



House of Commons
Health and Social Care
Committee

The treatment of autistic people and people with learning disabilities

Fifth Report of Session 2021–22



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*Report, together with formal minutes relating
to the report*

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Health and Social Care Committee

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We are particularly grateful to Professor Judy Laing, University of Bristol Law School, for her expertise and guidance throughout our inquiry.

Contacts

All correspondence should be addressed to the Clerk of the Health and Social Care Committee, House of Commons, London SW1A 0AA. The telephone number for general enquiries is 020 7219 6182; the Committee's email address is hscocom@parliament.uk.

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Contents

Summary	3
1 Ensuring autistic people and people with learning disabilities live independent, free & fulfilled lives	5
Introduction	5
The importance of community support	5
Overview of community support and provisions	8
Reducing the number of individuals in inpatient facilities	12
Discharging individuals from inpatient facilities	14
The Government's recent work	16
The "Trieste Model" of Care	17
The Trieste Model: community support	19
2 Reforming inpatient facilities	22
Introduction	22
Restrictive practices in inpatient settings	22
Data on the use of restrictive practices in inpatient settings	23
Mental Health Units (Use of Force) Act 2018 ('Seni's Law')	25
Other issues with inpatient settings	27
Sensory and wellbeing challenges	27
Distance from home	28
Workforce, support and training	29
Early diagnosis	32
3 Wellbeing and accountability	33
Introduction	33
Intellectual Disability Physician	33
Independent investigations	35

An appendix: Correspondence with NHS England & Improvement and the Care Quality Commission: data on autistic people and people with learning disabilities in inpatient facilities	37
Conclusions and recommendations	38
Formal minutes	43
Witnesses	44
Published written evidence	45
List of Reports from the Committee during the current Parliament	46

Summary

The poor treatment of autistic people and people with learning disabilities has been a long-standing problem for the NHS and care system. A now notorious example of this was exposed by reports and investigations into the Winterbourne View hospital which took place in 2011 and the fact that these issues have not been resolved even a decade later is a scandal in its own right, quite separate to the original tragedy. Although successive governments and NHS England & Improvement have focused on supporting autistic people and people with learning disabilities from Winterbourne View and many other institutions to live independent and fulfilled lives in the community, there remain over 2,055 people in secure institutions today where they are unable to live fulfilled lives and are too often subject to treatment that is an affront to a civilised society.

During our inquiry, we heard that this is often because of a lack of adequate community provision. Instead, autistic people and those with learning disabilities can find themselves experiencing intolerable treatment in inpatient facilities which has included being subject to abusive restrictive practices; being detained for long periods of time in facilities that do not meet their needs; and being kept long distances away from their family and friends. This is often because autistic people and those with learning disabilities are treated as if their condition is an illness instead of a fundamental part of their identity: the tragic result of this fatal misunderstanding is that they often do then develop mental or physical illnesses which are used to justify their continued detention.

Throughout our inquiry, we sought to place a spotlight on the needs of, and challenges facing, autistic people and people with learning disabilities. We have reviewed international best practice, such as the Trieste model of care, in order to identify where necessary change needs to be implemented. We have also assessed how the wellbeing of autistic people and people with learning disabilities can be improved in any setting, whether inpatient or community, and the need for independent reviews into the deaths of autistic people and people with learning disabilities.

Helen Whately MP (Minister of State for Social Care, Department of Health and Social Care) has made clear in her evidence to us that she considers the issues we are raising to be important and has shared her discontent that there remain significant problems with the treatment of autistic people and people with learning disabilities. While we welcome her stated commitment to addressing these problems, we have found that the actions taken by the Government to date are not sufficient for the scale of this issue. As such, we feel it is vital that the Minister's stated ambition is matched by the swift implementation of the tangible recommendations we have set out in this report.

Our report addresses the following key areas:

- **Chapter 1:** community support; reducing the number of autistic people and people with learning disabilities in inpatient facilities; and the benefits of the Trieste model;
- **Chapter 2:** the use of restrictive practices in inpatient facilities and wider concerns relating to the appropriateness and continued use of such facilities; and

- **Chapter 3:** the wellbeing of and accountability for autistic people and people with learning disabilities including the creation of a new role: the Intellectual Disability Physician; and the need for independent reviews into the deaths of autistic people and people with learning disabilities.

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

Introduction

1. Throughout our inquiry, we have had a clear focus on how best autistic people and people with learning disabilities can be supported to live independent, free and fulfilled lives in the community. The evidence we received demonstrated that current levels of provision for community services are totally inadequate. Many witnesses told us that this has resulted in autistic people and people with learning disabilities being avoidably admitted to inpatient settings where, too often, they do not receive the support they require and there are no specialists in their condition. These concerns are held not just by individuals and families but by doctors, local authorities and senior NHS leaders despite successive governments seeking to reduce the number of autistic people and people with learning disabilities in inpatient facilities.

2. In this chapter, we consider the:

- adequacy of current levels of community support and provision;
- Government’s progress in achieving its own targets to reduce the number of autistic people and people in inpatient facilities; and
- benefits of the Trieste model of care.

The importance of community support

3. Community support is integral to enabling autistic people and people with learning disabilities to live independent, free and fulfilled lives. Over past years and particularly in response to the Winterbourne View hospital scandal (2011).¹ Autistic people and people with learning disabilities; their families and friends; and stakeholders have consistently called for greater community-based support and provisions. This has been accepted by successive governments but without effective action being taken to deliver change.

4. In their evidence to our inquiry, a range of witnesses have argued that the current system of community support in England is “broken”, “systemically failing” or otherwise inadequate.² In commenting on the impact of the poor quality of available community support for autistic people and people with learning disabilities, Ian Birrell (journalist) told us that, in England, “We have a system that has a total lack of community provision”.³ Mr Birrell explained that:

There is a systemic failure, and it is not helping [autistic] people [and people with learning disabilities]. Actually, people are far more productive, far

1 See, for example: Department of Health, [Transforming Care: A National response to Winterbourne View Hospital](#), December 2012

2 See, for example: [Q19](#); [Q26](#); [Q54](#); [Q83](#); Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England ([ADL0001](#)); Dimensions ([ADL0004](#)); and Newbold Hope ([ADL0002](#))

3 [Q54](#)

better off, far happier and far better cared for with proper support in their community.⁴

5. Mr Birrell outlined a particularly harrowing example of an autistic teenager, Bethany, aged 17 who had been admitted to an inpatient setting in England as a result of a lack of adequate community support. Mr Birrell told us:

[Bethany] had only a foam mattress. She had nothing to do all day. She was watched and monitored by guards. She was fed through a hatch like a wild animal, like a dangerous creature”.⁵

What was the crime that this girl had committed? The only thing was that she had autism, and she lived in a society that did not provide adequate community care.⁶

6. Mr Birrell told us that community support and related provisions continued to be poorly funded and that, as a result, perverse funding incentives remained in place.⁷ Furthermore, he explained that community support “only works if there is proper finance and proper money given to care in the community, which actually delivers the care and support in the community that stops people getting into crisis.”⁸

7. Dr Ken Courtenay (Chair, Royal College of Psychiatrists Intellectual Disability Faculty) echoed those concerns. He told us that:

The guiding light is about supporting people in the community. Most families will say that is where they want their care to be provided, not necessarily in inpatient services. The efforts and the thrust of clinical staff is to support families to keep people in the community.⁹

8. During our inquiry, we heard from people with lived experience and first-hand knowledge of the challenges faced by autistic people and people with learning disabilities in the absence of that community support. Alexis Quinn (an autism activist, author, and Restraint Reduction Network Manager) told us about her experiences. Ms Quinn said that she “absolutely needed help” in a time of crisis but did not receive appropriate support and was instead admitted to an inpatient hospital. Ms Quinn explained that the decision to move her to inpatient care resulted in “millions [being] spent on turning me into a wounded storyteller”.¹⁰ Ms Quinn added that:

Any kind of autistic reaction to stressful life events like divorce, bereavement, going through puberty or changing year group at school can, and too often does, result in sectioning, because there is literally absolutely no community-based understanding, support or provision whatsoever. Sectioning is a constant threat that many of us have to live with, including myself.¹¹

4 [Q51](#)
5 [Q49](#)
6 [Q49](#)
7 [Q83](#)
8 [Q52](#)
9 [Q70](#)
10 [Q27](#)
11 [Q1](#)

She continued:

The Government needs to prioritise those services. They have to be community based. It is not about getting people out of hospital or stopping people going in. The services need to be there. If they are there, the problems will resolve themselves. It is a rights-based approach to help people in crisis.¹²

9. We also heard from Bengi O'Reilly, a senior NHS nurse, who told us of her autistic daughter's experience of being admitted to an Assessment and Treatment Unit¹³ as a consequence of a lack of adequate community support. Ms O'Reilly told us that:

[T]he journey to even getting there has been an incredibly terrifying and traumatic process. Back in 2018, we had been waiting for three years, desperately asking for some support with her mental health in the community. There was nothing, absolutely nothing. She continued to deteriorate before our very eyes. She started self-harming. She became suicidal and hit crisis point. Still there was no support. I was ringing every day and begging for support. At one point, I even said, "If you don't do something, my daughter will end up dead or in hospital."¹⁴

10. Bengi O'Reilly said that the provision of care had been "very variable" and that while there were some "very decent people working very hard and delivering very good care" others appeared to "totally lack compassion and care".¹⁵ She also told us that communication from staff was poor and that the care system was "very disjointed and fragmented" which had left her "desperately trying to pull things together and to co-ordinate things" while her daughter was "passed from pillar to post and professional to professional".¹⁶ Ms O'Reilly concluded that:

Our experience is that there is no support for people to stay in the community. There is no choice. You have no voice and no control over anything.¹⁷

11. Several witnesses also raised concerns that, because of the lack of adequate community support and provisions, some autistic people and people with learning disabilities had been put at unnecessary and avoidable risk of finding themselves stuck in a "revolving door". We have heard that autistic people and people with learning disabilities can sometimes find themselves being discharged from inpatient facilities and then readmitted shortly after; constantly moving between inpatient facilities and community settings.¹⁸

12. Baroness Sheila Hollins (Founder of Beyond Words) explained that "the difficulty" was that people should not really be in hospital "if the reason for being there is primarily containment of behaviour that has developed as a response to something traumatic

12 [Q5](#)

13 Assessment and Treatment Units (ATUs) are specialist institutions which are often located within mental health hospitals. Autistic people and people with learning disabilities are often detained in ATUs, although autistic people and people with learning disabilities can also be detained in non-specialist institutions. The purpose of ATUs is to provide appropriate assessment, treatment and support to autistic people and people with learning disabilities before such individuals move back into the community. ATUs are designed to host autistic people and people with learning disabilities for short-term placements.

