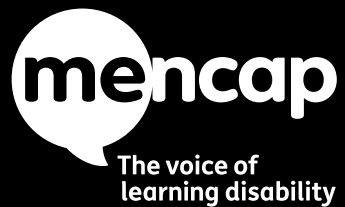




Out of sight

Stopping the neglect and abuse of people with a learning disability



Challenging
BEHAVIOUR
foundation



making a difference
to the lives of people with
severe learning disabilities





This report is dedicated to the late Professor Jim Mansell CBE, who was a powerful champion for people with a learning disability whose behaviour is described as challenging. He dedicated his working life to improving the support and services they and their families receive, to drive up standards and to ensure better lives and opportunities. His work and influence will continue.

“At the moment, we are spending large amounts of money putting people in places like Winterbourne View – very expensive services that are harming people. There is no doubt we need to take action to stop these kinds of services being used in this way as dumping grounds.”¹

Professor Jim Mansell CBE, *Everybody Matters* film



Contents

Page	
7	Actions needed
8	Introduction
11	Winterbourne exposed
14	Real people, real lives
22	Why are people sent to assessment and treatment units and other institutional settings far away from home?
30	At the assessment and treatment unit
43	Questions raised by these stories
44	What does good support look like?
48	Winterbourne – never again?
50	Time to take action

The care system is failing people with a learning disability and behaviour that challenges.

This report by Mencap and the Challenging Behaviour Foundation says **enough is enough**.

The way we support people with a learning disability and behaviour that challenges must change.

Actions needed:

- The government must show strong leadership and clearly set out what each player in the health and social care system is expected to do within an agreed timescale. It must also say who is accountable for the different parts of an action plan.
- The government must start a closure programme of all large assessment and treatment units to be completed in three years and ensure that smaller, local assessment and treatment units are integrated with local services.
- The government must tell commissioners to develop local services that meet the needs of children and adults with a learning disability and behaviour that challenges, including community-based intensive support services. There must be no excuse for sending vulnerable people far away.
- The government must carry out an urgent review to ensure that funding arrangements do not work against the incentive to get people out of assessment and treatment units and that 'economies of scale' don't force the continued development of larger units.
- The government must ensure that the Care Quality Commission (CQC) has the power to only register services that are in line with the policy recommendations in the Mansell reports.
- The CQC must conduct rigorous inspections, involving people with a learning disability and their families, and not shy away from taking action to deregister, or enforce their recommendations.
- The government must strengthen the law on adult safeguarding to keep people safe from abuse and ensure that rigorous action is taken against abusers and responsible organisations when abuse occurs.
- Commissioners must make sure that providers of care and support demonstrate that they are capable of meeting the needs of people who show behaviour that challenges and that they can provide the right environment and skilled staff.



Simon

“Simon spent 15 long months at Winterbourne View. We now know that during that time he was hit, pushed, abused and tormented. Can you imagine the horror I felt when the *Panorama* team showed us what was happening to my son?

“What Simon needed was more support in the residential care home where he lived – certainly not to end up in a place like that. Social services wouldn’t provide the funding for a few extra hours a day for the care he needed. So things got worse for Simon, and he was sent to an assessment unit. From there he was sectioned and removed to Winterbourne View.

“We tried so hard to stop them taking him there, but we were stripped of our role as parents and sidelined while those in ‘authority’ made the decisions for us. They used their power to just ship him off, sending him many miles away from home – away from the people who love him, too far from us to protect him from the terrible things that happened.

“You’ve seen what happened to our son. Please help to stop this – we must end the scandal of sending people like Simon to places where they are out of sight and out of mind, because we know what can and does happen.” **Simon’s mum**

Introduction

This was abuse at its worst. It happened to Simon in a country that prides itself on its history of human rights, and it was paid for by the NHS.

When the BBC’s *Panorama* exposed the appalling abuse going on at Winterbourne View – an assessment and treatment unit for people with a learning disability – a wave of public outrage followed.

The public may have been shocked to know that some of our most vulnerable citizens were being systematically abused, but many professionals were not. After all, this was yet another scandal about people with a learning disability to follow those exposed in Cornwall and in Sutton and Merton.

Cornwall, 2006

Care homes scandal: Abused.
Bullied. Confined. Drugged.

The Independent, 5 July 2006

‘Vulnerable people suffering from such conditions as autism and cerebral palsy endured years of bullying, harassment and physical ill-treatment at the hands of NHS staff, the inquiry into services in Cornwall found.’

‘The Health Secretary, Patricia Hewitt, says steps are being taken to ensure it does not happen again: “The abuse that’s been uncovered of people with learning disabilities is an absolute disgrace. It is completely unacceptable. The Trust has already taken steps to put things right in Cornwall, now we’ve got to learn lessons from that and make sure this does not happen again to other vulnerable people.”’

Sutton and Merton, 2007

Catalogue of abuse in NHS
care homes

the Guardian, 17 January 2007

‘People with learning disabilities had been subjected to physical and sexual abuse at a hospital in London, according to an investigation by the Healthcare Commission.’

‘The commission is launching an audit of learning disability services across England and will inspect 200 of them.’

These terrible events could not have been a surprise to the Department of Health, which had been warned in two reports by Professor Jim Mansell² of the serious consequences for people who show behaviour that challenges³ when they are sent to assessment and treatment units and other types of institutional setting that are far away from home.

The horror portrayed on our TV screens about Winterbourne was certainly not a surprise to many families with sons and daughters in similar units across the country. But for other families, it was utterly terrifying.

“I watched this shocking programme, through my hands in some parts, and switched off in tears when it got to the most disturbing part – a vulnerable young woman left shivering outside on the ground after being repeatedly doused in cold water by her so-called ‘carers’. My daughter Chrissy is in a privately run hospital like the one investigated last night.” **Chrissy’s mum**

This report tells the stories of **James, Chrissy, Joe, Emmanuel** and **Victoria**. Each section tells a part of their stories through the words of their families. You will hear about their experiences of not getting the right care locally, how they ended up in assessment and treatment units, what happened to them there and where they are now.

Through their stories, this report shows how providers, commissioners, regulators and the Department of Health have failed to act on the substantial amount of available guidance. It shows how they have allowed the care system to fail its most vulnerable people by not developing good quality local services for people with a learning disability and behaviour that challenges.

Mencap and the Challenging Behaviour Foundation (CBF) hope that this report inspires everyone involved in the care and support of people with a learning disability and behaviour that challenges to help demand action that will stop people being sent away.

These stories confirm the need for real and lasting change. We must stop allowing people to be so far out of sight that what happened at Winterbourne goes on happening to others again and again.

Winterbourne exposed



Terry Bryan was the member of staff who blew the whistle on Winterbourne. Here he explains why he did so:

“I blew the whistle because I had seen bad practice and poor attitudes, staff ignoring people when they were distressed and the threats – staff saying, ‘If you don’t stop banging your head against the wall then you won’t see your mum at the weekend’. I started recording what I saw and then wrote the email. It was quite low-level stuff, but it was enough to get people suspended.

“It took a secret camera to expose the scale of abuse going on. They wouldn’t have done what they were doing in front of me, as they said I was a ‘do-gooder’. As I watched the programme, I couldn’t believe what I was witnessing. I thought it would just be more of the low-level stuff I had seen. I didn’t think it would be that extreme.

“It was like a perfect storm – it wasn’t just one thing. Commissioners were happy to

send someone to a place like that. The management was inept. The training was sub-standard. They recruited strong-armed people, not caring people. The staff weren’t paid enough. There was no supervision. When the safeguarding team were alerted, they didn’t act. When I alerted CQC, they didn’t act. What else do you do?

