

Out of sight – who cares?

Restraint, segregation and seclusion review

**Progress report
March 2022**

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Foreword

Our first Out of sight report was written with the aim of highlighting and addressing issues of serious concern that had been known about and not addressed for too long. Cultures, behaviour, and the design of services did not always suit the people they were supposed to help. Restrictive interventions, such as restraint, seclusion and segregation, were used often and for many people.

The Out of sight report was intended to stop unacceptable practice, but also challenge the status quo to lever the change that must happen to improve the lives of people with mental ill health, autistic people, and people with a learning disability.

This has not happened and there are still too many people in mental health inpatient services. They often stay too long, do not experience therapeutic care and are still subject to too many restrictive interventions, which cause trauma. Families have told us clearly that the pain and harm for them and their family member continues.

The lack of community services, which can provide early intervention, crisis support and support for people living within their communities, means that people are more likely to end up in hospital. Additionally, for many people, the right housing is not available, nor the right support in place. This means that people are more likely to be living in unsuitable conditions, which then break down, which can lead to hospital admission. People end up moving around the system from one service to another because their needs are not being met.

Our first report made recommendations to improve services and the overall system. We acknowledge that the pandemic had an impact on services and the people that use them in a way that could not have been foreseen. We reflected on this in our [progress report](#) in December 2021. However, developments have not been at the required pace.

There has been some progress, though. There has been investment by the Department of Health and Social Care and NHS England and NHS Improvement into projects aimed to support people to come out of long-term segregation, and funding has been allocated to increase community support. We recognise that many staff have been working hard to try and bring about the changes needed.

People feel stuck in the system. We are calling on all partners to move forward, transferring the planning and good intentions into action, taking responsibility for implementing the changes needed. The focus must be on meeting people's individual needs. We need to move onto ensuring services fit around people rather than trying to fit people into services that can't meet their needs.

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Summary of findings

This report describes the progress made on the recommendations in our [Out of sight – who cares? report](#), published in October 2020, which looked at the use of restraint, seclusion and segregation in care services.

The recommendations were made for people with mental ill health, people with a learning disability and autistic people. However, there is more of a focus on people with a learning disability and autistic people, as we visited more services where they lived. This is reflected in the balance of evidence in this report.

This report updates on key themes, which means some recommendations are grouped together, rather than being in numerical order. We have reported on progress. We have also drawn attention to where progress has not been made.

We have shown whether each recommendation has been achieved, partly achieved, or not achieved.

We consider these recommendations have not been achieved

Recommendation 1 – people have a home and the right support in place

Recommendation 2 – people have the right community services commissioned

Recommendation 3 – people have the right support to avoid crisis

Recommendation 4 – people have their rights understood

Recommendation 5 – people receive the right support in hospital

Recommendation 7 – people have skilled staff to support them

Recommendation 8 – people have bespoke services

Recommendation 11 – people who experience restrictive interventions have these reported to CQC

Recommendation 13 – people who are segregated in hospital experience good quality regular independent reviews

Recommendation 14 – people have meaningful Care (Education) and Treatment Reviews because providers and commissioners are accountable

Recommendation 15 – all people in segregation in hospital are recognised through updating the definition of long-term segregation

Recommendation 16 – people see a reduction in the use of restrictive interventions

Recommendation 17 – people in children's and adult social care services experiencing restrictive interventions would have these reported to regulators

We consider these recommendations have been partly achieved

Recommendation 6 – improving how CQC regulates services for people with a learning disability and autistic people

Recommendation 9 – recording data to improve local services

Recommendation 10 – people's experience of person-centred care

Recommendation 12 – people who experience restrictive interventions have regular oversight by commissioners

There are no recommendations that we consider have been fully achieved.

We have come to these conclusions through weighing up the evidence from what stakeholders, including people with lived experience, have told us; what progress has been made; and what impact this has had on outcomes for people. Where we have no evidence of a positive impact on the outcomes people experience, we have concluded that the recommendation has not been achieved. Where some impact is evident, we have concluded that the recommendation has been partly achieved.

We have reviewed national published data to inform this report, including the NHS Mental Health Services Data Set (MHSDS) and Assuring Transformation data set and inspection reports of services for children and young people with special educational needs and disability. Data on mental health inpatients from MHSDS covers all people receiving care in a mental health hospital, including autistic people and people with a learning disability.

We have also used data and insight that we have gained from our engagement with our Expert Advisory Group, voluntary and community sector organisations, provider representatives, government departments, health and social care leaders, non-departmental government bodies, advocacy organisations, practitioners and people using services in health and social care. Throughout this report, we include stories of people's experiences of care. We have not used their real names.

Our findings from these sources have been corroborated, and in some cases supplemented, with input from subject matter experts.

CQC made a commitment to monitor and report on the recommendations. The responsibility for delivery of the majority of the recommendations lies with partners. Governance of those recommendations relating to people with a learning disability and autistic people must lie with the Department of Health and Social Care Building the Right Support delivery board to hold members to account and deliver the recommendations. The Department of Health and Social Care and partner organisations need to clarify how the recommendations relating to services for people with mental ill health will be progressed.

1. People's experience of person-centred care

Recommendation 10 (involvement of people and their families)

True person-centred care is key to ensure that people can live the lives they want. It is about ensuring that people, their families and advocates are listened to and involved in planning their care and support. It is about treating them with respect and as equal citizens. This is key to ensuring that people receive the right support at the right time.

If recommendation 10 was fully implemented:

- people would be involved in developing their support and care plans. This would be central to the care they receive
- families and advocates would also feel that providers and commissioners listen to them and involve them in decisions
- people, their families and advocates who have concerns about services would be able to escalate them easily to the providers and commissioners
- people who need the support of an independent advocate with the right specialist knowledge would be able to receive it.

Has recommendation 10 been achieved?

We consider that recommendation 10 has been partly achieved

Truly person-centred care that is co-produced by people, their families and advocates is essential for people to live positive lives. While there are examples of this, too many people are not experiencing person-centred care, especially within hospital settings.

Action needed:

- All services need to ensure that person-centred care is co-produced with people and their families, and services should be accountable for this.
- More high-quality advocacy needs to be made available to everyone who needs it.
- Services should listen to and act on the concerns of people, their families, and advocates to ensure that people are receiving the best possible support.

What we are seeing and hearing

We can see from the experiences that people have told us about in this and previous reports that people's care is often not person-centred. People and their families or advocates have not been central in developing their service, in finding the right place

to live and the right people to support them, or in developing their care plans. We therefore made recommendations to improve this.

We know that in some services this is happening. However, people are often not experiencing true co-produced person-centred care. Without this, people are more likely to hit crisis point.

The data for people with a learning disability and autistic people, taken from the [Assuring Transformation](#) data set for December 2021 finds that, for 59% of people with a learning disability and autistic people who were in hospital, it was recorded that the family was involved in discussing the care plan. For another 7% of people, the family was not involved at the request of the person. However, for nearly 1 in 10 people (9%) the family was not involved and for nearly a quarter of people (23%) it was not recorded whether the family was involved in discussing the care plan.

Below is an example of a home where we have seen true person-centred care where people are empowered to be able to live the lives they want to.

This is what we should expect to see in all services, across both health and social care.

Example of person-centred care in a care home

One person told our inspectors, "It's not a home, it's my home. I would live here for 20 years if I could!"

People said they were respected, encouraged, and emotionally supported, and commented on how much choice, control, and independence they have now.

Staff were excellent at exploring different ways to communicate with people, so they could express their needs and get their opinions heard. One person was supported to take complete control of their person-centred review, which included healthcare professionals. They were supported to write up the review outcomes and goals they wanted to work on in the future. The person told us they liked to see their 'own language' in their reviews, unchanged for health professionals.

The shared vision of a highly successful and inclusive service was driven by exceptional leadership. People, their relatives and health professionals thought the care home was a fantastic place to live. Comments included, "They've never given up on me", "Compassionate professionals", "Nothing is unachievable" and "Miracle home". Another person told us, "The home and staff have been amazing for me. When I arrived here my whole life was in a meltdown, I feel like they saved me."

People and their families still tell us that it is not always easy to raise and escalate concerns to providers or commissioners. Where they do, they can feel labelled as difficult or persistent complainers and are concerned that it will have a negative impact on how providers see and treat them or their loved one.

NHS England and NHS Improvement (NHSE/I) have told us that they are committed to co-production and involvement of people with a learning disability and autistic people and their families in the design and delivery of services and try to embed this in their national strategic development and work. They have also told us they remain

committed to [Ask Listen Do](#) and expect all local services, systems and regions to have clearly articulated escalation processes.

Advocacy

In our Out of sight report, we said that an investment and an action plan should be developed to ensure that all autistic people, people with a learning disability or people with mental ill health have access to an independent advocate. This would need adequate resourcing and specialist training for advocates.

We also said the action plan 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.

The Assuring Transformation data from December 2021 showed that most autistic people or people with a learning disability in hospital had access to an independent advocate. The data also suggests the quality of advocacy is improving, with 79% of organisations providing advocacy holding the Advocate Quality Performance Mark (QPM) in December 2021 compared to 71% at the beginning of the year. The QPM is a quality assurance assessment for providers of independent advocacy that is based on the principles contained in the Advocacy Charter and the Advocacy Code of Practice. However, this does not mean that everyone has access to advocacy.

When we spoke to leaders of advocacy organisations, they said that there is:

- a lack of resource for fully effective advocacy
- a lack of access to advocacy when a person is in seclusion or segregation
- a need for better collaboration with family members
- not enough staff skilled in advocacy, or in advocacy for people with autism and a learning disability
- no clear distinction at CQC between statutory and private advocacy provision in our reports.

NHSE/I have told us that £4.5 million in funding was allocated in 2021/22 for a review of advocacy for people with a learning disability and autistic people. The findings from this review will be shared with the Building the Right Support Delivery Board, which is run by the Department of Health and Social Care.

Advocacy providers have been concerned about the lack of funding for the provision of advocacy for a long time, and progress has been too slow.

Recommendations 1 and 8 (right home, right support and bespoke services)

People with mental ill health, a learning disability and autistic people want the same as everyone else – a home of their own.

Supporting people to remain in the community means having appropriate housing, with the right support available at the right time. It means working together with people and their families to develop true person-centred services with the right support in place. This helps prevent family or placement breakdown and avoids hospital admission.

When people are admitted to hospital, not having the right housing provision can lead to people being in hospital longer than necessary. To address this, we made [recommendations](#) for the government and commissioners to ensure that there was more of the right type of housing available, in line with our guidance, [Right support, right care, right culture](#) and the government's guidance, [Building the right support](#).

If recommendation 1 and 8 were fully implemented, people would:

- experience more joined-up care
- have their own single, personalised budget, agreed across education, health, and social care
- access the right support at the right time across education, health, and social care, including specialist community teams that understand their needs
- have access to the right type of housing and support to meet their needs in their local communities or communities of their choice
- be less likely to be in inpatient services
- live in a home that is bespoke, in the community of their choice with person-centred care.

Have recommendations 1 and 8 been achieved?

We consider that recommendations 1 and 8 have not been achieved

Not enough people are able to have a home of their own with the right support in place.

Action needed:

- People should be able to move to ordinary homes on ordinary streets with the right support and only be in hospital when receiving treatment.
- People's homes and support must be developed through co-production with people and their families.
- People's rights must be promoted to ensure person-centred support and true citizenship.

What we are seeing and hearing

People with lived experience, their families and commissioners continue to tell us that there is not enough provision of housing with the right support available. The Local Government Association tell us that there isn't enough of a joined-up approach between housing, social care and health. This is leading to some housing departments not being compliant with the Equality Act 2010 and duties to make reasonable adjustments to enable access to housing. In addition, some housing departments are not planning for any specific housing needs of people with a

learning disability or autistic people in their local community housing plans or, when they do, they do not consider access to an ordinary home on an ordinary street.

Data for April 2020 to March 2021 from the [Adult Social Care Outcome Framework](#) shows that 78% of working-age adults who were receiving long-term local authority support for a learning disability were living in 'settled accommodation'. This increased by one percentage point on the previous year. Settled accommodation is where a person can reasonably expect to stay as long as they want, as opposed to accommodation that is either unsatisfactory or where residents do not have the security of tenure, such as care homes.

Only 58% of working-age adults who were receiving secondary mental health services were living in settled accommodation at the time of their most recent assessment, formal review, or other multi-disciplinary care planning meeting. This figure had not changed from the previous year.

There is considerable regional variation in the proportion of adults with a learning disability or mental illness who live in settled accommodation, with the West Midlands having the lowest level.

The lack of suitable community housing alongside the lack of adequate community services to provide care and support, means that some people's needs aren't being met. Some people cannot be discharged from hospital and others are moved to inappropriate settings, which are more likely to lead to re-admission to hospital. When we have taken enforcement action against services that are not providing the right support, we have found that closing these services sometimes poses difficulties, as it can be hard to then find the right services due to the lack of suitable housing and support available.

The Assuring Transformation data published by NHS Digital shows that nearly a quarter (23%) of the 65 autistic people or people with a learning disability who were admitted to hospital in December 2021 were re-admissions of people who had been discharged within the last year.

Since the abuse scandal at Winterbourne View hospital, successive governments have promised and missed their targets to reduce the number of autistic people and people with a learning disability in inpatient units. The recent report by the [Health Select Committee](#) in July 2021 further highlights the lack of community provision for autistic people and people with a learning disability to be able to live fulfilled lives in the community.

Individual budgets

In our Out of sight report, we called for a system where budgets across education, health and social care can be pooled to meet individual needs. We often hear stories from people who tell us that there are delays in accessing the right support due to discussions and disagreements on which budget this should come from. This is often why people are moved to inappropriate settings in the community, as commissioners sometimes are under pressure to put budget before people's needs. This short-

sighted approach has long-term costs, as it can contribute to a crisis that leads to hospital admission.