14 [Q117](#)

15 [Q117](#)

16 [Q117](#)

17 [Q117](#)

18 [Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England \(ADL0001\)](#)

happening, or to exclusion from the community and lack of community support.”¹⁹ Julie Newcombe (Co-Founder of Rightful Lives) agreed. Ms Newcombe argued that “the vast majority of those autistic people and people with learning disabilities can live in the community”.²⁰ Ms Newcombe explained that providers needed to:

Put the person at the centre of everything and see them as people with potential, dreams and hopes and not as some kind of risk profile, then you can see how very successful lives are lived.”²¹

13. Dan Scorer (Head of Policy, Mencap) highlighted that NHS Digital’s monthly data indicated that, for autistic people and people with learning disabilities who are ready to be discharged from inpatient facilities into community settings, “the two top reasons” for delays to discharge were a “lack of housing options” and a “lack of community support.”²² Mr Scorer explained:

What we need is the right support in the community to stop people entering crisis in the first place. We need early intervention and support for people and their families so that we do not get anywhere near crisis situations. It is because of a lack of investment in specialist support in the community that many people reach that stage. We need a strategy of investing in community services and support to make sure that a new generation of people do not go into those in-patient settings.²³

Overview of community support and provisions

14. Our inquiry has heard that good-quality community support should include:

- allowing autistic people and people with learning disabilities to be close to home and spend time with families and friends;²⁴
- providing autistic people and people with learning disabilities with the right type and level of support to manage themselves when they become “triggered”;²⁵
- creating an environment where autistic people and people with learning disabilities are able to live comfortably including providing suitable housing;²⁶ and
- utilising Robust Multi-Disciplinary Teams that work in a co-ordinated fashion and in co-production with individuals’ families;²⁷ and forensic and intensive support teams to provide a community alternatives to admission.²⁸

However, we have also heard that, at present, the funding allocated to community

19 [Q92](#)

20 [Q12](#)

21 [Q12](#)

22 [Q41](#)

23 [Q18](#)

24 See, for example: [Q1](#); [Q3](#); [Q6](#); [Q8](#); [Qq96–97](#)

25 See, for example: [Q16](#); [Q34](#) and [Q37](#)

26 See, for example: Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England ([ADL0001](#)); The Challenging Behaviour Foundation ([ADL0013](#)); ([ADL0014](#)); ([ADL0007](#)); and [Q41](#)

27 The Challenging Behaviour Foundation ([ADL0013](#)); ([ADL0014](#)); and ([ADL0007](#))

28 The Challenging Behaviour Foundation ([ADL0013](#)); ([ADL0014](#)); and ([ADL0007](#))

provision is insufficient to provide that support.²⁹ Witnesses have argued that there needs to be adequate funding to ensure the provision of appropriate levels of resourcing and capacity;³⁰ a greater number of appropriately skilled staff;³¹ and a greater integration of services at the local level.³²

15. In his oral evidence to us, Ian Birrell commented that the lack of funding for community provision has led to inpatient care becoming the default care option for many autistic people and people with learning disabilities. Mr Birrell explained that:

I think money is clearly a factor, and it is a big factor in community provision, which has been hollowed out over the last decade. There are also profound issues that we need to ask about why we are paying so much money [...] [Some private operators] are making a lot of money through private equity and opaque ownership systems. We have to ask why we have a system that is wrecking people's lives. Those companies, with very bad records, continue to have people sent into them.³³

16. While financial responsibility for community provision typically rests with local authorities, the significantly higher costs of inpatient care are met by the NHS. We have heard that this funding arrangement acts to disincentivise local authorities from using, and investing in, community provision because it will increase the number of patients who become their responsibility rather than that of the NHS. In their joint written submission, the Challenging Behaviour Foundation, Mencap, Rightful Lives and Learning Disabilities England called for the removal of financial disincentives for community provision and for ring-fenced funding for local authorities to transform local community care.³⁴

17. On 21 May 2021, and in correspondence with us, Claire Murdoch (National Director of Mental Health, NHS England) and Dr Roger Banks (National Clinical Director for Learning Disabilities and Autism, NHS England) acknowledged that further financial investment in community support is vital. The letter stated that the successful transfer from an inpatient to a community based model of care will need a “transformative level of investment, not least because there are no cheap or easy community solutions for people with the most complex health and care needs.”³⁵ The letter also set out some current funding commitments for community services, including, for example:³⁶

- The learning disability and autism programme which is supported by NHS Long Term Plan investment that increases year on year during the life of the LTP: £17 million in 2019/20; £23 million in 2020/21; £76 million in 21/22; £80 million in

29 See, for example: Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England ([ADL0001](#)); The Challenging Behaviour Foundation ([ADL0013](#)); ([ADL0014](#)); ([ADL0007](#)); [Q2](#); [Qq5-6](#); [Q12](#); [Q49](#); [Q55](#); [Qq66-67](#) and [Q85](#)

30 [Qq61-62](#); [Q78](#); [Q85](#); and [Qq96-97](#)

31 [Q20](#) and [Q25](#)

32 [Q60](#)

33 [Q57](#)

34 Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England ([ADL0001](#))

35 Correspondence from Claire Murdoch and Dr Roger Banks to Rt hon Jeremy Hunt MP: [Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021](#), 21 May 2021

36 Correspondence from Claire Murdoch and Dr Roger Banks to Rt hon Jeremy Hunt MP: [Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021](#), 21 May 2021

22/23; and £131 million in 2023/24.

- Capital investment in the development of short term and permanent community accommodation to support people with a learning disability and autistic people. In 2019/20 approximately £15 million was given in grants to support the development of 92 units of accommodation. In 2020/21 approximately £16 million was given in grants to support the development of 63 units.
- £25 million allocated to the development of community services with a focus on autistic young people aged 14–25; £15 million ring-fenced for the provision of keyworkers for children, including those at risk of admission to mental health inpatient care; and £31 million of Mental Health Recovery funding for a range of projects including admission avoidance. Of this, £3.5 million will go towards supporting the identification and clinical triage of autistic young people on diagnosis waiting lists at risk of admission and £3 million to strengthen Care Education and Treatment Reviews (C(E)TR) policy for children and young people.

18. However, several witnesses argued that these funding arrangements are inadequate. For example, written evidence from the Challenging Behaviour Foundation states:

In 2013, NHSE spent £557m on inpatient care for patients who were autistic and/or had learning disabilities. A more up-to-date figure is not readily available, but we have yet to see the government commit resources anywhere near this figure to community services.³⁷

19. In its 2015 report: *Care services for people with learning disabilities and challenging behaviour*, the National Audit Office (NAO) identified that the absence of a “mechanism for pooling resources to build sufficient capacity in the community” was a barrier to meeting the Winterbourne View Concordat commitments.³⁸ Following this, in March 2017, the NAO published its assessment of *Transforming Care Programme: Local support for people with a learning disability*. In its report, the NAO estimated that £135-£195 million is required annually to provide support in the community for people with learning disabilities discharged from mental health hospitals. This estimate does not include a specific assessment of the financial costs of community provision for autistic people.³⁹

20. Furthermore, we have heard that, over the medium to long term there are likely to be significant savings associated with community care. Written evidence from Rightful Lives and Mark Brown estimate that the average annual cost of various community options including: living with friends and family (£13,802); supported accommodation (£38,699) and residential care (£80,397). This is compared with an average annual inpatient unit cost of £214,230.⁴⁰ Based on these figures, the annual saving per person is likely to be in the range £133,833 and £200,428.⁴¹ Rightful Lives and Mark Brown therefore conclude that “the more an individual is removed from their community or the greater the level of institutionalisation, the more expensive supporting people becomes”.⁴²

37 The Challenging Behaviour Foundation ([ADL0013](#)); The Challenging Behaviour Foundation; and ([ADL0014](#))The Challenging Behaviour Foundation ([ADL0007](#))

38 National Audit Office, [Care services for people with learning disabilities and challenging behaviour](#) [report], 4 February 2015

39 National Audit Office, [Local support for people with learning disability](#) [report], 3 March 2017

40 Rightful Lives and Mark Brown ([ADL0008](#)); and ([ADL0009](#))

41 Rightful Lives and Mark Brown ([ADL0008](#)); and ([ADL0009](#))

42 Rightful Lives and Mark Brown ([ADL0008](#)); and ([ADL0009](#))

21. Furthermore, Dan Scorer told us that at present, large amounts of money was being spent on the “wrong kind of care” and that a longer-term strategy was required to support autistic people and people with learning disabilities.⁴³ Mr Scorer explained:

There are many families we have worked with where the inpatient settings where their loved one has been charged upwards of £10,000 a week. We have to remember that a vast amount of money, about £0.5 billion a year, is going on buying the wrong kind of care. At the moment, that money is locked up in the system buying the wrong kind of care. That is why it is so important, as others have touched on, that we have investment up front to develop the community services that are needed to be able to close those beds permanently and release those resources for long-term investment in the kinds of services that we want to see.⁴⁴

22. In response to our questions about funding for community services, Helen Whately MP (Minister of State, Department of Health and Social Care) told us that she had established:

A piece of work to look into the funding question. I have yet to have the answers from that because we set up that piece of work right at the end of last year. We recognise that funding is part of the challenge.⁴⁵

23. Autistic people and people with learning disabilities have the right to live independent, free and fulfilled lives in the community and it is an unacceptable violation of their human rights to deny them the chance to do so. It is also more expensive to detain autistic people and people with learning disabilities in inpatient settings and this takes up resources that are not then available for more humane community care. We are therefore deeply concerned that community support and provision for autistic people and people with learning disabilities, and financial investment in those services, is significantly below the level required to meet the needs of those individuals and to provide adequate support for them in the community. Fixing this must be a greater priority for both the Department of Health & Social Care and NHS England & Improvement.

24. 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.

25. We also recommend that the Department then needs to redesign the financial

43 [Q27](#)

44 [Q27](#)

45 [Q139](#)

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.