“If people want to abuse someone, they will. They will do it behind closed doors. Generally, you can’t stop it. But when they do it in front of someone like a nurse, and the nurse doesn’t do anything about it, that’s the worry. That’s when it has become routine. That’s when it has become part of the culture and it self-perpetuates. New staff come in and that is what they learn.”

Whistle-blower at centre of ‘barbaric’ care home abuse exposé raised alarm last year – but was ignored by regulator

The Daily Mail, 1 June 2011

‘One member of staff trapped patients under chairs while he sat on them watching television. A female patient had shower gel squirted in her eyes and was left in a freezing garden after having a jug of cold water poured over her.’

‘Care services minister Paul Burstow said he was shocked by the revelations and had authorised a series of random, unannounced inspections of similar units by the Care Quality Commission (CQC).’

The role of the CQC and others

The CQC, charged with ensuring that these facilities are up to standard, has been strongly criticised for failing to act on the information it had been given. There was also great concern when it emerged that the CQC had inspected Winterbourne View prior to the *Panorama* programme and concluded that the service met its standards.

When we looked at the CQC inspection reports for the services where the people featured in this report resided, we were very concerned to see that, like at Winterbourne View, most of these units had been found to be compliant, but the actual experiences of those in the units tell a very different story.

While the 150 CQC inspections conducted after the events at Winterbourne appear to have been much more rigorous than previous inspections, building confidence in the CQC and its ability to detect and act robustly on abuse, neglect and poor practice will take a long time. This is not helped by the bland words used in its reports, such as ‘non-

compliance’ and ‘failing to meet essential standards’, which betray the seriousness of what this could mean. Hidden behind these words are stories of abuse, neglect and appalling care – of loved family members whose lives have been irrevocably damaged.

But simply to blame the CQC for not identifying and acting on abuse and poor practice lets everyone else off the hook. Commissioners and providers need to be delivering appropriate local support and services. They have a key role to play, both in developing a positive culture, where staff have the right skills and attitudes, and in monitoring their services on an ongoing basis. It should never get to the stage where abuse and poor practice are allowed to become embedded. Responsibility extends beyond the role of the CQC.

The scale of the problem

It would be wrong to believe that what happened to Simon and all the other people who lived at Winterbourne View was isolated or confined to one provider, or even one type of provider. In the months that have followed these appalling revelations of abuse, the CQC has investigated all similar units and a number of social care residential services across the country. What it found was shocking:

- **50% of the services were not only failing to meet standards around care and welfare, but also failing to meet standards around protecting people from abuse.**

A review of this CQC data⁴ showed that:

- **only 14% of people residing in the 72 inspected units were in places that fully complied with the standards inspected.**

The CQC inspections confirm that poor practice and putting people at risk of abuse is widespread.

The government review

Chillingly, Terry's account reveals that when he blew the whistle, it was on what he describes as the "low-level stuff". It goes on to describe how shocked he was to see what the secret cameras revealed. While some levels of abuse and neglect can be easier to identify and prevent, others are more hidden.

This presents a serious challenge to everyone involved in the commissioning, regulation and provision of care and support of people with a learning disability and behaviour that challenges. There are three crucial questions to consider:

- 1. Are we developing the right support and services?**
- 2. What rigorous practices and processes must we put in place to ensure that the risk of poor practice and abuse is minimised?**
- 3. How can we effectively identify and deal with it when it does exist?**

Clearly no one can be complacent – no one can afford to say "it never happens here".

There can be no question that there are widespread systemic failures in the care and support of people who show behaviour that challenges.

It is over one year since the events at Winterbourne were exposed and a series of investigations and reviews has been conducted. The CQC has now published its report on its inspection programme, and the government has released its interim report, which sets out the actions it believes are needed to address failures across all parts of the system.

All the reports agree that far too many people are being sent away, to assessment and treatment units and other institutional settings, and that they must be better protected and supported. There is no doubt that the government's final report will also set out the lessons learned and how practice needs to improve.

But will it just join the list of reports that have come before, each one barely gathering dust before the next scandal of abuse hits

the headlines? The fact is that well-meaning policy statements are simply not enough⁵. The government must accept responsibility, take leadership and use all the levers at its disposal to achieve the fundamental changes that are needed. Otherwise, the sort of abuse seen at Winterbourne View, Cornwall, and Sutton and Merton will continue indefinitely.

The ultimate test of the government's final recommendations is whether it will take the necessary steps to improve the lives of people like those in this report: James, Chrissy, Joe, Emmanuel and Victoria.

Real people, real lives

In this report, families whose loved ones have experienced poor care, neglect and abuse in all parts of the system tell their stories. They are just a few of the many that could be told. They show how the system fails to properly support and protect those who show behaviour that challenges.

Who are they?

People who show behaviour that challenges

Each person in this report has the same needs and feelings as anyone else. They are someone's son, daughter, brother or sister. They each have a learning disability, and they are also described as showing behaviour that challenges. It is important to understand what this means:

*'Behaviour can be described as challenging when it is 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.'*¹⁶

Behaviours that challenge can include aggression (eg hitting, kicking, biting), destruction (eg ripping clothes, breaking windows, throwing objects), self-injury (eg head banging, self-biting, skin picking) and many other behaviours. When the behaviour puts the safety of the person or others in some jeopardy, or has a significant impact on the

person's or other people's quality of life, those who care and support them may find it very difficult to cope and respond appropriately.

For example, someone with a severe learning disability and very limited communication skills may not be able to tell others that they have a sore ear, that they are thirsty or that someone has hit them and they are afraid. If they are not cared for by people who know how to support them, this is when the behaviour that challenges can be triggered or worsened.

We know that when people are living in an environment with staff who have the skills to support their behaviour and communication needs, their behaviour that challenges can often be reduced or eliminated altogether.

People who may need assessment and support

Individuals sometimes experience crisis situations that may require specialist intervention. At these times, what is needed is a good assessment of the cause of the problem, followed by a treatment plan to address those issues and access to good support that is close to home.

It should rarely be necessary to admit a person to an assessment and treatment unit. When it is necessary (for instance, when someone may have a complex mental health condition), it should be to a small unit that is close to their home. The facility should be able to provide specialist assessment and treatment, and enable the person to return to their local community as soon as possible.

A very small number of people with a learning disability need secure forensic services, such as those who have committed a serious offence like arson or sexual assault. Mencap and CBF's background policy paper⁷ explains this in more detail.

Many people are admitted to assessment and treatment units, and then detained under a section of the Mental Health Act 1983 (MHA). This is sometimes referred to as 'being sectioned' or 'sectioning'. While this may sometimes be necessary, there are concerns that detention under the MHA is being used too frequently, often in circumstances where it is perceived as the last option, where local services have broken down and there is no other alternative.

Too many people are being sent away to assessment and treatment units and other institutional settings that are too large and too far from home. Sometimes, these units do not actually provide the quality of specialist assessment and treatment services that is needed. Often, people with a learning disability end up in these places unnecessarily, because the right option for them is not available locally or because local services do not possess the skills to understand the cause of their behaviour.

All too often, these extremely expensive units, some run by the NHS and many others by the private healthcare sector, are simply being used as dumping grounds by commissioners looking for an easy 'solution' at any cost. As a result, people can be sent many miles away from home and then left for many years without any prospect of leaving.

None of the people in this report (or the hundreds of others like them) should have been sent to places where they were out of the reach of their families and where they were not only denied the help they needed, but also neglected and abused.

