The Government Response to the Joint Committee on Human Rights reports on the Detention of Young People with Learning Disabilities and/or Autism and the implications of the Government's COVID-19 response

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Foreword

1. Protecting the rights of people with a learning disability and of autistic people is a matter of the utmost importance to the Government. Rights must be upheld regardless of wider circumstances, no matter how unprecedented. This is especially so for those who may be at a particularly vulnerable time in their lives, in crisis or receiving treatment in specialist mental health inpatient settings.

2. We welcome the scrutiny of the Joint Committee on Human Rights ('the Committee'), and its carefully considered recommendations. The Government's manifesto committed to improve how people with a learning disability and autistic people are treated in law and to make it easier for them to be discharged from hospital. The work of the Committee keeps this important issue at the forefront of minds not just during but as we recover from the COVID-19 pandemic. In this document we respond to each of the recommendations made by the Committee.

Building the right support in the community

3. The Government wants everyone to have the opportunity to play a full part in their community, amongst family and friends. Everyone, including people with a learning disability and autistic people, should be able to live in their own home or in the place that is right for them. This should not be in hospital unless absolutely necessary for clinical reasons. Those that need care should have the right support, when they need it, to enable them to live as independently as possible and be able to fulfil their potential as a valued and equal member of our society.

4. The Building the Right Support national service model (Building the Right Support, national service model, October 2015) sets out the support that people with a learning disability and autistic people should receive if they need it. People with a learning disability and autistic people should have access to integrated, community-based, specialist multidisciplinary health and social care in their community in a way that is right for them as an individual. This will be reinforced in a new, all-age cross-Government autism strategy to improve the support that autistic people get throughout their lives. The strategy is expected to be published by the end of the year.

5. We do expect that there will be times when specialist inpatient care will be beneficial for some people. For example, where a mental health problem which has become serious cannot safely be treated in the community. Where this is the case, we are clear that this should be for as short a time, as close to home and the least restrictive as possible. Admission to hospital must have a clear, therapeutic benefit and should not simply be as a last resort because there is a lack of appropriate community support. There must be a plan for treatment and for discharge so that people do not become stuck there. While people are in hospital, they must receive high-quality care

and treatment that takes into account their individual needs, recognising that for some, an inpatient environment can be especially difficult and may exacerbate their problems.

Respecting and upholding rights

6. We know there are cases where the rights of people with a learning disability and autistic people have not been respected. The Government has been clear that these cases are completely unacceptable, and action is being taken to prevent this happening again.

7. As the Committee highlighted in its November report (Joint Committee on Human Rights, The detention of young people with learning disabilities and/or autism, November 2019), an independent review of the Care Quality Commission's (CQC) regulation of Whorlton Hall has been undertaken by Professor Glynis Murphy as a direct result of the shocking abuse uncovered by a BBC Panorama investigation (Professor Glynis Murphy, CQC inspections and regulation of Whorlton Hall 2015-2019: an independent review, March 2020). Further work to address closed cultures is also underway by the CQC (CQC, Identifying and responding to closed cultures, June 2020). In 2018, the Secretary of State for Health and Social Care commissioned the CQC to take forward a thematic review into restraint, seclusion and segregation. An interim report was published in May 2019 (CQC, Segregation in mental health wards for children and young people and in wards for people with a learning disability or autism, May 2019) and the final report is published this month. In response to recommendations in the interim report, we committed to ensuring each person with a learning disability and autistic person who was an inpatient would have their care reviewed.

8. For those individuals in long-term segregation (as of November 2019), independent case reviews have been undertaken, to ensure the right care is being provided and to support the person towards discharge. A Panel of experts chaired by Baroness Sheila Hollins, has been established to oversee this work. The Panel are examining the findings from these reviews and developing recommendations to the Government, NHS England and NHS Improvement and other health and care organisations. The Panel's recommendations will focus on improving the care of people with a learning disability and autistic people who are in long-term segregation, with the overall aim of supporting them out of segregation towards discharge and sustainable lives in the community.

Responding to the COVID-19 pandemic

9. In June, the Committee set out its concerns in relation to the impact of COVID-19 on the rights of people with learning disabilities and autistic people 'in inpatient settings (Joint Committee on Human Rights, Human Rights and the Government's response to

COVID-19: The detention of young people who are autistic and/or have learning disabilities, June 2020). The pandemic has resulted in unprecedented challenges for the health and social care system as a whole, including the care provided to this group of people.

10. In the months ahead, as we move beyond the immediate response to COVID-19, there will be a renewed focus on implementing Building the Right Support in full and taking forward the actions set out in the NHS Long Term Plan (NHS, The NHS Long Term Plan, January 2019). To date (as at the end of August) we have achieved a 27% net reduction in the number of people with a learning disability and autistic people who are inpatients in specialist settings since March 2015 and over 9,150 discharges to the community since March 2015. Within this there remains significant geographical variation. As of August 2020, 5 of the 44 Transforming Care Partnerships have already achieved the target rate for 2023/24 of 30 adults in a specialist inpatient setting per million adults. A further 13 achieved the March 2020 target of 37 adults per million in an inpatient setting. For children and young people 18 out of 44 Transforming Care Partnerships have already reached the NHS Long Term Plan target inpatient rate for 2023/2024 (12-15 children and young people in an inpatient setting per million children). This demonstrates that it is possible to meet the goals set and we will continue to identify and share best practice from areas making good progress to go further. This will be supplemented by targeted funding to support more rapid discharges. Transforming Care Partnerships across England have received £20m in funding through the Community Discharge Grant for 2020/21, with a further £42m in the following two years 2021/22 – 2022/23.

11. The Department of Health and Social Care (DHSC) is working with other Government departments and key delivery partners to publish a Building the Right Support Action Plan, including the Ministry of Housing Communities and Local Government on housing aspects, and the Department for Education (DfE) to ensure a focus on the care of children and young people. This plan will bring together all relevant actions in one place, set out milestones for delivery and make clear who is responsible for implementing changes. It will recognise the vital role that families play in supporting, advocating and caring for people with a learning disability and autistic people. To ensure this happens, involving families and carers will be a clear part of governance arrangements supporting delivery of the plan.

12. The best way to prevent the serious issues highlighted by the Committee from arising is to prevent admission to hospital in the first place. For many children and young people with a learning disability, or autistic children and young people, their pathway begins much earlier in their lives with challenges in accessing education. This often leads to exclusion, or elective home education, and an inability to access universal, early help and targeted services that are not reasonably adjusted. The new, all-age cross-Government autism strategy, work of the Children and Young People's Steering

Group, the Children and Young People's Transformation Board and the SEND Delivery Group are all seeking to improve the pathways for these children and young people. Ensuring those with the greatest strengths and needs are suitably identified (through dynamic risk stratification processes and at risk of admission registers) is a key part of our ambition and offering additional and enhanced support has been evidenced as preventing admission. The ambitious keyworkers programme - a direct action based on Dame Christine Lenehan's Review recommendation from "These are our children" (Dame Christine Lenehan, These are our children, January 2017) will be piloted during 2020/21 with a phased roll out as part of NHS England's Long Term Plan commitments.

13. The manifesto set out our intention to make changes to the way people with a learning disability and autistic people are treated in law. We will bring forward a White Paper on the Mental Health Act (MHA) 1983 (UK Government, Mental Health Act 1983, May 1983), following the independent review by Sir Simon Wessely (Sir Simon Wessely, Modernising the Mental Health Act, December 2018) , and consult on the proposed changes. A number of the review's recommendations address points the Committee has also made, such as putting Care (Education) and Treatment Reviews (C(E)TRs) on a statutory footing and that health and social care commissioners should have a duty to collaborate to ensure provision of community based support and treatment for people with a learning disability and autistic people to avoid admission into hospital and support a timely discharge back into the community.

14. The Government is determined that these actions and those of our delivery partners will ensure that care and treatment in inpatient settings will only ever happen where absolutely necessary and are of benefit to the person concerned. When it is required, that it will be of the highest standard that we would all expect. We are developing more community support to allow people with a learning disability and autistic people to live full lives with their friends and family. We must learn from the experiences of people with a learning disability and autistic people in inpatient settings, and their families, as brought to life by the Committee and deliver on the commitments we have made. By doing so we can ensure that their rights are protected.

Introduction

15. This is the Government’s formal response to the recommendations made by the Joint Committee on Human Rights in its report 'The detention of young people with learning disabilities and/or autism' published on 1 November 2019 and those made in its report 'Human Rights and the Government’s response to COVID-19: The detention of young people who are autistic and/or have learning disabilities' published on 12 June 2020.

16. The Committee launched its inquiry into the detention of young people with learning disabilities and/or autism in January 2019. This followed testimony given to a prior inquiry into the use of restraint and solitary confinement among children in detention settings and the Committee's conclusion that the detention of young people with learning disabilities, autism or both threatened their rights to private and family life, their right to freedom from inhuman and degrading treatment and their right to liberty and security and in some cases their right to life. The Committee sought to establish if the Government’s existing programmes of work to develop community alternatives to specialist inpatient services and to significantly reduce the number of people with learning disabilities and/or autism who are inpatients had been successful and if not, why not. The Committee examined what they considered needed to be done to ensure that the numbers of people formally detained under the MHA in inpatient settings are reduced more rapidly and whether the human rights of children and young people with learning disabilities, autism or both who are detained in mental health hospitals are being breached.

17. In its report, published in November 2019, the Committee concluded that young people’s human rights were being abused; that they were detained unlawfully contrary to their right to liberty, subjected to solitary confinement, more prone to self-harm and abuse and deprived of their right to respect for private and family life. The report made a number of recommendations which are summarised below:

    - The establishment of a Number 10 unit to urgently drive forward reform, minimise the number of people with learning disabilities and/or autism who are detained and to safeguard their human rights;

    - A review to be carried out by the Number 10 unit of the framework for provision of services for those with learning disabilities with new legal duties introduced for Local Authorities and Clinical Commissioning Groups regarding the care of people with learning disabilities and/or autism;

    - Stronger legal entitlements to support for individuals;

    - Care and Treatment Reviews and Care, Education and Treatment Reviews to be put on a statutory footing;

- Narrowing of the criteria for detention under the MHA to avoid inappropriate detention;

- Families of those with learning disabilities and/or autism to be recognised as human rights defenders, and other then in exceptional circumstances, be fully, involved in all relevant discussions and decisions; and

- Substantive reform of the CQC's approach and processes.