Reducing the number of individuals in inpatient facilities

26. Over recent years and, in particular, in response to the Winterbourne View scandal,⁴⁶ successive governments have recognised the importance of ensuring autistic people and people with learning disabilities are not avoidably admitted to inpatient facilities. That approach has been underpinned by a range of policy commitments and targets -- many of which have been delayed or missed. A significant reason for this appears to be a higher than expected rate of new admissions which has meant the total number of inpatients has reduced more slowly than anticipated.⁴⁷

27. This has meant that recent NHS figures show that there are at least 2,055 autistic people and people with learning disabilities in mental health inpatient settings in England (1,820 adults and 215 under 18s).⁴⁸ On 21 May 2021, we received correspondence from the NHS England & Improvement and the Care Quality Commission (CQC) which showed that for autistic people and people with learning disabilities in inpatient facilities, 83% of these individuals are cared for in settings rated as “Good” or “Outstanding” by the CQC; and 17% are in settings that are rated as “Requires Improvement” or “Inadequate”⁴⁹ (a further breakdown of this information set out in the appendix to this report). During our inquiry, we also found that:

- the average length of stay of autistic people and people with learning disabilities in Assessment and Treatment Units is six years;⁵⁰ and
- approximately 90% of autistic people and people with learning disabilities are kept in Assessment and Treatment Units for at least three months.⁵¹

28. One particular Government target that has received much attention was set out in the then *Government’s Mandate to the NHS 2018–19* and committed to an objective, initially set in 2015, of achieving a reduction of 35–50% of autistic people and people with

46 See, for example: Department of Health, [Transforming Care: A National response to Winterbourne View Hospital](#), December 2012

47 See, for example: Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England (ADL0001). The Joint Committee on Human Rights in its report: [The detention of young people with learning disabilities and/or autism](#) (November 2019) addressed issues relating to inpatient settings. The report stated: “The list of reviews, reports and policy initiatives above testifies to the fact that this issue [of reducing the number of autistic people and people with learning disabilities in inpatient settings] has been much examined. Moreover, there is widespread and long-standing agreement that a significant proportion of those in detention are there unnecessarily and should be discharged swiftly. This is clearly not happening.” See: para 28 of Joint Committee on Human Rights, [The detention of young people with learning disabilities and/or autism](#), 1 November 2019, HC 121, HL Paper 10 [report]

48 Correspondence from Claire Murdoch and Dr Roger Banks to Rt hon Jeremy Hunt MP: [Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021](#), 21 May 2021

49 [Correspondence to Rt hon Jeremy Hunt MP, Chair, Health and Social Care Committee, from Claire Murdoch CBE, National Director for Mental Health, NHS England, and the Care Quality Commission \[22 June 2021\]](#)

50 [Q133](#)

51 [Q133](#)

learning disabilities in inpatient care by March 2019.⁵² However, even that over-modest target was missed with data from NHS Digital showing that from 2,890 autistic people and people with learning disabilities in inpatient care in March 2015,⁵³ the number fell to at least 2,055 people in December 2020, a reduction of 29% rather than between 35–50%.⁵⁴ The *NHS Long Term Plan (2019)* consequently revised the timeframe for the target for reducing inpatient provision to this level—by a further four years—to 2023–24.⁵⁵

29. The delay to the deadline for achieving the target for reducing inpatient provisions, as announced in the *NHS Long Term Plan*, has been criticised by a range of stakeholders, activists and the Joint Committee on Human Rights.⁵⁶ In its joint written submission, the Challenging Behaviour Foundation, Rightful Lives, Mencap and Learning Disability England said that progress had been “unacceptably slow” and that “multiple targets for reducing inpatient numbers have been missed”.⁵⁷ Commenting on the Government’s key policy targets being missed, Dan Scorer explained that:

Certainly, the history of missed targets and broken promises has left people with learning disabilities, people with autism and family members deeply worried that the transformation [...] in the development of specialist services in the community is not happening at the pace that is needed. We now have a situation where, across the country, in some areas there are those services and in many others there are not. It is a real lottery.⁵⁸

30. Sir Norman Lamb, in commenting on his time in government and more generally on the *Transforming Care programme*, told us “We tried to pull off a revolution in the care of people with learning disability and people who are autistic. Ultimately, we did not pull it off. We made some progress but not nearly enough.”⁵⁹ Sir Norman explained that there was a concordat in which the key organisations—NHS England, local authorities via the Local Government Association, the Royal College of Psychiatrists—had signed up to commit to delivering key changes for autistic people and people with learning disabilities but that it had failed.⁶⁰ He described it as “the failure of a voluntary system to deliver results”.⁶¹

52 Department of Health and Social Care, [The Government’s revised mandate to NHS England for 2018–19](#), May 2019 [report]

53 [PQ Autism and Learning Disability: Psychiatric Hospitals \[UIN 238347\]](#), 28 March 2019

54 NHS Digital, [LDA Monthly Statistics from AT](#), December 2020 [data set]

55 [The NHS Long Term Plan \(2019\)](#) (paragraph 3.34). Specifically, the NHS Long Term Plan commits to halving inpatient provision for people with a learning disability and/or autism now by 2023/24, compared to 2015 levels. There are concurrent targets for the maximum numbers of adult and children in inpatient units – for every one million adults, there will be no more than 30 people with a learning disability and/or autism in inpatient care. For children and young people, the maximum is 12 to 15 children per one million.

56 See, for example: Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England ([ADL0001](#)). The Joint Committee on Human Rights in its report: *The detention of young people with learning disabilities and/or autism* (November 2019) addressed issues relating to inpatient settings. The report stated: “The list of reviews, reports and policy initiatives above testifies to the fact that this issue [of reducing the number of autistic people and people with learning disabilities in inpatient settings] has been much examined. Moreover, there is widespread and long-standing agreement that a significant proportion of those in detention are there unnecessarily and should be discharged swiftly. This is clearly not happening.” See: para 28 of Joint Committee on Human Rights, [The detention of young people with learning disabilities and/or autism](#), 1 November 2019, HC 121, HL Paper 10 [report]

57 Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England ([ADL0001](#))

58 [Q19](#)

59 [Q85](#)

60 [Q85](#)

61 [Q85](#)

31. Dan Scorer said that the Government’s and NHS England & Improvement’s lack of progress in meeting targets demonstrated a failure of policy as Assessment and Treatment Units should only be used for “a period of weeks or months” and only for “people in crisis”.⁶² He emphasised to us that the Units were hospitals, “they are not homes”.⁶³ Ian Birrell agreed and told us that, for autistic people and people with learning disabilities, the path back to living a fulfilling life had become “a slipway into hell”.⁶⁴

32. These concerns were also highlighted by a number of witnesses to our inquiry, including: Alexis Quinn,⁶⁵ Vivien Cooper OBE (Founder, Challenging Behaviour Foundation),⁶⁶ Ivan Olbrechts (Representative Body Member, Learning Disability England)⁶⁷ and Dr Theresa Joyce (Clinical Psychologist, and formerly National Professional Adviser on Learning Disabilities, Care Quality Commission).⁶⁸

Discharging individuals from inpatient facilities

33. A number of witnesses also told us that the pathways into and out of inpatient settings were often not appropriately managed and this this was a notable factor in inhibiting the discharge of autistic people and people with learning disabilities from inpatient settings into the community. Dr Ian Davidson (Autism Lead, the Royal College of Psychiatrists) explained:

What we are trying to do is get to the point whereby there is a clear purpose why [autistic people and people with learning disabilities] get admitted to hospital and why that is essential, and then that what is essential is done as quickly as possible and they get out again, just like in physical health. If you need to go in, there must be a very clear reason for going in, and you know when you are going in what that reason is. You know what your expected length of stay is going to be, you know what needs to be done while you are in there and you get out quickly. We are moving towards that model, but I have absolutely no hesitation in agreeing with people that we are a long way from that model. [...] There are still far too many people spending far too long in hospital, and that is what we need to work on.⁶⁹

34. Dr Ken Courtenay (Chair, Royal College of Psychiatrists Intellectual Disability Faculty) also raised concerns that “the threshold for admitting people was too low.”⁷⁰ He said that the provision of additional community support was required “before looking at inpatient admissions”.⁷¹ Dr Courtney explained that when an individual is admitted to an inpatient facility “it can be very difficult [...] to get them out. What is essential in terms of admissions to hospital—whether NHS provision or the independent sector—is that they have to be actively managed.”⁷² Dr Courtenay told us that autistic people and people with learning disabilities spend a long time in inpatient hospitals because:

62 [Q16](#)

63 [Q16](#)

64 [Q49](#)

65 [Qq1–5](#)

66 [Q48](#)

67 [Q14](#) and [Q45](#)

68 [Q91](#)

69 [Q58](#)

70 [Q69](#)

71 [Q69](#)

72 [Q55](#)

The in-patient pathway into hospital and the pathway out of hospital is not being managed as it should be. It should be managed by the community services, not just the in-patient services. That is essential.⁷³ [...] Often where in-patient services have to step in, it is because the system is not working well.⁷⁴

35. Dr Theresa Joyce and Baroness Sheila Hollins also raised concerns about the reliability of processes for discharging autistic people and people with learning disabilities from inpatient facilities once an individual had been admitted to one. Dr Theresa Joyce told us:

We have a lot of reporting systems, a lot of policies and a lot of guidance, but what we need is a situation where we make sure that people can be discharged. I have a lot of concern about a discharge model that says, “They’re not ready for discharge.” The issue is that they will never be ready for discharge while they are in a unit that is toxic to their health.⁷⁵

36. Baroness Hollins similarly explained that there was little planning around the needs of for autistic people and people with learning disabilities or the route to discharge for these individuals. Baroness Hollins explained that:

Very few of [autistic people and people with learning disabilities in inpatient units] have had any formulation; in other words, they had not had a multidisciplinary assessment. They did not have a treatment plan based on a multidisciplinary assessment. Because most of them were there because of autism or a learning disability, there was no obvious point for them to be discharged. For most of them, if they were diagnosed as on the autistic spectrum, there still may not have been any expertise in autism in the unit. For many who were suspected to be autistic people, no autism assessment was planned.⁷⁶

37. Several witnesses recommended that clinical contracts should be introduced to support the discharge of autistic people and people with learning disabilities from inpatient facilities. Dr Ken Courtenay said that he had proposed to NHS England that a clinical contract—a formal agreement between community services and inpatient services—was the missing element in the management of admissions.⁷⁷ He told us that each autistic person and person with a learning disability in an inpatient facility should have a clinical contract which:

- clearly states the purpose of the individual’s admission to the inpatient facility;
- provides information on the admission process as part of the assessment (i.e. when the admission will take place); and
- sets out a clear plan for discharge.⁷⁸

38. In its written evidence, the Challenging Behaviour Foundation supported the

73 [Q55](#)

74 [Q59](#)

75 [Q93](#)

76 [Q87](#)

77 [Q70](#)

78 [Q70](#)

introduction of clinical contracts. The Challenging Behaviour Foundation said that those clinical contracts needed to “stipulate in detail the actions to be taken during the admission by professionals and agencies, the timescales by which to achieve them, and to monitor progress against the expected outcomes.”⁷⁹ The Foundation concluded that this would help to achieve the aim of “drastically reducing the length and number of mental health inpatient unit stays for people with learning disabilities and autistic people”.⁸⁰

The Government’s recent work

39. We questioned Helen Whately MP, the Minister of State, Department of Health and Social Care, about the progress made on reducing the number of autistic people and people with learning disabilities in inpatient facilities. The Minister told us that she was “frustrated” by the lack of progress and that the Government “seemed to be coming across so many barriers and not making the progress that we should be making.”⁸¹ The Minister explained that as a result of this, she had established a Delivery Board called The Building the Right Support.⁸² The Board has six workstreams⁸³ which the Minister described as “six priority areas” including increasing community provisions and reducing admissions to inpatient facilities.⁸⁴

