House of Commons

Health and Social Care Committee

The treatment of autistic people and people with learning disabilities: Government Response to the Committee’s Fifth Report of Session 2021–22

Fourth Special Report of Session 2022–23

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Health and Social Care Committee

The Health and Social Care Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Department of Health & Social Care.

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Fourth Special Report

The Committee published its Fifth Report of Session 2021–22, The treatment of autistic people and people with learning disabilities (HC 21), on 13 July 2021. The Government response was received on 15 July 2022 and is appended below.

Appendix: Government Response

Introduction

We welcome the Health and Social Care Committee's report and are grateful to everyone who contributed their time and expertise to the inquiry, and for the recommendations on this complex and vitally important issue.

This document sets out our response to the Committee's recommendations. However, it should not be read in isolation. The Building the Right Support action plan, published on 14 July 2022, sets out a wider range of actions we are taking across government and across the health and care system to reduce reliance on mental health inpatient care for people with a learning disability and autistic people by building the right support in the community. In developing the action plan, we have taken into account the Committee's recommendations. Given the length of the action plan, we have not attempted to replicate all its content in this response. However, we have sought to draw out particularly pertinent actions and to cross-refer to relevant sections within the action plan throughout this document, with specific reference to the Committee's recommendations.

We share the Committee's conviction that people with a learning disability and autistic people should be able to live an ordinary life in their community, in their own home and with the right support in place.

We are taking action now to help achieve this, as well as preparing longer term reforms that will change the experiences of people with a learning disability and autistic people in relation to health and social care.

In particular, we are reforming the Mental Health Act to give people greater control over their care and to ensure that they are treated with dignity and respect. In response to the Independent Review of the Mental Health Act, we published a white paper in January 2021, which accepted the vast majority of the review's recommendations and sought views on the impact of these recommendations and how best to implement them in practice. We published our response to this consultation on the White Paper in July 2021.

The draft Mental Health Bill was published on 27 June 2022 and will go through pre-legislative scrutiny ahead of being introduced when parliamentary time allows. These once in a lifetime proposed reforms to the Mental Health Act will improve how people with a learning disability and autistic people are treated in law. They support the objectives of Building the Right Support and the aims of the NHS Long Term Plan in ensuring that more people with a learning disability and autistic people are supported in the community and that fewer are detained in mental health hospitals, especially for long periods of time. We say more about the detail of these reforms in relation to each of the specific recommendations in this response.

Part of ensuring people with a learning disability and autistic people receive the right care and support may, in limited circumstances, include treatment in a mental health inpatient setting. Under our proposed reforms to the Mental Health Act, this will only be if they have a co-occurring mental health condition (unless they are in contact with the criminal justice system). This should only be where care in their community is not appropriate. People with a learning disability and autistic people must have access to high quality care and support in these circumstances, as anyone should.

We also plan to retain capacity for forensic inpatient care so that people with a learning disability or autistic people who come into contact with the criminal justice system have a safe and appropriate alternative to prison. We know that over a third of people with a learning disability or autistic people who are inpatients, as at the end of May 2022, are detained under Part III of the Mental Health Act and around a quarter are detained with Ministry of Justice (MoJ) restrictions. However, we recognise that people with a learning disability and autistic people can face challenges at all stages of the criminal justice system, and detention in hospital comes with its own difficulties in terms of facilitating discharge. In the action plan, we set out what action we are taking to address this.

On 14 July 2022, we also published RedQuadrant's independent report 'Building the Right Support: An analysis of funding flows'. This report was commissioned following the Committee's recommendations on the issue of improving how funding works for people with a learning disability and autistic people who are, or are at risk of being, admitted to hospital. Given the length of that document we have not included all points of detail in this response to the Committee but have highlighted the most relevant findings.

We share the Committee's ambition to reduce reliance on inpatient admissions to mental health units for people with a learning disability and autistic people. We want the action plan, and the activities set out in this response, to drive further, faster progress in achieving the NHS Long Term Plan commitment to achieving a 50% reduction in the number of people with a learning disability and autistic people who are inpatients in mental health hospitals by March 2024. Although we have made progress towards this target, we acknowledge that there is still more that needs to be done. The inpatient total at the end of May 2022 was 2,010: this is a 30.7% net reduction since March 2015, when there were 2,900 people with a learning disability and autistic people in mental health hospitals. 27% of the 2,010 individuals are detained under MoJ restrictions–this means there will be greater limitations on whether they can be discharged and by when. Individuals are placed under MoJ restrictions due to the level of risk they are considered to pose, and these restrictions will only be lifted when it is considered safe to do so.

NHS England (NHSE) is undertaking a review of the NHS Long Term Plan, including plans for learning disabilities and autism, which will take account of the impact of COVID-19 to review existing commitments and set out the next steps on delivery against targets.

It is not just about reducing the number of people in mental health inpatient settings: it is about ensuring high quality, safe care for those that need it. This is why we are investing in and improving the provision of preventative community support. It is also about ensuring that any admission to a mental health hospital is for as short a time as possible, the least restrictive and as close to home as possible. We want people to be discharged back to the community as soon as they are ready, with equally high-quality care and support if it is needed. Building the right support in the community is essential to this ambition.

We have acknowledged, and continue to acknowledge, that progress in this area has not been as fast as we would have hoped. Joint action across organisations is essential so that there is a common vision across systems such as health, social care, housing, and education. This is why the Building the Right Support action plan brings together the full range of cross-government, cross-system actions that are happening now to drive progress. This includes significant reforms to deliver tangible, long-term change.

We agree entirely with the Committee that we must ensure people are safe and receiving high quality care now, whether that is in an inpatient setting or the community. Every autistic person and every person with a learning disability is an individual. It is important that the care people receive is tailored to each person's needs, strengths, and aspirations. We once again thank the Health and Social Care Committee for their report and recommendations to help us in achieving this.

Chapter 1: Ensuring autistic people and people with learning disabilities live independent, free, and fulfilled lives

Recommendation 1:

We recommend that the Department of Health & Social Care provides us with a complete assessment of the cost of providing community support for all autistic people and people with learning disabilities currently in inpatient units. Alongside this, an assessment should also be made of the cost of providing community support for all autistic people and people with learning disabilities funded by both the NHS and local authorities.

Once the costs of moving care and support to the community for these individuals currently detained in inpatient units are identified, we expect the Government to provide investment which matches these costs, including initial funding for double running if needed. This may require financial transfers from the NHS to local authorities in the short term, to ensure continuity of support. We expect this information by the end of 2021 and the new system to be up and running by the end of the 2022–2023 financial year.

Response

We accept this recommendation in principle. We agree that having clarity over the respective costs of providing community support for autistic people and people with a learning disability and costs associated with inpatient care is critical. This will help ensure that funding can be used most effectively to support people with a learning disability and autistic people to live independent, free and fulfilled lives in their community. We note the practical challenges in providing a complete assessment of costs as proposed by the Committee. We are committed to improving our understanding of these costs and have set out the work we are taking forward to achieve this below. In addition, we set out how we have invested additional funding for community support provision and established a system to support financial transfers from secondary health care to community support, including to local authorities, to ensure continuity of support.

