Care Quality Commission

Out of sight – who cares?

A review of restraint, seclusion and segregation for autistic people, and people with a learning disability and/or mental health condition

OCTOBER 2020

About the Care Quality Commission

Our purpose

The Care Quality Commission is the independent regulator of health and adult social care in England. We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Our role

We register health and adult social care providers.

We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.

We use our legal powers to take action where we identify poor care.

We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

Our values

Excellence – being a high-performing organisation

Caring – treating everyone with dignity and respect

Integrity – doing the right thing

Teamwork – learning from each other to be the best we can

Notes on the report

The art on the front cover was drawn by Alexis Quinn. Alexis has lived experience of being secluded and segregated. This is her artistic interpretation about how it feels to be in seclusion and segregation.

Trigger warning: In this report there is content and descriptions of people's lives and experiences, which some people may find distressing.

Where we found poor care or risks to people's human rights in our review, we took regulatory action against the service; you can see the full list of the action that we took in **appendix A**.

Some of the stories included in this report are illustrative and some are real life examples. Where we have used real life examples, we asked people to give their consent to include them, and we ensured that we changed any identifiable information, such as age, gender, or location, to protect their identities.

'Complex care' – what do we mean?

Throughout this report we have in places referred to care as being 'complex'. For the purposes of this report, we are defining complex care as care for people with multiple and sometimes interconnected health, communication and social needs. Their care typically requires coordination and input from a range of skilled professionals who may be employed by different organisations.

Contents

Restrictive practice is a human rights issue

To understand the issues around restraint, seclusion, and segregation you must hear from the people who have experienced it first-hand. This report tells the story of restrictive practices from their perspective.

Below is the story of Alexis, an academic, international athlete, and school teacher. Alexis was restrained and secluded many times before she was able to leave the hospital system.

ALEXIS'S STORY

I suffered a personal crisis when my brother died, and I was unable to access appropriate care in my local area. With my ability to manage my autistic reaction to trauma deteriorating, I sought help from mental health services. This proved to be my biggest mistake.

I entered hospital for an initial 72 hours' intervention. Due to a catastrophic clash between my autism and the environment, I became overloaded and entered a damaging cycle.

It felt cruel – like I was set up to fail. I would never, ever be able to tolerate the lighting, the noise, the chaos and the sensory charged box I was kept in. My different and sensitive autistic neurology was at the mercy of those who held the keys. I began to look as they described – violent and dangerous because I couldn't control myself.

In total, I was restrained 97 times and secluded 17 times. I was forcibly drugged. The drugs took over every aspect of my very being. My body was battered and bruised, and my identity was fractured. They didn't like the autistic part of me. I tried to tell them that autism is all of me, it's who I am. I argued that my autism couldn't be treated. They said I lacked insight. Knowing I couldn't change, and being labelled as "treatment resistant", I grew to hate myself and I lost hope. I'd never get out.

After three and a half years of restrictive practice in 12 different hospitals around the UK, I fled whilst on a Section 3 to Africa. There, I created a routine. I made my days predictable and my home autism-friendly. Nothing in my house aggravated my sensory system. I weaned myself off the drugs, sought private psychology for the trauma I experienced (starting with the death of my brother). After six weeks, I started work as a teacher again. The key to success is creating the right environment and treating psychological differences with dignity and respect.

Foreword

This review has shown that for some people who need complex care, the system lets them down. It is often seen as too difficult to get it right – they fall through the gaps.

To be clear, this is a report about the people we saw and the use of restrictive practice.[a] It is not a comprehensive overview of mental health, learning disability or autism care in England. However, the fact that some of the practices we saw were happening at all has implications for the wider health and care system.

We found too many examples of undignified and inhumane care, in hospital and care settings where people were seen not as individuals but as a condition or a collection of negative behaviours. The response to this has often been to restrain, seclude or segregate them.

We have seen how the very nature of mental health hospitals can be distressing, particularly for people with a learning disability and/or autistic people. This includes the physical ward environment as well as lack of access to psychological support. Unlike in a general hospital where you would have a plan for your treatment on admission, we saw people admitted with no assessment, treatment or discharge plans in place.

We also found that a lack of training and support for staff meant that they are not always able to care for people in a way that meets those individuals' specific needs. This increases the risk of people being restrained, secluded or segregated.

However, we did find that it is possible to get even the most complex care right. Delivering care in a system with complex funding arrangements and workforce shortages is undoubtedly difficult, but it can be done effectively.

Community services must be able to adapt and tailor care to individual needs. We found some providers could do this. People need support to be available in their community, close to where they live and accessible when needed.

Repeatedly throughout our review, families and carers told us that if they and their loved ones had received the right help and support earlier, or when in crisis, they may not have needed hospital care. Staff often echoed this.

We have seen how increased support in the community can stop people who might otherwise be labelled 'too complex' from needing to go into hospital.

While our review took place before the coronavirus pandemic reached the UK, the circumstances of people that have fallen through the gaps has not changed. Indeed, our concerns have become more pronounced. As raised by Mencap and the Challenging Behaviour Foundation in April and September 2020, coronavirus has left some people unable to access the care they needed, and has caused delays to people leaving hospital.[1,2] In some
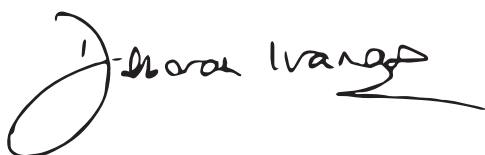
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a   See '**Background**' (page 6) for details

cases, this has led to restrictions on people's movements, and services having to restrict or stop families from visiting their loved ones, as well as increasing the risk of closed cultures developing.

Comprehensive oversight of the care provided, and specifically responsibility and accountability for the commissioning of care, is lacking. The absence of this scrutiny has led to people being kept in hospital indefinitely and experiencing increasing amounts of restriction. Now, more than ever, strengthened oversight and scrutiny of these care settings is needed when people are in prolonged seclusion and segregation.

It is clear there needs to be fundamental change in the way care is planned, funded, delivered and monitored for this group of people. This change needs to be led by national and local leaders and underpinned by a firm foundation of human rights, to deliver a culture where restraint, seclusion and segregation are no longer accepted and are only used in extreme cases. We all have a part to play to ensure that this improves.

Deborah Ivanova

Deputy Chief Inspector, Adult Social Care

Dr Kevin Cleary

Deputy Chief Inspector of Hospitals and lead for mental health

Introduction

Concerns about the use of restrictive practices and people being segregated are not new. Since the Mansell report in 2007, there have been many reports that have highlighted similar issues, especially around the care for people with a learning disability or autistic people.[3,b]

In October 2018, the Secretary of State for Health and Social Care asked us to carry out a review of autistic people, and people with a learning disability and/or mental health condition who may be subject to restrictive practices as a result of ongoing concerns in this area.

We asked a group of people with lived experience to evaluate the findings of previous reports about restrictive practice that related to autistic people, and people with a learning disability and/or mental health condition. These previous reports have highlighted that without the right care and support in the community early on, people were being admitted to hospital inappropriately. For example, the **Bubb report** in 2014 stated that, "for many years too many people with learning disabilities and/or autism have been, and continue to be, in inappropriate inpatient settings – often a very long distance away from family and their communities."[4]

We know if people are admitted to hospital this should be for the shortest period, with the least restrictive interventions possible. Unfortunately, many people stay too long in these settings and are subject to unnecessary restrictive interventions. In addition, our review found the length of time people spent in prolonged seclusion ranged from two days to seven months, and in long-term segregation from three days to 13 years. Almost 71% of people whose care we reviewed had been segregated or secluded for three months or longer. A few people we met had been in hospital more than 25 years.

Once admitted, a lack of joined-up thinking across the system, funding struggles and a lack of local service provision have meant that people have not been discharged back into the community. In these hospital services, high levels of restraint, seclusion and segregation, and a lack of therapeutic and social input are having a detrimental impact on individual people.

This report describes what we found about the current state of the care system for children, young people and adults who have diverse needs that are subject to restrictive interventions, and who are cared for in a range of settings. Although our review looked at a wide variety of services, the majority of people we saw had a learning disability or were autistic. As a result, we have focused this report on what we found in relation to them. However, our findings have implications and learning for settings that support people who have a mental health condition and/or who are living with dementia.

While this report tells the horrific experiences of some people's care, it also tells the story

of what is possible if people have the right support in place. Progress has been made with legislation such as the Mental Health Units (Use of Force) Act 2018 and community care-focused programmes such as **Transforming Care**, but this must happen at a quicker rate.[5] It is possible for people who need a lot of support from health and care services to lead fulfilling lives, close to their homes and communities.

During the course of our review, we heard from people who were subject to restrictions, their families and carers, and frontline staff about experiences of care. Their voices are at the heart of this report and underpin our findings.

Background

How we carried out our review

The scope of the work was broad, and included health and care settings that care for autistic people, and people with a learning disability and/or mental health condition. As a result, we have looked at people across many different services, conditions and sectors to form a view of restrictive practice.[c] Our sample size was specific, and so is not representative of all hospital or residential care for autistic people, people with a learning disability and/or mental health condition in England. We focused on the experiences of the people we saw, as well as information collected through our information requests – the majority of whom were people with a learning disability or autistic people.

When we started our thematic review, the national data collected in the Mental Health Services Data Set about the use of restrictive interventions was incomplete and inconsistent because some providers do not submit any data and others submit data that is not credible. CQC, NHS England and NHS Digital have since worked with providers to improve the quality and reliability of this data.

In compiling this report, we relied on the following evidence.

We visited:

- 43 hospital wards for people of all ages with a learning disability or autistic people, and specialist NHS and independent child and adolescent mental health wards

- 13 hospital mental health rehabilitation and low secure mental health wards, and 27 people in other mental health hospitals

- 27 care homes for the care of people with a learning disability or autistic people; 11 children's residential services that are jointly registered with CQC and Ofsted, and five of the 13 secure children's homes in England (two of these reviews were desktop reviews).

We also gathered information remotely through:

- 452 questionnaires on restrictive interventions, completed with registered managers of adult social care services, during inspections between July and October 2019

- assessing a sample of care plans at each service

- reviewing prescriptions and other medicines records

- writing to commissioners about the cost of placements.

The full list of services we visited and the scope of our review is in **appendix B.**

The people we saw with the most restrictive care – their backgrounds

The majority of people we reviewed in-depth on our visits to hospitals were autistic; 42 out of 66 had a formal diagnosis. This mirrored the results from our information request, which showed that 67% of people in long-term segregation

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c   See our **Terms of Reference**

on learning disability and child and adolescent mental health service wards were autistic.

Other people we met had a learning disability or a mental health diagnosis. Often, people with a mental health condition were diagnosed with a range of disorders, including anxiety and depression, psychosis, personality disorders, schizophrenia and post-traumatic stress disorder.

However, for some people, their diagnosis was unclear due to a lack of assessment, despite their clinical notes saying that they were displaying "autism traits or sensory issues".

The people we visited often had difficult or traumatic backgrounds, which had not been considered when developing a treatment plan. For example, 21 of the 66 people we visited in hospitals had been, or were, looked after children.[d] For some, this was because their family could not access care support. Where we had concerns about people's care we escalated them.

People told us that they were more likely to experience increased distress or deterioration in their mental health after a significant life event or at a certain age. This was particularly likely between the ages of 12 and 15.

Some people we met had experienced abuse in their family or had suffered physical or emotional abuse by staff in previous care settings. For example, in the secure children's homes, five out of six children had come from families where there had been domestic violence and abuse or neglect, with three excluded from education.

In addition, members of our Expert Advisory Group (EAG) and people and their families told us that their loved ones had experienced being restrained in schools for children and young people with special educational needs and disabilities.

In low secure hospitals, there was a particularly distinct group of young women in seclusion or long-term segregation who seemed to have a very similar history, which included abuse or neglect as a child and incidents of self-harm. Before entering adult services, they had been in child and adolescent mental health services (CAMHS), sometimes on low secure wards. These women tended to have a long history of multiple hospital admissions and placements in care institutions over their relatively short lives. They were being treated in long-term segregation or frequent repeated episodes of seclusion because of the risks they presented in the ward environment. One reviewer reflected on this pattern and commented that:

"…this young woman has been in 14 different places since her first admission at a number of different locations […] It seems that she has just been passed from place to place, with no clear overriding plan to get her out of hospital – even though it is apparent that hospital admissions have not helped her. This, in my view, is a common experience for women in low secure care – and is especially true of the trajectory of young women coming out of CAMHS services."

On average, people in long-term segregation and seclusion had experienced three different care settings in the previous five years, which highlights the failure of services to meet people's needs.

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d   A child who has been in the care of their local authority for more than 24 hours is known as a looked after child. **NSPCC**

Missed opportunities to avoid hospital – focus on people with autism

People often ended up in hospital because they did not have the right support, early on, in the community at the time they and their families needed it. This was particularly the case for people we saw who were diagnosed as autistic.

In this section, we explore the 'missed opportunities' for those people, and what support could have been put in place earlier to prevent admission to hospital. This includes issues around diagnosis, waiting times, transition planning and social care support.

Difficulties with getting an autism diagnosis

Getting a diagnosis for autism was a key concern, with families often waiting for long periods or having to fight to get a diagnosis.

This is supported by the findings of the 2019 **All Party Group on Autism report** and Self-Assessment Framework (SAF), which stated that on average adults have to wait 30 weeks after referral to get a diagnosis, with people in some areas waiting two years. This is the same for children, with many waiting for two years.[6]

NHS Digital data shows that from October to December 2018, only 18% of patients referred with suspected autism had their first appointment within 13 weeks, with 4% reported as waiting over 13 weeks, and 78% reported as having no contact date.[7]

The length of time people are waiting is contrary to best practice. The NICE (National Institute for Health and Care Excellence) Quality Statement QS51 states that people with possible autism who are referred to an autism team for a diagnostic assessment should have their first diagnostic assessment started within three months of their referral.[8]

People also told us of differences in the quality of diagnoses between different clinicians, and in

some cases, people were diagnosed with autism years after signs were first spotted.

Lack of early intervention for people with autism

Many families told us that, following a diagnosis of autism, early support was not always available from health, social care and education agencies. When care was commissioned, there was not enough knowledge about autism. In addition, people's individual needs were not understood until it was too late. People and their families also told us that a lack of knowledge, understanding, and support in schools sometimes led to children being excluded.

Families told us they felt that the 'system' was broken and was being reactive and not proactive to people's needs. They told us that receiving extra support while their family member was still living at home, or in the community, could have prevented the need for them to be admitted to hospital.

"Lucy was living at home and bi-monthly respite care had just started. However, after two months this was withdrawn as the service found it difficult [to support her]. The local CAMHS service could not offer support either."

For children and families, the onset of adolescence and puberty, as well as the transition period between child and adult services, was a key time when things could go wrong. These changes were often not planned for early enough, or were not successful because of a lack of a joined-up approach between local social care and education services, and families did not feel supported through these periods.

HARRY'S STORY

Jane (Harry's mum) told us about the journey for 22-year Harry, who is autistic. Harry also has a moderate learning disability, and he communicates his distress and needs in a way that others may find challenging.

Harry had been to a school for special educational needs. Jane knew that she needed more support to help her care for Harry. By the time he was 14 years old, Jane was calling the police regularly. She frequently requested extra help from services but was told that how he was behaving was not concerning enough.

Things got worse, Harry was suspended from school for throwing things and becoming more aggressive with belongings and furniture. Still there was no support and Jane was left to get on with it. This started to affect her own health.

Eventually care was arranged, but Jane did not feel involved in decisions around this. Harry was moved between different child and adolescent community services and at 18 was moved to adult services. During his time in community care, Harry experienced emotional and physical abuse by staff and other residents. Harry ended up being placed in hospital and then in segregation. There was no discharge plan in place and he is still currently in hospital.

Opportunity for the future

All of these issues present opportunities for the future. We know from our review that if families receive the right support when they need it, people have a much better chance of avoiding hospital admission. This stems from getting diagnosis as early on as possible, to getting help to look after their children in their communities and at home, as well as ensuring there is a better professional understanding of learning disabilities and autism. Greater integration between local services is needed so care can be centred around the individual.

A culture of restrictive practice: an equality and human rights issue

In this section, we look at Anna's care and how that relates to human rights.

Human rights breaches are not inevitable in any setting. To uphold people's human rights, providers need to always assess and keep under review if there is a less restrictive option for the people they are caring for. Under the Equality Act 2010, all healthcare providers have a duty to make reasonable adjustments for disabled people.[9] This includes, for example, adjustments to the environment and communication.

The British Institute of Human Rights has highlighted that to achieve this, there needs to be a service-level culture change, where staff care for all people from a human rights perspective.[10]

We saw some services taking a human rights approach, but this was not the case across all services. Anna's story shows when this is not the case.

ANNA'S STORY

Anna, 24, is a young woman with autism who was in long-term segregation on a mental health ward and was often secluded. Staff did not understand how her autism affected her and they did not make any reasonable adjustments. As a result, she experienced some breaches of her human rights.

Anna had difficulty speaking to staff because of her autism and did not understand metaphors or abstract concepts. The care team expected her to show that she was sorry before they ended her seclusion, even though Anna did not understand what this meant, or what the care team wanted her to say. This meant she stayed in seclusion for much longer than she needed.

