

The power of positive thinking

Challenging behaviour in people with autism is usually met with physical restraint and medication. Their overuse is now a national problem. But, finds Linda Jackson, an alternative idea is yielding striking results

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It used to take three adults to restrain teenager Richard Payne when he flew into a fit of rage and violence. It cost the taxpayer £350,000 a year to control the then 18-year-old, who would routinely attempt to smash windows and hit staff. Weighing fourteen-and-a-half stone, and standing over six feet tall, he could cut an intimidating figure.

That was three years ago. Today, thanks to a more holistic approach to the care and support of Payne (not his real name), who has autism and severely challenging behaviour, his life has been transformed. Crucially, efforts have been made to help him communicate better and to remove triggers for his anxiety. Now 21, Payne can swim in public swimming pools, climb walls at the local sports centre in Wakefield, West Yorkshire, and go to the cinema - all activities once considered too high a risk.

Experts believe that his programme, which focuses on individualised care and alternatives to physical restraint, could have far-reaching consequences for the treatment of Britain's growing population of people with severe learning disabilities and autistic spectrum disorders who have challenging behaviour.

Payne's turnaround began in 2003, when staff working for learning disability charity Choice Support were asked by his desperate social worker to devise a package of care. Adapting positive behavioural approaches promoted by the US-based Institute of Applied Behavioural Analysis, they looked at Payne's background and noted when his outbursts of aggression occurred. They soon discovered that one of the triggers was anxiety about time - and gave him a clock.

It emerged also that too much choice disturbed and confused Payne because he is attached to routine and ritual. Charts outlining meal choices and activity planners were set up. Staff showed him ways of communicating any anxiety and developed "breakaway" techniques, where staff would leave him if the behaviour was about to occur.

Transformation

Although there was optimism, nothing could have prepared the support workers for the results. Reports show that incidents of restraint have been reduced from an estimated 180 a year to none, while cases of physical injury to Payne or to staff - previously common - have been reduced dramatically.

"Richard is now able to do more things he enjoys, make real choices about what he does and no longer lives under the shadows of three threatening support workers," says Stephen Rose, chief executive of Choice Support. Furthermore, the cost of caring for Payne has been reduced by as much as £100,000 a year.

News of the success of the approach comes amid national concern over the treatment of people with learning disabilities and government forecasts that the number of people with challenging behaviour is set to rise sharply. Only two months ago, the Healthcare Commission inspectorate ordered a national review of all NHS and residential care units that care for people with learning disabilities after an inquiry revealed systematic, institutionalised abuse in Cornwall. In one case, a patient was left tied to a wheelchair for 16 hours; others were routinely drugged.



"There is no doubt that the use of restraint is a serious national problem," says Peter McGill, a specialist in learning disabilities and challenging behaviour, and director of the Tizard Centre at the University of Kent. "All too often, physical restraint and medication are abused as a method of controlling patients. A number of studies have shown that over 50% of people with challenging behaviour receive medication - just to sedate them. More than 50% are also subjected to regular physical restraint. These are just quick fixes and manage only the consequences of the problem."

Positive behaviour approaches such as the applied behaviour analysis programme are not new, McGill says. Nor are they expensive. Specialist courses offering training in this approach cost as little as £3,000. But despite evidence of the benefits, few professionals are putting them into practice. Those that do so tend to specialise in supporting adults. As a result, children and young people with challenging behaviour are often sent away to specialist residential schools by local authorities paying up to £200,000 a year for single placements.

"Unfortunately many of these places are not terribly specialist and most providers over-use restraint," says McGill. "This should only be used as a last resort. There is a huge need for a more preventative approach and a drastic increase in the number of psychologists specialising in treating people with learning difficulties."

Learning disability experts say the issue is critical and point to government statistics showing a 60% rise over the past two decades in the number of children born with complex disabilities. Many will have challenging behaviour. Increased survival rates of pre-term babies means the number is likely to increase further. Yet care for people with learning difficulties has not kept pace with medical advances. While positive behaviour programmes will not work for everyone, there are significant numbers of people who could be helped.