People at risk of abuse

People with a learning disability are known to be at greater risk of abuse than the general population. Despite the fact that those who show behaviour that challenges are viewed as being at an even greater risk of abuse, there has been surprisingly little research into just how prevalent this is. However, it is clear that they experience many situations that are abusive.

‘It is completely unacceptable that so many people with learning disabilities in the UK who show ‘challenging behaviour’ are prescribed long-term antipsychotic medication. We know these drugs can have serious side effects. There is little evidence that they help people with challenging behaviour, and we know that many people can be taken off these drugs without adverse effects. For organisations to continue to overprescribe these drugs in light of this evidence should be considered an example of systemic or institutional abuse.’ **Statement by Professor Eric Emerson**

The people in this report, like so many others who show behaviour that challenges, did not have their basic health and social care needs met. They experienced the overuse of medication, excessive use of restraint and seclusion, and were physically harmed by other service users and staff.

Here, in an article on restrictive physical interventions and people with a learning disability, the experience of service users in institutions are described:

‘Individuals spoke about staff using a range of punishments including seclusion; withdrawal of food and drink; physical punishments such as hitting or pulling hair; mechanical restraints; and other abusive practices such as cold or dirty baths and the forced wearing of nightwear all day.’⁹

People in this report

The first section of the report introduces James, Chrissy, Joe, Emmanuel and Victoria – each a member of a loving family and each with an important story to tell.

‘You squeal and squeal but they just hold you down’⁸



James

James experienced many years of abuse and neglect while living in places that were not right for him. It reached crisis point, and he was sent to the unit he is at now, where he has been seriously abused by other residents.

When our much-loved son James was a little boy, he struggled to understand the world around him and was unable to communicate with others. But all who knew him liked him, and some even came to love him. When a support worker at his school was about to move to a new job, she said to him: “James, I love you.” James, who normally never speaks, replied: “I love you.”

As a child, he was extremely hyperactive and managed to survive on just a few hours’ sleep each night. The slightest thing could make him very angry. He expressed this in destructive behaviour, but he never once sought to hurt another person. He really enjoyed physical activity and music, and had a delightful sense of humour. Since James

has a severe learning disability and autism, he mostly communicates through his body language and behaviour.

James is now 38 years old. His distress and behaviour has grown worse over the years because of everything he has been through. He now finds a lot of situations challenging and his behaviour will reflect this. As a result of poor care and abuse, his destructive behaviours have become more extreme, and now he will also strike out at people he finds threatening. When things are really bad, he self-injures. Much of his behaviour can be prevented if people support him well.



Chrissy

Deeply worried that Chrissy wasn't getting the right medication and support where she was living, her family welcomed her going into an assessment and treatment unit. But they don't want her to remain there permanently. When she comes out, they want her living in the right place for her, with staff who can support her properly, with the input from medical professionals that she needs.

Chrissy is 28 years old and a much-loved sister and daughter. If you could only see the Chrissy we know and love! She can be a real charmer – full of a sense of fun, someone who enjoys laughing and interacting with others.

She has a moderate to severe learning disability, autism and epilepsy, as well as behaviour that challenges. Since she was a little girl, she has had frequent outbursts where she just won't stop screaming – she'll pull her clothes off and lie on the floor self-injuring. The outbursts can be very intense.

She will gouge at her skin and rip her hair out, causing herself severe injuries. Once she even broke her foot during an outburst. It's very distressing to see her when she is like this, but when she does get the right care and support, things can be very different.

Sadly, Chrissy has not always received the right support, and many difficult things have happened to her because of this. We hope her story helps show how crucial it is to change the way people get support.



Joe

Joe had been successfully living with a friend in supported living, but he became unsettled when the manager and other familiar members of staff left. Nothing was done by social services to change his support despite his family's requests. After an incident, he was detained under the Mental Health Act and sent to a unit 130 miles away from home.

Our son Joe is 36 years old. He's a boisterous person, with a wicked sense of humour. He loves being out and about, and he has a big family who love him to bits.

Being at the unit means he hardly gets to see his three nephews, as they are too young to visit. He misses them and talks about them constantly.

Joe has a severe learning disability and behaviour that challenges. He doesn't use many words.

When communicating with Joe, staff need to listen to him and repeat back to him what

he has said. They must not try to pass it off with saying: "Ok Joe, yes mate," if they don't understand what he is trying to say, as Joe will become frustrated and upset by this, which will lead to incidents happening.



Emmanuel

After leaving school, Emmanuel was sent to a residential care home where they didn't understand his needs. His mother raised concerns, but they failed to put the right support in place. His behaviour worsened, and within six months of leaving school, he was detained under the Mental Health Act and sent to a unit far from home.

My son Emmanuel is 20 years old. He has autism and a severe learning disability, and can show behaviour that challenges if he gets stressed.

Emmanuel has a smile that lights up a whole room when he is happy, and he loves live music. He used to enjoy painting and cooking with me in the school holidays. He also used to love playing football.

Emmanuel went to residential school up until the age of 18. The staff at school did lots over the years to help him build up his skills, but over the last two years, since leaving school and not getting the support

he needs, Emmanuel has lost many skills. He doesn't play football any more, and he finds it difficult to move his feet when we encourage him to try and play.



Victoria

Victoria has spent a large part of her adult life in a range of placements difficult to visit. Frequently, her basic needs have been neglected or not understood and in the last but one unit she suffered abusive restraint. She is now in a residential college where she is being rehabilitated and her family hope that eventually she might be moved to a well run place closer to home.

My daughter Victoria is 41 with a moderate learning disability, autistic tendencies and what is sometimes termed challenging behaviour. A double whammy for Victoria is that she is also deaf. She picked up basic Makaton sign language in ten hours in junior school and when she was in a unit with deaf people using level two British Sign Language (BSL), she understood that too. You would be surprised to know how frequently the staff who have worked with her have no signing skills at all. There is no excuse for this.

We can normally work out why Victoria is cross and displaying challenging behaviour.

If she doesn't know what is going on, she will get very agitated. She picks up on vibes. If someone is apprehensive, it makes her anxious. If her sister comes in dancing and giggling, she will respond well and dance and giggle too.

Victoria is sociable, likes cups of tea and going out for meals. She can be affectionate and funny and can form strong bonds with people. Some staff have been brilliant with her. She is a good judge of character – her approval is a good recommendation. We communicate by signing and talking at the same time. We also write for her. She loves the Muppets and it is a ritual when she comes home, to chill in the evening and watch a Muppet Show.

Why are people sent to assessment and treatment units and other institutional settings far away from home?

The path that took James, Chrissy, Joe, Emmanuel and Victoria so far from home is a complicated one, but their stories have much in common.

Not getting the right support locally

The guidance shows how to successfully support individuals with complex needs¹⁰, but all too often it is not being put into practice.

James's, Emmanuel's and Victoria's families explain what can happen when assessment and support is not available locally.



James

When James left residential special school, there were no assessments or advice from social services. All we were told was that there were no local services or support available.

Eventually, a residential care home was found, but it was some way from his family home. Before long, we found him with untreated injuries and suspected he was being abused. We also suspected he was being locked in his room at night. After we complained, a local inspector of services found there was inadequate heating in the home and the residents were not being properly fed.

James was moved to another care home that was also far away, and still there was no proper assessment of his needs. The home claimed expertise in supporting people with autism, but we saw little evidence of this. James was neglected, and his health issues, such

as an untreated bleeding stomach ulcer, were ignored. They only agreed to take him to the doctor when we threatened to go to the local authority about it.