This is then repeated when people need to be discharged from hospital as health and social care can struggle to decide who will be responsible for the different costs of people's care.

At present when people are in hospital, local authorities have no responsibility for payment. This does not give them an incentive to support people to be discharged to community placements, as it will then come out of their budget. People who have been detained under certain parts of the Mental Health Act are entitled to section 117 aftercare which can help them to access community support. However, as reported in our [Monitoring the Mental Health Act in 2020/21 report](#), people do not always manage to access this.

The current funding system must be tackled and replaced by a system that ensures a person's budget follows them between services. The [Health Select Committee outlined in their July 2021 report](#) concerns regarding the current funding system. The money used to keep people in hospital needs to be reinvested in appropriate community support and housing to enable people to live the lives they want where they want.

2. People's experience of hospital care

Recommendation 5 (receiving the right support in hospital)

In [our Out of sight report](#) in 2020 we highlighted the awful experiences that many people in hospitals were having. We found that poor physical environments, restrictive cultures, poorly paid and unskilled staff meant that hospitals were not therapeutic environments. This often led to people becoming distressed, which led to restrictive interventions such as restraint, seclusion and segregation.

To address this, we made recommendations to the government, NHS England and NHS Improvement (NHSE/I) and commissioners to ensure that when people are admitted to a mental health hospital (including assessment and treatment units for people with a learning disability and autistic people), they receive planned, high quality, specialist care for the shortest time possible in a therapeutic environment. We have highlighted below what it would mean for people if these recommendations were implemented.

If recommendation 5 was fully implemented, people who are admitted to hospital would:

- only be admitted when essential for their treatment, and for the shortest time possible. The focus would be on discharge, and planning for this would start before admission
- be assessed by community health and social care teams before admission who understand their needs, with measurable objectives set for the admission
- receive high-quality, specialist care, in an appropriate environment, with small units for autistic people, specifically designed to meet their needs
- receive further assessments to screen for autism, sensory sensitivities, physical health, mental health needs, learning disability, trauma, and any other relevant assessments, so that the objectives set on admission and care plans would meet people's needs
- receive person-centred care in hospital environments that are therapeutic, enabling person-centred and trauma-informed care
- have a named budget holder, who must be responsible for commissioning a new placement within an agreed timeframe
- would have a named care co-ordinator and system navigator if they have multiple needs.

Has recommendation 5 been achieved?

We consider that recommendation 5 has not been achieved

There are still too many people in hospital, in environments that are not therapeutic, and people are staying there too long. There has been significant investment in improving therapeutic environments, however it is too early to see the impact.

Action needed:

- People must only be admitted to hospital when it is essential. It must be time-limited and only for treatment, not because there is a lack of support in the community.
- Culture must be changed to promote rights and ensure a co-produced person-centred, trauma-informed approach.
- Discharge planning and setting objectives must happen before or immediately after people are admitted.

What we have been seeing and hearing

There is still a long way to go to make this recommendation a reality. There are still too many people in hospital, and we are still hearing too many accounts of people in inpatient units receiving poor care and treatment. Recent stories that have made the headlines, such as '[Patient A](#)' and '[Tony Hickmott](#)', [Cawston Park Hospital](#), and the [BBC report on the failures of specialist mental health units](#), have highlighted that people are not always receiving the care and treatment that they should while in hospital and their discharge is not being prioritised. This is supported by findings from our inspections.

The [Health Select Committee's report from July 2021](#) further highlights that being in hospital is often not therapeutic, and that there is a lack of discharge planning. There is not enough appropriate community support available to help prevent admission and then enable discharge.

Scarlet's story of being in hospital

My name is Scarlet and I have bipolar. I stayed in hospital for four months because they couldn't get my medication right. I wasn't offered counselling.

I only saw the consultant once a week for ten minutes, and he would decide if you were staying in. I feel like decisions were made without me, and I'm not sure if my husband felt involved. I've still not seen my care plan. I have asked for it before and they said, "Oh, you've had one."

In terms of family visiting, I could see them once a week for about an hour, which is not long. I feel like family should have more of an input.

No-one acknowledges the trauma of being an inpatient. I don't think it helps when there are people with different levels of mental illness.

I called hospital a glorified prison. I live at home now and it is better for me, but you still have flashbacks to when you weren't allowed to bath on your own or go into the kitchen without asking a member of staff.

Therapeutic environment

Hospital environments can be overwhelming for everyone. People no longer have access to familiar things around them that give them comfort. They also lose their usual routine. Hospitals can be particularly difficult for autistic people, for example because they may have sensory sensitivities affected by environments. On top of this, if staff do not understand people's needs, such as the trauma they have experienced, their communication needs or how their autism affects them, the whole situation becomes even more distressing for people. This can lead to people being subjected to inappropriate restrictions.

Rather than being therapeutic, the ward environment is often focused on containment and risk management with people's distress looked at as behaviour to manage rather than a communication of unmet needs. Autistic people tell us that staff on the ward often do not recognise their autism diagnosis or understand how it affects them.

Additionally, people do not always have access to regular therapy to get better, such as psychology, occupational therapy or speech and language therapy. Access to education for children and young people may be limited.

Jasmine's story of being in hospital

I was admitted in hospital in April 2021 due to a bad episode of depression.

The nurses were always busy. I often felt like a burden and was afraid to talk to the nurses, as I felt like I was annoying them and adding to their workload. When I did ask them a question, they told me to talk to another nurse or come back to them later. I would get very confused as I did not know when 'later' meant. I discussed this in my ward round with my psychiatrist who spoke to the nurses about being more specific with me about timeframes. The nurses put this into action, and I was happy with the result.

I also did not feel safe in the hospital as there was a patient who was verbally and physically aggressive towards me. She once took my phone and refused to give it back to me. There was a nurse nearby, but they were busy talking to another patient. When I got her attention, she helped me get my phone back. I felt like the ward was very understaffed and nurses weren't very supportive.

Ali's story of being in hospital

When Ali went into hospital because of mental ill health, she thought there was a lack of staff, probably because of COVID-19 and having to self-isolate. There were a lot of agency staff, so there was no consistency. She said, "When I've been in hospital before it was similar. There was not very much therapeutic input. It was more about containment and medication. There's nothing to do or keep your mind off what you're experiencing."

There has been progress on working towards this recommendation. However, as yet, people have not felt a significant impact from this progress.

[The NHS Long Term Plan \(2019\)](#) has set a commitment that by March 2024 inpatient mental health services will be improved by increasing investment in therapies and activities, to give people a better experience in hospital. NHSE/I told us that to support acute mental health care that is therapeutic and purposeful from the outset, new funding has been secured to increase the number and mix of staff on the wards.

[NHSE/I have developed the Learning Disability Improvement Standards for NHS trusts](#). The standards are intended to help organisations measure quality of service and ensure consistency across the NHS in how they support people with a learning disability and autistic people. In 2020, 178 trusts participated. The Long Term Plan commitment is to roll them out across all NHS-funded services by March 2024.

In 2019, NHSE/I established [The National Quality Improvement Taskforce for children and young people's mental health inpatient services](#) for children and young people's mental health, learning disability and autism inpatient services. This has worked on a range of projects aimed at improving the quality of care for children and young people in mental health inpatient care. The Taskforce has:

- developed a national [Clinical Competency Framework](#) with Health Education England (HEE)
- commissioned [Specialist Autism Training](#) with HEE, co-designed and delivered with people with lived experience
- commissioned King's College London to work with 20 children's and young people's wards to deliver the [Safewards](#) programme by March 2023
- commissioned the Restraint Reduction Network to co-produce [documents and tools to help staff, families and inpatients understand blanket restrictions](#), as well as guidelines for people who have been subjected to a restrictive intervention and for the staff that have applied it.

Quality of inpatient care

Due to the lack of community services and hospital beds across all mental health services, commissioners are still sending people into inpatient units that we have rated inadequate.

The [Health and Social Care Committee's July 2021 report](#) showed that in June 2021, 170 people with a learning disability and autistic people were in hospitals rated inadequate, and a further 185 people were in services rated requires improvement.

It is possible to have a positive hospital experience. Despite working in difficult circumstances, staff can be caring, understand what it means to be autistic and help people to see family and friends and involve them in their care and support.

Rebecca's experience of inpatient care

I am autistic and have an eating disorder.

I was an inpatient during the Covid restrictions which was really challenging. I did struggle without my family being able to come in and visit me. When I was really struggling, I was allowed to see a psychologist. I explained I liked to take photos and they agreed I could use my mobile phone camera in the garden. Each day a part of my routine was taking photos of things in the garden (not patients) using mindful photography techniques; this helped me to cope.

When I was moved to another hospital after two weeks the change was overwhelming. In that hospital I met a member of staff that understood autism and created a visual routine for me, including daily one to one time with staff, gentle one to one exercise and occupational therapy. At times I struggled with distress, often around sensory overload from noise, things not being clear and ward rounds being difficult.

I can recall the kindness of a particular healthcare assistant who would always check in on all the patients when they started their shift. They made me feel human and took me on leave within the grounds to buy snacks from the vending machine to find some way of replicating normality. The ward also had an art room, which was open all day and up to 11pm. On many wards access to things like this are really restricted. That room felt like a place of safety, peer support and connection – it was a place where I was able to see a tiny bit of hope.

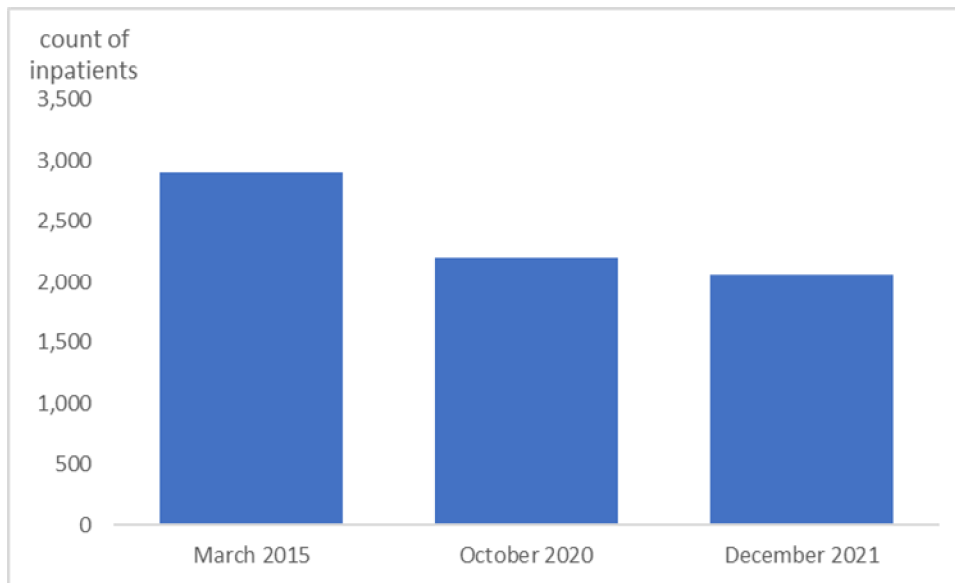
I know there was reluctance to admit me to hospital as I'd had admissions in the past, but those five weeks in hospital helped me to get to a place of hope where I could manage my mental health back in the community.

The number of people in hospital

Too many people are still spending too long in mental health hospitals too far away from home. NHS Mental Health Services Data Set (MHSDS) shows that, while the number of people in mental health inpatient services reduced in 2020, they have since rebounded to be similar to pre-pandemic levels. There were 25,023 inpatients at the end of October 2021, just 1.2% below the number of inpatients at the end of October 2019, with 1,199 of these being people aged 18 or younger.

The [NHS Long Term Plan](#) made a commitment that by March 2024 the number of autistic people or people with a learning disability in mental health inpatient facilities will be reduced by 50% compared to the number in March 2015. There has been progress on this. The [data from the Assuring Transformation collection published by NHS Digital](#) shows that at the end of December 2021, there were 2,065 autistic people or people with a learning disability in hospitals in England (figure 1). This is a 29% reduction on the March 2015 figure and a 6% reduction since we published our Out of sight report in October 2020.

Figure 1: Number of autistic people or people with a learning disability in hospital – March 2015 to December 2021



Source: NHS Digital, Assuring Transformation data set

The NHS Long Term plan also set a target that by March 2024 “for every one million adults, there will be no more than 30 adults with a learning disability and/or autism cared for in an inpatient unit.” Our analysis shows that at the end of December 2021 this number stood at 43, so there is further progress needed to meet this target.

However, the NHS Long Term Plan commitment that for every one million children and young people, no more than 12 to 15 children and young people who are autistic or have a learning disability would be cared for in inpatient facilities, is currently on track to meet the target.

The Assuring Transformation data for December 2021 shows that the number of people in hospital with a diagnosis of ‘learning disability only’ has nearly halved since March 2015, whereas the number of people with a diagnosis of ‘autism only’ has increased by 61%.

There has been an increase in the number of people having to go to hospitals ‘out of area’ (away from their local community). The [Health Service Journal](#) recently reported that out-of-area placements had returned to pre-pandemic levels through most of 2021 but then increased towards the end of the year. These increases have been put down to a number of reasons, which we have also highlighted in this report, such as workforce shortages, COVID-19 and lack of available beds. The Assuring Transformation data set for December 2021 shows that, after excluding newly admitted patients and those where the person’s home postcode could not be traced or derived, more than a third (36%) of autistic people and people with a learning disability in hospital are 50km or more away from home.

Getting out of hospital

Once admitted, many people are spending too long in hospital, getting stuck in the system, with an ineffective discharge process.

We recommended that where hospital admissions take place, there should be an immediate focus on discharge, with the person and their family central to discharge planning. However, we know that this is not occurring, and people are getting stuck in hospital, sometimes for many years.

