

With thanks

For ten years we have faced trauma and heartache at the hands of the system. It is a lonely place, but our shared bonds with each other have often been uplifting in even the darkest times.

To the people and families whose shared and parallel experiences are captured in this report, and to those who felt unable to speak - thank you. It is a genuine sadness to us all that so little has changed to avoid your continued pain.

The bonds we have as families, and our ability to work together to seek change wouldn't be possible without the facilitation and support of the Challenging Behaviour Foundation and Mencap over time. Their compassion, care and backing has been invaluable. With thanks to them for everything, including their support to develop this report.

Our lives, however harder because of the experiences we have faced, would be so much less rich without the people who experienced these events first hand: our sons, and daughters, brothers and sisters, nieces and nephews. We thank them, always, for being the light in the darkness.

Tea, smiles and empty promises

Winterbourne View, and a decade of failures
- a collection of family stories



For more information.

Challenging behaviour is a largely misunderstood method of communicating a person's needs, in lieu of other social, emotional or practical mechanisms to do so.

To find out more visit: www.challengingbehaviour.org.uk

Written by families

The Winterbourne View Scandal was exposed on the 31st May 2011 by BBC Panorama.

Like everyone who tuned in to the programme that night, it was anger, disbelief and disgust that filled our hearts, and our minds. Each emotion compounded by a dreadful reality; that the people we were watching were either our own family members, or those who had taken their place behind those doors.

The story was rightly a recognised scandal, and people and services reacted and responded to what they had seen. Promises were made at the highest level; in government, where we believed the power for change would lie.

The promises though, were broken. In the intervening ten years we have seen the government backtrack from their commitments; witnessed powerful inpatient units grow and thrive; and seen similar scandals repeated in people's lives, in people's homes, and on people's screens. The issue remains, and thus, so do we.

Tomorrow still, thousands of people will wake up inappropriately in units, at risk of overmedication and misuse of restraint, miles from their families and without a plan to leave any time soon. Some will face neglect, some will be abused, some may never have the opportunity to leave again.

The focus for too long has been on the wrong end of the system, on getting people out rather than stopping them going in in the first place. Report after report has been written, and ignored. We remain committed to the promises that others have failed to keep; to close the units, fund community support, and to safeguard and empower people who simply do not belong behind lock and key.

We need to stop the damage.

This report will highlight the impact that inpatient units can have on those inappropriately placed there, and the ongoing trauma they can experience both during and after their stays. We will show that families are being failed in the same way ten years on, and that it is possible, with a focus on prevention, to change the landscape, improve outcomes and transform lives.

A note on terminology

Assessment and Treatment Units and other inpatient units are settings available for people with a learning disability and/or autism to be 'assessed and/or treated' in line with their supposed, or actual, mental health needs. They are registered as hospitals and most people placed in them are detained under the Mental Health Act. Throughout this report, families will refer either to 'units' or to 'hospitals' to describe these settings.

'Our daughter is now in her own place but it took too long for this to happen and so many people are still in a terrible situation. This has to improve and the Government needs to do so much more'
(Anonymous family of someone who was at Winterbourne View)

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Why Tea, smiles and empty promises?

“We were told over a cup of tea that she would get the support she needed at Winterbourne View. Instead the promise of positive outcomes turned out to be pie in the sky and were broken by a regime of abuse.”

Wendy, mum of Kayleigh

“I attended meetings and had people coming up to me crying about what had happened to my son or sharing sympathetic smiles from across the room.

Everyone made noises about how much they cared for these issues. These same officials were unable to meet my eyes when we next met and the promised targets had not been reached.”

Ann, mum of Simon



Executive Summary

31 May 2021 marks the ten year anniversary of the exposure of abuse and mistreatment at Winterbourne View, an Assessment and Treatment (inpatient) unit on the outskirts of Bristol. The BBC Panorama documentary ‘Undercover Care’ highlighted a regime of physical and psychological abuse, neglect and mistreatment in a hospital intended to assess and treat some of society’s most vulnerable. That night, the families of people still at Winterbourne View, and the many others who had been ‘assessed and treated’ there prior, watched in horror as the reality of their family members’ experiences were exposed.

This collection of family stories has been developed by some of those families. Working with others who have experienced the system and its failings in the years since, the families highlight the continuation of issues that were all too familiar ten years ago, and are widespread to this day.

The persistent nature of such issues comes despite the ‘Transforming Care Programme’, a government-led programme of work to close inpatient hospital beds for people with a learning disability and/or autism, and to provide appropriate community support in its place. The initial target for this programme was for people in units to be receiving personalised care and support in appropriate community settings no later than June 2014. Over the course of the past 10 years, not one of the targets the government have set for themselves has been achieved.

The current government target is to reduce bed numbers by 50%, by 2024.¹

This report highlights that the focus on ‘getting people out’ of units, is at the wrong end of the system. Almost all beds made available through discharge are quickly re-filled by newly or re-admitted patients, in a failure of the community-based systems that should exist to stop people going in. This failure only adds to the vast numbers of people being traumatised by the system, as once someone is in a unit the reality is stark:

- The NHS target is for people to spend no longer than 32 days in adult acute inpatient mental health settings.² Meanwhile, the average length of stay for people with a learning disability and/or autism currently in inpatient units is 5.6 years.³
- Too many people in units are hundreds of miles from home.
- At least 102,010 restrictive interventions, such as physical and chemical restraint, segregation and seclusion have been used on inpatients with a learning disability and/or autism since figures were first reported in October 2018.⁴ This is likely to be the tip of the iceberg due to consistently low levels of reporting by inpatient providers. In February 2021, just 1 of 16 private providers and 31 of 56 NHS providers responded with their data⁵.
- People in units face a continued risk of abuse and mistreatment.

- There is little incentive for local authorities to fund the right community support to prevent people going into inpatient units, or to release people back to their communities. Whilst in there, under section, the bill is picked up by health authorities.
- Inpatient services are subject to quality controls by the regulator, but in many of the cases we have seen, their recent visits have failed to pick up the abusive practices happening in the services they inspect. Despite changes in the regulatory approach in the ten years since Winterbourne View, many families still lack confidence in the ability of regulators and commissioners to provide the necessary oversight and action to keep their loved ones safe.
- The CQC State of Care Report 2019/2020 found that in mental health services, 31% of inpatient wards for people with a learning disability or autism were either inadequate or required improvement.⁶
- Private units are paid extortionate sums for the assessment and treatment of people with a learning disability and/or autism. The average cost of an inpatient stay was £3,563 per week in 2015⁷, spiralling to £12,000 in some cases⁸. There remains little incentive for private units to discharge people.⁹
- Issues with commissioning appropriate housing and support in the community often cause significant delays and mean people remain stuck.¹⁰
- Even once discharged, the risk of readmission is high; the fragile and failing community-based systems remain a risk to all those trying to avoid crises.
- People who leave are often deeply traumatised and damaged by their experiences, often needing more complex support as a result, and putting them at risk of readmission.

Today over 2000 people remain in inpatient units, including more than 200 children.¹¹ Significant numbers of people with a learning disability and/or autism continue to be admitted.

This report further highlights new data that shows the impact of the coronavirus pandemic on people with a learning disability and/or autism:

Over three quarters (76.4%) of family members and carers said the severity of their loved one's challenging behaviour has increased during the COVID-19 pandemic. (34.2% said it has increased a lot, whilst 42.2% said it has increased a little)¹². This, coupled with a Social Care System already at breaking point, may mean that more people are at risk of entering inpatient services than ever before.

The backbone of this report is made up of family stories - real experiences of broken and traumatised people who faced the system ten years ago, and continue to do so to this day. The case studies they deliver highlight key themes relating to their own stories, and are echoed in quotes from those who

have experienced the system in the ten years since. The stories and themes highlighted include:

- **Dan's story**, which highlights the risk of becoming institutionalised, for people who enter units,
- **Ben's story**, which highlights the increased vulnerability people have to being abused, or further abused, after trauma,
- **Kayleigh's story**, which highlights the lack of appropriate community support available to prevent admission/readmission,
- **Simon's story**, which highlights the failure or unwillingness of local authorities to fund appropriate community support,
- **Sam's story**, which highlights the lack of accountability that exists when things go wrong, and
- **Leslie Junior's Story**, which highlights the risk of readmission that people face even once discharged from units.

These stories and themes could be accompanied by many more.

All stories reflect the damage done by inpatient 'care'. The trauma people and their families face whilst in units and when they come out of units is huge. Where people have been abused, sustained injuries, or experienced neglected health, the impact can be lifelong. Where large amounts of anti-psychotic medications are used to placate people in units, it can take years for people to come off these often physically damaging drugs. And where people have become institutionalised, it can take many years and significant support for them to reintegrate into society.

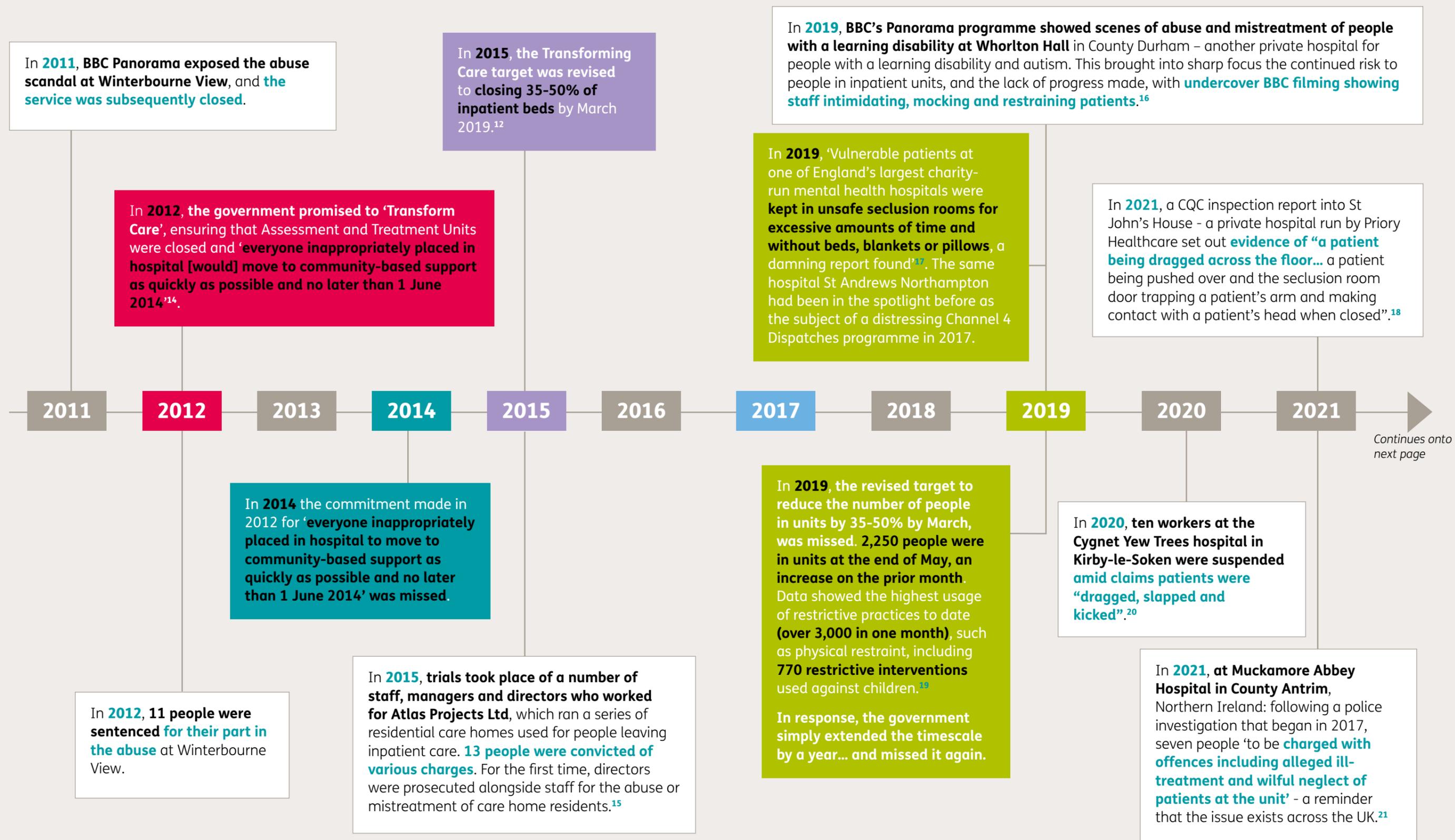
This damage is avoidable. The actions that need to be taken, as highlighted by families, reflect this:

The focus needs to shift to early intervention and preventing admission/readmission, as well as getting people out.