She had traffic light cards to help her tell staff how she was feeling, but these were taken when her room was stripped following an incident of self-harm. Staff misplaced the cards, which meant that she was not able to communicate to let staff know when she was becoming increasingly distressed.

Staff did not take account of Anna's sensory needs. The seclusion room had a bright day light and a dim night light but nothing in between. This made her feel distressed because of her autism.

At one point, staff stopped her mum from visiting her for five months – they said it was because of her behaviour. Staff said that she was too dependent on her mum, even though both Anna and her mum wanted the visits to continue.

The physical health care that Anna received was poor, and there were times when she was prevented from using the toilet. Anna's mum told us that the service did not refer her to a specialist after an incident that caused injuries on her arm and left her in pain for several months, despite her constantly asking for help for her daughter.

How does Anna's story have implications for human rights?

In Anna's case, there are several rights under the Human Rights Act 1998 that could have been at risk.[11]

Article 3 – inhuman or degrading treatment

Some of Anna's experiences amount to risks to her absolute rights. This includes Article 3 – the right to not be subjected to torture or to inhuman or degrading treatment or punishment. Your right not to be tortured or treated in an inhuman or degrading way is absolute. This means it must never be limited or restricted in any way. For example, a public authority can never use lack of resources as a defence against an accusation that it has treated someone in an inhuman or degrading way.

In Anna's case, there was a risk of inhuman treatment when she was in pain for several months due to the provider failing to get her medical treatment. As Article 3 is an absolute right, if there is a risk that this right may be breached, providers must address this with the highest priority.

Article 8 – respect for private and family life

Some of the things Anna experienced may have risked a qualified human right – a right that can be restricted if the restriction is lawful, for a legitimate aim and the least restrictive option to meet that aim. Providers must still do everything they can to ensure these rights are protected and demonstrate this.

Anna not being allowed to see her mum could have breached Article 8 rights to respect for private and family life, home and correspondence. Anna has the right to speak privately to her mum, to have choices about her possessions and her clothing, to have choice when she eats, to have privacy when using the toilet and to have support to express her needs – unless there is a legitimate reason why these things should not happen, for example a risk of self-harm or harm to other people. Even when there is a legitimate reason for a restriction, then the least restrictive option that addresses the risk should be put in place. For example, by making sure that Anna has as many choices as possible in her day-to-day life and reviewing these regularly with her.

Article 14 and Equality Act 2010 – the right to reasonable adjustments

Anna not having reasonable adjustments because she could not communicate with the care team could risk Article 14 connected to Article 8 of the Human Rights Act – the right to be free from discrimination. This also risks breaching areas of the Equality Act 2010.

Providers have a duty to make reasonable adjustments for disabled people – from ensuring the environment they are living in is meeting their needs, to having the right tools to communicate. In Anna's case this includes her traffic light cards. Not having these things in place stops people being able to access their basic rights as a human.

The reasonable adjustment duty is 'anticipatory'. This means that providers need to think in advance what disabled people with a range of impairments, including people with a learning disability or autistic people, might need.[12] The **NHS Accessible Information Standard** can help providers meet both their reasonable adjustment duty and their public sector equality duty.

However, it is important to note that staff need to make difficult decisions on a day-to-day basis. With Anna, staff may have needed to weigh up what the potential risk of self-harm is with the possessions she had in her room, versus her rights to have access to her phone and other possessions. A human rights-based approach can help to make these difficult decisions.

When can qualified rights be restricted?

The occasions where qualified rights, like Article 8 rights, might be restricted are when the situation is:

- lawful – for example Mental Health Act 1983 (MHA) or Mental Capacity Act 2005 (MCA) processes have been followed
- necessary – for a legitimate reason, for example to protect someone from harm or to prevent other rights being breached
- proportionate – the option that least restricts Article 8 rights, while still addressing the need, must be chosen.

This is by no means a comprehensive list of the ways Anna's rights are at risk of being breached. Providers have many other obligations, such as to the public sector equality duty. This states that if you are providing a health or care service you have a duty to consider whether you can advance equality for the people that you are serving.

What does this mean for our review?

In too many instances in this review we found that people's human rights were at risk of being breached. We found that:

- People's human rights were potentially being breached because staff did not have the understanding, tools or support needed to make the human rights-based decisions that would have helped them to provide better, safer care.
- People were not having their needs met. Environments they were living in were not adapted to their sensory needs and they were not being offered support to communicate. Some providers were not making reasonable adjustments legally required under the Equality Act 2010.
- People were experiencing unnecessary restriction that was causing them distress. Decisions about restrictive practices were not reviewed regularly to make sure that there was

the least restriction on people's rights possible at any given time.

- People were spending too long in highly restrictive situations, more likely to breach their human rights, because of failure to plan and progress long-term goals, such as discharge planning.

It can be extremely difficult for people and their families to influence changes to care so that they have their human rights upheld. People having access to independent advocacy is crucially important, but the availability and quality of advocacy was very variable. We address this later in the report.

Part 1: Hospital-based services

We found the poor physical environment and the restrictive practice culture of hospitals often lay the groundwork for the use of restrictive practices. They could lead to people becoming distressed and in turn being restrained. Often, people we saw did not receive specialist care or access to high-quality advocacy.

To understand how restrictive practices have been used, it is important to first understand the wider culture and environment of the hospitals in which they are used.

The quality of care and environment of hospitals

Most of the wards we visited were not therapeutic environments, and often people did not receive care tailored to their specific needs. We found particular issues with services not paying attention to the impact that the environment could have on people with a learning disability or autistic people. The low-quality care we saw was often due to poor physical environments and ward layouts, issues with staffing, and a lack care planning.

Reviewers found that staff were under pressure because of a high staff turnover, lack of appropriate training and high use of agency staff. In addition, we found poor staff cultures, and there was often a disconnect between the multidisciplinary team and frontline workers.

Being placed in an inappropriate environment can be damaging and creates a pattern of distress, restraint and seclusion, which often cannot be broken. In many cases, we found that the impact of the environment on people, such as the noise, heating and lights of the wards, had not been considered. In many cases staff did not understand people's individual needs and the distress that being in the wrong environment could cause, particularly for people with sensory needs. This could lead to people expressing their distress in a way that others find challenging, leading to staff resorting to using restrictive practices.

It is important to note that, specifically for people with a learning disability and autistic people, recommendations in national guidance from NICE state that these types of hospitals are only appropriate for the 'short-term' management of people.[13] But we found that

many people were staying in hospital for months or years at a time. The guidelines clearly state that people should only be in hospital if "all other options have been exhausted" – we found evidence of this not being the case.[14]

Ward environment and culture

The general ward environments and culture were often not suitable for autistic people, people with a learning disability and/or mental health condition.

- Wards could be noisy, chaotic and unpredictable, and were not conducive to creating a therapeutic environment. Sometimes they were not homely or welcoming, and lacked a quiet space or outdoor area that people could access freely.

- We were particularly concerned by blanket restrictions being in place – where rules and policies are applied to everyone without individual risk assessments. For example, on one ward we found that patients could not have access to their own bedrooms until after 10pm and that toilets had to be unlocked by staff. Patients were not allowed toiletries in their own rooms and could not have water bottles in the lounge. Staff made all hot and cold drinks, and snacks were only allowed at specific times. Snacks had to be eaten out of plastic bowls in the dining room, which had a seating plan. This was not a therapeutic environment as patients relied on staff so it was difficult to find space or do the little everyday things to comfort themselves.

- There were reports of teams not working together on the wards, with a disconnect between the nursing staff and therapy teams, friction between ward staff and management, and a lack of understanding between permanent and agency staff. Some ward staff felt they were not listened to and were not involved in the decision-making process for the people they cared for.

Opportunity for the future

Improving hospital environments must be a priority for the future. The **Independent Review of the Mental Health Act** has recommended

that the physical environment of wards needs to be improved, and that this should be done through co-production with people with lived experience to maximise homeliness and therapeutic benefit.[15]

Leaders in hospital also need to create a culture of listening to and understanding people. This includes using continual learning about how to minimise the use of restrictive interventions. It should run from creating a ward environment that meets the needs of the people being cared for, to ensuring that the staff team has been recruited using values-based recruitment. This is essential to ensuring human rights are upheld.[16]

Adaptions and reasonable adjustments must be made to enable better support, tailored to the needs of autistic people, and people with a learning disability and/or mental health condition. Being moved around the care system and in and out of hospital can be traumatic, with some of the people in the system experiencing further trauma from receiving poor quality care that does not meet their needs. We found few services offering psychological support or therapies to help them deal with any trauma they had experienced in their lives. Staff need to be trained in trauma-informed care in order to better understand people's histories, the impact of past traumas, and what may cause them further trauma.

Staffing levels and turnover

A consistent staff team who know the people on the ward well, who have received the relevant training and who are able to work together well as a team is crucial in providing good quality and consistent care for people.

- Staff described feeling overworked because of staff shortages and, at times, that it was unsafe to leave the ward to take a break.

- There was a high turnover of staff, and many wards had a high number of vacancies. This led to the reliance on agency staff who are not part of the established staff team. This reliance on agency staff means that staff did not always know the needs of the people they are looking after. This includes their likes

or dislikes, communication needs, and their personal histories.

- Shortages of regular staff meant that the focus is on managing crisis and risk, as agency staff were not able to work more proactively because they did not know the people they were caring for.

- Issues with staffing had an impact on the quality of care that people received. For example, it could lead to patients' leave being cancelled. It also meant that people in seclusion or long-term segregation could be left for long periods without interaction with other people or access to therapeutic and meaningful activities.

Staff training and supervision

To support a positive staff culture, staff need to feel well supported through supervision and training, and have opportunities to discuss and learn from incidents through reflective practice.

- We found that staff were not always receiving the right training, with no focus or training on human rights or value-based care. For example, in some specialist hospitals, frontline staff had not received adequate learning disability or autism training and were given e-learning instead of a full training package. The competence, skills and knowledge of staff actively involved in people's care was judged to be poor, very poor or below standard for 61% of people we reviewed in learning disability wards.[e]

- We found that staff were often not trained in different communication methods, including Picture Exchange Communication System (PECS) or Makaton, so were unable to communicate with the people they were looking after in a way they understood. Not being able to communicate in a way a person can understand is a potential breach of human rights and could lead to situations where people are unable to communicate. This, in turn, could lead to them becoming more distressed, and resorting to using restraint, seclusion or segregation.[17]

- Staff were also concerned about the quality of training. Staff described an increase in e-learning, which was seen as a 'tick box' approach to training. Some staff recognised their own shortfalls and were completing training in their own time.

- This lack of skills and knowledge of individuals affects people's rights to reasonable adjustments under the Equality Act 2010, and a lack of knowledge of human rights can lead to unnecessary restriction.[18]

Assessments and care planning in hospital

High-quality assessments and care planning are fundamental to providing person-centred care. These are essential to help staff understand people's backgrounds and needs, and what psychological support they might need.

The Mental Health Act 1983 (MHA) Code of Practice is clear that care planning requires a thorough assessment of the patient's needs and wishes, and that it should be agreed with the person receiving care.[19] Care plans should include details of activities and support that aid a person's recovery. However, we found that assessments were often not taking place, and that the quality of care plans was often poor.

- For 54% of the people we reviewed in long-term segregation and prolonged seclusion, care and treatment were generic and were not aimed at meeting their specific needs, such as sensory needs.

- People were often not getting the right care because they were not receiving the correct assessments and therapeutic input to inform their care plans, including diagnostic, communication, sensory and physical health assessments. We saw two hospitals where there were good assessments in place, and staff had a good awareness of people's needs, which led to good outcomes for people.

- Physical health needs, such as seizures and brain injury, were sometimes not properly assessed or followed-up, and were not always

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e   See **appendix D**, figure 13

considered as a potential factor in why people were distressed. In other cases, physical health needs were sometimes overlooked, and care teams had not considered them or what impact they might have on a person. For example, one person was vomiting, but staff were reluctant to take them to the GP. Later investigations revealed that the vomiting was invasive gastroenteritis linked to medicine they were prescribed.

- Although a high percentage of the people we reviewed had a positive behaviour support (PBS) plan (91%), and in low secure and rehabilitation services 94% of people had an active rehabilitation plan in place, the quality of these was often poor and included minimal therapeutic activities. Family members also felt staff should be doing more to interact with their loved ones and encourage participation in therapeutic activities.

- In some instances, reviewers described care plans as "generic" and "meaningless". For example, we found that the assessments for an autistic person, such as sensory and communication assessments, were not carried out.

   "There was no sensory assessment despite evidence [that Anna] was hypersensitive to sound and light and no plan was in place to address this..."

- Issues with staffing, including a high turnover of staff, and high use of agency staff and/or a high number of vacancies, had an impact of the quality of care people received. These issues meant that staff did not understand people's needs and could lead to patients' leave being cancelled. This not only has a therapeutic element, but is likely to be a breach of Article 8 of the Human Rights Act 1998, if it cannot be shown to be necessary and proportionate.[20] It also meant that people in long-term segregation or seclusion could be left for long periods without access to therapeutic and meaningful activities, and no interaction with others.

This lack of person-centred care planning, and lack of assessment and understanding of past traumas, meant there was often a focus on how the person was behaving rather than what was causing them distress, and little understanding of how that related to a failure to meet people's needs.

Opportunity for the future

In our review of care plans, it was difficult for reviewers to identify whether the activities outlined in the care plans were taking place, and we found examples of activities detailed in the plan that did not corroborate with what people told us had taken place in the recent weeks. We are currently working with the University of Warwick to create a tool to help reviewers identify this.

IN-DEPTH LOOK AT 12 CARE PLANS

Positive behaviour support (PBS) is one of several types of care plans currently used for autistic people, and people with a learning disability and/or mental health condition. This must be done in collaboration with the person.

As part of the review, we looked in depth at 12 PBS plans (care plans) of people who were in long-term segregation from different hospitals and wards, to check if they followed good practice.

However, we found that:

- most of the assessments were poor; none of the care plans addressed how the person's diagnosis affected them
- for all the autistic people, the sensory assessments were judged to be unsatisfactory or poor
- for people in long-term segregation on low secure wards, care planning and PBS plans were poor quality; people were being segregated from others – often for long periods – and were receiving care that was unlikely to do much to change their situation.

  "The PBS plan does not show a clear picture of who the person is, what they like and do not like, and how staff should communicate with them and support them."

  "…the negative language [in the plan] makes it look like it is Toby's fault… and not how he reacts due to his learning disability, autism and history of trauma. It does not clearly specify how staff should support him."

The importance of effective care planning is recognised as an essential element of delivering good, person-centred care. It is meant to ensure that the needs of the person are central to the development and implementation of support.

The quality of, and access, to advocacy

Everyone in hospital who is detained under the Mental Health Act (MHA) is entitled to an independent mental health advocate (IMHA) who is specifically trained to support them.[21] Access to high-quality advocacy is vital to make sure that people can raise concerns about their care, including serious concerns that may amount to human rights breaches.

The MHA Code of Practice states that services have a duty to make sure that people understand how they can use advocates.[22] Where people lack the capacity to decide whether they want the help of an advocate, the hospital manager should ask an advocate to meet the person so they can explain directly how they can help.

We found that:

- Access to high-quality advocacy varied across the hospitals we visited and that the role of an advocate was not consistent.
- There was some confusion between the provider and commissioner about who the advocate was, or which organisation provided the services. This led to people being denied access to the service. In some cases, there was no evidence that advocacy had been offered to people. Even where people were allocated an advocate, they were not always engaged in decisions about the person's care.
- There were examples of where the advocate was not informed of certain people on the ward.
- When people did have access to advocates, there were examples where advocacy was of a poor quality, where advocates were not upholding people's rights.
- Advocates were also under pressure themselves and felt they did not have enough time to support everyone that they were responsible for. One reviewer noted:

"IMHAs [Independent Mental Health Advocates] feel they are not able to have enough time to advocate fully for people at [hospital]. They have been asked to increase their input by the [clinical commissioning group] but there is no additional funding available."

JEN'S STORY – AN OPPORTUNITY FOR THE FUTURE

During our review, we saw a model of advocacy that had been specifically commissioned for Jen, who had been in hospital for many years. We describe Jen's story below, and have a made a recommendation that everyone should receive this level of personalised care.[f]

Jen had been moved around different hospitals, before being transferred to a hospital over 200 miles away from her home because of the step-down pathway it offered. However, her clinical commissioning group (CCG) had serious concerns about having to place her so far from home and so commissioned their own advocate to act as their "eyes and ears".

The advocate saw Jen once a week, initially focusing on building a relationship with her, and then spending time in her company, talking to her or directly observing her care. The advocate made a point of reading Jen's notes and speaking to the ward staff before attending her ward round to ask questions of Jen's care team and advocate her wishes.

In doing this, the advocate became increasingly knowledgeable about Jen and built up a relationship whereby Jen felt safe to tell her things or she was able to act in Jen's best interests.

The advocate challenged some of the daily restrictions in Jen's environment and in her routine, and also raised safeguarding alerts where she believed the standard of her care fell short of what was required.