Adam and his family's story of trying to leave hospital

My grandson Adam is a teenager and has been living in a hospital, detained under section 3 of the Mental Health Act, for five years.

Adam is an adorable lad with an amazing sense of humour and enjoys messy play and jumping. He is autistic, has a learning disability and a mental health condition. This can lead to him becoming distressed, which means that he is often violent to himself and others.

Adam rarely leaves his room as he prefers to stay in and will need to be restrained on a regular basis, although he sometimes actively seeks out restraint.

His staffing is four-to-one on good days, but this may go up to seven-to-one when he is poorly. His staff team in the hospital have gained his trust, are responsive to his needs and very caring.

Although the hospital started Adam's discharge planning on admission to the hospital, it has taken five years to get a plan in place for him to have his own home in the community and we have hit many hurdles along the way. These include:

- It took the local authority three years to appoint a coordinator to organise transition. We were concerned that decisions were being made on a basis of cost and not need.
- Finding a property took a long time. We now have one two miles from where Adam's mum lives.
- Identifying a care provider proved difficult. Many came to visit, certain they could provide the care, but would then change their mind.

Thankfully a provider has now been found. They are very engaged with us as a family. We have been able to write the job description for the registered manager and they will allow us to sift applications and be involved in interviews.

The longer Adam is in hospital, the more institutionalised he becomes. Staff are doing their best, but there are restrictions as it is a hospital environment.

The Assuring Transformation data shows that 55% of autistic people or people with a learning disability in a mental health hospital at the end of December 2021 had a total length of stay in hospital of more than two years. Around 355 people (17% of people in inpatient services) had a total length of stay in hospital of more than 10 years.

Nearly two-thirds (63%) of the 355 inpatients that have had a total length of stay of over 10 years are subject to [Part III of the Mental Health Act](#). However, there are 25 people recorded as having had a total length of stay in hospital of more than 10 years who are informal patients and not subject to the Mental Health Act.

While there may be variation in how delayed discharges are recorded, the MHSDS data available on delayed discharges of people in mental health inpatient services suggests these have increased through 2021. In October 2021 the recorded number of days of delayed discharge was 53% higher than the same point in the previous year. The main reason given for delayed discharges was that the person was waiting to go to a care home. The second most common reason was a delay awaiting housing, with getting supported accommodation being a particular issue.

The Assuring Transformation data shows that less than half (43%) of autistic people or people with a learning disability in a mental health hospital at the end of December 2021 had a planned date of discharge or transfer. Nearly two-thirds (64%) of those that did have a planned date were due to be discharged or transferred within the next 12 months. However, just over 1 in 5 (21%) were overdue for discharge or transfer.

The data also shows that in only 40% of cases, where a person has a planned date of discharge or transfer, was the relevant local authority aware that the person was being discharged to their area.

When we met with commissioners, they told us that local authorities need to be more involved in the journey towards discharge.

NHSE/I told us that:

- £116 million has been allocated during 2021/22 to support people with mental ill health through inpatient services and to ensure that people who are ready to leave inpatient facilities have the community support they need to do so
- the funding has also been used to address pressures in urgent and emergency mental health pathways to ensure that people with urgent and acute mental ill health can access high quality support promptly
- providers have implemented several initiatives to support more timely and effective discharges, including step-down supported housing, temporary accommodation solutions, additional capacity in home treatment teams and inpatient wards dedicated to supporting discharges, as well as home-based care packages.

Setting objectives for admission and screening assessments

During the original review for our Out of sight report, we found that people were often being admitted to hospital without a clear objective for what the stay in hospital would achieve. Once in hospital, people were not receiving screening assessments for autism, sensory needs, physical and mental health, trauma and learning disability, or were having previous diagnoses, such as autism, challenged or ignored. We therefore made recommendations to change this.

NHSE/I have told us that they are currently testing new approaches to help define the purpose or goals for people being admitted to hospital. This is to ensure that treatment and care is clearly set out and focused on discharge, so that people only stay in hospital for as long as their treatment takes to complete.

Recommendation 16 (restrictive interventions)

Our [Interim report in 2019](#) and Out of sight report in 2020 highlighted the serious concerns that we had regarding the use of restraint, seclusion and segregation for people with mental ill health, those with a learning disability and autistic people. This was of particular concern in inpatient units, but we found they were also being used in adult social care settings. We therefore made several recommendations to try to effect change. To date, little progress has been made. Far too many people are still subject to restraint and seclusion and more people than before are in long-term segregation.

If recommendation 16 was fully implemented, people would only be subject to restrictive interventions when absolutely necessary and for the shortest possible time because:

- providers would monitor their use in line with [best practice](#)
- they would be checked by appropriate statutory and regulatory bodies in line with guidance and regulations.

Has recommendation 16 been achieved?

We consider that recommendation 16 has not been achieved

Restrictive interventions continue and are often used inappropriately when people communicate their distress and unmet needs. There are more people in long-term segregation now than there were in 2019. Each restrictive intervention may cause further trauma.

Action needed

- The use of restrictive interventions must be reduced by services working with people, their families and advocates to understand people's distress and the best way to meet their needs.
- Projects, such as life planning and senior intervenors, need to be funded beyond March 2022.
- The current approach used for Independent Care (Education) and Treatment Reviews must be reviewed.

What we have been seeing and hearing

Restrictive interventions

There is a continued over-reliance on restrictive interventions. People are too frequently subjected to practices that are about containment and are not therapeutic. Restrictive interventions include restraint, seclusion and long-term segregation.

It is important to remember that each time a restrictive intervention is used, it has an impact on that person and staff; restrictive interventions can cause further trauma to people and add to feelings of dehumanisation.

MHSDS data shows that in October 2021:

- there were 1,920 people in mental health inpatient settings who were subject to restrictive interventions
- for those people, restrictive interventions were used 11,355 times
- of the people who were subject to restrictive interventions, 160 were children and young people
- the rate of restrictive interventions of children and young people was much higher than adults – averaging 20 restrictive interventions per child and young person, compared to almost five per adult.

Representatives from hospital and adult social care providers felt that the focus of monitoring shouldn't only be on the number of restrictive interventions, but that more qualitative information is needed alongside the figures to provide context about the use of restrictive interventions.

Restraint

The MHSDS data for October 2021 shows that physical restraints were used most frequently during the month, followed by chemical restraint (medicines used to restrain or control behaviour) (figure 2). Four hundred and twenty people were restrained using rapid tranquillisation (intramuscular injections of medicines) and this was used 1,125 times. This is an average rate of 2.68 uses of rapid tranquillisation per person.

Alexis's experience of chemical restraint (rapid tranquillisation)

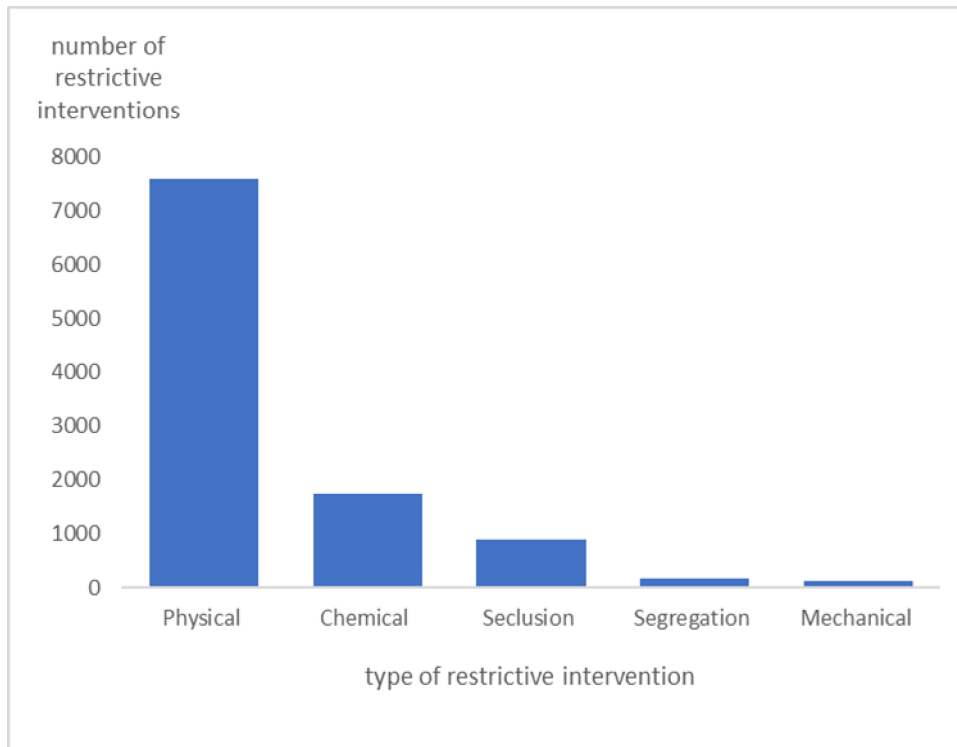
Your whole body and mind are invaded by the chemicals, and you are literally in a fog and can't see out. I used to beg for it not to happen, but it always did. I would be injected. You can't do anything other than wait hours for the drugs to wear off and the brain fog to clear. When it clears you have a hangover. Your body feels numb, and your mind feels heavy – you can't think clearly.

Then you sit in seclusion and wait for it all to happen again. You know it will happen again because the environment will get you overloaded. Then staff will respond with restraint and injections. You feel powerless to stop it. The wait is anxiety provoking and the begging is dehumanising.

MHSDS data for October 2021 shows that 65 people were subject to mechanical restraints a total of 130 times in the month (average rate of two uses of mechanical

restraints per person). Our Expert Advisory Group highlighted that it is not known which hospitals hold supplies for mechanical restraint such as leg straps, spit hoods and belts so that their use can be monitored.

Figure 2: Number of restrictive interventions, by type, in October 2021



Source: MHSDS data

Seclusion and long-term segregation

The MHSDS data shows that 520 people in mental health inpatient services were secluded at some point during October 2021 and 110 people were in segregation.

We are very concerned that there are more people known to be in long-term segregation now than when the Out of sight review was commissioned by the Secretary of State in November 2018. Our original review found 77 people in long-term segregation across all CAMHS services, low secure and rehabilitation wards and wards for people with a learning disability and autistic people.

NHSE/I told us that, as at February 2022, there are 126 autistic people or people with a learning disability in long-term segregation. This includes 15 children and young people.

People tell us how entering long-term segregation, and the lack of choice, control, and meaningful activity it can bring, dehumanises them and sometimes leads to them giving up hope.

The hopelessness of long-term segregation – a mother’s perspective

I have an autistic son who has been segregated for many years. Before he entered hospital, when he lived at home with me, he had some independence and was

making slow progress towards moving to his forever home. He could use kitchen appliances and made food for himself with minimal support.

The council had lined up two homes for my son. However, we didn't even get to the stage of viewing the homes, and we were simply told they weren't ready for him. This was over four years ago, and since then he has been stuck in a small, converted filing room segregated from all other patients at the hospital.

My son's autism means that he does not like uncertainty and change to routine, so taking him to this hospital for an unknown period of time with no indication or certainty of when he will be moving on to his forever home has caused him a lot of distress.

Due to his sensory needs, this environment wasn't suitable for him. There were locked doors and light switches on the other side of the room which he could not control himself. This increased his distress and could have been avoided, as I asked them to put the switches inside, but families are not listened to enough.

To begin with, the staff support for my son was two-to-one. However, because of the distress he shows now, it has now increased to five-to-one, with no real communication between him and the staff.

My son has to ask permission to eat and drink. His only contact with the world is through a hatch through which staff pass his meals. People wouldn't treat an animal the way my son is cared for.

I am not allowed to have real physical contact with my son. The last time I was able to enter the room to see and have close physical contact with my son was April 2021.*

My son is still in this situation. Currently, his care costs just under £1 million a year, but I think what my son really needs is to live out in the community in his forever home. Nothing has really improved, and I am wondering how has it come to this?

* As of February 2022

NHSE/I have received funding from the Department of Health and Social Care for national projects to help support people in long-term segregation. These are summarised below, but more information can be found [on the NHSE/I update on reducing long-term segregation](#). These projects are very welcome but have not yet had an impact on reducing the number of people in segregation.

Independent Care (Education) and Treatment Reviews

[Independent Care \(Education\) and Treatment Reviews](#) (IC(E)TRs) are available for all young people and adults with a learning disability or who are autistic, who are in long-term segregation. Although IC(E)TRs have taken place, they haven't had sufficient impact and haven't resulted in real changes to people's lives by enabling them to leave segregation and be discharged from hospital.

Following the recommendations from our [interim report](#), a programme of IC(E)TRs was established. We gave an overview of progress on this programme in [our progress report](#) in December 2021.

This programme has used the process available through the Care (Education) and Treatment review system, but with the addition of an independent chair appointed by the Department of Health and Social Care and a CQC Mental Health Act reviewer.

IC(E)TRs have had some success through the ability to bring together agencies to collaborate in new ways, and a clear leadership approach through the national Oversight Panel. The Oversight Panel has continued to build on and advocate our recommendations, with new proposals for change being developed and progressed by Baroness Hollins who has shared developments of the programme directly with the Secretary of State. This has been even more critical during the pandemic.

The ongoing scrutiny by the Mental Health Act reviewers involved in the panels has also enabled us to take further regulatory action, where we have identified failings in care, and to use this as a lever for change following the panels.

There were 77 people with a learning disability or autistic people in long-term segregation in hospital on 5 November 2019. All 77 people have had an IC(E)TR.

There have been some benefits to the IC(E)TR programme in improving care and moving people onto a more positive pathway. However, IC(E)TRs have not secured discharge for many of the people who have been seen. Of the 77 people, 71 remained in hospital at the end of the programme, with 49 still in long-term segregation. To respond to this, Baroness Hollins and the oversight panel recommended a second phase of IC(E)TRs to use the learning from the first programme.

