



Review of restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability or autism

Interim report

## Segregation in mental health wards for children and young people and in wards for people with a learning disability or autism

May 2019

# Care Quality Commission

## Our purpose

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

## Our role

- We register health and adult social care providers.
- We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- We use our legal powers to take action where we identify poor care.
- We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

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Excellence – being a high-performing organisation

Caring – treating everyone with dignity and respect

Integrity – doing the right thing

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

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# Foreword

This interim report focuses on 39 people who are cared for in segregation on a learning disability ward or a mental health ward for children and young people. Their world is narrowed to a highly restricted existence in a single room, or small suite of rooms. For many, their interactions with other people are characterised by distress and sometimes by the use of force by staff who consider this necessary to protect the person or others from harm.

Only a very small proportion of people with a learning disability and/or autism are in a specialist hospital and only a few per cent of those in hospital are cared for in segregation. This indicates that the people we have visited have the most severe and complex problems. They should be receiving expert care delivered by staff with highly specialised skills in a setting that is fully adapted to their specific needs. This is not the situation for a considerable number of the people visited by our review team so far.

The hospitals themselves are directly responsible for the quality of the care that they provide and we urge them to consider the findings in this report. We are also recommending that an independent review is undertaken of every person placed in segregation to confirm that they are receiving good care and that no opportunities are missed to end segregation or hasten discharge.

We are also calling for a strengthening of the safeguards that protect the safety, welfare and human rights of these people whose situation has rendered them highly vulnerable. Some of the hospitals we have visited have features of institutions that are at risk of developing a closed and even punitive culture. If this happens, it can be difficult to detect. The more that these hospitals are opened up to external and independent scrutiny on a regular and ongoing basis, the better. We suggest that strengthening the role that independent advocates play might be an important step in that direction.

However, although these are still early days for the review, we have already concluded that simply improving the care of people currently in segregation will not be enough. People will continue to be hospitalised and placed in segregation, and become 'stuck', unless a different and better system of care is put in place. This better system must make sure that people, and particularly children and young people, with behaviour that others find challenging receive effective help and so prevent admission to hospital. If a period of hospital care is in the person's interests, this must be provided close to home and last only as long as it remains in the person's interests. Throughout, the person must be supported by health, care and education workers who have the necessary skills and expertise. In our interim report, we suggest the qualities that such an improved system should possess. None of these are new suggestions or should be a surprise. The challenge is how to make it happen.

The Care Quality Commission is an important part of the mechanism that assesses and assures the quality and safety of care provided in these hospitals. We are committed to learning from the visits undertaken during the course of this thematic review and using this learning to strengthen our monitoring and regulation of these hospitals.

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## Adam's story

Throughout this report, we illustrate our findings by describing the experiences of some of the people we have visited. We have not used their real names.

Adam's story sums up the impact of a person's journey into long-term segregation.

Adam is a child with autism and a mild learning disability who was in long-term segregation in a hospital for children and young people with a learning disability, autism and mental health problems.

Adam attended a school for people with a learning disability for about 18 months from the age of five. He was then home-schooled until he was eight. People working with him were not able to cope with his behaviour; this meant that he did not receive education for two years. Adam was moved to a specialist residential home, but the move caused him a lot of distress and the placement broke down.

Adam was admitted to his current hospital when he was 10. Since admission, Adam has been confined to a seclusion room with dimmed lighting. His staff team consider that keeping Adam in segregation is less restrictive than him being on the ward. They conclude that it was necessary to restrain Adam at all times when he is in contact with other people.

The walls of the seclusion room are padded because Adam often throws himself at the walls and bangs his head on them. He is not permitted to use the adjoining lounge room routinely because this had not been fitted with padding. If Adam wants to use the lounge, staff use physical restraint – for example, staff hold Adam's lower arms and guide him away from the entrance to the lounge. He had only left the seclusion room 16 times in the 12 months before we visited him.

Adam soils himself, sometimes smearing faeces. Staff have abandoned attempts to help Adam to learn to use the toilet after early attempts had not been successful. He finds it difficult to tolerate wearing clothes due to the sensory issues associated with his autism. Because of this, he spends much of the time naked, sitting under a blanket. Staff feel unable to meet Adam's physical health and care needs. For example, Adam had been indicating physical pain for some time before staff responded to this.

Staff sit in the corridor behind a locked door observing Adam. Because there is no equipment that enables staff to communicate with him, they have to shout at him through a window. Adam sometimes watches television with staff. When this happens, the television is placed at the seclusion room window, with staff outside in the corridor. Education consists of a book held to the window.

Staff had carried out a functional analysis assessment 15 months ago to look at possible root causes of the areas of behaviour that were seen as challenging. Staff had not completed a sensory assessment that might have helped them to better understand Adam's sensory issues and how to support him with these.

Staff have developed a positive behaviour support plan, which includes descriptions of triggers and his communication needs. However, they have not implemented the plan in a consistent way. We conclude that this is due to a combination of the provider not having established a

consistent team of staff to work with Adam and the fact that most of the staff who care for Adam have only received basic online training in autism.

There is no plan to remove Adam from long-term segregation or support him to leave hospital. This is partly because a suitable community placement has not been identified.

## Summary

This interim report presents our initial findings on the use of long-term segregation<sup>a</sup> on mental health wards for children and young people and wards for people with a learning disability and/or autism. It draws on the return from an information request sent to 89 registered providers of these services.

These providers told us that there were 62 people who were in segregation. Of these, 16 people had been in segregation for a year or more. On average, people in segregation were placed in a hospital that was 87km away from their home address.

Around half of the people in segregation were in wards managed by the independent sector and half were in the NHS. Twenty-four of the places were commissioned by a clinical commissioning group, 30 by NHS England specialised commissioning, three by local authority commissioning, two by Welsh commissioning and three did not specify the commissioning arrangements.

We visited 39 people who were in segregation. What we found on our visits:

- Typically, the people in segregation had communicated their distress and needs in a way that others may find challenging. Services had been unable to meet their needs. Typically, the people we visited had had a very unsettled childhood and had been in and out of different residential settings. Moves were often triggered by a breakdown of the existing placement. The last such crisis had been the immediate cause of admission to hospital – which was seen as the only available option.
- A high proportion of people in segregation had autism (31 of the 39 people).
- Some of the wards did not have a built environment that was suitable for people with autism.
- Many staff lacked the necessary training and skills to work with people with autism who also have complex needs and challenging behaviour. Many staff who worked directly with the people in segregation were unqualified.
- Several people that we have visited were not receiving high-quality care and treatment. Some had not received the specialist assessments that would be expected for a person with complex needs.
- In the case of 26 of the 39 people, staff had stopped attempting to re-integrate them back onto the main ward environment, usually because of concerns about violence and aggression. For 25 people, staff believed that the person's quality of life was better in segregation than in the less predictable environment of the open ward.
- Thirteen of the 39 people were experiencing delayed discharge from hospital, and so prolonged time in segregation, due to there being no suitable package of care available in a non-hospital setting.

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<sup>a</sup> For the remainder of this report, we use the terms 'long-term segregation' and 'segregation' interchangeably.

Our conclusion from the review so far is that the 'current system of care', which incorporates national bodies, providers and commissioners, has failed people whose care pathway has ended with them being segregated in a hospital. The system is not fit for purpose.

Many of the 39 people we visited did not get the help they needed as children. There came a point when the only currently available option was to admit them to a hospital ward. The ward was an unpredictable environment with many sensory stimuli. These features may have contributed to the person's distress, which the person communicated in ways that endangered themselves or others. The staff on the ward may not have had specialist expertise to analyse, understand and manage these behaviours. Therefore, they considered that the only safe course of action was to isolate the person from other patients. The person then became stuck.

Attempts to move the person back into the open ward environment resulted in heightened distress or behaviours that endangered others, including staff. This reinforced staff's conclusion that segregation was necessary. Staff might also come to form the view that, for some people, it was not safe or even possible to discharge them directly from segregation to a non-hospital setting. The difficult task of finding suitable accommodation, and the accompanying bespoke package of care, may have been made more difficult by the challenge of coordinating the inputs of the various provider and commissioner organisations involved – and perhaps by disagreements about who should fund the care.

Not every element of this pathway was present for each of the 39 people we visited, and some of the people we visited were receiving high-quality care at the time of our visit.

However, there was enough commonality in their stories for us to put this forward as our initial impression of the current system. We will explore this further during the remainder of the review.