40. The Delivery Board is chaired by Helen Whately MP and first met on 3 February 2021. The Minister said the Delivery Board includes:

[...] all those who are involved in what needs to happen to fix this. It brings together different parts of Government—MHCLG, the Ministry of Justice and Home Office representation—with local government, LGA and ADASS, and with NHS England, of course, and representatives of users.⁸⁵

When we questioned the Minister about the efficacy of the Delivery Board, particularly in light of Sir Norman Lamb’s reflections on the work and failings of predecessor governments,⁸⁶ the Minister said that she shared the “concern and the unhappiness” about the situation but was committed to ensuring the Delivery Board is effective.⁸⁷

41. The Minister has also established The Building the Right Support Stakeholder Update Forum. The Forum is comprised of various stakeholders, voluntary organisations and people with lived experience, and first met on 23 March 2021. The Building the Right Support Stakeholder Update Forum and The Building the Right Support Delivery Board meet on a quarterly basis.⁸⁸ When questioned on the frequency of the Delivery Board’s and Forum’s meetings, the Minister said that the frequency with which the Board and Forum meets enabled work to continue “between one board meeting and the next” and explained that she created the Board and Forum “because I want to drive actual real change in a complicated and complex situation that involves many across our system.”⁸⁹

79 Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England ([ADL0001](#))

80 Challenging Behaviour Foundation, Mencap, Rightful Lives, Learning Disability England ([ADL0001](#))

81 [Q135](#)

82 [Q135](#)

83 [Q139](#)

84 [Q160](#)

85 [Q135](#)

86 [Q85](#)

87 [Q133](#)

88 [Qq134–135](#)

89 [Q159](#)

42. Since the Winterbourne View scandal, over 10 years ago, successive governments have committed to reducing the number of autistic people and people with learning disabilities in inpatient settings and prioritising community support for these individuals. However, missed and delayed policy targets suggest a more radical approach to unlocking funding for community provision is urgently needed. Too often autistic people and people with learning disabilities are assessed as needing to stay in an Assessment and Treatment Unit (ATU) not for temporary assessment or treatment but simply because appropriate community provision is not available, as evidenced by the shocking six year average length of stay.

43. While we welcome the vision set out by Helen Whately MP (Minister of State, Department of Health & Social Care), we believe this is a matter of delivery and not a matter for further review. At present, the work and output of The Building the Right Delivery Support Group is unclear and risks repeating the previous mistake of focusing on a “voluntary” approach to supporting autistic people and people with learning disabilities rather than addressing the fundamental flaws in funding flows that prevent community provision being adequately provided. The Group does not appear to have a clear plan for improving the practical support autistic people and people with learning disabilities receive when living in the community in order to avoid future admissions or readmissions to inpatient units.

The “Trieste Model” of Care

44. Our inquiry investigated different models of care for supporting autistic people and people with learning disabilities to live independent, free and fulfilled lives in the community. A number of our witnesses showed support for the Trieste model and highlighted it as a model that should inform policy in the UK.

45. The Trieste model for mental health care was established by Franco Basaglia, an Italian psychiatrist, in the 1960s. Franco Basaglia and others promoted a shift away from care being delivered in large mental health institutions to resources and services being provided in the community with the aim of better supporting individuals with mental health conditions.⁹⁰ In 1978, Italy introduced legislation (Law 180) leading to the closure of all asylums and mandated the creation and public funding of community-based therapeutic alternatives and affordable living arrangements. The Trieste model in particular relates to compulsory admissions. Key aspects of the model include: each mental health centre having a small number of beds; these facilities are available for a person in an acute mental health crisis in the short term and often close to their home; emphasis being on receiving day care at home or in a community centre; and individual admissions being reviewed weekly for those who require inpatient admissions. The system is built on dignity, respect for individual rights and an open-door policy.⁹¹ In practice, this has meant that the average length of stay in mental health facilities in Italy is 14 days. The average length of stay in equivalent inpatient facilities in England is 32 days.⁹²

46. Although the Trieste model was not designed specifically for autistic people and

90 See, for example, [Franco Basaglia and the radical psychiatry movement in Italy, 1961–78](#). Critical and radical social work vol. 2,2 (2014): 235–249; and [A Tale of Two Cities: The Exploration of the Trieste Public Psychiatry Model in San Francisco](#). Cult Med Psychiatry. 2015 Dec;39(4):680–97.

91 Ibid.

92 [Q53](#)

people with learning disabilities, it shows that a model that is legislated for and adequately resourced can work effectively to support people with complex needs to live in the community. In particular, this includes funding for community support; and reducing the frequency of admissions to, and lengthy stays in, inpatient facilities, which provides a template that may also be appropriate for certain types of mental health patients as we will examine in our forthcoming report on *children and young people's mental health*.⁹³ Reflecting on his international experience and research, Ian Birrell described the benefits of the Trieste model and the difference it could make if it was implemented in England. Mr Birrell explained:

I have to say that my mind was blown when I went to Trieste. I was very struck by the words of one psychiatrist I spoke to before going, who was not a massive ideological fan of the Trieste system. He said that if he was ever mentally ill he would want to be treated in Trieste, and when I went there I saw why. It is for the very simple reason that it is a system based on the rights of the people who need the help.

It is a system based on respect. It doesn't have restraint. The psychiatrist in charge said that in 41 years he had never once used restraint. How can we have a system in Trieste that does not use restraint and a system in Britain that relies on incarceration and restraint?⁹⁴

47. Sir Norman Lamb also provided support for the Trieste model in his oral evidence to our inquiry. He said that he “was absolutely thrilled to hear of the Committee’s interest in [the] Trieste model” and that he “was totally inspired” during his visit to Trieste.⁹⁵ Sir Norman explained that:

They have deinstitutionalised the care of people with mental ill health, people with learning disability and autistic people. We have a massive amount to learn.⁹⁶

In a similar vein, Baroness Hollins stated her support for the Trieste model and told us that:

Of course, I think what they are trying to do in Trieste, and succeeding in doing, is absolutely what we should be doing in the United Kingdom. The point about it is that there has to be an attitude of inclusion and admission when necessary, but for a short period of time.⁹⁷

48. While written evidence from the Royal College of Psychiatrists stated that the College had “no evidence” on the services in Trieste for autistic people, the general principles were “very important for all including autistic people.”⁹⁸ The Royal College’s written evidence said that the use of local mental health hubs in Trieste was now being replicated in England with the creation of Autism hubs in England to enable “lifetime planning and access to help and support from pre-diagnosis through to longer post diagnostic support”.⁹⁹

93 See: Health & Social Care Committee, [inquiry into Children and young people's mental health](#), HC1194

94 [Q52](#)

95 [Q86](#)

96 [Q86](#)

97 [Q97](#)

98 Royal College of Psychiatrists ([ADL0011](#))

99 Royal College of Psychiatrists ([ADL0011](#))

49. Dr Ken Courtenay and Dr Ian Davidson offered qualified support for the principles of the Trieste model but both questioned the merits of banning new admissions to secure inpatient settings as had been done in Trieste.¹⁰⁰ That said, Dr Ian Davidson told us that “many of the fundamentals of the Trieste model are ones that we fully endorse.”¹⁰¹ Dr Davidson also welcomed the Trieste model’s approach to the process for being admitted to inpatient facilities. He explained:

Admissions are very easy in Trieste. You can get in quickly and get out quickly without all the bureaucracy that we have in England around admissions. They have very much simplified the process. [...]. There has to be a very clear reason for admission and a very focused admission. They get done what needs to be done quickly and get the person back out quickly. That is very much the direction of travel we are going in.¹⁰²

The Trieste Model: community support

50. As noted earlier in this chapter, we heard that the lack of sufficient funding for community support has often undermined the ambition to keep autistic people and people with learning disabilities from being admitted to inpatient hospitals for lengthy durations. Dr Roger Banks (National Clinical Director for Learning Disabilities and Autism, NHS England), in commenting on the Trieste model and other international examples, said that an important aspect of those models of care was that “people have funding that follows them around rather than sitting with particular parts of the system”.¹⁰³ We are also aware that the Trieste model is significantly cheaper, potentially costing less than half of the asylum model which it replaced.¹⁰⁴

51. That view was supported by Dr Ian Davidson who told us that “the big difference in England is that the money did not flow into the community, whereas in Trieste it was very successful because all the money that was in the asylums has been retained in the community”.¹⁰⁵ He described that as the “fundamental difference” between the two systems.¹⁰⁶ Dr Ken Courtenay also highlighted the importance of well-resourced community support to the success of the Trieste model. Dr Courtenay explained:

What I like about the Trieste model is its emphasis on community services and community support [...]. It is very important that we develop community services but I do not think we have done that in this country. Until we actually do that and have commitment from everybody to have good, strong community services, we will continue to be in these situations.¹⁰⁷

52. In her oral evidence, Helen Whately MP told us that she was “aware of the Trieste model”¹⁰⁸ and that her mind was “absolutely open”¹⁰⁹ to alternative provision of care but

100 [Qq67–68](#)

101 [Q53](#)

102 [Q54](#)

103 [Q186](#)

104 See, for example: Ian Birrell (Tortoise), [Mental health: The country that closed its psychiatric hospitals Italy believes anyone can live freely, with the right support](#), 16 December 2019 [article]

105 [Q53](#)

106 [Q53](#)

107 [Q55](#)

108 [Q136](#)

109 [Q137](#)

she cautioned:

On saying that there should never, ever be any reason why somebody should be an inpatient, I guess I would like to see from Trieste and other places whether there is evidence that that really works.”¹¹⁰

53. While, in subsequent correspondence sent to us on 21 May 2021, Claire Murdoch, National Mental Health Director, NHS England) and Dr Roger Banks, (National Clinical Director for Learning Disabilities and Autism, NHS England) stated that “At this stage, the effectiveness of the Trieste model for people with a learning disability and autistic people who present severe challenges is not clear to us”.¹¹¹ That said, oral evidence given by Claire Murdoch to our inquiry into *Children and young people’s mental health*, showed some favour of the principles of the Trieste model. For example, Ms Murdoch stated that she was “a very big fan and advocate” of it.¹¹² That endorsement was supported by Professor Tim Kendall (National Clinical Director for Mental Health, NHS England) who said that he was “a big fan” of the Trieste model during the same session.¹¹³

54. The Trieste model of care—characterised by simplified and quicker admissions to and discharges from inpatient facilities; limited number of individuals in inpatient facilities for lengthy durations; and emphasis on well-resourced community support—presents a clear and better alternative to supporting autistic people and people with learning disabilities than is currently in place in England. Crucially, the Trieste model demonstrates that, when legislated for and well-resourced, autistic people and people with learning disabilities can be effectively supported in the community and without unnecessary and lengthy stays in inpatient facilities.