In February 2022, for the second phase, NHSE/I have identified 126 autistic people and people with a learning disability in long-term segregation who will now be offered an IC(E)TR. However, IC(E)TRs have not had the impact intended and this, along with some logistical difficulties, will need to be addressed as the programme moves forward. We will work with Department of Health and Social Care, NHSE/I and the oversight panel in the coming weeks as they develop and review the options for increasing impact and consider how we can use the resource available to secure the right system for people and their families.

Life planning

Work is underway to ensure everyone who has a learning disability or who is autistic in long-term segregation is offered a life plan. The life plan should help people to have a better quality of life in hospital and support their move to the community. There are also some advocacy pilots linked to life planning. However, there is only funding available for these until March 2022.

Senior intervenors

[The national Adult Senior Intervenors pilot project](#) is being established to introduce an additional senior person to support local services to plan for discharge, guide where there is challenge, and agree actions to reduce restrictions. There are seven senior intervenors nationally, to help speed up discharge from hospital for the 111 adults in long-term-segregation. Evaluation of the project is due in March 2022.

HOPE(S) Model

NHSE/I have commissioned [Mersey Care Foundation Trust to deliver a HOPE\(S\) programme](#) across mental health, child and adolescent mental health services, and learning disability and autism inpatient services across England. HOPE(S) offers training, support, and clinical interventions to reduce restrictive practice, develop positive cultures and strengthen clinical leadership in inpatient care.

The HOPE(S) clinical model is based on a philosophy of person-centred, human rights-based care, which includes an unconditional, relentlessly positive approach to reducing long-term segregation. They have begun recruiting specialist practitioners, but any impact will not be seen for some time.

Recommendation 14 (Care (Education) and Treatment Reviews)

Care (Education) and Treatment Reviews (C(E)TRs) were developed as part of NHS England's commitment to improving the care of autistic people and people with a learning disability in England, as part of the Transforming Care programme of work.

A C(E)TR is a meeting about the care, education and treatment of a child or young person who is autistic or has a learning disability who is either at risk of being admitted to an inpatient service or is in one. For adults it is a care and treatment review (CTR). In this report we are using the term C(E)TR to cover both types.

A C(E)TR identifies how each person can have the best quality of life, and how care and treatment can support this aim. An inpatient C(E)TR asks whether the person needs to be in hospital, and community C(E)TRs ask how the right services can be put in place for them to live safely in their communities.

In our Out of sight report we called for C(E)TRs to be statutory so that responsible organisations are held to account and people can receive the outcomes they deserve.

If recommendation 14 was fully implemented:

- all autistic people and people with a learning disability would have a C(E)TR if there is a risk of being admitted or if they are admitted to hospital
- providers and commissioners would ensure they carry out the recommendations in people's C(E)TRs because they are statutory, and they would be held to account if they are not followed through

- people's needs would be identified and understood by members of the C(E)TR panel because they have the relevant experience and understand the person's needs
- people would be able to get support from a specialist team when it is difficult to find solutions to prevent hospital admission or ensure discharge, using joined-up commissioning.

Has recommendation 14 been achieved?

We consider that recommendation 14 has not been achieved

Where Care (Education) and Treatment Reviews (C(E)TRs) are taking place, people are not seeing their recommendations acted on.

Action needed:

- C(E)TRs must be made statutory so that providers and commissioners are accountable for implementing the recommendations.
- While waiting for legislative changes, providers and commissioners must ensure C(E)TR recommendations are carried out.
- Autistic people must consistently receive both community and inpatient C(E)TRs.

What we have been seeing and hearing

For people with a learning disability and autistic people, Care (Education) and Treatment Reviews (C(E)TRs) are important to stop admission to hospital and, if admitted, progress towards discharge.

People with lived experience and their families have told us that they feel that C(E)TRs are the most important tool they have to make sure their viewpoints and needs are heard so that changes can happen. However, when C(E)TRs take place, often their recommendations are not carried out, which means they are not as effective as anticipated.

Despite proposals for C(E)TRs to become statutory in [the government's autism strategy](#) and the [Mental Health Act White Paper](#), this has still not been implemented. This means there is no accountability on providers, commissioners, or clinicians to ensure recommendations made within the C(E)TR are implemented. There are, however, quality assurance and escalation routes set out in the [NHSE CTR Policy and Guidance document](#). The Department of Health and Social Care remains committed to placing C(E)TRs on a statutory footing through reforms to the Mental Health Act.

NHSE/I collect local data from commissioners about the care and treatment of people with a learning disability and autistic people, including outcomes of pre-admission C(E)TRs.

NHSE/I's analysis showed the number of C(E)TRs carried out has risen each year up to 2020/21. The proportion of pre-admission C(E)TRs that resulted in a decision

not to admit the person to hospital has also increased year on year (to 84% between April to November 2021).

The Assuring Transformation data shows that at the end of December 2021, 84% of people in a mental health hospital who are autistic or who have a learning disability had received a C(E)TR within the last year. However, for nearly 1 in 10 people in hospital (9%) it had been more than a year since their last C(E)TR. This may have been affected by the challenges of the pandemic.

In December 2021, 180 people in hospital had a C(E)TR, and for just over half (52%) the outcome was that they were not ready for discharge. In 18% of C(E)TRs the person was deemed ready for discharge, a discharge plan was in place and a discharge date was planned within the next six months. However, the outcome of 15% of C(E)TRs in the month was that while the person was ready for discharge, there was no discharge plan in place.

Our Expert Advisory Group tell us that in their view the C(E)TR process is now less effective than it was in 2020. The key issues are:

- the right people are not always involved, so decisions are not followed through. Representatives from the local authority, such as social workers, are less likely to be present due to staffing pressures
- there is a lack of engagement from stakeholders
- the process on admission is not tight enough. An initial C(E)TR needs to set out the reasons for admission, and then a repeat C(E)TR needs to occur within three months
- some people told us that their areas do not complete C(E)TRs for autistic people who do not have a learning disability. Some community mental health teams are not aware of C(E)TRs
- some services, such as eating disorder services, may not even be aware that they should be ensuring that autistic people have a C(E)TR.

The Mental Health Act White Paper and the new autism strategy have called for C(E)TRs to become statutory. We have heard concerns recently from some stakeholders on our Expert Advisory Group that there is:

- variation across local areas in who is receiving a C(E)TR in the community to prevent admission
- variation in the quality of C(E)TRs and those recommendations are not always being followed through in either community or inpatient settings
- not enough accountability for ensuring the actions within C(E)TRs are completed and followed through.

A parent's story of his daughter's experience of C(E)TRs

My daughter is autistic. She has been in hospital for six years in different settings. She has had over 14 Care (Education) and Treatment Reviews (C(E)TRs).

The C(E)TR is an opportunity to hear an independent panel recommend changes that will improve care and remove barriers to discharge. I sit in a room with my daughter's commissioner from the clinical commissioning group, an Independent

Chair, an Independent Clinical Reviewer who checks on the medications, and an Independent Expert with Lived Experience who knows what it's like to be in hospital. All of these people were paid to travel, then stay overnight in a local hotel, whereas I had to drive 230 miles at 4am at my own cost. We are joined by some of her care team – others are too busy or send a colleague who has never met my daughter.

Recommendations have previously been made to improve the environment, change care plans, manage her weight, investigate health concerns raised by us (we recognise changes staff don't see), and involve her in more engaging activities – building on her positives rather than dwelling on risks.

Other recommendations have been around discharge planning and, at times, the removal from segregation and other restrictions.

These are recommendations that, if enacted, would see her care improve radically. They would mean she could come home, to a setting that would meet all of her needs.

They never happen. They are never actioned.

The staff who care for her aren't even made aware of recommendations made by this panel or any suggestions from previous reviews.

The Responsible Clinician's decision in all matters relating to my daughter is final, so the panel's recommendations mean nothing unless she agrees with them and that never happens.

So the failed care continues.

And the person who entered hospital as a scared child has grown into an institutionalised adult without hope. And we get to do it all again in six months' time.

3. People's experience of support in the community

Recommendation 3 (community teams and crisis support)

In our [Out of sight report](#) in 2020 we highlighted the importance of the right community care being in place to enable people, their families and those that support them to be able to get their needs met by appropriately skilled community teams across health and social care. Additionally, this also included access to crisis support and respite services.

This was because we heard from people that they were not able to access the right support at the right time from staff or services who understood their needs. This could contribute to them being admitted to hospital, and then could stop them from being discharged.

We called for all staff in community teams to receive training to help them support autistic people. This was not just for specialist teams but all teams, such as child and adolescent mental health teams (CAMHS), eating disorder teams, forensic teams and community mental health teams.

To ensure that there is adequate support in the community we made [several recommendations](#) to improve people's access to person-centred services.

If recommendation 3 was fully implemented:

- autistic people would be supported by staff in all types of community teams who understand their needs. This includes community mental health, CAMHS, forensic and eating disorder teams
- people would be supported by community teams to avoid crisis
- people experiencing crisis would be supported by community teams and support centres who have enough staff with the right skills to give individualised support to prevent them being admitted to hospital
- everyone supported by community teams could receive trauma-informed care
- people would be supported through transition periods, such as discharge from hospital or crisis teams or from childhood to adulthood
- people could access respite care that meets their needs and is close to home
- people with a learning disability and autistic people would be identified where there are risks of family or placement breakdown because each area has a local Dynamic Support Register. People on the register would receive more support from health and social care community teams to prevent them being admitted to hospital.

Has recommendation 3 been achieved?

We consider that recommendation 3 has not been achieved

There has been significant investment in improving community support. However, as the NHS Long Term Plan is to 2024, it is too early to see the impact.

Action needed:

- The number and quality of community teams must be further developed to prevent hospital admission.
- Autistic people must be able to access community support adapted for them, including crisis support where staff have the relevant skills and knowledge.
- As stated in the autism strategy for 2021 to 2026, people must be able to access a timely diagnosis of autism in line with NICE guidelines.

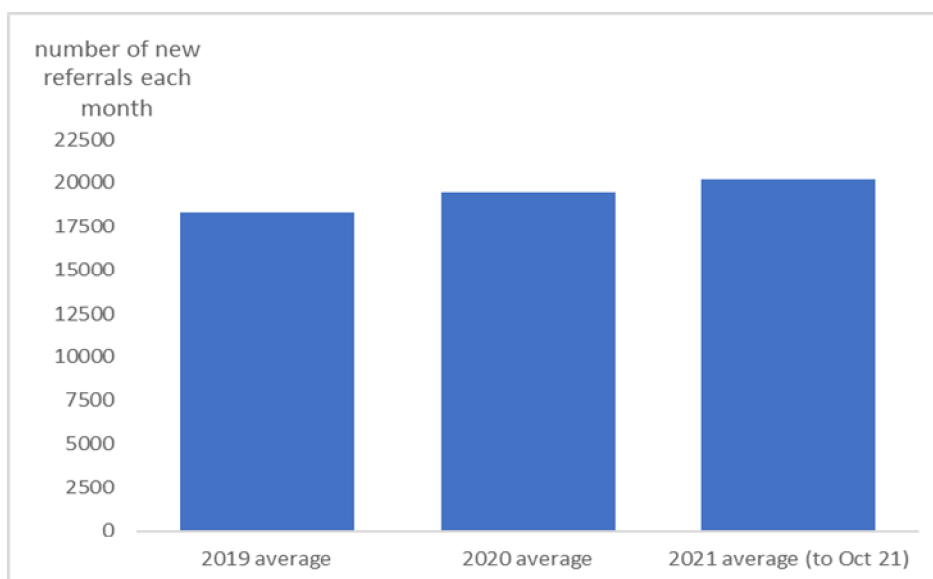
What we have been seeing and hearing

Our recommendations called for the development of community resources to ensure that people could be supported in the community and therefore avoid hospital admission. Far from an improvement, we have seen that people have found accessing community mental health support more difficult.

This is partly due to the impact of COVID-19. The pandemic has led to a mental health crisis in a system that was already overloaded.

New urgent referrals to crisis care teams fluctuate monthly but are increasing. The monthly average of new referrals to urgent mental health services in MHSDS data currently available for 2021 (January to October 2021) is 10% higher than the monthly average for 2019 and 4% higher than the monthly average for 2020 (figure 3).

Figure 3: Average monthly number of new urgent referrals to crisis care teams – 2019, 2020 and 2021 (to October)



Source: MHSDS data

While the [2021 community mental health survey](#) found that there had been a small increase in the proportion of people who would know how to contact crisis services outside of normal office hours, one-fifth (20%) said the last time they tried to access these services they were not able to get the help they needed.

The pandemic has had an impact on how people have been able to access community mental health support. The survey reported that:

“In response to social distancing measures, many services moved away from in-person care and offered remote care via telephone and video conferencing. Our analysis shows that people who received telephone-based care reported worse than average experiences in four key themes: overall experience, access, communication, and respect and dignity.”

The change away from face-to-face appointments has obvious implications for people with mental ill health, autistic people, and people with a learning disability. They may be disadvantaged, or even excluded, because they do not have the right technology or know how to use it without support, or they may lack the communication skills to be able to truly reflect their feelings and situation online or on the telephone.

A missed phone call from a healthcare professional can also mean that a person has not engaged and there is a risk they are discharged from the service.

Feedback from 12 senior managers in health and social care roles across eight local authority areas highlighted the need for further resources for crisis support. It was commonly reported that resources for crisis support in the community had only increased a little, while some felt there had been no change or that the situation was now worse due to the pressures of COVID-19.

Members of our Expert Advisory Group, which includes people with lived experience, told us of community crisis cafés and similar resources being shut down due to COVID-19 and not being reopened.

