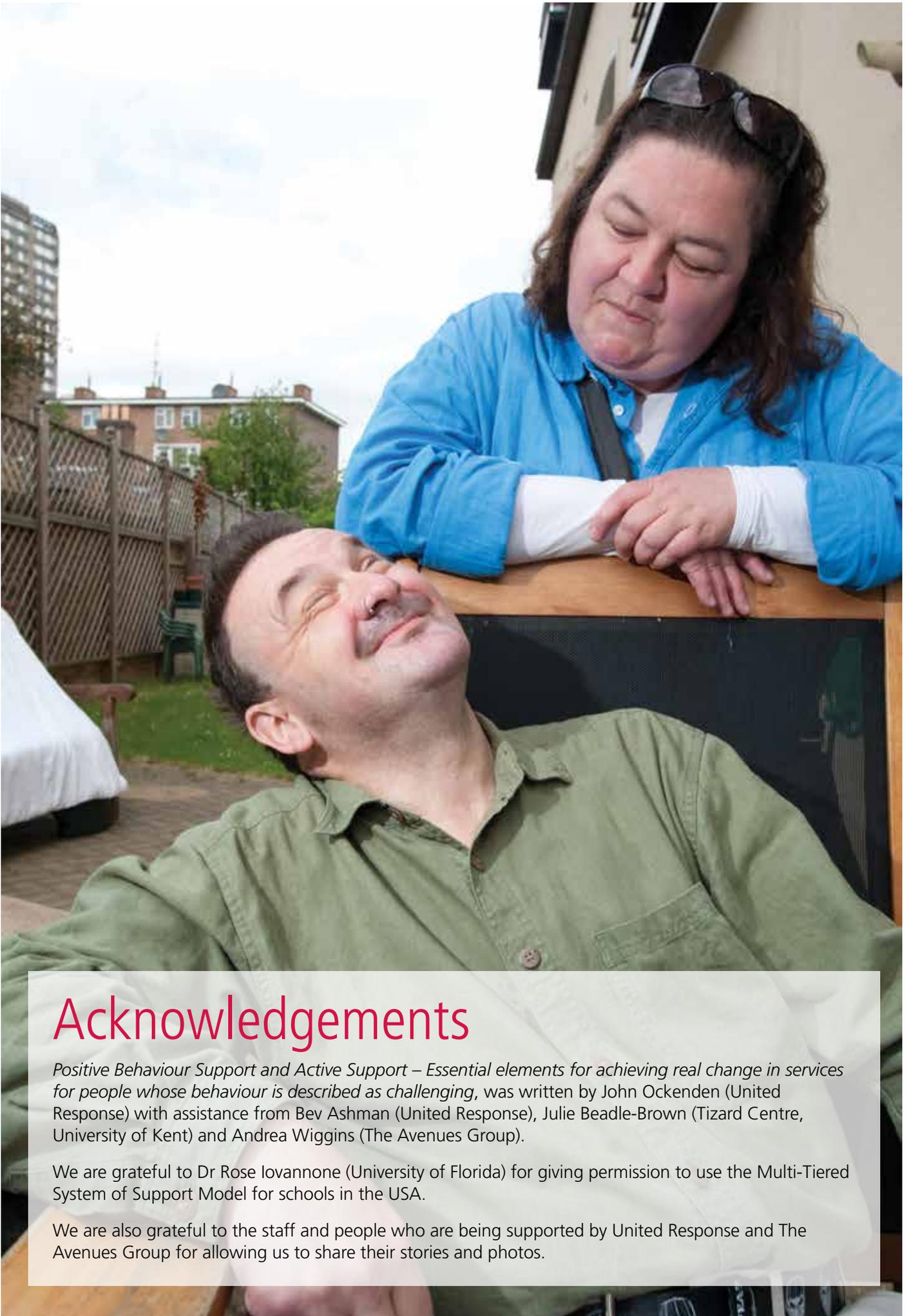


# Positive Behaviour Support and Active Support

Essential elements for achieving real change in services  
for people whose behaviour is described as challenging





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Challenging behaviour occurs as a result of a complex interaction between the individual and their environment and has been defined as “behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion” (RCPsych, BPS, RCSLT, 2007)

The report into the systematic abuse of people with learning disabilities at Winterbourne View offers the opportunity to finally deliver sustained improvements which will ensure that people with learning disabilities – and in particular those with complex needs and challenging behaviour – receive high quality, locally based and effective support.

The report and the associated concordat provide a framework of planned change across the network of organisations involved in the lives of people with learning disabilities (from government to workforce) in order to promote higher standards of support. A key feature of this change is the requirement to implement Positive Behaviour Support.