18. In March 2020, the Committee announced that it would undertake an inquiry into the implications for human rights of the Government’s COVID-19 response. The Committee published its second report; 'Human Rights and the Government’s response to COVID-19: The detention of young people who are autistic and/or have learning disabilities' in June 2020.

19. The second report by the Committee concluded that as a result of the COVID-19 pandemic and resulting restrictions on visits, the temporary suspension of routine inspections, the likelihood of the increased use of restraint and solitary confinement and the vulnerability of those in detention to infection with COVID-19 (due to underlying health conditions and the infeasibility of social distancing) may add to, and further compound, the issues the Committee highlighted in its earlier report.

20. The second report, published in June 2020, made eight additional recommendations which are summarised below:

    - NHS England must write immediately to all hospitals, stating that they must allow families to visit their loved ones unless there are clear reasons specific to the individual’s circumstances why it would not be safe to do so;

    - Figures on the use of restrictive practices, including physical and medical restraint and any form of segregation, must be published weekly, provided to the Secretary of State for Health and Social Care and reported to Parliament;

    - The CQC should carry out all their inspections unannounced;

    - The CQC must prioritise in-person inspections at institutions with a history of abuse/malpractice, and those which have been rated inadequate/requires improvement;

    - The CQC should set up a telephone hotline to enable all patients, families, and staff to report concerns or complaints during this period;

    - The CQC must report on reasons for geographical variation in practice with resultant harmful consequences;

- Rapidly progressing the discharge of young people to safe homes in the community must be a top priority for the Government. The recommendations from the Committee's 2019 report must be implemented in full; and

- Comprehensive and accessible data about the number of those who are autistic and/or learning disabled who have contracted and died of COVID-19 must be made available and include a focus on those in detention.

21. Owing to the need to focus attention and resources on responding to the global COVID-19 pandemic this year, we were unable to meet the original deadline to respond to the November report. As such we are providing a combined response to both the November report and the later COVID-19 focussed report.

22. The Government sets out its response to these recommendations in this document, including action already underway to ensure that people with a learning disability and autistic people receive the high-quality care and treatment we expect for everybody. We have largely structured our response according to the chapters in the Committee's own reports. Given the cross-cutting themes and recommendations in both reports, we have brought together a small number of recommendations where it makes sense to do so and where recommendations from the November report were repeated in the June 2020 report, we cross-refer to the appropriate place rather than duplicate our response. We have numbered the recommendations to make this document easier to navigate.

Summary of Committee recommendations

Recommendation number	November 2019 report recommendations
	Transforming Care
1	To urgently minimise the number of those with learning disabilities and/or autism who are detained and to safeguard their rights, a Number 10 unit, with cabinet level leadership, must be established to ensure reform is driven forward.
	Ending harmful detention
2	We therefore recommend that the Number 10 unit we propose, must review the framework for the provision of services for those with learning disabilities and/or autism. At a minimum the Government should introduce: • a legal duty on Local Authorities and Clinical Commissioning Groups to ensure the availability of sufficient community-based services. • a legal duty on Local Authorities and Clinical Commissioning Groups to pool budgets for care services for people with learning disabilities and/or autism.
3	There is a consensus that people with learning disabilities and/or autism need stronger legal rights. We agree. Any legislative proposals put forward by the Equality and Human Rights Commission, as well as those made by the Independent MHA 1983 review and campaign groups, must be acted upon. In addition to strengthening rights it is imperative that more is done to ensure young people with learning disabilities and/or autism are able to enforce existing ones. To this end, we repeat here key recommendations made in our “Enforcing human rights” report: • Public authorities must comply with their duty under s.6 of the Human Rights Act in order to prevent breaches of individuals’ human rights. • The Government must revise the financial eligibility criteria for legal aid with a view to widening access to those who would otherwise be unable to enforce their human rights. • Families must be given non-means tested funding for legal representation at inquests where the state has separate representation for one or more interested persons.
4	Care and Treatment Reviews and Care, Education and Treatment Reviews, when done well, can provide a crucial opportunity to develop viable alternatives to inpatient care. We recommend that they should be put on a statutory footing to strengthen their ability to perform this role.
	The legal framework for detention
5	We endorse the recommendation of the MHA Review that the criteria for detention under the MHA must be narrowed. Those with

	learning disabilities and/or autism must only be detained under the MHA, in situations where: a) treatment is necessary; b) treatment is not available in the community and only available in detention (i.e. the last and only resort); c) treatment is of benefit to the individual and does not worsen their condition; and d) without the treatment, there is a significant risk of harm to the individual or others.
	Families as human rights defenders
6A	Too often, the concerns raised by the families of those with learning disabilities and/or autism are considered to be hostile. The families are seen as a problem. This is unacceptable. They must be recognised as human rights defenders, and other than in exceptional circumstances, be fully involved in all relevant discussions and decisions. To ensure this we recommend: • Families should, unless there are exceptional circumstances, be given new legal rights to attend Care, Education and Treatment Reviews and Care and Treatment Reviews and any meetings at which decisions are taken about whether to place a young person in detention. They must also receive relevant reports.
6B	• The rights of individuals and their families to advocacy must be enhanced and enforced, including for those who are considered to be informal patients. Advocacy services should be funded entirely separately from care and support services.
6C	• It is wholly unacceptable that injunctions should be sought to prevent families from speaking out when they disagree with the way that their child is being treated. The Ministry of Justice must work with other departments to collect data on the number of injunctions sought by public bodies, including Local Authorities and Clinical Commissioning Groups, against families of those with learning disabilities and/or autism.
6D	• There should be guidance providing that no public authority should apply for an injunction which gags a parent of a child or young person with autism and/ or learning disabilities who is either in or being considered for placement in a mental health hospital unless they have obtained the specific approval for such an application from the Secretary of State for Health and Social Care.
	Conditions in places of detention
7A	The evidence presented in our inquiry reinforces the recommendations and conclusions we made in our report “Youth detention: solitary confinement and restraint.” We highlight two of those recommendations in the context of this inquiry: a) “that the use of separation in hospitals be more rigorously regulated. Each institution in the health sector must report data on

	extension of separations to the responsible Minister on a monthly basis, who will certify the information and lay it before each House for publication.” In its response to the report the Government accepted that that the regulation of hospitals that use separation could be improved and noted that the CQC’s review into the use of restrictive interventions will be looking further at this area. The Government also drew attention to the fact that that NHS Digital is now reporting data on restrictive interventions on a monthly basis. While we welcome this, we continue to believe that our recommendation should be implemented in full and we urge the CQC to take it up in the final report of its review which is due to be published in spring 2020. b) that while “there may be there may be exceptional circumstances in which prone restraint is preferable to alternatives, it must be more rigorously regulated by governing health bodies and regulators, including by annual publication of statistics for each institution (broken down by patients’ diagnoses, age and justification for not using an alternative method).” In its response to the report the Government highlighted recent improvements that have been made in the area of data collection including requiring that services include in the records they provide the duration of any use of prone restraint. This is a positive step forward and we hope that improved data collection will lead to more rigorous regulation.
7B	We recommend that on every occasion that anyone is restrained or kept in conditions amounting to solitary confinement their families must be automatically informed.
7C	Placing young people a long way from their home reduces their support from their families and undermines their right to family life under Article 8 of the European Convention on Human Rights (ECHR). It must stop. Until it is stopped, families must be given the financial support they need to be able to visit their loved ones.
7D	We note the Government’s proposal to establish an independent body to investigate serious healthcare incidents. We urge the Government to work with the Equality and Human Rights Commission to ensure that it is fulfilling its obligations under Articles 2 and 3 ECHR in relation to independent investigations of deaths of those with learning disabilities and/or autism in detention settings.
	The Care Quality Commission
8	Substantive reform of the CQC’s approach and processes is essential. We hope that the independent review of CQC’s regulation of Whorlton Hall between 2015 and 2019 being undertaken by Professor Glynis Murphy will make recommendations for such reform.
8A	In our view these should include: • Measures to ensure that inspections are more fleet of foot. For example, unannounced inspections should take place at weekends

	and in the late evening.
8B	• The use, where appropriate, of covert surveillance methods to better inform inspection judgements. In cases when tightly knit groups of staff seek to avoid scrutiny, whilst neglecting and abusing the most vulnerable people, inspectors should consider using the methods used successfully by journalists.
8C	• Where concerns are raised by patients and family members about treatment these must be recognised by the CQC as constituting evidence and acted upon.
8D	• Changes, including legislative changes if necessary, to make sure that the CQC is able to act more swiftly where concerns about a service are raised and substantiated.
8E	• A review of the system which currently allows a service to be rated as ‘Good’ overall even when individual aspects, such as safety, may have a lower rating.
	June 2020 report recommendations
	Visits and the right to family life
9	NHS England must write immediately to all hospitals, including private ones in which it commissions placements, stating that they must (whatever nationwide restrictions may be re-imposed in future), allow families to visit their loved ones, unless a risk assessment has been carried out relating to the individual’s circumstances which demonstrates that there are clear reasons specific to the individual’s circumstances why it would not be safe to do so. Where a mental health hospital does identify cogent reasons for prohibiting visits to a particular individual, the reasons for this decision must be provided in writing both to the patient and to their family. Such decisions must be reviewed on a regular basis, at least every 48 hours.
	Use of restraint and solitary confinement
10	Restraint must only ever be used as a last resort where absolutely necessary. Solitary confinement of children, and prolonged solitary confinement of adults, is contrary to the UN Mandela Rules on Prisoners and must be avoided. In order to understand how restrictive practices are currently being used, figures on their use, including physical and medical restraint and any form of segregation, detailing any incidences which go beyond 22 hours per day, must be published weekly by the institutions. These figures must be provided to the Secretary of State for Health and Social Care and reported to Parliament.
(repeats 7B)	On every occasion that anyone is restrained or kept in conditions amounting to solitary confinement their families must be automatically informed.