Because of the amount of time Jen has spent in hospital, the advocate played an active role in escalating her case to external agencies.

Access to good quality advocacy is an essential safeguard for people, especially people who are non-verbal, or extremely mentally unwell, and may be unable to speak up for themselves. It gives people someone who can champion their rights, support them to have a voice, and to promote their needs and wishes where they are not able to do this themselves. If an individual requests support from an advocate, the advocate should have oversight of their day-to-day care and care pathway, so that they can scrutinise and challenge the decisions of the care team.

As reported in our annual review of the Mental Health Act 2018/19, we welcome the recommendation of the Independent Review of the Mental Health Act that highlighted the need for better training for advocates and better-quality services.[23]

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f   See **recommendations** on page 47.

How restraint was used in hospitals

Restraint is widely known to be a part of practice in inpatient hospitals, but it should only be used as a last resort in situations where people may be a risk to themselves or others.[24] There are well-known strategies that aim to reduce the reliance on restraint, such as 'No Force First' and the HOPE model, as well as new restrictive practice training standards that are working to embed this in services.[g,25] However, we found that these strategies were not always in place.

In this section, we explore the different types of restraint, how they were being used and, most importantly, the impact on the people being restrained. We specifically look at physical restraint, chemical restraint (including rapid tranquilisation) and mechanical restraint.

The use of restraint varied significantly across the services we saw, despite them caring for people with similar needs. We also saw inconsistent reporting and recording of restraint, which we have reported on previously.[26]

In some services, restraint was rarely used and every effort was being made to avoid using it as they were using restraint reduction strategies (for example, HOPE and No Force First); in others it was a daily occurrence.

The people who were subject to restraint often told us of the lasting and traumatising effects that restraint can have on wellbeing. One person said:

"I feel absolutely f***ing sh*t about being restrained. It makes me feel …dehumanised. I don't feel like a real human being."

Physical restraint

We found a variety of different types of physical restraint were used. These included arm wraps, and supine (face-up) and prone (face-down) restraint. While most providers had stopped using prone restraint, in line with the MHA Code of Practice and national guidance, some providers still restrained people in the prone position.[27,28] We found:

- 81% of 313 wards for children and young people, and for people with a learning disability and autistic people, had used physical restraint in the month before our information request.
- 56 out of 313 wards had used prone restraint at least once in the month before our information request.
- Physical interventions were mainly used when a person was assaulting others or was being moved into seclusion. Other reasons included when a person was at risk of serious self-harm or needed urgent medical treatment. Staff also said that there were times when they needed to use restraint to give people personal care, such as needing to brush a person's teeth. In another case, physical restraint was used daily for someone who needed hands on them to have a shower.

Examples of good practice

- Using de-escalation techniques to pre-empt early signs that someone might be distressed.
- Several providers had introduced safety pods (large bean bags that people were laid on when restrained) to reduce the risk of harm from physical restraint, while others used an impact mat or cushion.
- Care plans that included the person's views and wishes detailing when and how to use physical restraint.
- Rather than taking a hands-on approach, staff supported people to manage their own self-harm, for example by untying their own ligatures. This was appropriately risk assessed and recorded.

The lasting effects of restraint

People told us that when they were restrained it could often re-traumatise them and have a lasting impact on their mental health. They told us that it felt like they were at times not seen as

g   See **appendix D** 'Examples of reducing restrictive practice strategies'

human or equal because they were completely powerless.

We found evidence of the impact of this on our visits. On one of the wards we visited there were no specific restraint care plans or guidance on restraining women who had experienced trauma, such as sexual abuse. For example, in one patient's notes it was noted that she preferred to be cared for by female staff – but there was no reference to this in terms of restraint. We found that male staff on the ward had occasionally been involved in restraining female patients, which could risk re-traumatising patients.

While it is important to understand that there may be extreme circumstances where restraint might be the only option for safety, providers must fully understand the impact this may have on people.

"It feels like my freedom has been taken away and I am powerless"

"There was an incident with John where they hurt him, he doesn't like anyone grabbing hold of him. The deputy ward manager said that the staff were under investigation, but they are now back."

"The provider has not escalated concerns including staff failing to treat Mo with dignity and respect – for example, ignoring him or threatening him with restraint in the prone position."

Criminal records

We saw some examples of people being prosecuted by providers for injuring staff when resisting restraint. The trauma caused to staff must be acknowledged and addressed. However, we are concerned that people are being criminalised for their actions while distressed in hospital. In our expert opinion, failing to assess and treat their needs may have contributed to their aggression. In addition, it is then more difficult to discharge someone with a criminal record or on a forensic section, which further compounds the problem.

Chemical restraint and rapid tranquilisation

In 2015, Public Health England reported that every day in England 30,000 to 35,000 people with a learning disability are prescribed psychotropic medicines when they do not have a mental health condition.[29] During our review, we found that several types of chemical restraint were used, from oral PRN ('pro re nata', as needed) medicines to injectable rapid tranquilisation. We found medicines were used as chemical restraint to control people's behaviour:

- Rapid tranquilisation was used in 34% (106 out of 313) of wards for children and young people and people with a learning disability and/or autism, in the month before our information request – a practice that has significant side effects and should only be used as a last resort.

- Over a one-month period, there were 720 incidences where rapid tranquilisation was used on CAMHS and learning disability/autism wards. It was more common on CAMHS wards where almost half of the wards (49%) that responded to the information request reported using rapid tranquilisation.

- Of the learning disability and autism wards, 24% used rapid tranquilisation, which equated to 186 incidents over a one-month period. People sometimes told us they felt the staff were too quick to use rapid tranquilisation and records showed that staff did not always use the least restrictive option.

- In many of the cases we reviewed, physical monitoring of people was either not recorded or not good enough. Not only is this not in line with NICE guidelines, but it puts people at risk of cardiac and respiratory suppression and, in turn, increased risk of death, particularly if they have co-morbidities.[30]

- Many of the care plans we reviewed did not include specific individualised ways of using de-escalation techniques before using practices like rapid tranquilisation and chemical restraint.

Using medicines to restrain people is against the principles of STOMP (stopping over medication of people with a learning disability, autism or both with psychotropic medicines) and STAMP (supporting treatment and appropriate medication in paediatrics).[31]

People and their families described the impact of taking these medicines. Some people complained that they were "drugged up" or given medicines that made them sleep for days.

"A father said that when he first visited [his daughter] on the ward she was 'pale, glassy eyed and not with it'. He was shocked at her appearance. He said the staff were very cagey about informing him about what they had given her."

Mechanical restraint

Mechanical restraint involves using a device (such as a safe suit, arm splints or harness) to prevent, restrict or subdue movement of a person's body, or part of the body, for the primary purpose of controlling how someone is behaving. While mechanical restraint was rarely used as a form of restraint, we found:

- 3% of children and adolescent wards and 5% of learning disability and autism wards were using some form of mechanical restraint in the month before our information request.
- At some services handcuffs and belts were being used. One hospital appeared to be using handcuffs routinely to move people to seclusion rooms, which was not in line with national guidance. We also saw where they had been used for people who had a history of abuse and trauma, which had not been taken into account.

- People with lived experience told us that there was a blanket approach, and many people were moved by secure transport in vehicles similar to police vans and no reasonable adjustments were made to individual needs.
- Lockable seatbelts or harnesses were sometimes used in vehicles to ensure people's safety (and the safety of others). This method of mechanical restraint was used for some people with a learning disability. During the review we found that this was used appropriately for people who needed it.
- Mechanical restraint, such as specialist clothing, was used by some providers to protect people who had a high risk of serious self-harm. For example, at one hospital, a person's care plan included using mittens to help prevent serious self-harm and staff were consistently reviewing this.

A different service type – restrictive practices in secure children's homes

As part of our review, we gathered information from five out of 13 secure welfare children's homes in England. People in the secure children's homes had often experienced an unstable background including domestic violence, abuse and/or neglect. However, unlike mental health services, some had criminal action pending or underway. Children's stay in a secure home is subject to court scrutiny and approval through section 25 of the Children Act 1989 or the Youth Justice system with special arrangements for children aged under 13.[32]

In this section we explore the differences between these services and hospital services. Overall, we found that there were smaller numbers of people cared for in a secure home, the goals of children's time in a home were clearer, services were more closely measured against how they were achieving the outcomes, and there was stronger oversight and monitoring of restrictive practices.

How restrictive practices were used

Services used forms of segregation, usually referred to as 'single separation' and 'managing away', depending on where it took place and for how long. However, it was unusual for children and young people to be cared for in isolation for prolonged periods (more than 48 hours).

- There was better oversight and monitoring of restrictive practices in the homes. We found that Ofsted would rate a service as requires improvement or inadequate if there were any concerns about the use of restrictive practices.
- There was a wider range of training available to prevent restrictive practices being used, for example on de-escalation, autism and attention deficit hyperactive disorder (ADHD) to training on adverse effects of childhood experiences, such as substance misuse and harmful sexual behaviour.

Improved assessments and care planning

For all the children we reviewed in the secure children's homes, there was a clear aim for the time they were at the home. This was agreed at an initial planning meeting and then reviewed at each review meeting. These homes carried out detailed, routine assessments on admission. At least four of the five services reviewed used the CHAT (Comprehensive Health Assessment Tool). CHAT assesses:

- physical health
- mental health
- sexual health
- substance misuse
- neuro-cognitive assessment (including assessments for autism and attention deficit hyperactivity disorder (ADHD)).

"These assessments support a psychological formulation of someone's distress and focused on the person's own perception of their difficulties."

We also found that discharge planning took place early in these services. However, services told us that they frequently needed to escalate concerns about discharge planning within local authorities to get a response. It is important to note that courts will not grant to allow secure orders to continue if there is not a need for this. The staff in these homes echoed concerns that there was a national shortage of community support for young people with complex needs, which led to failure in the community before being admitted.

OPPORTUNITY FOR THE FUTURE: A TRAUMA-INFORMED APPROACH TO CARING FOR PEOPLE

What stood out about these services was that they had a trauma-informed approach to care, whereby they provided people who had experienced trauma with an environment in which they felt safe and able to develop trust.

At four of the five locations reviewed, the secure children's homes used Secure Stairs. This is a model of care that focuses on individuals and supports a culture of compassionate care. It aims to ensure that every member of staff understands the children in their care in the context of their experiences, so that they are more informed about why the children behave as they do. The outcome is that children have a plan that guides staff on how to care for individuals according to their needs.

Staff received good training in this approach and there was a well-resourced dedicated team of staff to deliver the programme. This model of trauma-informed care was commissioned by NHS England and could be a model that is replicated in child and adolescent, learning disability and autism wards, and in low secure and rehabilitation services, to improve the assessment and treatment to better understand and meet people's needs.

Long-term segregation or prolonged seclusion in hospital

Our review looked at a variety of restrictive practices, but we looked in detail at 66 people who were subject to prolonged seclusion or long-term segregation. This is because we were most concerned about the isolating nature of their care.

Seclusion is more short-term, and long-term segregation is a way of isolating someone away from the main ward for a longer period.[h]

The MHA Code of Practice defines **seclusion** as: "the supervised confinement and isolation of a patient, away from other patients, in an area from which the patient is prevented from leaving, where it is of **immediate** necessity for the purpose of the containment of severe behavioural disturbance" but there is no specific time limit.[33] **Prolonged seclusion is over a period of more than 48 hours.**

Whereas **long-term segregation** is described as required "to reduce a sustained risk of harm posed by the patient to others, which is a **constant feature of their presentation**, a multidisciplinary review and…commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward on a **long-term basis**".[34]

The main reason we were told that people were placed in long-term segregation or seclusion was because providers said they were a risk to themselves or to others.

Overall, we found that:

- The length of time that people spent in prolonged seclusion ranged from two days to seven months, and from three days to 13 years for people in long-term segregation.
- Out of the 66 people we reviewed in depth, we only found evidence of consistently good quality care and treatment for three people.

For these people the care was individualised and they had more autonomy.

- There was a higher proportion of people from a Black or Black British background in prolonged seclusion on CAMHS wards, 24%, compared with 6% of all people on CAMHS wards in England. Similarly, for learning disability wards 11% of those in prolonged seclusion were from Black or Black British backgrounds compared with 5% of all people on these wards. This was not the same with long-term segregation, and we did not find the same across low-secure mental health wards.
- Almost 71% had been segregated or secluded for three months or longer. A few people we met had been in hospital more than 25 years, but how long they had been in segregation or seclusion had not been recorded beyond 13 years.
- While providers felt that segregation and seclusion was often necessary, their understanding of what this constituted varied. Where providers did not formally recognise their use of segregation or seclusion, people did not have the protection of the MHA Code of Practice to keep them safe.
- We were extremely concerned that people in segregation and seclusion did not have access to therapeutic and meaningful activities. What was described in people's care plans and by providers as 'therapeutic activities' were more observations of people, such as sleeping, pacing or eating.
- Standards of assessment, positive behaviour support plans and care plans were often poor, and these did not reflect people's needs.
- With a few exceptions, most of the environments we saw people living in were unacceptably poor and dignity and privacy were not maintained. Conditions were overly

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h   In the review we looked at people who had been secluded for 48 hours or more (prolonged seclusion) and those who had experienced frequent episodes of seclusion as well as people who had been segregated on a long-term basis.

restrictive. Liberty was deprived without clear justification or consideration for its long-term effect.

- Some people were caught in cycles of being placed in gradually higher security hospitals. For example, moving from low, to medium to high secure – where their freedoms are even more restricted – with no reflection about what was not working. For many of these people their pathway had previously included stays on medium secure units and there were no considerations about how to improve their care plans or assessments. Patients in secure care will be detained under the Mental Health Act. In many cases they may have committed an offence, although this was only the case for one person we met during our review.

- There were frequently restrictions on family or friends visiting or phone calls that people could make. For example, we saw evidence of people's leave being cancelled because of a shortage of staff. This is likely to be a breach of Article 8 of the Human Rights Act 1998.[35]

- In some cases, people in seclusion were not allowed to wear their own clothes. We found this was the case where there were risks of self-harm.

In particular, the physical environments for many people in **long-term segregation** were unacceptable and not in line with the MHA Code of Practice.[36] Issues included:

- a lack of access to outdoor space
- environments not being clean or hygienic, or that were in need of repair
- areas being too small, especially when people always had two or three members of staff with them
- lack of amenities, such as a table to eat at, crockery and cutlery, toilet paper and toiletries
- people having few belongings or having restricted access to them
- poor layouts, which did not allow staff to have full visibility
- a lack of good communication, for example, rooms without intercoms and/or staff leaving people alone.

Many of the physical environments of **seclusion areas** were also unacceptable and were not in line with the MHA Code of Practice. Issues included:

- a lack of access to personal belongings or TV/music
- hatches being used to give people food
- a lack of window providing natural daylight
- problems with lighting – while most areas had dimmable lights, or a bright day light and a dimmer night light, one seclusion room only had a full light that was left on 24 hours a day
- a lack of access to en-suite toilet, wash basin and shower.

We did find a few **examples of better-quality environments in long-term segregation:**

- some people had access to several private rooms, including a bedroom, separate lounge and bathroom or shower area, and direct access to outdoor space
- some environments had a homely feel, including personalisation, natural light and soft furnishings; and people were visible in a way that allowed staff to keep them safe at the same time as offering privacy
- we also reviewed some people in their own flats who had access to outside space and more activities.

Lack of oversight

We found providers' understanding of what constituted long-term segregation or prolonged seclusion varied. This means some people did not have access to the proper safeguards and checks.

If providers recognise when they are using seclusion, they should be carrying out two-hourly nursing reviews and four-hourly medical reviews. These need to take place to consider whether seclusion should end.

People in long-term segregation should receive daily reviews by a doctor, weekly reviews by the care team and reviews by a senior professional not involved in the case.

We found that:

- Records about reviews and reasons for placing someone in seclusion or long-term segregation were not always clear or detailed enough, and were not always reported to the commissioner (this is required for long-term segregation).

- Long-term segregation reviews were sometimes poor quality, and sometimes did not take place. They often did not include plans for ending long-term seclusion, and rarely involved the family or mental health advocate.

- People's seclusion should have been ended sooner in some cases. For example, we found evidence of text being copied and pasted from previous reviews, which were not representative of the situation at the time. As these influence decisions as to when

the patient can leave seclusion, incorrect information could have a direct impact on the person's liberty.

The impact of seclusion and long-term segregation on people

We often found that people who were subject to long-term segregation were segregated because the noisy and chaotic ward environment was causing them distress.

Erik's story brings together what we heard from several people throughout our review. We have described these experiences through a single persona to illustrate the impact that seclusion and long-term segregation can have on people's wellbeing and human rights.

ERIK'S STORY

Erik is autistic and doesn't like loud noises. Whenever he goes out, he wears ear defenders to reduce the noise.

Erik was placed in a busy ward with 11 other people. He couldn't cope with the noise and became very anxious so threw a chair. As a result, Erik was put in his own area of the ward away from others, in long-term segregation. Erik saw staff but no other people on the ward. This led to a deterioration in his mental and physical state.

Erik didn't get outside, and he had very little space. He lost weight because he didn't eat and drink much, he was only given food he could eat with his hands.