Scarlet's story of community support

My name is Scarlet and I have bipolar. Before I went into hospital, I was trying to get hold of the crisis team to prevent me from being admitted. If you have bipolar and other mental health conditions, you take comfort in routine, but I couldn't get my head around COVID-19.

I was trying to get help, but it seemed like there was nobody there. They could have been monitoring me more closely, like asking how I was sleeping. No-one came out to see me because of the pandemic, and the whole situation sent me off the rails.

I had a consultant phone call the day before I was admitted to hospital. On the letter I received it said I would be reviewed in two months' time, but if he had seen me in person, he would have seen I wasn't very well.

At the end of 2020, I transitioned to community services from hospital, but I felt like no-one spoke about the trauma caused by being an inpatient.

I had telephone meetings with the consultant and telephone meetings every three weeks with a community psychiatric nurse (CPN). They didn't consider me as a whole person. The CPN only asked about medication rather than looking at other factors, like if you are not exercising or not sleeping well or advising on psychology services. If you say you are low in mood, they will try to up your medication, so I'd avoid telling them.

I recently had a three-way phone call between my consultant, my nurse and me, and that was helpful because there are a lot of conversations and decisions about you but without you. Opening that up makes you feel more confident and more involved.

I'm going to ask about having an occupational therapist. When I've had one before, it felt like they were taking my needs into consideration rather than being so clinical.

I'm doing a lot better now, and I still have to really work on self-care and closely monitor myself.

Trauma-informed care

Understanding previous trauma and how this effects people is essential for providing the right care and treatment. People with mental ill health, autistic people and people with a learning disability are more likely to have experienced trauma. Trauma-informed care seeks to understand and respond to the impact of trauma on people's lives. [Baroness Hollins](#) reflected on the importance of trauma-informed care to the Secretary of State.

Trauma-informed approaches are not embedded across health and social care services. As highlighted in Scarlet's story, the impact of trauma following a hospital admission for people with a learning disability or autistic people is not commonly talked about and needs to be discussed following hospital admission.

Respite care

We have heard of some respite services closing or, during COVID-19, these have become harder to access. This has been putting additional pressure on people and their families. Some support services that help keep people well have not fully re-opened.

NHSE/I have told us:

- In 2020/21, as a response to the pandemic and winter pressures, local systems received £2.3 million to fund community respite care for autistic children and young people and people with a learning disability who have been identified as at risk of admission or mental health crisis. The funding saw a real benefit in reducing avoidable hospital admissions.
- In 2021/22, as part of the government Spending Review's COVID-19 response, local areas were allocated £3 million to continue their work with local partners to develop respite care that prevents children and young people escalating into

crisis. This work has included personalised short breaks and the use of personal health budgets.

Transition

We have heard from our stakeholders that there is often a lack of forward planning so young people, and their families don't experience a planned transition from children to adults' services.

Adam's story below shows how this can happen and the importance of good transition planning and the obstacles that can get in the way.

Adam and his family's experiences of transitioning to adult services

Adam is autistic, has a learning disability and a mental health condition.

Trying to bring in adult services so that they are already aware of Adam is almost impossible, as they do not want to be involved until he is 18.

However, when planning 'a home for life', adult services should at least have some involvement to ensure the correct processes will be in place for a smooth transition, but this seems to be a brick wall. They want to take over at 18 and then all the services will be re-assessed.

It is possible for people to experience positive support in the community that meets their needs, which makes all the difference to people's outcomes.

Ravikah's story of community support

I've been in and out of healthcare services for most of my life, having mental ill health, as well as suffering with issues around substance misuse and alcohol problems.

In January 2019 I suffered serious assault and injury and I spent a lot of that year in hospital. After that, I was stuck in my house, alone, suffering with post-traumatic stress disorder (PTSD) and terrible depression and anxiety. Then we were hit with a global pandemic. So what help was I getting?

I can honestly say that for one of the first times in my life that the mental health services were absolutely amazing. I was in need of specialist therapy for PTSD, which was organised via Zoom once a week, and my community psychiatric nurse (CPN) also called each week, which really helped me feel cared for and not so alone.

Finally, my PTSD was beginning to fade but, because of the fear of COVID-19, I started suffering panic attacks and anxiety that were so horrific I couldn't even contact my GP.

This is when my CPN was brilliant. She recognised that I was being triggered and had started to self-medicate with substances. She referred me to the right services who helped me realise that I needed to go back into therapy – which is working wonders right now.

For me, it's as though mental health services really stepped up throughout the pandemic, and for that I feel blessed and fortunate, thank you.

Support for autistic people

Autistic people are often not able to access the right support due to a lack of specific services or skilled staff to meet their needs. In particular, women and girls can be [misdiagnosed](#) with other conditions such as Emotionally Unstable Personality Disorder or can first present to services with an eating disorder.

Experimental data from NHS Digital on waiting times for autism diagnoses between April 2019 and June 2021 suggests that the number of new referrals for suspected autism is increasing. The proportion of new referrals for suspected autism in each quarter that were still waiting for an assessment of autism or any contact also seems to have been increasing. The data suggests that at the end of September 2021, over half (54%) of the new referrals made between April and June 2021 were still waiting for an assessment or any contact.

Delay in autism diagnosis has a huge impact on people who are in crisis and may be in danger of being admitted to hospital, as they are not able to access Care (Education) and Treatment Reviews.

Meena's story of getting an autism diagnosis

I spent two years on an NHS waiting list for autism diagnosis but was then removed because I moved out of the area. I had the option to go back on the waiting list under a new service but would likely have waited another two years.

I ended up paying for my assessment privately and was diagnosed at the age of 27 with autism, ADHD (attention deficit hyperactivity disorder) and central auditory processing disorder. This is, of course, something that not everyone is able to do, but I was fortunate.

I found the NHS process very challenging. Waiting lists are incredibly long and autism in females is very poorly understood, even among some professionals. For example, one GP actually said to me a few years back that I couldn't possibly be autistic because I am a woman with a partner and a job!

For this report we reviewed 21 inspection reports of services for children and young people with special educational needs and disability, which were published between October 2020 and November 2021. This review found that young people and their families often experience long waiting times for an assessment for autism. One inspection report described how children under the age of seven could be waiting over two years for an assessment.

The autism strategy for 2021 to 2026 acknowledges the importance of early diagnosis of autism for children, and that all too often children struggle to get the support needed following the diagnosis.

Mark's story of trying to get an autism assessment

It was only when lockdown started, and I didn't need to be around people as much, that I realised how much emotional effort I was putting into masking, and how accepting I was probably autistic would really help me.

My wife had been diagnosed in early 2019. This had been hugely beneficial to her wellbeing, so I booked an appointment with the same GP she had seen. A different GP contacted me, and after some questions decided to refer me and advised me that I would be assessed in the practice in six weeks, which seemed surprisingly quick.

I was later called back to be told I would be seen somewhere else, and the waiting time would be at least 12 months, possibly longer because of COVID-19.

So far, I have waited 18 months and I have had no further contact in that time.

I've thought about contacting the service to ask about waiting times, but I hate using the phone and I panic they'll not find my referral and I'll have to start all over again. The waiting times are bad, but it would at least be better if you were kept informed of how long the waiting time is.

Sometimes autistic people are told that they do not meet the criteria to access services.

Rebecca's story about community support

I am autistic and have an eating disorder. I was doing well with my recovery when the pandemic hit. Overnight everything changed. The level of anxiety I was experiencing was off the scale.

I reached out for help repeatedly and kept being denied care – often my autism/complex needs were given as a reason to decline potential care options. I personally don't feel that my needs are that complex; if I have a clear plan, routine and my sensory needs are understood I can cope quite well in unfamiliar environments.

The Crisis team concluded I wasn't severely depressed; I don't feel they fully understood how depression may present in someone that is autistic. I had a Care and Treatment review that agreed that a short, planned admission to a rehab hospital could help me to get back on track. At the point I was told that the Crisis team denied the recommendation from the CTR, I attempted to end my life.

The National [Autistic's Society's report, Left stranded](#) highlights the increased difficulties faced during the pandemic. The community respite care funding highlighted above, to support children and young people during the pandemic, was not made available for autistic children waiting for a diagnosis.

While some progress has been made by the publication of the government's [National strategy for autistic children, young people and adults: 2021 to 2026](#) and investments in the [NHS Long Term Plan](#), we hear from people and their families that

those who are autistic without a learning disability feel hidden from services. It is often difficult to access the right support as staff do not have the right skills and knowledge and therefore do not know how to ensure that the right reasonable adjustments are made. This leads to autistic people facing huge health inequalities when trying to access both mental and physical healthcare.

Account from an investigation and inquest into the death of an autistic boy – concerns about his care

In January 2020, a 14-year-old autistic boy who suffered from anxiety died as a result of suicide.

During the inquest, the coroner raised a number of concerns around staff knowledge and training. The coroner reported that the inquest “revealed a widespread lack of knowledge and understanding of autism”, including co-morbid mental health conditions, self-harm, suicidal thoughts, and how to communicate with an autistic child.

There were also concerns that, due to a lack of understanding around roles and obligations, staff did not correctly record the risk of self-harm and suicide in the boy’s Education, Health and Care Plan, and that there continues to be a lack of understanding among clinicians in this process.

The coroner reported a lack of training across all state agencies, and an absence of comprehensive, relevant, and mandatory training. The coroner said that this raises an ongoing risk to autistic children and their ability to access the services they require for their support, welfare, and safeguarding.

The coroner also raised several concerns about the boy’s care. For example, despite a number of referrals to child and mental health services, a clinical assessment was never received. The coroner raised concerns that ‘routine’ referrals are automatically classed as low risk, but there are children in this category who face considerable waiting times, and a high-risk of harm, which is unrecognised and unmanaged.

It was found that the referral made to children’s services two months before the boy’s death failed to appreciate the seriousness of the risks, and failure to allocate his case appropriately contributed to his death.

Source: [Courts and Tribunals Judiciary](#), published February 2022

NHS England and NHS Improvement

NHS England and NHS Improvement (NHSE/I) have told us they are investing in community support for people with mental ill health and a learning disability and autistic people. Several projects aim to increase community support, and therefore prevent people from going into crisis and needing hospital admission. These are part of the [NHS Mental Health Implementation Plan](#), which is until 2024 and therefore it is too early to report on impact.

In total, NHSE/I is investing £2.3 billion additional funding in mental health services by 2023/24. This seeks to shift the balance of care, with the large majority of new

investment going into community mental health services for children and adults – areas that have historically had very significant under-investment.

Adult crisis and community mental health

Some of the investment includes:

- nearly £1 billion additional funding for new models of integrated primary and community services for adults with serious mental illness
- around £300 million in enhancing adult mental health crisis services, including a range of alternative crisis services in every part of the country
- all mental health crisis services will be ‘open access’, via 24-hour urgent mental health helplines by 2024. This means that anyone can self-refer and there should be no exclusions. NHSE/I will share guidance on making reasonable adjustments for people with a learning disability and autistic people calling these lines
- ring-fenced investment in models such as crisis houses, sanctuaries, and crisis cafes in all parts of the country.

There is an ambition to end the practice of admitting people out of area for adult acute mental health care. While this has been challenging, especially during the pandemic, it remains a priority nationally and for all local areas.

Children and young people’s mental health services

There is nearly £1 billion of additional funding for children and young people’s community, crisis and schools services:

- crisis services are ahead of schedule, with 67% of the country currently having full or partial coverage of the four key components of a comprehensive crisis service. This is against a public commitment of 35%
- NHSE/I allocated £3.5 million of the 2021/22 Spending Review funding from Government to support earlier identification of children and young people at risk of admission to inpatient care and to avoid crisis point. The Spending Review funding was allocated for just one year and stops in March 2022.
- guidance and training for community services aims to improve access, assessment and treatment for children presenting with avoidant restrictive food intake disorder (ARFID). This condition may be more likely to occur in autistic children and young people, those who have ADHD (attention deficit hyperactivity disorder) or a learning disability
- in May 2021, the national children and young people’s Transformation and Mental Health Programme teams launched a joint project on improving integration between children and young people mental health services and acute trusts.

Dynamic support register

Local clinical commissioning groups or integrated care systems are expected to develop and maintain registers to identify people with a learning disability and autistic people, who may be at risk of being admitted to hospital. These registers should ensure that local health and social care services have good knowledge about people’s needs and that people are given the right support to live well in the community and to help prevent a crisis that might lead to them being admitted to hospital. Guidance about dynamic support registers is included in [NHSE/I’s Care \(Education\) and Treatment policy](#).

The use of dynamic support registers varies in areas and will have an impact on their role in preventing admission. Where they work well, all system partners are part of the conversation with families and people and the solutions are delivered.

To promote consistency, NHSE/I are developing guidance to support the implementation of the dynamic support register.

Keyworker scheme

Children and young people with a learning disability and autistic children in inpatient units or at risk of admission will have a [keyworker](#) to make sure they and their families get the right support at the right time. They will ensure local systems are responsive to meeting the young person's needs in a joined-up way and, whenever possible, to providing care and treatment in the community with the right support. This has been piloted in 13 areas with 14 others having adopted the system so that 27 local areas now have a keyworker programme. Development of key working services in the remaining integrated care systems will happen in 2022/23.

Recommendation 9 (reporting of data)

Getting a diagnosis of autism was a key concern in our Out of sight report, with people and families often waiting for a long time to get one. A diagnosis can help people understand how they see the world around them, so getting one as quickly as possible is important. It should also mean they can get the right support when they need it from community teams that understand their needs.

The government's autism strategy highlights that people are often waiting far too long for an autism assessment. National Institute for Health and Care Excellence (NICE) guidelines recommend that people should not be waiting for more than 13 weeks from referral to diagnosis.