Positive Behaviour Support is “characterised by educational, proactive and respectful interventions that involve teaching alternative skills to problem behaviours and changing problematic environments. It blends best practices in behavioural technology, educational methods and ecological systems change with person centred values in order to achieve outcomes that are meaningful to the individual and to his or her family.” (Bambara et al, 2004)

Positive Behaviour Support incorporates a recognition that reacting only to the occurrence of challenging behaviour, the use of ‘off the peg’ responses and of punishment, are limiting and counterproductive strategies. Rather, it focuses attention on the development of a constructive,

functionally informed approach to providing enhancements in the environment and the capacity of the individual. Consequently it relies on (and is not just improved by) the development of other person centred approaches including:

- Person Centred Thinking and Planning
- Effective Communication
- The National Autistic Society’s SPELL framework for supporting people on the autistic spectrum
- Active Support

All of these approaches have a role to play in the implementation of better support for people whose behaviour challenges but Active Support is most closely aligned to Positive Behaviour Support because of its emphasis on systematic changes to the whole environment and in the way services focus on promoting the quality of life of the people they support, a critical element of reducing challenging behaviour. In addition, Active Support is essential for the implementation of the other approaches listed above.

The purpose of this resource is to demonstrate the extent to which we believe Active Support underpins the effective implementation of Positive Behaviour Support and the role it can play in supporting people with challenging behaviour. We will also point to relevant resources.

Positive Behaviour Support is “characterised by educational, proactive and respectful interventions that involve teaching alternative skills to problem behaviours and changing problematic environments. It blends best practices in behavioural technology, educational methods and ecological systems change with person centred values in order to achieve outcomes that are meaningful to the individual and to his or her family”

# Active Support:

Active Support encompasses a range of approaches which aim to provide enough help to enable people to participate successfully in meaningful activities and relationships so that they gain more control over their lives, develop more independence and become more included as a valued member of their community irrespective of degree of intellectual disability or presence of challenging behaviour. To achieve this Active Support focuses on the skills of staff in enabling engagement and on the capacity of the service to provide accessible opportunities in a structured and predictable fashion.

Active Support has been shown to be important in determining the quality of life of people with learning disabilities (Mansell and Beadle-Brown, 2012), and in particular in increasing people's participation in daily life, social and community activities as well as increasing people's skills, adaptive behaviour and choice (McGill & Toogood, 1994; Jones et al, 2001; Stancliffe et al, 2007; Beadle-Brown et al, 2012; Felce et al, 1986; Mansell et al, 2002; Mansell and Beadle-Brown, 2012). Research over many years also indicates that Active Support should be a vital component in the support of people with challenging behaviour (McGill & Toogood, 1994; Jones et al. 2013).

The primary outcome of Active Support is engagement in meaningful activities and relationships but the way it looks in practice will vary depending on the individual requirements of the person being supported and the nature of activity or interaction they're engaged in.

There are **4 essential components** which promote engagement in activities and relationships:

1

**Every moment has potential:** Utilising the activities that need to be done (such as housework, shopping or gardening) and those that are available to do (such as visiting friends or relatives, playing sport or adult education) as opportunities for supporting people to be engaged throughout the day. These activities are often done by staff, with the people they serve acting only as non-participating spectators, if they are present at all. Active Support reverses this condition, so that people are involved in all the activities of daily living, even (or particularly) when the presence of challenging behaviour might result in such opportunities being withdrawn.

2

**Little and often:** Thinking about activities and relationships as a series of steps so that staff can identify those parts the person can do for themselves, those that staff can help them with and those that staff will need to do for them in order for the person to experience success. As a result staff can start small, enabling people to dip in and out and providing shorter opportunities for engagement throughout the day rather than solely focusing on single lengthy events.

3

**Graded assistance:** Providing the right amount and type of support at the right time – too much and the person will be 'over-supported' and hindered in their independence, control and status; too little and they will fail. Staff develop the skills they need to ensure the amount and type of help they provide is constantly adjusted to fit the particular activity, step or circumstance.

4

**Maximising choice and control:** Looking for opportunities for the person to express their preferences and be listened to, recognising that choosing within activities and relationships is a valuable opportunity for experiencing choice and control. Frequently responding to preferences this way increases the likelihood that the person will learn that making choices makes sense, and will make more of them.

## What is needed for successful implementation

Organising and improving support: Active Support requires the organisation and allocation of support so that people experience high levels of predictability and consistency, as well as coordination of the efforts of individual staff and the team as a whole to maximise the planning of support and the extent to which staff learn from each other.

Practice Leadership: Over the last two decades it has become apparent that Practice Leadership by front line managers/team leaders plays a key role in enabling implementation of Active Support. Research evidence and direct experience both indicate that no amount of organisational policy or staff development will have any impact on levels of engagement in its absence.

Practice Leadership involves the demonstration of good practice, observation of staff support and feedback on performance, a coaching process that can be executed by external experts or peers, but is most effective when performed by the immediate line manager of staff concerned. This role necessitates a shift in management behaviour away from bureaucracy and towards being an expert practitioner and coach.

The implication of this emerging understanding of how to implement good practice is that practice leaders need to be identified, nurtured and encouraged (and not, for example, punished reflexively for inadequate paperwork) and that expertise in good support needs to run throughout any organisation's line management structure. While this factor has surfaced in the implementation of Active Support, related approaches are likely to depend upon the same conditions if they are to gain traction in service delivery.

In addition to having the skills to provide Active Support, staff also need to be motivated to do so. To achieve this, senior managers must:

- Ensure the alignment of policies and procedures to Active Support
- Develop a motivational structure that recognises and rewards staff for enabling people they support
- Communicate clear messages so that staff understand that this is what they value, over and above anything else.