Appropriate trauma support must be implemented for people who have been in inpatient units, and their families.

A story of ten years

Then:



The current government target is to reduce bed numbers by 50%, by 2024. All prior targets the government have set for themselves have been missed, extended, and missed again...

With the March 2019 target having been missed there has been no clear communication from government about what strategy they are working to, and no published cross-government plan. Indeed, all signs seem ominous that the given target will once again fail to be met.

The current situation:

Significant numbers of people continue to be admitted to inpatient units. The tap of admissions has not been turned off.

Today 2,040 people with a learning disability and/or autism remain locked away, including 215 children. The average length of stay for current inpatients is more than five and a half years²², with a risk of readmission being the reality for all who leave.

Too many people in units are far from home. Being far from home means that the people who commission these services are even less likely to provide the necessary oversight to ensure that the expected quality of care is delivered.

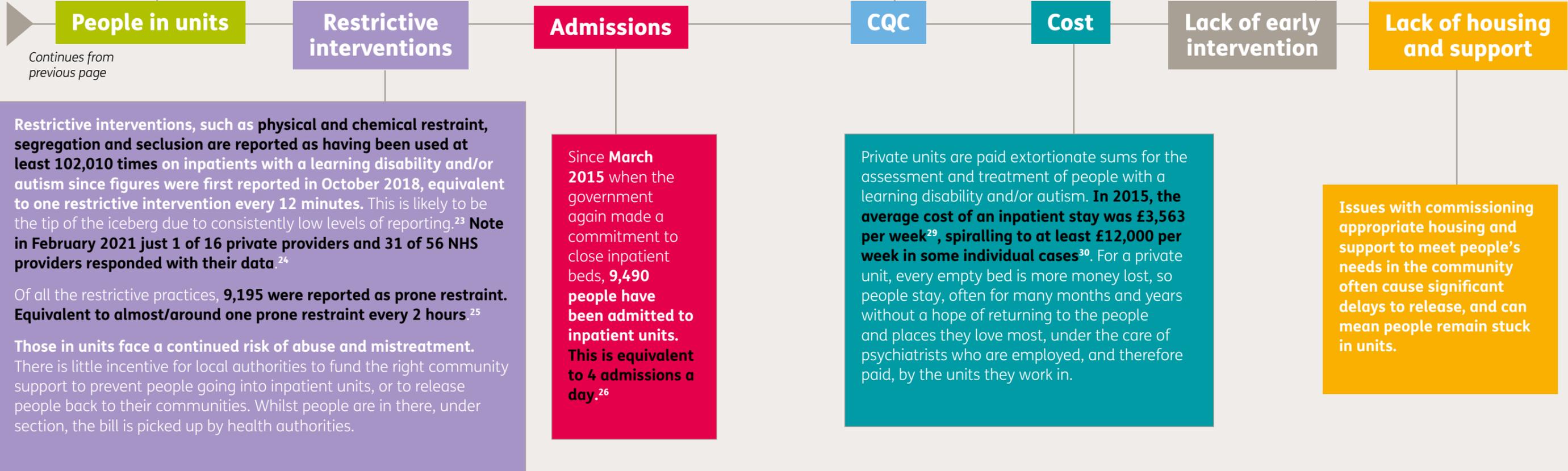
Inpatient services are subject to quality controls by the regulator, but in many of the cases we have seen, their recent visits have failed to pick-up the abusive practices happening in the services they inspect.

The abuse at Winterbourne View had been reported to the CQC in December 2010, but the CQC failed to respond 'believing that local safeguarding agencies would do so'. Those being abused in the service were left to be so for 5 further months.²⁷

Despite changes in the regulatory approach in the ten years since Winterbourne View, many families still lack confidence in the ability of regulators and commissioners to provide the necessary oversight and action to keep their loved ones safe.

The CQC State of Care Report 2019/2020 found that in mental health services, 31% of inpatient wards for people with a learning disability or autism were either inadequate or required improvement.²⁸

There remains a lack of early intervention in the community to ensure that people get the support they need, when they need it. This fails to prevent escalating needs, and puts many people on the pathway into units.



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Restrictive interventions, such as physical and chemical restraint, segregation and seclusion are reported as having been used at least 102,010 times on inpatients with a learning disability and/or autism since figures were first reported in October 2018, equivalent to one restrictive intervention every 12 minutes. This is likely to be the tip of the iceberg due to consistently low levels of reporting.²³ Note in February 2021 just 1 of 16 private providers and 31 of 56 NHS providers responded with their data.²⁴

Of all the restrictive practices, 9,195 were reported as prone restraint. Equivalent to almost/around one prone restraint every 2 hours.²⁵

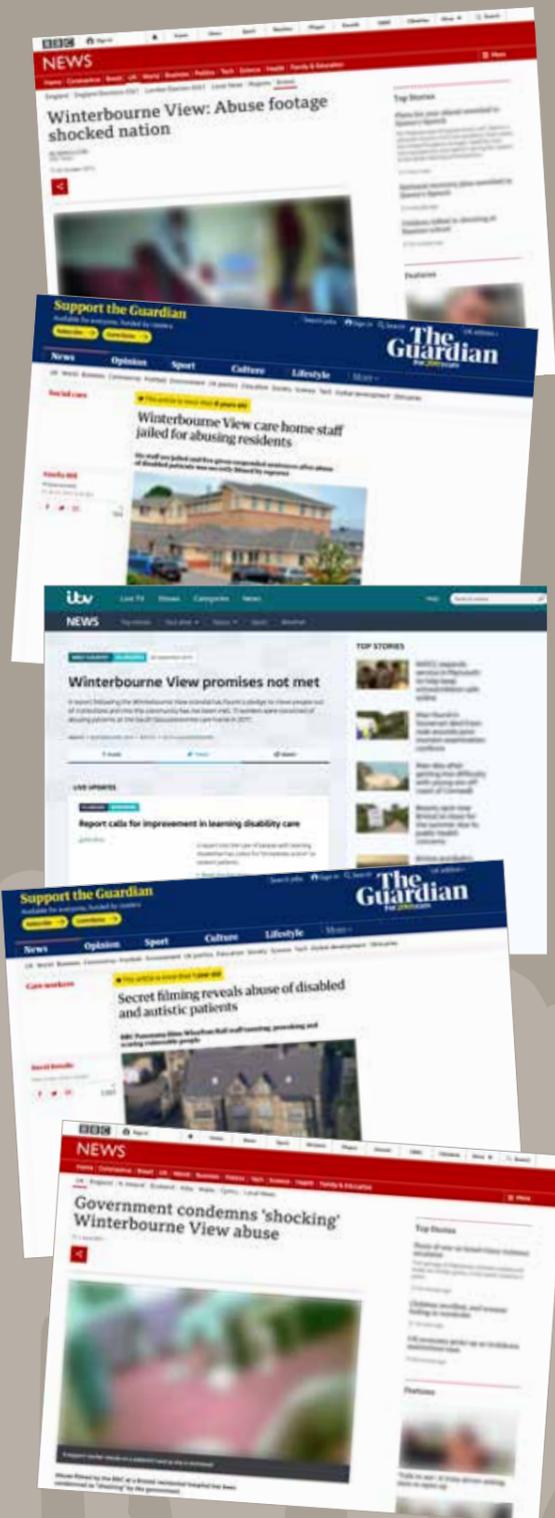
Those in units face a continued risk of abuse and mistreatment. There is little incentive for local authorities to fund the right community support to prevent people going into inpatient units, or to release people back to their communities. Whilst people are in there, under section, the bill is picked up by health authorities.

Since March 2015 when the government again made a commitment to close inpatient beds, 9,490 people have been admitted to inpatient units. This is equivalent to 4 admissions a day.²⁶

Private units are paid extortionate sums for the assessment and treatment of people with a learning disability and/or autism. In 2015, the average cost of an inpatient stay was £3,563 per week²⁹, spiralling to at least £12,000 per week in some individual cases³⁰. For a private unit, every empty bed is more money lost, so people stay, often for many months and years without a hope of returning to the people and places they love most, under the care of psychiatrists who are employed, and therefore paid, by the units they work in.

Issues with commissioning appropriate housing and support to meet people's needs in the community often cause significant delays to release, and can mean people remain stuck in units.

The people behind the headlines



48 people were identified as having been at Winterbourne View, each of whom has a unique story to tell. What is most striking though, are the parallels that exist between their stories, and those of others who have been through the inpatient system since.

The following are the stories of six people who were at Winterbourne View, and what followed for them. Two are in inpatient units today. These stories are further accompanied by quotes from people whose family members have similarly been locked away in units and put at risk, in spite of the ten years of 'progress' we should have seen.



Dan's story

- as told by his mum, Lorretta

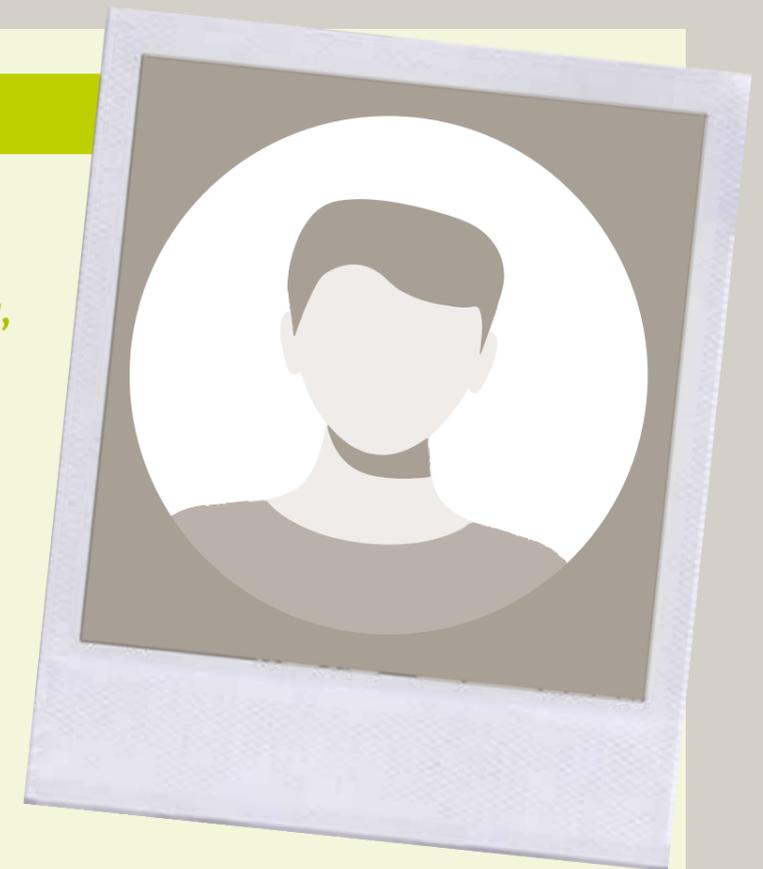
Dan has had five admissions, including Winterbourne View, between 2010 and present

Dan is now 31 years old, and his diagnoses include both a learning disability and autism. His mum, Lorretta, describes his experience of inpatient units, the readmissions he has faced, and the deterioration these environments have caused to his health, mental health and wellbeing.

You would think that after such horrendous treatment at Winterbourne View, we'd have been able to look forward to a brighter future. With all the coverage it gained and the shock waves it sent through the UK that something good would come out of it. This hasn't happened.

My son Dan has been permanently damaged through this whole experience of being in a place where he trusted he would be safe and mended to go back into the community. Because of this, he has been readmitted three times since - not for a few weeks, but for years of treatment. He is and has been on medication that has made him worse not better, and has acquired more mental illnesses as a direct result of this.

Dan's first encounter with a secure unit was when he was 20. He was sent to be assessed after taking an overdose; basically, he wanted to come home to live but social services decided he was high risk to his sister who was still a toddler at the time (not once did he hurt her). Dan was becoming more aggressive as he tried to communicate his needs - he was frustrated, highly anxious due to changes happening around him and therefore couldn't manage his own behaviours. He was sent to Winterbourne View when it was decided that the facility he was in was inappropriate.



Dan was constantly on the phone trying to tell me what was happening in Winterbourne View.

He told me of patients being held down and tablets being forced in their mouths and water being poured down their throats to make them swallow, whilst choking. He told me of staff prompting a reaction from patients, telling them to jump out of windows or telling them to carry on smacking their heads on windows etc. He remembers being pulled out of bed, hurt in the showers, and sprayed with water. The list goes on. When I challenged them about what Dan was saying, I was shrugged off and told he was lying. I never thought it could possibly be so bad.