	Inspections
11A	We are pleased to see the CQC are now switching to unannounced inspections. The CQC should carry out all their inspections unannounced; this is particularly important where any allegation of abuse is reported by a young person, parent, or whistle-blower.
11B	The CQC must prioritise in-person inspections at institutions with a history of abuse/malpractice, and those which have been rated inadequate/requires improvement.
11C	A telephone hotline should be established to enable all patients, families, and staff to report concerns or complaints during this period.
11D	The CQC must report on reasons for geographical variation in practice with resultant harmful consequences.
11E	The CQC must monitor how providers are supporting the right to family life of young people, including by facilitating family visits, and report this as standard within their inspection reports.
11F	Following the exposure of abuse at Whorlton Hall, the CQC's work to incorporate Professor Murphy's recommendations into a new strategy to improve the regulation of mental health, learning disability and/or autism services must continue at a greater pace.
11G	The Government must ensure inspectors have sufficient and appropriate personal protective equipment (PPE) so they can carry out inspections safely.
	Inappropriate detention and failure to discharge
12	Now, more than ever, rapidly progressing the discharge of young people to safe homes in the community must be a top priority for the Government. The recommendations from the Committee's 2019 report must be implemented in full. In particular, legislation must be introduced to ensure the availability of sufficient community-based services. The required amendments to the MHA 1983 to prevent inappropriate detention, must not be delayed.
	Data on COVID-19 infections and deaths
13	It is essential that we have comprehensive and accessible data about the number of those who are autistic and/or learning disabled who have contracted and died of COVID-19. This must include a focus on those in detention, for whom the state has heightened responsibility for their right to life. The data must be presented to show the number of those who have died in acute hospitals, having been transferred from other settings, and be published on a weekly or daily basis and be broken down by age.

1. Transforming Care

Recommendation 1: To urgently minimise the number of those with learning disabilities and/or autism who are detained and to safeguard their rights, a Number 10 unit, with cabinet level leadership, must be established to ensure reform is driven forward.

1.1 We agree with the principle of cabinet level leadership and accountability for an issue of this importance and complexity, however we do not agree that this should be through a separate Number 10 unit.

1.2 As a member of Cabinet, the Secretary of State for Health and Social Care has clear oversight and responsibility for this programme of work. Under his leadership, the DHSC is accountable and responsible for driving forward action and reform in conjunction with delivery partners across the health and social care system. To avoid the risk of diluting responsibility for this programme of work it is important that oversight and ultimate accountability resides in one place. It is entirely appropriate that this continues to be within DHSC. The Secretary of State for Health and Social Care continues to work closely with the Secretary of State for Housing, Communities and Local Government to ensure that Local Authorities provide housing, care and support in the community for people with a learning disability and autistic people, not just for those who have been detained in inpatient settings; and with the Secretary of State for Education to ensure that the right care and support is in place for children and young people.

1.3 The Government is clear that the focus should be on delivery, led by the Secretary of State for Health and Social Care, of those actions which will improve care and support for people with a learning disability and autistic people as a matter of priority. Building the Right Support (Building the Right Support, national plan, October 2015) is our national plan for improving the care and support for people with a learning disability and autistic people. There is consensus among delivery partners and stakeholders that Building the Right Support contains the necessary elements to ensure that there are credible alternatives to inpatient care.

1.4 DHSC remains committed to Building the Right Support and we want to improve all aspects of care and support, not just to focus on reducing inpatient numbers. This means ensuring the right support is developed in the community to reduce the risk of admissions in the first place. To facilitate this, DHSC officials, on behalf of the Secretary of State for Health and Social Care are leading the development of a new Action Plan. The Plan brings together core strands of work planned or currently underway, including actions of other government departments and delivery partners, to deliver the objectives of Building the Right Support in full. This plan, which we intend to publish as soon as possible, will complement the actions in the NHS Long Term Plan.

1.5 Alongside this, to further enhance partnership working between DHSC, other government departments and delivery partners, such as NHS England and NHS Improvement and local government, we will establish a new governance structure to implement the Building the Right Support Action Plan which will draw on the views and lived experiences of people with a learning disability and autistic people and their families. This will ensure there is clear oversight by DHSC Ministers and that all those with actions in the Plan are held to account for progress in improving care for people with a learning disability and autistic people.

1.6 DHSC works closely with the Cabinet Office Disability Unit. The aim of the Disability Unit is to build an evidence base and influence and drive policy across Whitehall for all disabled people. The Disability Unit is developing a National Strategy for Disabled People which aims to develop a positive and clear government vision on disability, make practical changes to policies which strengthen disabled people's ability to participate fully in society and ensure that lived experience underpins policies by identifying what matters most to disabled people. We will ensure that the needs of people with a learning disability and autistic people are considered in developing the strategy.

1.7 Given existing Cabinet level accountability for this work, provided by the Secretary of State for Health and Social Care, close working with the Cabinet Office Disability Unit and work already underway to bring together cross-government and delivery partner actions through the Building the Right Support Action Plan, an additional unit would serve only to complicate and dilute accountability, when the focus must be on taking action.

2. Ending harmful detention

Recommendation 2: We therefore recommend that the Number 10 unit we propose, must review the framework for the provision of services for those with learning disabilities and/or autism. At a minimum the Government should introduce:

- a legal duty on Local Authorities and Clinical Commissioning Groups to ensure the availability of sufficient community-based services.

- a legal duty on Local Authorities and Clinical Commissioning Groups to pool budgets for care services for people with learning disabilities and/or autism.

2.1 We agree that more needs to be done to ensure that the right services are available in the community for people with a learning disability and for autistic people, both to prevent unnecessary admissions and to speed up discharges. The NHS Long Term Plan (NHS, The NHS Long Term Plan, January 2019) commits to an extra £4.5 billion per year for primary care and community health services by 2023/2024. Increased investment in intensive, crisis and forensic community support will also enable more people to receive personalised care in the community, closer to home, and reduce preventable admissions to inpatient services.

2.2 We welcome the Committee's recommendation which is in line with the manifesto commitment to make it easier for people with a learning disability and autistic people to be discharged from hospital and to improve how they are treated in law. We note that there have been related proposals made by other reports and bodies. This includes the Independent MHA Review recommendation that health and social care commissioners should have a duty to collaborate to support a timely discharge back into the community. We will respond to that proposal in the MHA White Paper. We also acknowledge continued calls by campaign groups for enhanced legal rights to strengthen peoples' rights to independent living, with community alternatives to hospital care.

2.3 We therefore plan to consult through the MHA White Paper on new duties to make sure Local Authority and Clinical Commissioning Group (CCG) commissioners ensure an adequate supply of community services for people with a learning disability and autistic people. The consultation will help us understand how to achieve the effect we want and any wider implications. Further work to determine the exact nature of the duty would be informed by the consultation response. Any new duty would need to operate effectively alongside existing legal requirements. While there are existing duties on Local Authorities and CCGs to commission effective services, such as in the Care Act 2014 (UK Government, Care Act 2014, May 2014), the NHS Act 2006 (UK Government, National Health Service Act 2006, November 2006) and the Children and Families Act 2014 (UK Government, Children and Families Act 2014, March 2014), which contains joint commissioning arrangements for children and young people who have special educational needs and those who have a disability, they do not expressly mention the needs of people with a learning disability and autistic people. For these reasons we believe that it is right to consult formally on introducing a new duty with a clear focus on commissioning services for people with a learning disability and autistic people.

2.4 Any duty that requires an adequate supply of services to be commissioned for people with a learning disability and autistic people could create new funding requirements if there is not already a sufficient supply in place. We will undertake a formal new burdens assessment to establish implications for local government, informed by the consultation responses.

2.5 To give this duty additional impact, we plan to consult on creating a related duty that would ensure every local area understands and monitors the risk of crisis at an individual-level for people with a learning disability and autistic people in the local population. The aim would be to enable better planning for provision and to avoid unnecessary admissions to inpatient settings. This could involve Local Authorities and NHS commissioners working together to identify and monitor the support needs of individuals by way of a ‘risk’ or ‘support’ register often described as a Dynamic Risk Stratification and Support register, including an 'at risk of admission' component. Such a register would have to comply with data protection obligations. The establishment of such registers is existing NHS England policy and is contained in guidance but not in legislation. As such there is no formal requirement on local government to participate. By having this in addition to the duty described above, we consider that this would increase the likelihood of effective, joint action being taken locally and requiring commissioners to focus attention on people with a learning disability and autistic people in their population.

2.6 Section 75 of the NHS Act 2006 is the existing mechanism and enabling tool for amongst other matters, pooling budgets. It enables an NHS body and a local authority to enter into a partnership arrangement for the purposes of jointly exercising the functions of the NHS body or the health-related functions of the local authority if the arrangements lead to an improvement in the way in which those functions are exercised. However, we agree that there may be more that can be done specifically in relation to pooling budgets for services for people with a learning disability and autistic people and will consider this as part of the consultation. The consultation will provide an opportunity to explore the challenges around their use and reporting spend on services for people with a learning disability and autistic people.

2.7 While the consultation process is underway, we will develop and issue guidance to remind commissioning bodies of the importance of working together and making sure the right services are in place for this group for people with a learning disability and autistic people. This guidance will also encourage them to report spend more transparently, ahead of any changes to legislation. We will develop this guidance ready to inform the next financial year.

Recommendation 3: There is a consensus that people with learning disabilities and/or autism need stronger legal rights. We agree. Any legislative proposals put forward by the Equality and Human Rights Commission, as well as those made by the Independent MHA 1983 review and campaign groups, must be acted upon.

In addition to strengthening rights it is imperative that more is done to ensure young people with learning disabilities and/or autism are able to enforce existing ones. To this end, we repeat here key recommendations made in our “Enforcing human rights” report:

- Public authorities must comply with their duty under s.6 of the Human Rights Act in order to prevent breaches of individuals’ human rights.

