Feature

In celebration: living a life through Positive Behaviour Support

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Abstract

Purpose – The purpose of this paper is to provide a narrative account of one person’s experience of Positive Behaviour Support, against a backdrop of serial placement breakdowns.

Design/methodology/approach – The paper reflects on the human stories that lie behind the evidence base and presents one such story.

Findings – The paper proposes that such stories are as important as the evidence that is gathered around them, and have the power to challenge and to inspire.

Originality/value – This paper is celebratory, rather than analytic. It presents a life being lived and attempts to capture the virtues of its ordinariness.

Keywords Positive Behaviour Support, Person centred, Human stories, Case studies, Narratives

Paper type Case study

Positive Behaviour Support (PBS), since it first emerged in the 1980s, has become an established, if still somewhat under-utilised, model of intervention for people with learning disabilities and challenging needs. A small, but growing, evidence base suggests that PBS can be effective in achieving a range of positive outcomes including, but not solely concerned with, reductions in levels of challenging behaviours. A meta-analysis by Carr et al. (1999), for example, indicated both substantial decreases in problem behaviour and increases in positive behaviour as a result of PBS intervention, across 109 published articles. Positive changes to lifestyle, and longevity of effectiveness, were also reported, though less widely so. It also identified a range of factors that appear to enhance the effectiveness of PBS, including the availability of a functional analysis on which to base intervention, changing systems around the person involved, and intervening in natural settings with their usual carers. This analysis is usefully summarised elsewhere by Allen et al. (2005).

Despite the apparent benefits of PBS, its use is not as widespread as might be expected. Research indicates that a very small number of potential recipients of this type of support – 15 percent, according to Emerson et al. (2000) – actually receive it. Instead, it is more likely that their treatment will be characterised by the use of medication or restraint, or a combination of both, for which evidence of efficacy is either absent or questionable (Allen et al., 2005). This paradox is summed up by the authors as:

What works best is used least, and what works least is used most (Allen et al., 2005, p. 8).

So there appears to be both a body of evidence in support of the implementation of PBS, and also a failure to provide it to large numbers of those who need it. Where it is in use, its effectiveness can be demonstrated by a range of outcomes concerned with, for example, reductions in challenging behaviour, and in the use of medication and restraint;
such outcomes can be measured and quantified, and presented graphically as hard data. In addition, PBS considers improvements to quality of life to be as important, and these too are amenable to a range of measures that have social validity, employing a wide range of methodologies.

This paper seeks to celebrate the narratives that lie at the heart of these measures, since behind the graphs and the bar charts and the data analysis, there is often a human story, a story about a life being lived. Such stories can be as persuasive as hard data in demonstrating positive changes and, in some cases, in challenging corrupted cultures. For example, Close to Home (Felce and Toogood, 1988), in a snapshot of life on a hospital ward in the 1980s, presented one of the most harrowing accounts of dehumanizing treatment – in a supposedly civilised society in the late twentieth century – that it is possible to imagine. It would be difficult to believe that anyone could read an account of such a regime – validating degraded lives, lived in appalling conditions – and not want to challenge, and to overthrow, the culture that sustained it. Such accounts have the power to shock and to inspire, to demand change and to cause celebration when that change is achieved. There is a growing anthology of such stories; what follows is presented as an addition to that anthology.

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On a typical day for David there is much to be done. Before he can leave the house in the morning there may be the breakfast things to clear away, a laundry load to be put into the washing machine, or the car to be cleaned. Once any essential tasks are completed he can get into the car, click his seat belt into place, and start the day in earnest. Perhaps he needs to take a trolley around the supermarket for the weekly shop, or call into the bank, and then grab some lunch somewhere. If it is Saturday, he is likely to go to watch the local football team play a match in the afternoon, and have a quick drink in the clubhouse bar afterwards. Later, he will go home for his evening meal, then maybe watch a DVD.

This is, by any normal measure, an unremarkable day; a man going about his business, doing the ordinary things of daily living. But David is on the autistic spectrum, has severe learning disabilities, major communication deficits and some long-established challenging needs, and his days have not always been as ordinary as this. In order to understand the significance of this “ordinariness”, we have to turn the clock back almost 17 years.