Staff told Erik that to keep him and them safe, he wasn't allowed things, such as his computer and guitar. Erik got very bored and lost interest in doing anything, he felt fed up.

Erik started to have aches in his legs as he never got exercise or fresh air. Staff told Erik to lie on the bed whenever they came in because they found it difficult to deal with him when he was distressed. He started to lie on the bed every day.

He got used to talking through a window so didn't want to be near people. Erik didn't want to come out of long-term segregation as he thought he was dangerous and was institutionalised by the setting he was in.

What does Erik's story tell us about the impact of seclusion and long-term segregation?

Unfortunately, Erik's story or the others used in this chapter are not isolated incidents. People told us that the experience of being isolated had a huge effect on their psychological wellbeing years after they had experienced it.

We saw evidence of some of the long-term effects of prolonged isolation in such artificial environments. Issues included:

- people sleeping too much and getting into unhelpful sleeping patterns, which affected their opportunities to access therapeutic interventions
- people's physical health deteriorating, such as a decrease in mobility.

For some people, as they get used to being away from others, their comfort zone can shrink and it can become harder for them to be able to integrate with others because of the loss of social skills. This was particularly the case for some of the young women we saw in long-term segregation. Being isolated for long periods could reinforce a low sense of self, and that they are not good enough and should not be around other people. Often this was borne out of traumatic and abusive backgrounds and being passed around mental health services.

Providers told us that segregation or seclusion was sometimes the only option for staff when people were highly distressed. However, we have seen in the previous sections that improvements in staffing, the environment, and care planning could all help reduce the likelihood of these practices existing. Although it is currently lawful to isolate people for prolonged periods if this is the least restrictive way of keeping them safe, long-term segregation has real implications for people's human rights and long-term psychological wellbeing.

Why it is so hard to leave long-term segregation or seclusion

Long-term segregation and seclusion units are often not caring environments. Their impact is not limited to the time that people spend in these units and is often felt for some time after. We found that if people stay in units for long periods, their chances of moving out of segregation and out of hospital are diminished.

Through our in-depth reviews of people in segregation, we found that the main reasons for staying in long-term segregation for long periods included: difficulty in being reintegrated back onto the ward; becoming institutionalised; and a lack of small bespoke community packages of support with specialist staff teams available as an alternative.

We also found that:

- Out of 66 people, three children and 28 adults had been in long-term segregation for more than a year. Despite hospital teams recognising that being in hospital was not appropriate for these people, there was often a lack of alternative community care.

- A lack of suitable care in the community prevented discharge for 60% of people we met. Most people in long-term segregation needed bespoke packages of care in the community, but this was difficult to achieve.

- The majority of people did not have a plan in place to reintegrate them into the ward, as this was felt to be an unsuitable environment. This is despite the MHA Code of Practice being clear that there should be treatment plans in place that aim to end long-term segregation.

- Some autistic people (mainly those without a learning disability) did not have Care (Education) and Treatment Reviews (CETRs). These are plans to help people be discharged. From our reviews, we found that these are not always effective, and recommendations are sometimes not followed through, but they are another lever to support people to leave hospital.[i]

- Failed discharges can lead to a deterioration in people's care. Some people had community placements but were not able to cope in these because of a lack of early enough preparation and transition. A failed discharge experience can re-traumatise people who are already anxious about their new environment, and it can make them 'not want to go back' to the community for fear of being unsafe.

- There were some successful attempts to discharge people from segregation and hospital. In one example, we saw the hospital staff team supporting the person who was leaving hospital to get to know the community staff team before their discharge so moving into the community was not a shock to them. This requires 'double-funding' from the provider and can be difficult to arrange, but is indispensable in helping the person get to know their new environment in a supportive way.

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i   Care Education and Treatment Reviews are a requirement under NICE guidelines for people with a learning disability or autism diagnosis

WITH THE RIGHT SUPPORT IT IS POSSIBLE FOR THINGS TO IMPROVE – BETHANY'S STORY

Bethany is a young woman who has experienced long-term segregation and seclusion; here her dad describes her story.

Beth lacked a clear set of assessments and a full diagnosis, which meant her needs were never supported in the community. No-one understood that her challenging behaviour was a result of unmet needs – especially commissioning.

So, Beth was sectioned. Within days of hospitalisation she was placed in a seclusion room, a bare and sterile environment, designed to contain short-term distressed behaviour, because her autism prevented her coping with the noisy, bright environment of the ward and the sensory overload from so many other distressed patients.

Her regular staff had no training, no understanding of her diagnosis, her autism, her learning disabilities or her sensory diet. The agency staff were unable to understand her and had no desire to do so, so they just sat outside her door like security guards. No-one knew about her communication needs or processing delays. No-one understood her crippling demand avoidance profile.

So, Beth got more challenging. She self-harmed, tying ligatures and inserting items into her arms and opening wounds. She headbutted the wall in anger and frustration at hearing others being carried screaming into the rooms next to hers.

This anger and self-harm was met by regular restraint, she was held down by multiple people for up to four hours, the pain from her hypermobility feeding her futile resistance. She had her clothing forcibly removed, leaving her naked, or she was forced into thick secure clothing, which further tormented her sensory world.

Occasionally, handcuffs and leg straps were used to contain her, as well as suffocating spit hoods. Bruised, she would finally be injected and find comfort in exhaustion-fuelled sleep.

Left with no activities, she began inventing imaginary worlds and aliens to talk to. With no natural daylight or exercise, her skin suffered and her weight ballooned. An overload of unjustifiable medication was forcibly injected or slid to her under her door. Beth needs to form trusting relationships before she can engage, so her refusal to conform was seen as rebellion and another reason to keep the door locked. It stayed locked for three long years.

A media campaign, rather than commissioning or safeguarding, forced a review of her care and she was finally moved.

A new setting was created with Beth's input into the design and environment. Sensory overloads such as fluorescent lights were changed, a low stimulus layout and sole occupancy removed other triggers. Her comforts are allowed – her pets, her iPad, access to the internet and her own mobile phone with Zoom provide a means of communicating, engagement and distraction.

Her family were involved in training all of her team about her presentation and past life, and about Beth as a person, before Beth went anywhere near the new site.

All of her team are fully trained, and live and breathe autism, pathological demand avoidance (PDA) and No Force First techniques so her anxiety-driven behaviours are reduced to almost zero. Everything is about what is best for Beth, not the staff or the setting. The staff team is a constant group dedicated to her alone. She has a choice of activities that keep her constantly busy, but support therapeutic intervention and constant assessment.

It is true person-centred care.

The unnecessary medicinal straitjacket has been weaned off and replaced with compassion, understanding and a desire to move Beth to a productive, fulfilling life.

The seclusion cell has been replaced with unfettered fresh air and days out with her family and care team.

Quality discharge planning can help people get back to their communities

We know that discharge planning should happen as soon as someone is admitted to hospital, if not before then. This is clear in NICE guidelines and the MHA Code of Practice.[j,37,38] Good discharge planning is essential to make sure that, when discharge happens, it is successful and works well for the person. We found that between 57% and 63% of people we reviewed did not have a quality plan. We found that discharge planning for transition out of hospital was often inadequate, with actions to enable discharge rated as very poor, poor or below standard for 57% of people we met. This rose to 63% when looking at just people on CAMHS and learning disability wards.

We believe that while people are still being cared for in hospital, the length of the hospital stay must be minimised and effective discharge plans are another way to ensure this. We found poor support on discharge was often one of the key reasons why a community care placement would fail. A good quality discharge plan is one that is proactive and details the individual's specific triggers and understands them. For example, if an autistic person does not receive their food at the mealtime they expect, it might cause them distress and confusion and they may feel out of control. Ensuring that everything is being done to accommodate people's specific needs to prevent them from being set back increases the likelihood of them being discharged.

Discharge plans should be created collaboratively with the person, their family or carer or advocate, and regularly reviewed. The NICE guideline for people with a learning disability and/or autistic people recommends that this happens every three months with the person, their family members and specialists.[39]

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j   NICE guidelines and MHA Code of Practice state that 'as soon as someone is admitted to hospital, a discharge plan should be put in place'

Part 2: Community-based services

In the first part of this report, we looked at the environment and culture of hospital-based services, and how restrictive interventions from physical restraint to segregation were used. In this second part, we look at these issues for community-based services for people with a learning disability and/or autistic people.

Community-based services are widely accepted to be best placed to care for people with a learning disability and autistic people.[40] It is important to note that there is currently a joint national plan, **Transforming Care**, to move people from the hospital into the community. However, as of June 2020 there were still 2,085 people with a learning disability in hospital. Although numbers have decreased there is still a long way to go.[41] We found commissioners often struggled to locate an appropriate bespoke community package due to a combination of funding disputes and lack of appropriate housing.

During our review of community-based services we gathered evidence from:

- 452 questionnaires on restrictive interventions, completed with registered managers, during inspections between July and October 2019
- visits to 27 adult social care services identified as using restraint, for an in-depth review.

It is important to note that CQC currently only regulates supported living where personal care is provided. We do not regulate the care for people with only social or housing support.

Overall, we found that restraint was used a little less in community-based services than in hospitals, with most services promoting personalisation and a positive quality of life. However, the quality of care people received varied, and was affected by the numbers and skills of staff available.

The quality of care and environment in adult community services

Culture and environment

Overall, we found that people in adult social care services were experiencing better person-centred care than people in hospital. This meant that they were experiencing a better quality of life than the people we saw with comparable complex needs in hospitals. In particular, we found:

- Services were more likely to be able to personalise people's living environments to their individual styles and personalities.
- There were more services with a positive social environment, with activities that were relevant to each person's needs and interests.

  "The home was situated on the coast with access to the beach, countryside, pubs and festivals. We saw that staff were supporting young people to go out and take part in activities that they were interested in, including long walks, attending pubs, and music events. There were sensory items scattered around the home as well as access to sensory room."

- Some examples of people receiving good physical health care within the settings, where staff were aware of any medical conditions and continuously monitored people for any changes. This was particularly important for those who had communication needs and may have struggled to communicate when they were in pain or needed help. We also found examples of comprehensive health action plans and where people were receiving regular check-ups. Good physical health care plans incorporated information from associated care plans, hospital passports and existing risk assessments.
- Where there were concerns about the quality of care, it was often because people did not have access to therapeutic or meaningful activities, and/or had little involvement in their local community. For example, some

activity records showed that going out for drives or going to get takeaways was a person's main activity.

We also found examples where people were being cared for in **good physical environments**. This included:

- Single occupancy environments that could be adapted to people's needs, which gave them greater control over their environment. It also reduced the need for physical intervention as people did not experience distress because of their environment.
- People being able to personalise their walls with artwork and their hobbies.
- People being able to install underfloor heating or air conditioning.
- Safe furniture, lights that could be adjusted, and sensory items.

However, we found examples of **environments that were not suitable**. In these environments, we found:

- a lack of basic facilities and amenities, such as furniture
- people were not allowed access to their own kitchens, even with support staff
- poorly maintained buildings
- one individual whose water supply was cut off.

> ### MAKING THE IMPOSSIBLE, POSSIBLE: BRUCE'S STORY
>
> Bruce is a 25-year-old man who has been diagnosed as autistic with bipolar disorder, attention deficit hyperactivity disorder (ADHD), and generalised anxiety disorder.
>
> Bruce has had difficult experiences in many different educational, residential and hospital settings, including experiencing restraint. However, Bruce's needs are being well met by his current provider, and staff have never physically restrained him.
>
> The provider has taken time to get to know Bruce and his needs. For example, Bruce needs to make a lot of noise, which caused issues with some of his neighbours in previous properties. Bruce's current provider was able to find him a detached property by a canal where he can make as much noise as he needs. His house has a large garden with a vegetable patch, log cabin, trampoline, seating area and hammock. Windows are unsmashable, and walls are lined with MDF inside to prevent damage to plaster.
>
> Because of how others perceive him, Bruce can't use public transport and can be stopped from going to places. However, this has not stopped Bruce doing many activities with support from staff, including gardening, swimming the channel, hot air balloon ride and holidays.
>
> Bruce is involved in decisions about his care. He has detailed care plans that help staff to know every aspect of his care, including how they should respond to various topics of conversation. He is involved in his staff rota as he has strong views on how often certain staff should be with him. Bruce's mother has been fully involved in all aspects of his care.

Staffing levels and turnover

Overall, we found that there were good staffing levels in a lot of the services, and where staff were well-trained people received good quality support and access to meaningful activities. We also found examples where there was funding for one-to-one staffing, and a good understanding of individuals' needs. This contributed to more person-centred care.

However, there were instances where this was not the case. During our review, we saw:

- Some services were struggling to recruit enough staff and were using agency staff to cover vacancies. In one case, agency staff were not getting invited to supervision or team meetings, so did not have the same opportunity to contribute ideas and learn from others as permanent staff.
- The impact of restrictive interventions (which we explore in the next section) on staffing levels. In one case, this meant that people did not have the ratios of staff to resident set out

in their care plans, which in turn affected their ability to engage in activities.

Staff training and supervision

The type, quality and availability of staff training varied across providers.

- Our information request showed that there was a wide range of training available for staff in services where restraint was used. Where staff received suitable training, they said that it helped them to understand people's needs. However, we were concerned to find examples of a lack of training for staff to be able to understand people with a learning disability and/or autistic people. For example, one service had training on the Mental Capacity Act, but staff were not trained in communication tools like Makaton or Picture Exchange Communication System (PECS) to help people with a learning disability to communicate. Other services did not provide training on autism.
- Most services emphasised the use of proactive approaches and de-escalation techniques, as

well as care-planning using positive behaviour support. One service had trained all its staff in autism and communication methods.

- However, training was not standardised. As a result, each provider's training was slightly different and meant that some training was better quality than others, for example more person-centred and bespoke training courses were available and tailored to those in the service. It also meant that agency staff may not be trained in the relevant approaches for the different services they work for.

Care planning and assessments

In most adult social care services, staff knew and understood the behaviour of the people they were working with. Staff were able to talk about

people's likes and dislikes, their history, what was important to them and how to support them.

We looked in depth at the care plans and positive behaviour support plans for nine people living in restrictive environments in single accommodation, across different providers. We found that:

- Adult social care services provided more support, activities, and choice, increased the quality of life for people, and offered more person-centred care than hospital services.
- Some services needed to improve their care planning. For example, only two out of the nine people had physical health plans that included enough information about their specific needs to be satisfactory, only three had communication plans, and none of the sensory assessments were satisfactory.

How restrictive practices were used in adult community services

Our overall assessment of community services was that they were providing higher quality care, with fewer restrictive interventions. However, it is important to note that there is no national reporting system for restrictive practice so this is limited to those that reported this to us.

At present, there is no way of collating the figures nationally for the use of seclusion or segregation in social care settings. In addition, the use of these restrictive practices and restraint is not currently notifiable to CQC. Services do not have to report on using it unless it leads to a safeguarding alert being made.

Of the services that responded to our questionnaire, 62% (out of 452 services) told us that they used at least one type of restrictive intervention. We found that restraint (chemical, physical and mechanical) was used far more commonly than seclusion or segregation.

Physical restraint

Staff told us that stopping people from hurting themselves or others, including staff, was the main reason for using physical restraint. We found that:

- Of the sites we chose to visit (as they reported using restraint), 26 out of 27 services were using physical restraint on occasion.
- The types and levels of physical restraint used varied. These included arm holds, two-person standing escorts and supine restraint.
- Three out of the 452 services that completed the questionnaire said they used prone restraint. We did not find any evidence of the use of prone restraint on our visits to the 27 services.
- In the majority of services, when restraint was used, the methods were the least restrictive and least likely to cause harm. While physical intervention was included in many people's care plans, in a lot of cases we found that this had never been used, as staff supported people positively without needing

to use restraint. If restraint was needed in an emergency, staff knew the appropriate type of restraint to use.

- One person's care plan included details of the specific physical restraint technique to be used, including photographs so that staff understood when and how this could be used as a last resort. Their mother said she could not remember the last time physical restraint was used as staff supported this person in other positive ways, but they knew how to safely restrain the person in the least restrictive way if they ever had to in an emergency.
- Although there was less use of restraint overall, when it was used for some individuals, it was used often and we found evidence of the same person being restrained 100 times in a month.

It is clear that when restraint is used frequently, services can become stuck in a cycle of repeatedly restraining people, which can be hard to get out of. The services that used low levels of restraint had much more emphasis on preventative and de-escalation methods.

Mechanical restraint

Staff told us that mechanical restraint was mainly used to help people travel safely and enjoy going out. It was also used to minimise injury from self-harm. Types of mechanical restraint included using helmets and arm splints. We found:

- The most commonly used form of mechanical restraint was the use of harnesses or belts to transport people in vehicles. During the review we found that generally this was used appropriately by people who needed it.
- There was guidance available on when and how to use the mechanical restraints. For most people, staff tried to support them in other ways before using the mechanical restraint.
- Examples of better practice in the way staff used harnesses and vehicle adaptions; some services assessed a person's ability to

understand why they were being put into a seat with a seatbelt or harness, giving them a key to unlock their belt/harness on arrival so they had control, and using best interest decisions and reviewing these.