Funding for community support for people with a learning disability and autistic people who have been admitted to inpatient hospital, or who are at risk of admission, can be drawn from a wide range of sources across different organisations. Each person's support can be drawn from multiple funding sources and comprise different services drawn from the NHS and local authorities. This makes costing community support challenging, with the added complexity that each person's support is personalised and typically cannot be compared with another's. An individual's package of support may draw on both revenue and capital spending, which adds further complexity.

Examples of funding sources include:

- Funding by local NHS Commissioners. In 2021/22, local NHS commissioners (Integrated Care Boards (ICBs) from 1 July 2022) invested £2.3bn to provide health care for people with learning disabilities and autism, in several different areas, including the following. A breakdown of spending by individual funding streams isn't available as allocations are determined locally or determined on a case-by case basis:
    - NHS Continuing Health Care (CHC) which is a package of NHS-funded ongoing care for adults with the highest levels of complex, intense, or unpredictable needs who have been assessed as having a primary health need. Operational delivery of CHC is the responsibility of ICBs, with oversight from NHS England (NHSE). We have provided detailed statutory guidance, the National Framework, on the process for determining eligibility for CHC for an individual. Children and young people may also receive a 'continuing care package' if they have needs arising that cannot be met by universal or specialist services alone.
    - Funding under a Funding Transfer Agreement (FTA) (up to 31 March 2021) or Pathway Funds (after 31 March 2021). Under the Pathway Fund arrangements, funding is made available to invest in community services in line with costs released from provision of specialised mental health inpatient care. This is a transfer from NHS England or NHS -Led Provider Collaboratives as commissioners of specialised mental health services, to local health systems.
    - Aftercare as set out in Section 117 of the Mental Health Act places a duty on both health and social care commissioners to provide access to free aftercare services to people who leave hospital, who have been detained under the Mental Health Act.
    - Dowry payment, which is funding made available to support the ongoing care of inpatients with a stay of five years or longer on 1 April 2016, and who remain in inpatient care, to support them to move into the community. Arrangements for this payment are described within the NHS England Pathway Fund guidance.
- National NHS funding:
    - Dedicated funding through the NHS national programme on Learning Disability and Autism which seeks to deliver the NHS Long Term Plan commitments for people with a learning disability and autistic people. There is £70m of national programme funding for 2022/23 supporting development of community services including keyworkers for children and young people. (This is described in further detail below).

- Funding from local authorities which is used to meet general and specialised social care needs. Local authorities spend a significant amount on learning disability and autism services each year. For example, in 2020/21, £6.3 billion gross expenditure was spent on the long and short term adult social care support for people with a learning disability. Comparing this figure to gross expenditure in 2019/20, the aggregate spending has increased by 3.4%. There is a lack of comparable data for long and short term adult social care support for autistic people at present.
- Grant funding to Local Government from Central Government:
  - Community Discharge Grant, which is additional funding we are providing to local authorities (£62 million in England over three years, from 2020 to 2023) to support people with a learning disability and autistic people to be discharged from hospital, and address 'double running' costs. (This is described in further detail below).

Pathway Funds

Since 31 March 2021, Pathway Funds have replaced the FTA as a mechanism for releasing resources from specialised inpatient care, for reinvestment in community support to prevent admission and to help people leave hospital and return to the community. These Funds are intended to be a locally determined replacement for the FTA, which had been based on a payment of £180,000 per net inpatient reduction. Pathway Panels are expected to provide the governance for and oversight of each Fund, and will be implemented through NHS-led Provider Collaboratives.

Each Pathway Panel is expected to develop a Pathway Strategy which sets out, at minimum, how NHS Long Term Plan commitments to reduce the number of people with a learning disability and autistic people in inpatient settings is to be achieved, the scope for releasing resources for reinvestment in alternatives to inpatient care, and the priorities for investment. NHS England Pathway Fund Guidance sets out that local systems will align available funding streams for people with a learning disability and autistic people into a single funding envelope, with collaborative decision-making around how this will be invested–inclusive of people with personal experience and local voluntary sector partners. There is local discretion to decide which funding streams can be aligned, and the level of resource that can be released from specialist inpatient provision into local systems, for community reinvestment.

National NHS England funding

In the financial year 2022–23, £70 million of NHS national funding will be invested in community services and support for discharges, specifically for people with a learning disability and autistic people. The £70 million investment comprises of £40 million investment as part of the NHS Long Term Plan to continue to improve the capacity and capability of 7-day specialist multidisciplinary and crisis support for autistic people and people with a learning disability in every area of the country and £30 million of funding to continue putting keyworkers in place for children and young people with the most complex needs. This will support us to build adequate, high quality community support which can facilitate safe, timely discharge as well as prevent avoidable admissions or readmissions to inpatient settings. £84 million will also be transferred from NHSE specialised commissioning to local systems as part of the recurrent FTA. NHSE specialised commissioning funds secure services.

Community Discharge Grant

As part of the March Budget announced in 2020, we committed to £74 million in the UK (£62 million in England) to support the discharge of people with a learning disability and autistic people from hospital into the community. This will provide local authorities with additional money, over 3 years, to address any barriers to discharge and cover 'double running' costs such as establishing community teams, funding accommodation and staff training. Of the £62 million Community Discharge Grant in England, £20 million was made available to local authorities during summer 2020, £21 million of funding was issued for 2021 to 2022, and the remaining £21 million will be issued for 2022 to 2023.

The Community Discharge Grant is distributed to local government through payment of grants under Section 31 of the Local Government Act 2003. It is paid to a lead Local Authority on behalf of each ICS which signs a Memorandum of Understanding relating to its usage. Grant allocations are calculated based on an estimate of the double running costs that each ICS is forecast to incur over the year. Spending is monitored through a data recording tool developed in conjunction with local government. This tool collates data to help the government to understand how the grant has been used and how effective it has been, ultimately informing future decision making and providing us with a greater understanding of the costs associated with individual discharges.

Costs of community provision

As mentioned earlier in this response, there are practical challenges with estimating the costs of community support provision. There is no single, reliable source on the unit cost of providing community support for a person with a learning disability or an autistic person. This is due to the wide range of funding sources (as set out in paragraph 1.3) as well as the range of support that a person may draw on (from a social care package to access to a community- based NHS team) and limitations in data that is currently available.

Given this, we commissioned an independent specialist consultancy firm (RedQuadrant) in September 2021, to undertake a rapid review of funding flows associated with Building the Right Support including any financial incentives or disincentives which may exist in the system. This report was published on 14 July 2022.

RedQuadrant found that the average community placement costs for a Transforming Care Partnership area (work of Partnerships is now fulfilled by partnership arrangements within ICSs) ranged from £133,013 to £377,193 per year, or from £133,013 to £185,271 if exceptionally high-cost placements were excluded. They found that when exceptionally high-cost placements were excluded from averages, the cost of funding community-based solutions can be less or similar to the equivalent inpatient costs but otherwise could be higher. The weighted average cost of placements across the TCP areas for which data were collected was £223,520. We recognise that these figures may not be representative for each local area, however it illustrates the link between costs and the nature of each person's individual needs and the overall challenge of estimating the total cost of community support provision with accuracy.

