Another way:

transforming peoples' lives through good practice in adult social care

A case study report by the
Voluntary Organisations Disability Group (VODG)
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VODG

The Voluntary Organisations Disability Group (VODG)

The VODG is the leading umbrella group of voluntary sector providers of social care services for adults with disabilities. Our members' shared aim is to ensure that people with disabilities are supported in ways that they themselves define. We are committed to personalisation and the principle of "no decisions about me, without me".

Our ambition is to shape the development of social care policy, to influence its implementation and to provide sector leading information and research.

VODG members believe that meaningful engagement and fair negotiation between commissioners and providers, focused on the needs of people who rely on social care services, helps build strategic relationships, enhances service design and is more likely to ensure that beneficial outcomes and efficiencies are achieved.

If you're passionate about delivering services that people with disabilities want and are keen to have an influence and say in the wider sector then why not join us?

www.vodg.org.uk

Anthony Collins Solicitors

Anthony Collins Solicitors is a leading practice in the health and social care field and works in partnership with VODG and its members to develop best practice and efficient ways of working, especially in the light of the uncertainty created by the current climate of changes in funding, commissioning and personalisation.

In addition to our work for care providers, we are committed to supporting individuals in need including through publicly funded work in the fields of community care, special educational needs and mental health.

Anthony Collins Solicitors is delighted to have helped to make the publication of this report possible, we are passionate about the need to treat everyone with dignity and respect and, above all, to deal with them as individuals.

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About this report:

This report has been commissioned by the VODG and written by social policy journalist and editor Saba Salman (www.sabasalman.com), a regular contributor to the Guardian who also manages the VODG blog.

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“There is another way”

Foreword by Gavin Harding

When I watched the BBC Panorama programme earlier this year about abuse at the Winterbourne View care home in Bristol[1], I felt angry and upset. Once again, I saw people with learning difficulties being treated very badly with no dignity or respect.

The abuse at Winterbourne View was extreme but you have to remember that even in services where the care support is generally good, the views of people who are cared for might still be ignored. Too often, vulnerable people are sidelined.

Have you ever felt invisible? I have and I can tell you it was not a good experience. Like the time I sat in an assessment centre where people around me talked about me like I didn’t exist and I was made to feel like a naughty schoolchild. So often the “powers that be” go behind closed doors to make their decisions, the commissioner might as well just sit there with a calculator – because it’s about people, not savings - while the person with learning disabilities ends up on a conveyor belt of care.

There is another way, which is presented in this Voluntary Organisations Disability Group report. It’s about putting people with learning disabilities and their families at the centre of planning and delivery of care. The professionals should listen to and work with, at every single stage, the person using the service. I hope some of the information you read in this report will show the dignity you can give vulnerable people if, instead of just “giving them care” you actually involve them in shaping it – ask them how they want to be cared for and give them a voice.

Too often, what goes on means that people are treated without respect. Also there are people with learning disabilities who cannot communicate verbally, who have very high complex needs or whose behaviour sometimes challenges services, this lack of respect is really causing people with learning disabilities and family carers a lot of stress.

People with learning disabilities have rights and choices, just like everyone else. The professionals call it “co-production”. I call it treating people with respect and giving vulnerable people the same rights and choices as anyone else. More than anything it’s about listening to what people are saying; or sometimes not saying. Care is about people, it’s not just a process.

Gavin Harding, co-chair, National Forum for People with Learning Disabilities www.nationalforum.co.uk, chair, self-help advocacy group Voices for People

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[1] “Four arrests after patient abuse caught on film” www.bbc.co.uk/news/uk-13548222

Introduction

John Adams OBE

General secretary, Voluntary Organisations Disability Group (VODG)

Earlier this year, two words and a single venue came to symbolise all that is wrong with adult social care: Winterbourne View.

BBC's Panorama secret filming at the privately-run care unit for vulnerable adults in Bristol put the unit at the centre of allegations of abuse[2]. Vulnerable people were filmed being dragged, punched, slapped, doused with water and taunted. The 24-place unit cost an average of £160,000 per individual per year.

Winterbourne View is now closed, its owner, Castlebeck Care Group, has also shut two other sites[3] and a review by the health and social care regulator the Care Quality Commission has ordered root and branch improvements at the company[4].

There are 1.5m people with a learning disability in the UK and, while the Winterbourne case proves that pockets of bad practice remain, the social care sector's move away from long-stay institutions and towards advocacy and community-based approaches has increased the choice and control vulnerable people have over their lives.

As a national organisation campaigning on social care, the Voluntary Organisations Disability Group (VODG)[5] brings together over 50 leading voluntary sector pan-disability organisations. We work on behalf of our members to influence and develop social care policy, build relationships with government and other key agencies and keep members up-to-date on issues relating to the delivery of care.

Driven by the collective distress that followed the Panorama programme on Winterbourne View, the VODG wanted to demonstrate that social care need not be institutional, expensive, poor quality and delivered by untrained staff with low morale. Many providers deliver excellent, high-quality support and transform peoples' lives. But why and how does it work in some places and not others? We wanted to highlight the key ingredients for successful outcomes through a handful of case studies.