Dan came out of Winterbourne in January 2011. He lived in supported living with a good care provider, but he was so traumatised by his experiences that it was set up for failure. By this point Dan was scared of showers and was absconding from the property and walking the streets in his dressing gown. He burnt all his belongings, and was desperately anxious and distrusting. My son wanted to die.

After a few months Dan was re-admitted to another secure hospital. What followed were a series of transfers between units, and admissions, before it was finally decided that Dan would move into his own property close to our home. It was a bad transition and things went from bad to worse very quickly. Dan took tablets to kill himself, was re-sectioned and sent to a hospital which is where he is still nearly 1.5 years later.

Dan has had a diagnosis of post-traumatic stress disorder, bipolar, psychosis and has hallucinations- he wasn't diagnosed with any of these prior to Winterbourne View, nor did he show any symptoms. My son is autistic, with a severe learning disability and high anxiety, but all the other diagnoses are a result of abuse, mistreatment and overmedication. He self-harms now and has marks all over himself. He has trust issues and will never be as he was before he was made to leave home.

Because of all we have been through, I have had a breakdown and suffer with anxiety and depression myself. I have felt suicidal through the guilt of not being able to protect him, and have felt worthless and pushed out by 'the professionals' who don't value my opinion. The current hospital is 3.5 hours' drive away from home, which has limited how much we can visit Dan. The pandemic on top has made it even harder for us to see him, so he is isolated even more and safeguarding issues are being investigated even now.

Dan is due to move soon, something that should be a time of happiness for us all, but we're terrified of what comes next.

🔑 Key theme: Risk of being institutionalised

Dan has spent so much of his time before and since Winterbourne View in inpatient units, that his family report that he now feels safer in hospital than out, and that he shows clear signs of becoming institutionalised.

If someone becomes institutionalized, they gradually become less able to think and act independently, because of having lived for a long time under the rules of an institution³¹.

For the many people who have spent months and years in inpatient units, becoming institutionalised is a very real risk, as they can become very entrenched in the routines and practices of units. Dan is not alone in having changed so fundamentally that he struggles to cope within 'free' society. For many people, the seclusion, segregation, restrictions and medications enforced on them in inpatient units can lower their self-esteem, and reduce their life skills until their ability to function in the community is severely impaired.

“When he came out, he was totally overwhelmed with anxiety. He had panic attacks, and by his own choice would only access the bedroom and bathroom. Months on he still wants to sleep on the floor, as this is how he slept at the ATU. He was just so institutionalised and suffering so much trauma”
Leo (whose son, Stephen, was in units 2012-2018)

“My daughter became institutionalised, reliant on others for everything she lost her identity, she lost her trust in others, she lost her love for life and she lost her laughter... The family lost their daughter – she was replaced by a sad shadow who no longer believed what they said because they couldn't get her out or stop the cruel treatment she was receiving...”

Jeremy (whose daughter, Beth, was in units 2012-2015, and 2016-2019)



Beth, in units 2012-2015 and 2016-2019

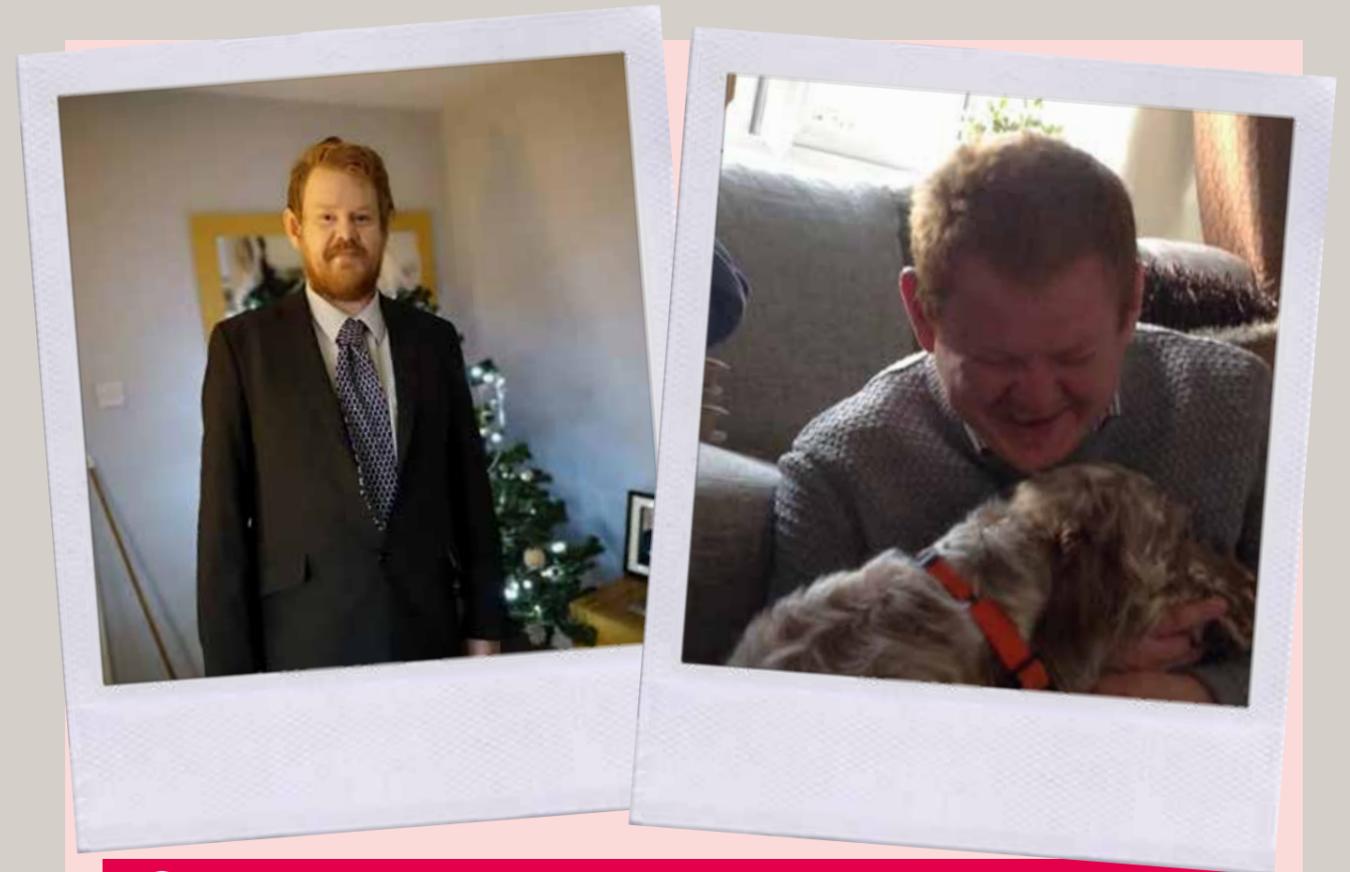
“Trust in humankind is still a huge mountain to climb and he, in truth, remains institutionalised which is heart-breaking.”

Lynne (whose son, Christopher, was in units 2007-2016)

“He remained in ATUs for five and a half years, where he lost the ability to speak clearly, his right to education and his right to family life.”

‘Juliette’ (whose son was in units 2012-2017)

Once someone has become institutionalised, it is very difficult for them to regain what they have lost. It can take many months, years or even a lifetime for people to feel safe, comfortable and ‘able’ in their communities. The signs of institutionalisation include: anxiety, depression, hypervigilance, social withdrawal and aggression - all symptoms that can equally risk people being returned to units once more.



Simon’s story - as told by his mum, Ann

Simon was in Winterbourne View from 2010-2011

Simon is now 47 years old, and he has a learning disability. His mum Ann describes the funding failures that led to his admission to Winterbourne View, and the impact that the abuse he faced has on him, even now.

Simon’s downward pathway ending in his shocking abuse at Winterbourne View was a completely unnecessary and avoidable occurrence. Having identified “trigger points” for Simon’s outbursts of difficult behaviour, the care company had asked for two additional hours of staff funding. They had been covering the cost themselves, but as a small company were unable to undertake this as a long-term commitment.

We were forced – indeed we were threatened by forcible removal if we didn’t allow him to be taken to an Assessment Unit, despite it being 40 minutes away and removed from the area that Simon had grown up in. His level of fear at unknown places and people must have been sky high. This unit was the first time that Simon experienced forcible restraint and we, his parents, were so outraged that we naively thought that the staff would be charged with assault! We were quickly put straight and told that it was Simon’s fault and we were



lucky that it wasn't him being charged. So it began.....then another unit, then ultimately to the horrors that were Winterbourne View.

By this time Simon was sectioned and things were totally out of our control legally. It proved impossible to find a solicitor with sufficient knowledge of the system to help and we were advised to sit it out, indeed we were powerless to do anything else. Whilst Simon was in Winterbourne View, his father (my ex-husband) unexpectedly and tragically died. We, his family believed that this was partly due to the stress of his son's incarceration.

Simon's abuse has been well-documented but of course there will be much that we are unable to piece

together. Suffice to say that the abuse was both emotional and physical and ultimately wore Simon down to a point that I no longer recognised the person that he had become. Visits were difficult; not only was I working but my husband was, at this point, dying of cancer having been very ill for many years. I was able to take Simon out but not permitted to visit his room and he was brought downstairs to the family room when I arrived.

The amazing Panorama team provided the catalyst that changed our lives. Now that his section three had been lifted, we were able to break Simon out from his confinement to return him to his care home, close by to me, where he had spent so many years. Despite returning to familiar surroundings, the same staff who had cared for and loved Simon since he was 18 years old (at this point he was 35) and his own possessions around him, it quickly became apparent that Simon was broken, and not the same individual that had left two years previously. Unable to live with his peers, the house was separated to provide Simon with a small self-contained area. Sadly this didn't really work either. The happy-go-lucky chap that had left us had returned as a confused, unhappy and understandably belligerent individual.

A landmark moment for us all occurred when a lovely bungalow, in a quiet spot was identified as suitable for Simon. Originally a school caretaker's house it was undergoing a conversion to

become a supported living house when it was decided that it was not suitable for the original recipient. Unbelievably, it was actually in my home village and all his own staff could move with him. Some things are just meant to be!

It has not been a bed of roses over the past five years since he moved. Having been diagnosed with post-traumatic stress disorder, a specialised consultant was hard to find. Though it's been amazing how the money materialised to try to repair the damage done, but couldn't be found for prevention!

Simon now has the best of care. His staff love him and don't just care for him, some of them having been with him for over 20 years. He lives in a calm environment surrounded by people who know him and accept him into the community. A ring of protection has been thrown around him by good, understanding professionals and imaginative and creative carers, but I am always aware that this veneer is still paper thin and fragile. A change in funding, a staff change, any small thing has the ability to bring everything tumbling about our ears.

So even now ten years on, immeasurably damaged but still standing, we forge our path and move forwards into the future, thinking ourselves lucky that Simon has a future.

Key theme: Failure, or unwillingness, to commission the right support

Simon's admission to a unit could have been avoided had just a few additional hours of support been funded. Instead he was eventually admitted to Winterbourne View, **where the average support cost was £3,500 per week**³². **The additional hours Simon needed at the time would have cost far less to fund.**

As a result of the trauma he experienced at Winterbourne View, Simon needs the hours he needed then, and more, meaning that the commissioners continue to pay far more than they would have done had they met Simon's needs in the first place.

The cost of supporting a person with a learning disability in the community varies depending on a person's needs, but commissioning arrangements mean that it can be difficult to access increased support during crises, or when things change. All too often we hear stories of people whose family members are admitted to inpatient units because of a local failure or unwillingness to fund the additional support that people need.

This is all the more nonsensical when considering that such needs are often relatively basic, and thus relatively inexpensive, particularly when compared to the inpatient alternative that people often reach.

Irrespective of the financial costs, the human impact of failing to meet such needs is often devastating.

“For my son, all of his traumatising, enduringly damaging experiences could have been avoided if he had been appropriately, comprehensively assessed and his needs identified. His needs should have then been met by commissioning a suitable service. Instead, support was purchased based on what was available, often with little evidence of expertise, save that which was self-proclaimed.”
‘Dennis’ (whose son was in units 1999-2000 and 2007-2013) .

“Local commissioning did not check that local providers were capable of meeting her needs – how could they when they themselves didn’t know what she needed.”
Jeremy (whose daughter, Beth, was in units 2012-2015 and 2016-2019)

“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.”
Sue (whose son, Joe, was in units 2010-2012 and 2018-2020)



Kayleigh’s story - as told by her mum, Wendy

Kayleigh was in units, including Winterbourne View, from 2004-2014

Kayleigh is now 35 years old, and her diagnoses included both a learning disability and autism. Her mum Wendy describes the lack of appropriate community support to meet her needs now and in the past, and how fragile her support remains as a result.