We will report our full findings and recommendations in our final report in the spring of 2020. However, based on our findings so far we have made a number of recommendations for immediate action:

**Recommendation 1:** Over the next 12 months, there should be an independent and an in-depth review of the care provided to, and the discharge plan for, each person who is in segregation on a ward for children and young people or on a ward for people with a learning disability and/or autism. Those undertaking these reviews should have the necessary experience and might include people with lived experience and/or advocates.

**Recommendation 2:** An expert group, that includes clinicians, people with lived experience and academics, should be convened to consider what would be the key features of a better system of care for this specific group of people (that is those with a learning disability whose behaviour is so challenging that they are, or are at risk of, being cared for in segregation). This group should include experts from other countries that have a better and/or different approach to the care for people with complex problems and behaviours that challenge.



**Recommendation 3:** Urgent consideration should be given to how the system of safeguards can be strengthened, including the role of advocates and commissioners, and what additional safeguards might be needed to better identify closed and punitive cultures of care, or hospitals in which such a culture might develop.

**Recommendation 4:** All parties involved in providing, commissioning or assuring the quality of care of people in segregation, or people at risk of being segregated, should explicitly consider the implications for the person's human rights. This is likely to lead to both better care and better outcomes from care.

**Recommendation 5:** Informed by these interim findings, and the future work of the review, CQC should review and revise its approach to regulating and monitoring hospitals that use segregation.

# Introduction

Healthcare professionals working in mental health and learning disability services have powers to detain people in hospital. Once there, staff can use force or restrictions if they deem these necessary to keep the person or others safe from harm. In these circumstances, staff may restrain the person, usually by holding them, or isolate the person from other patients by secluding or segregating them. Appendix A explains the different types of restrictive intervention.

In our report on *The State of Care in Mental Health Services 2014-2017*, we commented on the frequent use of restraint on mental health wards and the wide variation in reported use. We called for clearer definitions of types of restraint, improved reporting and improved training for staff – particularly in de-escalation and positive behaviour management practices that minimise the need to use restrictive interventions.

There have been longstanding concerns about hospital care for people with a learning disability and/or autism. This came to national attention following the exposure of abusive practices at Winterbourne View Hospital.<sup>1</sup> Despite the intense focus on these hospitals during the period of the Transforming Care Programme<sup>2</sup>, there are still major concerns. There continue to be reports of inappropriate use of seclusion and restraint, poor ward environments, poor quality of care, excessive length of stay and damaging impact on patients and staff.<sup>3</sup> In response to these concerns, the Joint Committee on Human Rights is carrying out an enquiry into conditions in learning disability inpatient units and into the detention of children and young people with learning disabilities and/or autism.<sup>4,5</sup>

It is often families that highlight concerns about the care of people with a learning disability and/or autism. Families may report a deterioration in their relative's health after they have been admitted to hospital.<sup>3,6</sup> They may feel disempowered, not listened to and that staff do not respect their expertise. When their relative is admitted to a hospital many miles from the person's home, this may disrupt family contact, family relationships and affect the family's ability to influence care.

In 2018, the relative of a person who was cared for in segregation made their concerns about their care public. In response to this, the Secretary of State for Health and Social Care asked the Care Quality Commission (CQC) to review and to make recommendations about the use of restrictive interventions in settings that provide inpatient and residential care for people with mental health problems, a learning disability and/or autism.<sup>7</sup> The work was commissioned under Section 48 of the Health and Social Care Act 2008, which grants CQC the power to conduct a special review or investigation.

This interim report presents our preliminary findings on the use of segregation on mental health wards for children and young people and wards for people with a learning disability and/or autism. It draws on the return from an information request sent to 89 registered providers of these services and our visits to 35 wards where we assessed the care of 39 people.

This report describes emerging themes about the pathway that these people have followed, their current care and treatment and what prevents them from leaving hospital. We illustrate our findings with the stories of some of the people that we have met during our visits.

This interim report reflects the experience of the people we spoke with. However, it is still early days for the review and we cannot yet be certain that it describes the complete picture of the system of care for people whose personal pathway of care has ended in segregation.

We will publish a full report in March 2020. As well as containing a more detailed analysis of our findings about this group of people, the full report will consider the use of other types of restrictive intervention in a wider range of settings, including adult social care. That report will include our final recommendations to improve practice.

## **What does good care look like?**

There is expert consensus about good practice in the care and treatment for adults and young people with challenging behaviour associated with learning disability, autism and other mental health needs. This is contained in a body of guidance from the National Institute for Health and Care Excellence (NICE).<sup>b</sup> Recommendations typically include specialist assessments and interventions based on the principles of positive behavioural support. When such interventions are implemented appropriately, there is evidence that they reduce challenging behaviour and the use of restrictive interventions.<sup>8</sup> The guidance also notes the importance of family involvement and support, especially for children and young people. Families need support at times of crisis, during admission and when there are delays in achieving effective discharge plans.

Staff should also be trained in delivering physical interventions in a safe way, while understanding the need to ensure they are only used when no other option is available. This requirement is further supported by several policy documents, all of which stress the need to only use physical interventions as a last resort, for the shortest possible time and only in the context of a properly constituted care plan.<sup>9</sup>

Staff must be competent in and supported to deliver these effective interventions. Therefore, the guidance also considers staff training, supervision and support, with an emphasis on training to deliver proactive strategies that reduce the risk of challenging behaviour.

Training alone is not enough. Staff also need emotional support if they are to keep the positive attitudes that are required.<sup>10</sup> Working with people with severe challenging behaviour can have a

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<sup>b</sup> In relation to autism and challenging behaviour, they include CG128 “Autism spectrum disorder in under 19s: recognition, referral and diagnosis”; CG142 ‘Autism spectrum disorder in adults: diagnosis and management’ and NG11 “Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges”. In relation to children and young people, they include NG 69 “Eating disorders: recognition and treatment”; CG28 “Depression in children and young people: identification and management”.

physical and emotional impact on staff. Staff may sustain physical injuries, particularly when they use physical restraint.<sup>11,12</sup> This may have a negative impact on the therapeutic relationship with patients. Healthcare assistants and support workers are the staff groups that are most likely to sustain injuries.<sup>10</sup>

The Mental Health Act Code of Practice outlines features of the rooms that may be used for segregation. It states that:

*“The environment should be no more restrictive than is necessary. This means it should be as homely and personalised as risk considerations allow. Facilities which are used to accommodate patients in conditions of long-term segregation should be configured to allow the patient to access a number of areas including, as a minimum, bathroom facilities, a bedroom and relaxing lounge area. Patients should also be able to access secure outdoor areas and a range of activities of interest and relevance to the person.*

*“Patients should not be isolated from contact with staff (indeed it is highly likely they should be supported through enhanced observation) or deprived of access to therapeutic interventions. Treatment plans should aim to end long-term segregation.”<sup>13</sup>*

There is also guidance on how to adapt ward environments for people with autism, ensuring that they take account of individual sensory needs.<sup>14</sup> This includes managing noise, lighting, smell and movement. This is necessary because sensory overload can result in severe distress which can be displayed as challenging behaviour.

NICE guidance describes good practice for commissioners. When they commission hospital care for a person with a learning disability and/or autism, commissioners should ensure that services set service-level and individual outcomes and that service providers show evidence of achieving these outcomes. NICE recommends that this evidence includes satisfaction and quality-of-life ratings, outcomes measured by personalised and validated tools, reduced behaviour that challenges and less use of restrictive interventions, participation in education by children and young people, contact time with specialist professionals and quality checks by user-led organisations.<sup>15</sup>

On a more strategic level, commissioners are required to develop clear care pathways and appropriate community services. This was outlined in *Building the Right Support* and the *National Service Model*. The strategic intention is to support people with a learning disability and/or autism to live alongside others in their local community – in the same way as any other citizen.<sup>16,17</sup>

## **How are we conducting the review?**

The review has two phases:

**Phase 1** (commenced January 2019): explores the use of restraint, prolonged seclusion and segregation in mental health wards for children and young people and in wards for people with a learning disability and/or autism.

**Phase 2** (commencing June 2019): will explore the use of prolonged seclusion and segregation in mental health rehabilitation and low secure wards and restrictive practices in social care homes for adults with a learning disability and/or autism, children’s residential services and the 13 secure children’s homes in England (in partnership with Ofsted).