1994-1999

In 1994, aged 19, David moved out of his family’s home and into residential care, in a spirit of optimism as he entered this new phase of his life. This optimism turned out to be misplaced. What he experienced during the next five and a half years was a series of re-locations, from one service to another, of various shapes and sizes, under different regimes of care, and of variable quality. For each of these moves David had minimal, if any, warning or preparation. He moved house four times in three years and, by the end of 1999 – having briefly returned to his parent’s home, and then to his current placement – he had done so five times in five years. Each new, ill-suited, placement presaged a deterioration in David’s well-being and in his behaviour, and – because of his propensity for causing damage during behavioural outbursts – an increasing barrenness and austerity in his living environments. By the time of his fifth move David was at a very low ebb; he has no formal language and could not convey in words his responses to this ever more unpredictable and changing world around him. However, his non-verbal communication very clearly gave the impression of someone who was physically exhausted, emotionally labile, highly anxious, and perhaps depressed. His days were characterised by frequent episodes of distress and extreme challenging behaviour, and an inability to participate in meaningful activity.

So what went wrong? What causes a young, largely healthy, man in his twenties to reach such a level of hopelessness and anguish? One answer to this question lies in the dispiriting truth that high quality, person-centred, residential services for adults with learning disabilities can be very hard to find. Many services may aspire to such quality, but fail, in large part through being founded on a number of dubious principles, for example:
that high quality can be achieved through a combination of good intentions and accident;

that people with learning disabilities (and, especially those who have challenging behaviour) will, ipso facto, benefit from living with other people who are like them (as if this fact alone will create harmonious living – in reality, the opposite of harmonious living is frequently achieved, where people's competing needs cause conflicts, tensions and a lack of equity);

that they should not be exposed to the mundane chores of daily life;

that weekends are a time for rest and relaxation; and

that challenging behaviours are unacceptable acts of defiance, etc.

David's specific experience of poor quality services can be summarised by some key characteristics which were present, in varying degrees, in one or more, and, in some cases, all his first three, placements:

- A lack of proper planning, typified by a 'make it up as we go along' approach to the coordination of staff activity on a shift-by-shift basis.
- Extremely high levels of staff turnover – David met over a hundred support staff during those years, including 60 in one 20-month placement (though some he will have met only once . . .).
- The very large numbers of staff involved engendered a similarly diverse skill mix, and a workforce with a high proportion of young, well motivated, but inexperienced carers who were expected to support someone with complex needs.
- Inflexible staff rotas, necessitating an early afternoon shift handover which served to disrupt the flow of David's day.
- A timetable of activities predicated on a need for 'block treatment', taking little account of individual preferences (and with a preponderance of pseudo-leisure – ten pin bowling, sensory rooms and the like – and unstructured time).
- Artificial restrictions and abnormalities of routine (in one service David was not allowed in the kitchen, on the grounds that it would not be safe for him to do so, and there would be nothing for him to do in there anyway).
- Record keeping which was generally of a poor standard, both in terms of how information was presented – illegible handwriting of unintelligible meaning was common – and its accuracy – for example, a tendency towards misleading the reader by putting a gloss on inconvenient truths.
- A recurring failure for services to be properly managed, by an experienced, knowledgeable, manager who had the skills necessary to lead a team of staff in a coherent and effective manner.

Cumulatively these factors had an enormous impact on David. Here was a man known – insofar as our best information and insight allowed us to know – to require predictability, familiarity, and consistency, all those characteristics that provide the comforting reassurance of routine. Instead he was confronted by a world that was entirely unpredictable, contradictory and chaotic. After all, how can a service provision which moves from one location to another, at short notice and with perfunctory preparation, and is delivered by a vast number of different carers, whose personnel change from day to day, from week to week, and who are overseen by equally transient managers, marshalling inadequate resources – how can such a service hope to provide anything even remotely resembling the degree of consistency and continuity required? Of course, it cannot, and it did not.

Given this persistent upheaval, it is, perhaps, not surprising that David responded in the way that he did: he protested, he shouted, he got upset and angry, he lashed out – a sane reaction, some might say, to a crazy world. And, as each failing service floundered, dragging David further down into behavioural turmoil, so he became less emotionally resilient, and increasingly difficult to manage, making it ever more likely that the next service
would flounder also – a classic, seemingly uninterruptible, vicious circle. When the third placement served notice, towards the end of 1999, David was potentially homeless.

**A fresh start**

It was around this time that a proposal was made that David should take up a vacancy at a residential service in an adjoining county. This was seen by some as an appropriate solution since it would provide – in the words of one care manager – “a roof over his head”, a rationale that was flagrantly dismissive of a central principle: that David should remain geographically close to his family, his social networks and the town where he had always lived (and should not, in contrast, be subjected to what *Valuing People* would later describe as a “take what you are given” attitude to housing provision). David's parents, who were, and remain, his assertive advocates, understandably opposed such a plan, and were pivotal in ensuring that it was not pursued. Instead, whilst a new local service was sought, David returned to his parents' home for what was to be an extremely difficult period for him and for them. David was severely distressed and seemingly inconsolable, and his parents did their best to support him, whilst also trying to maintain their own working lives and some sense of normality – a balance of competing priorities that was transparently fragile.