In recommendation 9 we called for all local authorities and clinical commissioning groups to have to report on the data regarding the number of autism diagnostic assessments they are completing for adults and children.

We also asked for the number of people with a learning disability and autistic people who were admitted to hospital to be reported and broken down by each local authority and clinical commissioning group.

If recommendation 9 was fully implemented:

- people should wait less time for an assessment of autism because local areas would have better oversight through the data reported, highlighting areas that need to improve
- each local area would report on the number of people with a learning disability and autistic people admitted to hospital.

Has recommendation 9 been achieved?

We consider that recommendation 9 has been partly achieved

As stated in the autism strategy, accurate data is needed to be able to monitor and improve the current waiting times. Data is in place but needs further improvements to give an accurate reflection. The data available shows that waiting times for an assessment for autism are still far too long.

Action needed:

- As stated in the autism strategy for 2021 to 2026, people must be able to access a timely diagnosis of autism in line with NICE guidelines.
- The data available needs to reflect referrals, assessments and waiting times for children and young people.

What we are seeing and hearing

As reflected in the chapter above, people are still waiting too long to receive an autism diagnosis.

In July 2021, the government's new ['National Strategy for autistic children, young people and adults'](#) was published. This states that there have been significant improvements in autism reporting, including the introduction of the [autism diagnosis waiting times data](#). This data is reported at national, clinical commissioning group and provider level. This is still seen as experimental data and is constantly being reviewed. Currently, the data relates largely to adults, as most referrals and assessments for children fall outside of the scope of the NHS Digital collection.

The autism strategy sets out how the government will develop an action plan to improve data collection. The government has committed £13 million to begin reducing waiting times for children, young people and adults. This includes the backlog created by the pandemic. This is a welcome investment. However, as we can see from the previous chapter, this is yet to have significant impact.

Commissioners report monthly on the number of people with a learning disability and autistic people who are admitted to inpatient units through the Assuring Transformation data. This data is reported at national, integrated care system, transformation care partnership, clinical commissioning group and provider level. This helps to build up a regional picture of how many people are being admitted to inpatient units.

4. Improving people's rights

Recommendation 4 (human rights)

In our Out of sight report we found that people's rights, including their human rights, were at risk of being breached. We highlighted the need for staff to understand and embed the principles of the Human Rights Act so that where restrictive interventions are being used, staff reflect and understand their impact.

This included people's rights under the Equality Act 2010 to have reasonable adjustments in place to meet their needs. We therefore made recommendations to ensure that people's rights were met in inpatient units and in adult social care services.

If recommendation 4 was fully implemented, people:

- would have all their rights met, including their human rights. This is because:
 - human rights would be embedded within the service provided to the person
 - staff would understand the Human Rights Act and the Equality Act
 - the appropriate resources would be in place to support people to meet their needs
- in inpatient units would be given accessible information to help them understand their rights under the Mental Health Act and what to do if they do not feel these are being met
- with a learning disability and autistic people would have had reasonable adjustments put in place to meet their needs, such as individual sensory or communication needs.

Has recommendation 4 been achieved?

We consider that recommendation 4 has not been achieved

People's human rights continue to be at risk. They are not benefiting from reasonable adjustments under the Equality Act or from an understanding of human rights.

Action needed:

- Leaders within organisations should promote knowledge and understanding of human rights and rights under the Equality Act.
- Individual reasonable adjustments should always be in place for autistic people and people with a learning disability.

What we are seeing and hearing

From the stories that we have shared in this report and others that are frequently reported on, we know that people are not always having their rights acknowledged and respected. People are often not seen as individuals, of equal value and worth, whose views are listened to and respected. Recognising the humanity of each person and making sure this underpins all aspects of care is fundamental to supporting all people.

The information below relates specifically to autistic people and people with a learning disability.

Findings from IC(E)TRs

Forty-six of the 77 IC(E)TRs (60%) included evidence related to poor care and potential human rights breaches. These included restrictions on access to personal possessions, fresh air, activities, telephones, and visitors for which there was no justifiable reason or clear rationale. We found that steps taken to manage people's risks did not consider the impact on their dignity and were frequently unnecessarily harsh or overly restrictive. We also found that people's needs in relation to physical health were not being considered or accommodated, such as people being denied access to dentists or opticians.

Equality Act

Understanding of the Equality Act and ensuring that individual reasonable adjustments are made for people with a learning disability and autistic people is essential for ensuring that true person-centred care is delivered. Where this is not in place, restrictive interventions are more likely to occur as staff teams are less likely to understand people's needs such as communication needs or sensory sensitivities. From 2016 all health and social care services should be complying with the Accessible Information Standard which set out a specific, standard approach to ensuring disabled people's needs are met.

Claire's experience of person-centred care

I am autistic and have significant physical and mental illnesses.

During one of my mental health admissions a nurse worked with me to look at ways I could communicate with the staff in times of distress, and we came up with a cue cards system. These were cards I designed myself that I could either give to staff if things were in the process of escalation. Or else, if I was going into shutdown, I could leave a card in front of where I was curled up (likely on the floor). Each card had a corresponding list of things that might help me settle and things that could put me in even more overload. All staff had access to these lists.

These were co-developed with the ward team, and they really helped me express myself safely and helped the staff respond appropriately. There were many

occasions, which may have led to restrictive measures, that were diffused before getting to that point.

However, I tried implementing them with staff on wards in subsequent admissions and they either didn't want to engage, or not all staff knew about the system. There were times I would be in shutdown and staff would be shouting at me or even trying to physically manhandle me, which inflicted further trauma upon me. I felt particularly distressed, as almost all those incidents could have been avoided had the staff engaged with the cue cards system I offered them early in the admission.

Accessible information

In our Out of sight report we recommended that people in inpatient units are given accessible information about their rights. However, the Mental Health Act reviewers we spoke with found there had been little progress on this. Mental Health Act reviewers check whether people detained under the Mental Health Act have been given information about their rights. They found that this is more of a tick-box exercise without consideration of whether the person had understood what they are being told, if they have been able to retain that information, or what measures could have been taken to improve this. The [British Institute of Human Rights has provided guidance](#) to support inpatient units in doing this.

5. Skilled staff to meet people's needs

Recommendation 7 (workforce)

In our Out of sight report, we highlighted that the workforce needed investment to ensure that people were supported by staff who had the right training and qualifications and who felt valued in the work that they did. We therefore made recommendations to support workforce development.

If this recommendation was fully implemented, people would:

- have enough staff to support them, with the right skills and competencies to provide high-quality, person-centred care to enable people to lead the lives they would like
- be supported by staff in health and social care who understand their needs
- never be restrained, unless absolutely necessary, and only by staff whose training in the use of restrictive interventions would be certified as complying with the Restraint Reduction Network training standards as required by the Mental Health Units (Use of Force) Act 2018
- have sensory assessments, communication plans and other reasonable adjustments made in line with the Equality Act when they are in inpatient units or using adult social care services
- not have their human rights breached, because staff have the right knowledge to recognise when this may be happening, and leaders would take action to ensure that this is challenged and changed
- be involved in the recruitment process, including staff interviews, to ensure the right staff are recruited to be able to meet their needs.

Has recommendation 7 been achieved?

We consider that recommendation 7 has not been achieved

Rather than an improvement in the workforce, we have seen a staffing crisis develop, partly due to the impact of COVID-19. Although significant work has been carried out to implement Oliver McGowan training and introduce human rights training to child and adolescent mental health services, the impact of the training is yet to be fully realised.

Action needed:

- The government needs to ensure that further urgent investment is made in the workforce to improve pay and ensure that staff have the right skills and knowledge to support people to lead the lives they want to lead.

What we are seeing and hearing

Scarlet's story of staffing

My name is Scarlet and I have bipolar. During my inpatient stay, there was a lot of agency staff, so you didn't know who was going to be there for support. The nurses seemed too busy with paperwork. It was healthcare support workers who were on the ward floor, and they had more time for me than doctors and nurses.

Rather than seeing an improvement in the recruitment and retention of the workforce, we have seen a deterioration in the numbers of staff in health and social care and an increase in the use of bank and agency staff. This has partly been because of the pandemic. We have reported on these issues in our [State of Care report](#), where we said, "Health and social care staff are exhausted and the workforce is depleted". There have been calls for the government to urgently review the needs of the workforce through qualifications, additional training and pay increases.

This was further evidenced in feedback from 12 senior managers in health and social care roles across eight local authority areas and a meeting with representatives of hospital and adult social care providers to get their feedback on what progress they felt had been made towards the Out of sight recommendations. One of the common areas of concerns raised was staffing levels. It was noted that services are struggling with recruitment and retention of staff and there was anxiety about staff leaving care jobs for higher paid, less demanding roles and the impact this would have on people using services.

Provider representatives talked about the need to have more funding for staff and a model that invests in workers and retains experienced and skilled staff. There is also concern within social care about the number of staff who left the profession due to the mandatory vaccination regulation and how this has affected the workforce.

Training

Training of staff was also raised as a concern by providers, with issues such as the lack of consistent training across the system. Providers spoke about the difficulties of keeping training up to date. It was noted that in some services, having one training session on a topic such as autism is still considered sufficient.

Oliver McGowan training

For people with a learning disability and autistic people, it is vital that staff have the right level of training to be able to provide high-quality support. This includes understanding the importance of ensuring that people's sensory, cognitive and communication needs are met. We highlighted these concerns in our Out of sight report. Our Mental Health Act reviewers have reported concerns that the lack of staff with the skills to understand and meet people's needs had been worsened by the pandemic.

Following the death of Oliver McGowan in 2016 and the [2nd annual LeDeR report](#) published in 2018, the Government published '[Right to be heard](#)', its response to the

consultation on proposals for introducing mandatory learning disability and autism training for health and social care staff. It outlined strong support for ensuring that all health and social care staff should receive mandatory training in learning disabilities and autism, at a level appropriate to their role. This is currently known as '[Oliver McGowan Training](#)'. The Department of Health and Social Care invested £1.4 million to develop, test and trial the Oliver McGowan Mandatory Training with over 8,000 people in 2021. Pilots have been completed and a positive interim evaluation of the pilot training has been published, with a final report due in Spring 2022. The outcomes of this evaluation will inform the wider roll out of the training. There is strong support from government and all stakeholders, including CQC, to implement this training.

Human Rights Framework and Training

NHSE/I have told us that the children's taskforce has commissioned the British Institute for Human Rights (BIHR) to deliver human rights training to over 2,000 staff. This training is bespoke to inpatient children and young people mental health, learning disability and autism services and supports providers' wider commitments to reducing restrictive practices.

The training provides organisations and staff with a common framework for assessing human rights. Four hundred and seventy staff have attended the training to date. This will continue to be implemented until the end of 2022.

Other training in social care

The latest [Skills for Care workforce data](#) shows that 46% of social care staff have a record of training on equality, diversity and human rights. While more than half (56%) of social care staff have a record of training on the Mental Capacity Act and deprivation of liberty, only 8% have recorded training on mental health. Only 10% of social care staff have a record of training on autism, while only 9% have recorded training completed on learning disability. It should be noted that completing training data is not mandatory in the workforce data collection.

Restrictive interventions training

If our recommendations had been met, we would hope to see that people were never restrained, unless it is absolutely necessary for their safety or other people's safety, as all staff know how to de-escalate and avoid restrictive interventions. However, as reported above, the rate of reported restrictive interventions in October 2021 was nearly five per adult and 20 per child. There are also more people in long-term segregation now than there were in 2018.

Training in trauma-informed care was seen as positive in supporting staff to understand the experiences of people they care for, and the effect trauma had on them, rather than just seeing their behaviour.

Provider representatives told us about staff needing to feel supported and confident to challenge when restrictive interventions are used. They spoke of the importance of having visible leadership that demonstrated a positive and open culture.

The latest Skills for Care workforce data shows that only 10% of social care staff have a record of training on physical interventions.

Use of Force Act training

Implementation of the [Mental Health Units \(Use of Force Act\) 2018](#), also known as [Seni's Law](#), was delayed and will now come into force on 31 March 2022. The statutory guidance accompanying the Act, which applies to mental health hospital inpatient settings, describes what providers should include in their policy on the use of force. The policy should set out the plan or approach the provider will take to reduce the use of force within their mental health unit(s). This should include:

- the provider's commitment to minimising the use of force
- the preventative action the organisation is taking to minimise the use of force
- information on how the risks associated with the use of force will be managed.

Providers will also have to ensure that their training for staff in the use of restrictive interventions is certified as complying with the Restraint Reduction Network training standards. Complying with the training standards will:

- protect people's fundamental human rights and promote person-centred, best interest and therapeutic approaches to supporting people when they are distressed
- improve the quality of life of people and greater understanding of people's needs from those supporting them, therefore reducing restraint
- reduce reliance on restrictive practices by promoting positive culture and practice that focuses on prevention, de-escalation and reflective practice
- increase understanding of behaviour as communication, such as of emotions or needs, which if unmet can result in distress
- where required, focus on the safest and most dignified use of restrictive interventions including physical restraint.

6. Ensuring people have the right local services

Recommendation 2 (commissioning)

In our Out of sight report, commissioning was identified as an area where improvement was needed.

The quality of commissioning is central to ensuring that people live in the best places. The standard of commissioning and the knowledge and expertise of commissioners makes the difference between people having their needs met and a positive future or living in an unsuitable place where their needs are not met.

All too often, people are moved to inappropriate places as the right ones cannot be found locally. People told us that commissioners did not always understand the needs of autistic people or people with a learning disability, which contributed to people being placed inappropriately. We therefore made recommendations to improve national oversight and ensure greater quality assurance of services and people's care.