- The Government must revise the financial eligibility criteria for legal aid with a view to widening access to those who would otherwise be unable to enforce their human rights.

- Families must be given non-means tested funding for legal representation at inquests where the state has separate representation for one or more interested persons.

2.8 In response to the previous recommendation, we have set out our intention to consult on changes to legislation that would require collaboration to ensure adequate provision of community services. This would further support people with a learning disability and autistic people to live independently with the right support, in their community, as called for and recommended by other reports and organisations, including those highlighted by the Committee.

2.9 The Government entirely agrees that public authorities must comply with their duty under s.6 of the Human Rights Act to comply with the ECHR, except as the result of one or more provisions of primary legislation, the authority could not have acted differently, or in instances where provisions of primary legislation mean that the authority could not have acted differently and where it was acting to enforce those provisions. CQC is committed to working closely with people who use services, families and professionals to improve its approach in a way which more effectively safeguards their human rights and has released new guidance for inspectors on closed cultures.

2.10 In February 2019, the Ministry of Justice (MoJ) published its Review of Legal Aid for Inquests (Ministry of Justice, Review of Legal Aid for Inquests, February 2019). This concluded that it would not introduce non-means tested legal aid for bereaved families to attend inquest hearings. The evidence gathered as part of this review on financial eligibility will be considered as part of their wider Means Test Review, looking at the thresholds and criteria for legal aid entitlement. It was initially intended that this review would conclude this summer. There will however be some delay to this publication date, due to the COVID-19 outbreak. The intention is that this review will now conclude in spring 2021. MoJ will then publish a full consultation paper setting out future policy proposals in this area. They will seek to implement any final recommendations as soon as practicable.

Recommendation 4: Care and Treatment Reviews and Care, Education and Treatment Reviews, when done well, can provide a crucial opportunity to develop viable alternatives to inpatient care. We Recommend that they should be put on a statutory footing to strengthen their ability to perform this role.

2.11 We recognise and agree with the importance of C(E)TRs. Placing C(E)TRs on a statutory footing could require Responsible Clinicians to take into account the findings and recommendations made as part of C(E)TRs in the patient’s statutory Care and Treatment Plan and explain why any C(E)TR recommendations may not have been followed. We are considering this recommendation and will publish further detail in the White Paper on MHA Reform in due course.

2.12 C(E)TR policy already makes clear that all patients in an inpatient care setting will have their care reviewed at least every twelve months and for children and young people under 18 these should take place every three months. Completing C(E)TRs should not be a tick box exercise. C(E)TRs should place the individual and their needs at the heart, with a clear commitment to actions being taken forward.

2.13 Assuring Transformation data shows consistently that community C(E)TRs have a big impact on keeping people out of hospital. NHS England and NHS Improvement regional data collection data at the end of July 2020 showed that, of the community C(E)TRs undertaken since April 2019, 82% led to a decision not to admit the person into inpatient care.

2.14 C(E)TRs also help to improve the quality of care people receive in hospital by asking important questions and making recommendations that lead to improvements in safety, care and treatment. They are designed to be person and family centred and to challenge the reasons for a person being in an inpatient setting. They reduce the amount of time people spend in hospital and bring people together to try to resolve any problems that may keep people in hospital longer than necessary. They do this by helping to improve current and future care planning, including plans for leaving hospital.

3. The legal framework for detention

Recommendation 5: We endorse the Recommendation of the MHA Review that the criteria for detention under the MHA must be narrowed.

Those with learning disabilities and/or autism must only be detained under the MHA, in situations where:

a) treatment is necessary;

b) treatment is not available in the community and only available in detention (i.e. the last and only resort);

c) treatment is of benefit to the individual and does not worsen their condition; and

d) without the treatment, there is a significant risk of harm to the individual or others.

3.1 We are committed to responding to the Independent Review of the MHA and plan to publish a White Paper in due course. This will pave the way for reform to the MHA and tackling the issues raised by the Review. It will set out our plans to improve the Act so that patients have a better experience and get better outcomes. For example, by enabling patients to set out their preferences around care and treatment in advance, and measures to make sure that patients are not detained for longer than is absolutely necessary.

3.2 The Government is grateful to the Committee for its endorsement of the Independent Review's recommendations about how to reform the criteria under which decisions about patient detentions are made, and for its recommendation on how these should be considered with particular regard to people with a learning disability and to autistic people.

3.3 We are committed to taking steps to address the inappropriate use of detention of people with a learning disability, or autistic people, recognising that the mental health inpatient environment can fail to meet the specific needs of this group. In its manifesto, the Government committed to making it easier for people with a learning disability, or autistic people, to be discharged from hospital and improving the way that people with learning disability and autism are treated in law.

3.4 We also want to reduce the need for admission and detention under the Act by seeing that people get the care and treatment they need at an earlier stage in their local community. Through investing an additional £2.3 billion a year by 2023/24, we will work to transform the nation's mental health services.

4. Families as human rights defenders

Too often, the concerns raised by the families of those with learning disabilities and/or autism are considered to be hostile. The families are seen as a problem. This is unacceptable. They must be recognised as human rights defenders, and other than in exceptional circumstances, be fully involved in all relevant discussions and decisions. To ensure this we recommend:

Recommendation 6A: Families should, unless there are exceptional circumstances, be given new legal rights to attend Care, Education and Treatment Reviews and Care and Treatment Reviews and any meetings at which decisions are taken about whether to place a young person in detention. They must also Receive relevant reports.

4.1 We absolutely agree that families have a critical role to play in C(E)TRs. However, there are existing legal rights attributed to those with parental responsibility for children and young people and we do not propose to introduce new rights in relation to C(E)TRs. Existing rights include those set out in the Children Act 1989 (UK Government, Children Act 1989, November 1989). The MHA Code of Practice (para 19.38) (Department of Health, Mental Health Act 1983: Code of Practice, October 2017), clearly sets out best practice when it comes to the involvement of parents, and states that those with parental responsibility should be consulted about proposed decisions concerning their child, subject to the child or young person's right to confidentiality.

4.2 The Mental Capacity Act 2005 (UK Government, Mental Capacity Act 2005, April 2005) applies to young people (those aged between 16 and 18), and under section 4(7)(b) it states that decision makers must, where practicable and appropriate, seek the views of people like parents who are engaged in caring for the child or young person.

4.3 C(E)TR policy is very clear about the expectation of family engagement and participation in reviews. It is a key tenet of the C(E)TRs that they are person and family centred. The NHS England Care and Treatment Reviews Policy and Guidance (NHS England, Care and Treatment Reviews Policy and Guidance, March 2017) states that: "Parent carers (or those with parental responsibility) for children and young people should always be part of the review (unless there are exceptional circumstances or significant safeguarding reasons to prevent this, in which case this should be clearly noted)." There may be rare occasions where it is not appropriate (either because of the safety of the child or young person or by choice made by those with capacity) for families to attend, and it is necessary to allow some flexibility to enable this. These exceptions aside, there are mechanisms within the C(E)TR process to check and challenge where family are not involved. The record of each C(E)TR lists who is present at each meeting and we would expect others involved in the process, such as the independent expert by experience, to challenge why family are not involved should that be the case.

4.4 Given existing mechanisms for family involvement we do not, at this point, intend to introduce a new law. However, there is work underway to review and improve the C(E)TR process through a policy review already in process. In addition, Ministers are committed to taking action on the findings from the independent case review work led by Baroness Hollins. We await the recommendations from this work and will take action as required. The NHS England C(E)TR policy review will also consider any recommendations or findings from Baroness Hollins' review.

Recommendation 6B: The rights of individuals and their families to advocacy must be enhanced and enforced, including for those who are considered to be informal patients. Advocacy services should be funded entirely separately from care and support services.

4.5 The MHA review made a series of recommendations regarding Independent Mental Health Advocates (IMHAs), to which we will formally respond in the White Paper. IMHAs are commissioned by Local Authorities, to ensure independence from the detaining authority, any changes therefore represent a new burden for Local Authorities. We are working with advocacy providers, and with the LGA and ADASS to understand the cost implications and implementation challenges.

4.6 In terms of improving the quality of advocacy services, we have committed to launch a pilot programme, in partnership with Local Authorities and others, to identify how to respond appropriately to the particular needs of individuals from ethnic minority backgrounds. This will provide evidence on how we can tailor advocacy support to specific groups. Additionally, we will work with NHS England to undertake a review of current advocacy provision for people with a learning disability and autistic people to identify areas for improvement.

Recommendation 6C: It is wholly unacceptable that injunctions should be sought to prevent families from speaking out when they disagree with the way that their child is being treated. The Ministry of Justice must work with other departments to collect data on the number of injunctions sought by public bodies, including Local Authorities and Clinical Commissioning Groups, against families of those with learning disabilities and/or autism.

Recommendation 6D: There should be guidance providing that no public authority should apply for an injunction which gags a parent of a child or young person with autism and/ or learning disabilities who is either in or being considered for placement in a mental health hospital unless they have obtained the specific approval for such an application from the Secretary of State for Health and Social Care.

4.7 We agree that injunctions should not be used to prevent family members from speaking out about poor care and will take action to reinforce this message. The then Minister of State for Care, Caroline Dinenage MP set this position out during an oral evidence session (3 April 2019) and it was noted by the Committee in their November report. It is also not the policy of NHS England and NHS Improvement use an injunction in this way. NHS England and NHS Improvement has previously reported, as confirmed to the Committee as part of their inquiry, that they had not sought any injunctions and had not been notified of any taken out by local NHS organisations, although there is no requirement for this to be reported.

4.8 To emphasise that injunctions of this kind are not appropriate, DHSC will issue guidance on their use and require health and care bodies to inform the Secretary of State that they have applied for an injunction and the outcome of such an application. Existing legislative powers will be used to require this information to be provided. As this will be a new requirement for Local Authorities, a new burdens assessment will be undertaken ahead of implementation.

4.9 By requiring health and care bodies to notify the Secretary of State, it will also be possible for DHSC to gather data on the number of injunctions sought, as recommended by the Committee. The MoJ does hold a database on all injunctions, however given the specific nature of the injunctions referred to by Committee, it is not possible to reliably identify them through this mechanism.