## **Provider information return**

In December 2018, we contacted 89 registered providers that manage mental health wards for children and young people or wards for people with a learning disability and/or autism. We asked for information about all patients that were currently being cared for in segregation or prolonged seclusion.<sup>c</sup> We received a return from 84 providers, and one provider’s data was too late to be included in this interim report. The four providers that did not respond to the request comprised one that provided mental health wards for children and young people and three that provided wards for people with a learning disability and/or autism. Forty-nine of the providers that responded were NHS services and 35 were independent healthcare services.

## **Site visits**

As part of phase 1 of the review, we visited hospitals where patients are subject to segregation. A small team led by a CQC Mental Health Act reviewer carried out the visits. Teams may also have included a CQC inspector, a specialist advisor (an expert in their field) and an Expert by Experience (a person with lived experience as either a person who has used the service or a carer). These visits were ongoing at the time of this interim report.

The table below summarises the questions that underpin the assessments made during the hospital visits. This interim report offers only partial and initial findings to some of these questions and focuses exclusively on those people who were in segregation.

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<sup>c</sup> When we use the term ‘segregation’ in this report, we mean long-term segregation. The definition used in our provider information request for long-term segregation was: ‘Nursing or caring for a person in enforced isolation, regardless of whether the procedures and requirements of the MHA Code of Practice 2015 for long term segregation are met. The enforced isolation must have been in place for 48 hours or more. It should still be considered segregation even if the patient is allowed periods of interaction with staff and or peers.’

It’s important to note that the MHA Code of Practice differs slightly from the definition we used. It defines long-term segregation as: “a situation where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward on a long-term basis”.

The MHA Code of Practice defines seclusion as ‘the supervised confinement and isolation of a patient, away from other patients, in an area from which the patient is prevented from leaving, where it is of immediate necessity for the containment of severe behavioural disturbance which is likely to cause harm to others. Prolonged seclusion is longer than 48 hours (see appendix A).

This interim report is confined to those people who were in long-term segregation.



## Literature review and expert advice

The work is informed by a review of the literature on the care of people with mental health problems, a learning disability and/or autism who display behaviours that services find challenging.

The review is further supported by an expert advisory group (EAG) that comprises experts from a wide range of backgrounds (see appendix B). It includes people with lived experience, carers, front-line staff, academics and clinical experts, commissioners, advocates, provider organisations, voluntary sector organisations and other national stakeholders. The EAG provides both expert advice and informed and constructive challenge. Their views on key issues are reflected in our initial conclusions.

## About this interim report

This interim report presents the initial findings and initial conclusions concerning segregation in mental health wards for children and young people and in wards for people with a learning disability and/or autism. It describes what the information return told us about the 62 people that providers reported were in segregation and what we found when we visited 15 hospitals and 35 wards at those hospitals that accommodated 39 people in segregation.

At the time of this interim report, we had not completed visits to all of the people cared for in segregation nor had we fully analysed the considerable body of information collected while visiting these 39 people. The findings reported here focus on the key issues drawn from the insights of CQC staff on each of the reviews, visiting the 35 wards where the 39 people were receiving care.

## **How we escalate concerns**

CQC and NHS England have an agreed procedure to follow if the team visiting the site identifies concerns for individuals, or regarding the provider (see appendix C).

We have used this process on eight of the 15 visits that we have carried out so far. We have raised three safeguarding alerts with the appropriate local authority. We have discussed concerns with local inspection teams where we have identified that there may be areas of practice which need to be investigated through our regulatory powers. We have escalated our concerns regarding the care and treatment of nine people to NHS England.

# Our findings so far

## What we were told from the provider information request

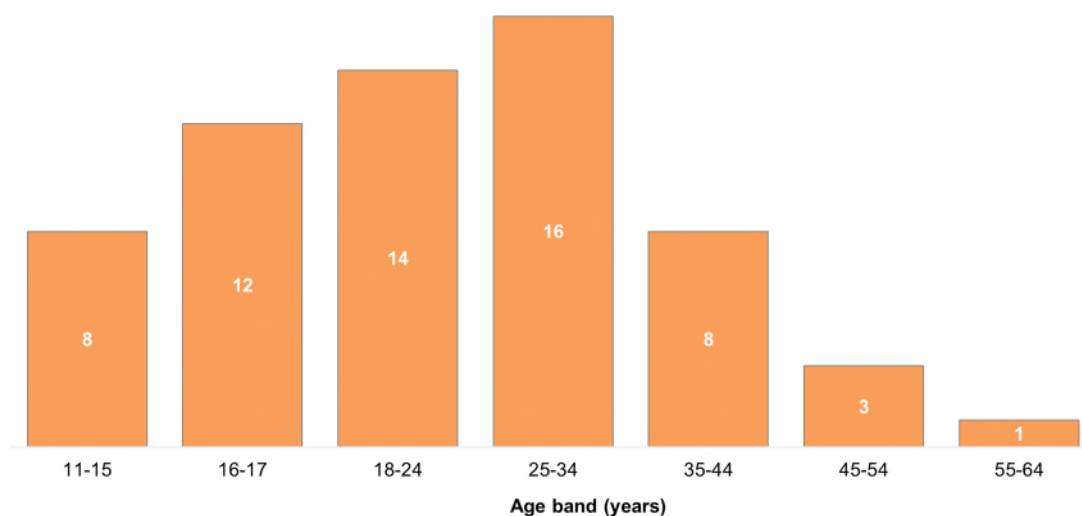
The information in this section is taken from the provider information return and is subject to checking at hospital visits. We had not completed all the visits at the time this interim report was published.

**The number of people in segregation and who they were:** Providers informed us about **62** people who were in **long-term segregation** at the time of the information return. The actual number of people subject to these restrictions in these settings was higher than this. We know this because during the first 15 hospital visits, we identified nine people who were segregated but who had not been included in the provider information return. In some of these instances, this was because the provider had not recognised that the way in which they were providing care met the definition for long-term segregation.

Thirteen of the 20 children and young people, and 10 of the 42 adults, who were segregated were female. Figure 1 shows the distribution of the ages of the 62 people. There were children as young as 11 years old among the 62 who were segregated.

Providers told us about the diagnoses of 60 people in segregation, 27 (45%) of whom were diagnosed with autism. Our early visits suggest that this might be an underestimate of the true picture and that an even higher proportion of these people may have autism – often co-existing with one or more mental health condition. Of the 39 patients we have reviewed so far, we found that 31 had autism (79%).

**Figure 1: The age distribution of people in segregation\***



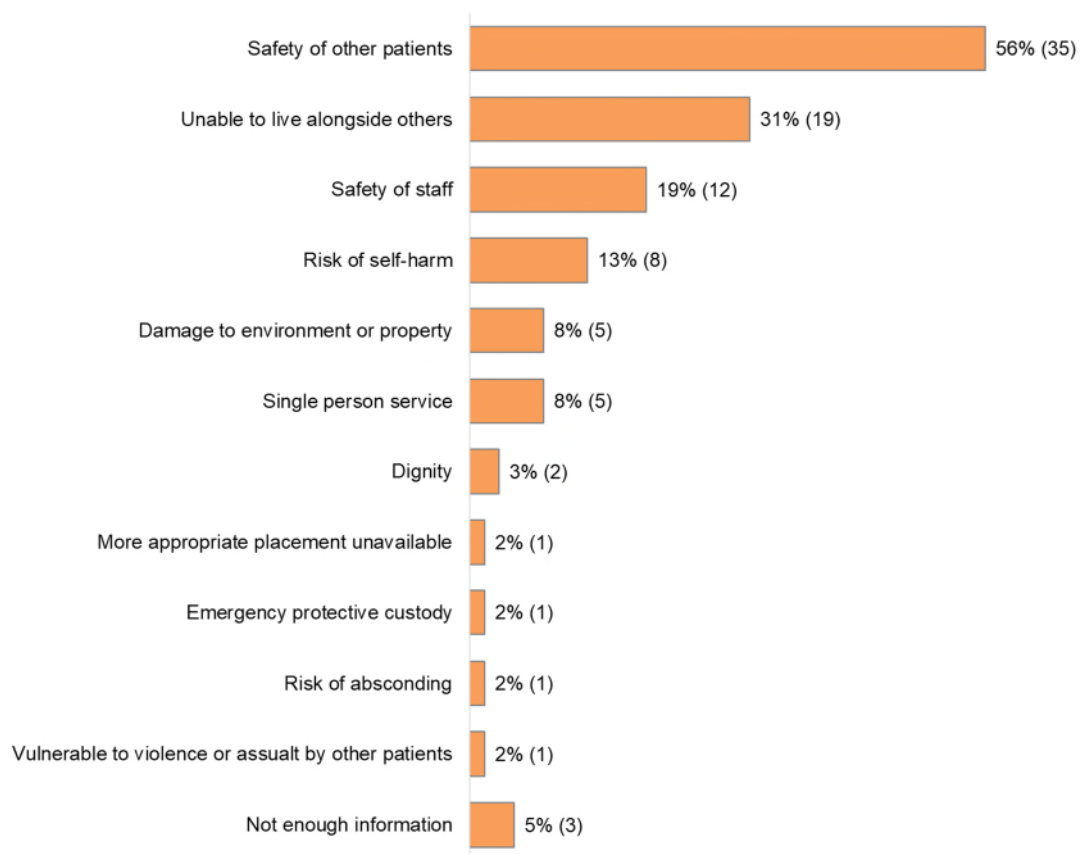
\*Number of people in each age band is shown on the bars.