From the time Kayleigh was 18 months the behaviours started. She found her feet and that was it. We lived in a tiny village which was very protective, so she could not go far without being spotted. She was a little escape artist.

When she was 13, we moved home and area. From a tiny protective community to a city. It got to the point that in a normal home we couldn’t keep her physically safe, we were exhausted.

She went to a residential school. She was 15 years old. The placement lasted a year. In the next residential placement (from 16 to 17yrs) she hit a member of staff on a Friday afternoon. The police were called and she was taken into custody, then to court the next day.



The placement closed with immediate effect. The local authority couldn't find anywhere for her. I was on the phone saying 'just send her home, while you look for another placement' but they wouldn't agree to this as they said she needed 2:1 staffing (for restraint if needed) and they couldn't find two staff. They couldn't access any senior managers to authorise her coming home. The courts closed at 1pm and they sent her to prison.

I was gutted. Gutted in every way possible because not only had she gone to prison but there was absolutely no need for it.

She was charged with common assault. Anyone else would get a

suspended sentence or community service. Kayleigh went to prison and stayed 4 months on remand. Her vulnerability could not be managed in a normal wing so she was placed on a health wing with acute mentally ill prisoners. Here, she learnt how to self-harm including cutting herself and tying ligatures to hang herself from a sink tap.

I was advised the best option was a 'welfare bed' in a unit but there were none available so the criminal route was taken and she was sentenced to a hospital order. This means that you can only be released when the responsible individual says you're not a danger to yourself or others. My understanding was that she would be assessed and treated and be back in the community within three to six months. 10 years later I got her out!

Kayleigh lived in Winterbourne View for 3 years before the Panorama documentary.

I was told by Winterbourne View that there would be something in the press. I watched Panorama and it just blew me away. Just thinking about it now breaks my heart. I was so shell-shocked. I had no idea at all what was coming. She was in there being 'treated' and she was the one saying to the staff 'Why are you hurting us?!'

While there Kayleigh made allegations. I would ring and question the manager who always had a logical and appropriate explanation for incidents. There was insurmountable guilt

afterwards. I believed and trusted the professionals over my daughter.

Winterbourne View was closed a few weeks later and a new placement was needed.

The new place was a new unit with a brand new team. Within a few weeks it had broken down. She'd been pushed, hit and made allegations against staff. I don't think this was deliberate institutional abuse, more a lack of experience.

A rapid move placed her in another unit, and then finally into her own home.

Kayleigh has lived in her own home for seven years. Myself and her brothers live within five miles. She loves her home. She loves being able to go out when and where she chooses.

She's now deemed to have capacity so if she asks her support to 'go away' they have to go. That's when it goes wrong. Generally, it is so much better because she has freedom. She has recently been to Thorpe Park which she loves. So it's as normal a life as possible.

The downside has been that when she becomes distressed because of her PTSD, she drinks copious amounts of alcohol and plays loud music as a coping mechanism. She's in a semi-detached house and the neighbour is not sympathetic to trauma. She now has an injunction that says she can't play music loudly at all. But Kayleigh loves her house and does not want to move.

Kayleigh has an obsession with emergency services. Throughout her seven years she's been in contact with police, fire and ambulance services. The ambulance service will only attend if her support staff confirm the need. She has a community behaviour order (CBO) and if she contacts them and they deem it not to be an emergency she goes back to court. She's been in and out of prison five or six times in those seven years. When her mental health is poor she engages the emergency services which breaches her CBO and ends with another prison stay.

Kayleigh was under the forensic mental health team but they are so over stretched that if she doesn't attend an appointment they will close because she isn't engaging. Kayleigh needs continuity and to be able to build a trusting relationship with a professional but she's had five or six different professionals in approximately six months. So the system fails her.

We continue to live life on a knife edge.

Quick facts:

People with a learning disability and/or autism may be inappropriately arrested and charged when they express their needs in 'challenging' ways. Whilst it is the case that people who have a learning disability and/or autism and have capacity are capable of committing crimes, a lack of understanding of the function of 'challenging behaviour' and subsequent adaptability to meet people's needs means that people with a learning disability can spend inordinate amounts of time in forensic services, or inappropriately in mainstream prisons, for comparatively minor crimes, or for simply expressing their needs.

Kayleigh effectively spent ten years in forensic services and prisons as a result of a 'common assault' against a member of her care staff, perpetuated during a crisis. She remains at risk of spending more time in prison, despite her vulnerabilities in such environments.

26% of people with a learning disability and/or autism in inpatient services under a forensic section of the Mental Health Act have been there for 10 years or more³³.

Key theme: Lack of appropriate support.

The inappropriate support Kayleigh experienced prior to, and during her time in inpatient care, led to an escalation in behaviours, and to her being inappropriately 'managed' with medication, and with criminalisation. Many other families report that something very simple could have avoided their family member's admission, and ensured that they remained in the community where they belong.

Many of the people who enter inpatient units do so in a state of crisis. This is rarely an unpredictable crisis, and is often the culmination of failures to meet their needs in the community and support their struggling families.

This issue is not new. In 2007, the report 'Mansell 2: Services for people with learning disability and challenging behaviour or mental health needs' highlighted precisely the issues that many families experience to this day:

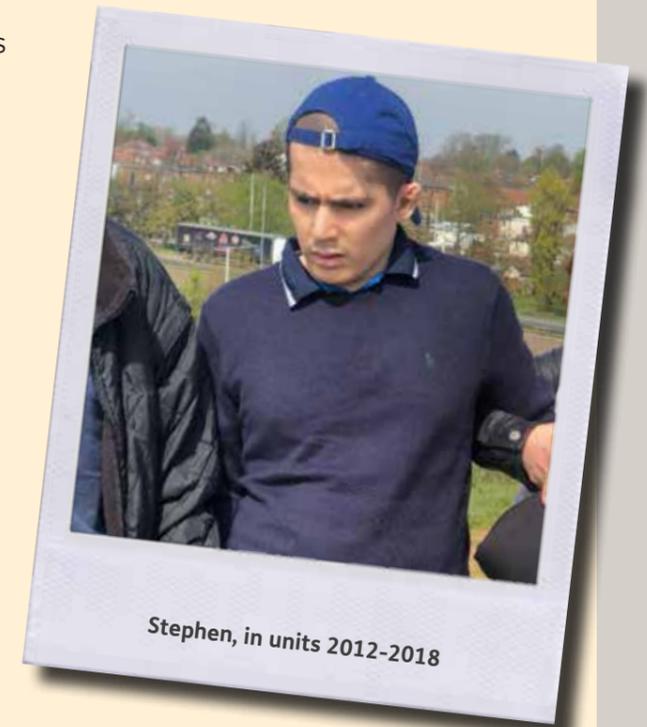
"Often, community-based services have not been sufficiently well developed and well organised to serve them. Placements break down as people whose behaviour presents a challenge can no longer be supported. For those who have been living with their families,

there are insufficient local placements prepared to take them. For people already in supported accommodation or residential care, the placement is unable to cope. For some individuals, this means they are required to move from one place to another over and over again, causing distress to them and their families."

Once a crisis has already been reached, there are rarely alternatives given to inpatient care. Families like Wendy's are told they can expect their family member to be 'assessed and treated' as an inpatient for a period of weeks, but 355 people have spent more than 10 years in units³⁴, and Kayleigh herself was an inpatient for ten.

The infrastructures in place to keep people out of units are variable across the country, and are often poor. This lack of appropriate community support leads to numerous individuals entering inpatient settings every year - a situation that is usually avoidable.

The government has focused so heavily on reducing bed numbers that little pressure has been put on local areas to develop options in line with people's needs, and so the issue continues.



"He does not need assessment and treatment. He is yet again in hospital because the right community support is not in place."

'Louise' (whose son has been in units 2014-present)

"He started self-harming when staff changed at his school and he wasn't supported properly to understand the change. He was eventually admitted to a unit. It felt like he was admitted just for being autistic."

Leo (whose son, Stephen, was in units 2012-2018)

**“My daughter ended up going into an inpatient unit at 14 as she was self-injuring. She had been referred to CAMHS. No one talked about the fact she may have autism, they thought it was an identity crisis and depression”
‘Anna’ (whose daughter was in units 2005-2021)**

The lack of focus on preventing admission means that there is a similar lack of focus on preventing the crises that people and families face. Still, people are told to “call the police” on their struggling children, as if a legal system, unfamiliar with people with a learning disability and/or autism and the issues they face, would ever be an appropriate mechanism to support people’s needs. It is striking how many people enter inpatient units from police cells, or from NHS hospitals because there are no alternatives for providing the initial crisis support, particularly in a system that rarely works ‘out of hours’.

In Kayleigh’s case, it is a constant concern that something could go wrong. Her trauma means that she often plays loud music to distract herself from her thoughts, but she risks being criminalised once more for doing so because some of those around her describe this as antisocial. Kayleigh still struggles with her mental health, but the consistent and regular input she needs from a trusted mental health professional continues to fail to materialise, putting her at constant risk of deterioration in her health and support.



Ben’s story - as told by his sister Emma and mum Claire

Ben was in Winterbourne View from 2009-2010.

Ben is now 30 years old, and his diagnoses include both a learning disability, and autism. His sister, Emma and mum, Claire describe his treatment in Winterbourne View, and the further abuse he faced once he left. They describe how Ben’s needs have increased as a result.

Ben was admitted to Winterbourne View when he began to suffer extreme anxiety in an inappropriate school placement. He was 18 years old.

Within weeks of his arrival, Ben was admitted to a dental hospital having ‘lost a tooth’. We quickly discovered that he had in fact lost two teeth and had his jaw broken during an ‘incident’. It was alleged that this had happened during a restraint, but the evidence didn’t stack up and, years later, a nurse was struck off the register for having ‘punched or kicked’ Ben in the face - the true cause of his severe injury.



Ben was injured on numerous occasions at Winterbourne View and became a shell of himself- during visits he would sit, shaven headed and bruised, rocking in a chair, something that was completely out of character for the sociable and engaging man we knew.

He was finally discharged after 11 months to a 'specialist' residential placement. The continued lack of oversight of Ben's support allowed him to be abused again in the setting that was supposed to be his platform back into a happy life. Here, he was subjected to actions that were described in court as 'torture' and 'false imprisonment' at the hands of another abusive regime.

The damage done to Ben is significant. He has PTSD and spends his life on high alert, always wondering who might be next to harm his body or mind. It is a fallout that he, and we, live with every day.

The trauma he has experienced, and the subsequent impact on his ability to communicate effectively without challenging behaviour, mean that Ben remains at constant risk of returning to an inpatient setting. He has had a turnover of around 400 staff in four years because he struggles to trust those who support him even now.

With time, extreme patience and specialist support Ben is able to live in his community, in his own home, with his dog. It isn't without substantial input from us, we work tirelessly still to make sure his placement is secure, and his life good. It is exhausting and feels so avoidable.

Rarely do we reflect on how different our lives could have been too. Our family has been decimated by the trauma and fight that we have experienced, united only by the sadness we feel about what could have been. We're shattered by the realities of all that has happened to a dearly loved son and brother, a man who never deserved to face the agonising trauma that

marks his every day. Whilst we fight daily for him, and us, to get the support needed to recover and move on from the trauma this has caused; **we're faced with the agonising reality that Ben, and his life, could have been so much different had his admission to Winterbourne View been avoided all those years ago.**

Key theme: Increased vulnerability to further abuse

Ben was so traumatised and broken by his experiences in Winterbourne View that his vulnerability to further abuse was increased when he came out. He was subsequently a victim of another abuse scandal, this time in a residential care home, where he was physically, mentally and psychologically abused, and falsely imprisoned. It took him years to feel able to speak out about his experiences, because he had experienced the repercussions of doing so before.

Many people with a learning disability and/or autism struggle to maintain their awareness of what should and shouldn't happen to them after their abuse, making them all the more susceptible to the future abusive actions of others.

This is a common feature for many of the people we know, including those whose stories feature in this report. Many of those in inpatient units who are mistreated and abused never have their experiences exposed, but the trauma remains.

The current lack of support that exists for victims of abuse who have a learning disability and/or autism means that this issue pervades to this day, and is likely to do so until understanding is embedded in services, and effective trauma support is developed across the UK.

Ben's post trauma needs make him a more 'challenging' person to support. He requires daily reassurance, uses challenging behaviour to communicate his needs more frequently, and needs an increase in psychological support. This means that his staff team must be more specialist and resilient, that the external input needed from other agencies is significantly increased, and that the pressure on those around him, including his family, to support and maintain his healing is substantial.