55. 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.

56. In pursuing that policy, 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***

110 [Q136](#)

111 Correspondence from Claire Murdoch and Dr Roger Banks to Rt hon Jeremy Hunt MP: [Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021](#), 21 May 2021

112 Health & Social Care Committee, oral evidence: [Q55 – inquiry into Children and young people’s mental health](#), HC1194 [23 March 2021]

113 Health & Social Care Committee, oral evidence: [Q54 – inquiry into Children and young people’s mental health](#), HC1194 [23 March 2021]

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.*

57. Furthermore, we recommend that autistic people and people with learning disabilities should never be admitted to an 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.

2 Reforming inpatient facilities

Introduction

58. During our inquiry, we have also considered the quality of care autistic people and people with learning disabilities receive when admitted to inpatient facilities. In this chapter, we address:

- the use of restrictive practices in inpatient settings;
- *Mental Health Units (Use of Force) Act 2018* ('Seni's Law');
- the appropriateness of inpatient settings including, for example, sensory and wellbeing challenges and the distance inpatient facilities are from individuals' homes; and
- staffing and workforce issues related to inpatient settings.

Restrictive practices in inpatient settings

59. Restrictive practices are described as deliberate acts on the part of other person(s) that restrict a patient's movement, liberty and/or freedom to act independently in order to:

- take immediate control of a dangerous situation where there is a real possibility of harm to the person or others if no action is undertaken; and
- end or reduce significantly the danger to the patient or others.¹¹⁴

60. We have heard that the use of restrictive practices in inpatient facilities typically involves at least one of the following:

- Physical restraint (including "prone" restraint) where often there are many members of staff "around or on top" of autistic people and people with learning disabilities with, in some instances, this taking place for "an hour or more".¹¹⁵
- Chemical restraint where autistic people and people with learning disabilities are given anti-psychotic medication and in some cases when these individuals do not have a mental health diagnosis but there is misunderstanding of "triggers" and lack of experience in supporting individuals to manage their behaviour.¹¹⁶
- Long-term segregation and seclusion where autistic people and people with learning disabilities are kept in isolation for long durations often in "cell-like conditions".¹¹⁷

61. Concerns about the use of restrictive practices on autistic people and people with learning disabilities in inpatient facilities have been highlighted by successive Care Quality Commission (CQC) reports. For example, in its report: *Out of sight – who cares?* (October 2020), the CQC said:

114 Department of Health, [Mental Health Act 1983: Code of Practice](#), 2016

115 [Q16](#) and [Q36](#)

116 [Q34](#) and [Q37](#)

117 [Q37](#)

We found too many examples of undignified and inhumane care, in hospital and care settings where people were seen not as individuals but as a condition or a collection of negative behaviours. The response to this has often been to restrain, seclude or segregate them.¹¹⁸

62. Furthermore, in her oral evidence, Alexis Quinn (an autism activist, author and Restraint Reduction Network manager) powerfully described her experiences of being subject to restraint, seclusion and segregation in inpatient hospitals. She told us of being “transported in cages and handcuffs [...] carried like a batter ram”, where there were “six to 10 men pinning me to the floor, pulling my pants down, injecting me with sedatives and then secluding me”.¹¹⁹ Ms Quinn said that hospital was “the most inappropriate place” for autistic people because of the frequent use of restrictive practices.¹²⁰ She asserted that restraint should be “a last resort, when there is an immediate threat to self or others” but too often it was used “to ensure compliance and for coercion” in inpatient settings.¹²¹

63. Responding to Ms Quinn’s oral evidence, Dan Scorer (Head of Policy, Mencap) told us that the use of “antipsychotic medication”, “physical restraint, including prone restraint”, and “people being kept in seclusion and segregation” did not meet people’s needs and created “lasting physical and mental trauma”.¹²² Vivien Cooper OBE (Founder of the Challenging Behaviour Foundation) similarly explained that:

The system channels you to a route that you do not want to be on, which is a route of exclusion, restrictions, taking things away and limitation. What we need to do is to understand the person and what their needs are, and meet them as soon as possible.¹²³

64. Dr Theresa Joyce (Clinical Psychologist, and formerly National Professional Adviser on Learning Disabilities, Care Quality Commission) told us that the use of restrictive practices causes greater stress and harm to autistic people and people with learning disabilities which can then fuel individuals’ suffering in, and poor experience of, inpatient settings. Dr Joyce explained:

The issues around assessment and treatment lead to a lower set of expectations. Once a person is behaving in a certain way, we expect it of them, and the treatment that you give—which is often restraint or medication and not very focused on positive behaviour support—continues. You end up with quite demoralised staff who have low expectations and poor skills. Then you end up with [...] a sort of institutional approach of depersonalisation and social distance, and you stop seeing the person as human.¹²⁴

Data on the use of restrictive practices in inpatient settings

65. We have heard that the use of restrictive practices in inpatient facilities remains high. For example, recent NHS Digital figures show that, in March 2021, 4,355 restrictive interventions were reported; and 1290 of these were against those under the age 18. The

118 Care Quality Commission, [Out of sight – who cares?](#), page 3, October 2020 [report]

119 [Q1](#)

120 [Q2](#)

121 [Q2](#)

122 [Q16](#)

123 [Q20](#)

124 [Q91](#)

figures show that physical restraint was the most common type of restrictive intervention.¹²⁵ In commenting on the monthly data published by NHS Digital, written evidence from the Challenging Behaviour Foundation has stated that “There is no clear evidence of a reduction in restrictive interventions according to data in the NHS Digital Mental Health Services Data Set.”¹²⁶ In addition to this, in his written evidence, Professor Chris Hatton (Professor at the Faculty of Health, Psychology and Social Care at Manchester Metropolitan University) expressed concern over “the lack of completeness” in reporting the number of restrictive interventions. Professor Hatton explained that this is likely to mean that “[restrictive] intervention statistics will be under-estimated and make it almost impossible to evaluate policy progress”.¹²⁷

66. Julie Newcombe (Co-founder of Rightful Lives) explained that data on the use of restrictive practices indicated that there was “a particularly high incidence of restraint and seclusion of autistic people” which demonstrated a “poor understanding” of autism and how autistic people show that they are distressed.¹²⁸ Ms Newcombe added:

Again, we need to remember that this group of people have a very specific set of needs. [...] we still hear about abusive practice, broken limbs, endless hours in bleak segregation cells, bullying, gaslighting and over-medication. People are left dirty and hungry, and families are threatened and side-lined.¹²⁹

67. Dr Ian Davidson (Autism Lead, Royal College of Psychiatrists) acknowledged that restrictive practices had risen, as has detention under the *Mental Health Act 1983* and told us that “we are aware of the need to address that.”¹³⁰ Dan Scorer also told us that the data on the use of restrictive practices highlights the need for immediate action. Mr Scorer explained:

[...] the way people are treated in these in-patient settings and the environment they are in is not remotely representative of what they need. [...] Clearly, what we are talking about are problems with environment and support and not with the individuals, who can be supported and lead fulfilled lives in the community.¹³¹

The No. 1 thing we would want to hear from the Government is what they are going to do to tackle the unacceptable use of a range of restrictive practices. On one hand, there is the use of physical restraint, including prone restraint, which is extremely dangerous and should only ever be used very briefly in the most exceptional circumstances, but we know that is not the case. It is used in a far more widespread way.¹³²

68. In correspondence sent to us on 21 May 2021, Claire Murdoch (National Mental Health Director, NHS England) and Dr Roger Banks (National Clinical Director for Learning Disabilities and Autism, NHS England) also acknowledged the issues relating

125 NHS Digital, [Learning Disability Services Monthly Statistics AT: May 2021, MHSDS: March 2021 Final](#). This information is based on submissions provided by 29 out of 75 inpatient providers.

126 The Challenging Behaviour Foundation ([ADL0013](#))

127 Manchester Metropolitan University ([ADL0012](#))

128 [Q32](#)

129 [Q32](#)

130 [Q57](#)

131 [Q44](#)

132 [Q44](#)

to the use of restrictive practices in inpatient settings and the challenges facing them in reducing their use.¹³³ Ms Murdoch and Dr Banks wrote:

Restrictive interventions and restraint should only ever be used as a last resort, when all attempts to de-escalate a situation have been employed. We would wish to move to a position where manual interventions as part of a planned approach to care are at an absolute minimum and exceptional and as such are subject to specific reporting requirements. We are developing policy and guidance on seclusion and long-term segregation and the use of mechanical restraint in NHS commissioned services.¹³⁴

69. When we questioned Helen Whately MP (Minister of State, Department of Health and Social Care) told us:

I find myself asking, as I am sure others listening today are, how this is still happening in our system. We have known for some years about problems in the system and in inpatient units. There are problems with restraint. An in-patient unit can only rarely be the right place for somebody to be. How is this still happening? None of us must give up.¹³⁵

Mental Health Units (Use of Force) Act 2018 ('Seni's Law')

70. *The Mental Health Units (Use of Force) Act 2018* (colloquially referred to as 'Seni's Law') received Royal Assent on 1 November 2018 but has not yet been brought into force by the Government.¹³⁶ The Bill was introduced in the House of Commons in July 2017 following the death of Olaseni 'Seni' Lewis. Mr Lewis died in 2010 as a result of being forcibly restrained by 11 police officers while he was a voluntary patient in a mental health unit. The Government has said that the Act is intended to "minimise the use of force and ensure transparency and accountability about the use of force in mental health units and related settings in England."¹³⁷

71. The Act includes a range of new measures to oversee and manage the appropriate use of force in mental health units. First, it mandates service providers to appoint a 'responsible person' for the mental health unit for the purposes of the Act. The responsible person must:

- produce a written policy on the use of force which sets out what steps will be taken to reduce the use of force;
- keep a record of any use of force;
- provide patients with information about their rights in relation to the use of

133 Correspondence from Claire Murdoch and Dr Roger Banks to Rt hon Jeremy Hunt MP: [Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021, 21 May 2021](#)

134 Correspondence from Claire Murdoch and Dr Roger Banks to Rt hon Jeremy Hunt MP: [Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021, 21 May 2021](#)

135 [Q131](#)

136 [Mental Health Units \(Use of Force\) Act 2018](#)

137 Department of Health and Social Care, [Open consultation: Open consultation Mental Health Units \(Use of Force\) Act 2018: statutory guidance for NHS organisations in England and police forces in England and Wales – draft for consultation, 25 May 2021 \[webpage\]](#)

force; and

- provide training to staff in appropriate use of force.