# Positive Behaviour Support:

## 1. Assessment and analysis

In order to effectively support people whose behaviour is challenging, staff need to base their support and interactions on a comprehensive understanding of the relevance of the behaviour for the individual. This needs to take account of both the person's immediate situation and environment, including their physical and mental health, and the broader background of their entire life. Furthermore, these contexts need to be understood within the wider range of physical, social and occupational settings experienced by the person.

It is important to recognise the impact that staff beliefs and attitudes have on their responses to people who present challenging behaviour. The dominant interpretation of challenging behaviour is that people displaying it understand what they are doing and how it affects others. This unhelpful misattribution of culpability, commonly arising in the context of emotionally stressful circumstances, leads to an increased risk of the use of punishment as staff reach to their experience of child-rearing or criminal justice, or for the logic of natural consequences, for ways of responding.

Therefore, for ethical as well as rational reasons, objective assessment and analysis are cornerstones of Positive Behaviour Support. A range of assessment tools (including direct observation) are used to gather qualitative and quantitative information about the person, the environment and their behaviour from a range of people who know the person well. Analysis of the information gathered is then used to produce a summary (or more realistically, a hypothesis or best guess) of the current understanding of the behaviour.

As well as providing meaningful, objective information to underpin intervention strategies, this process slows things down and ensures that those involved explore what's happening dispassionately, rather than leaping in with quick fixes and/or restrictive practices.

## 2. Planning

Following assessment and analysis, Positive Behaviour Support requires the development of an intervention plan. Again this deliberate process promotes careful selection from a range of possible components and mitigates against a rush for a quick fix. Indeed because long standing challenging behaviour is likely to be maintained by chronic quality of life deficiencies, Positive Behaviour Support plans must specifically address unhelpful lifestyle and environmental issues, regardless of the degree to which it seems that they are connected to the incidence of challenging behaviour.

Intervention plans should primarily focus on changing the circumstances of the focal person so that occurrences of challenging behaviour become less frequent. Such changes identified by assessment and analysis will typically relate to the physical and social environment the person experiences, and the support they receive. In addition, the plan may include teaching of new skills, either designed to replace the challenging behaviour or to promote coping and self-reliance. Positive Behaviour Support plans particularly benefit from work that addresses the attitudes held by, and emotional experiences of, those who support the person in daily life. Overall, these proactive strategies should form the bulk of the intervention plan.

However, reactive strategies need to be developed for deployment when the behaviour occurs. Those issues that assessment and analysis have suggested are directly related to the maintenance of challenging behaviour (because, for example, they reinforce it) need to be addressed, but the main emphasis of Positive Behaviour Support reactive strategies is that they should bring about a rapid return to calm normality. To this end, strategies that might be counter-intuitive (for example they may continue to reinforce the behaviour) should be considered if they enable rapid cessation of the behaviour, but only because their potentially negative effect is diluted by the plan's more powerful proactive strategies.

Intervention plans should be discussed with significant stakeholders, including those expected to implement them, and should be ethically sound and realistic in their scope and ambition.

### 3. Implementation

Positive Behaviour Support recognises that intervention plans must take account of the capacity of a person'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. Similarly, the mode of communication used to inform those with responsibility for implementation needs to reflect their linguistic and technical understanding.

Careful consideration of such implementation issues is a prerequisite for the level of consistency that Positive Behaviour Support requires of any successful implementation. Attempts to reverse the consequences of poor or misguided support are readily undone by occasional returns to such longstanding practices.



### 4. 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 Positive Behaviour Support's 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 their supporters enhances authentic and relevant appraisal of intervention effectiveness.

Positive Behaviour Support also recognises the importance of providing feedback on the effects of implementation to those responsible for it, to support both immediate maintenance and future developments of the plan. Because of the attention paid to contextual fit, notwithstanding any potential for wider changes in the person's circumstances, its likely success, while significant, will only be partial. Positive Behaviour Support plans are always expected to change to reflect changes in the person's life, variation in the capacity of their 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.

In order to effectively support people whose behaviour is challenging, staff need to base their support and interactions on a comprehensive understanding of the relevance of the behaviour for the individual.

# Explaining the fit:

## 1. Assessment and analysis

The purpose of Active Support is primarily to promote engagement and improve the quality of life of people supported – also a primary aim of Positive Behaviour Support. As such, its techniques are designed to enable rapid identification of a range of personal preferences (e.g. for support and communication style, activity presentation, types and intensity of activity) and individual strengths and needs, 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 the person to be an active participant in their own lives. Instead of regarding challenging behaviour as a reason to withdraw opportunities, supporters learn how to regulate their approach (for example through graded levels of assistance) in order to facilitate successful involvement.

These characteristics are particularly helpful when supporting people whose behaviour challenges as

they involve the sort of changes in communication and presentation commonly identified through functional analysis. Similarly, high levels of ecological validity and potential generalisation arise from Active Support's focus on the natural and ordinary fabric of daily life.

Services providing Active Support will already be delivering the levels of effective team work 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.

Engagement is emphasised because of its positive correlation with quality of life, and because it is a necessary platform for all other valued lifestyle aspirations and accomplishments. Accordingly, Active Support delivers on Positive Behaviour Support's fundamental commitment to see past any challenging behaviour to the quality of life beyond.