**The length of time that people had been kept in segregation (in their current stay in hospital):** According to the provider information return, adults had been in segregation longer than children and young people (median of 184 days vs 41 days, respectively). The longest time that an adult had spent in segregation was 9.5 years. For a child or young person, the longest was 2.4 years. Sixteen of the 62 people had been in segregation for more than a year.

**Why people were in this situation:** Figure 2 shows what the provider told us in the information return about why the 62 people were in segregation. Some providers gave more than one reason per patient. The most commonly stated reason was for the safety of other patients (35 people) or staff (12 people). For 19 people who had been segregated, the providers told us that their inability to tolerate living alongside others was a factor.

**Figure 2: Reasons given for the use of long-term segregation\***



\*Providers gave multiple reasons for some patients, so numbers do not add up to 62. Bars show percentage of patients in long-term segregation associated with each reason. Number of patients is shown in brackets.

**The distance that people in segregation were from home:** Our provider information return told us that on average, people in segregation were placed in a hospital that was 87km away from their home address (range 4 to 291km). There was little difference between children and young people and adults in terms of distance from home. Thirty-four (55%) patients in long-term segregation resided on a ward that was more than 50 km from their home address.

**The providers and commissioners of the care:** Thirty-three people in segregation were in wards managed by the independent sector and 29 in wards managed by the NHS. Twenty-four of the places were commissioned by a clinical commissioning group, 30 by NHS England specialised commissioning, three by local authority commissioning, two by Welsh commissioning and three did not specify the commissioning arrangements.

## **What we have learnt so far from our visits**

At the time that this interim report was written, we had visited 35 wards (18 learning disability wards and 17 mental health wards for children and young people) in 15 hospital locations and assessed the care of 39 people who were in segregation. The 39 people whose care we assessed included the nine people who had not been included in the provider information return.

**The pathway that ended in segregation:** The parents of one young person in segregation described how, after their child had been excluded from residential special school, they had sought support from the community team to help them manage. This had not been available and, by the time help and support was offered, the person's challenging behaviour had escalated to the point where a hospital placement was the only option.

This was not an unusual experience. A substantial number of people we visited had been excluded from schools – sometimes on multiple occasions. Typically, the people we visited had been in and out of different settings such as residential schools, special education schools and different community services from a young age. Often, moves were triggered by a breakdown of the existing placement. It was almost always the case that the last such crisis had been the immediate cause of a person being admitted to hospital. We heard stories of where the person's non-hospital, residential community placement had broken down because of a sudden or escalating challenging situation which caused staff working with the person or the family to conclude that they could no longer meet the person's needs. The person had ended up in hospital because there was nowhere else for them to go.

### **The pathway into hospital and segregation**

**Adam** is a child with autism and a mild learning disability who was in long-term segregation in a hospital for children and young people. Adam attended a school for people with a learning disability for about 18 months from the age of five. He was then home-schooled until he was eight. He communicated he was distressed in a way that people found difficult to deal with; this led to him not receiving education for two years. Adam was then moved to a specialist residential home, but the move caused him a lot of distress and the placement broke down, so he was admitted to hospital where he was first secluded, and then segregated.

**Jane** is an adult with autism and a borderline learning disability. Sometimes, she communicates her feelings of distress by becoming aggressive and violent and by harming herself. Jane has been in specialist residential care from childhood. She was admitted to

hospital because she became violent and aggressive when she was distressed as a way of communicating. Since her teenage years, she has been in five different medium secure hospitals. Jane is in long-term segregation on a learning disability rehabilitation ward. Jane was originally placed in seclusion. She was placed in long-term segregation to end seclusion because it was felt to be a less restrictive option.

**Rachel** has a severe learning disability, autism and bi-polar disorder. She is nonverbal and sometimes uses violent and aggressive behaviour as a way of communicating her feelings of distress. Rachel went to a special education school but was moved to a residential school when she was 11 because staff were unable to meet her needs. Rachel was moved between seven different hospitals and community placements up until early adulthood. These all broke down due to staff finding her behaviour challenging, and she was admitted to hospital and put in long-term segregation.

Thirty-one of the 39 (79%) people in segregation we had visited by the time of this report have autism, often in association with other conditions. This is considerably higher than the 45% figure taken from the provider information return. People with autism may find it difficult to cope with a new and unpredictable environment and unfamiliar sensory stimuli. This was the case for many of the people we visited – who communicated their distress through aggression or other behaviours that staff found challenging. Our findings from initial visits suggest that this was a factor that contributed to staff members deciding to isolate the person from other people.

**Living conditions, restrictions and safeguards:** Some of the wards we visited provided a high-quality living environment that could be adapted to the needs of people, including those with autism. However, several of the wards did not have a built environment that was suitable for people with complex needs, especially for people with autism. They were noisy and had a layout that did not achieve the necessary balance between ensuring safety while allowing people access to quiet, personal space when they needed it.

Some of the suites or rooms used for segregation were bare and offered little access to natural light or fresh air.

Many of the 39 people who were in segregation lived highly restricted lives. Some were confined to a single room. Some were required to eat food on their laps, rather than at a table. In some cases, people were restricted to eating 'finger food', or served out of a takeaway container rather than on a plate; without a clear rationale in place.

In addition to being segregated, many of the people we visited were subject to other restrictive interventions. These included physical restraint at times when staff deemed that their behaviour was endangering themselves or others, and planned restraint in the form of holds, for when the person was accompanied into the grounds of the hospital. Some people were prescribed medication – often for the explicit purpose of managing behaviour that staff found difficult to manage by other means.

Some wards made extensive use of closed-circuit television (CCTV), with cameras in toilets and bedrooms. The use of CCTV could contribute to the safety of staff and people who use services. However, in some services the monitors that staff used to observe people who were in segregation were not always placed in a secure or private part of the building. This meant that other patients or visitors might be able to see the screen. This risked further compromising the privacy and dignity of the person being observed.

Staff sometimes restricted people's access to their family. On one ward, the person did not have access to a phone to use in private or have the opportunity to meet with relatives alone or without being observed. Some family members that we spoke with were not always aware that they were being watched on CCTV.

When we visited the 15 hospitals, we identified nine people who were in segregation who the provider had not included in the information return, in some cases because they had not recognised the patients as being in long-term segregation. This meant that these people were not afforded the rights and protection required by legislation. For example, one person was restricted in their movements and did not have access to most of the facilities that other patients had. The provider had not identified the person as being in segregation. During our visit the person was still residing in the locked unit. We brought this to the attention of the provider who made the necessary adjustments to their care.

We will explore these issues more fully during the remainder of the review. This fuller analysis will include an evaluation of the extent to which the ward areas' use of segregation complied with the requirements of the Mental Health Act Code of Practice. These conditions and restrictions may also mean that people are not having their rights under the Human Rights Act 1998 upheld. We discuss this later in the report.

**The quality of staffing of the wards:** We found that several of the hospitals that we have visited did not employ staff with the necessary skills to work with people with autism who also have complex needs and challenging behaviour.

In addition, many of the staff we saw, including those working directly with the people in segregation, were unqualified healthcare or nursing assistants. Many hospitals used agency staff to fill a substantial number of shifts.

Some of the hospitals provided their staff with little or no training in autism. Training may amount to a brief module at induction or a basic package delivered through e-learning. This basic level of training would not fully equip staff with the skills necessary to anticipate, de-escalate or understand and interpret individual behaviours: skills essential to the care of this group of people with very complex needs.