For McGill, getting professionals such as clinical psychologists and specialist nurses involved in early intervention is a first step. He says there is no inevitability that people with severe learning disability will have challenging behaviour - it depends how much support goes in. However, the key to the success of any positive behaviour programme is the adoption of the approach by frontline staff and carers.

This was a hurdle faced by Choice Support, which was forced to disband an agency team caring for Smith and employ more sympathetic staff open to fresh ideas. The charity describes the transition period as "difficult" and admits it took several months to set up a new, person-centred service that proved to be the key to breaking the vicious, incident-restraint-incident cycle.

Rose admits that even he was originally "a bit sceptical" of the approach put forward by his regional director, Dave Jackson, and supported by manager Steve Reynolds. "Now I've seen it work I am a complete convert," Rose says. "This method has proven itself. We had to get new staff and a new manager that were untainted by the negative culture that permeated the existing team. Now we are beginning to use it with other people. You can adopt the principles with anyone."

Having saved £100,000 in care costs, care commissioners in Wakefield are now asking Choice Support to support other people in the area. The charity is also working with 20 other local authorities to support people with challenging behaviour.

Caroline Briggs, director of finance and commissioning for Eastern Wakefield primary care trust, says she is delighted with the impact on Payne's life. "He is able to go out and do a lot more and has reduced his needs dramatically. Hopefully, other people will benefit from this approach where it is seen as appropriate. At the same time, people involved in this case will take their learning with them."

Breaking the cycle

One of the keys to the new approach of looking after Richard Payne was breaking the incident/restraint/incident cycle and creating a structure for his day.

Staff believed that his service had become one where restraint was seen by him as a form of punishment, making him resist further. To break the cycle, regional director Dave Jackson and service manager Stephen Reynolds took the risk of stepping back from restraint when it appeared risky to do so. Alternative ways of managing escalating behaviour were tested, using non-aversive techniques such as the introduction of distraction methods.

Reynolds recalls: "On one occasion, when I was in Richard's house but not working directly with him, staff reported that Richard's behaviour was escalating during meal preparation and requested support. I entered the living room to be met by Richard pacing the room and banging his head periodically on the living-room window. I asked the

three staff on duty to leave and wait on the patio. I began to fold and tear a blank piece of paper, ignoring Richard's increasing pacing. I produced what could be feasibly recognised as a paper mask.

"Holding the mask to my face, I asked Richard: 'Does this look like David?' (one of the staff on duty). Richard replied: 'No, Rachel,' then gestured for the mask before placing it on his own face and then laying it on the table.

"From this point I was able to redirect Richard back on to the task of lunch preparation, while staff filtered back in to continue supporting Richard with the cooking of his meal."

A new approach: Positive behavioural support

The Institute of Applied Behaviour Analysis was founded in 1981 by Gary LaVigna and Thomas Willis to promote positive approaches of working with people who have challenging behaviour. Central to its values is that aversive or punitive techniques must not be applied.

This more holistic approach is often known in Britain as positive behavioural support. At its heart is the aim to blend the rights of people with disabilities with a practical science about how learning and behaviour change occur. The overall goal is to increase quality of life.

The process starts with a full assessment. Details are taken not only of the person but also of their family background, medical history and living environment. Practitioners then go on to identify when challenging behaviour is likely to occur - and from this they infer the meaning of the behaviour to the person.

Positive interventions that cover environmental changes are then introduced. This might involve decreasing noise levels, or increasing/decreasing staff cover. At the same time, opportunities are created for the individual to learn new skills. These might be skills directly related to the behaviour, such as anger management or ways of asking for help.

All support workers work consistently with the approach and are trained to understand the needs of the individual. They are issued with guidelines on how to cope with challenging behaviour, when it occurs, safely and quickly.