4.10 The guidance will set out expectations on appropriate behaviours of health and care bodies, as well as a requirement to notify Secretary of State. It will make clear the limited circumstances in which it may be appropriate to use injunctions, such as to prevent unlawful sharing of information which would identify an individual and set out alternative approaches to mitigate their use. For example, the guidance will emphasise that a constructive dialogue with parents is vital, as they are often the people who know their family member best. The guidance will also make it clear that parents should play a central role in helping to shape what is needed and what the appropriate care and support would be.

4.11 We note that there is nothing in law which prevents authorities from applying for injunctions, and it is for the courts to determine whether it is appropriate to grant them based on the circumstances of the case. There are circumstances where courts may have a role in determining a dispute about whether family can disclose confidential patient information. For example, where the parents of a competent child or young person with the relevant capacity want to share details of the child's treatment or other personal information without their consent. While the child could potentially take action to prevent disclosure, either by themselves or through an authorised third party, they may not want to bring a claim against their family (and it will often not be in their interests to do so). In these circumstances it may be appropriate and in the best interests of the child for the Local Authority to bring an injunction application to seek the court's view on whether the child's right to privacy needs to be protected.

4.12 In order to make it a binding requirement for health and care bodies to seek approval of the Secretary of State before seeking an injunction, primary legislation would be required. Given the low number of injunctions we understand are being sought, it is not considered to be proportionate to make such a change at this time. We are also concerned that injunctions are usually sought in very urgent circumstances and therefore requiring approval from the Secretary of State may not be practically possible or that delays, however small, may have significant consequences. We will keep this position under review and take further action should it be deemed necessary.

5. Conditions in places of detention

Recommendation 7A: That the use of separation in hospitals be more rigorously regulated. Each institution in the health sector must report data on extension of separations to the responsible Minister on a monthly basis, who will certify the information and lay it before each House for publication.

In its response to the Committee's report, 'Youth detention: Solitary confinement and restraint' (Joint Committee on Human Rights government response, Youth detention: solitary confinement and restraint: Government Response to the Committee's Nineteenth Report of Session 2017-19, July 2019), the Government accepted that the regulation of hospitals use of separation could be improved and noted that the CQC's review into the use of restrictive practices will be looking further at this area. The Government also drew attention to the fact NHS Digital is now reporting data on restrictive interventions on a monthly basis. While we welcome this, we continue to believe that our recommendation should be implemented in full and we urge the CQC to take it up in the final report of its review which is due to be published in Spring 2020.

Recommendation 10 (from June 2020 report): In order to understand how restrictive practices are currently being used, figures on their use, including physical and medical restraint and any form of segregation, detailing any incidences which go beyond 22 hours per day, must be published weekly by the institutions. These figures must be provided to the Secretary of State for Health and Social Care and reported to Parliament.

5.1 We agree that we must have a clear understanding as to how restrictive practices are used and that there must be transparent reporting about their use. This is vital in improving practice and minimising all types of force used on patients so that it is genuinely only ever used as a last resort. This is a central aim of the Mental Health Units (Use of Force) Act 2018 (UK Government, Mental Health Units (Use of Force) Act, November 2018). The purpose of the Act is to increase the transparency and accountability of mental health services' use of force. As well as setting out the requirements for recording and reporting the use of force (s.6) it makes clear that staff should be trained in the appropriate use (s.5) and that the Secretary of State must ensure that at the end of each year statistics are published regarding the use of force by staff who work in mental health units (s.7(1)).

5.2 NHS England and NHS Improvement already requires providers of NHS funded care for both children and young people and adults with a learning disability and autistic people to report the use of restrictive practices via the Mental Health Services Data Set (MHSDS) published by NHS Digital (NHS Digital, Mental Health

Services Data Set). This is a national reporting requirement which has continued during the COVID-19 pandemic. This report moved from an annual report to a monthly report starting from April 2020.

5.3 NHS England and NHS Improvement are committed to undertaking a regular analysis of the monthly data collection on restrictive practices within the mandated MHSDS. They recognise that there is room for improvement in the quality and content of submissions and are working with providers, the CQC and NHS Digital to highlight the need for accurate, and timely submissions from all providers on the use of all restrictive practices in line with the national definitions and guidance.

5.4 There are significant additional resourcing, contractual and system impacts that need to be addressed in order to collect and publish reliable data weekly. Whilst NHS England and NHS Improvement continue to make improvements in the quality of existing monthly data collections and accuracy of the reporting of the use of long-term segregation, they will also explore the logistics, feasibility and contractual changes needed to implement weekly reporting by providers of the most restrictive practices (seclusion and segregation).

5.5 The Mental Health Units (Use of Force) Act statutory guidance, which is currently under development, will require mental health units to report this information on a monthly basis in line with current NHS England and NHS Improvement requirements. If NHS England and NHS Improvement make any further changes to implement weekly reporting, we will update the statutory guidance to ensure a consistent approach. The JCHR's recommendation is also being fully considered as part of the CQC's final report on Restraint, Seclusion and Segregation. The report is due to be published in the autumn of 2020.

Recommendation 7B: We Recommend that on every occasion that anyone is restrained or kept in conditions amounting to solitary confinement their families must be automatically informed.

5.6 We agree that the family, those with parental responsibility and the responsible authority in the case of Looked After Children should be informed when restrictive practices are used, subject to any consent required from the child or young person. We are also clear that, where use of restraint is necessary to safeguard children, young people and others from harm, it should be consistent with clear values and sound ethical principles, comply with the relevant legal requirements and case law and be consistent with obligations under the European Convention on Human Rights, the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities.

5.7 As the JCHR notes, the Mental Health Units (Use of Force Act) (s.5) requires there to be a record as to whether the 'notification regarding the use of force was sent to the person or persons (if any) to be notified under the patient's care plan.' In order to take further action and in line with the Committee's recommendation, as we develop the statutory guidance to support implementation of the Mental Health Units (Use of Force) Act, we will consult on including as best practice that families, carers or advocates are notified after every use of a restrictive intervention.

5.8 Chapter 34 of the MHA 1983 Code of Practice (MHA Code of Practice) sets out the Care Programme Approach (CPA). The CPA is an overarching system for co-ordinating the care of people with mental disorders. As part of the CPA all patients should have an individualised care plan or positive behavioural support plan which details care and treatment. Chapter 26 'Safe and therapeutic responses to disturbed behaviour' sets out clear guidance (at paragraph 26.16) on how patients and their families should be as fully involved as possible in developing and reviewing positive behaviour support plans (or equivalents). These plans provide the opportunity to record the wishes and preferences of families and carers and how they might want to be involved in or informed about the use of restrictive interventions. At both 26.68 and 26.117 the MHA Code of Practice makes it clear that following the use of a restrictive intervention (restraint, seclusion or segregation) family members should be informed in accordance with any prior agreements set out in the plan.

5.9 Adherence to the MHA Code of Practice will help to identify a 'good' rating in the care and treatment of people subject to the Act. A failure to apply the Act and its Code by providers may show a breach of one of the requirements of the Health and Social Care Act 2008 (UK Government, Health and Social Care Act, July 2008), (Regulated Activities) Regulations 2014 (UK Government, Health and Social Care Act 2008 (Regulated Activities) Regulation, November 2014), or the CQC (Registration) Regulations (2009) (CQC, Care Quality Commission (Registration) Regulations, November 2009). The CQC is working with DHSC to develop the statutory guidance to support implementation of the Mental Health Units (Use of Force) Act guidance and are considering how to incorporate the Act's requirements within its regulatory approach.

5.10 In addition, NHS England and NHS Improvement's Quality Taskforce is currently developing a new national policy about the use of segregation and seclusion in Children and Young People specialist hospitals. This will include a requirement to inform the family or the person with parental responsibility (this will be the local authority if a child is Looked After) every time an episode of segregation or seclusion is used. This will depend on the young person's consent where that is appropriate. The inclusion of this requirement will support the communication and involvement of families in decision making.

Recommendation 7C: Young people must not be placed long distances from home as it undermines their right to family life under Article 8 ECHR. Financial support must be made available to ensure that families are able to visit their loved ones.

5.11 We agree with the Committee that maintaining family contact is critically important and we accept this recommendation in principle. We are very clear that people with a learning disability or autistic people who have complex needs should have expert, person-centred care and that every effort should be made to ensure that where children and young people need to be admitted to inpatient care it is as close to home as possible and for the shortest possible time.

5.12 The NHS Long Term Plan commits to significant investment in community services and to ensuring that every local area will have a seven-day specialist multidisciplinary service and crisis care by 2023/24. This will enable more people to receive personalised care in the community, closer to home, and will reduce preventable admissions to specialist inpatient settings. Local areas are currently developing plans to set out how they will deliver the aims set out in the NHS Long Term Plan, including in relation to reducing reliance on specialist inpatient services. Ensuring adequate access to appropriate accommodation in the community will be an important part of this.

5.13 Paragraph 19.123 of the MHA Code of Practice makes clear that 'Local Authorities are under a duty in the Children Act 1989 to: promote contact between children and young people who are children in need, or looked after children, and their families, if they live away from home, and to help them get back together (paragraphs 10 and 15 of Schedule 2 to the Children Act 1989), and arrange for people (independent visitors) to visit, advise and befriend children and young people looked after by the authority wherever they are, if they have not been regularly visited by their parents (paragraph 17 of Schedule 2 to the Children Act 1989).' NHS England also worked with DfE to develop guidance on 'Statutory visits to children with special educational needs and disabilities or health conditions in long term residential settings' which includes guidance on children in mental health inpatient settings (Department for Education and Department of Health, Statutory visits to children with special educational needs and disabilities or health conditions in long-term residential settings, November 2017). In addition, in 2016 NHS England funded the development of the document 'Keeping in Touch with home - how to help children and young people with learning disabilities and their families keep in touch when they are living away from home' (The Challenging Behaviour Foundation and Mencap, July 2016).

