person and of the presence of challenging behaviour. Establishing such individual preferences is largely an experiential process, focusing on commonplace everyday possibilities, and supporting people to be active participants in their own lives. Instead of regarding challenging behaviour as a reason to withdraw opportunities for participation, supporters learn how to adjust their approach in order to facilitate successful involvement. The principles of "little and often" and "maximising choice and control" are very important to exploring the possibilities of new activities and establishing skills and preferences with individuals with challenging behaviour. These two principles encourage staff to frequently present people with opportunities in manageable chunks (the length, organisation, and complexity of which is determined by the individual). This not only supports the development of a good understanding of people's needs and preferences (and potentially the triggers for challenging behaviour), but also gradually increases engagement and ultimately quality of life.

Services successfully implementing active support will already be delivering the levels of effective teamwork and practice leadership required by positive behaviour support, and will be skilled in employing observation and feedback as a key means of establishing crucial features of individual support. From practical experience, it appears that the assessment of the relationship between challenging behaviour and other factors (where this is not technically complicated) need not require all staff to be trained in positive behaviour support, or the involvement of external professionals to address challenging behaviour. With effective practice leadership, provided by a line manager with some knowledge and capability in the area, and a secure grounding in active support, relatively unskilled staff teams can develop a more helpful understanding of what challenging behaviour does for a person, and how they might rearrange the social and physical environment to improve the person's experience.

Planning

In implementing active support it is recognised that most people with intellectual disabilities and challenging behaviour live with others or are served by a number of supporters who

work at different times of the day, or both, and that these characteristics demand high levels of planning. Critical consideration is given to the organisation and sequencing of activity, so that people substantially get what they need when they need it. In this respect, active support addresses, by default, two of the most commonly identified functions of challenging behaviour: avoidance of aversive situations such as having to wait for something they are expecting, having to deal with something unexpected, or having to cope with uncertainty and anxiety about what will happen over the course of even short periods of time; and the gaining of needed interaction or activity. Even those people with challenging behaviour who live on their own are likely to be supported by a team of staff, sometimes more than one at a time, and therefore still require staff to work together to provide consistent support across time and across team members, with the person at the centre of that support.

Written plans and profiles help staff to deliver styles of support identified through assessment, and to focus on enabling successful engagement. This, in turn, affords opportunities to provide positive reinforcement for adaptive behaviour, and for the person to exercise increasing choice and control. Again, both of these developments mirror goals of positive behaviour support, and will frequently provide sufficient change to yield decreasing levels of challenging behaviour.

Implementation

Delivering the support people need, how and when they need it, requires a range of organisational provisions: the roles of those who support the person need to be clear, practice leadership needs to be provided, and managers need to use a variety of management styles when working with staff to integrate the plan into their daily work practices. Successful implementation of active support requires services to take account of individual and collective attitudes and ideologies in designing interventions. Both active support and positive behaviour support have to pay attention to the skills and abilities of staff or other supporters in delivering the support people need.

Monitoring and Reviewing

Successful implementation and maintenance of active support requires a range of approaches which monitor and seek to improve changes in how staff support people and the behaviour and quality of life of people supported. These include simple monitoring tools that focus on changes from the person's perspectives (and which may be small in scale) that can be analysed in team meetings, and compared with evidence from direct observation to give a clear sense of change over time. Services providing active support are accustomed to the sort of objective evaluation required when supporting people whose behaviour is challenging. Conversely, staff who have not implemented active support frequently struggle to gather and process evidence with sufficient rigour to be useful to positive behaviour support interventions.

Conclusion

Both conceptually and from practice experience, it appears that active support is an essential companion to positive behaviour support in providing better support for people whose behaviour is challenging. For the majority of people with intellectual and developmental disabilities, active support, when well implemented, delivers the support, the environment, and the quality of life necessary to potentially render challenging behaviour unnecessary. While a number of individuals will require the intensity and precision of positive

behaviour support, the majority would benefit significantly (and sufficiently to minimise challenging behaviour) from the implementation of active support. Where positive behaviour support is needed, its effective implementation is made significantly easier by, and could be argued to be dependent on, a number of service characteristics that are inherent to successful implementation of active support. In particular, implementing active support ensures that staff and managers are focused on improving the quality of life of the people they support, not just on reducing challenging behaviour. It also develops skills of staff in objective assessment, analysis, monitoring and evaluation, and in coherent and realistic planning. The whole organisation approach required for active support facilitates the implementation of positive behaviour support. In particular, the level of structure (of time, resources, and accountability) and the positive culture embedded as part of active support facilitates considered, informed, rational, and proactive support for those with challenging behaviour. Finally, if the front-line manager is already working as practice leader on a day-to-day basis, this can much more easily be extended to included leading practice with regards to behavioural interventions.

When positive behaviour support is implemented in circumstances where active support is already embedded in working practices and service ethos, services can expect to exploit those characteristics, and achieve therapeutic effect. However, without active support, staff are much less likely to have the skills and confidence to fully put into practice proactive strategies, such as engaging people in meaningful activities, using adapted communication, and applying autism-friendly approaches (Beadle-Brown, Leigh, et al., 2014; Beadle-Brown, Beecham et al., 2014).

At a time when, in the United Kingdom at least, positive behaviour support is increasingly understood to be not only necessary but sufficient in services for people with challenging behaviour, it is important not to lose sight of the effectiveness and relevance of active support in promoting better quality of life and support that works for everyone with intellectual disabilities, not just those with challenging behaviour.

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