- Examples where mechanical restraint, such as arm splints, 'stable-doors' or a harness to stop someone from getting out of a wheelchair, was not being monitored by the service, commissioners or professionals from community teams. This lack of oversight was concerning.

Chemical restraint

Medicines were used as chemical restraint in all services except one that we visited. Chemical restraint is where a medicine is used to restrict the freedom of movement of a person or, in some cases, to sedate people. We found that:

- In some cases, staff did not have appropriate guidance to help them decide whether to use a medicine. Care plans did not include de-escalation techniques and staff were unaware of triggers that may cause a person to become distressed.

- The outcome and effectiveness of medicines was not always recorded. This meant that staff could not be assured that future doses would be used appropriately. We saw an example where a person had repeated medicines administered and the reason recorded as "incident probable".

- It was not clear from records that medicines were always used as the last resort or were the least restrictive option. Guidance lacked detail about when a medicine was needed, and the dosage that should be given.

- Some services were taking the right precautions, involving family members, appropriately monitoring, using STOMP,[k] and using chemical restraint as a last resort. However, this should be the case for all services.

The examples of good practice we saw on our visits highlighted that in order to improve, services must provide clear guidance about when it is appropriate to use PRN and other medicines, and include details on less restrictive options and de-escalation techniques before using a medicine. They must also ensure they monitor the effects of medicines on the person's physical health.

A better culture than hospitals?

Many adult social care services had a culture that was focused on prevention and de-escalation of distressed behaviours, including using positive behaviour support (PBS) plans.

In these services, staff had good knowledge and understanding of how to support people, there was minimal use of restraint and the services promoted openness and active learning.

Several services told us about the importance of good communication and supporting people to have choice and control in their lives. When people's communication needs were met, we found that they were less distressed and it could result in fewer incidents and restraints. This highlights the important role of communication in good quality care.

"There was a positive culture of 'no force first' and of active learning about the young people and about how to minimise the need to use restraint."

"Jennifer had choice and control about who she has in her living space, if she does not want a member of staff with her, she tells them, if she wants them to come back later or for another member of staff to support her, she has control over these decisions."

In one example, a new manager had created a culture where staff felt they could be open about how they felt after incidents and felt supported to raise concerns. As a result, there was a dramatic reduction in the number of restraints.

Although some services were using restrictive practices, on the whole community services were providing a more person-centred approach.

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k **STOMP principles** (stopping over medication of people with a learning disability, autism or both with psychotropic medicines).

Oversight and accountability of restrictive practices

External bodies, such as commissioners, were not always aware of the levels of restrictive interventions, sometimes due to a lack of contact with people once they had moved into the service. There was more monitoring of restrictive practices at a provider level than at a commissioner level.

Local monitoring of services – providers

Most services had systems in place for recording and monitoring the use of restrictive interventions, but how they did this, and the quality of the systems varied.

Examples of good practice in monitoring restrictive practices included:

- Detailed records, with involvement from senior managers and external stakeholders, and data analysis that was used to inform learning and practice.
- Comprehensive recording systems, for example well-designed forms with specific measurable information that could be compared.
- Regular reflection at team meetings about learning from individual incidents of restraint.
- Debriefs with people about restraint incidents.
- Including information about post-incident support in positive behaviour support (PBS) plans and/or care plans.
- Using Talking Mats – an interactive resource that uses three sets of pictures (topics, options and a visual scale) to support people to say how they felt about incidents.

Examples of poor practice in monitoring restrictive interventions included:

- Some services not recording the use of interventions. In a rare example, a staff member told us that they did not record the use of restraint for one person because it was "so frequent (daily) and low-level", that it was seen as a part of their care.

- Ineffectual and over-complicated monitoring systems that used multiple different forms and prevented staff from entering enough information. For example, one service had a daily log, a behaviour log, a PRN record and an incident form – all of which had slightly different information recorded.
- Discrepancies and inconsistency between data sources that meant trends could not be analysed. This included, for example, different information in monitoring data and incident forms.
- A lack of involvement from external professionals or agencies, and a lack of evidence about what monitoring activities were taking place.

Local monitoring of services – commissioners

There is no national oversight for people living in adult social care services who are subject to highly restrictive environments.

Providers are not legally required to tell commissioners or CQC about incidents of restraint or seclusion or that a person is living in a segregated setting. We found that:

- Of the 272 services that said they used restraint in response to our information request, only 44% told us that they would report episodes of restraint to their clinical commissioning group (CCG) or local authority in the current system.
- Monitoring of restraint by commissioners is often limited to an annual review. Commissioners were not always aware of the level of restrictions placed on the clients and when people had been placed in a service, the oversight of their care by the CCG or local authority was minimal.

Due to our concerns over this lack of oversight, we have recommended that there needs to be a consistent reporting and oversight system for restrictive practices in social care, as there is in hospitals, so that national trends can be identified.[I]

Segregation and seclusion in community services

As there are currently no recognised definitions of restrictive practices in community services, it was often hard to identify the use of segregation and seclusion. For the purposes of this review, we used the same definitions as hospital settings, and we recommend that if a system is introduced, it mirrors hospital definitions. We did find it was used less frequently in community services, but that it was still used in some cases.

We also found that some community services were using single person accommodation that was not segregation but where people were living alone.

Use of seclusion

The term seclusion is not common in adult social care services, and we found that different terminology was being used across the services. In some services, seclusion was referred to as "time-out" or "locked door". We found that:

- Out of the 452 services that responded to the questionnaire, 24% reported that staff sometimes ask people to go to a specific area such as their bedroom because of behaviour, but staff do not stop them from leaving these areas if they want to.

- 9% of services sometimes asked someone to go to a specific area due to their behaviour and then prevented them from leaving.

- Services used seclusion for a variety of reasons, with safety of the person or others, including staff, being the most common reason. Some of the people that we saw who were in seclusion did not have authorised Deprivation of Liberty Safeguards (DoLS) in place for this restriction, so the restriction was unauthorised and may be a breach of their human rights.

- While seclusion was being used in the care homes and supported living services we visited, not all services recognised or recorded

that they were using it. For example, in one service, staff withdrew from the person's flat when their behaviour was "challenging" and effectively locked the person in. The review team identified this as seclusion by our definition,[m] but the service did not and therefore it was not recorded.

Use of segregation versus single person accommodation

As with seclusion, the term segregation is not widely recognised in adult or children's social care services, and we found that different terminology was being used across the services.

Sometimes people were in single person accommodation but not segregated as they could leave freely. Other times we identified they were segregated as they could not leave. This made it challenging to identify when people were in segregation or not and to get a true picture of what is fully going on.

People were usually living in single person accommodation because it was distressing for them to live with other people, or their behaviour had an impact on other people.

Use of single person accommodation as good practice

Living in a bespoke placement in a community environment that was tailored to a person's needs often led to a better quality of life. People were generally happier and less distressed, which led to fewer incidents and less use of restraint.

People, families and staff told us that they were able to go out and, with support, take part in community activities, and were generally happy with their care.

The most successful services had adapted people's environments to meet their preferences and needs with a person-centred approach.

m   See **appendix E** for the glossary

People were then able to follow their own chosen activities and routines with staff support. For example, as in Bruce's case, one supported living provider found an isolated property for a person who had difficulties interacting with other people, so that they could live in a safe peaceful home and take part in community activities on their own terms.

Use of single person accommodation as segregation

Overall, we found that most people were not left on their own all the time. Staff worked with them in their homes and supported them with their personal needs, meals and other activities.

However, some of the people we met did not have staff with them all the time and were locked into their flats at times. This was equivalent to what would be known as seclusion in hospital.

On our 27 visits to adult social care services, we met 17 people who were locked in their flats and then monitored outside of their flat or room. This meant that their human rights were not protected, and they could neither come out nor ask staff for help when they needed it.

For some people who were locked in their accommodation without staff present, there was no written clear justification or clear written best interest decisions as to why this was the case. In addition, we did not see care plans to show how staff were going to support people to move forward to being in a less restrictive environment.

Children's residential services – restrictive practice and the environment

As part of our review, we looked at 11 children's residential homes that are registered with both CQC and Ofsted.[n] These services provide residential and respite care for children and young people who were typically aged between 10 and 18 years old at the time of our visits, and who had complex needs. This included severe learning disabilities, physical disabilities, acquired brain injuries, trauma, or other complex mental and physical health needs.

We found that the culture, use of restrictive practices and environments of these unique services differed from hospital and other community settings.

Environment and culture

The environments of children's residential services ranged from houses on residential estates to services that looked more like hospitals.

We found that these services were in very high demand, with commissioners placing children in services from across England. One service had 48 different local authorities placing people at the service. Another provider was receiving up to 200 applications a week for children and young people with mental health difficulties. This meant people could be placed a long way from home and their families.

Types of restraint used

Physical restraint

This was the most common type of intervention used. Even when this was needed, we found that it was "low level" holds (holding and linking young people's arms, wrists, hands and elbows), leading young people by the hand, and controlling movements while eating. While we did find evidence of supine (face-up) restraint, there were no prone (face-down) restraints.

Chemical restraint

This was used in six of the 11 children's services. How frequently they were used varied significantly between services. We found examples of oral PRN medicines being offered to calm young people in moments of distress, for example to manage symptoms before or after incidents of self-harming, or as a sleep aid.

However, we did also find an example of anti-psychotic medication being used on someone who did not have a mental health diagnosis, which would be classified as chemical restraint. Other uses included managing obsessional thoughts and auditory hallucinations. In a few services, we were concerned that individual protocols were not in place for PRN medicines, and that side effects were not considered.

Mechanical restraint

This was used in four out of the 11 services we reviewed, but in these services it was rarely used as a form of restraint. As with other services, some young people were restrained by safety harnesses and ankle straps when travelling. Other examples included using high-sided beds, bed rails, and safe suits to help manage spasms. In most cases this was being recorded and in care plans.

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n   A small number of services need to register with both Ofsted and CQC– with Ofsted as a children's home, and with CQC for the regulated activity they provide under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 (HSCA). The majority of children's homes provide some form of health service, ranging from basic first aid to high level healthcare. Where a service offers 'regulated activities' as set out in the HSCA 2008, the provider also needs to register with CQC to ensure they meet essential standards of quality and safety. The **guidelines** for joint registration are currently under urgent review, and have been withdrawn (as of December 2018).

Use of seclusion and segregation

None of the children's residential homes we visited were using long-term segregation. However, we did find evidence that services were using seclusion, although this was not always recognised as such. For example, in two services, children and young people had been prevented from leaving their room by staff holding the door handle upright. While this was not usual practice by the service, services must recognise this as seclusion so appropriate safeguards can be put in place.

Some services were initiating periods called "time-outs". This consisted of children and young people being removed and taken to another area of the residential home (a bedroom or a quieter communal space). During a time-out, the children and young people were typically left for a few minutes while being observed (and doors left open), and then supported to re-join. The uses for this were not always clear in care plans, but was sometimes recorded as a risk of harm to themselves or others.

While there are very few of these services in the country, and they are only available to children, the fact that they were still using forms of restrictive practice highlights the need for a central reporting system, so that the use of restrictive practice in these services can be properly monitored.

Part 3: Commissioning

A central theme throughout the services we visited were issues and disputes about funding and commissioning placements. This often prevented people from receiving the best possible care across settings.

We found that funding arrangements for individuals' care were complex, and it was not always clear whether commissioners had the oversight or knowledge required to ensure that this was meeting the person's needs.

Considerable amounts of money are being spent to support people in restricted environments in hospitals. However, in the view of reviewers carrying out the visits, money available would often be better spent on providing individual person-centred care in the community.

As mentioned, there are national programmes aimed at reducing the numbers of people in hospital, but there are still many people in hospital that could be cared for in the community. It is important to note that when we compare placement costs for hospital packages and community care packages, these figures are not directly comparable, as they were not at the same points in time or related to the same individual placements – we include them to illustrate the broad funding differences.

Issues with commissioning – cost and oversight

Hospital care packages

It was difficult to get information about the cost of care for people who are in prolonged seclusion or long-term segregation in hospital. Commissioners responsible for the care were not easy to identify and did not always respond to our requests for information.

We estimated that the cost of care for someone in prolonged seclusion or long-term segregation could range from £650 to about £2,300 a day.

There was variation in who paid for the care of people in long-term segregation. From our information request, we found that most

people – both children and young people, and adults with learning disability and/or autistic people – were funded by either specialist commissioning (52), through NHS England, or clinical commissioning groups (CCGs) (49). Three adults were funded by Welsh commissioners and the funding package was not specified for two people, but it may have been a health commissioner.

For people on low secure and rehabilitation wards who were in prolonged seclusion and long-term segregation, the majority of care was funded by NHS England.

It was not always clear how commissioners monitored how people's needs are being met by the money spent on the care package. We found that people's needs were frequently not met and/or they were being cared for by staff who were not trained to meet their needs. They were also not receiving the assessment and treatment that they were admitted for. This could lead to potential breaches of people's human rights not being picked up and addressed by commissioners.

Adult social care packages

Funding for adult social care packages in supported living or care homes also varied, with commissioning from local authorities, continuing health care and education funding streams. Some people had a combination of all of these.

We visited a range of services including supported living services, residential care homes and nursing homes. Funding was organised differently depending on the service, so it was difficult to compare service costs.

For people we visited, fees ranged from £250 to £1,400 a day. These included people who were living in single person accommodation with full staff support, and the costs were similar to the fees for caring for someone in long-term segregation in hospital. These could be covered by a combination of health and care commissioners.

Commissioning and hospital discharge

There were mixed views about whether the availability and arrangements between different systems of funding had an impact on plans for ending segregation and discharge from hospital. Staff and family members often suggested that they "suspected funding to be an underlying issue", but many felt that the money was available, it was just difficult to access. Many had encountered difficulties with understanding how to access various funds available. Some providers and families told us that discharge to the community had been delayed or even blocked due to funding issues.

"The local authority commissioner said the need for "full wrap around support" makes reproducing the level of care at the hospital in the community almost impossible, especially within the same budget. Any community package would be more expensive than the current arrangement and funding is a factor in making the decisions."

However, several commissioners did not identify that issues with funding affected discharge planning. Instead, issues with finding appropriate care and the higher risks associated with care in the community were given as common reasons for delays in discharge.

Some providers told us that replicating the person's care in the community would be more expensive. However, in most cases we found that community care packages were not more expensive than hospital care packages. If funded correctly, these provide people with person-centred care, tailored to their needs, with their own staff team, and closer to their home with access to the community.

Issues around funding arrangements seemed to be more complex than relative costs of different care options. Issues were often related to where the responsibility for funding lies, because inpatient care can be funded by NHS England or the CCG, while community care can be funded by CCG or the local authority.

We found that discharge can be delayed due to a lack of agreement about how the new placement will be funded. This can also be because at times there needs to be funding for the existing and the new placement to support the transition period. However, it is important to note that the **Community Discharge Grant** recently announced is designed to address this issue, and all Transforming Care Partnerships should have access to a pot of £20 million to support discharges for the next two years.

Furthermore, families and other organisations raised concerns about the financial incentives of independent providers discharging people in long-term segregation, as this would mean a loss of income for those providers.

Is hospital care value for money?

Considerable amounts of money are being spent to support people in restrictive environments in hospitals. However, we found that these environments are often not appropriate to meet the needs of the people with mental health conditions or a learning disability, and/or autistic people. As a result, the people we met were being segregated and not receiving the care and treatment they required and were frequently at risk of having their human rights breached. This does not represent good value for money. The money available would be better spent on providing individual person-centred care in the community.

Conclusion

We carried out this review in response to serious concerns about potential breaches of human rights due to the use of restraint, seclusion and segregation in care settings for people who, in some cases, cannot advocate for themselves.

Through our review, we found that time and time again people were not getting the care they need, when they need it. We have attempted to reflect what we saw and the many examples we found of care that was undignified, inhumane and that potentially breached people's basic human rights. We are grateful to those who have shared their experiences with us, and hope this will go some way to illustrate the trauma they have been through when they have sadly been failed by the system that was established to care and protect them (whether due to hospital admission from lack of crisis care, segregation or inappropriate use of restraint).

Cumulatively, the evidence that we have gathered points to a system where people with complex needs fall through the gaps. We cannot be confident that their human rights are upheld, let alone be confident that they are supported to live fulfilling lives.

We found it is possible to support people well in the community, but care packages are often not available. This failure in care started at the beginning of people's journey from the point of reaching out for help, through receiving diagnosis, to post diagnostic support and crisis intervention, when needed. The current lack of specialist providers and community housing that meets people's needs also directly contributed to people being admitted to hospital and then further delayed their discharge.

Once in hospital, we saw how the assessment and treatment that people are admitted for is failing, and how people are frequently not receiving the care that they are entitled to. The workforce is stretched with not enough skilled staff who have received the right training to be able to care for people who are vulnerable and traumatised.

We have also seen that families are often not listened to and are pushed aside by the system. In particular, families described the difficulties they experienced in accessing funding for their children. This included concerns about who should be paying for care between local authorities and NHS bodies, all of which prevent people from being put at the centre of their care.