We continue to consider other findings in RedQuadrant's report. In particular, they found that savings generated by inpatient bed reductions were found to be unlikely to be sufficient to meet the costs of many people still to be discharged from inpatient care. We are mindful that savings are not necessarily released when a person is discharged from a mental health hospital–most inpatient beds stay open as new people may need to be admitted as other people are discharged from hospital. Releasing or transferring funding from these beds would be challenging, particularly if a person with a learning disability or autistic person is in a general mental health bed. This further emphasises the importance of adequate investment in community support and wider resources, including the additional funding we have made available under the NHS Long Term Plan and the Community Discharge Grant, as set out in paragraph 1.6.

RedQuadrant's report highlighted a lack of comprehensive financial information at a national level about the specific group of people who are, or are at risk of being, inpatients. We recognise the need to improve how data is collected and better understand the specific costs related to Building the Right Support. That is why we are starting work to address RedQuadrant's primary recommendation, that there is a need for comprehensive financial monitoring on the specific group of people who are within the scope of Building the Right Support, covering NHS and local government expenditure. A task and finish group, reporting directly to the Building the Right Support Delivery Board, will look to develop targeted solutions to funding support effectively across systems and improve our overall financial oversight of expenditure related to Building the Right Support.

We recognise that RedQuadrant's report highlighted wider issues within the system as part of their rapid review, including a need to change the culture amongst the health and care workforce to provider more tailored care for people with a learning disability and autistic people. We have set out action we are taking to develop the workforce in Chapter 1 of the action plan. In Chapter 2 of the action plan, we set out wider actions we are taking to support people to have safe, timely discharges and in Chapter 3, we go further to set out how we are investing in and improving community support provision. We also set out long-term improvements we are making across public services, including in how support is funded, in Chapter 5 of the action plan.

Recommendation 2:

We also recommend that the Department then needs to redesign the financial incentives in the healthcare system so that local authorities do not seek to 'offload' autistic people and people with learning disabilities onto the NHS or place these individuals in inpatient facilities. The Department must instead offer a credible alternative and provide additional support so that autistic people and people with learning disabilities can live independent and fulfilled lives in the community.

Response

We accept this recommendation in full. We agree that there must be credible alternatives so that people live independent, free, and fulfilled lives in their community, and there must not be any financial incentives or disincentives which prevent this from happening.

We are taking action to ensure people receive the right support in the community through our proposed reforms to the Mental Health Act. We set out these reforms in our draft

Mental Health Bill, published 27 June 2022. These reforms will support government's objective to improve outcomes for people with a learning disability and autistic people through improving the way they are treated in law.

As outlined in our draft Mental Health Bill, we are proposing to introduce new duties on Integrated Care Boards and local authority commissioners to ensure an adequate supply of local, community support for people with a learning disability and autistic people who are at risk of admission under the Mental Health Act, with the express purpose of avoiding detention under the Act. This will help ensure people receive the right care and support which is based on their needs and close to friends and family, enabling them to live full lives in the community. It will prevent people reaching crisis because of a lack of robust, appropriate support in the community.

In order to ensure these new duties are effective, we are proposing that all Integrated Care Boards must have dynamic support registers. These registers will help local areas to understand the support needs of people with a learning disability and autistic people living in the community who are at risk of admission, so that care can be planned and/or provided as appropriate. This will help to ensure that the community support provided is the right support and avoid gaps in provision.

We are also proposing to limit the scope to detain people with a learning disability or autistic people for treatment under section 3 of the Mental Health Act unless they have a clear mental health need. This means that a person with a learning disability or an autistic person will only be able to be detained for treatment under section 3 of the Act if they have a co-occurring mental health condition that requires treatment in hospital.

Following the publication of our draft Mental Health Bill on 27 June, Parliament will undertake pre-legislative scrutiny (PLS). PLS will provide an opportunity for Parliament to engage directly with stakeholders, including patients and carers, through written and oral evidence submissions. Such engagement will help ensure that the legislation achieves its intent of delivering a Mental Health Act that better respects the individual needs, choices, and preferences of patients. The Government would then seek to introduce the Bill formally when Parliamentary time allows.

Chapter 3 of the Building the Right Support action plan emphasises the fundamental importance of high quality community support and sets out the wide range of actions we are taking to ensure adequate provision. This includes work to improve our understanding of 'What Good Looks Like', a project being led by the Local Government Association, the Association of Directors of Adult Social Services, and the Building the Right Support Advisory Group which is made up of people with personal experience. This project seeks to identify the conditions which enable good practice for people with a learning disability and autistic people, their families, and carers, as well as any barriers to people accessing high quality community support. The final report on this work is expected in September 2022 and will be disseminated within the health and care system to improve services.

In addition, we recognise that housing provision is a critical element of ensuring people receive the right support in the community so that they can be discharged from inpatient services in a safe and timely manner. Assuring Transformation data shows that in May 2022, 46% of people whose care plan detailed a 'delayed transfer of care' had a lack of suitable housing provision as a reason for their delayed discharge. Chapter 3 of the Building the Right Support action plan sets out the actions we are taking to address this, which include:

- investing at least £300 million over the next 3 years, as part of adult social care reform, to embed the strategic commitment in all local areas to connect housing to health and care services and boost the supply of supported housing
- investing £15 million in 2022 to 2023 with a further annual commitment of NHS capital funding for community accommodation, to be prioritised according to need, made up to financial year 2024 to 2025

Recommendation 3:

We recommend that the Trieste model of care is implemented for autistic people and people with learning disabilities by the Department of Health & Social Care and NHS England & Improvement.

All new long-term admissions of such people to institutions should be banned except for forensic cases. For cases where there is a severe co-morbidity any admission longer than three months should be subject to the safeguard as set out in the next paragraph.

Response

We agree with the Committee that admissions into mental health inpatient settings for people with a learning disability and autistic people should be for the shortest time possible, however we do not agree that admissions should be banned altogether. We do not intend to implement the Trieste model of care although our reforms to the Mental Health Act seek to prevent non-therapeutic, long term admissions. For this reason, we do not accept this recommendation.

Wherever possible, we want people to have access to the right care at the right time in their community, close to home. This is the ambition we have set out in the Building the Right Support action plan, and we are investing in and improving the provision of adequate, preventative community support as set out in Chapter 3. We recognise that there will be times when people with a learning disability or autistic people with a mental health condition, as with any person with a mental health condition, would benefit from high-quality inpatient care. When this is the case, we want to ensure that this option is available so that people, and those around them, have safe, therapeutic care that is right for them. However, we want much less reliance on inpatient care than at present. We are taking action to reduce the overall admissions of people with a learning disability or autistic people, which we set out below.

We are taking extensive action to ensure that admissions from the community are only ever therapeutic and for as short a time as possible through proposed reforms to the Mental Health Act, set out in our draft Mental Health Bill. We are proposing to limit the scope to detain people with a learning disability or autistic people for treatment under section 3 of the Act without a co-occurring mental health condition. This means that a person with a learning disability or an autistic person will only be able to be detained for treatment under section 3 of the Act if they have a co-occurring mental health condition that requires treatment in hospital. Where somebody with a learning disability or an autistic person is detained for assessment under section 2 the Act, this can only be for up to 28 days where they do not have a co-occurring mental health condition that justifies a longer stay. This reform will help reduce the number of people with a learning disability and autistic people subject to lengthy detentions under Part II of the Act.