Crucially, staff didn't know how to manage James's behaviour. It was a vicious circle, where the lack of good support made him more anxious, which then caused his behaviour to get worse. Restriction and restraint became the order of the day. We found out that at one point he had been restrained by five people for 20 minutes until he 'calmed down'. We know how very frightened he would have been by this.



Emmanuel

After leaving school, Emmanuel was moved to a group care home. It was the wrong place for him – no proper assessment had been done and the home just didn't match his needs. Even though I'd suggested he go to a local care home with more experienced staff, social services just wouldn't listen. I think they thought it was too expensive – they wanted a cheaper option.

It became clear after two or three months that the care home wasn't working. The staff weren't used to someone with Emmanuel's needs. I tried to suggest how they could better interact with him, but they didn't listen.

Emmanuel doesn't like big rooms with lots of people in them, but that's where he was spending all of his time. The TV was on all day, and the noise was just too much for him. It was also a 'house rule' that everyone had to eat together

– they didn't understand his autism. To access food he had to be sociable, which he didn't like, so he stopped eating three meals a day. On one occasion, he physically turned the table up. That was him saying he couldn't live like this.

Because the home was so noisy, Emmanuel was spending lots of the day in bed and most of the night awake. The placement was breaking down for the staff and for him. His behaviour was getting worse, and he was repeatedly inflicting injuries on himself. I asked them to move him, but they ignored my request. They said they would bring someone in to assess him. A psychologist did come round, but because Emmanuel was in bed, she never saw him. I asked them to put a behaviour support plan in place and to do a proper assessment of his sensory needs, but none of this took place.

“Other staff left, and the agency staff who came in just didn't know how to engage with him”



Victoria

Victoria has not had an easy ride. Her father died just before her ninth birthday and there was a lot of family stress. She was expelled from the local special school about three years later. She went to a ghastly residential school, a five-hour train journey away. There was no signing whatsoever, but lots of medication. I insisted they take her off medication after the summer holidays before the new Christmas term. They said that her behaviour had deteriorated anyway while on drugs, which shows what a weird illogical attitude exists towards medication and the vulnerable. She was thirteen, lonely and bewildered.

A history of failed placements

The fight for the right support often starts in childhood. An ongoing battle to find the right school, combined with the lack of good support for the family, can mean that the only option is residential school. As the child becomes older, families must struggle to find the right support for them as an adult.

“Every time a placement has broken down, we’ve asked for her to be moved somewhere nearby”

As one emergency leads to another, families become exhausted and frightened for their loved one. As one unsuitable care provider is replaced by the next, they eventually run out of options.



James

When James moved into adult services when he was 19 years old, things went downhill very quickly. Those who know him have seen the way his behaviour has deteriorated. Failed placements, the lack of appropriate support and the abuse he has been subjected to have all made him increasingly angry and frustrated. He has developed a number of challenging behaviours, and he has been labelled aggressive and violent.

James had an awful experience at the first care home he was in, but the second home was just as bad, if not worse. Not only were the staff a huge problem, but James was bullied by other residents. Living with other people who show behaviour that challenges was very damaging for him. It meant he was constantly living in fear and anxiety, and he began to copy other people and develop new challenging behaviours.

Of course, as our concerns grew across the three years he spent there, we asked that he be moved away from another resident who was bullying him – this request was dismissed. Things came to a head when James became extremely anxious – he reached such a distressed state that he had a breakdown and was admitted to an assessment and treatment unit.

On top of the trauma he had endured in previous placements, they found that he had an untreated urinary tract infection. This would have caused him considerable pain. He also had an untreated chest infection. By this time, James had lost a stone in weight, but at last he was getting properly assessed, although it could all have been avoided if he had received proper assessment and support in the first place.

Six months later, James was discharged and sent to another residential care home where

he would spend the next seven years. Again, this was many miles from home. Although there were occasional periods when the management and staff were good, for the majority of the time there was unskilled and inadequate care.

There was also inappropriate behaviour from staff and neglect that amounted to abuse. He was also given medication that was not needed. After our local authority failed to make good on their promise of commissioning a local service, we spent many months searching for an alternative. Eventually things deteriorated so badly for James that we felt we couldn't wait any longer – he had begun self-injuring. We were so concerned that we felt there was no choice but to have him admitted to the specialist learning disability unit where he still lives.



Chrissy

After leaving school, Chrissy moved into a residential care home near us, where the staff were good and understood how to communicate with her. She got lots of attention because it was a new service, and she was the only person there at the beginning. Her medication was working well, and although she still had outbursts, crises were avoided.

But things began to deteriorate. Three other women moved in, and then the service moved to a different location – the new place was much too small. Around the same time, Chrissy had to change medication as tests found her blood count was dropping. The new medication caused her to gain weight and become ‘zombie-like’ – it changed her into a different person. We said: “This just isn’t Chrissy”. The psychiatrist agreed to change her dosage, but they couldn’t get the balance right. It was important

that her neurologist and psychiatrist worked together as the medication affected her seizures, but this didn’t happen. In the end, after an alleged attack on a service user, she was asked to leave the service.

After another placement broke down due to inadequate medical support, it was suggested she go into an assessment and treatment unit. We were supportive of this – we just wanted her to be safe. She was in a terrible state when she arrived at the unit – she had bald patches from pulling her hair out and was covered in bruises and abrasions from self-inflicted wounds.

“Although there were occasional periods when the management and staff were good, for the majority of the time there was unskilled and inadequate care”



Victoria

As Victoria got older, she experienced other residential placements that didn't support her in the way that she needed. She was offered a place at a specialist signing unit closer to home but the offer was withdrawn. So it was decided she would be sent to another unit instead. Her favourite staff at the place where she was were told to trick her in order to get her there. They told her that she was going on holiday. She was taken on a nine-hour journey and left with people who had no signing skills and who had never met her before. This has not helped her sense of security. Imagine how she must have felt.

So many sad things have happened to Victoria. In the various places she has lived, her aggression has been learned; I hope it can be unlearned. When she was at the junior school, the headmistress remarked on how gentle she was. After

about the age of 16, at the respite place where there were no outings and a great deal of bored frustration, she became more aggressive and upset. She started ripping her clothes. There was quite a violent fellow client there – I don't think he hurt her but he could have outbursts that had an effect on Victoria.

Other families will recognise this as what has become an all too familiar story: when local services fail to offer the right support, their loved one is sent to one unsuitable place after another and, step by inevitable step, the family slowly loses control.

“In the various places she has lived, her aggression has been learned; I hope it can be unlearned”

A crisis response

“Sectioning our son was not only inappropriate but also cruel and abusive. He has a learning disability and autism, no language and limited understanding – he would not have understood in any way what was happening to him. He was driven miles away to a totally new place, unlike anywhere he had been before, and left with strangers. He had no contact with us, his own parents, who have been the one constant in his world. It would have been terrifying for him.” **A parent**



Joe

For 18 months, we had been voicing our concerns about the quality of care Joe was getting. In the end, there seemed to be one incident that resulted in Joe being sectioned, which there was just no need for. Joe had been living happily for many years with his friend. His behaviour had got worse, but this was clearly him communicating that he was unsettled and unhappy with the many different staff coming into the house to support him. The change was too much for him, and the staff didn't have the skills.