The seeds of David's extrication were sown in November 1999 when the design of a new service was entrusted to providers who were committed to the principles of PBS. They were approached directly – by David's parents – with the question of whether they would be prepared to construct a new service around him (a previous approach to them, made by the care manager, had simply enquired about existing vacancies in their residential homes – there were none). This decision – to enlist a specific service provider – was the first of three critical decisions that were made at that time. The second of these was that David would, in the short term at least, now live alone, his experience of living with other people having been a success neither for him nor for them. A property was found which was available to lease, for the foreseeable future, as David's next home. Third, responsibility for founding the new service was given to a skilled manager, herself a protégé of PBS, and well versed in person-centred approaches.

From the outset the new manager – guided by the local NHS specialist service, and based on a proper functional analysis – adopted a PBS approach to how this new service would look. Staff were recruited with care and consideration, in order that the workforce reflected David's known preferences regarding the personal characteristics of those who support him. Crucially, the staff rota was designed such that, from day one, David's preferred rhythms and routines of the day could be accommodated, with two to one support. This rota eschewed the usual template used in residential services, requiring the early afternoon shift handover. Particular attention was paid to the smooth flow of David's daily routines so that potential flashpoints – activity transitions, unexpected changes of plan, and the aforementioned handover period, which still had to occur at each end of shift – were kept to a minimum.

Systems and structures were put in place which ensured that David had around him an organisational framework that enabled the planning, recording and monitoring of his life to be properly conducted. Staff undertook induction training, both specifically related to David himself, and, more generally, about PBS, including proactive strategies and physical intervention techniques.

Achieving this degree of preparation in the time available – approximately one month – was not easy, but a shared sense of purpose and commitment among those involved made it possible. David moved into the new single-person service immediately after Christmas, in December 1999, on the eve of the new millennium.

Naturally, the early weeks and months of the service were difficult for all concerned. David was once again surrounded by people who – with two exceptions, staff members who, loyally, moved with him from the previous placement – were strangers to him, and to each other, and rectifying this state of affairs would undoubtedly take time. But, of course, one of the tenets of PBS is its long-term focus, and the energy expended at this time was, in large part, an investment for the future. Throughout 2000 serious incidents of challenging...
behaviour – over a hundred – continued to occur; during the process of people becoming familiar with each other mistakes, inevitably, are made, communications are misunderstood, new activities are attempted that misfire, people disagree with each other over the best course of action, things go wrong. These are the normal artefacts of human interaction, and they typically improve as relationships grow, and the participants acquire an increasing understanding of each other. As this process evolved in David’s new home, he still found there were occasions when he needed to protest, to register his strong feelings about aspects of the world around him. Meanwhile, his staff were able to practice and refine their skills in important areas such as recognising the early warning signs, effective defusion and redirection, and crisis management when necessary. In 2001 there were 50 behavioural incidents, approximately half the number of the previous year.

Gradually, over time, David’s staff team was able to introduce further elements of PBS. Skills teaching, initiated tentatively at an early stage, spread into a range of domains in his life – he learnt to make choices, to participate more fully in his own personal care, to contribute to the housework, and to the shopping (Box 1).

Objects of reference were introduced as communication aids, and additional monitoring systems were developed. As the knowledge and confidence of his support staff increased, they became able to offer him a wider range of community experiences, to try new venues and ventures, to take some risks. 2002 saw a further significant reduction in the number of behavioural incidents, the total half again of the year before.

There were still setbacks: David broke his arm in a riding accident in 2001 causing some inevitable disruptive consequences for his daily routines and range of activity. Lease arrangements on property required that he move house twice more in the years that followed, but this time the re-locations were prepared for, planned and sensitively conducted – and only the bricks and mortar were different; his systems of support, including his team of staff, moved with him, and were able to replicate service design.

There were discussions about funding arrangements which at times were difficult and unsettling. But throughout those difficulties, and now through these more recent years, David’s service has continued to evolve, and has established a degree of stability and normality that would not have seemed possible at the outset (Box 2).

David has now lived at his current address for seven years. The indoor environment looks rather different from the one he first entered in November 1999 – that was necessarily bare, lacking any warmth or welcome. Now, his home has some of the bric-a-brac and adornments that most people take for granted, and which add some colour or décor to a living area. David now accepts these as routine features of his environment, and it has a more homely ambience (Box 3).