Under our proposed reforms for all detentions under the Act, a clinician will need to justify that the individual presents a risk of 'serious harm'. This is a higher bar than at present, which currently states that detention should be in the interests of 'own health or safety' or 'with a view to protection of other persons'. This takes into account that in some cases there may be a need to detain an individual if there is a substantial risk of serious harm to the individual or others, while recognising that detention in itself could be harmful to people's mental health and should be taken into account as a risk. Requiring that the potential harm is significant will mean detention will only be permitted in the most serious of cases.

As we implement the Building the Right Support action plan, we continue to consider best practice across systems, including international examples of good care. We will consider any emerging evidence which indicates success in different contexts and in particular, positive outcomes for people with a learning disability and autistic people. In relation to the Trieste model of care, we are mindful that attempts to replicate the approach outside of its particular geographical, political, and socio-cultural context have not been successful. We are also aware of the contextual and operational differences between systems in Trieste and systems in England. Implementation of the Trieste model would require a whole-system change beyond care and support for people with a learning disability and autistic people which is a complex consideration beyond the immediate scope of Building the Right Support. In order to be effective, tthe Trieste model would require changes across all aspects of health and social care, education, voluntary and community sector, communities, and society. This would need to be supported with robust evidence.

Recommendation 4:

We recommend that by the end of 2021 the Department and NHS England & Improvement:

I) introduce weekly formal reviews of the suitability of admission for all autistic people and people with learning disabilities who have been kept in inpatient facilities for three months or more; and such reviews should be used to determine whether it is in individuals' interest to remain in such facilities. Furthermore, with the agreement of individuals' families, these reviews could take-place on a monthly-basis;

II) ensure that those reviews are conducted by experienced clinicians who have no financial or personal connection including with working the inpatient facility concerned so as to guarantee their independence;

III) where the reason for a long-term admission (greater than three months) is due to a lack of appropriate community support and provision, the NHS should be required to find and set up community provision within eight weeks using the funding from the inpatient facility. The Mental Health Act 1983 should be amended to include automatic compensation for the breach of human rights involved for individuals for whom this is not delivered; and

IV) proceed with removing the definition of autism as a disorder in the forthcoming reforms to mental health legislation in line with the commitments provided by the previous Secretary of State.

Response

As set out in response to recommendation 3, we agree that where admission is absolutely necessary, it should be for the shortest time possible, with high quality, therapeutic care. We agree that care plans should be regularly reviewed to ensure a person is receiving safe, appropriate care and has a clear path towards discharge. In Chapter 1 and Chapter 2 of the Building the Right Support action plan, we set out a range of commitments to improve the quality of inpatient care and to make it easier for people to leave hospital when it is safe for them to do so. We accept this recommendation in part and set out the reasons for this below.

In relation to part (I) of this recommendation, our planned amendments to the Mental Health Act will make fundamental changes to the way the Act will apply to autistic people and people with a learning disability. As set out in our response to recommendation 3, and in detail in our draft Mental Health Bill, we will limit the use of the Mental Health Act beyond 28 days for civil patients who have a learning disability or are autistic and who do not have a co-occurring mental health condition. In addition, we will revise the criteria for all patients to ensure that detentions are only made when there is otherwise a risk of serious harm to the patient or others, and when it will serve to provide a therapeutic benefit to the patient. Therefore, many of the longer term cases for which recommendation 4 (i) is intended, would no longer arise under the Act. Where they do arise, for civil patients, we are clear that it should provide a therapeutic benefit based on an assessment of the person's needs and what is best for them.

For the more limited number of individuals who may be admitted to a mental health hospital in our proposed restricted circumstances, we agree that inpatient care should be regularly reviewed and are taking action to strengthen existing processes. This will include a new review point after three months of detention under Section 3 of the Mental Health Act, while retaining the current check at 6 months, thereby creating an additional check of the need to detain. Similarly, the draft Mental Health Bill aims to provide for an additional right for a patient to appeal to the Mental Health Tribunal within the first year of detention. This increases the number of opportunities to appeal to the Tribunal from two to three times in the first year.

We also intend to increase the frequency of automatic referrals to the Tribunal to ensure that patients who lack the ability and initiative to make an application to the Tribunal can benefit from the safeguard of a referral to the Tribunal on a more regular basis. A hospital manager must refer a section 3 patient to the Tribunal, three months from the day on which the patient was first detained under section 3, including any period in which a patient was detained under section 2 for assessment. Where a section 3 patient's detention is renewed, the hospital managers must make a referral to the Tribunal, 12 months from the day on which the patient was first detained and thereafter on any subsequent renewal, a referral must be made on the expiry of each 12 months period of detention.

Responsible Clinicians would be expected to review their caseloads routinely and discharge people who no longer meet the risk threshold, or for whom the treatment is no longer therapeutically beneficial. In doing this, they will consider the person's Care and Treatment Plan (CTP). Where someone has received a C(E)TR this will inform their CTP. Therefore, if a C(E)TR indicates that detention is no longer therapeutic for that individual, this information should be available to the Responsible Clinician when they consider the individual's ongoing detention.

We also expect that planning for discharge should take place before admission occurs wherever possible. Family members–alongside the individual - should always be involved in decisions about the person's care (unless it is inappropriate for their family to be involved). As we expect these reforms to the Mental Health Act to significantly improve current processes and to ensure that people who are admitted will receive therapeutic treatment for mental health conditions, we do not intend to implement weekly formal reviews in the way recommended by the Committee. We are also making wider improvements to existing review processes, which are set out below.

As the Committee will be aware, people with a learning disability and autistic people who are admitted to inpatient settings should receive a Care (Education) and Treatment Review (C(E)TR). These are formal reviews that intend to improve the quality of care people receive through making recommendations for their safety, care, and treatment and to overcome any barriers to their discharge. C(E)TRs are an important part of discharge planning and avoiding inappropriately lengthy detentions.

For people with a learning disability and autistic people in hospital, commissioner oversight visits should be happening at least every 8 weeks for adults and every 6 weeks for children and young people to make sure that there is a reason for them to be in hospital, that they are being properly cared for, and to take action to tackle any barriers to discharge.

It is expected that the appropriateness of a person's continued stay in a mental health hospital should be under constant review by clinical teams. In addition, as set out in NHSE guidance, C(E)TRs should take place every 3 months for children and young people who have an educational, health and care plan in hospital, every 6 months for adults in a non-secure mental health hospital, and every 12 months for adults in a secure mental health hospital. For people in long-term segregation in a mental health hospital for three months or longer, clinical teams should regularly review the appropriateness of this and explore alternatives that will allow the person to leave long-term segregation. In addition, the Mental Health Act Code of Practice requires that three monthly reviews of the patient's circumstances should be undertaken by an external hospital alongside a patient's Independent Mental Health Advocate (if appropriate) and commissioner.

We are further strengthening the C(E)TR process through proposed reforms to the Mental Health Act. We are proposing that C(E)TRs are placed on a statutory footing which means that those responsible for the individual's care must have regard to the recommendations made in these reviews, which would include actions to support the individual towards discharge (where relevant). Where recommendations are made about the community support which should be in place to ensure someone can be discharged, the relevant commissioner will need to have regard to these.