The purpose of this good practice report is to offer snapshots - case studies from VODG member organisations - depicting the core issues that help improve the lives of vulnerable people. The group of people that concerns this report include those with severe and complex needs, with sensory impairments or who have a autistic spectrum disorder.

Our report follows a Guardian roundtable event held in association with the VODG earlier this year as a response to the Winterbourne View scandal. The roundtable explored what has to be done to ensure those cared for have access to person-centred support and local services which meet their individual need[6]. The roundtable's intention was not to look for blame, or simply to respond to the Panorama programme, but to better understand the precursors of successful and empowering support.

[2] "Four arrests after patient abuse caught on film": www.bbc.co.uk/news/uk-13548222

[3] "Care home firm at heart of abuse allegations closes third unit": www.guardian.co.uk/society/2011/aug/17/castlebeck-care-homes-close-unit

[4] "CQC calls on Castlebeck to make root and branch improvements": www.cqc.org.uk/newsandevents/pressreleases.cfm?cit_id=37478&FAArea1=customWidgets.content_view_1&usecache=false

[5] About VODG: www.vodg.org.uk/about.html

Existing social care policy combined with important initiatives such as Think Local, Act Personal[7] has the potential to improve care delivery for individuals. The drive towards personalisation[8], for example, boosts choice and control and means support should be tailor-made with the service user at the centre of their own care. The co-production agenda[9] also offers greater opportunity for professionals to involve those cared for in the planning and delivery of their own support package.

"Most families provide long term love, care and support to their relative. They know the person really well, are highly motivated to ensure that they get the right support and services to deliver a good quality of life, and have huge knowledge and expertise about the person. For many people with learning disabilities, a number of people come into their lives at various points and can be very important to them but they often fulfill this role for short periods, whereas families are the constant. Even if the person leaves the family home, they do not leave the family and families can be engaged and provide input in various ways. Working in partnership with families as allies makes sense on every level, it is crucial for providers to engage with families."

Vivien Cooper, founder of campaign and support organisation the Challenging Behaviour Foundation (CBF)[10].

The case studies in this report, in different ways, reflect the Think Local, Act Personal framework Making it Real - Marking Progress towards personalised, community-based support[7]. They demonstrate a commitment by the organisations involved to develop plans which avoid crisis, place people in community settings and fully consider the needs of families and carers. In short they put the person first and at the centre of planning and service delivery - and as a result achieve better outcomes.

The backbone of VODG's work is to highlight the importance of the triangle of support – the critical relationship between commissioner, provider and the service user and his or her family. The case studies in the report show how through focusing on the triangle of support, significantly better outcomes can be achieved, often for less money[11].

The following testimony illustrates the need for action:

"We wanted the best for our autistic son; we got Winterbourne View.

Winterbourne View is now synonymous with appalling standards of care for the learning disabled, but three years ago, when my son was 18, I thought the residential unit in Bristol was the best care available.

[6] "Beyond Winterbourne" blogpost about the Guardian roundtable event: www.vodg.org.uk/cgblog/19/105/Beyond-Winterbourne-a-blueprint-for-success-in-social-care.html

[7] The VODG is an original signatory to and closely involved in Think Local, Act Personal partnership. Making it Real - Marking Progress towards personalised, community-based support is a set of statements from people who use services and carers which set out what they would expect, see and experience if personalisation is working well in an organisation. www.thinklocalactpersonal.org.uk/

[8] "Expert guide to personalisation": www.communitycare.co.uk/Articles/2011/08/19/109083/personalisation.htm

[9] Social Care Institute for Excellence co-production briefing: www.scie.org.uk/publications/briefings/briefing31/

[10] Challenging Behaviour Foundation website:

www.challengingbehaviour.org.uk/

[11] VODG Gain Without Pain report available to download:

www.vodg.org.uk/resources/vodg-publications.html

Luke (not his real name) was diagnosed with autism at three and coped well at our village school in the South West, supported by a classroom assistant, and later at a special unit for autistic children.

But his behaviour became more challenging and at 18, aware of how his condition denied him the same opportunities as other young people, he tried to take his own life. He was on a life skills course at a local college when he broke a window and tried to jump from the building.

Local provision was inadequate, said our local authority, so it was decided Winterbourne View was the nearest place that could meet his needs. After speaking to both the psychiatrist and manager from Winterbourne View, my wife and I felt relief and gratitude that, in this crisis, the authorities had pulled all the stops out to find good quality care, especially when we were told it was going to cost around £3,000 a week.

We hoped it was the right place - we could not have been more wrong.

While I'm not suggesting Luke suffered the same experience as the vulnerable patients filmed by BBC's Panorama programme being pinned down, hit and verbally abused, he was immediately unhappy.

When we phoned every evening, he was frightened and wanted to come home. I arranged to take him out on his first weekend but I was told he could not go out with me because no staff were free to accompany us. I insisted I see him and argued that, as a voluntary patient, he should be allowed out. I got two hours with him.