However, we saw what is possible when people **are** put at the centre of their care, and bespoke packages of trauma-informed care are put in place that allow them to thrive. Another alternative is possible. We need to make this the reality for all autistic people, and people with a learning disability and/or mental health condition who need complex care. Having community care packages that are designed around the individual, which help prevent and de-escalate instances of behaviour that others find challenging will, in turn, prevent admission to hospital and end the cycle of institutionalisation.

These potential abuses of human rights, and the inappropriate placements people have been suffering in are not a newly emerging problem. The answers as to what good sustainable community care looks like were first set out by **Mansell** in the 1990s.[42] However, as highlighted in **the Bubb report** in 2014, when things work for the individual it is "too often despite the system not because of it".[43] We need the government, NHS organisations and local authorities to work creatively to remove the barriers that have stopped people from getting the care they need for too long, and putting in place the funding, community placements, crisis teams and skilled staff who understand the people they care for.

There have been too many missed opportunities to improve the lives of autistic people and people with a learning disability and/or mental health condition, whose behaviour others find challenging. Immediate action is needed to put an end to the abuses in human rights that we have seen throughout this review. This action must be owned and led from the top by government, delivered by local systems working together, and involve people and their families to ensure the needs of the individual are met.

Recommendations

This report was focused on restrictive interventions, but we found many people were subject to these because of failures much earlier on in their journey of care. Autistic people, and people with a learning disability and/or mental health condition should be cared for close to their homes in community-based services in line with best practice. However, we have seen this is not always the case. The NHS Long Term Plan already has goals to increase community mental health provision, but this needs to happen as quickly as possible for people with complex needs.

Recommendations for national system change

1) There must be a single point of ministerial ownership for the delivery of these recommendations. This will require the minister to work with delivery partners in health, education, social care, justice and local government to pool budgets locally and work together as soon as additional support needs are identified for autistic people, and people with a learning disability and/or mental health condition. This must include:

   a) Improved community-based capacity and improved capability across education, health and care.

   b) Proactive development of specialist multidisciplinary and multi-organisational teams that are focused on providing the necessary services and support in the community to prevent admission to hospital.

   c) Proactive development of appropriate housing.

Lead organisations: *Department of Health and Social Care, Ministry of Housing, Communities and Local Government and Ministry of Justice*
Other responsible organisations: *Home Office and Department for Education*

2) There must be a named national specialist commissioner for complex care who has oversight for:

   a) Ensuring commissioners are held to account for their decisions.

   b) Ensuring there is a named individual who is responsible for people with complex care in each local area, to ensure that reviews of care are carried out every three months.

   c) Developing new quality standards for commissioning specialist learning disability and autism services to ensure local commissioners of specialist services have training in learning disabilities and autism.

   d) Monitoring whether local commissioners are checking and visiting services to ensure the care being delivered is line with human rights.

Lead organisation: *NHS England*
Other responsible organisations: *Department of Health and Social Care, Department for Education, Ofsted, commissioners, local authorities*

3) Community teams across the country must have skills in caring for autistic people, and people with a learning disability and/or mental health condition to prevent them from having a crisis, and support them when they do, in line with and expanding on the NHS Long Term Plan commitment 3.35. These may be new or building on existing teams skillsets. This must include:

   a) Ensuring teams have specialist autism expertise.

b) The development of trauma-informed care that is delivered across community teams for autistic people, and people with a learning disability and/or mental health condition, of all ages.

c) Clear focus on support during transition periods between services and from childhood to adulthood.

d) Respite and crisis support that is close to home to prevent admission to hospital. The service provided should be easily accessible, and inclusive of children and young people. This should include a Dynamic Support Register for all local areas.

Lead organisations: *Department of Health and Social Care and NHS England*
Other responsible organisations: *Local authorities and commissioners*

4) There must be human rights embedded in the commissioning and delivery of care for children and adults with a learning disability, autistic people and people with a mental health condition. Individuals' needs must be taken into account and reasonable adjustments made to meet these needs, thereby fulfilling the need to make adjustments that are reasonable in the context of the ward and other people.

a) People should be given accessible information about their rights such as resources produced by the British Institute of Human Rights and the Equality and Human Rights Commission.[44]

b) Human rights must be integral to the planning and delivery of care, this includes training in human rights and checks against whether reasonable adjustments are taking place.

Lead organisation: *Department of Health and Social Care*
Other responsible organisations: *NHS England, local authorities, commissioners, Department for Education, Ofsted, Ministry of Justice, CQC, health and care providers*

5) There must be high-quality, specialist care for people who are in hospital for short periods, which must be focused on discharge, in line with and expanding on the NHS Long Term Plan commitment 3.36.

a) Before admission to hospital people must have assessments through community teams so that their needs are understood and they have clear and measurable objectives set for their admission to hospital, and receive care in an appropriate environment.

b) On admission, further assessments must take place, including for autism, sensory, mental health, physical health, trauma, learning disability and any other relevant assessments. This is to ensure that the objectives and care plan are meeting people's needs. There must be a contract in place stating the timeframe for these assessments to take place.

c) All inpatient mental health units must provide a therapeutic environment to enable the delivery of trauma-informed and person-centred care in line with existing evidence-based models such as Secure Stairs. In particular, autistic people must be cared for in small person-centred units with the right sensory environment, as recommended by the National Institute for Health and Care Excellence (NICE).[45]

d) Discharge planning must start before admission, without fail, with a clear timeframe in place. Discharge planning must involve all relevant sectors, who will be involved in providing support in the community.

e) There must be a named budget holder for the person's care. Where a new placement is required to enable discharge, the named budget holder, which is likely to be a clinical commissioning group (CCG) or local authority, must be responsible for commissioning the identified requirements within an agreed timeframe.

f) There must be a named care coordinator and system navigator for people with complex needs and their families.

Lead organisation: *NHS England*
Other responsible organisations: *Commissioners, providers, local authorities, police and/or probation service*

6) CQC must improve its regulatory approach for providers of services for autistic people, and people with a learning disability and/or mental health condition. This will include (as well as recommendation 11):

a) Reviewing our key lines of enquiry and assessment frameworks to ensure that human rights, community-first care, and a positive culture are embedded within these.

b) Reviewing our approach to how we rate providers who have people in prolonged seclusion or are using unnecessary restraint, and ensuring that these providers are not rated as good or outstanding.

c) Tracking progress made against the recommendations from independent reviews of seclusion and long-term segregation. This includes recommendations made in Care Education and Treatment Reviews (CETRs).

d) Reviewing our registration processes to prevent services renaming or repurposing services after enforcement action has led to closure.

e) Improving how we listen to people with lived experience and their families, how we use this information in our monitoring, inspection and rating of services, and ensuring that any concerning information that is shared with us is shared with appropriate agencies for investigation.

f) Checking on how services give access to advocacy and involve people and their families in care.

g) Increasing the number of unannounced and evening/weekend inspections.

h) Checking on timely diagnosis of autism for all services.

i) Checking on timely assessments, discharge plans and person-centred care plans.

j) Ensuring that all providers of services comply with the mandatory training requirement for learning disabilities and autism.

k) Ensuring that providers are delivering all relevant training around mental health needs, trauma-informed care, human rights and restrictive interventions.

l) Using our unique position to report on all providers' efforts to reduce the use of restrictive interventions, noting good practice and highlighting where more work is required.

m) Reporting annually on our Closed Culture programme of work and ensuring that defending and upholding human rights is at the heart of our approach and that our staff have effective training in this area.

n)   Discussing with the Department of Health and Social Care the limits of our regulatory approach and what further legislative changes may be required for mental health inpatient units.

Lead organisation: *CQC*
Other responsible organisations: *Department of Health and Social Care*

7)   There must be enough staff with the right skills, competencies and experience to provide high-quality person-centred care for autistic people, and people with a learning disability and/or mental health condition. We recommend the following apply for **both health and care settings**:

a)   The government and commissioners must ensure that there is enough funding for training of all staff caring for people.

b)   All providers of services must comply with the forthcoming requirement for Oliver McGowan Mandatory Training on learning disability and autism (for all health and care staff).

c)   All providers of services must train their staff in de-escalation methods and alternatives to restrictive interventions.

d)   All providers must use training providers certified by the Restraint Reduction Network where training includes the use of restrictive interventions in line with the Mental Health Units (Use of Force) Act 2018.

e)   Employers must ensure their staff's understanding of human rights and the Equality Act 2010 is kept up to date.

f)   Providers should have policies around values-based recruitment and be able to show evidence of this.

Lead organisation: *Department of Health and Social Care*
Other responsible organisations: *Commissioners, local authorities, and providers*

8)   Commissioners across health and social care should encourage and support the creation of smaller, bespoke services for autistic people, and people with a learning disability and/or mental health condition, in line with *Building the Right Support* and its *supplementary guidance for commissioners*.[46,47]

Lead organisation: *NHS England*
Other responsible organisations: *Commissioners*

9)   Local authorities and clinical commissioning groups must report on:

a)   The number of autism diagnostic assessments carried out in the community for children and adults.

b)   The number of people with a learning disability and/or autistic people who are admitted to hospital.

The above information must be broken down by each local authority and clinical commissioning group, it must be shared with partner organisations and published regularly.

Lead organisation: *Government*
Other responsible organisations: *Local authorities, NHS England and NHS Digital*

10) People, their families and advocates must be involved in the development of services and care plans. Services must support families to do this, especially where families are located far away from people's placements. There must also be a way for them to escalate any concerns.

Responsible organisations: *NHS England, commissioners and providers*

Recommendations on restrictive practices

11) There must be a contractual requirement on providers to inform commissioners and the NHS England regional team (depending on parliamentary approval of a regulatory requirement to inform CQC) when segregation or seclusion begins in hospitals.

Lead organisation: *Department of Health and Social Care*
Other responsible organisations: *CQC, NHS England and providers*

12) There must be enhanced monitoring by commissioners to ensure a plan for ending restrictions is in place and milestones for achieving it are met. There must be a named person in the provider with oversight for this to report to the commissioner. Where progress is not made, this should be escalated to NHS England.

Lead organisations: *Commissioners, local authorities and providers*
Other responsible organisations: *CQC and NHS England*

13) There must be guidance developed to ensure independent reviews required by the Mental Health Act (MHA) Code of Practice are of a consistently high standard and are focused on reducing the restrictions.

   a) A responsible clinician under the MHA Code of Practice must also provide regular updates on the necessity for continued use of long-term segregation and seclusion.

Lead organisations: *Providers, professional bodies and the Department of Health and Social Care*
Other responsible organisations: *CQC*

14) Care Education and Treatment Reviews (CETRs) are made statutory so that the responsible organisations are held to account. In addition:

   a) There must be a CETR for all people with a learning disability or who are autistic when they are admitted to hospital or where there is a risk of admission

   b) CETR panel members should have the relevant background and experience to match the patient's presentation.

   c) Where CETRs are complex, there should be a specialised team who can be brought in to help find resolution including ensuring joined-up commissioning.

Lead organisations: *Government and NHS England*
Other responsible organisations: *Department of Health and Social Care and CQC*

15) The Department of Health and Social Care must amend the Mental Health Act 1983 Code of Practice to change the definition of long-term segregation to include people who are segregated for reasons other than violence and to strengthen the guidance on how to safeguard people.

Lead organisation: *Department of Health and Social Care*

16) Providers should review their practice to ensure that restrictive interventions are used for the shortest possible time in line with *The National Institute for Health and Care Excellence (NICE) guideline on Violence and aggression: short-term management in mental health, health and community settings*, rather than using such interventions as longer term solutions.[48] This should be checked by CQC and NHS England.

Lead organisations: *Providers*
Other responsible organisations: *NHS England and CQC*

17) A national reporting mechanism must be developed for the use of restrictive interventions in children's services and adult social care services to mirror that used in hospitals.

    a) In addition, there must be a regulatory change to ensure that providers are required to notify CQC for certain restrictive practices in children's services and adult social care services.

Lead organisation: *Government and NHS Digital*
Other responsible organisations: *Department of Health and Social Care, CQC, Department for Education, and Ofsted*

Further work that is outside of the scope of this review

- The government should consider a cross-departmental review of restrictive practice for children with special educational needs and disabilities, including schools and anywhere children are living away from home.

- Department for Education should ensure that there is a clear definition of restrictive practices, including the use of restraint, segregation and seclusion, in educational settings and children's services.

- The government should ensure that a wider system discussion takes place regarding the practice of people being prosecuted by providers for the injuries caused to staff from people who are highly distressed in hospital, leading them to have a criminal conviction that they did not have before being admitted to hospital.

- An investment and an action plan should be developed to ensure that all autistic people, and people with a learning disability and/or mental health condition have access to an independent advocate. This will need adequate resourcing and specialist training for advocates. This must expand on the recommendation of the Independent Review of the Mental Health Act and also apply to those who are informal patients and those receiving social care who have their liberty restricted under legislation.

- CQC will publish a brief report on progress that has been made on these recommendations in Winter 2021/22.

Appendices

Appendix A: Action we took

Where we were concerned about the quality of care, or there were potential human rights breaches, we took immediate regulatory action. Examples of concerns included people who were:

- Confined to a single room (bedroom or seclusion room) for lengthy periods (months or years) during which they had few (or no) opportunities to leave. Some of these rooms were dirty and were completely devoid of anything but a bed or mattress on the floor.
- Not able to access toilets, so having to go to the toilet on the floor.
- Left sitting naked with no attempts to support them to overcome sensory issues.
- Left on their own with no engagement from staff, no therapy or meaningful activities, or no personal possessions.
- Not able to wear their own clothes, with no clear rationale.
- Given food in polystyrene containers without cutlery.
- Not able to access to fresh air.
- Isolated from families and friends and the outside world.

During our review, we took the following action:

- For both child adolescent and mental health wards and wards for people with a learning disability or autism, we raised eight safeguarding alerts, escalated concerns about 11 people and seven wards to NHS England, escalated 13 wards or services within CQC, which resulted in seven inspections with a change of rating for six services and increased monitoring for others.
- For low secure and rehabilitation wards, we raised three safeguarding alerts, escalated concerns regarding four people to NHS England and escalated concerns about two services within CQC.
- In social care, we raised five safeguarding alerts and escalated concerns within CQC for nine locations, which resulted in three inspections.

Appendix B: How we carried out the review

We carried out this review using our powers under section 48 of the Health and Social Care Act 2008. To make sure we looked at all settings where people with a mental health condition or a learning disability and autistic people might be subject to restrictive interventions, as requested by the Secretary of State for Health and Social Care, we divided the settings into four groups and looked at groups 1, 2 and 3 in two phases: phase 1 – November 2018 to June 2019, and phase 2 – March 2019 to November 2019.

Group 1

We looked at group 1 settings in the first stage of our review. These were settings where we had the greatest concerns, including:

- Specialist NHS and independent sector wards for people of all ages with a learning disability and/or autistic people. These included assessment and treatment units and low and medium secure wards for people with a learning disability and/or autistic people.
- Specialist NHS and independent child and adolescent mental health wards.

We considered all forms of restrictive intervention in group 1 settings.

We sent a bespoke information request to these providers between 15 and 29 January 2019. We asked them to identify all people subject to segregation and/or prolonged seclusion during December 2018. They also reported the use of restraint for the same period. This information was used to select sites for an in-depth review of people's care.

Groups 2 and 3

Groups 2 and 3 formed the second stage of our review. We looked at prolonged seclusion and long-term segregation only in the following (group 2) settings:

- NHS and independent sector mental health rehabilitation wards.
- NHS and independent sector low secure mental health wards.

We also carried out exploratory work to identify and describe whether and how restrictive interventions are used in the following (group 3) settings:

- Residential care homes designated for the care of people with a learning disability and/ or autistic people.
- Children's residential services that are jointly registered with CQC and Ofsted. These services provide care for young people with very complex needs – such as severe learning disabilities and physical health needs.
- Secure children's homes in England (these are children's homes that provide a locked environment and restrict a child or young person's liberty). These homes are registered with Ofsted but not with CQC. As a result, we carried out this aspect of the work in close collaboration with Ofsted.

During April 2019, we sent an information request to group 2 hospital providers to identify all people subject to prolonged seclusion and long-term segregation. This was used to identify hospitals for site visits.

We sent a similar information request to adult social care services asking about the use of restraint, seclusion and segregation. We used the results of this, together with knowledge from local inspection teams, to identify the 27 services for site visits.

Reviewers also completed a questionnaire with all adult social care services for people with a learning disability and/or autistic people as part of inspection activity between July 2019 and November 2019. In total, 452 questionnaires on the use of restrictive interventions were completed and analysed.

We visited 11 children's residential homes between September and October 2019, and attended three Ofsted inspections of secure children's homes during November 2019. Two desk-based assessments were carried out alongside these visits.

Group 4

The settings in this group were deemed out of scope for the purposes of this review and included:

- Medium secure or high secure mental health wards – secure units that admit children and young people or that are specifically designated for the care of people with a learning disability would be considered in group 1.
- Mental health admission wards for working age adults or for older people with a mental health condition.
- Residential care homes designated for any other groups of clients (for example, care homes for older people).
- Any other non-health or non-social care setting (for example, immigration detention centres).

Our approach

As part of the in-depth reviews, we met with people who have been subject to restraint, prolonged seclusion and long-term segregation, and their families and carers. We interviewed staff including ward managers, qualified staff and support workers. Wherever possible we talked with commissioners and advocacy workers. We also reviewed the physical environments of services and people's care plans.