Our proposed reforms to the Mental Health Act will also require that patients detained under certain sections of the Act receive a Care (Education) and Treatment Review within a set timeframe. The draft Bill sets out that the responsible commissioner must make arrangements for an initial post-admission C(E)TR to be held within 14 days of detention for children and adults with an Education Health and Care Plan under the Children and Families Act 2014, and 28 days for adults without an Education Health and Care Plan. Further C(E)TRs must take place at least once every 12 months from the date of that first review, during which time the patient continues to be detained. These are maximum timings, meaning that C(E)TRs can and should take place sooner, and more frequently for some people as set out in guidance. This should ensure that individual needs are properly understood, and the right support can be put in place to enable the person to leave hospital in a timely manner.

We agree with the principles of part (II) of this recommendation and have ensured this is the case for C(E)TRs. C(E)TRs involve an independent panel including a Clinical Expert who is qualified to work in healthcare and has specialist experience and an Expert by Experience who either is autistic, has a learning disability or is a family carer with personal experience of services.

NHSE is currently working on a refresh of the C(E)TR policy. The refreshed policy will have an increased focus on the physical health of people in hospital and will include an increased emphasis on the importance of the actions that should follow from a C(E)TR, and the role of the Integrated Care System. This will support us to ensure that progressing a person towards discharge is a priority from day one of being in hospital.

To support people with a learning disability and autistic people in long term segregation in hospital to move towards discharge, they receive an additional review of their care through an Independent Care (Education) and Treatment Review (IC(E)TR). These reviews are chaired by an independent expert provided by DHSC with the aim to support a person to move into the community or the least restrictive setting as soon as possible. This programme of work is overseen by Baroness Hollins and an independent, expert Oversight Panel. In addition, as set out in Chapter 1 of the Building the Right Support action plan, we are extending our pilot of Senior Intervenor roles until March 2023. Senior Intervenors are independent experts of health and social care practice who will work with people and systems, on a case-by-case basis, to move to a less restrictive setting or into the community by finding solutions to problems that may be preventing this from happening.

With regards to part (III) of this recommendation, we agree that people should not be detained in inpatient settings due to a lack of community support. However, we do not intend to introduce the requirement to pay compensation under the Mental Health Act. As set out elsewhere in this response and in the action plan, we are focused on developing and delivering the right support in the community and on reforms through the Mental Health Act to prevent any non-therapeutic long-term hospital stays. Our reforms are intended to ensure no one becomes ‘stuck’ in an inpatient setting and that they can only be detained under the Mental Health Act if the care they are receiving has a therapeutic benefit. We also intend to introduce new duties on commissioners to ensure an adequate supply of community provision and for local areas to hold dynamic support registers. Reforms will also include a new power for the mental health tribunal to recommend that aftercare services are set up in the community so that a patient can be discharged. These steps will provide safeguards to ensure no one is unnecessarily detained in hospital.

In addition to commissioners having a good understanding of people’s needs through dynamic support registers, so that the right provision is in place in the community, we regularly collect data on reasons for delayed discharges through the Assuring Transformation data set that is published on a monthly basis. This data allows us to understand areas of concern which may be preventing safe, timely discharges.

We agree with part (IV) of this recommendation in full. As part of our proposed reforms to the Mental Health Act, neither a learning disability nor autism can be considered a mental health disorder warranting compulsory treatment under Section 3 of the Mental Health Act.

Recommendation 5:

We recommend that autistic people and people with learning disabilities should never be admitted to inpatient facilities that has received an "inadequate" rating from the Care Quality Commission (CQC). The Department for Health & Social Care must bring forward measures to ensure that service commissioners can no longer buy services from settings that have been rated "inadequate" by the CQC.

Response

We agree with this recommendation in principle. We agree and expect that people with a learning disability and autistic people should experience high-quality care and treatment in inpatient settings.

The NHS is committed to providing autistic children, young people, and adults or those with a learning disability with the best possible care and treatment. The NHS will take action to avoid people with a learning disability and autistic people being admitted to hospital settings rated inadequate by CQC, including people being moved from a unit that is closing. There may, however, be exceptional occasions when a person is admitted to a unit rated inadequate. For this reason, we are not accepting this recommendation in full.

We are clear that where, exceptionally, admissions to an inadequate hospital setting occur, this will be with the involvement of the person (where they have capacity or based on a best interest decision making process where they do not) and their carer/family. It will also be based on an assessment of the risks and benefits that concludes this is the most favourable option for that person. Additional mitigations and safeguards will be put in place to monitor their safety, wellbeing, and treatment.

NHSE will monitor this approach to admissions to inadequate rated services, by reviewing the number of any exceptional new admissions over the next six months, to ensure we are delivering this as intended. We will check progress on this approach to admissions to mental health inpatient units rated inadequate by CQC. We will agree with NHSE and CQC the best way for this to be reported to the Building the Right Support Delivery Board.

In Chapter 1 of the Building the Right Support action plan, we set out the wider range of actions we are taking to ensure people have safe, appropriate care in inpatient settings. This includes robust regulation by CQC, which is welcomed. CQC are taking action to ensure that providers of learning disability and autism services meet expectations for high quality care. They have already taken significant action against services that are poorly performing, which has included cancellation of several providers' registrations (stopping them from delivering regulated activity), restricted admissions, warning notices and reduced ratings. 'Right Support, Right Care, Right Culture' sets out what CQC expect good care to look like for people with a learning disability and autistic people.

We recognise the importance of commissioners having the right knowledge and skills to buy services that are best for people with a learning disability and autistic people. Evidence from work such as the independent reviews of people in long term segregation and the CQC's 'Out of Sight' report indicate that commissioners would benefit from additional support to build knowledge and design creative commissioning solutions that best meet the needs of people with a learning disability and autistic people of all ages.

That is why Chapter 3 of the Building the Right Support action plan sets out the actions we are taking to support commissioners. We will continue to roll out an accredited commissioning qualification for current and aspiring commissioners by April 2023. This commissioning qualification has been developed to support the commissioning workforce to develop their skills, knowledge, and expertise in commissioning for people's lives. Training providers for the commissioning qualification engage families and people with personal experience as co-trainers. Furthermore, by April 2023, a training programme for senior leaders will be rolled out to increase their skills and knowledge to support local commissioners.

Chapter 2: Reforming inpatient facilities

Recommendation 6:

We welcome the Government's announcement that it will bring into force the Mental Health Units (Use of Force) Act 2018 in November 2021. This will go some way to reducing the use of restricted practices in inpatient facilities. However, we remain concerned that the use of restrictive practices remains commonplace in many inpatient facilities and therefore still presents a long-term risk to autistic people and people with learning disabilities.

We recommend that in addition to the requirement of the Mental Health Units (Use of Force Act) two further reforms are introduced: i) use of restraint on individuals in inpatient facilities is published twice every calendar year; and ii) all providers are required to meet with both families and commissioners within a month of each incidence of restraint, whether chemical or physical, to explain why it happened and what measures are being taken to prevent a reoccurrence.