If recommendation 2 was fully implemented, people:

- would be in settings that are meeting their needs, rather than causing harm
- would experience more joined-up, consistent care, as there would be an effective mechanism for commissioners to be held accountable for their decisions
- with multiple needs would have a named person to make sure they receive regular reviews every three months
- would be supported in the right way in the right place because commissioners understand their needs and have had relevant training to help them develop their skills and make the right decisions
- would receive the right care in line with human rights because commissioners are checking and visiting services to ensure this.

Has recommendation 2 been achieved?

We consider that recommendation 2 has not been achieved

The appointment of a national commissioner has not been possible to achieve, because it requires a change in legislation. However, we welcome the recent announcement that a named lead for learning disabilities and autism will be on each local integrated care board.

Action needed:

- Commissioners need to develop the right services for people and with people, empowering them to lead the lives they want to lead.
- Local commissioning needs to have central accountability.
- Consideration should be given as to how this might be implemented locally alongside the new responsibilities of integrated care systems.

What we are seeing and hearing

For people with a learning disability and autistic people, the lack of a national commissioner meant there has been no-one to drive the delivery of new services and support a pace of change that is necessary to respond to the urgency of the situation. Commissioners are still not always working in partnership, and the focus remains on fitting people into available services with insufficient focus on designing the support that the person needs.

However, the appointment of a national commissioner who would have authority over health and local authorities requires a change in legislation. This has been explored and has not been possible so far. Discussion continues on the feasibility and appropriateness of implementing this recommendation.

The [government recently confirmed their intention that all integrated care boards should have a named learning disability and autism lead](#). NHSE/I proposes to issue statutory guidance on this matter to assist integrated care boards.

People are telling us that they are not able to get the services they need, and that professionals do not listen to what they or their loved ones tell them they need.

The staffing crisis is also having an impact, as there are frequent changes in social workers. Far from the three-month reviews that we recommended, commissioners from the local authority are often not attending C(E)TRs and are not aware of when people in hospital are ready for discharge.

It can also be difficult for autistic people, who can find that commissioners do not understand their needs and therefore are less likely to be eligible for assessment and support under the Care Act 2014.

A new training qualification has been established for commissioners by Skills for Care and partners – [Commissioning for Wellbeing – learning disability and autism](#).

This is designed to support both health and social care commissioners to:

- have a good understanding of people with a learning disability and autistic people
- know what good co-production looks like
- look at innovative practices and recognising when things go wrong.

Eighty-one commissioners have so far completed the qualification so, while this is a welcome initiative, there is still a long way to go to ensure all commissioners have the knowledge and understanding needed to support people.

In response to our Interim report in 2019, the then Minister of State at the Department of Health and Social Care, Caroline Dinenage, committed to stronger oversight arrangements for people with a learning disability and autistic people in

specialist mental health, learning disability or autism specific inpatient services. This led to a new [host commissioning framework](#) where, from March 2021, all inpatient services for people with a learning disability or autistic people should have a host commissioner in place, who should be a commissioner from the local area who oversees the quality of inpatient units in their area.

As part of the NHSE/I response to the [Safeguarding adults review](#) (SAR) concerning the deaths of Joanna, Jon and Ben at Cawston Park hospital, NHSE/I has committed to carrying out reviews to check the safety and wellbeing of people with a learning disability and autistic people in a mental health inpatient setting. This includes people whose care is being funded by NHS England and NHS Improvement, clinical commissioning groups and Mental Health Learning Disability and Autism Provider Collaboratives.

The intention of the reviews is for commissioners to check that people are safe and well in inpatient settings and take action if there is any evidence to suggest they are not. It is hoped that these reviews will have taken place by spring 2022. Following on from what we found in our Out of sight report, there are still concerns about how effectively hospital admissions meet some people's needs and this needs to be further addressed by commissioners.

Recommendation 12 (monitoring restrictions)

If this recommendation was fully implemented, people:

- would have restrictive interventions monitored more closely by commissioners
- would have a plan in place that includes milestones to make sure that restrictions will end. Commissioners would check these milestones are being met. Where they are not, this would be escalated to NHS England.

Has recommendation 12 been achieved?

We consider that recommendation 12 has been partly achieved

Action needed:

- All commissioners and provider collaboratives need to ensure that people are receiving the least restrictive care possible and, where there are restrictions in place, there are clear steps to ensure these are ended.

What we are seeing and hearing

In the feedback we received from 12 senior managers in health and social care roles across eight local authority areas we heard from several that their ability to effectively monitor the use of restrictive interventions was limited. Two individuals from different local authority areas commented that the pandemic had impacted their monitoring activities.

However, some were more positive about their ability to effectively monitor the use of restrictive interventions. One commented that a multidisciplinary approach is taken to review cases involving restrictive interventions. They also noted that, where COVID-19 restrictions permitted, they would aim to visit services to ensure they see where individuals live and speak to them, as well as staff and family members.

As outlined in the chapter above for recommendation 2, there is commissioning oversight for people with a learning disability and autistic people in inpatient services. This is through host commissioning services, C(E)TRs and the Care Programme Approach. For those in long-term segregation there are additional IC(E)TRs. However, the impact of this improved monitoring and oversight is yet to be seen because people in hospital are still experiencing restrictive interventions and remaining in long-term segregation.

7. What CQC has done to improve people's experiences

Recommendation 6 (CQC)

Following our Out of sight review, we knew that we needed to improve, as we had not always identified poor care and abuse.

We therefore made a recommendation for CQC to make the improvements necessary.

If this recommendation was fully implemented, people would:

- benefit from our improved focus on human rights, positive cultures and person-centred care
- know we are better able to identify unsafe services and take action
- know that we would not rate services as good or outstanding where people are unnecessarily restrained, segregated or secluded
- know whether services are meeting the recommendations from independent reviews of seclusion and segregation and Care (Education) and Treatment Reviews (C(E)TRs), as we report on this
- know that we will listen to them about their experience and use this information to improve our monitoring and inspecting of services and share their concerns with appropriate agencies for investigation
- be more likely to be receiving advocacy services due to our increased monitoring of this
- know that we are monitoring waiting times for assessments for autistic people and checking they have timely assessments, care plans and discharge plans
- know we will take action where providers have not ensured their staff are suitably trained to meet people's needs
- be supported using the least restrictive interventions possible as we will monitor use of restrictive interventions more effectively.

Has recommendation 6 been achieved?

We consider that recommendation 6 has been partly achieved

CQC has improved how we regulate services for people with a learning disability leading to more enforcement action where services do not meet people's needs. There is further work to complete to ensure this improved person-centred approach is implemented in other settings.

Action needed:

We will improve how we assess:

- all community services
- experiences of care for people with mental ill health
- experiences of care for autistic people who don't have a learning disability
- care pathways through our future regulation of local authorities and integrated care systems.

Improving our regulatory approach

We said that we needed to improve our regulatory approach. We have outlined below some of the work that we have done towards this.

People with lived experience, their families, and stakeholders such as NHSE/I have told us that they can see that we have changed our approach and are taking more enforcement action within learning disability services. However, we recognise that there is still much more to do to replicate this person-centred approach in mental health and community services.

Improving our regulation of services for people with a learning disability and autistic people

We have developed a new approach to improve the way that we look at hospital and adult social care services for people with a learning disability and autistic people. This includes ensuring inspectors focus on specific areas that are particularly relevant to people with a learning disability and autistic people, such as communication and engagement, their individual health needs, out-of-area placements, access to advocacy and use of restrictive practices. We also encourage inspectors to look into [the use of surveillance](#).

In order to put people's experiences at the centre of our new approach, and make sure that services are in line with [our guidance, Right support, right care, right culture](#), we have:

- reviewed and updated our guidance for inspectors, so that we promote inclusivity and champion human rights, dignity and equality. We encourage inspectors to assess and report on aspects of care that are particular to people with a learning disability, such as their aspirations and achievements, progress with life skills, sense of fulfilment and whether the provider has made suitable reasonable adjustments. Going forward, we will be asking providers of a range of services how they meet the needs of autistic people and using learning from our work in learning disability services to change the way we inspect
- spent more time speaking to more people in the service (and their families and carers), supported by new communication tools
- increased our contact with commissioners and professionals who may visit a service to get their views on the service
- increased the range of tools, guidance, and experts to support our inspection teams
- visited services unannounced and out of hours, often going back to a service to see what care is like at different times of the day.

During our review, we found that many staff working in services had not received meaningful training to understand what it meant to be autistic or have a learning disability. This is essential and we have started to look at this by:

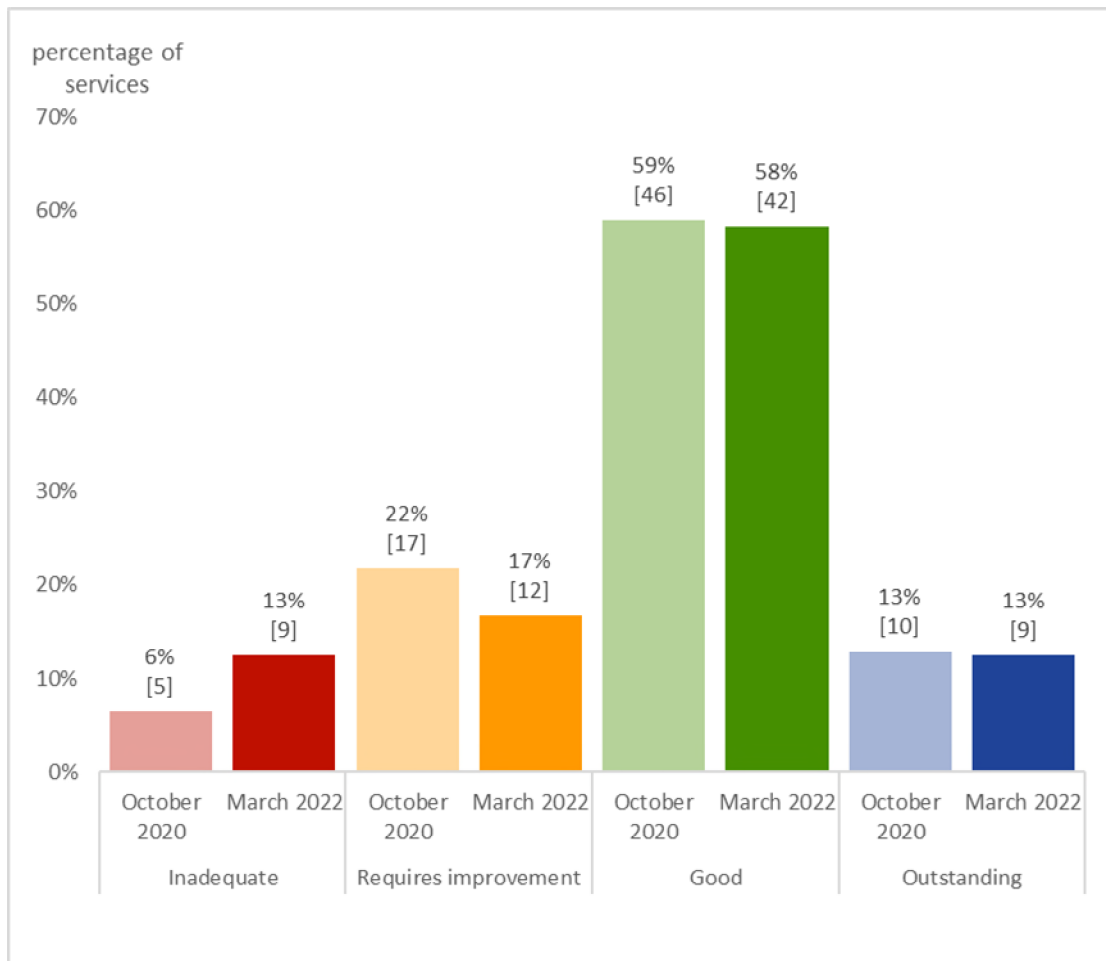
- improving the training for our own staff on learning disability and autism (which was developed by CQC autistic staff)
- ensuring new providers proposing to deliver a service for people with a learning disability and autistic people have an induction programme, ongoing learning, and development plan for staff
- looking at poor training as an indicator of a closed culture
- piloting a [quality of life tool](#) that focuses on the implementation of peoples plans, effective staff training and evidence of this being embedded into practice.

We have used this new approach to inspect hospitals and care homes where there was the highest risk that people may not be safe, and their rights may not be respected.

Latest ratings data for March 2022 show there are 16 independent hospitals and NHS trusts that provide mental health services rated inadequate and 60 that are rated requires improvement. Both the number and proportion of overall ratings of inadequate or requires improvement have slightly increased since we published our Out of sight report in October 2020.

Our latest ratings (as of March 2022) for inpatient wards for people with a learning disability and autistic people show that nine services (13%) were rated inadequate while 12 (17%) were rated requires improvement. While the number and proportion of ratings for inpatient wards for people with a learning disability and autistic people that are requires improvement has decreased since October 2020, inadequate ratings have increased (figure 4). This is partly due to improvements in the way we identify poor care, and also that our recent inspections have been based on risk. Figure 4 suggests the quality of inpatient care for people with learning disability and autistic people has not improved.

Figure 4: Ratings for inpatient wards for people with a learning disability and autistic people – October 2020 and March 2022



Source: CQC

Since our Out of sight report was published in October 2020, 16 adult social care services and two independent hospitals that provided care for people with a learning disability and autistic people have closed because of the enforcement action we have taken.

Our enforcement activity in services for people with a learning disability and autistic people increased by 25% in 2021 compared to 2020.

Out-of-hours inspections

In our Out of sight review, people frequently told us that we needed to do more out-of-hours inspections. This was also included in Glynis Murphy’s recommendations. We therefore stated in our closed cultures guidance that inspection teams should undertake out-of-hours visits where possible.

Between April 2021 and January 2022, over half (52%) of the 42 inspections of learning disability and autism services that used the new inspection approach have included some out-of-hours inspection activity.