## 2. Planning

Active Support recognises that most people live with others and are served by a number of supporters who work at different times of the day, and that these characteristics demand high levels of planning. Without this, services will usually fail to provide the help people need and any support offered is likely to be inconsistent and unpredictable. Critical consideration is given to the organisation and sequencing of activity, so that people substantially get what they need when they need it, and so that a pattern of “events-through-time” is established. In this respect, Active Support addresses, by default, two of the most commonly identified functions of challenging behaviour: avoidance of stimuli (events) that are aversive, frequently because they are unexpected and therefore difficult to understand; and the gaining of needed interaction or activity.

Active Support recognises that the development of predictability is vital in developing people’s understanding of what’s happening, both now,

and next, and in any attempt to increase levels of engagement in real activity. Similarly, while plans must be person centred and collaborative, they must also provide for unforeseen circumstances and healthy levels of flexibility. Services well practiced in Active Support provide the sort of structure that works for everybody, while furnishing an underpinning for the more precise arrangements required by people whose behaviour is seriously challenging.

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.

## 3. 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 (particularly modelling and coaching of good practice) 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. Active Support expects services to take account of individual and collective attitudes and ideologies in designing implementation. These considerations ally Active Support with Positive Behaviour Support in its attention to the skills and abilities of mediators (normally staff) in delivering the support people need.

No plans can ever predict or allow for all eventualities so those responsible for implementation need to be adaptable and flexible, taking unforeseen opportunities for engagement spontaneously and exploiting opportunities to reinforce behaviour that is not challenging and to maintain interest and momentum. Like Positive Behaviour Support, Active Support is being implemented well when it is made invisible by the successful and natural lifestyles it enables.

Effective implementation of Active Support promotes increased levels of engagement, skills development and choice making: all common features of effective Positive Behaviour Support implementations.

## 4. Monitoring and reviewing

Active Support provides a range of approaches which promote effective evaluation of implementation and changes in behaviour. These include the development of simple monitoring tools that focus on changes from the person’s perspective (and which may be small in scale), that can be analysed in supervisions and team meetings, and compared with evidence from direct observation to give a clear sense of change over time. This process of evaluation maps relationships between different factors operating in a person’s perspective. For example, establishing

links between the way a person is supported and incidents of challenging behaviour, so that plans can be adapted 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.

# Illustrating the Fit:

An analogy from schools in the USA that provide education for children with learning disabilities and challenging behaviour serves to illustrate the broad relationship between Active Support and Positive Behaviour Support. Sugai et al (2000) describe interventions in such settings as requiring three tiers of focused staff activity. Tier 1 represents the universal routine teaching-based running of the school and classroom with an emphasis on structure, support, effective communication, consistency and positive relationships. Because it provides facilitating the mediator for effective education and interaction, no child or adult is excluded from the expectations and benefits of Tier 1.

Where more support is required, Tier 2 addresses specific challenging behaviours, providing more targeted attention to small groups of students and interventions for particular areas of concern alongside Tier 1 strategies. The goal of Tier 2 support is to avoid the cost and intensity of Tier 3 intervention.

However, and as necessary, Tier 3 is incrementally added in response to the sort of persistent and intense challenging behaviour that typically causes significant disruption to the environment. It provides for complex and labour intensive analysis and the development of a detailed, multi component intervention plan focused both on the decrease of problematic behaviours and an increase in more acceptable alternatives.

The relationship between these three tiers is represented in Fig 1. The multi tiered system of behavioural support is conceptualised as a continuum. When Tier 1 is implemented for all, then Tier 2 is only required for some children, while only a few need Tier 3.

Tellingly, Sugai and colleagues make the point that when all three tiers are present and available, Tier 3 support is indeed only required by a few, but in the absence of the everyday facilitation provided by Tier 1 (and to some extent Tier 2), many more children require the intense and costly support of Tier 3 interventions.

In adult services for people with learning disabilities whose behaviour challenges, the parallel is clear. Active Support is the equivalent of Tier 1 and should be a requirement for all. As an adjunct, Positive Behaviour Support that is individual and focused, but not highly technical (at the Tier 2 level of intervention), can be provided for some people by those who support them everyday, while the few whose complexities require help from separate specialist services should receive Tier 3-like interventions.

This intensive and expensive support that should be needed only by a few (those represented by the tip of the triangle) is however required by many more people in the absence of Active Support.