The Act requires providers to have regard to all relevant Care Quality Commission and NHS guidance when a patient dies or suffers a serious injury in a mental health unit following the use of force. It also imposes a new duty on the Secretary of State for Health & Social Care to produce an annual report on the use of force. The Act also requires body cameras to be worn, if reasonably practicable, by police officers who attend a mental health unit for any reason.¹³⁸

72. In her oral evidence, Julie Newcombe stressed to us the importance of bringing the *Mental Health Units (Use of Force) Act 2018* into force. She said:

We are still waiting for Seni’s law. It was approved by Parliament two years ago, but it has not been enacted in law yet. First of all, we need to start doing that and make sure that it gets made into law. It is about monitoring it. [...] We already know that a lot of hospitals do not always report all the incidents of restraint and segregation that they are supposed to report. The numbers are probably higher than you see in the reports. Yes, change the law, but make sure that you monitor it as well¹³⁹

Professor Phil Fennell (Emeritus Professor, Cardiff University’s School of Law and Politics) agreed. He said that “the one thing that could be done” to support autistic people and people with learning disabilities would be to bring ‘Seni’s Law’ properly into force “as we would then have a handle on what is going on restraint-wise”.¹⁴⁰

73. Helen Whately MP, Minister of State at the Department of Health and Social Care, explained that the delay in the coming into force was because “the Government have been developing the statutory guidance to support the implementation of that Act.”¹⁴¹ Following our oral evidence session with the Minister, the Government launched a consultation on the statutory guidance for the Act¹⁴² and announced its plans to publish final statutory guidance and begin commencement of the Act in November 2021.¹⁴³

74. 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***

138 [Mental Health Units \(Use of Force\) Act 2018](#)

139 [Q33](#)

140 [Q108](#)

141 [Qq143–144](#)

142 Department of Health and Social Care, [Open consultation: Open consultation Mental Health Units \(Use of Force\) Act 2018: statutory guidance for NHS organisations in England and police forces in England and Wales – draft for consultation](#), 25 May 2021 [webpage]

143 Hansard, [Consultation on Use of Force in Mental Health Units](#), vol 696, 25 May 2021 [debate]

- 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.*

Other issues with inpatient settings

Sensory and wellbeing challenges

75. We also heard that the poor treatment of autistic people and people with learning disabilities in inpatient settings is exacerbated by facilities that have no specialist expertise in these conditions and no support for the needs of autistic people and people with learning disabilities. For example, Alexis Quinn, Restraint Reduction Network Manager, explained that being held in inpatient settings often led her to experience a “sensory overload [...] triggered by a chaotic and sensory-charged environment that [she] had no choice to be in.”¹⁴⁴ For Ms Quinn, this ultimately meant that she was “put at odds with myself and grew to hate the autistic part of myself, which I had never hated before. I often say that I was helped to hate myself by professionals.”¹⁴⁵

76. This concern was reiterated to us by several other witnesses. Baroness Sheila Hollins (Founder, Beyond Words) explained that for autistic people and people with learning disabilities admitted to inpatient facilities, it was “very rare to find any evidence of a sensory assessment, or an awareness of people’s specific sensory or environmental needs”.¹⁴⁶ Furthermore, Ian Birrell (a journalist who has campaigned on these issues) told us that:

We know that, with something like autism, being held in those circumstances—perhaps with the noise of a mental health institution or in solitary confinement, and treated in that disrespectful way—makes their condition much worse.¹⁴⁷

77. Dan Scorer (Head of Policy, Mencap) agreed and he said that inpatient settings were “extremely damaging”.¹⁴⁸ Mr Scorer went on to explain that:

If we look at the environment, as Alexis set out very powerfully, it is not suited to people with autism. There are bright lights, noise and staff constantly changing around, which is not the kind of environment that is remotely therapeutic for people; it is actively damaging and triggers behaviours that then reinforce justifications for detention.¹⁴⁹

[...] what we need [...] is understanding of learning disability and autism, and understanding that that environment triggers behaviours for people. It creates a vicious cycle; the inappropriateness of the environment leads to behaviours that are clamped down on with the use of restraint, chemical restraint, segregation and seclusion.¹⁵⁰

144 [Q2](#)

145 [Q2](#)

146 [Q87](#)

147 [Q49](#)

148 [Q16](#)

149 [Q16](#)

150 [Q34](#)

Distance from home

78. The location of inpatient settings and the distance of inpatient facilities from individuals' family and friends was also raised by witnesses. Ivan Olbrechts (Representative Body Member at Learning Disability England) told us "I fail to see how it is ever in somebody's best interests to be a long way from home" and highlighted the fact that the *Transforming Care programme* acknowledged that "provision needs to be closer to people's homes."¹⁵¹ Julie Newcombe (Co-founder of Rightful Lives) reflected on the experiences of her son, Jamie, who has autism. Ms Newcombe explained that, for Jamie, being kept away from his family and friends while he was held in an inpatient hospital had had an avoidable detrimental impact on his wellbeing. Ms Newcombe explained that:

It was just me and him [Jamie] out and about in the community for a couple of hours each day. Then he would go back on the ward and I would get reports of restraints and over-medication, and that he had been in seclusion that morning, and whatever. That just goes to show the usefulness of being close to home. If I had not been able to do that, I would not have been able to work as hard as I did to get him out.¹⁵²

79. This concern was also raised by Vivien Cooper OBE (Founder, the Challenging Behaviour Foundation) also said:

We are supporting families whose relatives are placed long distances from home. That means not only that the person is picked up and put somewhere in an unfamiliar environment by people who do not know them, but that their families struggle to maintain the contact that they want to maintain. They often travel for hours and hours to visit their relative and then come up against other barriers.

[...] lots of families are told that, if they visit their relative, when they leave their relative is upset, understandably because they want to be with their family. The relative is upset and therefore their behaviour escalates. Therefore, the service tries to restrict visits for families.¹⁵³

80. When we questioned Helen Whately MP about the lengthy distances autistic people and people with learning disabilities can be from home, when in inpatient facilities, she said that she agreed that there should be "fewer people in in-patient settings". However, if someone was in an inpatient setting, it was "much better that it should be close to home" so that the individual could stay in touch with friends and family because "that will help you while you are an inpatient and help your return to the community when you are discharged".¹⁵⁴

81. Inpatient facilities do not consistently meet the needs of autistic people and people with learning disabilities and too often this is because of factors such as the unnecessary use of restrictive practices; inpatient facilities being unable to accommodate individuals' needs to avoid sensory overload; and the distance inpatient facilities are from individuals' homes.

151 [Q21](#)

152 [Q22](#)

153 [Q22](#)

154 [Q155](#)

82. ***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:***

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

Workforce, support and training

83. We have heard that the treatment of autistic people and people with learning disabilities can be hindered by a lack of support and training for staff working in inpatient settings. In its report: *State of Care 2018/19* (October 2019), the Care Quality Commission (CQC) noted that:

Issues with staffing were a common feature across a number of these hospitals. These included our concerns with staff skill mix not reflecting the needs of the people on the ward, and a lack of registered learning disability nursing time being routinely addressed by relying on high numbers of healthcare assistants or other non-registered roles. We also found issues with staff not having adequate training and difficulties in recruiting and retaining staff.¹⁵⁵

84. In its subsequent report: *Out of sight – who cares?* (October 2020), the CQC similarly noted:

We found that staff were not always receiving the right training, with no focus or training on human rights or value-based care. [...] The competence, skills and knowledge of staff actively involved in people’s care was judged to be poor, very poor or below standard for 61% of people we reviewed in learning disability wards.¹⁵⁶

85. These issues have also been raised during our inquiry by a range of witnesses. Bengi O’Reilly, a senior nurse whose young autistic daughter is in an inpatient facility, highlighted the challenges facing staff and autistic people and people with learning disabilities in inpatient settings. Ms O’Reilly explained:

Many of the units are run by agency staff. There is a very high turnover of staff, so there is lack of consistency in care. The ATUs [Assessment and Treatment Units] are not even NHS hospitals. They are private organisations.

The quality of care is completely variable. The standards of care are very

155 Care Quality Commission, [The state of health care and adult social care in England 2018/19](#), October 2019, pp.64–64

156 Care Quality Commission, [Out of sight – who cares?](#), October 2020, p.15

low. That is why perhaps some of our quality concerns are not acted on; they are not unusual and there are no quick-fix solutions.¹⁵⁷

86. Dan Scorer (Head of Policy, Mencap) also told us that staff working in inpatient settings can lack the skills and support to meet the needs of autistic people and people with learning disabilities, particularly those who are non-verbal. Mr Scorer explained:

If someone with a learning disability is admitted to hospital and they cannot communicate or they are non-verbal, they rely on family members and carers to advocate for them. That is absolutely essential to make sure that staff in the hospital can understand the person's needs and put in place the right kind of care and support for them. If that is not there, it is a massive problem.¹⁵⁸

87. Sir Norman Lamb (former Minister of State in the Department of Health) and Dr Ian Davidson ((Autism Lead, the Royal College of Psychiatrists) both raised concerns about the “generic training” being given to staff that left them unable to appropriately support autistic people and people with learning disabilities.¹⁵⁹ Dr Davidson outlined current training initiatives that have been launched by the Royal College of Psychiatrists:

In terms of the training and stuff, yes, we have done a huge amount of training. We are working our way through. We have diagnostic services now for people who do not have learning disabilities and who are not children. We are able now to give more training opportunities about autism to psychiatrists working in other fields so that they can get better at recognising it and get better at doing reasonable adjustments. There is a wide range of things going on. I am not pretending that it is going fast enough. I am not suggesting that.¹⁶⁰

88. Dr Theresa Joyce (Clinical Psychologist, and formerly National Professional Adviser on Learning Disabilities, Care Quality Commission) was clear that, in her view, autistic people and people with learning disabilities “were largely being cared for by staff who were unqualified.”¹⁶¹ Dr Joyce explained that staff are “given very poor guidance sometimes by clinical teams who, I think, sometimes did not really have a handle on what they should have been doing.”¹⁶² Dr Joyce explained that these issues can have longer-term negative consequences for workforce morale and the treatment of autistic people and people with learning disabilities in inpatient facilities. She explained:

The issues around assessment and treatment lead to a lower set of expectations. [...] You end up with quite demoralised staff who have low expectations and poor skills. Then you end up with what Ian [Davidson] talks about, which is a sort of institutional approach of depersonalisation and social distance, and you stop seeing the person as human.¹⁶³

89. When we questioned Helen Whately MP about issues relating to workforce, support

157 [Q119](#)

158 [Q11](#)

159 [Q78](#); [Q95](#)

160 [Q60](#)

161 [Q91](#)

162 [Q91](#)