Once discharged, many people with a learning disability and/or autism have increased needs as a result of the trauma they have faced, the institutionalised nature of their previous support, and/or the sheer lengths of time they have been removed from society in environments that can, in themselves, cause harm. Their vulnerability to further harm is often so increased that additional support and training is necessary for those supporting them into the future to do so properly.

“Over ten years on he remains so traumatised he has been unable to re-enter society in any shape or form. He also remains physically very poorly... Our loved one went into these places for care and treatment... and yet when he finally broke free he was in a feral state and in need of total rehabilitation - that basically says it all”.

Lynne (whose son, Christopher, was in units 2007-2016)



“He was covered in bruises and gashes from where he had hit himself from being anxious. He was put on six anti-psychotic drugs, two of which were for epilepsy, even though he has no diagnosis of psychosis or epilepsy. When we arrived, he was so drugged that he fell asleep when he sat down with us. The long-term effects of sedation mean that my son has now lost the little speech he had.”

Leo (whose son, Stephen, was in units 2012-2018)

Many families report the same issues, and others, in the years following inpatient care:

- Where large amounts of anti-psychotic medications are used to placate people in units, it can take years for people to come off these often physically damaging drugs.
- Where people have sustained physical injuries, the impact can be lifelong.
- Where people have become institutionalised, it can take many years and significant support for them to reintegrate into society.

Leslie Junior's story

- as told by his dad, Leslie

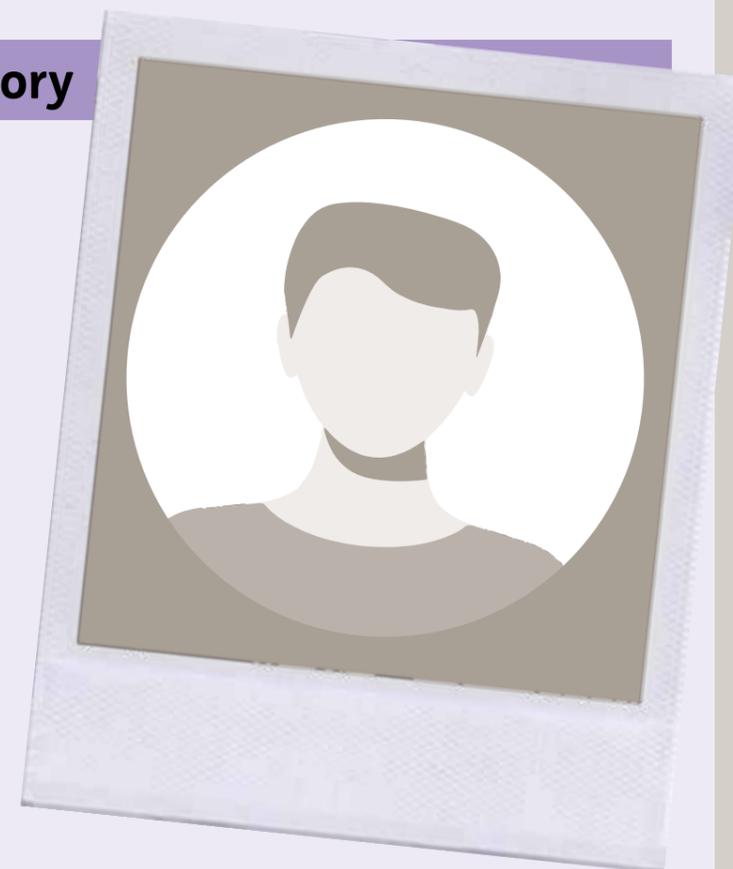
Leslie has had three admissions, including Winterbourne View, from 2008 – present

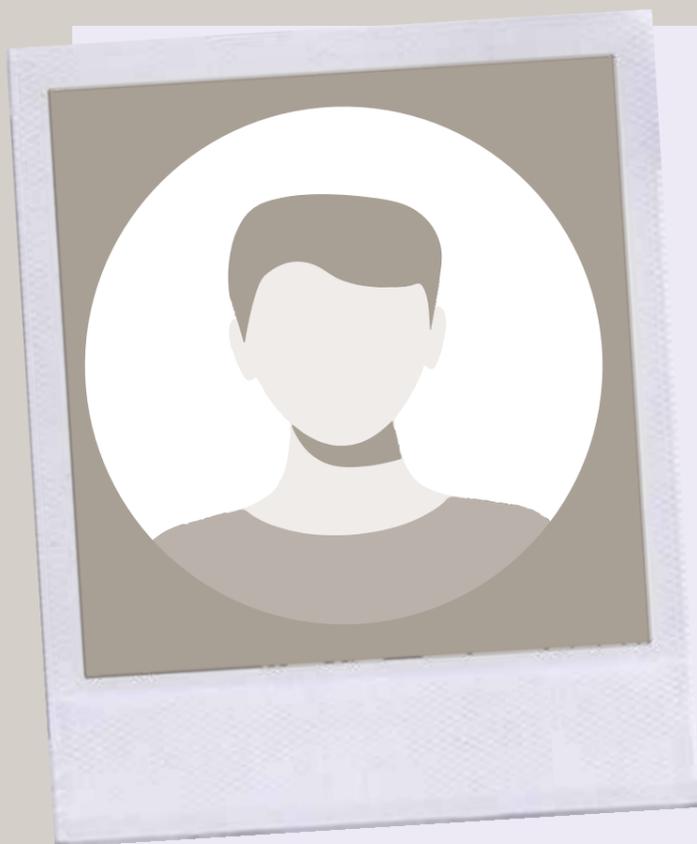
Leslie Junior is now 31 years old, and his diagnoses include both a learning disability and autism. His dad Leslie Senior describes his experiences at Winterbourne View, and how a lack of adequate support since has led to a series of readmissions to units.

Leslie, who has autism, started struggling with anxiety in his teens. Aged 18, Leslie attempted to take his own life and was admitted to Winterbourne View. To relate the harrowing experiences he has experienced since then would take pages. Instead, I will focus on how Leslie's story was published in the Transforming Care policy document to illustrate why change was needed and yet the failure to deliver on those promises has ironically resulted in Leslie being back in crisis and back in hospital.

When we were told by Winterbourne View management how Leslie would receive care and therapy, we were relieved and hopeful. We believed it was the very best option, but we couldn't have been more wrong.

We visited weekly and always insisted on going into the hospital. We saw patients were bored and unhappy – many were overweight. The staff seemed to use reward and punishment as treatment. I asked a staff member what activities and therapy they were doing and she said, “we can't do any therapy with the patients as the alarm is always going because patients are kicking off.” A lot of things gave us misgivings about the place, but we had no idea about the abuse.





After three months there, Leslie got worse. We knew that their idea of therapy was a sham and asked our local authority to get him out of there. It was difficult at first, but credit to them they listened and worked hard to get Leslie discharged.

After spending a total of 14 weeks at Winterbourne View, he was discharged then went on to a school for young people with special needs during which time a psychologist assessed Leslie as suffering from PTSD. Leslie was obsessed with physical restraints and often talked about the 'alpha male' from Winterbourne View who was later imprisoned. Leslie admired his tattoos and saw him as a role model.

Following the Panorama documentary and the implementation of the

Transforming Care programme, we attended meetings with our local authorities who worked hard on a care package designed to meet Leslie's needs. Leslie wants to be like other people, so independent living with his own house plus the support of a team of full-time carers, community disability nurse and psychologist was the right solution.

In August 2015, he finally moved into his new house in a nice area, close to the family and with 24/7 care with the carers' facilities on the ground floor so that Leslie had privacy. The house was perfect. He needed to be able to do things like take his own bin out – things that everyone does. Everything seemed to be working well. Leslie was taking great strides and even got a part-time job in a restaurant kitchen.

However, in November 2016, he had a setback and started hitting his head against an outside wall. The authorities were informed and an emergency meeting held. Then it was explained how, just 10 months into his new care package, both his psychologist and disability nurse had gone and not been replaced. The team of carers needed specialist support and were struggling to manage Leslie's increasingly challenging behaviour and resistance to help.

The care providers continued to tell the local IATT (Intensive Assessment & Treatment Team) that if specialist support was not provided they would be unable continue working with Leslie

to no avail. At a meeting in July 2017, they handed back the contract and it was agreed a new support agency should be found.

We worked alongside the new care agency to try to cope with his increasing resistance to support. A psychologist was found but after three sessions she left for a different role and we couldn't find a replacement. Leslie now started resisting even our help. We knew he was at risk but felt powerless and didn't know where to turn. Last November, Leslie had a conflict with a neighbour and the police were called out. Thankfully, they were understanding and recognised that Leslie needed help. He wasn't eating properly and was very thin, so the police took him to hospital. Leslie was assessed and then admitted to his local inpatient hospital under section two. After four weeks, he was assessed as not being psychotic and could leave once the police had resolved things with his neighbour. In the meantime, he was weaned off the medication he had been on for five years.

Leslie then returned to his own home. However, the right support he needed still hadn't been put in place. He continued to turn away his carers and had been landed with a £83 a week bill to contribute to his care costs. Leslie was extremely distressed and threatening violence – a desperate response to make something change.

One day, the care team called to say they couldn't get an answer from Leslie. We immediately thought the worse – that he has harmed himself. Thankfully he was ok, just refusing support again, but our son wasn't safe. Meetings were held and a consultant reported that Leslie needed intensive specialist therapy as a result of his experiences. Last month, he was admitted to an inpatient unit in Exeter – 50 miles from the family home – under section two where he will hopefully receive the specialist autism support and therapy he needs so he can return to his home.

We believe five years of medication without talking therapy was inadequate, it was contrary to the original care plan and if pro-active support had been in place, we would not be where we are now. There should be more funding and community support for autistic people suffering from anxiety.

To this day, we don't speak to our son about Winterbourne View – he wants to wipe it from his memory. Yet he continues to be at risk, and we feel helpless.

If Leslie was given specialist support by a care team with the skills, experience and training, we believe he would have a chance of a happier life.

Key theme: Risk of re-admission

Leslie Junior has been admitted or readmitted to units on three different occasions. He is currently in a unit once more.

His is far from an isolated case. In fact, many other families who have had family members in an inpatient unit have seen them readmitted over time. In many cases, this is due to either being discharged into an inappropriate placement without enough specialist learning disability and autism support, or because there has been a change in their support.

Once someone comes out of an inpatient unit, almost all families will speak of their fear that they may be admitted again if things break down in the community. This concern is not unfounded; fragile infrastructures mean that people can all too easily return to crisis point, because of something as simple as a change in staffing or management, or even just a bad day.

After the Winterbourne View abuse scandal, the government promised to move people with a learning disability and/or autism out of inpatient units and provide appropriate support in the community. Despite these promises, research shows that there have been 9,490 admissions to inpatient units since March 2015³⁵, including an unknown number of readmissions of people who were previously resident at Winterbourne View.

“There was no safe space locally for him, and as a permanent property had still not been sourced, he was again admitted to hospital under a section. This is his sixth birthday as an inpatient under the Mental Health Act.”

‘Louise’ (whose son has been in units 2014-present)

“My son lost his home due to being sectioned, and was kept 130 miles from us. It was horrific. He then lived successfully in a new home of his own for six years, until the service provider could not retain staff and he became anxious. A multi-disciplinary team meeting was held and it was decided that day to ‘remove him again from his home’. He was moved the following day, again leaving his home behind.”

Sue (whose son, Joe, was in units 2010-2012 and 2018-2020)

While the government announced a Community Discharge Grant last year to help to get people out, what is clear from these families’ stories is that effective community support is

often not available to stop people ending up in inpatient units. There needs to be more focus on delivering early intervention specialist support in the community to prevent admission in the first place, and minimise the risks of readmission when people are discharged.

Even good support feels fragile to many families, who have been let down so often by the system that they struggle to believe any progress being made is permanent. The system itself is under-funded, and it is little wonder that people and their families struggle to relax today when tomorrow feels so uncertain.

“He has been in his own home for eight years. The situation remains fragile and there is no doubt that this will be the case for the foreseeable future. The damage done to him has left enduring wounds that can never properly heal. That is the nature of PTSD, when the affected person lacks the internal resources to manage any aspect of the problem, and external help in the form of therapy is not available.”

‘Dennis’ (whose son had two admissions 1999-2000 and 2007-2013)

“I don’t think I will ever feel that my son is safe in his support, as things have changed so quickly over the past 11 years and have had devastating consequences for him and all his family. My son has been removed against our wishes on several occasions and had to leave his home, possessions, family and friends behind, not knowing if he would see them again. He was taken from two homes and never went back - how must that feel?”