**The quality of assessment, care and treatment provided:** Consistent with the staffing situation, we have found substantial variation in the standard of care and treatment provided to people who are in segregation. Some wards did provide high quality care. They had assessed

and identified the person's complex needs and had devised and were implementing a plan of care to meet those needs.

However, consistent with our initial findings about staffing, some people had not received the specialist assessments that would be expected for a person with complex needs. For example, staff had not carried out sensory assessments for seven of the 30 people with a diagnosis of autism.<sup>d</sup> Where assessments had taken place, the findings were not reflected in the daily plan of care and so were not influencing how staff worked with the person.

Most of the people had a positive behavioural support plan in place, but these varied both in their quality and in the extent to which staff worked to the plan.

### **Variation in the quality of assessments**

**Adam's** team undertook a functional assessment when he was first admitted, looking at possible root causes of the areas of behaviour that were seen as challenging. They had not reviewed this assessment in the 15 months since that time. Staff had also not completed a sensory assessment that might have helped them to better understand his sensory issues and how to support Adam with these.

**Jane** had a positive behaviour support plan and a care plan, but these were not focused on her diagnosis of autism. Moreover, Jane had not had a sensory assessment and did not have a sensory care plan to support her needs.

**John's** current staff team did extensive planning before he arrived at hospital. This included talking to his family and working with his previous care team to understand his needs. When he arrived, they carried out an assessment. This helped to understand his behaviour and they used this to inform a positive behavioural support plan with his short, medium and long-term goals. From this, they identified what caused John distress and tried to avoid these triggers for example natural light.

**Rachel** has a positive behaviour support plan and a care plan that she and her family have been involved in creating. Sometimes staff restrained Rachel to protect her or others from being hurt. This now happens less often because staff use de-escalation techniques.

We will explore the quality of specialist assessments and care planning more fully during the rest of the review.

**Why people remain in segregation:** For 26 of the 39 patients we visited, staff had stopped attempting to reintegrate the person back into the main ward environment. In some cases, staff were concerned about increased levels of violence and aggression. For 25 people, staff had also

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<sup>d</sup>We did not have information about sensory assessments for one person.

concluded that the person's quality of life was better when they were in segregation than when they were exposed to the less predictable environment of the open ward.

Thirteen of the 39 people that we visited were experiencing delayed discharge from hospital, and so prolonged time in segregation, because there was no suitable package of care available in a non-hospital setting. For some, the commissioners had found it difficult to find a suitable placement. Three of the people had been discharged from the hospital previously but then readmitted when that placement could not meet the person's needs.

Staff and advocates have told us that the cost and question of who will fund an alternative placement can delay discharge. In one example a suitable property in the community, that would meet the person's needs, could not be found for the budget available. Members of our expert advisory group have suggested that there may be conflicting incentives in the system for commissioning care and treatment for this group of people that contribute to delayed discharge.

### **Barriers to moving on**

**Adam** had no plan to be moved from long-term segregation and there was not a plan to support him to leave hospital because no suitable community placement had been identified.

**Jane's** staff team had been looking for ways to support her to leave hospital, but this had failed because there had not been a community service available that could support Jane's specialist needs properly. The commissioner responsible for future funding of Jane's care disagreed with the staff team regarding Jane's diagnosis. The hospital staff wondered whether this decision was related to funding rather than the person's needs and Jane's independent mental health advocate felt powerless. Jane remained on the ward and little progress was being made with her care and treatment. Jane's family thought that the hospital staff were doing the best they could to care for Jane, given the circumstances. However, they felt that Jane was 'stuck in the system'.

**Rachel** did not have a firm discharge plan because no provider had been found that could meet her needs in the community.

**John** was being supported to take gradual steps to leaving long-term segregation, including supporting him to have gradual access to natural light that he didn't have in his last placement. John's advocate noticed that he had started to develop a positive relationship with staff and that they had tried to provide choice where possible. The team working with John had specialist training specific to his needs and of other people in the unit, including in autism. The team were working with John and the local clinical commissioning group to identify the right next placement for him.

## Emerging themes

At the time of the publication of this report, the review is still in its early days. The themes draw on the insights of the CQC staff who met with 39 people in segregation – supported by the provider information request, the literature review and the views of members of our external advisory group.

We start from the principle that, when any person is placed in segregation in a hospital ward, this is a poor outcome for the person, for the staff providing the hands-on care and for the health and care system that brought it about.

### The typical pathway of care that leads to segregation

The individual stories of the people whose care we have reviewed so far have features in common. These features suggest that the current ‘system of care’ does not support people with complex needs and contributes to people being isolated from the main ward and being placed into segregation. We will test this further during the remainder of the review. The common features can be best explained in the form of a pathway through the current system of care:

- **A child who displays behaviour that may be seen as challenging may not receive the help they need.** The common picture is of a child being excluded from school followed by repeated failed residential placements.
- **There comes a point when a judgement is made that the only available option is for the person to go into hospital.** This judgement usually comes after there has been a crisis and the care team conclude that the person cannot continue in their current placement. Because of the circumstances, these decisions are often made at pace, and placements are often based on availability rather than suitability. Those responsible for these decisions would have concluded that there is no alternative, community-based option that offers the intense support needed to maintain a placement outside of hospital.
- **The ward is an unpredictable environment that exposes the person to unfamiliar sensory stimuli.** Most of the people we visited so far have autism – either as a main diagnosis or co-existing with a learning disability. A person with autism may communicate their distress at an unfamiliar environment in ways that staff and other patients may find challenging and could put themselves and others at risk.
- **The staff teams on the wards may not have specialist expertise to analyse and understand how to best support people with complex needs.** Therefore, they may not put in place the care packages that respond effectively and appropriately to their needs. This means that they do not act to de-escalate situations.
- **The situation escalates further, and staff come to consider that it is necessary, and in the interests of others on the ward to isolate the person from other patients.** This intervention may provide some immediate protection for the person or

others affected by their behaviour. Staff may not fully consider the long-term impact of this isolation.

- **The person becomes stuck in a system.** When staff attempt to move the person back into the ward environment, this may result in the person becoming distressed and communicating this in a way that staff find challenging. This reinforces the view that segregation is the only option. Staff might not consider it safe or even possible to discharge a person directly from segregation to a non-hospital setting.
- **Staff who do put in place plans for discharge may find it challenging to identify the right accommodation and a bespoke care package.** This is compounded by the challenge of coordinating the inputs of the various provider and commissioner organisations involved. Disagreements about who should fund the person's care also impact on this.



## Segregation, human rights and equality

The people that we visited lived highly restricted lives. Often, they were confined to a single room or to a small suite of rooms. Given their situation, our review must consider the implications for their human rights. Members of our external advisory group have emphasised the importance of this perspective. The Joint Committee on Human Rights (2018-19) recently stated, “We have become increasingly concerned by the steady stream of claims about conditions in Assessment and Treatment Units [*for people with a learning disability or autism*]. These units are supposed to care for some of the most vulnerable people in society, and yet it seems that some ATUs are failing in this task”.<sup>18</sup>

If a decision to place a person in segregation is made without the necessary process having been followed, this may be in breach of the right to liberty and security - Article 5 of the European Convention on Human Rights (as incorporated into the Human Rights Act 1998) which states, “*No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law.*” The relevant section of Article 5 is (e) “*the lawful detention... of persons of unsound mind...*”.<sup>19</sup> Establishing whether there has been a breach of this article will depend on the facts of the case. A court would consider the degree of restriction and the reason why the restriction was imposed.

Rights under Article 8, a right to respect for private and family life, are not absolute rights. They can be interfered with as long as the measure is in accordance with the law (for example the Mental Health Act 1983 or the Mental Capacity Act 2005), has for a legitimate aim and is necessary. A legitimate aim could be, for example, to prevent a high risk of someone harming themselves or others. For a measure to be necessary it must be the least restrictive option that will meet the aim. It is possible that the use of segregation may breach a person’s rights under Article 8 if these measures could have been avoided or if segregation is prolonged beyond the point that is necessary.

Even if the decision to place a person in segregation is lawful, meets a legitimate and is necessary, there could be breaches of Article 8 in terms of the conditions someone is experiencing while in segregation. Decisions about how care is provided, such as restrictions on access to family and friends, access to outside space or to possessions while in segregation, could breach Article 8 if each decision does not meet the test of whether it is lawful, legitimate and necessary.