163 [Q91](#)

and training, the Minister explained that one of the workstreams of the Building the Right Support Delivery Board would address workforce issues.¹⁶⁴ The Minister also highlighted the ‘Oliver McGowan’ training, which has been led by campaigner, Paula McGowan, whose son, Oliver, passed away following a series of mistreatments by staff at an inpatient facility. The Minister explained that the training is mandatory for “everyone working across the NHS—doctors, nurses, healthcare assistants and others”,¹⁶⁵ and it will aim to provide a “shift both in understanding and in skills, to give better care to those with learning disabilities and autism.”¹⁶⁶ The Minister told us that:

[T]he particular focus of the work that I have been driving on the improvement of clinical care has been through the Oliver McGowan mandatory training to improve the understanding of skills across the whole of the NHS and social care workforce. We should also, clearly, look at specialist roles as well.¹⁶⁷

[...] The [Oliver McGowan] training is currently being trialled. The pilots will be evaluated, so that we can roll out a truly effective training model across the health and social care system. There is no point in a training model that is not effective. This is too important for that. We need to roll out an effective model that is not only skills but also the understanding and the cultural change that you will appreciate and have referred to.¹⁶⁸

90. We have significant concerns about the quality of training and support provided to staff working in inpatient facilities and the negative consequences this can have on the treatment of autistic people and people with learning disabilities in inpatient facilities. While we welcome the pilot of the ‘Oliver McGowan’ training, it is clear that, in some cases, there is a lack of understanding amongst staff working in inpatient settings that autistic people and people with learning disabilities do not need to be “cured” and instead need to be consistently put at the centre of their care. Ultimately, a system based on incarceration, restraint and seclusion will create an environment which dehumanises both staff and inpatients. But, if in limited circumstances, autistic people and people with learning disabilities are to be held as inpatients, it is essential for staff to be properly trained so that autistic people and people with learning disabilities receive adequate support from people who understand their condition.

91. 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;*

164 [Qq154–155](#)

165 [Q171](#)

166 [Q147](#)

167 [Q154](#)

168 [Q146](#)

- 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.*

Early diagnosis

92. A number of witnesses highlighted the issue of late diagnosis of autistic people as a cause of why too many individuals are detained in inpatient facilities. For example, in commenting on the work of Starfish+, a children and young people’s service, Sir Norman Lamb (former Minister of State in the Department of Health) told us that “their whole approach with young people, children and teenagers is to stop them going into an institution in the first place. [...] They demonstrate that it is possible to keep young people out of institutions. You have to get it right in those early years.”¹⁶⁹ Similarly, Ian Birrell (journalist) told us:

We need far more money and effort put into early diagnosis of autism. In a lot of cases the autism is not diagnosed until the girls hit crisis. Girls tend to go inwards when they hit adolescence and have a crisis. They harm themselves or have eating disorders, or whatever. I think that behind a lot of the rise in eating disorders and self-harming is the issue of autism being undetected.¹⁷⁰

93. **We conclude that the benefits of early diagnosis for conditions like autism are well-understood and late diagnosis presents a particular risk that autistic people will end up with mental illnesses such as anxiety and/or depression.**

94. ***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.***

169 [Q105](#)

170 [Q57](#); [Q83](#)

3 Wellbeing and accountability

Introduction

95. During our inquiry, we have also investigated issues relating to the wellbeing of and accountability for autistic people and people with learning disabilities. In particular, we have received calls for the introduction of an Intellectual Disability Physician to better support the needs of autistic people and people with learning disabilities. We have also taken evidence which has provided a spotlight on the challenge facing those wanting to secure reviews into the death of autistic people and people with learning disabilities. In this chapter, we address:

- the case for creating a new role of Intellectual Disability Physician to better support the wellbeing of autistic people and people with learning disabilities; and
- the need for independent reviews into the deaths of autistic people and people with learning disabilities in both inpatient and community settings.

Intellectual Disability Physician

96. As part of a wider call to train more staff to support autistic people and people with learning disabilities in inpatient settings and also in the community, Sir Norman Lamb (former Minister of State in the Department of Health) and Dr Ken Courtney (Chair of the Royal College of Psychiatrists Intellectual Disability Faculty) proposed the creation of a new role—Intellectual Disability Physician. Dr Courtney, along with individuals from the Royal College of General Practitioners and Royal College of Physicians, have made the case that a new role in the NHS is required to expertly coordinate care, lead and train multi-disciplinary teams and build an evidence base for successful interventions.¹⁷¹ Intellectual Disability Physicians are already practicing in the Netherlands having been introduced with an associated training curriculum.¹⁷²

97. Dr Courtney and his colleagues highlighted an evidence base that demonstrated that primary care is not always able to meet the needs of autistic people and people with learning disabilities. Research published in 2018 by the charity Dimensions indicated that the majority of GPs do not believe they are sufficiently trained to meet the needs of autistic people and people with learning disabilities.¹⁷³ Moreover, autistic people and people with learning disabilities said they were less likely to be listened to by a GP; less likely to be involved in decisions about their healthcare; and felt that their GP did not make reasonable adjustments.¹⁷⁴

98. Explaining the rationale for establishing this new role within the NHS, Dr Courtney said that people with intellectual disabilities will, on average, “have around 11 comorbid disorders compared with people in the general population, who maybe have five.”¹⁷⁵ Sir Norman Lamb noted that the principle behind the proposal for the new discipline was

171 Developing the ID Physician: A gap in the market

172 [Q81](#)

173 Dimensions, [My GP and me: making primary care fair](#), May 2018

174 Dimensions, [My GP and me: making primary care fair](#), May 2018

175 [Q81](#)

that not enough was known about “the complex interaction between a number of physical health conditions and learning disability” but that “the average length of life is much shorter than for other people.”¹⁷⁶

99. Dr Courtney explained that a senior medical specialist “who understands comorbidity, multimorbidity and complex disorders” would be particularly advantageous in hospitals and other inpatient settings where medical staff may not be “very au fait or aware of how [comorbidities] present in people with learning disabilities”.¹⁷⁷ Sir Norman Lamb agreed and said that the care of people with learning disabilities was often “massively suboptimal”.¹⁷⁸

100. Dr Courtney also made the case that at a minimum every NHS Trust in England should have “one skilled decision-making doctor within an organisation, who can work with people with learning disabilities and who have physical health problems.”¹⁷⁹ He said that an Intellectual Disability Physician working with families, hospital colleagues and GPs (in line with the Dutch model) could avoid admissions to some inpatient facilities; reduce the length of stay in such facilities; and provide better quality care.¹⁸⁰ Sir Norman Lamb supported this view.¹⁸¹ Sir Norman said that the creation of Intellectual Disability Physicians would “start to confront the shocking short life expectancy that we have completely failed to resolve over many years of trying.”¹⁸²

101. When we questioned Helen Whately MP (Minister of State, Department of Health and Social Care) about proposals to establish an Intellectual Disability Physician role, she told us:

I take the approach that we should look at whatever is the best way to improve the outcomes and reduce the inequalities in outcomes and health treatment for those with learning disabilities and autism.¹⁸³

102. The physical health and wellbeing of autistic people and people with learning disabilities requires greater prioritisation. We believe that the creation of an Intellectual Disability Physician to co-ordinate care in line with the model established in the Netherlands should be fully explored by the Department and NHS England & Improvement; and that this model would be a positive approach to addressing key problems facing autistic people and people with learning disabilities.

103. 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.

176 [Q95](#)

177 [Q81](#)

178 [Q95](#)

179 [Q81](#)

180 [Q81](#)

181 [Q95](#)

182 [Q95](#)

183 [Q154](#)

Independent investigations

104. We also received evidence that highlighted the importance of independent investigations into the death of autistic people and people with learning disabilities in inpatient and community settings. The notion of using independent panels to investigate mortality is not in itself new. In 2013, the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD) recommended “the establishment of a National Learning Disability Mortality Review Body to take forward the reviews of deaths of people with learning disabilities”.¹⁸⁴

105. In 2015, NHS England & Improvement created the learning from deaths of people with a learning disability programme (LeDeR) to review the deaths of autistic people and people with learning disabilities. Until 2021, the University of Bristol delivered the programme, having been commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England to do so. However that review process was not intended to be independent of the NHS. An academic review of the programme led by Professor Pauline Heslop (Professor of Intellectual Disabilities Studies, University of Bristol) concluded that mortality reviews had taken place independently of local areas but factors including “difficulties in allocating some deaths to reviewers wholly independent of direct care provider agencies in some areas” could risk “further challenges” to the independence of LeDeR’s mortality reviews.¹⁸⁵

106. Dr Sara Ryan, an autism specialist at the University of Oxford whose son, Connor, drowned whilst in inpatient care, told us that the LeDeR programme was “inadequate and not fit for purpose”.¹⁸⁶ Dr Ryan, however, noted that as far back as the 1950s independent investigations into mortality in healthcare had achieved “an exponential impact” in reducing deaths.¹⁸⁷ The University of Bristol’s analysis of the LeDeR programme found that it had produced high quality mortality reviews but such reviews not being a mandatory requirement meant quality could be subject to local variation.¹⁸⁸

107. Citing the case of Laura Booth, whose death occurred after a gross failure of care¹⁸⁹ and required public campaigning to secure an inquest, Dr Sara Ryan emphasised the importance of establishing an independent board to review deaths.¹⁹⁰ Dr Ryan argued that the extent to which autistic people and people with learning disabilities die only as result of complex multiple morbidities was exaggerated and said that a lack of proper care was a significant factor in high mortality rates:

These deaths are through things like scabies, constipation, malnutrition, starvation and drowning. These are not deaths through having multiple morbidities [...]. These are deaths through the fact that medical professionals and health and social care professionals do not see a person with learning disabilities as anything other than somehow a flawed person.¹⁹¹

184 Norah Fry Research Centre University of Bristol, [Confidential Inquiry into premature deaths of people with learning disabilities](#) (CIPOLD), March 2013, p 10

185 Journal of Intellectual Disabilities, [Establishing a national mortality review programme for people with intellectual disabilities: The experience in England](#), November 2020

186 [Q126](#)

187 [Q126](#)

188 Journal of Intellectual Disabilities, [Establishing a national mortality review programme for people with intellectual disabilities: The experience in England](#), November 2020

189 See: <https://www.judiciary.uk/wp-content/uploads/2021/05/Laura-Booth-2021-0137-Redacted.pdf>

190 [Q122](#)

191 [Q126](#)

108. In 2020, 97% of deaths had been reviewed by LeDeR.¹⁹² Claire Murdoch (National Mental Health Director, NHS England) told us that the LeDeR programme had investigated more than 9,000 deaths which had created “probably the biggest repository of learning anywhere in the entire world”.¹⁹³ Ms Murdoch acknowledged that more work needed to be done and told us “I will be absolutely clear that I want us to do the do, to make the changes.”¹⁹⁴ Ms Murdoch explained:

We [NHS England and Improvement] are proposing that any parent or relative who wants a LeDeR review should request one, not fight for one, and have one. All people with learning disability or autism who are black or from ethnic groups should have one. A new addition is that all people with autism should. That is somewhat different from saying every single death. It is because we want to make it easy in every instance where it seems that it will add value for a review to happen, and certainly for parents, carers and family members. We really must focus on action. We probably have the biggest set of learning of anywhere in the world.¹⁹⁵

109. In correspondence sent to us on 21 May 2021, Claire Murdoch and Dr Roger Banks (National Clinical Director for Learning Disabilities and Autism, NHS England) told us that it would be possible to make mandatory investigations into the deaths of autistic people and people with learning disabilities within the LeDeR process. However, they warned that this would not be straightforward because of legal responsibilities in terms of notification of deaths and respecting the rights and wishes of patients and families.¹⁹⁶ Accessing sufficient resource and expertise to review the death of every autistic person or person with learning disabilities was also regarded as a potentially problematic.¹⁹⁷

110. In recent years there have been too many incidences of autistic people and people with learning disabilities dying in inpatient settings. Families and friends have too often had to go to extreme and difficult lengths to have independent reviews into such deaths. Of even greater concern is that in some cases, the poor treatment of autistic people and people with learning disabilities has led to people dying unnecessarily in hospital. The evidence we heard presented a compelling case for making mandatory, subject to family consent, an independent review of every autistic person and person with a learning disability who dies in inpatient settings or community settings.