Sue (whose son, Joe, was in units 2010-2012 and 2018-2020)



Joe, in units 2010-2012 and 2018-2020

Sam's story

- as told by his dad, Steve

Sam was at Winterbourne View from 2009-2011

Sam is now 32 years old, and his diagnoses include both a learning disability and autism. His dad Steve describes the lack of accountability faced by those responsible for his mistreatment at Winterbourne View, in spite of the impact it continues to have on his and his family's lives.

Sam lived with his mum. He was a big lad and got excluded from his special school at 16.

She was finding it more challenging to look after him - he'd run away and I'd have to go looking for him. He'd gone to respite for many years but he had got too much for them.

His mum called the community team in and we agreed for him to go into a place - Winterbourne View - to be assessed. We thought this would be to find out what his needs were, what support he needed. We thought this would help Sam.

I went to see him a few days after. I was welcomed by a nurse and allowed to go and see Sam on the ward. Everyone was friendly, nothing seemed untoward. Sam's mum went to meetings and I visited and was able to take Sam out.

I started seeing changes in Sam. Not just the way he was but his physical appearance. I arrived to take him out to the pictures and when he came downstairs he was a mess. He had food on his top. I took him back to his room to get changed.

Things started to change. We stopped being allowed on the wards. We had to meet in the foyer and eventually they provided a visitor's room.

They'd bring Sam down and he would have marks on his wrists and neck - all he kept saying had happened was 'restraint'. When I asked what for he said 'bad, bad'. I knew Sam could be



challenging and I trusted they would be following good practice. Sam started demonstrating some restraints on me. One time he grabbed my arms with such force, looked straight into my eyes and told me I was going down. I said to his mum we've got see about getting him out of here.

His mum looked at loads of places and the social worker was supportive. When the transition team went to visit him at Winterbourne View they raised concerns - they couldn't get records, it was a closed shop, staff didn't want to speak to them.

Sam was at Winterbourne View for 2 years and he left before the Panorama programme. When Panorama came out, I looked back through all Sam's records in detail. I saw the high scale of restraints - 45 in just a few months - and all the medication he was on. I remembered when he had grabbed my arms and realised he had been mimicking what was happening to him or maybe crying out for help.

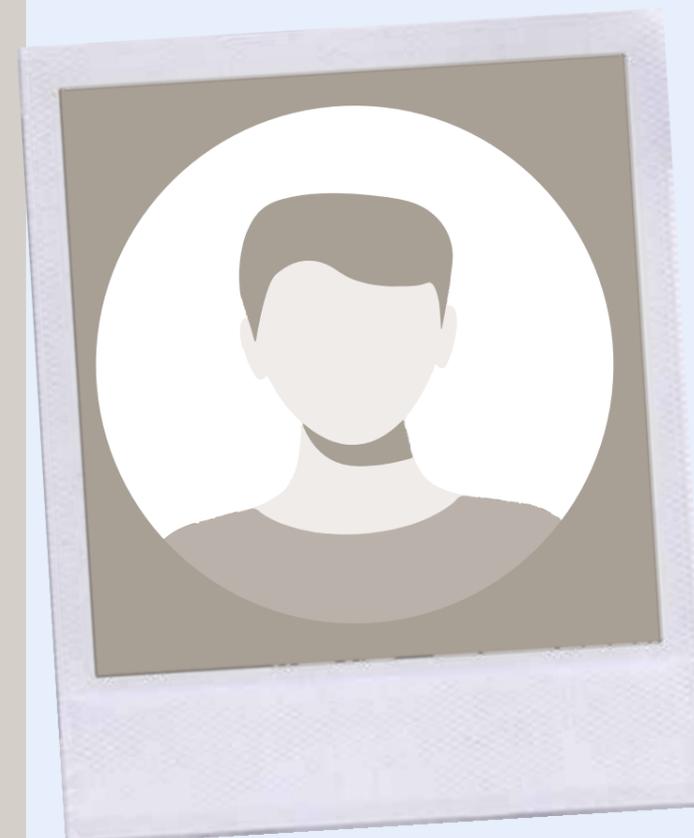
The place Sam went to live next worked really well. He is still there now which says something about the place. The owner had his own child with special needs. He had the right values and could relate to all the parents. He got them involved. He made time for Sam and the others living there and for the parents. We had his mobile number. He asked me to represent other

parents and be a safeguarding parent rep. Sam has prospered. He was one of the lucky ones. It's a proper home, a proper house, not a hospital environment - it's completely different.

To look after someone with Sam's needs you need to have special skills. The staff didn't just see it as a 'job' - they took time, and they'd ring us if things were wrong.

We were phoned by the social worker and told the Panorama episode about Winterbourne View was going to air. We were told we needed to be prepared.

After 15 minutes watching it I was on the phone to Sam's mum. It was



frightening what we saw. It shocked the nation. His sister was crying – and finding it very hard to cope. I broke down a couple of times.

Looking back at everything – as a parent your job is to protect your child. I felt like I failed on that. I should have spotted the signs instead I took what staff and the doctors were saying on face value.

It really affected us all and it really hit his sister big time. We are never going to really know the full scale of what Sam went through.

Sam has been in his home now for 10 years and I could count on one hand how much they have had to restrain him.

Me and other families fought for accountability so it wouldn't happen again. There was the court case. I spent years pushing for the psychiatrist at Winterbourne View to be held to account by the General Medical Council but he wasn't. Winterbourne View took over my life. I was on the news all the time. The anger didn't go away. My health got affected, my job and finances. Eventually after five years I had to stop.

What's hurt me is I'm tired of seeing all the reports and promises and nothing being done. Words on paper but no action. It shouldn't have to be families that have to fight and campaign. We have to deal with our own emotions and our children's. It should be the people in power.

We've still got places like Winterbourne and still got abuse in these places.

Sam still brings up Winterbourne View, it's still there in his mind – he's got a very good memory.

Key theme: Lack of accountability when things go wrong.

When things go wrong and people are abused, neglected or mistreated in inpatient settings, it is rare for true accountability to be faced. Most commonly it is the people at the bottom of the structure, existing in cultures that allow abuse and mistreatment to thrive, who face justice for their part (if at all). Those responsible for developing and maintaining said culture, or for failing to carry out their duty of care either directly or indirectly, walk away.

Those who do face justice are often able to use the 'behavioural challenges' that people with a learning disability and/or autism can present to mitigate in their defence in court – irrespective of the fact that the reason for such challenge is often the abuse or mistreatment sustained at their hands.

One former employee, convicted for his part in the treatment of people at Winterbourne View, said at the time: "It was a very difficult place to work, a tough place to work. We were under-staffed and working 12-hour days without a break."³⁶ This culture was perpetuated by Castlebeck Ltd. who owned Winterbourne View, and the various managers and professionals who worked in positions of greater power in the unit, none of whom faced justice for their part in the failures exposed.

The people at Winterbourne View were placed there by commissioners. They relied heavily on such professionals to keep them safe, and to ensure that the service met the standards expected for their care. All of the commissioners placing people at Winterbourne View failed to do this, and it was BBC Panorama (tipped off by a former employee of the unit) who were responsible for the exposure of the abuse people were experiencing.

With a lack of accountability, in many cases organisations and commissioners are free to make the same mistakes again. The lack of accountability is reflected in a lack of urgency to get it right. Justice is rarely achieved, and it won't be until the repetition of history is stopped.



**"[There are] a lot of bad practices all across the board and no accountability..."
Leo (whose son, Stephen, was in units 2012-2018)**

**"If you don't get the abuse on film it really doesn't seem to count... The sad truth is poor providers are allowed to flourish when they are not monitored and held accountable by those who commission the care."
'Vicky', whose son was in units**

“There has often been a lack of leadership, momentum and communication. Family have driven the progress and have had to seek help from several voluntary advocates and charities.”

‘Louise’ (whose son has been in units 2014-present)

“The mistakes were endlessly repeated, resulting in repeated failures and traumatising experiences. Our son is often implicitly accused of ‘behaving badly’. Who, it might legitimately be asked, is really behaving badly?”

‘Dennis’ (whose son has had two admissions from 1999-2000 and 2007-2013)

Following the Winterbourne View scandal, corporate accountability and responsibility arrangements *were* strengthened by law. This means that it is now supposedly easier to charge and take to trial those who oversee abusive regimes in social care. Despite this, since the law was strengthened just one director has faced imprisonment for their failure to protect people with a learning disability and/or autism who were entrusted to their care (in a residential setting).³⁷

The system continues to fail.

Quick facts:

Winterbourne View was owned by Castlebeck Ltd. Following the closure of the service, Castlebeck was bought by Danshell, which has since been bought by Cygnet.

This cycle of providers and services simply changing their name and continuing under a different guise is troubling. With each change of provider, annual reports are archived and information lost. Too often it appears that services are allowed to continue in the same way, with a ‘clean’ record, and often without people or families having knowledge of what came before, or the risks that may be posed by a failure to change.

“One of [the units Kayleigh was in] was run by an organisation that has had various different names, and each time they receive a bad CQC report, a simple name change ensures all past reports are lost forever in the system. Same staff team, same responsible individual, same poor care with a different name.”

Wendy, mum of Kayleigh

“Nothing has changed since Winterbourne View, they close a building and re-open somewhere else with all the same management structure, same staff, same values. The abuse continues to happen and nothing changes.”

Sue (whose son, Joe, was in units 2010-2012 and 2018-2020)

The abuse continues.

In the last ten years, we have seen coverage of high-profile cases of abuse and mistreatment of people with a learning disability in inpatient units, and beyond.

But we know that is just the tip of the iceberg – it goes nowhere near reflecting the daily experiences of people with a learning disability and their families.

Over the course of the past ten years, other cases will have gone unrecorded and/or unreported, including some experienced by families in this report. This is still happening today.

People with a learning disability and/or autism continue to face the same trauma that we know all too well, and many families face a daily struggle to protect their family members.

“The unit our son was in was closed following the discovery of a controlling and abusive culture. Its failings were not widely publicised and rarely, if ever quoted in the broader debate. There are likely to be many more such cases.”
‘Dennis’ (whose son was in units 1999-2000 and 2007-2013)

The Joint Committee on Human Rights Inquiry into the detention of young people with a learning disability and/or autism, 2019: ‘We regard ourselves as a civilised society with a respect for human rights. Most people would say we should take extra care to support young people and those who are disabled. But the brutal truth is that we are failing to protect some of the most vulnerable young people - those with learning disabilities and/or autism. And indeed, we are inflicting terrible suffering on those detained in mental health hospitals and causing anguish to their distraught families.’³⁸

The truth, devastating though it is, is that we fear daily that another scandal will occur. We know too that for each exposed scandal, another ‘case’ flies under the radar, another person and their family experience trauma, and another road to justice begins – a process that will likely fail to provide the accountability deserved.

This is not just the ‘Winterbourne View scandal’ but a system-wide failure of structures and support. For that reason, and because people with a learning disability and/or autism continue to be undervalued, and placed at increased risk in inappropriate settings, or without appropriate support, we remain able to say with confidence, and with unbearable sadness, that this will happen again.

Ongoing trauma.

The stories and quotes included in this report come from families whose loved ones have experienced trauma, and have been traumatised themselves. This is the effect of inappropriate community and inpatient care, the damage from which is ongoing for those who experience the system.

People with a learning disability and/or autism often have an inherent predisposition to finding change and other circumstances traumatic, as well as an increased likelihood of experiencing traumatic events like abuse, neglect, restrictive practices and overmedication. It’s no surprise, therefore, that the families in this report speak so frequently of their family member’s trauma.

The Learning Disability Senate stated that: ‘People with learning disabilities can be traumatised by the system providing them with care, if for example, they experience difficult interactions including physical restraint and seclusion. These experiences have a negative impact on them and can impact their families. When this happens it must be recognised and addressed and specialist person centred support should be made available for affected individuals and their families’

“My son was horrifically abused. [He] was extremely vulnerable with no speech, he was regularly thrown down into the prone position with several staff on top of him, he was kicked and spat at by members of staff with psychological torture thrown in. Predictably, this broke him, his innocence and childhood was stolen along with his trust in humankind.”

Lynne (whose son, Christopher, was in units 2007-2016)

“My son has been dehumanised, traumatised and brutalised. It is strongly suspected that he is suffering from PTSD.”

‘Dennis’ (whose son was in units 1999-2000 and 2007-2013)

“She was repeatedly restrained. This continued on a daily basis, intra-muscular medication was administered, and she was placed in seclusion for an extended period of time. These experiences were completely new to my family member and she found them intensely traumatic, resulting in a catastrophic deterioration in her mental state.”