Patients appeared to have little to do apart from eat sweets or smoke cigarettes. Our nightly calls were often interrupted and when we asked Luke about it he said, referring to patients being restrained, it was because "somebody was kicking off". We were horrified. Luke became fixated and talked continually about restraints. We were desperate to get him out of there but were told that if he did not return after a home visit, he would be sectioned.

I gave Luke a phone so he could call me (one without a camera, which I thought would comply with regulations) but staff took it away along with the CDs and DVDs we had got to raise his spirits. We were told it was hospital procedure because he might break the CDs and cut himself.

Finally, after 14 weeks it was agreed Luke could leave as long as he went straight to a residential college. All this time, we had felt cut out of the loop. Imagine how we felt when we saw that Winterbourne View wasn't a good place and we were disempowered by the system designed to help us. As parents, we've been discounted during our struggle to be heard and taken seriously. Good practice guidance requires professionals to consult and work close with families, but this theory is rarely a reality.

A psychologist appointed by the local authority to assess Luke at the residential college reported that he was suffering from post-traumatic stress disorder as a result of his experience.

Now we feel we have the right care for Luke. There were no specialist professionals trained in autism at the college so for the last year he has lived at home with flexible, tailor-made support from a local autism organisation. They're finding coping strategies for his difficult behaviour and working out what triggers it, rather than just trying to prevent it.

People with learning disabilities should be put at the heart of their own care and their families shouldn't be out on a limb."

In this report, care providers, all of which are VODG members, describe how people who services often describe as "challenging" can be supported to live their lives to the full.

Their stories point to some key issues that need to be addressed and embraced when encouraging high standards of care. There are, for example, those whose lives have been transformed thanks to strong commissioner-provider relationships and a flexible approach that has saved commissioners money.

The examples show the benefits of promoting good practice or how support from highly specialist professionals can reap rewards. They describe how to make the theory of personalisation and co-production a reality and outline the incredible results of well-supported transition from residential care to independent living.

Above all they plainly demonstrate person-centred values being put into action, possibly the best way for providers to assure quality at every level. This means organisations being explicit about their values and the behaviours which demonstrate them being lived out, and then working hard to embed this culture from the boardroom to the frontline.

"Ensuring that service users are at the heart of their own care is vital from an organisational and governance point of view. It makes sense commercially, as well as being the right thing to do. Governance arrangements need to embed the cultural drivers that can deliver the type of outcomes demonstrated by VODG members in the following case studies. Such drivers include openness to new ideas, the dedication of scarce resources to planning and giving staff space to be creative and engage in meaningful partnerships with commissioners. Care providers that reaffirm a commitment to person centred services and participate in local and regional networks to learn from and share best practice are, in our experience, best placed to meet the challenges the sector faces."

John Wearing, partner at Anthony Collins Solicitors LLP, a legal firm specialising in health and social care.

The snapshots in this report are by turns powerful, uplifting and moving but, above all, they are achievable; as such, they point to the way forward if we are to make the lives of vulnerable people more equitable.

Strong commissioner-provider relationship, personalised and responsive service delivery: MacIntyre and Oxfordshire county council

Joe (not his real name) was the archetypal square peg in a round hole. Four years ago, the then 17 year-old with a severe learning disability was no longer able to attend his local special school, was sectioned and placed in an assessment unit for six months. He was often restrained by a four-strong staff team 15 times a day. His daily diet consisted of nothing but crisps. A habitual self-harmer, on a good day he might anxiously tear bits of paper into shreds instead of cutting himself or lashing out at someone else. On a bad day, he was a risk not only to himself, but to his family.


MacIntyre offers a personalised approach thanks to a successful relationship with commissioners.

Pic: MacIntyre

There was no existing provision in Oxfordshire where Joe's family lived; common consensus would have dictated that the only option left to Oxfordshire county council, which is responsible for his care, was intensive support in an out of county institutional setting.

That was until the council's creative-thinking commissioners explored a flexible, bespoke programme with MacIntyre, who provide care and education services for children and adults with a learning disability. The charity supports around 900 children and adults, at 120 services across the UK including registered care homes, supported living schemes, lifelong learning facilities, residential special schools, a further education college and a range of community-based learning programmes.

MacIntyre supports Joe through its No Limits scheme. No Limits, aimed at post-16 year olds with severe learning difficulties and severe behavioural, emotional and social difficulties, provides a personalised learning programme delivered in the the young person's own community. The programme is transforming Joe's life.

Now, 20-years-old, Joe lives in supported housing in Oxfordshire. He eats healthily and has coping strategies to manage his anxiety. He has a "tear box" full of leaflets, for example, should he want to resort to his old habit of ripping paper. As Joe's life becomes more stable, the initial £238,000-a-year support costs have reduced to £100,000. Best of all, he is rebuilding his relationship with his family.

"Joe lives a full life," says MacIntyre's Natalie Macpherson, head of No Limits. "He feels more in control of how he lives." One landmark moment was when Joe and his family went out for a walk on their own for the first time.