It is possible that the use of segregation may breach a person’s rights under Article 8 if these measures could have been avoided or if segregation is prolonged beyond the point that is necessary.

The Human Rights Framework for Restraint produced by the Equality and Human Rights Commission refers to ‘use of force principles’ for using restraint that have been established by human rights case law. The routine use of physical restraint, for example every time that the person is escorted through the open ward or in the hospital grounds, may be in breach of

Article 8 if these actions were not proportionate. For example, this might be the case if this was not the least restrictive option to deal with the risk of harm people posed to themselves or others.

Article 8 rights might also be breached if the restrictions, placed on a person over time, are not justified by the risks posed. These restrictions might be due to features of the physical environment (such as being held in a bare room or having little access to natural light) or restrictions imposed as part of a regime to manage perceived risk (for example, the use of CCTV) or a combination of these.

If restrictive interventions and practices cause very significant distress to the person concerned, they might breach Article 3, the right to be free from inhuman or degrading treatment. This is an absolute right.

Only a court could decide if the Human Rights Act 1998 has been breached in any individual case. However, our early visits have made us sufficiently concerned to emphasise the importance of considering the human rights of people subject to segregation. Staff in services must only impose such restrictions on people after careful thought as to whether they are for a legitimate aim and are the least restrictive option available. Once in place, staff must review them regularly to check whether they are still necessary and that they remain a proportionate response to the risk.

Providers have a duty under the Equality Act 2010 to make reasonable adjustments for a disabled person using their services, including people with autism. Reasonable adjustments could include changing the physical environment in which care is provided to reduce the stress it causes to someone with autism or meeting the person's specific communication needs. Without adequate sensory assessments and training around autism, these health services are less likely to make the necessary reasonable adjustments. Providers of services which are paid for by the NHS also have a legal duty to identify, record, flag, share and meet the communication needs of disabled people using their service (the Accessible Information Standard). This is another issue that we will explore further.

## **Initial conclusions and recommendations**

The thematic review will consider the use of a range of restrictive interventions in a range of settings. We will report our full findings and recommendations in our final report in the spring of 2020. This interim report focuses exclusively on the experience of those people cared for in segregation on a mental health ward for children and young people or on a ward for people with a learning disability and/or autism.

By the time of this interim report, we had visited about two-thirds of the people in England who are in this situation. Although, we have not fully analysed the considerable body of evidence gathered during those visits, a picture has emerged of their journey through care.

Although few in number, these people are among the most disadvantaged members of our society. They have severe and complex problems and may communicate distress in a way that others find highly challenging. All the people we have visited have had contact with health, care and education services for many years. Despite this, the treatment and care provided have not enabled them to live anything approaching a normal life. Their world is narrowed to a highly restricted existence in a single room, or small suite of rooms. Their interactions with other people are often characterised by distress and the use of force by staff to manage behaviours that put the person or others at risk.

### **Care and the system of care**

Day-to-day responsibility for the quality of care for people we have visited sits squarely with the managers and staff of the hospitals. They must ensure that their buildings are adapted to the needs of the people they admit and employ staff who have both the expertise required to care for people with the most complex problems and the skills to minimise the use of force or other restrictive interventions to manage behaviour that they find challenging.

However, even if all hospital staff provided the quality of care that we saw in the best hospitals we visited, people with learning disability or autism will continue to be admitted in a crisis, and so be at risk of becoming 'stuck' in segregation. We have concluded that many of the people we have visited have been let down by health, care and education services, often over the course of many years. We think it likely that opportunities were missed early in the person's life to prevent admission to hospital and that, once admitted and segregated, more could have been done to prevent segregation or to end it sooner and facilitate discharge from hospital. The 'system of care' that produces this result must change.

In this interim report, we include recommendations both about what can be done immediately to assure the quality of care provided to people in segregation today and about the need to change the system of care for those people with a learning disability and/or autism who have the most complex problems.

**Recommendation 1: Over the next 12 months, there should be an independent and an in-depth review of the care provided to, and the discharge plan for, each person who is in segregation on a ward for children and young people or on a ward for people with a learning disability and/or autism. Those undertaking these reviews should have the necessary experience and might include people with lived experience and/or advocates.**

This formal review should start by considering any recent assessments of the person's care – including care, education and treatment reviews by NHS England<sup>20</sup>, the information gathered by CQC when it visited the person and assessments made by the body commissioning the person's care. This review should consider:

- The condition of the rooms in which the person is segregated, the type and necessity of other restrictions placed on the person and the extent to which these restrictions adhere to legal frameworks.
- The quality of the assessments and care provided to the person, the extent to which these are in line with best practice, including NICE guidance, and whether staff have the skills and training necessary to provide the expert care required.
- Whether continuation of segregation is absolutely necessary and is in the person's best interests while they are in hospital.
- Why an alternative placement is not available or thought to be appropriate. This would consider factors that might be preventing or delaying discharge – including the role of commissioners.

This work should be overseen by a national group with the expertise to advise providers and commissioners about the adequacy of the care being provided, and the authority to intervene if system problems are delaying discharge or transfer to a more appropriate setting.

Consideration should be given as to whether this review process should be extended to those placed in segregation since our review started.

**Recommendation 2: An expert group, that includes clinicians, people with lived experience and academics, should be convened to consider what would be the key features of a better system of care for this specific group of people (that is those with a learning disability and/or autism whose behaviour is so challenging that they are, or are at risk of, being cared for in segregation). This group should include experts from other countries that have a better and/or different approach to the care for people with complex problems and behaviours that challenge.**

This work would not start from a blank sheet of paper. The literature review indicates that there is a body of guidance on good practice. Based on the pathway through care of these 39 people, a better system of care would:

- Intervene early to ensure that children with behaviour that others find to be highly challenging, and their families, receive effective and consistent support and help.
- Provide an effective response to the crises that may punctuate the person's early life and offer options that are genuine alternatives to hospitalisation.
- At times when it is in the person's interests to receive care in a residential or hospital setting, provide a built environment that is fully adapted to the person's needs and is close to the person's home.
- Ensure that all who interact with the person have at least basic awareness of autism and related conditions that affect how people think and interact with others.
- Ensure that people with the greatest needs are treated and cared for by staff with the greatest expertise; and that this expertise is available to the person for as long as it is needed – regardless of where the person resides.
- Have commissioning/funding arrangements that put the power to make decisions about care and placement in the hands of the person or their advocates.
- Build expertise, knowledge and understanding about how best to meet the needs of people with these very complex problems and an effective and sustainable mechanism for improving the quality of care and treatment provided.

## **Safeguards**

As well as leading highly restricted lives, many of the people we visited have little or no control over their lives or over decisions about their future. Staff working in these hospitals must make every effort to enable a person to communicate their wishes and to be a full partner in decisions about their treatment, care and future. This requires staff with highly developed and specialist skills and a staff culture that values the people they are caring for.

We have visited hospitals that do meet this requirement. However, it is troubling that some of the hospitals we have visited have features that were present at Winterbourne View.<sup>21</sup> Many of the people have been in hospital for a long time. In some hospitals, the people placed there are from different areas, many are far away from home and a number of different commissioners fund the places. We know from our inspections that some hospitals for people with a learning disability and/or autism have high staff turnover, vacant posts and make high use of agency and bank staff. In this interim report, we have commented on the fact that a high proportion of the staff are unqualified workers and that, in some of the hospitals we have visited, there is little evidence of staff training in some of the essential skills for working with people with learning disability and/or autism who have complex needs and behaviour that staff find challenging.

We are not saying that the presence of these features indicates that a hospital has the 'closed and punitive' culture that typified Winterbourne View, but they do make it more likely that such a culture will develop. If that happens, the challenge for bodies that oversee and assure the quality of care is that, because of their closed and inward-looking nature, staff may attempt to conceal abusive practices.

**Recommendation 3: Urgent consideration should be given to how the system of safeguards can be strengthened, including the role of advocates and commissioners, and what additional safeguards might be needed to better identify closed and punitive cultures of care, or hospitals in which such a culture might develop.**

This might include strengthening and extending the role of advocates, to ensure that every individual in segregation has a truly independent advocate who is appropriately trained to recognise good and poor care and the quality of staff behaviour.

## **Human rights**

We believe segregation is a human rights issue and should be viewed as such. We will explore this further during the remainder of the review.