‘Sami’ (whose family member was in a unit 2013-2015)

“The environment was torture for her. She was kept in a bright ward with strip lights that hurt her eyes. It was a ward full of distressed youngsters. She couldn’t cope with this. It triggered the behaviours that put her in the unit in the first place – an unbreakable circle of restrictive interventions followed – restraint, seclusion, segregation, secure clothing, PRN to sedate her and a straight-jacket of antipsychotic medication that reduced her from a person to a diagnosis”

Jeremy (whose daughter, Beth, was in a unit 2012-2015, and 2016-2019)

“Due to a non-existent transition, my son was sectioned two months after his 18th birthday. He had never been restrained before in his life, but now was regularly pinned to the floor in prone position by up to ten people, and placed in seclusion.”

‘Juliette’ (whose son was in a unit 2012-2017)

“He suffered his first epileptic seizures for many years, probably as a result of issues around medication and the stress under which he was living.”

‘Dennis’ (whose son was in units 1999-2000 and 2007-2013)

“At one point she inserted a ball point pen fully into her arm. She tied ligatures from her own clothing round her neck. She wanted to die to escape the torture.”

Jeremy (whose daughter, Beth, was in a unit 2012- 2015, and 2016-2019)

“My son thought he was in prison, and to us, it felt like he was being punished for being autistic. Rather than his behaviours being seen as a communication of what he might not be coping with, or struggling to understand, my son was medicated and contained.”

Isabelle (whose son, Matthew, was in units 2015-2017)

In addition to this, people with a learning disability and/or autism may communicate their trauma differently, through behaviours and actions that may be more difficult to identify as responses to a traumatic events. This decreases the likelihood that they may receive appropriate and compassionate support.

Even when identified, there is little in the way of specialist trauma support available, many people with a learning disability may face months, or years, even a lifetime of ‘living with’ their trauma without the necessary therapeutic inputs.

‘Living with’ trauma without support can increase the likelihood of a person being re-admitted to a unit. They are more likely to require mental health inputs as a result of the trauma they have already experienced, and become more vulnerable to abuse, mistreatment and inappropriate treatment in future. The issue becomes cyclical.

Many people with a learning disability are unable to access the mainstream services available to other victims of abuse, instead often having to ‘bury’ their trauma with the expectation that they will simply move on from all that they have experienced. This, of course, is an impossibility and leads to the various diagnoses of post-traumatic stress disorder highlighted in this report, and experienced well beyond.

As a result of trauma, the support around the person, whilst all the more necessary, can feel even more fragile – people and their families are left to face the reality that little specialist support exists to ensure that the status quo is maintained.

On the periphery of the trauma experienced by people with a learning disability and/or autism is the trauma experienced by their families. By the time someone is admitted to an inpatient unit, families have often already spent a lifetime fighting systems, lacking support, and seeing the degree to which their family member is disabled by society. This, coupled with facing the experience of inappropriate inpatient care, can be devastating.

It is impossible to share conversations with families who have experienced inpatient care, and not be struck by the trauma their family members have faced, and the impact this has had on the whole of the family. It is a common thread across all of the stories in this report.

These are just some quotes, shared with us by other families, to highlight the devastating reality people face:

“It was hell on earth what my child, as well as his family went through. These horrors don’t just affect my child but his family as well.”

Leo (whose son, Stephen, was in a unit 2012-2018)



“It took all my physical and emotional strength to deal with the continual horrors faced within the services, balanced with the need to protect my youngest son from harm. Sadly, I didn’t succeed.”

Lynne (whose son, Christopher, was in units 2007-2016)

“As a mum, you feel bereft when your child is taken into a residential setting, being looked after by other people. There should be another option.”

‘Tina’ (whose daughter was in units)

“My greatest sorrow is that I didn’t look after my son myself. I couldn’t have done a worse job and wouldn’t have had to put up with the ‘unprofessionals’ in ATUs, abusers, and those who just don’t care, along the way.”

‘Vicky’ (whose son was in units)

“The damage to my daughter from this experience is immeasurable – 18 months after leaving seclusion she still has flashbacks. She still requires huge amounts of support for the trauma she suffered. She takes months to trust new people and finds any sort of new experience hugely difficult to tolerate. Nothing we can do will ever make up for the lost years and the trauma... She was blamed for placements failing. The trauma it caused her was never considered. She was seen by the local authority as an expensive drain on resources – both in money for care packages and the staff’s time.”

Jeremy (whose daughter, Beth, was in units 2012-2015, and 2016-2019)

“His support broke down and the only way I can describe my son at that time was ‘feral’. It was the most traumatic period of our lives.”

Sue (whose son, Joe, was in units 2010-2012 and 2018-2020)

“We are only now beginning to see the person whose true nature and personality has for so long been obscured because of the oppressive, damaging environments in which he has had to live.”

‘Dennis’, (whose son has had two admissions between 1999-2000 and 2007-2013.

At the time, when my son was away, I was on autopilot. The travelling was really tiring and on top of that there were the emotions of leaving your 13 or 14 year old child so far away. But the physical exhaustion didn’t fully hit us until he came home. I got ill with everything under the sun. 3 years of exhaustion, of travelling 150,000 miles and fighting to bring him home”

Phill (whose son, Josh, was in a unit 2012-2015)

Of the families whose stories and quotes featured in this report, all have identified a lack of trauma support after inpatient care for their family member.

- All highlight an increase in their family member’s support, and emotional needs as a result of their inpatient experiences.
- Similarly, all families have further identified an impact on their own health and wellbeing, and that of other family members.

A recent report by the Challenging Behaviour Foundation found:³⁹

59% of families who participated in a survey experienced regular guilt pertaining to their experiences of having a family member with a learning disability

Over 72% of participants had experienced, at least once, all of the following as a result of the experiences of the system: Panic attacks; insomnia/disturbed sleep; inability to work/job loss; disagreement with friends/family members; family members leaving home; relationship breakdown; depression; anxiety and fearfulness.’

The damage is preventable.

People with a learning disability and/or autism are repeatedly admitted to inpatient services inappropriately, often due to a lack of the right support in the community. Many, indeed most, admissions are entirely preventable.

As these stories show, for some, a few additional hours of community support could have sufficed to prevent admission. For others, an alternative to inpatient treatment once crisis was reached was required. This is an issue highlighted over the course of the ten years since Winterbourne View, with very little progress having been made to ensure others are not admitted inappropriately, even now.

Many families will speak of how quickly things can reach crisis point when things go wrong, highlighting the need for early intervention, and listening to families who feel unable to cope.

For too long the focus has been on numbers, with targets being assigned to areas to get people out. The units, though, stay open and ready to take more people in the wake of those who leave, and a continued lack of community support means that there are always people at risk of being the next to fill the beds.

Good support in the community is possible. It requires a multi-disciplinary approach with a real will to avoid the inpatient alternative. To make this effective, the targets and incentives must change, and the focus must move to prevention as well as fixing what has already been done wrong.

Case study: Avoided admission

I received a phone call at work one day informing me that my daughter was being assessed later that day by the mental health team with a view to her being sectioned and hospitalised.

This was extremely frightening, as I did not know what our rights were in regard to challenging this decision. We felt we were not listened to by anyone, including her care providers. We spent hours explaining my daughter's needs, but everyone seemed to think that, as 'professionals', they knew best.

During this time, I contacted two of my daughter's former support workers. They were an invaluable support as they have known my daughter all her adult life and understood her needs, and how to support her well in the community.

They had set up their own service and were convinced that they could offer her a secure and happy home. They got in touch with the local authority to offer her a place. Unfortunately, even though it had been agreed that my daughter was not currently in a safe or suitable environment and was at imminent risk of being sectioned, the local authority were not willing to fund the placement.

After seeking advice and legal support, and with the involvement of a lawyer, it was finally agreed that she would be funded to move to the placement. She has been in her new home since August last year and is quickly returning to the happy, bubbly, fun loving young lady that we have been missing for so long. She accesses the community daily and has become a bit of a celebrity in the neighbourhood due to her singing and bubbly personality.

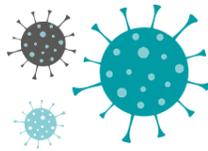
As a family we are slowly healing from the trauma of the last few years and we are extremely thankful that my daughter is now where she needs to be.

Annemarie, mum of Catherine.



Impact of the Coronavirus pandemic

The coronavirus pandemic has compounded many of the issues faced by people with a learning disability and/or autism, both in inpatient units and in the community.



In the community:

The system, already in crisis is struggling even more to cope, risking admission for even more vulnerable people. Research undertaken by Mencap and the Challenging Behaviour Foundation⁴⁰ has found:

● Almost two thirds (**63.0%**) of family members and carers said their loved one's support needs had increased during the COVID-19 pandemic.

● Over a third (**36.1%**) of family members and carers said the amount of social care support their loved one receives from the local authority has decreased (with 16.3% stating support had stopped completely).

● **73.1%** of family members and carers said the amount of care and support they are providing to their loved one with a learning disability has increased during the COVID-19 pandemic.

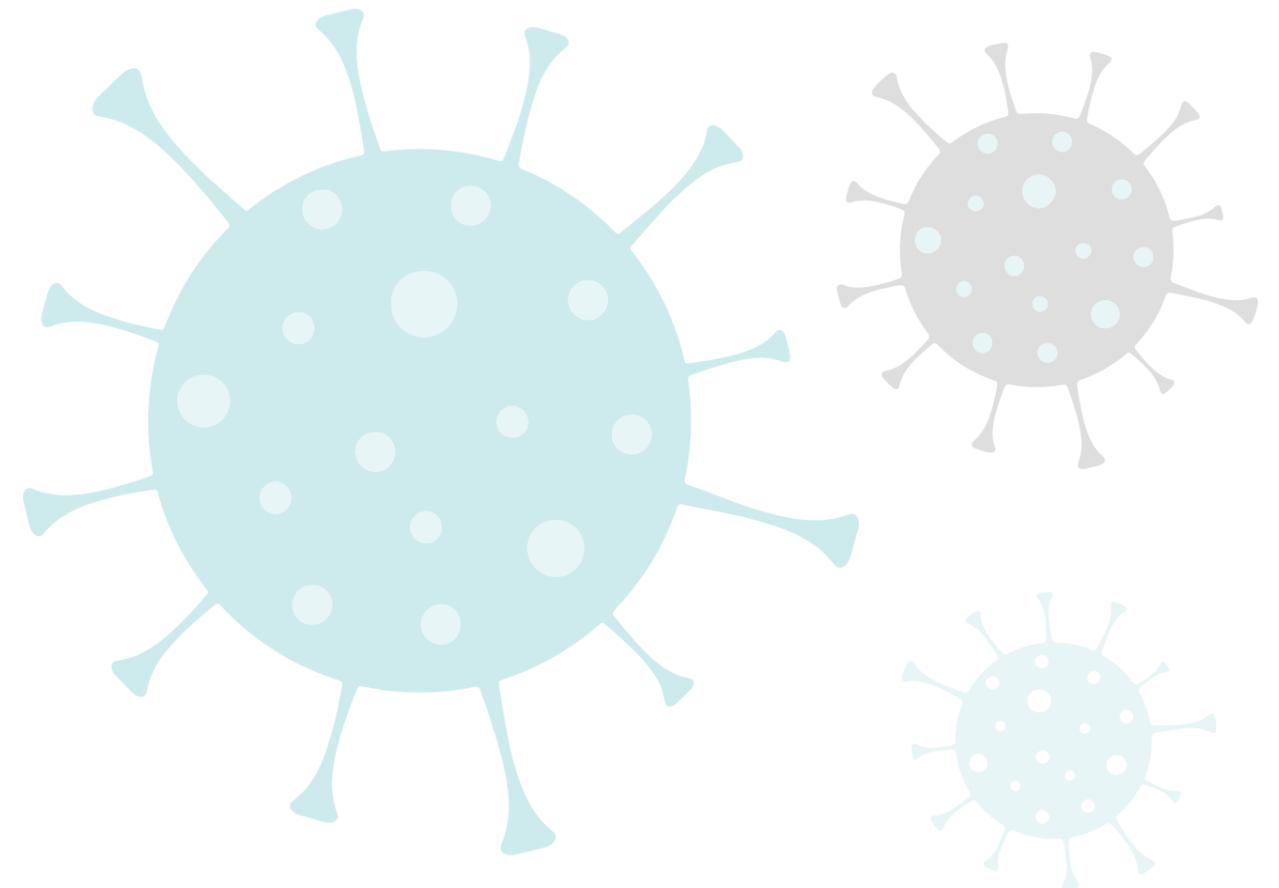
● Over three quarters (**76.4%**) of family members and carers said the severity of their loved one's challenging behaviour has increased during the COVID-19 pandemic. (**34.2% said it has increased a lot, whilst 42.2% said it has increased a little**)

Meanwhile, in inpatient units:

Over the last year, much of the oversight of service quality, already lacking before the pandemic, has worsened as doors have been even more firmly closed.