MacIntyre's multidisciplinary approach involves social services, education and health professionals along with Joe's family in an intensive learning and support plan. The tailor-made plan includes encouraging Joe to learn through his interests, a focus on developing family relationships and risk assessed trips to local shops, for example. Depending on need, No Limits can include round-the-clock support or a few hours a day. Care is delivered either at the family home or, as in Joe's case, in supported accommodation.

Janet Johnson, Oxfordshire's strategic lead for special educational needs and learning disability, adds that provider flexibility is key: "Most providers offer limited options, for example 38 or 52 week placements with price fixing at the beginning of the contract, No Limits is bespoke to the young person and family's needs, with the level of support and costs reviewed regularly". The other essential ingredient is localised provision, "parents do not want their child to be placed in a residential institutions along way from home and the local authority is able to make sure that the young person is kept safe".

Macpherson and Johnson stress that the relationship between provider and local authority is vital. This takes time and involves partners in education, social care, health and adult services.

Macpherson explains: "You've got to find the right person in the local authority to speak to, someone who shares the same values and creativity." Oxfordshire and MacIntyre share what Macpherson describes as a transparent, open and honest partnership: "If there's something we think we cannot do, we will say. If something is too expensive, Oxfordshire will want to see if we can reduce costs. It's about the best way to ensure an affordable package that meets young people's needs."

The fact that the council and primary care trust operate a pooled budget system – putting funding into a central pot instead of operating in financial silos – is equally important. Macpherson explains: "Pooled budgets mean everyone is around the same table - the money is being spent together, in the most effective way to meet the young person's needs."

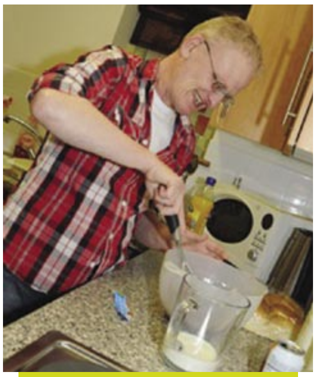
Macpherson adds that to replicate the MacIntyre-Oxfordshire partnership, it is vital to come to the table with workable solutions. "Identify the areas of need and be innovative, above all be solution-focused," she says. "The biggest reward is seeing people thrive and become stable, both the young people and their families."

More information:
www.macintyre.org
www.oxfordshire.gov.uk

MacIntyre
Providing support...your way

Successful transition from residential care to independent living: Affinity Trust

Last Christmas was the first time in 14 years that Alex (not his real name) had spent the festive season with his family. It was also the first time his parents had come to his house for Christmas dinner, the first time the 46-year-old had shopped for the meal, prepared it, laid the table and even chosen the wine.



Affinity Trust supports clients to move from residential to independent living.
Pic: Affinity Trust

The family event and Alex's involvement in it would have been inconceivable just a year before. Back then, Alex, who has a severe learning disability, was living in a care home in Kent, having already spent many years in a long-stay hospital ward. His challenging behaviour ranged from kicking to spitting and usually resulted in him being restrained by four members of staff, one pinning down each of his limbs, for up to 45 minutes.

In July 2009, the local primary care trust, keen to encourage Alex towards more independent living, began working with care provider the Affinity Trust. A painstakingly planned and gradual transition process began, involving six months of supported visits to a potential housing association bungalow not far from Alex's parents' home. Alex visited the property for a few hours with Affinity Trust staff, then ate a meal there, then had overnight stays before moving to the new home in October last year.

The key challenge was making sure that everyone – from Alex's family to commissioners, for example – was signed up to the transition plan "so everyone in that person's life knows what's happening", says Michele Cawley, Affinity Trust operations manager in Kent and Essex.

Affinity Trust carried out detailed risk assessments with the aim of moving away from the restraint-based approach that had dominated Alex's life. A search through Alex's files revealed that the restraining had begun when he had bitten his own hand in one aggressive episode. But while he had never harmed himself again, the restraining had continued on a precautionary basis.

Cawley explains: "We explored what might happen if we didn't restrain Alex and drew up a new approach, one where staff could withdraw – without Alex coming to any harm – and allow him to calm down." Instead of pinning him down, it was agreed that Alex's two-strong support staff team would move to a nearby room. As the aggression was usually directed towards one staff member at a time, the other support worker would use calming techniques such as talking about favourite activities. "Alex began to be able to calm himself down while staff could see he was safe and still talk to him," adds Cawley.

Alex has learned coping mechanisms for his frustration and anxiety. For example, one of his favourite activities is buying CDs and he would get incredibly angry if he could not go CD shopping. Now, says Cawley, he has a planner in his kitchen which sets out future shopping trips. "It's about giving Alex a focus - he can now see when he is planning to buy a new CD, and look forward to it."

The new approach is working – in July Alex got agitated only once. He has support from two staff members every week, including a night worker (although the more settled he becomes, the more he is dropping his lifelong habit of night-time waking). Alex support hours have recently reduced from 210 to 201 and in the future he may only need one support worker.

While his residential care home was a sparse environment with his personal items confined to his bedroom, Alex's bungalow is very much his own. His electric guitar is usually propped against the wall in the front room and his arts and craft projects are displayed on the walls. He regularly invites his parents for dinner and last year he enjoyed a trip to Thorpe Park and a holiday at Alton Towers.