**Recommendation 4: All parties involved in providing, commissioning or assuring the quality of care of people in segregation, or people at risk of being segregated, should explicitly consider the implications for the person's human rights. This is likely to lead to both better care and better outcomes from care.**

## **The role of CQC**

Our early visits to people being cared for in segregation have caused us to question how we assess the quality of care provided in these settings. Visits undertaken as part of this thematic review focus in-depth on an individual who is in extreme circumstances. This has given us a unique view of the quality of care provided from the perspective of that person and of the effectiveness of the safeguards that are in place. We are undertaking work to understand how this view of care differs from that gained during a 'routine' CQC inspection visit or Mental Health Act monitoring visit.

**Recommendation 5: Informed by these interim findings, and the future work of the review, CQC should review and revise its approach to regulating and monitoring hospitals that use segregation.**

## **Next steps**

During phase 2 (June to December 2019), we will expand our exploration of the use of restrictive practices to a wider group of settings. We have already sent provider information returns to 116 providers of low secure and rehabilitation mental health wards and 4,335 adult social care services. We will work with Ofsted to consider the use of restrictive intervention in children's residential services and secure children's homes.

# Appendix A

## Types of restrictive intervention and the principles that should underpin their use

**Restraint:** The Mental Capacity Act 2005 (MCA) defines restraint as when someone “uses or threatens to use force to secure the doing of an act which the person resists, OR restricts a person’s liberty whether or not they are resisting”.

**Physical restraint:** any direct physical contact where the intention of the person intervening is to prevent, restrict, or subdue movement of the body, or part of the body of another person.

**Prone restraint:** (a type of physical restraint) holding a person chest down, whether the patient placed themselves in this position or not, is resistive or not and whether the person is face down or has their face to the side. It includes being placed on a mattress face down while in holds; administration of depot medication while in holds prone and being placed prone onto any surface.

**Chemical restraint:** the use of medication which is prescribed and administered for controlling or subduing disturbed/violent behaviour, where it is not prescribed for the treatment of a formally identified physical or mental illness.

**Mechanical restraint:** the use of a device (eg belt or cuff) to prevent, restrict or subdue movement of a person’s body, or part of the body, for the primary purpose of behavioural control.

**Seclusion and long-term segregation:** Both seclusion and segregation are ways to manage the threat or actual use of violence. Seclusion may be viewed as the management of immediate violence, whereas segregation is the management of a longer-term threat of violence. According to the MHA 1983 Code of Practice (2015) the difference between the two practices is that patients in seclusion are alone, whereas patients subject to long-term segregation should continue to have contact with and receive therapeutic interventions from staff.

**Seclusion:** The MHA Code of Practice defines this as ‘the supervised confinement and isolation of a patient, away from other patients, in an area from which the patient is prevented from leaving, where it is of immediate necessity for the purpose of the containment of severe behavioural disturbance which is likely to cause harm to others’. The following practices should be recorded as seclusion:

- Staff lock a person in a seclusion room.
- Staff lock a person in a bedroom.
- Staff place a person in a room and prevent them from leaving either by locking the door, holding it shut or by standing in the doorway.
- A patient asks to be isolated from others and then staff prevent them from leaving the area in which they are isolated.



The following practice should not be recorded as seclusion:

- Staff restrain a person in any situation other than those described above.
- Staff tell/ask a person to go to a particular area, but that person is free to leave that area.

There is no time limit on seclusion. A patient could be in seclusion for an hour, a day, a month or longer. The use of prolonged seclusion should be reviewed periodically and as with other restrictive interventions used only where considered strictly necessary.

**Long-term segregation:** The Mental Health Act Code of Practice defines this as ‘a situation where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward on a long-term basis’.

# Appendix B

## EAG membership

ADASS (The Association of Directors of Adult Social Services)

Article 39

Association for Real Change

BILD (The British Institute of Learning Disabilities)

British Medical Association

Central and North West London NHS Foundation Trust

Children's Commissioner

Council for Disabled People

Dimensions

Equality and Human Rights Commission

Experts by Experience

Family member

INQUEST

Independent Mental Health Services Alliance

Lancaster University

Mind

Mitford Unit

National Autistic Society

NHS England

NHS Improvement

NHS Providers

Northumberland, Tyne and Wear NHS Foundation Trust

Ofsted

Positive Behaviour Support Academy

Race Equality Foundation

Reach Housing and Enablement Services Ltd

Rightful Lives

Royal College of Nursing

Royal College of Psychiatrists

Royal college of Psychiatrists - Child Faculty

SeAp

Senate

Sherwood Training Academy

Skills for Care

Stronger Together

The Challenging Behaviour Foundation

The National Autistic Society

University of Oxford

Young Minds

# Appendix C

## **Joint agreement on escalation of concerns arising from the thematic review of the use of restraint, prolonged seclusion and segregation**

NHS England recognise the vital importance of CQC's thematic review and have been fully supportive of any work that will drive improvement in the quality of care for children, young people and adults.

NHS England have already undertaken reviews of children and young people who have been cared for in seclusion or long-term segregation to provide additional assurance on the quality of care and to inform NHS England of changes it may need to make its own commissioning and assurance processes. NHS England and the CQC have worked closely together to align reviews and to share information and learning wherever possible. The recommendations from NHS England's own reviews will be actioned to ensure the quality of care is of the highest possible standard.

The Care Quality Commission (CQC) and NHS England (NHSE) are committed to working together to improve the care of children, young people adults with mental health conditions with a learning disability, autism or both who are subject to restraint, prolonged seclusion and long-term segregation.

During the course of the thematic review, CQC staff will visit mental health and learning disability wards where people are subject to these restrictive interventions ([https://www.cqc.org.uk/sites/default/files/20181203\\_restraint-thematic\\_tor.pdf](https://www.cqc.org.uk/sites/default/files/20181203_restraint-thematic_tor.pdf)).

### **CQC's responsibilities**

When a CQC reviewer encounters care and treatment that falls below the fundamental standards of care, they will follow CQC's usual procedures for acting on and escalating concerns. The lead reviewer will:

- Bring the concern to the attention of the most senior member of provider staff on site and ask them to take any immediate action required. If necessary, the lead reviewer will also notify more senior provider managers of their concern.
- Immediately notify the Director of Nursing -North East and National Specialised Commissioning- Quality (referred to from now as the Senior Point of Contact NHS England) via [england.qstqualityissuealert@nhs.net](mailto:england.qstqualityissuealert@nhs.net)
- Consider raising a safeguarding alert to the appropriate local authority.
- Notify the commissioner of the concern. This will either be the CCG or the contract manager for the provider (this will be the contract manager for the area where the provider setting is located)
- Submit a notification to the NHSE's dedicated central LTS/Seclusion mailbox [[england.seclts@nhs.net](mailto:england.seclts@nhs.net)] for thematic oversight through the NHS England National Oversight Group.
- Inform the CQC relationship owner for that provider of the concern.
- Inform the senior responsible officer (CQC) for the thematic review of the concern.

**The CQC relationship owner for the provider** will be responsible for any further actions. They will:

- Escalate the concern within CQC as required.
- Convene an immediate management review meeting to consider further action. – which may include:
  - an inspection visit to the provider;
  - enforcement action against the provider.
- Manage any ongoing joint work with NHS England, commissioners, local authorities and other bodies involved in the person’s care.

### **NHS England’s responsibilities**

- The National Senior Point of Contact will alert the relevant NHS England Regional Director.
- The Regional Director will invoke the Local Operational Policy for escalation.
- The Regional Director will be accountable for oversight of actions following the escalation.
- The Regional Director will be accountable for ensuring that assurance is provided to CQC on actions being taken, copy to [england.seclts@nhs.net](mailto:england.seclts@nhs.net) WITHIN 7 days

NHS England National Oversight Group, Reducing Restrictive Practices When a notification is received via [england.seclts@nhs.net](mailto:england.seclts@nhs.net):

- All escalations and actions taken will be logged onto a centralised spreadsheet as a national record
- Reporting on this (supressed/anonymised) will be to the National Oversight Group, Reducing Restrictive Practices identifying any thematic learning/issues that may need addressing arising from this

### **Oversight**

The learning disability and autism reducing restrictive practices national oversight group will oversee the operation of this agreement.

### **Signed**

Dr Paul Lelliott – CQC  
Deputy Chief Inspector  
Hospitals (Lead for mental  
health)



Claire Murdoch CBE NHSE  
– National Mental Health  
Director



Ray James CBE NHSE –  
National Learning  
Disabilities Advisor



# Appendix D

## Glossary

**Advocate** – An Independent Mental Health Advocate (an IMHA) is specially trained to work within the framework of the Mental Health Act to meet the needs of patients.