Fig 1 – The relative requirement for Tiers 1, 2 and 3 interventions

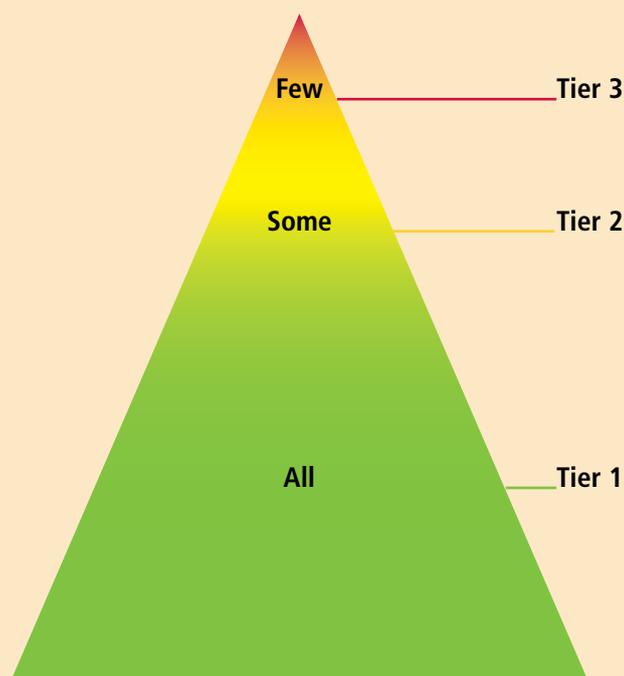
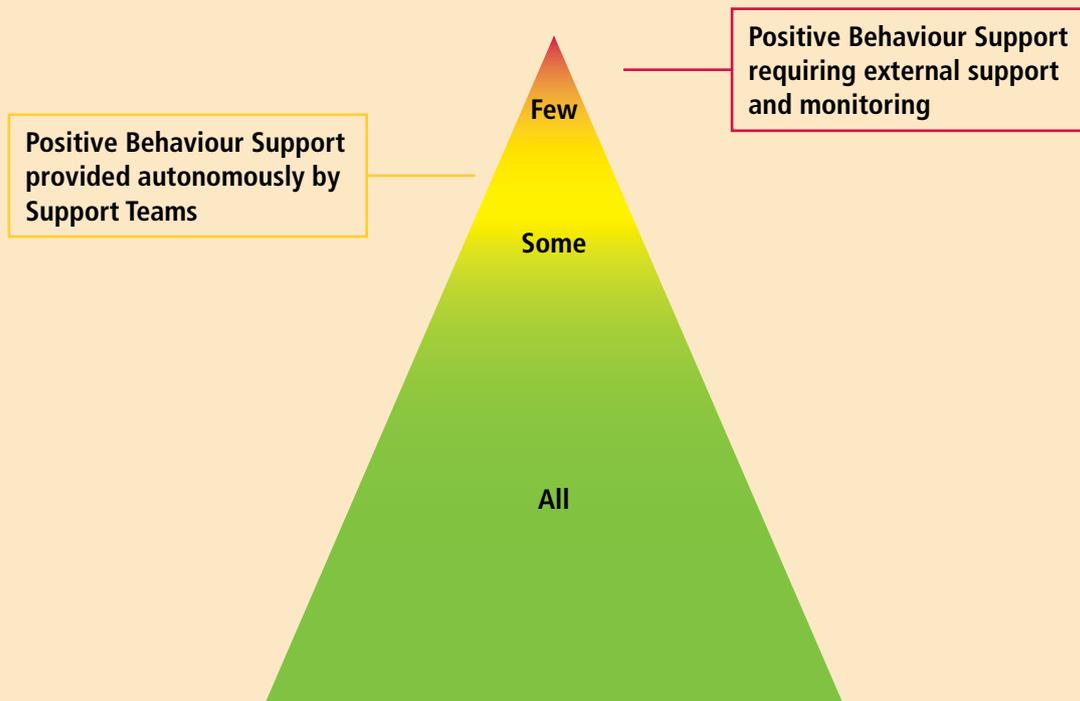


Fig 2 – Active Support and Positive Behaviour Support



## Conclusion

Active Support shows itself to be an essential adjunct to Positive Behaviour Support in the search for improved support for people whose behaviour challenges for two reasons:

**1.** Challenging behaviour is generally a rational, normal response to adverse circumstances, not an aberrant, perverse anomaly. Active Support recognises the common need for predictability, for sensitive and flexible help to engage successfully in everyday activity, to make choices and to exert control over how we lead our lives day to day. When these lifestyle (or quality of life) features are absent or impaired, all human beings respond by behaving in ways that would be described as challenging.

Consequently, Active Support provides conditions in which challenging behaviour generally decreases, particularly by improving people’s quality of life: helping people to develop new skills, gain self-confidence and experience choice and control. For many individuals, Active Support delivers enough of what they need to render challenging behaviour unnecessary.

Whilst 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.

**2.** Where Positive Behaviour Support is needed, its effective implementation is dependent on a number of service characteristics that are inherent to Active Support, eg:

- a.** Objective assessment, analysis, monitoring and evaluation
- b.** Coherent and realistic planning
- c.** Implementation that is flexible and sensitive to the critical role of mediators
- d.** A level of structure (of time, resources and accountability) that facilitates considered, rational and proactive support

Positive Behaviour Support that is implemented in circumstances where Active Support is already embedded in working practices and service ethos can reasonably expect to exploit those characteristics, and achieve therapeutic effect. Positive Behaviour Support that is implemented without Active Support is likely to require high levels of external support and scrutiny if it is to have any impact on the lives of those it is intended to reach.

# Recommendations

## 1. Department of Health

It is important that the government should provide leadership around good practice and recognise that staff need to have more basic skills in order to implement Positive Behaviour Support well. There needs to also be a recognition that if services for people with learning disabilities provided more person centred support generally, the need for expensive specialist challenging behaviour services would reduce (although possibly not disappear entirely). Therefore, we recommend that the Department of Health should recognise Active Support as an essential strand of good support and that it should be included by default in expectations of services for people with learning disabilities and autism more generally. As part of this, a clear definition should be given as to the nature of Active Support and the training and support staff need to receive. The research is clear that just taking staff out for a day's classroom-based training is not sufficient to implement Active Support in practice – there has to be an element of in situ or interactive training that helps staff to apply knowledge from training through observation, feedback and modelling to shape up their skills.