Response

We agree with this recommendation in principle. We agree that there are too many instances of restrictive practices being used for people with a learning disability and autistic people. We agree about the importance of gathering information about restrictive practises and ensuring that families and commissioners are involved as appropriate. We are clear that, where needed, inpatient care must provide a therapeutic benefit and be the least restrictive possible. We are taking action to ensure this.

In relation to part (i) of this recommendation, we agree with the principle that there must be robust reporting around the use of restrictive practices. We are already taking steps to ensure and encourage this as usual practice. We publish monthly statistics from the Mental Health Services Data Set on the use of restrictive practices in the care of people with a learning disability and autistic people. We are committed to continue improving data quality and reporting compliance to ensure we build a strong understanding of the use of restrictive practices and identify any areas of concern. Over time, definitions in the Mental Health Services Data Set regarding restrictive practices have changed to be more inclusive to support greater transparency and oversight.

As the Committee is aware, the Mental Health Units (Use of Force) Act—also known as Seni's Law—received Royal Assent in November 2018 and has been partially commenced. The Act, which applies to NHS-funded care, aims to reduce their use of force and increase the transparency and accountability of the use of force (restraint) in mental health units so that force is only ever used proportionately and as a last resort. On 7 December 2021, we published the statutory guidance on the use of force in mental health settings and the government response to the consultation on the guidance. The majority of the provisions within the Act were brought into force on 31 March 2022 and the rest will be brought into force as soon as possible.

The publication of the statutory guidance represents an important step in increasing accountability and reporting of the use of force. It states that the Secretary of State for Health and Social Care must ensure that, at the end of each year, statistics are published regarding the use of force by staff. Officials are working to commence the outstanding sections of the Act as soon as possible, which includes sections 6, 7 and 8 on data and reporting.

In addition, the NHS Standard Contract (2022 to 2023) necessitates providers of mental health services to submit data and information to commissioners on a quarterly basis as part of reporting requirements. The NHS Standard Contract also includes a condition for providers of mental health and learning disability services and mental health and learning disability secure services to have regard to the Standards for Inpatient Mental Health Services to encourage high quality service provision.

In relation to part (ii) of this recommendation, we agree with its principle and expect that families are involved in the care and support of their loved one, as appropriate, which includes notification of any incidences of restrictive practice. We are taking steps to ensure this is the case. Information about the use of force and patients' rights must be published for patients. The Use of Force Act statutory guidance states that this should include a notification sent to the person(s) families, carers or independent advocate(s), identified in the patient's care plan or positive behavioural support plan (or equivalent), following every use of force, and they must also be involved in post incident reviews. It also requires that the record of the use of force used on a patient by a member of staff must include whether a notification regarding the use of force was sent to the persons (if any) who are expected to be notified under the patient's care plan.

Furthermore, the Use of Force Act statutory guidance sets out how we expect mental health units to meet the requirements of the Act. The Act makes it a legal requirement for providers to have a policy to reduce the use of force within their mental health unit, and the statutory guidance includes expectations of what the policy should include and how it should be developed and published. This policy should include the details of how patients, their families, carers, and independent advocates will be involved in care planning. As the regulator, if CQC considers the requirements of the Mental Health Units (Use of Force)

Act 2018 and this statutory guidance are not being met, it may take action as appropriate in accordance with its statutory powers and policies. CQC is also developing and improving its monitoring of the use of restraint at a provider level.

Chapter 1 of the Building the Right Support action plan sets out the wide range of actions we are taking to ensure high quality care and reduce the use of restrictive practices. For example, we are taking targeted action to support people to leave long-term segregation. As set out in our response to recommendation 4, this includes extending the Senior Intervenor pilot until March 2023, with the aim of reducing the length of time people with a learning disability or autistic people remain in segregation and supporting them to move to a less restrictive setting or to leave hospital. Senior Intervenors are independent experts of health and social care practice who work with people and systems, on a case by case basis.

Recommendation 7:

We recommend that, in addition to the implementation of the Mental Health Units (Use of Force Act) (i.e. 'Seni's Law'), all Assessment and Treatment Units (ATUs) are closed within two years and replaced with person-centred services that are:

- *designed for easy discharge as well as easy admission*
- *physically designed and maintained to meet the needs of autistic people and people with learning disabilities;*
- *located close to the homes of autistic people and people with learning disabilities; and*
- *only admits autistic people and people with learning disabilities for short periods of time*

Response

We accept this recommendation in principle. We agree and expect that care must be person-centred in line with the elements that the Committee has recommended. However, we do not accept the recommendation that all mental health inpatient units used by people with a learning disability and autistic people should be closed within two years. We have set out the reasons for this below.

As set out in response to recommendation 3, we are clear that we only want people to be admitted to inpatient settings where this offers a clear, therapeutic benefit. Where this is the case, it should be for the shortest time possible. Our proposed reforms to the Mental Health Act will support this aim and will drive an overall reduction in the number of people detained in inpatient settings. As set out in our draft Mental Health Bill, our proposed reforms will mean people with a learning disability and autistic people (who have not been admitted through the criminal justice system) will only be able to be detained for treatment under Section 3 of the Mental Health Act if they have a co-occurring mental health condition. This will limit the scope to detain people with a learning disability or autistic people under the Act and mean that they cannot be detained for longer than 28 days under Section 2, unless they have a co-occurring mental health condition which requires treatment in hospital.

Where an admission for treatment does not meet these criteria, it must not take place. We want to ensure that there are no inappropriate admissions, including as a result of a lack of community support. As outlined in our response to recommendation 2, and in detail in our draft Mental Health Bill, we are proposing reforms to the Mental Health Act which include placing new duties on Integrated Care Boards and local authority commissioners to ensure an adequate supply of local, community-based support for people with a learning disability and autistic people at risk of admission. We want to ensure people receive the right care and support which is based on their needs and close to friends and family, enabling them to live full lives in the community. Chapter 3 of the Building the Right Support action plan sets out the wide range of actions we are taking to make this happen.

As the Committee noted in recommendation 3, it is also important to retain some inpatient capacity to meet the needs of people with a learning disability and autistic people in defined circumstances in future, including for forensic inpatient care. This is so that people with a learning disability or autistic people who come into contact with the criminal justice system have a safe and appropriate alternative to prison. The Assuring Transformation data set shows that in May 2022, 92% of people with a learning disability and autistic people who are in mental health hospitals were detained under the Mental Health Act. Of this 92%, 27% of people were detained under Part III forensic sections with restrictions and 11% under Part III without restrictions. Whilst the action plan seeks to reduce these numbers, we expect to continue to require some capacity for restricted patients in the future.

When people with a learning disability and autistic people do need to be admitted to a mental health inpatient setting, we are taking action to ensure their care and treatment is of high quality. Chapter 1 of the Building the Right Support action plan sets out our actions in detail. This includes ensuring the environment best meets a person's needs. For example, NHSE invested in three initiatives in 2021 to 2022 (as part of COVID-19 Mental Health Recovery Funding) which:

- funded some mental health trusts to reduce common sensory aversions for autistic people in inpatient mental health settings
- commissioned the University of Reading to develop an evidence- and community-informed sensory assessment tool to improve staff ability to assess and accommodate for sensory sensitivities in inpatient settings
- commissioned the National Development Team for Inclusion (NDTi) to refresh the Green Light Toolkit, an audit framework designed to identify opportunities for improving inpatient settings

We welcome the more robust approach that the CQC is taking to inspecting learning disability and autism services to ensure that providers meet expectations for high quality care. They have already taken significant action against services that are poorly performing, as set out in paragraph 1.49. On 21 July 2021, we published our response to the recommendations made by the CQC in its 'Out of Sight - who cares?' report. In our response, we confirmed agreement, in full or in principle, to all of the recommendations made which named DHSC as the lead. Work is underway to implement these recommendations.