An inexperienced member of staff was in the house with Joe and this made him anxious. He asked to go in her car. When she said no, he got repetitive and demanding, so she locked herself in the kitchen and rang the manager. Joe was left in the hall and couldn't get into the kitchen. He didn't understand what was happening or why she had done that –

he would have been very confused. The following day, Joe was sectioned. The doctor who came round actually questioned whether it was necessary for Joe to be sectioned as he seemed calm and stable, but the social worker pressed for it. Once he was sectioned, we lost control.

Some families describe the detention of their family member under the Mental Health Act as a sudden and unexpected event. Others suggest that services viewed meeting their son or daughter's needs as too complicated and that admission solved a problem for the service.

People should only be detained under the Mental Health Act when they meet the specific criteria for detention, and families should always be informed of their rights once the person is detained.

But families report they are often uninformed, and that when this happens they feel like they have lost control.



Emmanuel

Three months after I had voiced my concerns and with no proper intervention, Emmanuel was suddenly sectioned and moved to an assessment and treatment unit around two hours' drive away. I first heard about it after he had been admitted to the unit. I had visited him the day before at the care home, and no one had told me this was planned. They had already decided it would happen following an incident about four days prior when Emmanuel had been physically aggressive to a female carer in the garden.

The signs that the placement wasn't working were all there. I had asked them to move him or at least to put the proper support in place – this never happened. Emmanuel, a young man only six months out of school, was then sent to a unit far away from his family where he remained for over 18 months.

The emotional cost of this experience to Emmanuel and us has been huge. The financial cost to the state has also been excessive. I still cannot believe how expensive the unit was.

At the assessment and treatment unit

The stories all show how desperate their families were to get them the right help. Though faced with the prospect of their son or daughter being sent to a unit, often many miles from home, their strong hope was that this admission would be for the best.

“Care and treatment is the last thing they gave her”

Surely a thorough assessment was exactly what was needed? With a treatment plan that would enable much-needed behaviour support to be put into place. Maybe this could be the start of better times ahead? They were right to expect this, and there are many units that provide exactly that.

Certainly for James and Chrissy, their parents initially welcomed them going into the unit.



James

When he arrived there, James was in a very bad state. He was very troubled, withdrawn and had been refusing to eat. He was totally insecure. For the first few months, things went well. And with much work from skilled and caring staff, there were some positive signs of progress.



Chrissy

Chrissy went to an assessment and treatment unit because she wasn't getting the right medication and support she needed in the community. In the end, we were just desperate for her to be safe and hoped that professionals in the unit would get her medication right. We didn't want her to be there long-term – we want her back near us. If she was in a local service where the staff knew what they were doing, then I would feel happy that she was safe, but this has not happened yet.

Getting assessment and treatment in the unit

‘What works best is used least, and what works least is used most.’¹¹

Professor David Allen

Assessment and treatment units report that they can find themselves dealing with issues, such as missed symptoms of physical ill health, that really should have been identified by community services. A psychiatrist from one unit gave an example of someone being admitted with behaviour that had become very challenging, but within hours they found he had six deep cavities in his teeth, causing him extreme pain. Following treatment for this, he was back to his old self.

It is even more concerning that some families report that people are admitted to these settings but not actually assessed or treated.



Chrissy

It hasn't been ideal. The main reason Chrissy went into the unit was to get her medication changed successfully. This seems to be happening, but it took them a year to start doing anything. Initially, she did not get the careful monitoring that we'd hoped for. The way they found out it was better for her to stop taking a particular drug was because they had forgotten to give it to her!

“Initially, she did not get the careful monitoring that we'd hoped for”



Victoria

We have a lot of issues about her medical care. There has been a catalogue of errors, misjudgement and often indifference. Victoria's physical health has continued to deteriorate. There have been ongoing health issues since 2008. Victoria broke her ankle at one placement and we did not think it had healed properly but they said it had. Last November, the current placement took her to A&E and found she had an unhealed fracture in her foot. She also only had the first x-ray on her knee in 2012, despite it being a problem for the last four years. There were a further two separate incidents where she lost two front teeth both times.

We were promised an urgent report by the manager but we didn't receive it and the manager denied saying we could have one. More alarmingly, when Victoria came home at the end of 2010, to our horror, her eye had gone bright green –

we were told this had happened ten days previously. They hadn't bothered to let us know. We now find that she is blind in that eye and we are trying to organise for her to have it operated on.

Being so far from home

For families, leaving their son or daughter in a place so far from home is the first of many challenges they will have to face.

“It's a five-hour round trip”



Joe

Joe was sectioned and sent away to an assessment and treatment unit 130 miles from where we live. It's a five-hour round trip. We agreed to drive him there after he had been sectioned. It was heartbreaking having to leave him there. We visit Joe every other weekend, but in the winter we can't visit because the unit is in a very isolated area and there is too much snow.

It breaks our heart when we've spoken to him on the phone. Sometimes he's been upset and crying, but there was nothing we could do. Joe doesn't understand how far away he is. He doesn't understand that we can't just pop round.

Institutional and poor care

It soon becomes apparent to families that the standard of care may be poor and not person-centred. There is also a risk of the individual losing skills and becoming less independent than they were before.

'The risks associated with congregate, institutionalised services and poor-quality care remain as relevant today as three decades ago'¹²

The CQC programme of inspections of 150 hospitals and care homes for people with a learning disability in 2012 found that many of the services were not meeting essential standards around care and welfare:

'When speaking to staff about two care plans, they agreed that they were not actually accurate.'¹³

'We found that staff were very controlling in their attitude. Examples of this approach included adherence to 'house rules' that were routinely given as explanations about patient's choices, care and treatment, and restriction to food and drink.'¹⁴

'We found the high security environment, noise levels from panic alarms and the two-way radios, and strict adherence to perceived house rules created a highly charged atmosphere.'¹⁵

Inspections often fail to identify the poor quality of care and abuse in assessment and treatment units. When Joe was at the unit, an inspection found the service was fully compliant with all the essential standards of quality and safety: 'People who use this service were viewed as individuals, and their needs for privacy and dignity were respected by staff.'



Joe

It has not been good for Joe being at the unit. It is a real 'institution' with 26 beds. There are set times for things, and everything revolves around set activities. This is the opposite of what Joe was used to. Previously, he was living in his own place with a friend and doing the activities he enjoyed.

Being in the unit has de-skilled Joe. When he lived in his own home, he tidied and vacuumed with the right support. He also made sandwiches for himself. He can't do anything like that now – he's not allowed to.

When we visit Joe, we often find that his clothes have gone missing and he is wearing other people's clothes. He often hasn't had a bath or a shave. Joe needs full support around personal care and choosing his clothes, but he isn't getting this. He used to like looking trendy, but now he doesn't care. It's really upsetting to see.

When we go to see Joe, we always see the same faces – people seem stuck there. We have been fighting to get Joe out since he got there two years ago. We never see any other visitors, so we don't know whether anyone else is fighting for the others. Who's putting pressure on their local authorities and primary care trusts (PCTs) to get them out?



Victoria

With regard to other indignities, Victoria's clothes have frequently been locked up. The first time this happened, it affected her behaviour because she started to throw her clothes on the floor whereas previously she would have put them away. One unit sent her home with a hole all the way through her shoe. We complained to the local authority (LA) and were assured that the manager personally inspected her shoes every morning. Yes, they really did say this. Good job we took a photograph, not to mention we kept the actual shoe! This is trivial compared with some other things but it shows how dismissive the LA was, even when we proved our point. On one visit, we heard a member of staff speak very aggressively to one of the other residents. We raised this, and from then on we were not able to visit her room and could only see her in a family visiting room.