"Alex is part of the community," adds Cawley. "He loves sports so goes to a football session once a week and likes to try and predict how many goals he is going to score on the way there." His social life includes a regular disco night and visits to a local pub that makes him "a knickerbocker glory to die for" says Cawley. He has, she says, raised his aspirations: "He's a fun loving bloke, changing all the time and so different to the person I met almost two years ago."

As for Alex's family, they are rebuilding their relationship with the son who went into institutional care at the age of 14. His older sister, who remembers her parents shutting her in her room to shield her from her sibling's outbursts, is getting to know her brother. Her children, meanwhile, are getting to know their uncle properly.

Alex's parents, both in their 70s, recently told Cawley that their biggest fear was the uncertainty of what would happen to their son when they died. "His mum told me she's finally happy – because she knows her son has his own life now, and she never thought he would."

More information: www.affinitytrust.org

affinitytrust
SUPPORTING PEOPLE WITH LEARNING DISABILITIES

Personalisation and co-production: Deafblind UK

Personalisation and co-production puts the individual at the heart of care delivery. *Pic: DeafblindUK*

Lucy (not her real name) knew she wanted the same freedom of choice as her siblings, both of whom had moved away from the family home in the North East when they went to university. Until two years ago, however, it seemed unlikely that the profoundly deaf young woman, who has cerebral palsy and no discernible speech, would realise her aims. Not only did Lucy lack confidence but her full-time carer mother was anxious about her vulnerability and very protective of her daughter.

Yet today the 24-year-old lives in her own flat a stone's throw from the family home, is on an independent living skills college course and plans to carry out a supported volunteer work placement at the end of her college course next summer.

Lucy's journey towards independence is as a result of the flexible support offered by DeafblindUK, the national charity for people with a combined sight and hearing loss. The charity's approach to Lucy's care combines personalisation – giving more choice and control to the individual – with co-production, where service users collaborate on the design of their service.

Lucy was given an individual budget through her local authority to use to organize her care in a way which suited her. Initially DeafblindUK were approached to provide eight hours weekend support in 2009 whilst Lucy was still at college. Lucy's mum was, as her primary carer, extremely wary about involving "outsiders" in her daughter's care. However, within three months, staff had built up a relationship of trust with the family and when Lucy left college the weekly support increased to 37 hours to increase her opportunities and allow her mum to continue working.

Following Lucy's desire for more independence – and recognising her mother needed some respite – support staff adopted a creative, flexible approach to allow Lucy's mother to "bank" five of the 37 hours a week and save it to use on respite care. Kieran Carr, DeafblindUK director of operations, explains: "We hadn't tried that before, but as part of the co-production approach, we knew it was something both Lucy and her mum wanted. We negotiated how that would work and reached an agreement that suited everyone."

After a couple of respite sessions at weekends, when Lucy's mum had a complete break from her caring duties and Lucy felt more independent of her family, DeafblindUK staff supported Lucy during a weekend stay at an outward bound centre. "It was the first time Lucy had ever been away from her mum," recalls Carr. "That helped us to build trust with both her and her mother; it gave them both the confidence to take the next step."

The next step was something Lucy never thought she would be able to do – she moved into a flat with round-the-clock support. "At the back of Lucy's mum's mind was the worry about who would care for her daughter as she herself got older," says Carr. "The benefit to Lucy of being supported to live independently is that she can lead a more independent life, the benefit to her mum is that she can continue to work full time and is defined by something other than her caring role, and the benefit to them both is that their relationship is much more equitable."

Placing people at the heart of the care process in co-production, adds Carr, means having faith in the ability of people to make decisions about their lives. He explains: "Lucy's mum is obviously a key part of Lucy's life, but it was Lucy herself who wanted to live in her own place. As she did not have capacity to make that decision herself her mum applied for a deputy order from the Court of Protection so she could make it on her behalf [the Court of Protection is a specialist court for all issues relating to people who lack capacity to make specific decisions]. We had to have faith that decision could work."

From an organisational point of view, adds Carr, it means centrally-based managers empower their local teams to work with individual clients to create a truly personalised service. There is also a need for creativity in care so care providers think beyond rigid time structures as the traditional approach often allocates set hours on set days in a one-size-fits all service.

Carr says Lucy's mum recently described the change in Lucy's situation as "miraculous": "She said she really likes fact that their relationship feels more equal and she pops round to visit her just like any mother would a grown-up child." And what does co-production mean for Lucy? "It means that even with support around her, she has more independence than before and, crucially, she sees herself as equal to her siblings and peers, which is what she's always wanted."

More information:
www.deafblind.org.uk

DEAFBLIND
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Regional and local leadership, networking and promoting good practice: North West Network and the Salford Provider Forum

How far will £125 go in social and health care? It goes a long way if you happen to be a health or social care professional in the North West of England who values sharing good practice.