For hospitals, as well as the in-depth visits we:

- assessed a sample of care plans
- reviewed prescriptions and other medicines records
- wrote to commissioners regarding the cost of placements.

We visited 27 care homes for the care of people with a learning disability or autistic people; 11 children's residential services that are jointly registered with CQC and Ofsted, and five of the 13 secure children's homes in England (two of these reviews were desktop reviews).

For adult social care services, we also gathered information remotely through:

- 452 questionnaires on restrictive interventions, completed with registered managers of adult social care services, during inspections between July and October 2019
- assessing a sample of care plans at each service
- reviewing prescriptions and other medicines records
- writing to commissioners about the cost of placements.

Throughout our review, we have worked with an Expert Advisory Group (EAG). They shared their experiences, which shaped the way we have written this report. This comprised people and organisations who have expert knowledge of learning disability and autism or lived experience of restrictive interventions.

In depth review of positive behaviour support plans

As part of our review, we conducted an in-depth review of 12 positive behaviour support plans (PBS), which focused on plans for people in long-term segregation. The aim of this review was to determine the extent to which the PBS plans complied with good practice.

A framework for analysing the plans and rating the findings was developed by a steering group, which included CQC staff and two advisors from the PBS Academy.

The framework considered the following factors:
- functional assessment
- person-centred plan
- physical health needs
- mental health needs
- communication needs
- sensory needs
- diagnoses addressed in plan
- daily activities
- skills building
- choice
- quality of life
- positive goals for future
- family involvement

The rating for each of the factors analysed was defined as:
- 0 = not present
- 1 = present but poor quality
- 2 = present but unsatisfactory
- 3 = present and good
- 4 = outstanding.

Appendix C: Summary of the Expert Advisory Group's review of previous reports and recommendations on restrictive practices

Written and analysed by Jeremy Harris, Alexis Quinn, Kirsten Peebles and Isabelle Garnett

Autistic people and people with a learning disability, and/or mental health condition should have equal rights and enjoy the same opportunities as everyone else. Yet too many have had their human rights denied and have not been supported to assert themselves. Findings from numerous previous reports, investigations and documents, as discussed in this appendix, indicate a systematic disregard.

The authors of this appendix are people with lived experience who acted as members of the Expert Advisory Group (EAG) on the thematic review. We conducted an investigation that looked for, and mapped, recurrent themes in previously published health and social care reports. In the EAG, we were attempting to avoid coming up with the same old recommendations and having them ignored. Creative solutions to old problems were needed and this seemed the most effective way to see what had gone wrong in the past.

In total, more than 30 documents were analysed. We purposefully sought reports that were published after the Mansell Report in 2007, particularly focusing on those published after the Winterbourne View Scandal in 2011. The mapping exercise revealed a comprehensive collection of investigations, reports and 'reports into reports' into the poor state of health and social care for autistic and learning disabled people (see below for full list of analysed reports). Other reports, such as serious case reviews, LeDeR (Learning Disabilities Mortality Review) reviews, public and independent inquiries, safeguarding reviews, Prevention of Future Deaths reports, academic studies (including **A Trade in People**), were not considered.

From these documents, we were easily able to elicit common themes and trends that create, sustain and enable the ill treatment, human rights violations and poor life opportunities for autistic people, people with a learning disability and people with a mental illness in the very systems supposed to help them.

These recurrent themes fell into the following five categories:

- missed opportunities
- crisis point and admission
- inpatient units: quality of care and restrictive practices
- pathway out of segregation and hospital
- community support: quality of care and restrictive practice.

The themes identified resonated with us as experts by experience, particularly as they put the individual and their rights in focus. Frustratingly, the recurring themes were so ubiquitous, begging the question: "How many times do the same factors need to be identified before there is change?".

There has been no need to reinvent the wheel in this report from CQC, and those preceding it; the wheel identified has yet to be created – and here we are again. In our numerous meetings, where people with lived experience, parents, carers, CEOs, psychiatrists and other stakeholders met, we almost unanimously came up with the same ideas and themes as those identified in previous reports (as also evidenced in our mapping exercise).

The problem remains that the implementation of recommendations has been badly hampered by factors only the government and its 'big systems' can control: adequate, fit-for-purpose administration, funding, accountability and

inspection regimen. Improvements in these four areas would enable departments and authorities to make transformative change.

The reports highlight tension between people's needs and the provision available. This is especially evident in the warehousing of people in institutions and the predictable reaction of autistic people and people with a learning disability to this environment. The system then responds in the only way it can – the use of restrictive practice, rather than the enablement of community living. The money is spent on extortionate inpatient placements that could benefit more people in the community. The lack of upfront community funding seems to be the key contributory factor to the failure on the part of all involved to deliver reform.

Almost every report identified the frustrating lack of accountability within the system. The EAG firmly believes that the current approach to accountability is insufficient. People with a learning disability and autistic people need CQC to implement an inspection framework that is fit for purpose, one that is focused on upholding people's rights. Without this, human rights abuses of our most vulnerable will not only continue, but also be inevitable.

Those tasked and paid to "police" the system need to do so. They also need to develop a means to find, manage and deal with unlawful practice. There must be greater oversight and accountability as we presently see the clear consequences of repeated failure to take on board the recommendations of past reports.

Many reports have highlighted a need for a culture change. The EAG unanimously agreed that people's human rights must be safeguarded. Power must be handed back to individuals (and their families), enabling them to make choices and be the rightful authors of their own destinies. If this does not occur, any additional money will be wasted and make little difference to the lives of autistic people, people with a learning disability and/or people with a mental health condition.

Legal references

Care Act 2014

Equality Act 2010

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Clements L, Aiello A, **Unacceptable delay: Complaints procedures for disabled children and their families**, 2019

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Department of Health and Social Care, **Right to be heard': The Government's response to the consultation on learning disability and autism training for health and care staff**, 2019

Department of Health and Social Care, **Serious Incident Investigation Report Secretary of State Case Review into Beth**, 2019

Education Select Committee, **Special Educational Needs and Disability**, 2019

House of Commons Committee of Public Accounts, **Care services for people with learning disabilities and challenging behaviour**, Fifty-First Report of Session 2014-15, March 2015

Joint Committee on Human Rights, **The detention of young people with learning disabilities and/or autism**, 2019

Joint Committee on Human Rights, **Youth detention: solitary confinement and restraint**, 2019

Lenehan C, Geraghty M, **Good Intentions, Good enough? A review of the experiences and outcomes of children and young people**

in residential special schools and colleges, Council for Disabled Children, 2017

Lenehan C, **These are our Children**, Council for Disabled Children, 2017

NHS England, **Children and Young People Transforming Care Workforce** (CYP TCW) – Report and Recommendations, 2018

NHS England, **Ask Listen Do**, 2019

Rightful Lives, **Eight-Point Plan**, 2019

Transforming Care and Commissioning Steering Group, **Winterbourne View – Time For Change: Transforming the commissioning of services for people with learning disabilities and/or autism**, 2014

Voluntary Organisations Disability Group, **A time for action: ending the reliance on long-stay inpatient units**, VODG, 2019

Appendix D: Supporting data

An information request was sent to wards for people with a learning disability and/or autism, child and adolescent mental health service (CAMHS) wards, and low secure and rehabilitation wards for people with a mental health condition. They were asked to provide information about the people in prolonged seclusion or long-term segregation for the most recent complete month.[o]

FIGURE 1: PERCENTAGE OF WARDS, BY TYPE, USING LONG-TERM SEGREGATION OR PROLONGED SECLUSION

	Number of wards responding	% using LTS*	% using prolonged seclusion
People with a learning disability and/or autism and children and young people	313	31%	20%
People with a mental health condition on low secure/rehabilitation wards	466	9%	20%

*Long-term segregation

FIGURE 2: NUMBER OF AUTISTIC PEOPLE AND/OR PEOPLE WITH A LEARNING DISABILITY AND CHILDREN AND YOUNG PEOPLE IN PROLONGED SECLUSION OR LONG-TERM SEGREGATION BY AGE BAND

FIGURE 3: NUMBER OF PEOPLE ON A MENTAL HEALTH LOW SECURE/REHABILITATION WARD IN PROLONGED SECLUSION OR LONG-TERM SEGREGATION BY AGE BAND

Note: One person excluded from analysis due to data quality issues.

o. Whilst numbers are low in some of the charts patient confidentiality has been maintained.

FIGURE 4: THE REASON WHY THE PERSON WITH A LEARNING DISABILITY AND/OR AUTISM AND CHILD/YOUNG PERSON IS IN LONG-TERM SEGREGATION

Safety of other patients

59% (35)

Unable to live alongside others

32% (19)

Safety of staff

20% (12)

Risk of self-harm

14% (8)

Damage to einvironment or property

8% (5)

Single person service

8% (5)

Dignity

3% (2)

More approrriate placement unavailable

2% (1)

Emergency protective custody

2% (1)

Risk of absconding

2% (1)

Vulnerable to violence or assault by other patients

2% (1)

Note: The 'number of people with a given reason' does not add up to the previously reported number of people subjected to long-term segregation, as a provider may have reported multiple reasons for long-term segregation for a single person.

FIGURE 5: THE REASON THE PERSON ON A MENTAL HEALTH LOW SECURE/REHABILITATION WARD IS IN LONG-TERM SEGREGATION

Safety of other patients

71% (10)

Violence/continuous threats of violence

21% (3)

Behaviour that challenges

7% (1)

Returned to ward after period of seclusion and segregation instituted

7% (1)

Note: The 'number of people with a given reason' does not add up to the previously reported number of people subjected to long-term segregation, as a provider may have reported multiple reasons for long-term segregation for a single person.

FIGURE 6: ETHNICITY OF PEOPLE IN CHILD AND ADOLESCENT MENTAL HEALTH (CAMHS) WARDS, AT DECEMBER 2018

Ethnicity	On CAMHS wards in England at 31/12/18	In prolonged seclusion during December 2018 (from PIR)	In LTS* during December 2018 (from PIR**)
Asian or Asian British	5%	6%	0%
Black or Black British	6%	24%	5%
Mixed	6%	18%	9%
Not known / Not stated	6%	0%	0%
Other ethnic groups	2%	12%	0%
White	74%	41%	86%

* Long-term segregation
** Provider information return

FIGURE 7: ETHNICITY OF PEOPLE IN LEARNING DISABILITY WARDS, AT DECEMBER 2018

Ethnicity	On learning disability wards in England at 31/12/18	In prolonged seclusion during December 2018 (from PIR)	In LTS* during December 2018 (from PIR**)
Asian or Asian British	4%	0%	2%
Black or Black British	5%	11%	6%
Mixed	3%	0%	2%
Not known / Not stated	8%	5%	0%
Other ethnic groups	1%	0%	0%
White	80%	84%	90%

* Long-term segregation
** Provider information return

FIGURE 8: ETHNICITY OF PEOPLE IN LOW SECURE WARDS, AT MARCH 2019

Ethnicity	On low secure wards in England at 31/03/2019	In prolonged seclusion during March 2019 (from PIR)	In LTS* during March 2019 (from PIR**)
Asian or Asian British	7%	3%	7%
Black or Black British	14%	3%	0%
Mixed	5%	7%	7%
Not known / Not stated	5%	7%	0%
Other ethnic groups	3%	3%	0%
White	67%	76%	86%

* Long-term segregation
** Provider information return

FIGURE 9: HOW FAR AWAY AUTISTIC PEOPLE AND/OR PEOPLE WITH A LEARNING DISABILITY AND CHILDREN AND YOUNG PEOPLE IN PROLONGED SECLUSION AND LONG-TERM SEGREGATION ARE FROM HOME
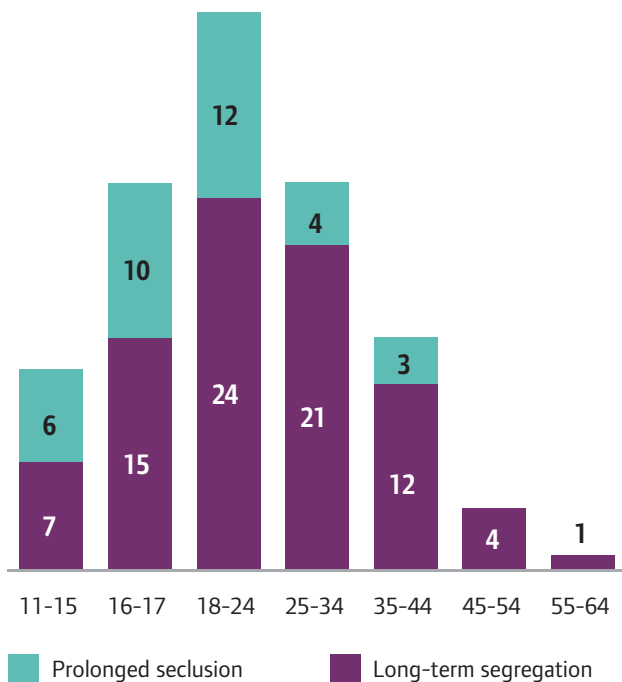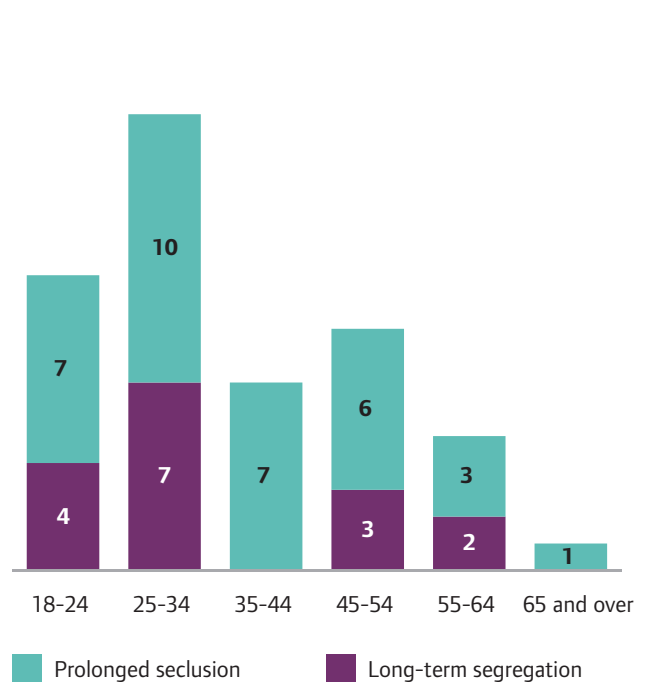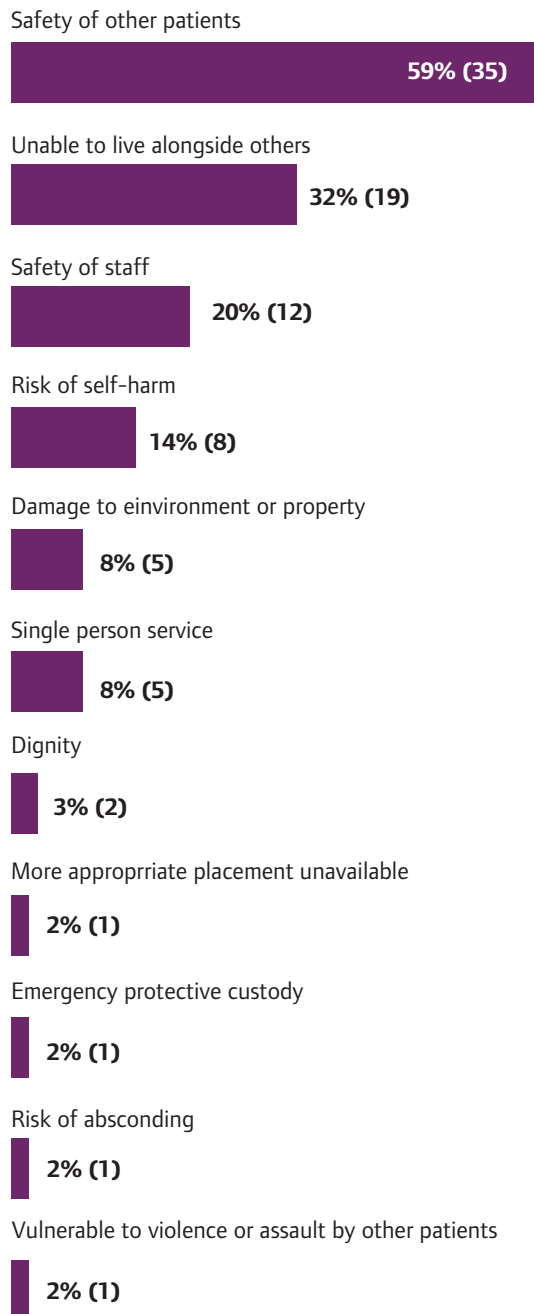
	Average* distance (km)	Minimum distance (km)	Maximum distance (km)	People >50 km from home	% of people >50km from home
Prolonged seclusion	32	2	309	14	45
Long-term segregation	81	4	291	38	60
Adults with a learning disability and/or autism	72	2	291	33	57
Children and young people	56	4	309	19	53

Note: Distance figures available for 94 out of the 120 people in long-term segregation and prolonged seclusion.
*Median average