The risk of abuse and neglect

The CQC programme of inspections of 150 hospitals and care homes for people with a learning disability found that many were not meeting essential standards around protecting people from abuse:

*'The patient went on to tell us that they did not have a good relationship with some staff, "Some of the staff are nasty to me, they put fingers up to me. These are male members of staff."'*¹⁶

*'A fourth patient told us, "Staff pretend to be polite when there are visitors."'*¹⁷

“In the unit they were abusing their power, and it is simply barbaric”

Worst of all, families may sometimes start to see a deterioration in behaviour and experience the growing sense that something is not right. Even though their son or daughter can't tell them what is going on, they know that something is wrong. They

may start to notice things such as a strange bruise on their loved one's face. They talk to staff, who just say that the person is clumsy and it's nothing to worry about. But they know that something is badly wrong.

A CQC inspection undertaken in 2010 found that James's service was compliant with the essential standard around safeguarding. This would have been around the same time that James was being assaulted.



James

After James arrived, a good manager left their post. This person had done a good job of developing a culture focused on positive behaviour support. When this person moved on, things started to deteriorate badly. James couldn't phone and tell us what was going on in the unit because he is unable to speak.

It was impossible for us to determine if the increase in his challenging behaviour was his way of telling us that something was wrong. Suddenly, a large number of staff left, and we became so worried that we contacted the CQC and found out about some serious safeguarding issues.

There was evidence that criminal assault, verbal abuse and institutional abuse had occurred in the unit. We were told that these incidents had not involved James, but whether or not he had witnessed them was unknown.

We were appalled that we had been kept in the dark and demanded to view James's records. These revealed that James had been physically and sexually assaulted by other patients in the unit. He had also received numerous 'unexplained injuries', such as finger lacerations and bumps on his head. We were shocked at the lack of concern about such incidents, which were described as minor in the records we saw. It was only much later, after we complained, that these incidents were referred to the safeguarding team.

A CQC inspection report, which was conducted five months after Victoria left the unit, found the service was meeting all the essential standards of quality and safety. It said:

'Patients were safe and had their health and welfare needs met by competent staff. Staff were supported through training and supervision to give the care and treatment patients needed.'



Victoria

Secrecy, deceit and lies have occurred at some units. At one unit, Victoria lost her second front tooth. The first loss had been her fault at a previous placement – she had damaged the roots by self-aggression over a period of time. After this, she had been noticeably careful not to repeat the experience. We were told it was self-harm. However, we discovered the truth. Her sister was worried because when she leaned over towards Victoria, she flinched as though about to be struck. That got us thinking and, on phoning the unit to ask if anyone had been hitting Victoria, we were informed by a worthy individual: “Well, she was punched in the mouth by X”. When we enquired higher up, the director of nursing was duly outraged. “Who told you?” he blustered indignantly.

Significantly, their own records had indicated that Victoria had become

aggressive to other clients – prior to this placement, this was not the case. They had deliberately covered up that another client had punched her in the mouth; she had learned more aggression from fear and she was put at risk by putting her in the same section as this aggressive client. When Victoria was removed from danger and put in a place by herself, she was calmer and happier.

We discovered that, in Victoria’s last but one placement, she was being restrained – they had not disclosed this. I found out at a tribunal meeting a year after she was sectioned that five people were holding her down. The tribunal was not very sympathetic to this unit and asked how her mother managed to take her out on her own and her family did not need to restrain Victoria while at home. In July 2010, Victoria was given notice to leave and we were informed that now

they “only restrained her four or five times per week”. I wonder how many times they were restraining her before if they thought four or five times per week was not a lot. When we asked them this, they refused to comment. Restraining deaf people takes away their ability to communicate, which is barbaric and completely unnecessary.

At home, we never restrain her. If we hold her hand and make eye contact, we can calm her down. In the unit, they were abusing their power – it was simply barbaric. There was no proper strategy in place for managing her behaviour, and they hadn’t done a proper risk assessment that took her health issues into account. They do not use restraint at the college where she is now. This proves that the need for restraint for Victoria is nonsense. She should never have had to go through this.

How do they get out?

Problems surrounding the discharge and transfer to an appropriate support service near home seem common.

Most people agree that any admission to an assessment and treatment unit should be time-limited and should include an appropriate assessment, a treatment plan and timely discharge. Many units report that they start to plan the discharge of the person as soon as they are admitted. However, the evidence suggests that people are spending far too long in these units.

“It has been a horrendous two years as we just haven’t been able to get Joe home”

The CQC Count Me In 2010 census looked at providers of inpatient learning disability services. It found that 67% of all patients in England and Wales had been in hospital for one year or more, 53% for two years or more and 31% for more than five years.

The CQC’s recent inspection programme found that one person had been living in an assessment and treatment unit for 17 years.

There are no circumstances where this can be appropriate and yet, in a CQC inspection report from 2011, the inspector seemed to think that remaining at the unit was a positive thing:

‘The manager and deputy manager were able to tell us about many positive experiences of patients since being here and were pleased that placing authorities had continued with and in some cases increased the length of stay for some patients due to the positive progress being made.’

The stories of James, Chrissy, Joe, Emmanuel and Victoria illustrate this evidence and show how hard it is to get discharged and negotiate an appropriate package of support closer to home. The funding arrangements that are currently in place in many areas can work against the incentive to get people out. Funding disputes seem to be common

between health and social services, and while the battles go on, the impact on the individual is forgotten and they remain completely stranded. In James’s case, this has been for five years.

In the stories below, it is also incredible that parents and families are often expected to find alternative provision for their son or daughter. This is a failure by the NHS and social services to carry out their legal responsibilities.



James

James remained in the specialist learning disability unit for five years.

Following the safeguarding investigation, the unit has been adapted so that there is now a single-person service for James within it. In an improved physical environment and with staff support tailored to his needs, James's challenging behaviour has greatly reduced and things have slowly improved.

But James should never have been placed in the unit to begin with – it would not have been necessary had he not been left in an obviously failing placement. A year after he arrived, we were told he was ready to leave. But since then, four years went by while the authorities argued over the funding package needed to bring James back to where he belongs. Finally they have agreed and we have found a house for James where he can live independently with a 24-hour care

package. However, the fact is that he remained 150 miles from home, too far away from the people who love him, for five years.



Chrissy

Chrissy is still in the unit after two years, as there has been a funding dispute and claims that there is no local provision that could meet her needs.

Her medication changes should be completed soon, so we need to start planning her future placement, especially as we know it could take about a year to find somewhere suitable. The commissioners were refusing to start planning because of a dispute over which area will fund Chrissy's package of care when she leaves. They are still not starting to plan, despite me involving a solicitor. This is the fourth time I've had to involve a solicitor because of problems getting the right care for Chrissy.



Emmanuel

Emmanuel spent 19 months in the assessment and treatment unit but has now moved to a small residential care home in our local area. He had to stay at the unit six months longer than necessary as there were disagreements about where he should go. It was initially proposed that he move to a 12-bed facility even though the psychiatrist from the unit recommended that he live with no more than three people. Emmanuel's social worker said she didn't have to follow the recommendations. In the end, I took legal advice and, following this, the local authority backed down.

Emmanuel left hospital seven months ago and his quality of life is slowly improving as he has moved into a small residential placement, near my home.

Emmanuel is still housebound in the home as the effect of a long spell in

hospital and never coming home in two years has damaged his confidence.

He is slowly getting to know his care team and his communication is improving. He has even managed to do a little cooking with them.