5.14 As with other NHS specialist services, there is no national scheme providing funding for family visits. For young people detained as part of the MHA, the MHA

Code of Practice (19.122) states that 'Local authorities should consider whether it would be appropriate to provide financial support to enable families to visit children and young people placed in hospital, taking into account their duties to promote contact between children and young people and their families. Such duties arise when children and young people are being looked after by local authorities as well as when they are accommodated in hospital for three months or more.' It notes that for families on low incomes, covering travel costs of visiting may be essential, especially if their child is placed out of area. Given the nature of specialist care, which may not always be available close to home, it is therefore a local decision for commissioners to agree with families/carers any financial support that should be made available in line with the MHA Code of Practice. However, we agree with the Committee on the importance of families being able to visit their children and when revising the Code of Practice, we will seek to improve and strengthen guidance in regard to supporting families to maintain contact.

5.15 In addition, this is something that the NHS England and NHS Improvement Quality Taskforce will consider as part of the workstream led by the Parents Council into the impact of children and young people being placed out of area or a long way from home. The aim of the taskforce, announced in October 2019, is to improve current specialist children and young people's inpatient mental health, autism and learning disability services in England. Anne Longfield OBE, Children's Commissioner for England, is chairing an independent oversight board to scrutinise and support the work of the taskforce.

5.16 The Children's Commissioner and the Oversight Board of the Quality Taskforce has been given wide-ranging scope to track progress on rapid improvements in existing services, examine the best approach to complex issues such as inappropriate care, out of area placements, length of stays and oversee the development of genuine alternatives to care, closer to home.

5.17 The establishment of the Quality Taskforce and the independent Oversight Board, is in addition to the package of measures in the NHS Long Term Plan to ensure that all NHS services operate at safe and effective levels, as well as immediately injecting a boost in care quality.

Recommendation 7D: We note the Government's proposal to establish an independent body to investigate serious healthcare incidents. We urge the Government to work with the Equality and Human Rights Commission to ensure that it is fulfilling its obligations under Articles 2 and 3 ECHR in relation to independent investigations of deaths of those with learning disabilities and/or autism in detention settings.

5.18 Patients in mental health, learning disability and autism services have a right to expect the highest quality and safe care which will have a positive impact on their lives and help support their recovery. This government and the NHS are clear that patient safety remains a top priority.

5.19 The Government is fully committed to its obligations under Articles 2 (the right to life) and 3 (the prohibition of torture, inhuman or degrading treatment) of the European Convention on Human Rights (European Convention on Human Rights, Articles 2, November 2018). It is right that, as the EHRC set out, the health and social care system must identify, investigate and learn from preventable deaths and incidents which seriously impact on patient safety. We must learn from each of these, to ensure that people with a learning disability and autistic people receive the same high standard of care we would expect for everyone in our society. To improve learning across the NHS we published the National Guidance on Learning from Deaths in 2017 (NHS, National Guidance on Learning from Deaths, March 2017). The response to the recommendations which follow, sets out the actions that the CQC are taking to better identify these cases, so that we can take the necessary steps across the health and social care system to avoid them being repeated.

5.20 The Healthcare Safety Investigations Branch (HSIB) was set up in 2016 as an operational arm of NHS Improvement under Secretary of State Directions. It carries out a small number of national investigations (up to 30 a year) focusing on the problems with systems and processes in the NHS rather than determining individual fault or blame. HSIB carried out one investigation as a result of a death of an autistic person: 'Undiagnosed cardiomyopathy in a young person with autism' (HSIB, Undiagnosed cardiomyopathy in a young person with autism, June 2020). HSIB have made eight safety recommendations as a result of this investigation.

5.21 The Health Service Safety Investigations Bill was introduced in the House of Lords in the previous Parliament in October 2019 to improve patient safety and create a learning culture across the NHS. We will bring forward those proposals when Parliamentary time allows. The legislation will establish an independent body with legal powers to investigate patient safety concerns and share recommendations to prevent similar incidents recurring. The new independent body will continue the work of HSIB to conduct high-level investigations into patient safety incidents in the NHS and for the NHS to learn from these incidents.

5.22 The Government continues to support proposals to introduce a statutory medical examiners system to provide additional scrutiny of the medical circumstances, and cause, of deaths. This will improve the quality of death certification and avoid unnecessary distress for the bereaved. There are also a number of processes already in place to ensure that issues of patient safety or deaths of patients in inpatient settings are properly investigated. This may include a Serious Incident Review or where a safeguarding referral is made. The Local Authority via the Local Safeguarding Partnership or Local Safeguarding Adult Board has a statutory duty to investigate certain types of safeguarding incidents/concerns.

5.23 A review may also take place under the Learning Disabilities Mortality Review (LeDeR) programme if the person has a learning disability. This requires a review of every death of a person with a learning disability aged 4 years and over, regardless of the cause of death or the place of death. The purpose of reviewing deaths is to identify if there are any potentially avoidable contributory factors associated with the deaths of people with a learning disability. Reviewers do not review the deaths of people with a learning disability that they themselves have supported. This is so that they do not make any assumptions about the care provided and can be objective in assessing the circumstances leading to their death.

5.24 Under CQC (Registration) Regulations 2009 mental health providers are required to report any death of a patient detained under the MHA (1983) to the Care Quality Commission without delay. Under the Coroners and Justice Act 2009 (UK Government, Coroners and Justice Act 2009, November 2009), coroners must conduct an inquest into a death that has taken place in state detention, and this includes deaths of people subject to the MHA (1983). Providers are also required to ensure that there is an appropriate investigation into the death of a patient in state detention under the Act.

5.25 In circumstances where there is reason to believe the death may have been due, or in part due to, to problems in care - including suspected self-inflicted death - then the death must be reported to the provider’s commissioner(s) as a serious incident and investigated appropriately. Consideration should also be given to commissioning an independent investigation as detailed in the NHS Serious Incident Framework (NHS, Serious Incident Framework, March 2015). The Framework sets out the considerations for mental health providers to meet their duties under Article 2 of the European Convention of Human Rights. Mental health providers should consider whether investigations of deaths are compliant with Article 2 where there is an unexpected death of a person detained under the MHA 1983. Normally, the coroner’s inquest will ensure Article 2 compliance either on its own or alongside an investigation commissioned by the mental health provider. The Department of Health and Social Care published Article 2 of the European Convention on Human Rights and the investigation of serious incidents in mental health services (Department of Health, Serious Incidents Article 2 of the European Convention on Human Rights and the investigation of serious incidents in mental health services, November 2015) guidance to the NHS on these matters.

6. The Care Quality Commission

Recommendation 8: Substantive reform of its [CQC's] approach and processes are essential. We hope that the independent review of CQC's regulation of Whorlton Hall between 2015 and 2019 being undertaken by Professor Glynis Murphy will make recommendations for such reform.

6.1 The Glynis Murphy independent review was published in March 2020 and the CQC has accepted in full all the recommendations in the review. Phase Two of the review will be presented next year.

6.2 The CQC is committed to working closely with people who use services, families and professionals to improve its approach in a way which more effectively safeguards their human rights. This includes bringing forward inspections and the development of guidance for inspectors on closed cultures including how to focus inspection on the experiences of people using the service and their families, particularly in relation to upholding human rights and protection from abuse.

6.3 In June 2020, following on from publication of supporting information for inspectors in November 2019, the CQC released new guidance for inspectors on closed cultures. A closed culture is poor culture in a health or care service that increases the risk of harm. This can include abuse and human rights breaches. This guidance which was developed in conjunction with people who use services, Experts by Experience, families, Local Healthwatch and stakeholders, will enable the CQC to better identify and respond to services that might be at risk of developing closed cultures. The CQC has a programme of work on Closed Cultures.

6.4 The CQC is already working towards many of the Committee's recommendations as part of a programme of work and accepts all of the recommendations made to it in principle, although further consideration is needed of future use of covert surveillance. More detail for each of the recommendations is set out below.

Recommendation 8A: Measures to ensure that inspections are more fleet of foot. For example, unannounced inspections should take place at weekends and in the late evening.

Recommendation 11A (from June 2020 report): We are pleased to see the CQC are now switching to unannounced inspections. The CQC should carry out all their inspections unannounced; this is particularly important where any allegation of abuse is reported by a young person, parent, or whistle-blower.

6.5 The JCHR acknowledged in its June 2020 report that:

> "We are pleased to see the CQC are now switching to unannounced inspections. [Rec 11a:] The CQC should carry out all their inspections unannounced; this is particularly important where any allegation of abuse is reported by a young person, parent, or whistle-blower".

6.6 In the past year, the CQC has increased the amount of shorter, unannounced inspections, which take place at weekends. The CQC recognises that this approach can help to uncover human rights breaches in certain circumstances, for example when there are concerns about the culture on night shifts. On occasion, the CQC have used out of hours inspection visits to uncover regulatory and human rights breaches and has taken action as a result.

6.7 The percentage of unannounced inspections in hospitals with wards for people with a learning disability or autism has increased from 62% between April to June 2019 to 77% between January and March 2020.

6.8 The CQC's programme of MHA Visits are almost entirely unannounced visits to wards. The CQC complete around 1200 visits per year across registered services. They may be carried out during weekends or evenings although this is not a regular approach due to the reduced access to patients and clinical staff out of normal hours.

6.9 The new guidance to inspectors on closed cultures states that inspectors should look at all the evidence to assess the truth of people's experience in using the service by always carrying out unannounced inspections; always using an Expert by Experience; and carrying out evening and weekend inspections.

6.10 In addition, all inspectors and regulatory colleagues will be required to undertake a series of training sessions throughout summer 2020 on the guidance and closed cultures more broadly. As of the 10th July 2020, 1,395 colleagues have completed this training. All operational staff will have completed this training by the end of August 2020. Follow up sessions for staff will take place throughout the year.

Recommendation 8B: The use, where appropriate, of covert surveillance methods to better inform inspection judgements. In cases when tightly knit groups of staff seek to avoid scrutiny, whilst neglecting and abusing the most vulnerable people, inspectors should consider using the methods used successfully by journalists.