As part of its role to bring together relevant work across systems and encourage effective partnership working, the Building the Right Support Delivery Board will have oversight of the work to implement these recommendations. This will ensure we are doing all we can to make progress across health and care systems.

Recommendation 8:

We recommend that staff involved in the treatment of autistic people and people with disabilities in inpatient settings receive training in care planning which has a clear and unhindered focus on:

i) understanding that autistic people and people with learning disabilities have non-treatable conditions and therefore should not be assessed as having treatable or preventable conditions;

ii) putting autistic people and people with learning disabilities and their families at the heart of their care and treatment planning;

iii) reducing and, where possible, eliminating the use of physical or chemical restraint, and seclusion; and

iv) ensuring that all Integrated Care Systems implement such high-quality training and care planning for all autistic people and people with learning disabilities and that all staff receive this training by April 2023.

Response

We agree that staff in inpatient settings must receive appropriate training which enables them to provide high-quality, person-centred care and that this should include the principles set out by the Committee in parts (i-iii) of this recommendation. We do not accept (iv) in full, and so accept this overall recommendation in part.

We are clear that having the right workforce with the right skills and training to support people with a learning disability and autistic people is crucial in ensuring a person receives the best quality care and support. We set the actions we are taking to ensure this is the case below, and in further detail in Chapter 1 of the Building the Right Support action plan.

In relation to part (i) and part (ii) of this recommendation, as the Committee noted in their report, we are taking action to support health and social care staff to have a better understanding of learning disability and autism through the Oliver McGowan Mandatory Training. Following an investment of £1.4m to develop and trial this training with over 8000 people in 2021, the National Development Team for Inclusion published an independent evaluation of the trials in June 2022 which will inform next steps. By trialing the training and involving people with personal experience in its delivery we have ensured the training is meaningful, sustainable, and not just a tick box exercise.

The Health and Care Act 2022 introduces a new requirement for CQC registered providers from 1st July to ensure their health and social care staff carrying out regulated activities receive specific training on learning disability and autism appropriate to their role. It also creates a duty for the Secretary of State to publish a Code of Practice, which will make provisions about the nature of the training, including the content, delivery, and the ongoing evaluation of the training. We will undertake a consultation on the Code of Practice and say more about timings on this in due course.

In addition, we provided £1.5 million of funding in 2021 to 2022 to develop training for staff working in adult inpatient mental health settings in line with tier 3 of the Core Capabilities Framework for supporting autistic people. In 2022 to 2023, NHSEI are investing £1.5 million of funding into the development and trialling of autism training for staff working in adult inpatient mental health settings.

Our proposed reforms to the Mental Health Act will further support part (i) and part (ii) of this recommendation. We are proposing to reinforce the position that learning disability and autism are not conditions which can be 'removed' through treatment. As set out in response to previous recommendations, our reforms propose that people with a learning disability and autistic people (who have not been admitted through the criminal justice system) will only be able to be detained for treatment under Section 3 of the Mental Health Act if they have a mental health condition and their admission has a clear, therapeutic benefit. In addition, we will place recommendations from Care, (Education) and Treatment Reviews (C(E)TRs) on a statutory footing, for certain detained patients, meaning that they must be taken into account as part of someone's Care and Treatment Plan. The patient and their family are central to the Care and Treatment Review process.

In relation to part (iii) of this recommendation, we agree that the health and social care workforce should have appropriate training to support good quality care and reduce the use of restrictive practices and have taken forward work to ensure this. We have worked with partners to develop training standards and certification to minimise the use of restrictive practices. Services across health and social care are expected to only use training in restrictive practices that is delivered by an organisation with UKAS (United Kingdom Accreditation Service) accreditation and therefore compliant with the Restraint Reduction Network (RRN) training Standards. The NHS Standard Contract requires all providers of mental health and learning disability services to ensure all relevant staff have received training in restrictive practices that is delivered by an organisation with UKAS accreditation. The Use of Force Act statutory guidance also sets out the requirements for staff training in the use of force.

In addition, the HOPE(S) model will be delivered through NHS-led provider collaboratives to embed good practice across inpatient services with the aim of reducing overall reliance on restrictive practices. The model, developed by Mersey Care NHS Foundation Trust, is a national training model which follows a human-rights based framework and provides person-centred and trauma-informed approaches to working with people in long term segregation. Recruitment is underway for HOPE(S) specialist practitioners as part of this work.

In relation to part (iv), we agree with the Committee that ICSs should ensure staff have the necessary training to support people with a learning disability and autistic people. Informed by the independent evaluation report of the trials, we are in the process of taking forward the recommendations made to finalise the Oliver McGowan Mandatory Training. We do not expect to meet the Committee's recommended timeframe for all staff to have had this training by April 2023. As set out in paragraph 2.19, the Health and Care Act 2022 introduces a new requirement for CQC registered providers from 1st July to ensure their health and social care staff carrying out regulated activities receive specific training on learning disability and autism appropriate to their role. It also creates a duty for the Secretary of State to publish a Code of Practice, which we will consult on and say more about the timings for this in due course.

We are taking wider action to ensure ICSs deliver our ambitions for people with a learning disability and autistic people. We will deliver the NHS Long Term Plan commitments to improve services and outcomes for people with a learning disability and autistic people, reducing reliance on inpatient provision in mental health hospitals and increasing community capacity. To do this effectively, we know that systems must ensure they understand their local unmet need and gaps in care, including local health inequalities.

During the passage of the Health and Care Act 2022, we set out the expectation that all Integrated Care Boards (ICBs) will have a named lead for learning disability and autism and for Down's syndrome. This will ensure that every ICB has an expert with knowledge and understanding of what good health and support looks like for people with a learning disability and autistic people of all ages. NHSE will be sending out guidance to ICBs across the country about these roles.

Recommendation 9:

We recommend that the Government analyses the speed at which autism is diagnosed especially in children and young people and puts in place a strategy to increase early diagnosis with measurable outcomes by the end of the financial year 2021–22.

Response

We accept the Committee's recommendation to improve diagnosis and work is already underway to this end. We recognise that getting a timely diagnosis of autism is key to ensuring that autistic people can access the right support as early on as possible in life. This is why we have put forward actions as part of our refreshed national autism strategy, which was published in July 2021 and will be implemented over 5 years. This has been extended for the first time to include children and young people, in recognition of the importance of ensuring that people receive the right support throughout their lives. It has been backed by over £74 million in the first year alone.