“He had to stay at the unit six months longer than necessary as there were disagreements about where he should go”



Joe

Joe has been in the assessment and treatment unit for the last two years. Just before he went into the unit, it was confirmed that the PCT would fully secure his package of care when he leaves. Because of this, the local authority has not helped us look for somewhere suitable for him to move on to. We have had to find a provider we are happy with and contact housing providers to find a suitable house for Joe.

At the advice of the psychologist at the unit, Joe is moving into a single-person service. We were concerned about this at first, as we don't want Joe to be isolated, but we have agreed it might be best, at least to start off with. It was left to us to sort all this out. Had we not been doing it ourselves, nothing would have happened.

It was a real struggle to get the PCT to agree to it all. After a year of hassling, they eventually agreed. We've been

decorating the property, and now it's all ready for Joe. We've interviewed staff, and they're now completing their training and getting to know him. The date for him to move in has been agreed after lots of pressure from us, so hopefully he will be in his new place soon.

It has been a horrendous two years, as we just haven't been able to get Joe home. At times, we thought we would never get to where we are now. I'm worried about how he is going to cope with living alone with just two members of staff, having been in an institutional setting for two years. I think he's going to find it hard to adapt, and it will take time for him to relearn the skills he's lost. We find it very distressing that Joe will have to adjust to ordinary living because he was left in an environment he should never have been in.

“It was left to us to sort all this out. Had we not been doing it ourselves, nothing would have happened”



Victoria

The good news is that Victoria is no longer sectioned and is not restrained in her current placement – we are really pleased about this as it has improved her behaviour. Well done to the current placement!

Even though things have improved, her health is at a critical point. Victoria is over five stone heavier than she was, mostly due to the over-reliance on drugs that have caused her to gain weight, which has aggravated her joint problems.

I think that the NHS has a lot to answer for – the overuse of restraint and too much reliance on drugs. I am not trying to say these never have a place but they certainly have been abused. There is a great deal of difference between common-sense humanitarian restraint and the type of unnecessary violence used to hold down a deaf, terrified autistic person. Having five people

holding you down is not my idea of care. This was not only barbaric but stupidly counter-productive.

We want Victoria to live closer to home but only when she can be given the right support to meet all her needs, including staff who know BSL and can provide educational activities for her. The residential college is currently rehabilitating her so she can achieve this. It would be nice to see her closer to home, so we can do the things we love doing together as a family.

“It would be nice to see her closer to home, so we can do the things we love doing together as a family”

Questions raised by these stories

- Why are local services unable to support the people in this report so they can live near their families in their local communities?
- Why aren't proper assessments carried out and behaviour support plans put in place?
- Why do some staff working in these units accept neglect and abuse as the norm?
- Why are people put in places where staff don't have the necessary skills or training to communicate with them?
- Why have the families of the people in this report been left to find suitable support for their sons and daughters themselves without help from the very services being paid to support them?
- How can someone end up in an assessment and treatment unit when all they needed was a change in their medication or to be treated for a urine infection?
- How did the CQC and adult safeguarding teams miss these clear examples of neglect and abuse?
- Why are decisions around funding and placement allowed to take so long?
- How can those responsible – the government, regulators, commissioners and providers of the services – allow these things to go on?

What does good support look like?

The fact that such slow progress has been made is inexcusable, especially when we know how to provide the right support for people in their local communities. Where good practice exists, it is clear that there are benefits both to the people and to the local services.

A report by the Association for Supported Living in 2011¹⁸ shared the stories of ten people with a learning disability, each living happily in an ordinary home on an ordinary street. At one time, they had all been in institutions because their behaviour was deemed to be challenging. Both the stories in that report and the stories contained here show that if people are supported in a way that meets their needs, the results are life-changing.

“It is not quick work – you need a long-term strategy, but the benefits are clear.

“The quality of people’s lives is improving. Before, when we were sending people out of area, money was just disappearing out of Salford.

“Now we are spending money investing in local services to ensure that people with a learning disability and behaviour that challenges can have a fulfilling life in Salford.”

How Salford is making it happen

“Supporting people with a learning disability and behaviour that challenges is everyone’s job – social care and health professionals, commissioners, providers, housing, and children’s services.”

In the last five years, 16 people with a learning disability and behaviour that challenges living out of area have returned to their communities. We asked the team at Salford to tell us how they made it happen:

1. We made it a priority

For the last six years, we have been committed to developing the right local services to make sure that people who are out of area can move back to Salford.

2. We have a joint service with a pooled budget

Here in Salford, the NHS and the council have become a joint service. This means no arguments about continuing healthcare or what contributions health and social care should be making. We can just concentrate on what people need, make sure this is in place and get them back to Salford as soon as possible.

3. We have good information about people, starting with children

Getting good information about how many people were out of area had to be the starting point. We then reviewed their needs, and over the last six years we have been working to bring everyone back. We made sure that we included young people from the age of 14 who are at risk of going into placements out of area, for example those currently at residential school.

4. We work in partnership

The community team, made up of both health and social care professionals, is the core team working with people with a learning disability and behaviour that challenges. Joint assessments are done with the mental health team and children and young people’s team. When doing a multidisciplinary assessment, we think: ‘What does this person need?’ Sometimes it will just be a matter of getting an appropriate flat for someone with the right support. Other times, more specialist input is needed, for example a psychologist might need to come in and work with the person’s support team.

We work closely with housing associations to get the right housing for people. We make sure it is high-quality and near local amenities, so people can be active citizens. We are deeply committed to making sure people can live in an ordinary house on an ordinary street.

5. We provide training and build capacity

We want to demystify behaviour that challenges. Salford City Council and NHS Salford run training in managing behaviour that challenges for everyone supporting people with a learning disability – including independent providers, day services staff and respite staff. The training involves families and focuses on positive behaviour support.

Six years ago, local respite services might not have been able to support some very complex people, but through training we have built up the skills and confidence of staff so that they can.

We are also skilling up generic services, not just learning disability services. We work with acute hospitals so that they are able to support people who show behaviour that challenges who come into hospital.

6. We focus on human rights and the Mental Capacity Act

Human rights is at the centre when planning people's support and doing risk assessments. We ask ourselves: 'What can we do to give the person as much freedom and choice as possible?'

In line with the Mental Capacity Act, we want to ensure everything is done in the least restrictive way possible. We do an annual restrictive practice audit, which covers all providers, respite services and day services. We ask what restrictive practices are being used and why. Everything needs to be justified, from a locked cupboard in someone's house to the use of physical or chemical restraint. We have been doing this for three years, and it is going well. It is not about telling services off for doing it wrong, it is about finding out what support is needed to make services better.

7. We all work to the same policy

In Salford, we have one policy for adult services around managing behaviour that challenges that covers health, the local authority and the third sector. It means that everyone is on the same page and committed to supporting people with behaviour that challenges to live in Salford.

As well as making sure adults do not have to go out of area to get their needs met, we have worked with colleagues in children's services to support them to develop the one-policy approach across education, health and the local authority. This will equip children's services with the right skills, so that young people do not have to go to school out of area, however complex their behaviour.



Michael

Michael is one of the people who Salford City Council and NHS Salford have brought back to live in their local community. He lives in his own tenancy with two others and receives 24-hour support from experienced staff. When Michael gets stressed and anxious, the staff know how to reassure him that everything is ok and how to help him calm down. Michael has made lots of progress since moving back.

“I am 31. I enjoy gardening, swimming, looking after my tropical fish, word searches and jigsaws, and following my football team, Blackburn Rovers. I also enjoy visiting my sister and baby niece. I do voluntary work at a tourist attraction nearby. I also like shopping, holidays and going to the Gateway youth club on Friday evenings.