Three years ago, the North West secure commissioning team provided £3,000 of funding equivalent to £125 from each 24 primary care trusts in the region. The funding was donated to set up a new network promoting a different approach to learning disability care. The combined £3,000 funding and ongoing support from commissioners and the NWTDT (North West Training and Development Team, a training and consultancy organisation supporting children, adults with disabilities, families, statutory and support organisations) resulted in the North West Positive Behaviour Support (PBS) Network, a membership body of 70 organisations advocating a proactive response to challenging behaviour, rather than physical restraint.

The positive behaviour approach places the individual at the heart of the care, encouraging professionals to look at what triggers challenging behaviour rather than simply focusing on how to stop that behaviour. The network's aim is to embed the ethos into all learning disability services in the North West and its remit now includes training and setting training standards to ensure consistency among the area's care providers.

"PBS looks at people's quality of life and a proactive response to challenging behaviour," says Dave Williams, a learning disability nurse specialist who chairs the network. "It's better than using a highly restrictive approach with excessive medication and restraint; it's values-based."

Members come from children and adult services, nursing, psychology, psychiatry, speech and language and occupational therapy. There are statutory and independent sector providers on board, all 24 PCTs and all local authorities.

The Winterbourne View scandal has made the network's aims more relevant than ever, exposing the need for staff to have high quality training, not only to ensure individuals' safety, but make sure that those cared for are supported without physical interventions.

The group hosts two conferences a year at Lancashire's Edge Hill University, which has become an important link in the network. The events allow good practice to be shared and enable providers to hear from parents of those with learning disabilities as well as from those with disabilities themselves. In addition, the network is exploring the possibility of developing a module on the university's Behaviour Analysis and Intervention degree and masters courses, which would further incorporate the positive behaviour approach.

Other developments include a three-day managers course, which allows participants to hear from individuals affected by bad practice and physical restraint. Williams adds: "It's powerful to hear from someone who has been affected by bad practice such as staff allowing 'punishments' to be meted out by fellow service users, or being given less food if they 'misbehave'."

There is also training for families with a half-day course to help carers demystify the professional jargon they might come across, for example. "It also helps with some practical support," says Williams, "like how to understand the messages behind the behaviour - excessive hand flapping or self-harming – and how to reduce the frequency of those behaviours."

The network has also drawn up some training standards and encourages members to send in their training packages to see how they measure up. While not an accreditation, Williams says that it does throw down the gauntlet for high standards and consistent training.

The biggest challenge in establishing this kind of network, says Williams, is to agree a common direction: "Be clear about what your goals are, what it is you can and cannot do – we cannot work with individuals or find placements, for example, we're about sharing good practice and keeping people up to date."

A focus on positive behaviour support, adds Williams, would mean that those with leaning disabilities would live in less restrictive environments and access community facilities. "They'd require less use of expensive secure beds or expensive out of area placements, which saves local and regional commissioners money," says Williams. "Individuals would have a better quality of life." Without it, he adds, "it is likely the number of individuals with challenging behaviour will continue to live in restrictive environments, with support plans that provide limited access to ordinary community facilities, which in turn requires high levels of funding."

Williams agues that the network-based approach can embed the positive strategy across entire regions: “It’s a fantastic opportunity for improving the lives of those with learning disabilities across an entire area - we should all be striving for that. Positive behaviour support should be second nature – for families, for providers and for commissioners.”

More information: dave.williams@salford.gov.uk

Positive
Behaviour
Support

NW PBS Network

Local leadership: Salford Providers Forum

Salford Providers Forum has been held on a bi-monthly basis for the last 10 years. It was set up following the launch of the Learning Disability Partnership Board as a way of ensuring that all providers in Salford were involved in service delivery and development in a positive way.

The forum, consisting of 15 organisations, provides a platform for exchanging information on local, regional and national developments. It also ensures any Salford response to national policy has input from all providers, not just the local authority and is used to share information about staff training.

Without the group, say its members, information would not be delivered in a consistent way, learning disability services would feel more disjointed and sharing good practice between providers would be harder to facilitate. The opportunity for providers and commissioners to meet in a proactive way, for example, would be lost.

For more information: www.salford.gov.uk

Specialist support and a person-centered approach: The National Autistic Society

Articulate and with a vast vocabulary at his disposal, Steve (not his real name) could use some persuasive language in an argument. Unfortunately, his Asperger syndrome and his size and strength also meant that his defiant words were usually accompanied by physical outbursts.

Ever since he was a child, Steve would bite, kick and punch. Even if staff at his residential special school in the South West of England felt that restraining him seemed excessive, his challenging, destructive and unpredictable behaviour left little choice.

Specialist support and person-centred care helps individuals live their lives to the full.
Pic: The National Autistic Society

Unable to absorb and process information, to predict outcomes or to follow instructions or requests, he was confused and anxious. Throughout his school life, his staffing ratio was three to one, though at crisis points this would be increased to four to one.

However, thanks to very specialist support in the residential care placement he moved to eight years ago at the age of 19-years-old, Steve's staffing level dropped to one to one. He has a qualification in retail and now lives in supported housing in the community. The National Autistic Society's Prospect House in Lancashire, which specializes in caring for adults with autism and Asperger syndrome, has transformed Steve's life.