6.11 The CQC will be reviewing its use of all forms of surveillance as part of its closed cultures work, scoping work is underway and stakeholder input will be sought towards the end of the year.

6.12 The Health and Social Care Act 2008 provides the CQC with extensive powers to gather evidence overtly. Covert surveillance activities may only be undertaken by the CQC where this is authorised in accordance with the Regulation of Investigatory Powers Act 2000 (RIPA) and the associated Codes of Practice.

6.13 The CQC has limited covert surveillance powers under RIPA to authorise the use of Directed Surveillance and Covert Human Intelligence Source. The CQC does not have the power to undertake Intrusive (covert) surveillance under RIPA, for example, covert surveillance in private and residential areas such as bedrooms and bathrooms.

6.14 RIPA provides a legislative framework which ensures that any covert surveillance carried out under it must be necessary, proportionate and compatible with human rights. Failure to act in accordance with RIPA may result in a breach of section 6 of the Human Rights Act 1998 and/or the exclusion of evidence from consequent civil and/or criminal proceedings.

6.15 The CQC has taken a decision not to use its covert surveillance powers under RIPA at present. However, the CQC is keeping its position under review and it has started to explore the potential use of covert surveillance to contribute to the evidence it can gather about quality of care and welfare of those who use the services regulated by it. Phase Two of the Glynis Murphy review due to be presented next year is looking at the use of surveillance in care settings. The use of surveillance is also one of the six workstreams in the Closed Cultures Project which is exploring the ways the CQC can use a range of approaches to improve the prevention and detection of abuse.

6.16 The CQC has developed the necessary arrangements, including processes, policies and templates, to support lawful authorisation of covert surveillance powers in compliance with RIPA in the event of a decision by the CQC to exercise its covert surveillance powers.

6.17 The Investigatory Powers Commissioner’s Office (IPCO) is the regulator for the use of covert surveillance and adherence to RIPA. A recent IPCO inspection of CQC findings was positive and praised the CQC for the progress it has made in the development of its operational readiness.

6.18 Journalists and TV companies are not public authorities, so they are not subject to RIPA (though they may be liable under other legislation, for example, for breaching a person’s human rights or data protection rights). The CQC cannot undertake covert surveillance in the same manner as TV companies for this reason. Therefore, the CQC would not be able to accumulate evidence in the way a journalist working undercover is able to.

Recommendation 8C: Where concerns are raised by patients and family members about treatment these must be recognised by the CQC as constituting evidence and acted upon.

6.19 In the MHA the CQC has a duty to review complaints raised by patients, family members or others and has the power to investigate if appropriate. The CQC typically receive around 800 calls per month relating to the use of the MHA. Around 2,500 each year are triaged as MHA Complaints. Information from all complaints and calls is shared with inspection teams and used as intelligence.

6.20 If anyone contacting the CQC has safeguarding concerns, the CQC will take action including on multi agency safeguarding processes where needed in response to any organisation concerns that are raised. A new risk assessment tool for incoming calls to the customer contact centre and some experimental intelligence development work looks at how to analyse the comments given to the CQC in “everyday language” by people who use services to see if they can assess the level of risk to dignity in a service.

6.21 The CQC has launched a new Give Feedback on Your Care service which encourages members of the public including people who use services, their families and carers to share any concerns they have about care they receive from providers and services. This information is an important part of the monitoring function and can lead to MHA visits and response inspections.

6.22 A planned, wider review of methodology will look at how people who use services and their families can be better supported to raise concerns and have their concerns responded to. Work is already underway to understand how the CQC can better engage with people who have limited verbal communication. This work is a priority for the closed cultures team. In addition, concerns raised by patients and their families will be considered earlier in the CQC inspection processes, along with a strengthening of engagement with advocates for people who use services.

Recommendation 8D: Changes, including legislative changes if necessary, to make sure that the CQC is able to act more swiftly where concerns about a service are raised and substantiated.

6.23 The CQC is working with DHSC to review the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.This includes considering whether the scope and extent of CQCs enforcement powers remain sufficient, and in particular whether the 2014 Regulations allow the CQC to identify and respond decisively to mistreatment.

6.24 The guidance for inspectors, MHA Reviewers and their management teams about responding to closed cultures confirmed that where there is a higher inherent risk of a closed culture, services will be monitored more closely so that swift action will be taken when necessary.

6.25 The CQC has also taken action to:

- develop a decision-making tool for inspectors about taking regulatory action where there are inherent risks or warning signs of a closed culture. This means also that a focussed inspection should be triggered more consistently when there are concerns raised.
- develop a new insight monitoring tool to draw together information and analysis about independent mental health and learning disability healthcare services. This was launched in December 2019.
- introduce an aid for colleagues in their call centre to help to ensure they are collecting as much information as possible, and to help identify safeguarding and vulnerable groups, and signs of closed cultures.

6.26 The number of concluded successful prosecutions brought by the CQC has risen from 5 cases a year for 2017/18 and 2018/19 to 15 cases for 2019/20 with a further 2 concluded cases and 14 live prosecutions so far this year.

Recommendation 8E: A review of the system which currently allows a service to be rated as ‘Good’ overall even when individual aspects, such as safety, may have a lower rating.

6.27 The CQC welcomes this recommendation which aligns with work that the CQC is taking forward around closed cultures. The ratings system is being considered as part of CQC's work on its future strategy. Overall service ratings are generated in different ways in different sectors, with varying levels of complexity (CQC, How we aggregate ratings using the rating principles: adult social care services, April 2019). This reflects the broad range and scale of services that CQC regulate.

6.28 Currently the ratings approach for NHS trusts is much more complex than for care homes or small independent healthcare providers due to having to aggregate an overall rating from a wider range of core services.

6.29 As the CQC set out in their Interim report on Restraint, Seclusion and Segregation, the CQC’s early visits to people being cared for in segregation caused them to question how they assess the quality of care provided in these settings.

Recommendation 5 of the report states that “Informed by these interim findings, and the future work of the review, the CQC should review and revise its approach to regulating and monitoring hospitals that use segregation.” This recommendation aligns with work that the CQC is taking forward around closed cultures.

7. Visits and the right to family life

Recommendation 9: NHS England must write immediately to all hospitals, including private ones in which it commissions placements, stating that they must (whatever nationwide restrictions may be re-imposed in future), allow families to visit their loved ones, unless a risk assessment has been carried out relating to the individual's circumstances which demonstrates that there are clear reasons specific to the individual's circumstances why it would not be safe to do so. Where a mental health hospital does identify cogent reasons for prohibiting visits to a particular individual, the reasons for this decision must be provided in writing both to the patient and to their family. Such decisions must be reviewed on a regular basis, at least every 48 hours.

7.1 On 22 September 2020, NHS England and NHS Improvement wrote to NHS and independent sector providers of mental health, learning disability and autism inpatient care stating that they must allow families to visit unless a risk assessment has been carried out that indicates it would be unsafe to do so. NHS England and NHS Improvement regional teams are monitoring the implementation of this guidance and addressing any issues that are raised. NHS England and NHS Improvement would expect patient and family members to be informed where visits cannot happen and with clear reasons given for this. NHS England and NHS Improvement's expectation is that any decisions not to allow visits should be kept under regular review.

7.2 NHS England and NHS Improvement has, throughout the pandemic, stated that visits should continue where there is a clear need to do so. NHS England and NHS Improvement has published guidance to support providers and ensure that decisions about visits are made on a case by case basis with practical considerations being made to minimise the risk of infection to patients, staff and visitors. Some examples of this communication and guidance are:

- Amanda Pritchard, Chief Executive at NHS Improvement and Chief Operating Officer at NHS England and NHS Improvement published a bulletin to providers on 17 June (Amanda Pritchard, COVID-19 NHS Leaders Update, June 2020). The message includes a section on visits for people in a specialist inpatient care setting (NHS, Visiting healthcare inpatient settings during the COVID-19 pandemic, June 2020). It sets out that there should be reasonable adjustments to allow certain groups of people, including those with a mental health condition, a learning disability and people with autism, to have a family or friend visit because of significant distress and associated risk of harm of not having a visitor. This applies to all inpatient settings.

- On 19 May, NHS England and NHS Improvement published legal guidance for mental health, learning disability and autism, and specialised commissioning services supporting people of all ages during the Coronavirus pandemic (NHS, Legal guidance for mental health, learning disability and autism, and specialised commissioning services supporting people of all ages during the Coronavirus pandemic, May 2020). This states that providers are responsible for ensuring that the welfare of patients is taken into consideration when making decisions about visits. Special consideration should be made in circumstances where the visitor is a family member of a child or someone with a mental health issue such as dementia, a learning disability or autism. The guidance also makes clear that under the MHA Code of Practice, patients should be supported to maintain contact with family and friends through digital means and that telephone and internet facilities should already be accessible to patients to support this.

- As noted by the Committee, NHS England and NHS Improvement also published guidance on visits in inpatient settings on 8 April, which has now been superseded by 5 June guidance. This offers practical considerations and advice for conducting visits safely, including the use of virtual visits where appropriate.

- Furthermore, on 22 July the Department published guidance (Department of Health and Social Care, guidance on policies for visiting arrangements in care homes, July 2020) on visits to residential (social) care settings. The document sets out that care homes can now arrange visits that are in line with guidance to limit further outbreaks and protect staff and residents. Local directors of public health will also lead assessments on visiting within their local authority. They will be expected to take a measured, risk-assessed approach, considering the situation in specific care homes as well as the community context, including any local outbreaks.

8. Use of restraint and solitary confinement

Recommendation 10: In order to understand how restrictive practices are currently being used, figures on their use, including physical and medical restraint and any form of segregation, detailing any incidences which go beyond 22 hours per day, must be published weekly by the institutions. These figures must be provided to the Secretary of State for Health and Social Care and reported to Parliament.

8.1 We respond to recommendation 10 alongside recommendation 7A (November 2019 report) earlier in our response (paragraphs 5.1 to 5.5) as they both relate to reporting on restraint.

Recommendation 7B (repeated from November 2019 report): On every occasion that anyone is restrained or kept in conditions amounting to solitary confinement their families must be automatically informed.