**Autism** – Autistic Spectrum Disorder is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.

**Challenging behaviour** – The Challenging Behaviour Foundation describes this as a range of behaviours which some people may display to get their needs met. Behaviours might be things such as hurting others (eg hair pulling, hitting, head-butting), self-injury (eg head-banging, eye-poking, hand-biting), destructive behaviours (eg throwing things, breaking furniture, tearing things up), eating inedible objects (eg cigarette butts, pen lids, bedding) and other behaviours (eg spitting, smearing, repetitive rocking stripping off, running away).

**CQC Mental Health Act reviewer** – Carries out Mental Health Act (MHA) monitoring activity for CQC.

**Functional assessment** – A method for understanding the causes and consequences of behaviour and its relationship to particular stimuli, and the function of the behaviour. The function of a particular behaviour can be analysed by typically identifying (1) the precursor or trigger of the behaviour, (2) the behaviour itself, and (3) the consequence of the behaviour.

**Learning disability** – A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty understanding new or complex information, learning new skills and coping independently.

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

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

# Appendix E

## Further analytical information

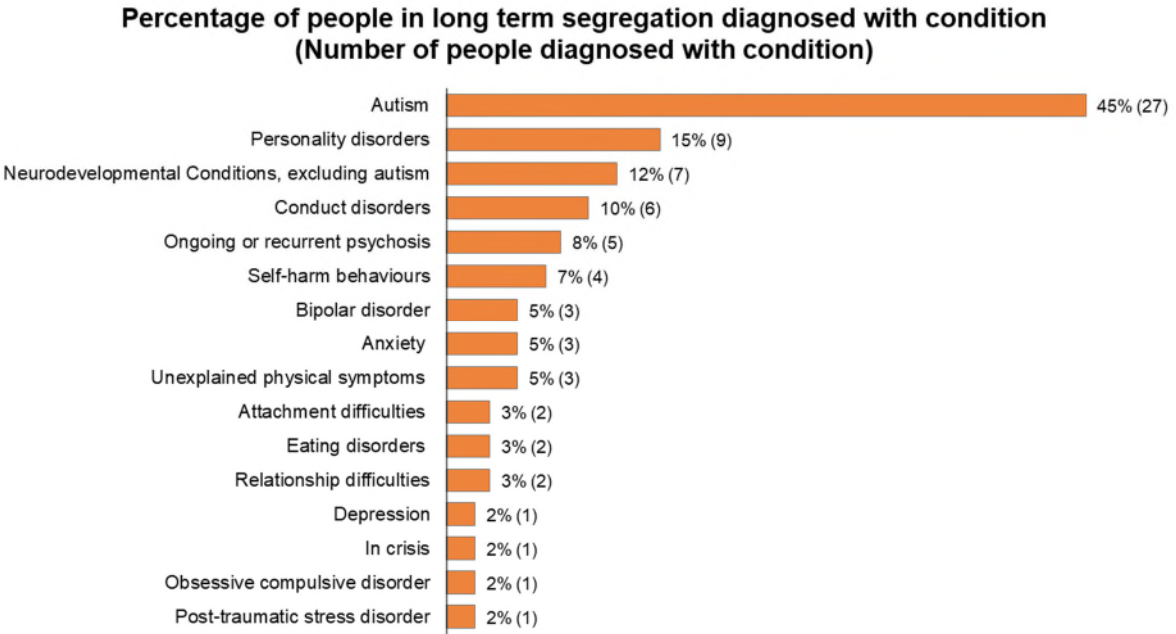
Data taken from the interim analysis of provider information returns relating to people in long-term segregation in mental health wards for children and young people and wards for people with a learning disability and/or autism.

Please note that due to the lack of baseline measures for people in these settings involved, we cannot yet comment on whether some groups of people are disproportionately represented within those subject to long-term segregation.

### Ethnic groups of people in long-term segregation:

Ethnicity	Number of people (% of all people in long-term segregation)
White – British (Welsh, Scottish, English, Northern Irish)	52 (84%)
White – any other White background	4 (6%)
Mixed – any other Mixed background	2 (3%)
Black or Black British – Caribbean	2 (3%)
Black or Black British – African	1 (2%)
Black or Black British – Any other Black background	1 (2%)
Asian or Asian British - Any other Asian background	-
Other ethnic group – Arab	-
Other ethnic group – Any other	-
Prefer not to say	-

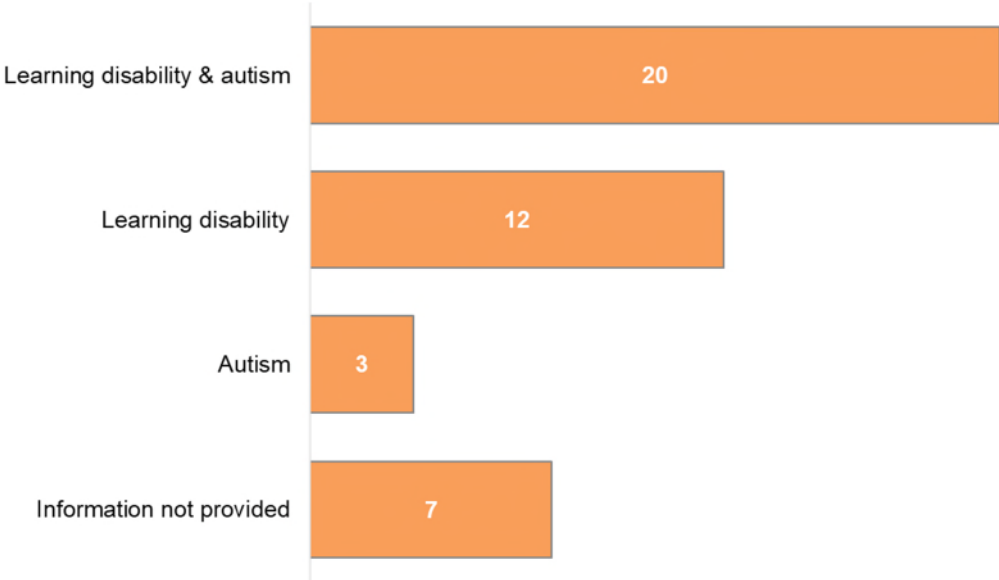
# Diagnosis of people in long-term segregation



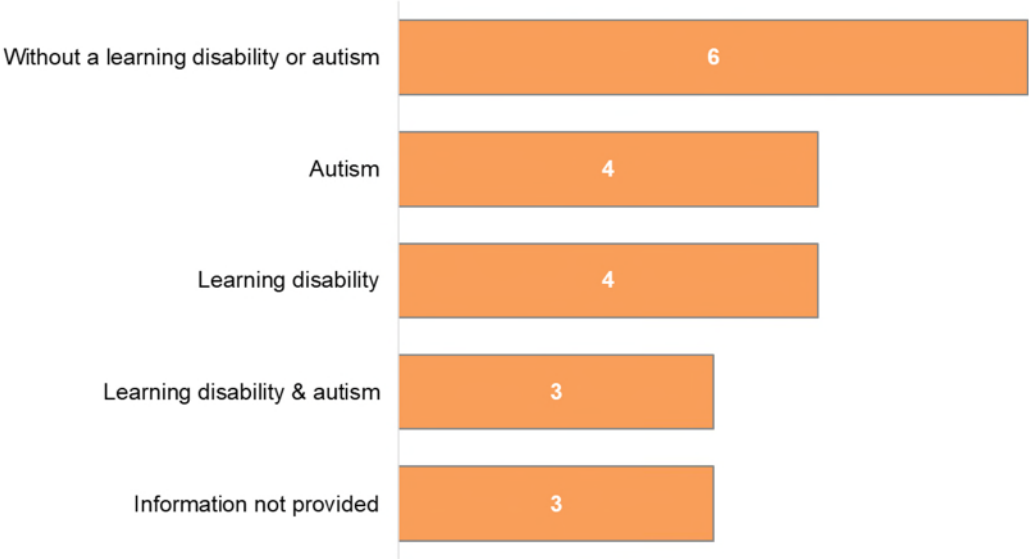


**Diagnosis with age breakdown\*:**

**Adults in long term segregation**



**Children/young people in long term segregation**



\*Number of people is shown on the bars.

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