The Joint Committee on Human Rights report, stated in June 2020⁴¹: “Now that institutions are closed to the outside world as a result of the Covid-19 pandemic, the risk of human rights abuses are even greater. Unlawful blanket bans on visits, the suspension of routine inspections, the increased use of restraint and solitary confinement, and the vulnerability of those in detention to infection with Covid-19 (due to underlying health conditions and the infeasibility of social distancing) mean that the situation is now a severe crisis”.

As we come out of the pandemic, many people with a learning disability and/or their families are likely to need even more support and this must be made available. Over three quarters (76.4%) of family members and carers are worried about the longer-term impacts of the COVID 19 pandemic on their loved one's mental health.



Action speaks louder than words.



We've seen many reports, with countless recommendations over the years, but few have materialised into action. As families, it is not our role to provide fine details to those who can, and should make things happen, but to use our experiences to highlight what needs to change.

We have therefore thought carefully about what to recommend, and have drawn on our own knowledge of what has been consistently ignored or undervalued to highlight these key areas.

1. Avoiding trauma in the first place

- People must be able to get the right support in the community, at the right time.
- We don't want the system to be reactive in letting people be traumatised, then trying to support them to deal with the trauma.
- We need the system to be proactive, investing in the right support in the community that will reduce the likelihood of trauma happening. Not traumatising people in the first place.

2. The focus needs to shift to early intervention and preventing admission/readmission, as well as getting people out of inpatient units

Such a shift would reflect a recognition of the damage admissions can cause and a commitment to stop the damage.

There must be a robust focus on this in a cross-government action plan, detailing routes through which admission and readmission can be realistically avoided for those at risk now, or who may be in the future. The focus should be on:

Getting the right support when people and families need it, including:

- Suitable respite available for people and their families
- Crisis support for people and their families, including 24/7 input from multi-disciplinary teams and flexible social care provision which can be used as an alternative inpatient admission in a crisis situation.

- In a similar format to the Community Discharge Grant, there must be an Early Intervention and Prevention Grant available to incentivise local areas to ensure people get the support they need early on, to prevent crisis situations and emergency admissions.

There must be accountability for those who fail to build successful infrastructures for this purpose, recognising the often long-term damage this causes to our family members.

- There must be appropriate training and pay for support staff.
- Housing, including specially adapted and single-person bespoke provision must be available to those who need it. There must be adequate funding for this, and a focus on understanding who may need such provision at an early stage so that plans can be implemented before admission becomes necessary.

3. Appropriate trauma support must be implemented for individuals and families

There must be a robust focus on the traumatic impact of inpatient services on people with a learning disability and/or autism and their families in a cross-government action plan. This must ensure:

That trauma-informed services are available for those who have been in inpatient services, or who require it to avoid admission in the first place.

- People's history of trauma, whether in inpatient units or not, should be recognised, appropriately shared and taken into account when commissioning services.
- Care-planning must take full account of traumatic experiences and how these may have impacted on the person's behaviour and trust.

That support post-inpatient care is both informed and empathic to people's needs, including any increased needs.

- There must be appropriate training and support for organisations and their staff in delivering trauma-informed care, and ways of working with families.

That support is available to people with a learning disability and their families when they need it, within their local communities:

- Psychologists and community teams must understand how to work with people with a learning disability who have experienced trauma.
- Commissioners must ensure that appropriate trauma support is commissioned, which meets the needs of people with a learning disability and families.

No more Tea, smiles and empty promises.

Featured within this 'collection of stories' are the lives of six human beings who have been severely damaged by a system intended to 'care' for them.

As families, we have been forced to bear witness to a continuing crisis, each day joined by more people whose lives and families' lives are being corrupted by the same failures. We share in the sorrow of each new story that joins our own.

When writing this report, we felt it was important to reflect on the lack of change from a human perspective, to use our platform as family members of people whose experiences were publicised, to highlight the experiences of the many others who haven't been, and to speak frankly about the challenges our families, and others still face.

At the core of this are our loved ones- who have experienced a lifetime of stigma, and the worst side of 'care'.

This report cannot capture all of the issues with the system, nor does it give a voice to all who have experienced these. The key themes we highlight could be joined by many more - the voices could number into their thousands.

Multiple governments have failed to make the necessary change to protect some of society's most vulnerable people, not just from abuse and mistreatment, but also from a simple lack of care, attention, flexibility and thought.

Truly, it isn't rocket science. In all of the failures, many of us have seen glimpses of what could and should have been. We've seen people avoid admission even when they've reached crisis point, albeit frequently through the sheer determination of families to make it so, often through media and legal pressure.

We've seen people live independent and joyful lives in their communities just as they should. We've seen committed, caring and determined workers, who have changed lives and minds. And we've seen professionals who have it right, who are committed to making the difference we're all so desperate to see. We've even seen the odd Assessment and Treatment Unit finally close a bed!

The issue remains though, and whilst in 2011, the need for change was urgent- ten years on, in the wake of new scandals, new stories, and a pandemic that has compounded it all, it is all the more so.

For our family members, and all others whose lives have been affected, destroyed by or lost to the system - the time is now.



Signposting for people and families affected.

If you are worried that someone you know with a learning disability and/or autism is at risk of admission to an inpatient unit, or is currently in an inpatient unit and you are concerned about their care, please see the following for further information and where to go for support:

- **If your relative has a severe learning disability**, you can contact the **Challenging Behaviour Foundation Family Support Service: 0300 6660126** or **email support@theCBF.org.uk**
- **For people with a learning disability and their families and carers**, you can contact the **Mencap Helpline: 0808 8081111** or **email helpline@mencap.org.uk**
- **If your relative is autistic** you can contact the **National Autistic Society's Autism Inpatient Mental Health casework service: <https://www.autism.org.uk/what-we-do/help-and-support/autism-inpatient-mental-health-service>**

Resources:

www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/when-things-go-wrong.html

www.mencap.org.uk/advice-and-support/displaying-challenging-behaviour/meeting-challenge-guides-families

www.autism.org.uk/advice-and-guidance/topics/inpatient-mental-health-hospitals/autistic-people-and-inpatient-mental-health-hospit



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- ² <https://www.gov.uk/government/consultations/reforming-the-mental-health-act/reforming-the-mental-health-act>
- ³ NHS Digital (2021) Learning Disability Services Monthly Statistics (AT: April 2021, MHSDS: February 2021 Final). Reference tables data. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-services-monthly-statistics-at-april-2021-mhsds-february-2021-final>
- ⁴ Mencap and CBF press release, 27th May 2021. See Note 1 below.
- ⁵ NHS Digital (2021) Learning Disability Services Monthly Statistics (AT: April 2021, MHSDS: February 2021 Final). Reference tables data. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-services-monthly-statistics-at-april-2021-mhsds-february-2021-final>
- ⁶ CQC (2020). State of Care Report 2019/2020: www.cqc.org.uk/sites/default/files/20201016_stateofcare1920_fullreport.pdf
- ⁷ HSCIC (2015) Learning Disability Census Report. England 30 September 2015 experimental statistics. <https://files.digital.nhs.uk/publicationimport/pub19xxx/pub19428/ld-census-initial-sep15-rep.pdf>
- ⁸ We are aware of some individual cases where the weekly cost has been £12,000 or more.
- ⁹ www.communitycare.co.uk/2017/07/05/locked-learning-disability-units-want-son-home/
- ¹⁰ NHS Digital (2021) Learning Disability Services Monthly Statistics (AT: April 2021, MHSDS: February 2021 Final). Reference tables data. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-services-monthly-statistics-at-april-2021-mhsds-february-2021-final>
- ¹¹ NHS Digital (2021) Learning Disability Services Monthly Statistics (AT: April 2021, MHSDS: February 2021 Final). Reference tables data. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-services-monthly-statistics-at-april-2021-mhsds-february-2021-final>
- ¹² Mencap and the Challenging Behaviour Foundation (2021). Experiences during the COVID-19 pandemic and coming out of lockdown: people with a learning disability and their family members/carers – online survey
- ¹³ www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf
- ¹⁴ <https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>
- ¹⁵ <https://www.bbc.co.uk/news/uk-england-devon-29904799>
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- ¹⁷ <https://www.independent.co.uk/news/health/mental-health-care-seclusion-inadequate-cqc-segregation-st-andrews-learning-disability-autism-a8945986.html>
- ¹⁸ www.bbc.co.uk/news/uk-england-suffolk-56279805
- ¹⁹ www.mencap.org.uk/press-release/human-rights-scandal-government-continues-ignore
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- ²¹ Analysis by Mencap and the Challenging Behaviour Foundation of admissions data in the NHS Digital Assuring Transformation dataset, March 2021 (April 2021)
- ²² NHS Digital (2021) Learning Disability Services Monthly Statistics (AT: April 2021, MHSDS: February 2021 Final). Reference tables data. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-services-monthly-statistics-at-april-2021-mhsds-february-2021-final>
- ²³ Mencap and CBF press release, 27th May 2021. See Note 1 below for how these figures have been calculated.
- ²⁴ NHS Digital (2021) Learning Disability Services Monthly Statistics (AT: April 2021, MHSDS: February 2021 Final). Reference tables data. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-services-monthly-statistics-at-april-2021-mhsds-february-2021-final>
- ²⁵ See Note 1 for information about how this was calculated
- ²⁶ Mencap and CBF press release, 27th May 2021. See Note 2 below for how these figures have been calculated.
- ²⁷ <https://sites.southglos.gov.uk/safeguarding/adults/i-am-a-carerrelative/winterbourne-view/>
- ²⁸ CQC (2020). State of Care Report 2019/2020: www.cqc.org.uk/sites/default/files/20201016_stateofcare1920
- ²⁹ HSCIC (2015) Learning Disability Census Report. England 30 September 2015 experimental statistics. <https://files.digital.nhs.uk/publicationimport/pub19xxx/pub19428/ld-census-initial-sep15-rep.pdf>
- ³⁰ We are aware of some individual cases where the weekly cost has been £12,000 or more.
- ³¹ <https://dictionary.cambridge.org/dictionary/english/institutionalized>
- ³² <https://www.communitycare.co.uk/2012/08/07/winterbourne-view-a-case-study-in-institutional-abuse/>
- ³³ NHS Digital (2021) Learning Disability Services Monthly Statistics (AT: April 2021, MHSDS: February 2021 Final). Reference tables data. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-services-monthly-statistics-at-april-2021-mhsds-february-2021-final>
- ³⁴ NHS Digital (2021) Learning Disability Services Monthly Statistics (AT: April 2021, MHSDS: February 2021 Final). Reference tables data. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-services-monthly-statistics-at-april-2021-mhsds-february-2021-final>
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- ³⁶ <https://www.bbc.co.uk/news/uk-england-bristol-20092894>
- ³⁷ <https://www.express.co.uk/news/uk/814348/care-boss-jailed-Atlas-Project-Team-Limited-residents-locked-punishment-rooms>
- ³⁸ <https://publications.parliament.uk/pa/jt201919/jtselect/jtrights/121/12103.htm>
- ³⁹ Challenging Behaviour Foundation (2020) 'Broken, The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support required', compiled the experiences of 214 families with family members in services across the system (5% of whom were in an inpatient unit).
- ⁴⁰ Mencap and The Challenging Behaviour Foundation (2021). Experiences during the COVID-19 pandemic and coming out of lockdown: people with a learning disability and their family members/carers – online survey. See Note 3 for further information.
- ⁴¹ <https://committees.parliament.uk/work/218/the-governments-response-to-covid19-human-rights-implications/news/115225/coronavirus-has-left-young-people-in-detention-facilities-highly-vulnerable-to-human-rights-abuses/>

Note 1

Mencap and CBF have used NHS Digital MHSDS Data to calculate these figures for restrictive practices used against people with a learning disability and/or autism in inpatient units. Please note some of these interventions may together combine to count as one restrictive intervention episode, i.e. multiple types of intervention could be used at once.

Note 2

Mencap and CBF have used the Assuring Transformation data from NHS Digital to calculate the number of admissions or readmissions between March 2015, the start of the Government's Transforming Care programme, and April 2021, the latest dataset. Figures for admissions exclude data relating to hospital transfers.

Note 3

Mencap and The Challenging Behaviour Foundation (2021). Experiences during the COVID-19 pandemic and coming out of lockdown: people with a learning disability and their family members/carers – online survey.

Mencap ran a survey with 476 family members and carers of people with a learning disability in the UK. For more information please contact research@mencap.org.uk