And there have been other positive developments: he has had holidays, been camping, and stayed overnight in a hotel (Box 4). Wakeful nights, a perennial problem, have reduced to negligible levels – a considerable benefit. He continues to develop new skills, which serve to maximise his participation in the routines of everyday life.

Single person services, of course, do not come cheaply, and those involved in David’s care and support have frequently been aware of the scrutiny of cost-conscious commissioners keeping an eye on budgets. The success of this service can suggest that David is “fixed”, and, some will argue, no longer requires the level and nature of support he receives. But there is a powerful counter-argument: that its success, and David’s improved quality of life, have been achieved precisely because he has, finally, the kind of support he needs. Changing the support would, the counter-argument maintains, inevitably diminish the service’s effectiveness. The argument, for the moment, has been won, but the motivation for such conversations may re-emerge in the future. For nearly two years David has been deemed eligible for funding via NHS Continuing Healthcare, and this has provided a security of sorts. But David’s service providers, and his parents, have no sense of complacency about what might lie ahead.
Reflecting on David’s story

The opening paragraph of this account provides a snapshot of what David’s life now looks like. He is not ‘fixed’: he still displays challenging behaviour – there may be two serious incidents each month in a bad year, one a month in a good one. Living alone appears to suit him. He lives alone but is not on his own; he has the constant companionship of people who know him well and value him. They spend time together, sometimes doing the things that David wants to do, and sometimes the things that need to be done. Remarkably, the core of his staff team has remained largely intact: the manager, and the two other staff members present at the beginning, are still with him, and the rest have been so for several years (Box 5).

It is one of the features of the PBS model that positive inputs create positive outcomes – in David’s case, personal outcomes such as reduced levels of challenging behaviour and improved sleep patterns, and service outcomes, such as this low staff turnover – and those

Box 1. Going shopping

David has a new three piece suite in his lounge. It didn’t just turn up uninvited – he went with staff to the shop, tried out a few different styles, sat down in each of them, and seemed to prefer one more than the others, so that’s the one they went for (Mr & Mrs A, David’s parents).

Box 2. Happy birthday

For David’s birthday this summer we had a barbecue in the back garden of his house. Lots of people came – we were there, together with his brother and sister-in-law, and several staff who weren’t on duty that day; it was quite busy. For about two hours, he seemed happy to sit and eat with the crowd, and to mingle, and to relax, and to enjoy the occasion and the weather. This was, for us, a very significant event (Mr & Mrs A).

Box 3. Feeling at home

His furniture used to be secured to the floor – any moveable object was at risk. We no longer need to do that and, for the last couple of Christmases, we’ve put up a tree and decorations so that it actually looks like Christmas here. David seemed really happy about that (Home manager).

Box 4. On holiday

Two years ago he went on holiday to Wales, and had a great time. Our favourite memento of that trip is a photo of David, all smiles, sitting with two staff members at the top of Mount Snowden (Home manager).

Box 5. Committed staff

During the terrible winter weather we got completely snowed in: rail and road systems were paralysed, and it was extremely difficult for some staff to get to work. But one of them has a 4 x 4, so he took this out on the road and collected some of the others so that we had enough cover for shifts, and they stayed overnight to be sure that they would be in the following day. They were just brilliant (Home manager).
positive outcomes mean that further positive inputs are possible. Accordingly, David’s highly person-centred service, provided by a committed staff team who are effectively led within a PBS framework, has liberated him from the vicious circle that once entrapped him, and replaced it with one that is demonstrably virtuous.

So what helpful lessons can be learnt from David’s experience? Clearly, his story provides further evidence of the potential power of PBS in creating positive and enduring change in people’s lives. In his case, it is the product of more than ten years concerted effort by those who ordinarily support him – “specialist” input has been negligible for several years. We have learnt that David is more accepting of change, more amenable to new routines, to innovation, than was for a long time believed to be the case; in this respect he has frequently confounded our expectations. His story is also a further, and chastening, reminder of the potentially traumatic consequences of poor service planning and delivery; this is not a revelation, but nonetheless a reality that can bear reiteration.

Hopefully, David’s story also has elements that will resonate with, and add power to, the body of similar accounts which serve as a reminder of the people who lie at their heart. Good quality data, importantly, help us to measure change, and to quantify progress; they can provide compelling, and frequently heartening, evidence of accomplishments. In David’s case, the data confirm the enhancements to his quality of life, evidenced, for example, by a varied schedule of community activities, frequent opportunities to practice new skills, low levels of challenging behaviour and so on; these are all routinely measured and monitored. But perhaps equally compelling, and equally heartening, are the narrative descriptions of the journeys that are being measured: these are the human stories that deserve to be told, and to be celebrated.

References


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