Care (Education) and Treatment Reviews

In Out of sight, we saw that the recommendations from Care (Education) and Treatment Reviews (C(E)TRs) were not always being implemented. We therefore recommended that CQC track progress made against these.

We have created guidance for our operational staff to enable this to be implemented from April 2022. In order to have a rating of good for the question “is the service effective”, providers will need to progress C(E)TR recommendations. However, this has not had an impact yet, as it is still to be implemented.

Reporting on timely diagnosis of autism

We are currently developing our approach to monitor and report on the length of time that both children and adults are on waiting lists for a diagnosis of autism and if this is in line with [NICE guidelines](#) or not. However, this has not had an impact yet as it is still being developed.

Improving how we look at services for people with a learning disability, autistic people and people with mental ill health

Human rights

We published our new strategy in May 2021, which said we would:

- identify better ways to gather experiences from a wider range of people, including people with a learning disability and those who are detained under the Mental Health Act
- work with others to develop a better understanding of risk across all health and care to help reduce avoidable harm, neglect, abuse and breaches of human rights
- look to see how people are able to influence the planning and prioritisation of safe care, as equal partners.

We are carrying out a range of tasks to fulfil these strategy commitments, including:

- publishing an ‘equality objective’ on amplifying the voices of people more likely to have poor access to care or poor experiences of using care and appropriately weighting the feedback we receive from them
- considering which tools we need to develop to ensure that we receive feedback from a wide range of people, including those with needs for accessible communication
- embedding human rights into our draft new single assessment framework. In particular, the key question about ‘caring’ is more aligned to human rights in principles of fairness, respect, equality, dignity and autonomy
- considering the relationship between safety and human rights in our programme of work on safety.

Independent reviews of seclusion and long-term segregation under the Mental Health Act Code of Practice

In the review we saw that there was inconsistency in the quality of independent reviews for people in long-term segregation or prolonged seclusion. We therefore recommended that CQC tracked the progress of these reviews.

We are updating and revising the methodology for our Mental Health Act (MHA) reviews to complete focused reviews of seclusion and long-term segregation. These reviews will include scrutiny of the quality of independent reviews for people in long-term segregation or prolonged seclusion. The revised methodology is due to be trialled from April 2022.

Monitoring restrictive interventions

Through our Mental Health Act monitoring duties we highlight concerns about restrictive interventions in services that treat people who are detained. We recognised that we needed to improve our monitoring of restrictive interventions. We have done this by:

- improving our training on restrictive interventions
- requiring our inspectors to report on restrictive interventions in adult social care services for people with a learning disability and autistic people, which gives us more ability to monitor and identify concerns
- ensuring all operational staff have annual training on human rights and know how this relates to restrictive interventions
- developing our new regulatory model, which will allow us to review and update ratings in a more dynamic and responsive way
- asking adult social care providers to submit data annually on how many people have restraints or restrictions in their care plan, the number of recorded restrictions, and whether there are any restrictions on people visiting
- checking if all providers' training on restrictive interventions complies with the Restraint Reduction Network training standards.

Regulatory change

Under the current system there is no legislation that requires providers to notify us of incidents of long-term segregation, seclusion or restraint. We are discussing the possibility of legislative change with the Department of Health and Social Care, as suggested in recommendations 11 and 17.

Reviewing our registration processes

All providers must register with us before they are able to provide a service. In our Out of sight review we found that some providers were applying to register a service under a different name after we had taken enforcement action to close their service.

To tackle this, when a provider wants to open a new service, we review all available information, including the regulatory history of a previously registered provider or registered manager. For services for people with a learning disability and autistic people we have improved the way we assess an applicant's understanding of our guidance, Right support, right care, right culture, to ensure they understand the expectations for good quality care.

Supported Living Improvement Coalition

Our regulation of services for people with a learning disability and autistic people focuses on what it means to be a citizen. Our ambition for people receiving care and support is to have more choice, independence and control over their lives and the care they receive.

We have convened a Supported Living Improvement Coalition, led by people with lived experience, their relatives, and carers. The group is structured so that people can tell their stories to a range of stakeholders who can work with them to identify, resolve, and embed the improvements that are needed.

The Coalition has representatives from advocacy groups, care providers, clinical commissioning groups, local authorities and housing developers. With leadership and support from across social care, the Coalition aims to achieve greater safety and quality of supported living options for people with a learning disability, autistic people and people with mental ill health and drive improved outcomes for them.

Listening to people and acting on what they tell us

We are improving how we gather the views of people who use services.

[In our closed cultures guidance](#) we have included details on how CQC teams can review intelligence before and during inspection, gather feedback from advocates and request contact details for relatives, advocates, staff and visiting professionals.

In 2021, we received 20% more whistleblowing notifications relating to services for people with a learning disability and autistic people than we did in the previous year, increasing from 1,336 to 1,607.

We are also improving:

- how we escalate issues in health services, in collaboration with NHSE/I
- the way we use the knowledge and work of advocates across CQC
- our tools to help us to listen to people, such as talking mats (a communication and interactive tool that uses specially designed symbols to help communication).

Advocacy

In our Out of sight review, we identified that we were not listening to advocates enough to help us to hear people's voices more effectively. We are addressing this through:

- including details on how our teams can do this in our closed cultures guidance. The guidance also helps our teams to ensure that information is gathered from relatives and other important people to develop care plans
- ensuring we check how services are involving advocates through our [quality of life tool](#)
- developing training on the different types of advocacy for CQC's operational staff
- ensuring that advocacy is a key area of focus in our new assessment framework.

Trauma-informed care

We are developing training for our staff on trauma-informed care so that our staff can better reflect how services are using a trauma-informed approach.

8. What the government has done to improve people's experiences

Recommendation 1 (single ministerial ownership)

If this recommendation was fully implemented, people:

- would experience more joined-up care as there would be a single minister overseeing this work
- would receive more responsive support as different sectors could pool budgets together locally
- could access the right support at the right time across education, health, and social care, including specialist community teams that understand their needs
- would have access to the right type of housing
- would only be admitted to mental health inpatient units when this is essential for their treatment.

Has recommendation 1 been achieved?

We consider that recommendation 1 has not been achieved

There is a single minister overseeing the Building the Right Support Delivery Board. However, the action plan is not yet finalised and without clarity of governance and clear responsibility for delivery there is insufficient evidence of impact on people's lives.

Action needed:

- The action plan needs to be finalised and fully implemented, supporting the delivery of a model of care based on meeting individuals' needs.
- There needs to be stability of leadership
- Accountability should be clear; each partner should be held responsible for their actions and called into account where progress is insufficient.

What we are seeing and hearing

We have reported in the above chapters what we are seeing and hearing about progress towards people having the right services with the right support at the right time. People are telling us that they are pleased about the initiatives and discussions that are taking place, but that this is not enough. They want to see positive impact.

The Department of Health and Social Care is key to driving forward many of the recommendations in our Out of sight report. An important lever for this has been

through the establishment of the Building the Right Support Delivery Board to take forward the work. The Board is chaired by the Minister of State for Care and Mental Health. The Department is working with the Building the Right Support Delivery Board to develop an action plan. We are waiting for the action plan to be published.

However, an action plan is not enough and there needs to be delivery, alongside further investment, to ensure this recommendation is progressed and that people feel the impact of the plan.

Recommendation 11 (oversight of long-term segregation)

During our Out of sight review we found that it was not possible to identify the numbers of people in long-term segregation. It was not reported to NHSE/I and there was not a regulatory obligation for providers to notify us. We therefore made a recommendation to change this.

If this recommendation was fully implemented, people in long-term segregation would be known about:

- by commissioners and NHSE/I regional teams
- by CQC.

This would lead to increased oversight of the service.

Has recommendation 11 been achieved?

We consider that recommendation 11 has not been achieved

Action needed:

- CQC and the Department of Health and Social Care are currently discussing regulatory change proposals due to go to public consultation in autumn 2022.

What we are seeing and hearing

One of the findings from the IC(E)TRs and this progress review is that it is still difficult to know in real time how many people are segregated and where those people are. It is therefore difficult to have sufficient oversight of the numbers of people in long-term segregation.

Since the publication of our Out of sight report, we have been discussing with the Department of Health and Social Care about changing the regulations. We have put forward an initial proposal. This work is due to go to public consultation in autumn 2022 before a decision is made if the proposal will be put forward for legislative change.

Recommendation 13 (reviews of long-term segregation)

During the Out of sight work we had concerns about the quality of independent reviews recommended by the Mental Health Act Code of Practice for people in long-term segregation. We therefore made recommendations to improve these.

If this recommendation was fully implemented, people:

- would have regular reviews by a responsible clinician looking at why they were in long-term segregation and whether it was necessary to continue it
- would have consistency in independent reviews of long-term segregation. These reviews would be of a high standard and would reduce and end restrictions.

Has recommendation 13 been achieved?

We consider that recommendation 13 has not been achieved

Action needed:

- The Department of Health and Social Care needs to progress this recommendation.

We remain concerned about the quality and frequency of reviews by independent clinicians. This will have been compounded during the pandemic. The Department of Health and Social Care will be refreshing the Code of Practice as part of the Mental Health Act reforms.

Recommendation 15 (definition of long-term segregation)

During our review we found that some providers were uncertain as to what constituted long-term segregation. We used a wider definition than is in the Mental Health Act Code of Practice to ensure that we looked at people who were in long-term segregation for reasons other than violence, such as protecting them from themselves or others.

We therefore recommended that the Mental Health Act Code of practice definition of long-term segregation was changed.

If this recommendation was fully implemented, people in inpatient units:

- would be safeguarded when they were separated from others, whatever the reasons for that separation.

Has recommendation 15 been achieved?

We consider that recommendation 15 has not been achieved

Action needed:

- This proposal has been accepted by the Department of Health and Social Care. It needs to be progressed through legislative changes as part of the Mental Health Act reforms.

What we are seeing and hearing

There can still be different interpretations of what constitutes long-term segregation across different organisations.

[We have developed a new brief guide](#) for our staff that uses this wider definition to include people who are segregated because they are at harm from themselves or others.

Currently CQC, Independent Care (Education) and Treatment Reviews and NHSE/I are using the same definition as is in our brief guide.

The Department of Health and Social Care have accepted the recommendation and committed to making the change to the Mental Health Act Code of Practice. This will happen when it is able to be laid before parliament.

Recommendation 17 (reporting of restrictive interventions in adult social care and children's services)

During our review, we highlighted that there was no reporting mechanism for when restrictive interventions are used in adult social care services or children's services registered with both Ofsted and CQC. We therefore recommended that a national reporting mechanism was developed that reflected the one used for hospitals (MHSDS). We also requested regulatory change to ensure providers notify us of certain restrictive practices.

If this recommendation was fully implemented, people in adult social care and dual Ofsted and CQC registered children's services would:

- have better care, as the improved reporting mechanisms and data mean we can monitor it and act when concerned. This would reduce the use of restrictive interventions, as they will only be used when appropriate.

Has recommendation 17 been achieved?

We consider that recommendation 17 has not been achieved

Action needed:

- CQC and the Department of Health and Social Care are currently discussing regulatory change. These discussions are ongoing.

What we are seeing and hearing

Since the publication of our Out of sight report, we have been discussing with the Department of Health and Social Care about changing the regulations. We have put forward an initial proposal that includes recommendation 11 and 15. This work is due to go to public consultation in autumn 2022 before a decision is made if the proposal will be put forward for legislative change.

Recommended further work

In addition to the recommendations, our Out of sight report highlighted further work that was out of scope of our review.

This work included:

- 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.
- The 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.

What progress has been made towards this further work

There have been reported cases in the [media about inappropriate use of seclusion and physical restraint in schools](#), which the [challenging behaviour foundation reported on in April 2021](#).

The Department for Education is considering recent recommendations on [restraint from the Equality and Human Rights Commission](#) (published in June 2021) including definitions of restrictive practices, and will respond to that report in due course.

These areas of work need to be taken forward urgently.

The Department of Health and Social Care have explored the prosecution of inpatients but have not identified a way to build any evidence on this beyond anecdote. We would recommend that a cross-organisational discussion takes place, to include or be led by people with lived experience to take this forward.

9. Conclusion

As can be seen throughout this report there is still much to be done to ensure that people with mental ill health, those with a learning disability and autistic people, get the right support at the right time. Most of the recommendations we made in our Out of sight report in 2020 are not sufficiently progressed to have the impact that is needed.

Throughout this report we have tried to reflect on what we are seeing and hearing from people and providers, as well as relevant data. We know that there are still too many people in hospital unnecessarily, that too many people are subject to restrictive interventions, and that not enough people are able to access the support they need in the community.

This must change. Fundamental to that change is a change in approach and expectations. Working in real partnership with people with lived experience and their families must be the foundation on which this change is based. Changes must be co-produced at system level, provider level and at an individual level. Families' views should not only be listened to, but acted on, so that people can have the right care and support that they need and want, to be able to lead their best lives.

This may not be easy. It requires policymakers, planners, regulators, commissioners and professionals to recognise the expertise of people and their families – those who have the ambition and understanding of what matters in each person's life. It requires a change in our perception from a focus on services to a person's needs, and a change in the view of a patient or a person who uses health and social care services to a citizen, with equal worth.

Those changing views and perceptions then need to be supported by systems that make it easy for the funding and delivery of support to follow the person throughout their lives. Moving from health to social care, childhood to adulthood, education to social care, and mental health to learning disability services should not be a barrier or a battle, but a recognition of the changes in people's lives that they may need different support for.

Progress needs to be made and the governance for this must lie with the Department of Health and Social Care Building the Right Support delivery board to hold members to account and deliver the recommendations. We invite the Department of Health and Social Care and partners to clarify how the recommendations relating to services for people with mental ill health will be progressed.