## 2. For Service Providers

### Organisational awareness of Active Support

The implementation of person-centred approaches requires a whole organisation approach. All senior managers should familiarise themselves with the principles and elements of Active Support and what is needed for implementation, as well as understanding the extent to which it supports the implementation of Positive Behaviour Support and other person centred approaches. There are a number of resources listed at the end of this document which provide more detailed information.

### Training

When seeking or funding training on Positive Behaviour Support for staff, service providers should either ensure that the Positive Behaviour Support training includes a substantial component focusing on Active Support OR should seek to provide staff with additional training on Active Support. Classroom based training should include, at the very least, information about engagement in meaningful activities and relationships and why engagement is important in promoting quality of life and reducing challenging behaviour, and about the four essentials of Active Support. It should also cover the importance of helpful routine and consistency. However, it is very important that staff also receive the hands on training to gain the skills and confidence to try. Ideally, all staff should have training, as a cascade model relies on front-line managers having substantial expertise and skills to pass the information on.

If staff are receiving training in Active Support independently of Positive Behaviour Support training, the links with other person centred approaches including Positive Behaviour Support should be made clear.

The implementation of person-centred approaches requires a whole organisation approach.

### Practice leadership

Service providers need to ensure that the front line managers whose role it is to lead the practice of their team are skilled in Active Support as well as Positive Behaviour Support, and have practice leadership as a clearly defined part of the job. They should have the time, training and support to observe, model and coach their staff. Training for frontline managers should support them to make the links between all aspects of their job role and to the support they give staff. They should be supported to develop the skills to provide feedback and encourage reflection and problem solving with respect to both good and poor practice to individual staff and to teams in both supervision and team meetings.

### Aligning policy and procedures

Policy and procedures need to be aligned so that they are supportive of person-centred action such as Active Support and Positive Behaviour Support. Organisations need to strike a balance between monitoring systems and processes and attending to a broad range of outcomes for people supported and the quality of the support staff provide on a day by day basis. Senior managers should ensure that they also know what good support for challenging behaviour looks like. They should visit services asking the right questions and looking at relevant components of support. In this way, they can develop appropriate motivational structures that will maintain good practice. Auditing processes in particular must include observational approaches.

### Learning from other organisations

In addition to acquiring and reading the resources available, senior and middle managers should visit and learn from the experience of other organisations who have already taken an organisation-wide approach to implementing person centred approaches.



### 3. For families and friends

Families and friends of those who are supported by services can play an important role in improving the quality of support for their loved one. If they are aware of the importance of Active Support and Positive Behaviour Support this puts them in a stronger position to ask care managers and services themselves for evidence that such person centred approaches are provided.

Organisations have a responsibility to encourage families and friends to increase their understanding of good practice and should, for example, invite them to attend training on Active Support as well as Positive Behaviour Support. Families and friends should expect to be welcomed and encouraged in this endeavour.

For people on individual budgets where families and friends support the recruitment of staff, an awareness of Active Support will support the process of recruiting staff with the right attitudes and preferably the right training and experience.

### 4. For commissioners and care managers

All commissioners should make themselves aware of what good person centred support looks like for people with learning disabilities.

When commissioning services for someone with a learning disability and challenging behaviour, commissioners should choose services that they know provide good Active Support in alliance with Positive Behaviour Support. Commissioners may use their previous experience to guide their choice but will often need to visit to observe current staff support in services familiar to them, and should always do so when considering services they have not visited before.

The provision of both Active Support and Positive Behaviour Support will be easier to achieve in small dispersed settings that are designed around the needs of the individuals they support. Such support should be included in service specification and/or contracts for people who may show behaviours described as challenging.

Individual budgets should include funding for training staff not only in Positive Behaviour Support but also in Active Support; as time goes on it is hoped that the workforce will become more skilled at person centred approaches in general.

Local authorities should consider the provision of training and awareness raising sessions on Active Support for all stakeholders including families and those who are personal assistants employed on personal budgets. This is especially important when funding care packages for people with challenging behaviour.

The provision of both Active Support and Positive Behaviour Support will be easier to achieve in small dispersed settings that are designed around the needs of the individuals they support.

Active Support should be a core competency for all staff in learning disability or autism services.

## 5. For inspection and quality assessment agencies

Inspectors (or anyone else responsible for monitoring the quality of social care and health services) need to be familiar with what good practice for people with learning disabilities looks like and what it is possible to achieve in terms of quality of life, despite challenging behaviour, autism, or other complex needs. They should receive basic awareness training in Active Support and Positive Behaviour Support and lead inspectors of learning disability services should have more extensive knowledge of such approaches.

They need to have the skills to observe and to identify whether people are engaged in a range of meaningful activities and relationships, and to identify whether the focus of behaviour strategies used is on promoting quality of life or simply on managing behaviour. They need to be able to check whether any paperwork completed is matched by what is seen in practice.