“I was at an assessment and treatment unit for about 12 years. It was not nice being there. It had high fencing. I didn't get out much. Before I went there, I was living with my foster parents. I ran away from their home, and I can't remember much more.

I then went to the unit. Now I'm living in my own home. I get lots of support and my life is good. I am much happier now.

“I don't think it is a good idea for people with a learning disability to be sent away.”

Winterbourne – never again?

With each scandal, governments have vowed and failed to make sure it never happens again. What happened at Winterbourne and the investigations that have followed show why the government must lead everyone in the actions necessary to achieve real and lasting change. Until this happens, stories like those of James, Chrissy, Joe, Emmanuel and Victoria will continue to be told.

What must happen?

The government must show strong leadership and clearly set out what each player in the health and social care system is expected to do within an agreed timescale. It must also say who is accountable for the different parts of an action plan.

The government must start a closure programme of all large assessment and treatment units to be completed in three years and ensure that smaller, local assessment and treatment units are integrated with local services.

The government must tell commissioners to develop local services that meet the needs of children and adults with a learning disability and behaviour that challenges, including community-based intensive support services. There must be no excuse for sending vulnerable people far away.

The government must carry out an urgent review to ensure that funding arrangements do not work against the incentive to get people out of assessment and treatment

units and that ‘economies of scale’ don’t force the continued development of larger units.

The government must ensure that the CQC has the power to only register services that are in line with the policy recommendations in the Mansell reports.

The CQC must conduct rigorous inspections, involving people with a learning disability and their families, and not shy away from taking action to deregister, or enforce their recommendations.

The government must strengthen the law on adult safeguarding to keep people safe from abuse and ensure that rigorous action is taken against abusers and responsible organisations when abuse occurs.

Commissioners must make sure that providers of care and support demonstrate that they are capable of meeting the needs of people who show behaviour that challenges and that they can provide the right environment and skilled staff.

What happened to Simon?

This report began with the story of Simon and the horrific abuse he experienced. The fact that Simon is now living back in local services underlines that he should never have been sent to Winterbourne View in the first place. His mother describes what his life is like now:

“Disability or no disability, Simon had a fundamental right, like everyone else, to choose how to live his life. But the people who should have been listening to him and supporting him to make choices denied him this right.”



Simon

“Simon is now back living near us, and he is loving every minute of his life. He is at the same residential care home he was in before he was sent away, but the service has been adapted so that it meets his needs. They have done this by developing a flat for him adjoining the care home, where he lives with his support team. It is his own space, an oasis of quiet and calm.

“Simon is always doing things – he is out more than he is in! He has a voluntary job as a caretaker at the local community centre that he really enjoys and that he takes very seriously. He is so proud of the reflective jacket he gets to wear. He also enjoys baking cakes to share, walking the dog with his family and shopping in his local town where everyone knows him. These are just normal everyday things but they are incredibly important to Simon.

“After everything Simon has been through, it’s wonderful to see how content he is now. There have been difficult times since

his return, but I don’t see how sending someone with Simon’s needs away to a unit can ever be justified. To take someone from a small home in a rural environment and move them into a large, impersonal unit on a business park staffed by complete strangers is never going to have a positive outcome. Simon needs peace and calm – a quiet orderliness around him. The sheer volume of all the other people surrounding him must have been very disturbing and difficult to cope with. There is not even a ‘money’ argument – Simon’s package of care now costs about half as much as it did for him to be in Winterbourne View. The staff he has now have been wonderful and are truly dedicated. I know that not only is Simon happy, he is safe.”

What happened to Simon and the others in this report makes utter nonsense of the decision to place any of them in assessment and treatment units or other institutional settings. It is outrageous that the NHS spends such large amounts of money sending people away to services that fail them. But more importantly, it is unforgivable that our most vulnerable citizens have been so seriously neglected and abused by the very services that should have supported and protected them.

We need strong national leadership from the government – things must change. It is unacceptable for people with a learning disability to be abused. It is unacceptable for them to be sent miles away from home. It is unacceptable for their human rights to be trampled on. Enough is enough. The government must ensure that its final report on Winterbourne View sets out a clear action plan and that it is delivered.

Time to take action

How would you feel if what happened to James, Chrissy, Joe, Emmanuel and Victoria had happened to your son, daughter, brother or sister?

If what happened to the people in this report is not good enough for the people you love, take action with us to make sure these things don't happen to anyone else.


There are a number of things you could do, from writing to your MP to sharing your own story. Go to www.mencap.org.uk/outofsight, email campaigns@mencap.org.uk or call **020 7696 5613**.

If you are worried about the care of a loved one and need support or advice, call Mencap Direct on **0808 808 1111** or the Challenging Behaviour Foundation on **0845 602 7885**.

If you work in the NHS or social care and have concerns relating to malpractice at work, you can contact the Whistleblowing Helpline on **08000 724 725** or visit www.wbhelpline.org.uk

Endnotes

- 1 www.challengingbehaviour.org.uk/strategy-group/everybody-matters-film/everybody-matters.html
- 2 Mansell 1 & 2 reports: Department of Health. (2007 (revised edition) and 1993). *Services for people with learning disabilities and challenging behaviour or mental health needs*.
- 3 See page 14 for definition of ‘behaviour that challenges’.
- 4 Emerson, E. (2012). *A review of the results of the 2011/12 focused CQC Inspection of Services for People with Learning Disabilities*. Improving Health and Lives: Learning Disability Observatory (IHAL).
- 5 National Development Team for Inclusion (NDTi). *Incentives for achieving change in private sector learning disability hospitals*.
- 6 Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. (2007). *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*.
- 7 Mencap and CBF’s background policy paper can be downloaded from www.mencap.org.uk/outofsight
- 8 MacDonald, A, McGill, P and Deveau, R. (2011). ‘You squeal and squeal but they just hold you down’. Restrictive physical interventions and people with intellectual disabilities: service user views. *BILD, International Journal of Positive Behavioural Support*, 1 (1), 45–52.
- 9 MacDonald, A, McGill, P and Deveau, R. (2011). ‘You squeal and squeal but they just hold you down’. Restrictive physical interventions and people with intellectual disabilities: service user views. *BILD, International Journal of Positive Behavioural Support*, 1 (1), 45–52.
- 10 A range of policies and practice guidance is available – see our background policy paper at www.mencap.org.uk/outofsight
- 11 Allen, D, James, W, Evans, J, Hawkins, S and Jenkins, R. (2005). Positive behavioural support: definition, current status and future directions. *Tizard Learning Disability Review*, 10 (2), 6–8.
- 12 Cambridge, P, Beadle-Brown, J, Mourne, A, Mansell, J and Whelton, B. (2006). *Exploring the incidence, risk factors, nature and monitoring of adult protection alerts*. Tizard Centre.
- 13 From the batch of CQC inspection reports published on 8 February 2012.
- 14 From the batch of CQC inspection reports published on 8 February 2012.
- 15 From the batch of CQC inspection reports published on 8 February 2012.
- 16 From the batch of CQC inspection reports published on 21 March 2012.
- 17 From the batch of CQC inspection reports published on 21 March 2012.
- 18 The Association for Supported Living. (2011). *There is an alternative*.



To download copies of this report (full and easy read)

Go to www.mencap.org.uk/outofsight

To order copies of the report

Email publications@mencap.org.uk

Call 020 7696 6900

www.mencap.org.uk