FIGURE 10: HOW FAR AWAY PEOPLE IN MENTAL HEALTH LOW SECURE/REHABILITATION WARDS IN PROLONGED SECLUSION AND LONG TERM SEGREGATION ARE FROM HOME

	Average* distance (km)	Minimum distance (km)	Maximum distance (km)	People >50 km from home	% of people >50 km from home
Prolonged seclusion	19	2	312	7	44
Long-term segregation	91	17	118	6	75

Note: Distance figures available for 24 out of the 50 people in long-term segregation and prolonged seclusion.
*Median average

FIGURE 11: THE PERCENTAGE (NUMBER) OF AUTISTIC PEOPLE AND/OR PEOPLE WITH A LEARNING DISABILITY AND CHILDREN/YOUNG PEOPLE IN PROLONGED SECLUSION AND LONG-TERM SEGREGATION DIAGNOSED WITH CONDITION

Condition	Prolonged seclusion	Long-term segregation
Autism	23% (7)	67% (53)
Personality disorders	13% (4)	20% (16)
Neurodevelopmental conditions	17% (5)	9% (7)
Conduct disorders	13% (4)	10% (8)
(Suspected) first episode psychosis	23% (7)	
Ongoing or recurrent psychosis	13% (4)	6% (5)
Bipolar disorder	10% (3)	5% (4)
Self harm behaviours	7% (2)	5% (4)
Suspected autism	10% (3)	
Attachment difficulties	3% (1)	5% (4)
Unexplained physical symptoms	3% (1)	4% (3)
Depression	3% (1)	4% (3)
Anxiety		5% (4)
In crisis	3% (1)	1% (1)
Drug and alcohol difficulties	3% (1)	
Relationship difficulties		3% (2)
Eating disorders		3% (2)
Post-traumatic stress disorder		1% (1)
Obsessive compulsive disorder		1% (1)

■ Prolonged seclusion   ■ Long-term segregation

FIGURE 12: THE PERCENTAGE (NUMBER) OF PEOPLE IN A MENTAL HEALTH LOW SECURE/REHABILITATION WARD IN PROLONGED SECLUSION AND LONG-TERM SEGREGATION DIAGNOSED WITH CONDITION

Condition	Prolonged seclusion	Long-term segregation
Ongoing or recurrent psychosis	70% (21)	38% (6)
Personality disorders	33% (10)	44% (7)
Anxiety	10% (3)	13% (2)
Autism	3% (1)	19% (3)
Bipolar disorder	3% (1)	13% (2)
In crisis	10% (3)	
Depression	3% (1)	6% (1)
Drug and alcohol difficulties	7% (2)	
Suspected autism		6% (1)
Post-traumatic stress disorder	3% (1)	

■ Prolonged seclusion   ■ Long-term segregation

FIGURE 13: HOW REVIEWERS JUDGED THE STANDARD OF CARE OF AUTISTIC PEOPLE AND/OR PEOPLE WITH A LEARNING DISABILITY AND AND CHILDREN AND YOUNG PEOPLE IN LONG-TERM SEGREGATION
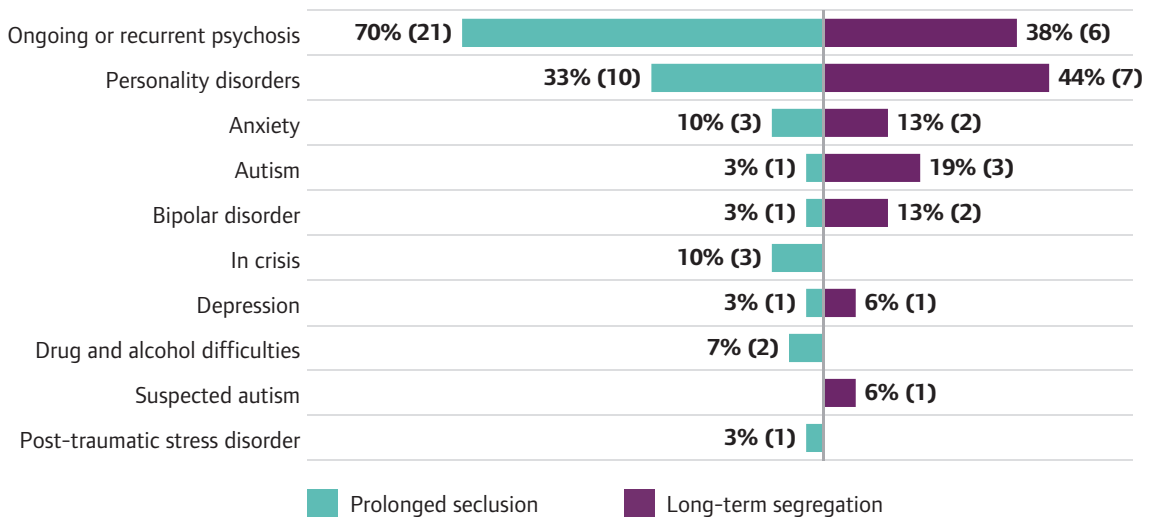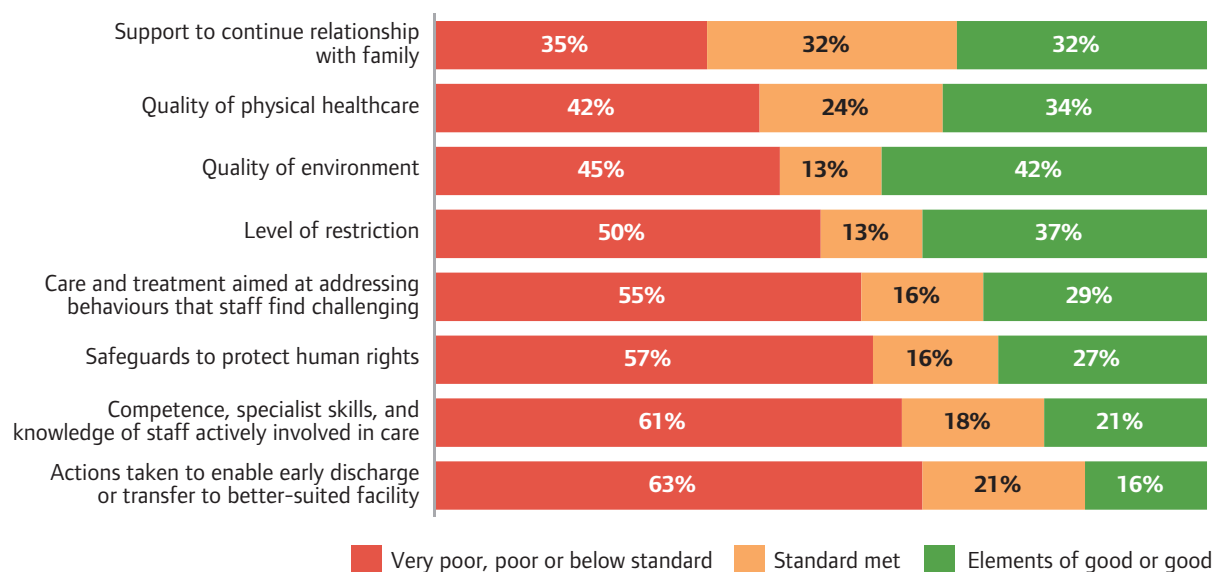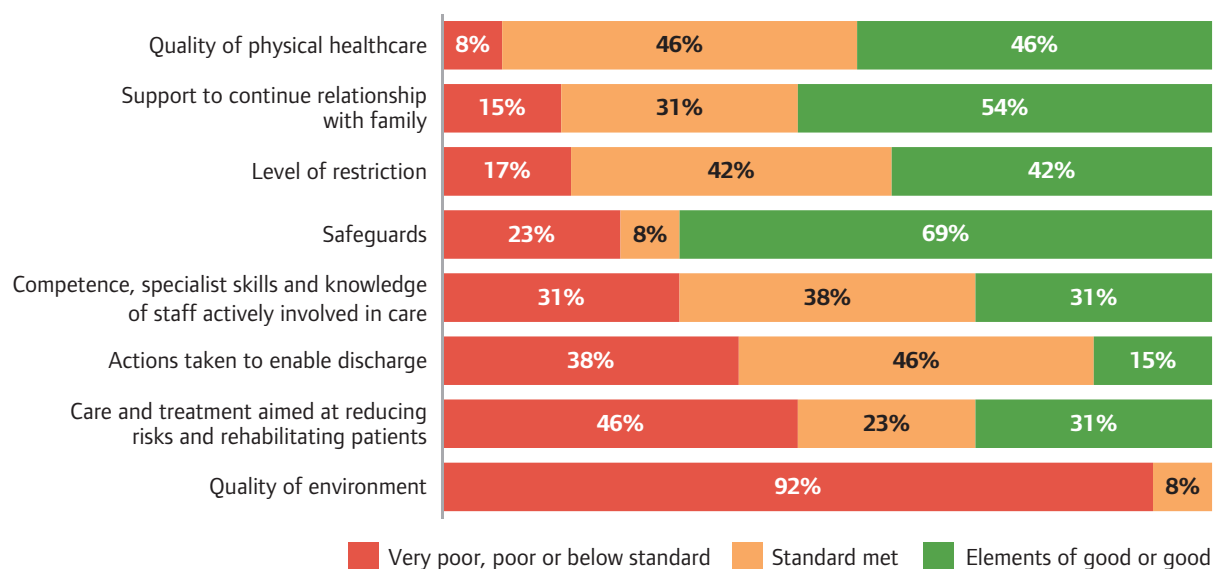
	Very poor, poor or below standard	Standard met	Elements of good or good
Support to continue relationship with family	35%	32%	32%
Quality of physical healthcare	42%	24%	34%
Quality of environment	45%	13%	42%
Level of restriction	50%	13%	37%
Care and treatment aimed at addressing behaviours that staff find challenging	55%	16%	29%
Safeguards to protect human rights	57%	16%	27%
Competence, specialist skills, and knowledge of staff actively involved in care	61%	18%	21%
Actions taken to enable early discharge or transfer to better-suited facility	63%	21%	16%

Note: Reviewers ratings of key areas. Figure based on ratings completed for 38 people in long-term segregation at the time of the reviewers' visits across all questions with the exception of 'Safeguards to protect human rights' (37) and 'Support to continue relationship with family' (34).

FIGURE 14: HOW REVIEWERS JUDGED THE STANDARD OF CARE OF PEOPLE IN MENTAL HEALTH LOW SECURE/REHABILITATION WARDS IN LONG-TERM SEGREGATION

	Very poor, poor or below standard	Standard met	Elements of good or good
Quality of physical healthcare	8%	46%	46%
Support to continue relationship with family	15%	31%	54%
Level of restriction	17%	42%	42%
Safeguards	23%	8%	69%
Competence, specialist skills and knowledge of staff actively involved in care	31%	38%	31%
Actions taken to enable discharge	38%	46%	15%
Care and treatment aimed at reducing risks and rehabilitating patients	46%	23%	31%
Quality of environment	92%	8%	

Note: Figure based on ratings completed for 13 people in long-term segregation at the time of the reviewers' visits across all questions, with the exception of 'Support to continue relationship with family' (12).

CQC ratings data

Review teams visited services with a range of ratings from CQC.

FIGURE 15: 37 HOSPITALS VISITED IN PHASE 1 AND 2

	Number of overall rating	Percentage of overall rating
Outstanding	6	16%
Good	16	43%
Requires improvement	9	24%
Inadequate	6	16%

FIGURE 16: 27 SOCIAL CARE SERVICES VISITED IN PHASE 2

	Number of overall rating	Percentage of overall rating
Outstanding	2	7%
Good	21	78%
Requires improvement	4	15%
Inadequate	-	-

FIGURE 17: 452 SOCIAL CARE SERVICES INCLUDED IN QUESTIONNAIRE

	Number of overall rating	Percentage of overall rating
Outstanding	17	4%
Good	345	76%
Requires improvement	82	18%
Inadequate	7	2%
Not yet rated	1	0.2%

Examples of reducing restrictive practice strategies

Mental Health Act – A focus on restrictive intervention reduction programmes in inpatient mental health services, showcases good practice examples from five NHS mental health trusts where we have seen effective approaches to reduce restrictive practice.

Appendix E: Glossary

Advocate – someone who helps another person to express their views, wishes and feelings, and stands up for the other person's rights. Independent Mental Health Advocates (IMHAs) provide an additional safeguard for people who are subject to the Mental Health Act. They enable people to participate in decision-making.

Attention deficit hyperactivity disorder (ADHD) – a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness.

Autism/autistic spectrum disorder – a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.

Blanket restrictions – rules or policies that restrict a person's liberty and other rights, which are routinely applied to everyone within a service, without individual risk assessments to justify their application.

Care (Education) Treatment Review (CETR) – this is a meeting about a child or young person who has a learning disability and/or autism and who is either at risk of being admitted to, or is currently detained in, an inpatient (psychiatric) service.

Challenging behaviour – some children and adults with severe learning disabilities typically display behaviour that may put themselves or others at risk, or that may prevent the use of ordinary community facilities or a normal home life. This behaviour may include aggression, self-injury, stereotyped behaviour or disruptive and destructive behaviours. These behaviours are not under the control of the individual concerned and are largely due to their lack of ability to communicate.

Challenging behaviour is defined as:

"Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities."[49]

Clinical commissioning group – a group of GP practices in a particular area that work together to plan and design health services in that area. Each CCG is given a budget from NHS England to spend on hospital care, rehabilitation and community-based health services.

Code of Practice – statutory guidance to health professionals on how they should carry out functions under the Mental Health Act.

Complex care – for the purposes of this report, complex care is defined as people with multiple, and sometimes interconnected health, communication and social needs. Their care typically requires co-ordination and input from a range of skilled professionals who may be employed by different organisations.

Deprivation of Liberty Safeguards (DoLS) – procedures prescribed in law to deprive a resident or patient of their liberty in order to keep them safe from harm. These procedures can only be used when the patient or resident lacks capacity to consent to care and treatment.

Dialectical behavioural therapy (DBT) – a type of talking treatment that focuses on how thoughts, beliefs and attitudes affect a person's feelings and behaviours. It encourages people to develop coping skills for dealing with different problems. It is used to help people who experience emotions very intensely.

Functional assessment – a method for understanding the causes and consequences of behaviour and its relationship to particular stimuli, and the function of the behaviour. The function of a particular behaviour can be analysed by identifying the precursor or trigger of the behaviour, the behaviour itself and the consequence of the behaviour.

Learning disability – a learning disability affects the way a person understands information and how they communicate. This means they can

have difficulty understanding new or complex information, learning new skills and coping independently.

Long-term segregation – a situation in which a patient is not allowed to mix freely with other people on their ward or unit on a long-term basis. Long-term segregation is used when a patient presents a high likelihood of causing serious injury to others over a prolonged period of time.

Makaton – a system of language that uses symbols, signs and speech to enable people to communicate. It supports the development of essential communication skills such as attention and listening, comprehension, memory, recall and organisation of language and expression.

Mechanical restraint – using some kind of equipment to prevent a person moving their body freely, in order to prevent them from hurting themselves or someone else.

Medium secure unit – a hospital providing care and treatment to people who have chronic mental disorders, present a serious risk of harm to others and whose escape from hospital must be prevented.

Mental Health Act reviewer – a person employed by CQC to review the use of the Mental Health Act 1983.

Personality disorder – a condition that causes people to think, feel, behave or relate to others differently from the average person. People with a personality disorder may have disturbed ways of thinking, impulsive behaviour and problems controlling their emotions.

Positive behaviour support (PBS) plan – a person-centred framework for providing long-term support to autistic people, and people with a learning disability and/or mental health condition, who have, or may be at risk of developing, behaviours that challenge. It is a blend of person-centred values and behavioural science and uses evidence to inform decision-making. Behaviour that challenges usually happens for a reason and maybe the person's only way of communicating an unmet need. PBS helps us understand the reason for the behaviour, so we can better meet people's needs, enhance their quality of life and reduce the likelihood that the behaviour will happen.

PRN medicines – medicines that are taken when they are needed, as opposed to medicines that are to be taken at specific times during the day. (PRN is an abbreviation of the Latin *Pro re nata,* meaning as needed).

Seclusion – restricting someone's movements by leaving them alone in a room or separate space that they cannot leave, in order to prevent them hurting themselves or someone else.

Sensory assessment – many autistic people have difficulty processing everyday sensory information. Any of the senses may be over- or under-sensitive, or both, at different times. These sensory differences can affect behaviour and can have a profound effect on a person's life. A sensory assessment assesses individuals' sensory needs and how these may best be met.

STOMP (Stopping over medication of people with a learning disability, autism or both with psychotropic medicines) – a national project involving many different organisations which are helping to stop the over use of psychotropic medicines. STOMP is about helping people to stay well and have a good quality of life.

Trauma and trauma informed care – incidents that people experience as being physically or emotionally harmful, or life-threatening, can cause trauma. Trauma can have lasting adverse effects on an individual's functioning and mental, physical, social, emotional or spiritual wellbeing. A trauma-informed approach to healthcare aims to provide an environment where a person who has experienced trauma feels safe and can develop trust.

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