If inspection or quality monitoring agencies are looking at the lived experience of people in the services, observing and providing feedback to services related to Active Support, then services are more likely to focus on providing good support to people, rather than meeting perceived requirements to complete paperwork that often does not reflect what really happens in the lives of the people supported.



This photo depicts models who do not have a disability.

## 6. Skills for care

Active Support should be a core competency for all staff in learning disability or autism services. There also needs to be a recognition that it should be both a verbal and a practice competency. Other person centred approaches such as SPELL, alternative or augmentative communication or Positive Behaviour Support should also be taught at a basic level with options for people to take it to a more advanced level if they are supporting people who need such approaches. This would have a substantial impact on the occurrence of behaviour that challenges for many people and reduce the need for specialist challenging behaviour services.

# Some examples of the impact of Active Support

## Geraldine

Geraldine is a middle aged lady who lives with three other people in a suburb of a city in the south of England. She has a moderate learning disability and a visual impairment, and lived for some years in a number of small institutions before moving to her current home. Geraldine is often charming, considerate and affectionate. She has a number of skills and enjoys interacting with others. However, she frequently experiences episodes of acute distress, shouting and swearing, jumping up and down, banging her feet and hands hard on the floor, and scratching her face so repetitively that it bleeds. Staff struggle to support Geraldine when she behaves in this way and find that their reactive strategies have little effect beyond supporting her to calm down a little, before the next episode.

It had been suggested that Geraldine was the victim of abuse in one of her previous placements, so attempts were made to establish an intervention that would help her recover from the psychological damage involved. Sadly, despite a number of attempts involving members of the local learning disability team, no-one was able to make any progress in this area because of Geraldine's cognitive impairments. Other proactive strategies within the Positive Behaviour Support plan included teaching her coping skills (so she can better deal with conflict with her co-tenants) and improving lighting and the use of visual contrast in the décor and fabric of her home so that she can find her way around better. None of these interventions had an impact on the frequency, duration or intensity of Geraldine's challenging behaviour.

However, a new manager with expertise in Active Support was appointed to lead practice in Geraldine's service. One of his first acts was to change the way that staff support, and the events of the day, were planned and organised. In particular, he focused on increasing the predictability of what happened when, and with whom. Some of this involved scheduling existing activity in a more structured way, but even more predictability was enabled by increasing the amount that Geraldine and her co-tenants were involved in everyday activities around their home – things that staff might have done by themselves in order to be "kind" to the people they supported. Rapidly, Geraldine's challenging behaviour diminished to a very low level (and when it happened it was usually because staff had forgotten to maintain the agreed structure).

Furthermore, many of the old strategies the service had tried now proved effective – they weren't wrong, they just weren't part of something that enabled Geraldine to make sense of her world. Active Support brought the structure and coherence that she required.



## Lucy

25 year old Lucy relishes her independence. As well as holding down a part-time job, she volunteers, has a boyfriend and lives in her own flat. Lucy was receiving one hour's support at both ends of the day, plus an hour's support a week to go shopping. Although the aim of this support was to teach her the life skills she needed to live independently, she was actually struggling to keep her house in order. Rather than teaching her how to cook, the staff were cooking microwave meals for her. She was hoarding everything, from leftovers to rubbish. This behaviour was beginning to put her tenancy at risk, and she would respond with verbal aggression to any attempts staff made to help her.

We decided the best way of instigating a change in Lucy's lifestyle was to sit down and discuss things with her and her parents. One thing that wasn't working was the structured 'To do' list she had for everyday things, on which different jobs were allocated for every day. Lucy leads a very busy life so having a specific job for each day didn't work. We developed a new one which simply listed all of the things that needed doing that week, and asked her to tick off each one as she did it.

As well as enabling Lucy to take control of looking after her home in her own way, we also developed a routine with Lucy that complemented her lifestyle more naturally. For example, Lucy was sometimes missing her morning bath, because she worried about missing her bus or being late on the days she worked. So instead, we suggested she adapt the routine so that she bathed in the evening on those days.

When it came to helping Lucy with mealtimes, we agreed to help her write a weekly menu and shop only for what she needed. This cut down the

amount of out of date food she had in the fridge and reduced the amount of waste in the rubbish bins. We also suggested she write dates on any plastic tubs of leftovers so she could control how long to keep things for.

When it came to cooking, we realised all Lucy needed was to be given the opportunity to take control: she was so used to things being done for her, rather than with her, that she had never had the confidence to give it a go.

After one month of changes, we met with Lucy and her parents once more to review how things were going. The new routine we had developed with Lucy was working and her house was now much more comfortable. She was getting on so well, in fact, that when we arrived to help prepare dinner, she had already done it without us! We had noticed that on the days her boyfriend stayed over, she did not really need or want us around. She enjoyed looking after him and would naturally get the flat looking nice before he came. So we decided, with agreement from her parents, to reduce the hours of support we provided.

On the surface, the support we've given Lucy may seem very minor. But Active Support is almost always about the little things that make a big difference in giving people control to do things for themselves. With Lucy, it was more important to talk her through what to do and why, rather than show her through actions. She needed routine, but it had to be one designed around her. And it had to be consistent to work.