The transition to Prospect House was gradual, ensuring Steve was aware of the change and prepared for it. A rigorous assessment process ensured staff could help his development and after day visits as well as longer overnight stays, he moved in.

During Steve's first year, staff worked on his lack of spatial and social awareness and encouraged him to understand the impact of his physical outbursts and manage them. Prospect House manager Amanda Ponton explains: "It was essential that before his arrival all risks were identified and positive behavioural support plans [which look at what triggers behaviour, instead of simply trying to stop the behaviour] were in place as well as a structured developmental programme. Steve responded well to our structured and low-key environment."

Support workers encouraged Steve to follow his interests and supported him to start a work placement focusing on his interest in football. This led to a voluntary job at Accrington Stanley Football Club as a post-game cleaner, and he developed such good working relationships with the owner and crew that he was offered complimentary tickets to all home games.

Steve then completed some coaching qualifications while coaching at children's football clubs during school holidays and got a second job at a charity shop, first sorting through donations then operating the tills and stock. By the third year he began to venture out more into the community.

Staff began seeing huge changes in his behaviour and aspirations, Ponton adds: "Getting out and about in the community was a massive achievement - and one that he managed with not one noted issue or incident." A cash exchange store employed Steve part-time, initially he helped manage stock but soon he was operating the tills and completed an NVQ award in retail.

Four years after moving to Prospect House, Steve was ready for transition into supported living. At the end of June 2007 he moved into a local housing association supporting living complex. As well as a member of staff on 24-hour duty between the three flats, Steve had one to one support for certain activities, with 72 hours a week funding for extra support. It speaks volumes that he now has only four hours a day extra funding.

Ponton explains: "What's really helped Steve is our very structured, consistent and predictable approach, and that, combined with person-centred planning that puts the individual at the heart of their own care and involves them in decision-making, has changed Steve's life. The approach means using someone's interests – like Steve's love of football, for example - to access services in community."

Now, says Ponton, when she sees Steve he will not only give her a run down of his latest achievements, but might tell a joke. "He also has the confidence to challenge things he is not happy with – but not with physical force. The other day I heard him say he was unhappy because the communal area in the flats wasn't available, and I look back and think 'this is the same man who would come in and slap you'. He has recognised that he is important and that people around him value him."

Key to Steve's development has been the very specialist support that the National Autistic Society has given him. "What frustrates me is that even now people with autism and Aspergers do not fit neatly into general learning disability or mental health services; there should be special approach with autism." As Ponton says, people with autism wrongly spend months on mental health wards because they do not respond to regime or treatment – what they need is specialist autism services.

"Unless you speak the language of autism, then you might as well be standing in front of someone speaking French," argues Ponton. "You have to understand how someone with autism communicates and see the world through their eyes to support them; if you don't, it's just like denying someone an interpreter."

More information:
www.autism.org.uk

The National Autistic Society

Conclusion: key elements for successful outcomes

Despite unprecedented funding pressures and the challenges thrown up by the shocking lapses in standards at the Winterbourne View residential care unit in Bristol earlier this year, the vast majority of us working in social care create positive outcomes for service users.

This report provides a glimpse of remarkable and inspiring practice and is a timely reminder that the social care sector can be an enormous force for good. It is possible to treat service users as equal partners in care delivery while creating cost-effective and innovative solutions for commissioners.

While this report is by no means an exhaustive list of the elements needed to deliver successful outcomes, several key themes emerge:

- **Working together and leadership:** the need for commissioners and providers to work together to build an honest and trusting relationship with personalised service delivery at its heart (see MacIntyre case study page 9)
- **Integrated solutions:** the value of using a pooled budget system to complement the person-centered approach, with partners sharing a central pot instead of operating in financial silos (see MacIntyre case study page 9)
- **Planning:** the importance and long-term value of developing tailor-made, detailed and gradual transition plans, involving the entire family and supporting individuals as they move towards independent living (see Affinity Trust case study, page 10)
- **Putting people and families at the centre:** the vital role of co-production and personalisation – a two-pronged approach that involves individuals collaborating on and helping shape their support and having choice and control (see DeadblindUK case study, page 11)
- **Networking:** the benefits of local leadership, professional networking and promoting good practice (see North West Network and the Salford Provider Forum case study, pages 12-13)
- **Sharing good practice:** the need to share training standards, ensuring consistency in the provision and quality of care (see North West Network and the Salford Provider Forum case study, pages 12-13)
- **Positive behavioural support and skillful communication:** the recognition that certain complex needs require a person-centered method and support from highly specialised professionals trained in specific conditions. A positive behavioural support approach looks at what triggers challenging behaviour, and not just on stopping such behaviour (see North West Network and National Autistic Society case studies, page14)

As this report proves, a strong value driven relationship between provider and commissioner allows for the design of cost-effective, high quality support. The commissioner spends less and does the right thing. The provider wins the opportunity to put their values into action. The individual achieves outcomes that enrich their life and wellbeing. This is a win-win-win situation.