We know some autistic people do not receive a diagnosis until later in adolescence or even until adulthood, and that in many areas people are waiting longer than the National Institute for Health and Care Excellence (NICE)-recommended 13 weeks between a referral and first autism assessment. The NICE guidelines Autism spectrum disorder in adults: diagnosis and management, Autism spectrum disorder in under 19s: recognition, referral and diagnosis, and Autism spectrum disorder in under 19s: support and management state that people should be waiting no longer than 13 weeks between a referral for an autism assessment and a first appointment. The NICE guideline does not recommend a maximum waiting time for the whole diagnostic pathway, recognising that making a diagnosis can be complex and involve a range of different professionals and agencies.

Recognising the complex nature of diagnosis, we are taking action to improve the process and overall waiting times. As part of the NHS Long Term Plan, we invested £2.5 million to test and implement the most effective ways to reduce autism diagnosis waiting times for children and young people, in England. We will build on this with a further investment of £2.5 million, per year until March 2024, to test and implement the most effective autism diagnosis pathways for children and young people.

To improve early identification, we have invested £600,000 into significantly expanding an autism early identification pilot in Bradford. This pilot will be tested in at least 100 schools over the next three years, to assess if new approaches can achieve diagnosis faster. The pilot involves teams screening children and young people who are likely to be autistic and bringing multidisciplinary teams together in school settings to diagnose children more rapidly. This assessment complies with the National Institute for Health and Care Excellence (NICE) guideline on the diagnosis of autism. The early findings are positive. Education staff report that they are better able to identify and put in place the support children need to thrive in their education.

We need to better monitor changes in autism diagnosis waiting times and are committed to improving the data on waiting times for autism diagnostic assessments. NHS Digital started collecting data about autism diagnosis waiting times from April 2018 and the data was first released in November 2019. These are experimental statistics, and work is underway to improve the quality and reliability of the data. It is important to note that the current data is based on reporting of diagnoses by mental health organisations; community services (where children are typically diagnosed) are not currently reported in this dataset. We are working with NHSE and NHS Digital on an action plan to bring together different sets of data so we can monitor and fully report on waiting times for children and young people.

Chapter 3: Wellbeing and accountability

Recommendation 10:

We recommend that the Department and NHS England & Improvement undertake an assessment of the merits of establishing the Intellectual Disability Physician as a new professional discipline within the NHS with the objective of reducing admissions and the length of hospital stays for people with intellectual disabilities; as well as improving the quality of care autistic people and people with learning disabilities receive. We expect an update on this matter by the end of 2021.

We accept this recommendation in full. In line with the Committee’s recommendation, DHSC have undertaken an assessment of the merits of establishing a learning disability physician.

While we support the aims of this recommendation, we have concerns that creating a separate learning disability physician role could result in segregation within the system and other unintended consequences, such as discontinuity and lack of consistency of such specialist provision across areas and regions.

We are interested to see the outcome of the work being taken forward by experts from the Royal College of Psychiatrists, the Royal College of Physicians (London), the Royal College of General Practitioners, and Health Education England on the development of a learning disability physician role. Our view is that offering specific training in this area to all senior health professionals will have the widest impact, with the least chance of unintended consequences.

To this end, Health Education England (HEE) and the Royal College of Physicians have worked with people with personal experience and education providers to co-produce training for doctors, nurses, and allied health professionals working at a senior level. It is designed to add to their existing skillset and to address a number of cross-cutting themes to enable medical practitioners to provide high quality and person-centred care for adults with a learning disability. The Medical Needs of Adults with a Learning Disability training is nearing final stages of approval and we hope to be able to see the first cohorts start in early 2023.

As set out in our response to recommendation 8, we want the health and social care workforce to have the right skills and knowledge to provide safe, compassionate, and informed care. The Oliver McGowan Mandatory Training is intended to ensure this.

In addition to this work, Chapter 1 of the Building the Right Support action plan sets out the actions we are taking across systems to ensure that the physical health needs of people with a learning disability and autistic people are met. These actions include disseminating learning from the Safe and Wellbeing reviews that NHS England has undertaken for all autistic inpatients and inpatients with a learning disability who were in mental health inpatient care as at 31 October 2021. As outlined in our response to recommendation 4, NHSE are carrying out a refresh of the C(E)TR policy which will include an increased emphasis on the importance of physical health. Our proposed reforms to the Mental Health Act will further strengthen the C(E)TR process.

Recommendation 11:

We therefore recommend that the Government and NHS England & Improvement bring forward the necessary financial and workforce resources required to mandate the independent review of the deaths of all autistic people and people with learning disabilities in inpatient and community settings and ensure there is a structured way to make sure any learning that emerges is disseminated across the system with clear actions following.

Response

We share the Committee's concern about the incidences of autistic people and people with a learning disability dying in inpatient settings. We agree with the importance of learning from and improving quality of care to ensure that the deaths of people with a learning disability and autistic people in hospital are not medically avoidable. However, we do not accept this recommendation as we do not intend to require the independent review of the deaths of all autistic people and people with a learning disability. We have set out the reasons for this below.

As the Committee is aware, there is already an extensive programme of work in place to review the deaths of people with a learning disability and autistic people–'Learning from Lives and deaths, people with a learning disability and autistic people' programme (known as LeDeR) - supported by an annual report and Actions from Learning report aimed at improving services (both published). Since it was introduced, the deaths of over

13,000 people with a learning disability have been reviewed. NHS England revised their LeDeR policy in March 2021, specifically in response to the body of evidence coming from reviews. The most significant changes included:

- introducing a two-level approach to reviews (all deaths notified to LeDeR to receive an initial review and where it appears there are concerns or lessons to be learnt, an in-depth focused review will take place);
- focused reviews in respect of the death of a person from an ethnic minority (given known risks outlined in previous annual reports);
- establishing a dedicated workforce to carry out LeDeR reviews locally and strengthening local governance; and
- expanding the scope of LeDeR to include autistic people.

LeDeR reporting has included the deaths of autistic people since January 2022. This means that all autistic adults with a clinical diagnosis of autism whose deaths are notified will have a review carried out by their local system.

Anyone can report the death of a person with a learning disability (over the age of 4) or an autistic person (over the age of 18) to the NHS. This includes family doctors (GPs), health and social care staff, family members, friends, and carers. This can be done online, and more information found at: leder.nhs.uk. The information provided when reporting a death will be used by the LeDeR programme to better understand the needs of people with a learning disability or autistic people and to improve future services.

Deaths may also be reviewed through statutory processes, such as safeguarding adult processes and coroners' reports. All children's deaths are reviewed as part of the child death review process. We do not therefore consider that there would be an additional benefit to mandating LeDeR reviews.

It is also important to note that there would be practical challenges to mandating LeDeR reviews. In particular, it is unclear exactly who would be obliged to report under any requirements and what this requirement would entail in addition to existing processes and checks. For example, many people with a learning disability and autistic people do not have a formally recorded diagnosis. There are estimated to be approximately 1.2 million people with a learning disability in England, with around 300,000 people recorded on GP learning registers. Often for those who do have a diagnosis, the responsible body aware of this (e.g. their GP) may not be informed about their death until a later date, with more than half of all learning disability deaths taking place in a hospital setting. As set out above, all deaths notified to LeDeR will have an initial review. However, we are not complacent about this issue and will continue to keep LeDeR reporting under review to ensure there is sufficient robust data to inform learning.