Lucy is now confident and proud of what she can do for herself. And she isn't scared to be assertive and tell us what she wants. She has become the independent woman she always wanted to be.

When it came to cooking, we realised all Lucy needed was to be given the opportunity to take control: she was so used to things being done for her, rather than with her, that she had never had the confidence to give it a go.

## Simon

Simon has a severe learning disability, epilepsy and autism. For half of his 60 years, Simon has lived in institutions, often in locked wards and always experiencing limited opportunities for interaction and activity. Simon's challenging behaviour (pushing and barging into people, grabbing people's wrists and pulling them, running off, throwing himself onto the floor both in and out of the house) meant that his life was very impoverished.

Even when he moved into the community, Simon was never really involved in his personal care, home or neighbourhood life: for long periods, he would sit alone in his bedroom. When they happened, activities in the community were always with 2:1 support and were difficult as Simon would run away, barge people and display other challenging behaviours.

Simon doesn't use words to communicate: his challenging behaviour tells us when he can't cope and needs to escape from what's happening.

The Positive Behaviour Support plan we developed indicated that his behaviours were probably triggered by not knowing what was coming next or what was expected of him. In response, Simon's support team used the Active Support principle of "Little and often" to guide their work with him.

In particular, they concentrated on preparing and presenting activities in such a way that they would make sense to Simon and ensured that new activities progressed at a pace that he could handle.

The best example is the way we supported Simon in the community. We started from scratch and to begin with we just concentrated on going for a short walk in a country park. We reasoned that this was likely to give Simon the best chance of doing something successfully, and we made sure that staff presented this activity consistently (we always went by the same route to the same park, for example) and that we didn't change our expectations until Simon was clearly confident about what was happening.

And gradually Simon has become more confident, so we have carefully expanded the range of options. He now visits several different country parks in the area, but also walks into town to do his banking and shopping. By using the principle of little and often, we have supported Simon to do things he would never have done successfully before, and all without any instances of challenging behaviour. As a consequence, we've been able to reduce the level of staffing to 1:1 for most community activities, which, given his previous life experiences, is a huge achievement for everyone.

## Resources

Ashman, B, Ockenden, J, Beadle-Brown, J and Mansell, J (2010) *Person-centred active support: A handbook*. Brighton: Pavilion Publishing.

Beadle-Brown, J, Richardson, L, Ashman, B, Ockenden, J and Mansell, J (2012) *Promote Active Support (LD302, LD303)*. Brighton: Pavilion Publishing.

Mansell, J and Beadle-Brown, J (2012) *Active support: enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.

Mansell, J, Beadle-Brown, J, Ashman, B and Ockenden, J (2005) *Person-centred Active Support: A multi-media training resource*. Brighton: Pavilion Publishing.

Allen, D and Baker, P (editors) (2013) International Journal of Positive Behaviour Support Special Issue – defining positive behaviour support. *BILD, International Journal of Positive Behavioural Support*, 3,2.



## References

Bambara, L, Dunlap, G, and Schwartz, I, (eds) (2004) *Positive behavioural Support: Critical Articles on Improving Practice for Individuals with Severe Disabilities*. Austin, Texas: Pro.ed

Beadle-Brown, J, Hutchinson, A and Whelton, B (2012) Person-centred active support – increasing choice, promoting independence and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disability* 25 (4), 291-307

Felce, D, de Kock, U and Repp, A (1986) An eco-behavioural comparison of small community-based houses and traditional large hospitals for severely and profoundly handicapped adults. *Applied Research in Mental Retardation* 7, 393-408

Jones, E, Felce, D, Lowe, K, Bowley, C et al (2001) Evaluation of the dissemination of active support training and training trainers. *Journal of Applied Research in Intellectual Disabilities* 14 (2), 70-99

Jones, E,; Lowe, K, Brown, S, Albert, L, Saunders, C, Haake, N, Leigh, H (2013) Active Support as a primary prevention strategy for challenging behaviour. *BILD, International Journal of Positive Behavioural Support*, 3 (1), 16-30

McGill, P and Toogood, S (1994) Organizing community placements, in *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services*, ed. Emerson, E, McGill, P and Mansell, J. London: Chapman & Hall

Mansell, J and Beadle-Brown, J (2012) *Active support: enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.

Mansell, J, Elliott, T, Beadle-Brown, J, Ashman, B and Macdonald, S (2002) Engagement in meaningful activity and “active support” of people with intellectual disabilities in residential care. *Research in Developmental Disabilities* 23 (5), 342-52

Royal College of Psychiatrists, British Psychological Society & Royal College of Speech & Language Therapy. *Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. College report CR144, 2007.

Stancliffe, R.J, Harman, A, Toogood, S, and McVulley, K.R (2007) Australian implementation and evaluation of active support. *Journal of Applied Research in Intellectual Disability* 20 (3), 211-27

Sugai, G, Horner, R, Dunlap, G, Hieneman, M, Lewis, T, Nelson, C, Scott, T, Liaupsin, C, Sailor, W, Turnbull, A, Turnbull, H, III, Wickham, D, Ruef, M, & Wilcox, B. (2000). Applying positive behavioral support and functional assessment in schools. *Journal of Positive Behavioral Interventions*, 2, 131-143

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