8.2 The recommendation on informing families after every occasion of restraint repeats recommendation 7B from the November 2019 report. Our response is set out at paragraphs 5.6 - 5.10.

9. Inspections

9.1 Many of the recommendations that relate to the CQC are already in place or under way. However, we are clear that there is still more work to do with people who use services, families and others, to improve the services available to people with a learning disability and autistic people.

Recommendation 11A: We are pleased to see the CQC are now switching to unannounced inspections. The CQC should carry out all their inspections unannounced; this is particularly important where any allegation of abuse is reported by a young person, parent, or whistle-blower.

Recommendation 11B: The CQC must prioritise in-person inspections at institutions with a history of abuse/malpractice, and those which have been rated inadequate/requires improvement.

9.2 The CQC's approach to unannounced inspections is set out in response to the Committee's recommendation 8a, in its report published November 2019.

9.3 At the start of the pandemic, the CQC took a decision to halt routine inspections. However, throughout the COVID-19 pandemic they have continued to inspect where there are whistleblowing concerns or other evidence that people might be at risk of harm. The CQC commenced a full programme of focussed responsive inspections in May 2020. They have and will continue to go into services during the COVID-19 pandemic where they are alerted to serious concerns about people's care and where there are human rights breaches, as well as crossing the threshold where required.

9.4 In September 2020 the CQC began a transitional inspection programme, to move past the crisis period. They will use learning from during this period to inform their approach and will be working towards reinstating a programme of full visits in all settings.

Recommendation 11C: A telephone hotline should be established to enable all patients, families, and staff to report concerns or complaints during this period.

9.5 As set out above (recommendation 8C) the CQC launched its new Give Feedback on Care service in January 2020. It captures information about people's experiences of the care services they or their loved ones use or that they have experience of through their work. People can give feedback on the phone or online. The new service was designed around the needs of users and a full accessibility audit (carried out by the Digital Accessibility Centre) was completed, which involves testing by people with physical, sensory and mental impairments.

9.6 The new service asks more targeted questions in order to capture the information our inspectors need in their work and presents clearer information to users about how their information is used. Since its launch there has been more than 10,000 pieces of feedback about services.

Recommendation 11D: The CQC must report on reasons for geographical variation in practice with resultant harmful consequences.

9.7 The CQC currently reports on reasons for geographical variations in practice in its annual State of Care report and other national reports including Beyond Barriers (CQC, Beyond Barriers, July 2018) and the State of Mental Health Care.

- The 2017/2018 State of Care report (CQC, The state of health care and adult social care in England 2017/2018, November 2018) said experience of care varies depending on where they live and what services they use; and that these experiences are often determined by how well different parts of local systems work together.

- In ‘Beyond Barriers’, it is reported via reviews of local health and care systems that ineffective collaboration between services affects access to care and support services in the community, which in turn leads to increased demand for acute services.

- The CQC review of children and young people’s mental health services found that some children and young people were ‘at crisis point’ before they got the specialist care and support they needed, with average waiting times varying significantly according to local processes, systems and targets.

- The CQC has also highlighted the issue of inappropriate out of area placements for mental health, which vary considerably by region.

9.8 Part of CQC’s role is to provide an independent voice on the state of health and adult social care in England on issues that matter to the public, providers and stakeholders. Geographic variation has a significant impact on people’s care, which is why the CQC already report on it as listed above. The CQC will be reporting on geographic variation in access and quality in this year’s State of Care and are undertaking a series of Provider Collaboration Reviews to look at how local systems worked together during the COVID-19 pandemic.

9.9 Publishing data on variation is important as it confirms that local areas and organisations do things differently, leading to different outcomes. Highlighting this also shows how different areas are implementing improvements. This has a direct impact, which is evident from CQC's research with providers and local areas. When the CQC publish data on regional variation it highlights how and why organisations are good or improving. This challenges local perceptions and showcases how change can be implemented. 'Driving Improvement' is the CQC's most downloaded and distributed provider guidance. The sharing of this information allows others to think that improvement is possible for them as well as they can see tangible ways that other organisations have achieved improvements.

Recommendation 11E: The CQC must monitor how providers are supporting the right to family life of young people, including by facilitating family visits, and report this as standard within their inspection reports.

9.10 The CQC expects services to ensure that they are supporting people to stay in touch with family members in line with national guidance. Their new closed cultures guidance highlights the importance of ensuring that services do not put in place blanket restrictions such as restricting all family visits and ensuring these are considered on a case by case basis. Reporting arrangements will be considered as part of determining the CQC's post COVID-19 methodology.

Recommendation 11F: Following the exposure of abuse at Whorlton Hall, the CQC's work to incorporate Professor Murphy's Recommendations into a new strategy to improve the regulation of mental health, learning disability and/or autism services must continue at a greater pace.

9.11 The independent reviews have produced important and valuable recommendations which the CQC have accepted in full and are in the process of implementing. All the recommendations have been reviewed and are being taken forward by a dedicated closed cultures policy team which has responsibility for ensuring they are delivered.

9.12 The CQC started a major organisational transformation programme in 2019 which will deliver significant benefits for people who use services, providers, stakeholders and colleagues. It will strengthen technology, processes, capability and culture to ensure they can successfully deliver their future strategy from 2021 and be an efficient and responsive regulator.

9.13 The CQC is committed to working closely with people who use services, families and professionals to improve its approach in a way which more effectively safeguards their human rights. This includes bringing forward inspections, how to focus inspection on the experiences of people using the service and their families, particularly in relation to human rights and protection from abuse.

9.14 The CQC have been working to strengthen how we collect intelligence from people who contact us with information of concern and will now be able to report against population groups and protected characteristics as well as the location of care.

Recommendation 11G: The Government must ensure inspectors have sufficient and appropriate personal protective equipment (PPE) so they can carry out inspections safely.

9.15 The CQC have confirmed that this has not been an issue and that they have been provided with sufficient PPE for its inspectors. Work is also underway within the CQC to procure a longer-term solution for the provision of PPE.

10. Discharges

Recommendation 12: Now, more than ever, rapidly progressing the discharge of young people to safe homes in the community must be a top priority for the Government.

The recommendations from the Committee's 2019 report must be implemented in full. In particular, legislation must be introduced to ensure the availability of sufficient community-based services. The required amendments to the MHA 1983 to prevent inappropriate detention, must not be delayed.

10.1 We agree that discharge must continue to be a top priority for the Government. During the COVID-19 pandemic, NHS England has been consistent in its advice that people should be continued to be discharged from specialist inpatient care in a timely and safe way. NHS England issued guidance on discharges for people with a learning disability and autistic people on the 25 March.

10.2 We set out our proposed actions on sufficiency of community-based services and on amendments to the MHA at recommendations 2 and 3.

11. Data on COVID-19 infections and deaths

Recommendation 13: It is essential that we have comprehensive and accessible data about the number of those who are autistic and/or learning disabled who have contracted and died of COVID-19. This must include a focus on those in detention, for whom the state has heightened responsibility for their right to life. The data must be presented to show the number of those who have died in acute hospitals, having been transferred from other settings, and be published on a weekly or daily basis and be broken down by age.

11.1 We agree that it is essential to publish accurate data on the number of deaths from COVID-19 amongst people with a learning disability and autistic people. In doing so, we can better understand the impacts of COVID-19, including for people in inpatient settings, improving transparency and informing local and national policy development.

11.2 NHS England currently publish two sets of weekly data related to this topic: the number of deaths in acute settings from COVID-19 of a person with learning disabilities and/or autism (published for the first time on 14 May); and the number of notifications of deaths from confirmed or suspected COVID-19 reported to the LeDeR programme (published on the first time on 18 May).

11.3 On 14 May, the CQC published data on the deaths of individuals in all settings registered to provide learning disability services (CQC, Understanding the impact of coronavirus on autistic people and people with a learning disability, May 2020) . On 17 June, in their Insight Report Issue 2 (CQC, Insight Report Issue 2, June 2020), the data was split between deaths of people receiving care from community-based adult social care services, and from residential social care.

11.4 Taken together, these data sources provide us with an understanding of the impacts of COVID-19 for people with learning disability and autistic people. However, we recognise that it is difficult to compare between the datasets. Therefore, DHSC have commissioned Public Health England to undertake a thorough analysis of the numbers of deaths of people with a learning disability, including looking at the age, gender and ethnicity of people with a learning disability who have died. This review will draw on the LeDeR data, NHS England and NHS Improvement data on deaths in acute settings, and the CQC data to give as complete a picture of the impact of COVID-19 on this group of people as possible. It is anticipated that this analysis will be published as soon as possible. It is anticipated that this analysis will also be published in an easy read/accessible format. NHS England and NHS Improvement has commissioned the University of

Bristol to report on findings from a review of 206 deaths of people with a learning disability during the COVID-19 pandemic.

11.5 There is less available data relating to the deaths from COVID-19 of autistic people. Generally, across all datasets, diagnosis of autism is poorly recorded. This is a pre-existing problem which we are working to address with pre-existing programmes of work (such as the introduction of specific fields in the MHSDS to record a diagnosis of autism). While this data issue cannot be immediately resolved, we have commissioned rapid research to establish the impacts of COVID-19 on autistic people and their families. This research is expected to be completed shortly and will feed into the refresh of the cross-government all age autism strategy.

11.6 The monthly Assuring Transformation dataset publishes information in relation to people with a learning disability and autistic people in mental health inpatient settings. This includes the number of inpatients with a learning disability and autistic people who have died, rounded to the nearest 5, and suppressed where less than 5. In April 2020, 5 deaths were reported in inpatient settings. In March 2020 and between May and August 2020 less than 5 were reported, with the actual figure suppressed. CQC's fourth Insight Report fourth Insight Report (CQC, COVID-19 Insight Issue 4, September 2020), published on 16 September, reported that between 1 March and 4 September there were 13 deaths notified to them of detained patients with a learning disability and/or autism, the majority of whom were not flagged as related to COVID-19. Please note that these figures are published rapidly after the latest cut-off date and therefore further deaths within this period could be reported at a later date.

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