Replicating the practice contained in this report requires not only confident, strong leadership, but a change in organisational culture so providers and commissioners look afresh at what works and what does not. A change in culture is more crucial than ever, given the financial cutbacks we face. The Making it Real markers of progress describe a number of key themes and criteria endorsed by VODG, which offer an effective framework, for thinking about cultural change[12]. Cultural change is achieved by keeping the triangle of support (the critical relationship between commissioner, provider and the service user and his or her family) in balance and using co-production to achieve personalised support. It also means using social capital – mutually supportive local networks - to care for people and create solutions that benefit not whole families but the wider community.

> *"A true person-centred approach to designing and delivering support and care is a shift away from the traditional one size fits all methodology, and draws on input from all those who know the person well."*
>
> Viv Cooper, founder of the parent-led Challenging Behaviour Foundation.

If we are to lead by example, then our good practice must be more widely disseminated. While we cannot deny the existence of substandard pockets of care, allowing the malpractice to overshadow successful outcomes does a disservice not only to frontline staff, but to the inspiring individuals whose lives they are helping transform.

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[12] Think Local, Act Personal: Making it Real - Marking Progress towards personalised, community-based support. www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/TLAP/MakingItReal.pdf

APPENDIX A:

participating organisations and case studies

MacIntyre

MacIntyre provides learning, support and care for more than 900 children and adults with learning disabilities, at more than 120 MacIntyre services across the UK. The diverse range of services includes registered care homes, supported living schemes, accredited training schemes and lifelong learning services, as well as residential special schools and a further education college.

www.macintyrecharity.org

Affinity Trust

Affinity Trust offers high quality support to 650 adults with learning disabilities throughout England and Scotland. The organisation helps individuals live as independently as possible by providing tailored support to meet their aspirations and goals in life.

www.affinitytrust.org

DeafblindUK

DeafblindUK is a national charity offering specialist services and human support to deafblind people and those who have progressive sight and hearing loss acquired throughout their lives.

www.deafblind.org.uk

NWPBS

A membership body of 70 organisations advocating a proactive response to challenging behaviour, rather than physical restraint. The positive behaviour approach places the individual at the heart of the care.

dave.williams@salford.gov.uk

National Autistic Society

The society is for people with autism (including Asperger syndrome) and their families. It provides information, support and pioneering services and campaigns for a better world for people with autism.

www.autism.org.uk

With special thanks to Mencap for general support with case study information
www.mencap.org.uk

For further information about any of the case studies mentioned this report please contact - info@vodg.org.uk

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APPENDIX B: references and sources used in this report

- National Forum for People with Learning Disabilities www.nationalforum.co.uk
- BBC News “Four arrests after patient abuse caught on film” www.bbc.co.uk/news/uk-13548222
- Guardian newspaper “Care home firm at heart of abuse allegations closes third unit” www.guardian.co.uk/society/2011/aug/17/castlebeck-care-homes-close-unit
- Care Quality Commission “CQC calls on Castlebeck to make root and branch improvements” www.cqc.org.uk/newsandevents/pressreleases.cfm?cit_id=37478&FAArea1=customWidgets.content_view_1&usecache=false
- Guardian/VODG roundtable event “Beyond Winterbourne” www.vodg.org.uk/cgblog/19/105/Beyond-Winterbourne-a-blueprint-for-success-in-social-care.html
- Think Local Act Personal (TLAP) www.thinklocalactpersonal.org.uk
- Community Care magazine “Expert guide to personalisation” www.communitycare.co.uk/Articles/2011/08/19/109083/personalisation.htm
- Social Care Institute for Excellence co-production briefing www.scie.org.uk/publications/briefings/briefing31
- Challenging Behaviour Foundation www.thecbf.org.uk/
- Putting People First Department of Health guidance www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118
- Dilnot Commission on Funding of Care and Support www.dilnotcommission.dh.gov.uk
- Law Commission report on Adult Social Care www.justice.gov.uk/lawcommission/publications/1460.htm
- VODG Gain Without Pain report on how the voluntary sector can save time and money www.vodg.org.uk/resources/vodg-publications.html

APPENDIX C:
list of VODG members

Action on Hearing Loss
Advance
Affinity Trust
ARC
Avenues Trust
Brandon Trust
The British Home
The Camden Society
Camphill Village Trust
Canterbury Oast Trust
Certitude
Choice Support
Crossroads Care
DeafBlind UK
Dimensions
The Disabilities Trust
Elizabeth Fitzroy Support
Enham
Epilepsy Society
Guide Dogs
Guideposts Trust
Hft
Key Ring
Leonard Cheshire Disability
Livability
MacIntyre
Martha Trust
mcch
Mencap
MS Society
The National Autistic Society
NCYPE
Norwood
Outlook Care
Outward
Papworth Trust
QEF
Real Life Options
RCHL
Royal London Society for Blind People
RNIB
Scope
SeeAbility
Self Unlimited
Sense
SignHealth
St. Elizabeth's Centre
Sue Ryder
Thomas Pocklington Trust
Turning Point
Turnstone Support
United Response
Vitalise
VoiceAbility
Walsingham
The Westminster Society
Wired

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