111. *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.*

192 [Q182](#)

193 [Q182](#)

194 [Q182](#)

195 [Qq182–183](#)

196 Correspondence from Claire Murdoch and Dr Roger Banks to Rt hon Jeremy Hunt MP: [Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021](#), 21 May 2021

197 [Q183](#); and Correspondence from Claire Murdoch and Dr Roger Banks to Rt hon Jeremy Hunt MP: [Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021](#), 21 May 2021

An appendix: Correspondence with NHS England & Improvement and the Care Quality Commission: data on autistic people and people with learning disabilities in inpatient facilities

Correspondence with NHSEI and the CQC [22 June 2021] ¹⁹⁸			
	Number of inpatient units	Number of inpatients (Assuring Transformation dataset - 31/03/21)	Further information
Inpatient units rated "inadequate" by the CQC (overall rating)	7	170	1 unit (35 patients) included has been deregistered since 31/03/21. This equates to 8% of all inpatients with a learning disability, autism or both at 31/03/21.
Inpatient units rated "requires improvement" by the CQC (overall rating)	15	185	1 unit (10 patients) included has been deregistered since 31/03/21. This equates to 9% of all inpatients with a learning disability, autism or both at 31/03/21.

¹⁹⁸ [Correspondence to Rt hon Jeremy Hunt MP, Chair, Health and Social Care Committee, from Claire Murdoch CBE, National Director for Mental Health, NHS England, and the Care Quality Commission \[22 June 2021\]](#)

Conclusions and recommendations

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

1. Autistic people and people with learning disabilities have the right to live independent, free and fulfilled lives in the community and it is an unacceptable violation of their human rights to deny them the chance to do so. It is also more expensive to detain autistic people and people with learning disabilities in inpatient settings and this takes up resources that are not then available for more humane community care. We are therefore deeply concerned that community support and provision for autistic people and people with learning disabilities, and financial investment in those services, is significantly below the level required to meet the needs of those individuals and to provide adequate support for them in the community. Fixing this must be a greater priority for both the Department of Health & Social Care and NHS England & Improvement. (Paragraph 23)
2. *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.* (Paragraph 24)
3. *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.* (Paragraph 25)
4. Since the Winterbourne View scandal, over 10 years ago, successive governments have committed to reducing the number of autistic people and people with learning disabilities in inpatient settings and prioritising community support for these individuals. However, missed and delayed policy targets suggest a more radical approach to unlocking funding for community provision is urgently needed. Too often autistic people and people with learning disabilities are assessed as needing to stay in an Assessment and Treatment Unit (ATU) not for temporary assessment or treatment but simply because appropriate community provision is not available, as evidenced by the shocking six year average length of stay. (Paragraph 42)
5. While we welcome the vision set out by Helen Whately MP (Minister of State, Department of Health & Social Care), we believe this is a matter of delivery and

not a matter for further review. At present, the work and output of The Building the Right Delivery Support Group is unclear and risks repeating the previous mistake of focusing on a “voluntary” approach to supporting autistic people and people with learning disabilities rather than addressing the fundamental flaws in funding flows that prevent community provision being adequately provided. The Group does not appear to have a clear plan for improving the practical support autistic people and people with learning disabilities receive when living in the community in order to avoid future admissions or readmissions to inpatient units. (Paragraph 43)

6. The Trieste model of care—characterised by simplified and quicker admissions to and discharges from inpatient facilities; limited number of individuals in inpatient facilities for lengthy durations; and emphasis on well-resourced community support—presents a clear and better alternative to supporting autistic people and people with learning disabilities than is currently in place in England. Crucially, the Trieste model demonstrates that, when legislated for and well-resourced, autistic people and people with learning disabilities can be effectively supported in the community and without unnecessary and lengthy stays in inpatient facilities. (Paragraph 54)
7. *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.* (Paragraph 55)
8. *In pursuing that policy, 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.* (Para 56)

9. *Furthermore, we recommend that autistic people and people with learning disabilities should never be admitted to an 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. (Paragraph 57)*

Reforming inpatient facilities

10. *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 restrictive 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. (Paragraph 74)*
11. *Inpatient facilities do not consistently meet the needs of autistic people and people with learning disabilities and too often this is because of factors such as the unnecessary use of restrictive practices; inpatient facilities being unable to accommodate individuals’ needs to avoid sensory overload; and the distance inpatient facilities are from individuals’ homes. (Paragraph 81)*
12. *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:*
 - i) *designed for easy discharge as well as easy admission;*
 - ii) *physically designed and maintained to meet the needs of autistic people and people with learning disabilities;*
 - iii) *located close to the homes of autistic people and people with learning disabilities; and*
 - iv) *only admits autistic people and people with learning disabilities for short periods of time. (Paragraph 82)*
13. *We have significant concerns about the quality of training and support provided to staff working in inpatient facilities and the negative consequences this can have on the treatment of autistic people and people with learning disabilities in inpatient facilities. While we welcome the pilot of the ‘Oliver McGowan’ training, it is clear that, in some cases, there is a lack of understanding amongst staff working in*

inpatient settings that autistic people and people with learning disabilities do not need to be “cured” and instead need to be consistently put at the centre of their care. Ultimately, a system based on incarceration, restraint and seclusion will create an environment which dehumanises both staff and inpatients. But, if in limited circumstances, autistic people and people with learning disabilities are to be held as inpatients, it is essential for staff to be properly trained so that autistic people and people with learning disabilities receive adequate support from people who understand their condition. (Paragraph 90)

14. *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.* (Paragraph 91)
15. We conclude that the benefits of early diagnosis for conditions like autism are well-understood and late diagnosis presents a particular risk that autistic people will end up with mental illnesses such as anxiety and/or depression. (Paragraph 93)
16. *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.* (Paragraph 94)

Wellbeing and accountability

17. The physical health and wellbeing of autistic people and people with learning disabilities requires greater prioritisation. We believe that the creation of an Intellectual Disability Physician to co-ordinate care in line with the model established in the Netherlands should be fully explored by the Department and NHS England & Improvement; and that this model would be a positive approach to addressing key problems facing autistic people and people with learning disabilities. (Paragraph 102)
18. *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. (Paragraph 103)

19. In recent years there have been too many incidences of autistic people and people with learning disabilities dying in inpatient settings. Families and friends have too often had to go to extreme and difficult lengths to have independent reviews into such deaths. Of even greater concern is that in some cases, the poor treatment of autistic people and people with learning disabilities has led to people dying unnecessarily in hospital. The evidence we heard presented a compelling case for making mandatory, subject to family consent, an independent review of every autistic person and person with a learning disability who dies in inpatient settings or community settings. (Paragraph 110)
20. *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.* (Paragraph 111)

Formal minutes

Tuesday 6 July 2021

Virtual meeting

Members present:

Jeremy Hunt, in the Chair

Dr James Davies

Dr Luke Evans

Barbara Keeley

Anum Qaisar-Javed

Dean Russell

Laura Trott

Draft Report (*The treatment of autistic people and people with learning disabilities*), proposed by the Chair, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Summary agreed to.

Paragraphs 1 to 111 agreed to.

A paper was appended to the Report as Appendix 1

Resolved, That the Report be the Fifth Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Adjourned till Tuesday 13 July 2021 at 9.00 am

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the [inquiry publications page](#) of the Committee's website.

Tuesday 09 February 2021

Alexis Quinn, autism activist, author and Restraint Reduction Network Manager [Q1–5](#)

Dan Scorer, Head of Policy, Public Affairs, Information and Advice, Mencap; **Vivien Cooper**, Founder, Challenging Behaviour Foundation; **Julie Newcombe**, Co-Founder, Rightful Lives; **Ivan Olbrechts**, Representative Body Member, Learning Disability England [Q6–48](#)

Tuesday 13 April 2021

Dr Ian Davidson, Autism Lead, NHS and Royal College of Psychiatrists; **Dr Ken Courteney**, Chair, Royal College of Psychiatrists Intellectual Disability Faculty; **Ian Birrell**, Journalist [Q49–84](#)

Sir Norman Lamb, former Minister at the Department of Health; **Baroness Sheila Hollins**, Founder, Beyond Words; **Dr Theresa Joyce**, Clinical Psychologist and former National Professional Advisor on Learning Disabilities, Care Quality Commission; **Professor Philip Fennell**, Emeritus Professor, Cardiff University [Q85–116](#)

Tuesday 27 April 2021

Bengi O'Reilly, an individual with lived experience; **Dr Sara Ryan**, an individual with lived experience [Q117–130](#)

Helen Whately MP, Minister of State for Social Care, Department of Health and Social Care; **Fiona Walshe**, Director for Mental Health and Disabilities, Shielding and Volunteering Policy, Department of Health and Social Care; **Claire Murdoch**, National Mental Health Director, NHS England; **Roger Banks**, National Clinical Director for Learning Disabilities and Autism, NHS England [Q131–190](#)

Published written evidence

The following written evidence was received and can be viewed on the [inquiry publications page](#) of the Committee's website.

ADL numbers are generated by the evidence processing system and so may not be complete.

- 1 Challenging Behaviour Foundation; Mencap; Rightful Lives; and Learning Disability England ([ADL0001](#))
- 2 Dimensions ([ADL0004](#))
- 3 Fennell, Phil (Professor Emeritus of Mental Health and Mental Capacity Law, Cardiff University) ([ADL0010](#))
- 4 Manchester Metropolitan University ([ADL0012](#))
- 5 Newbold Hope ([ADL0002](#))
- 6 Rightful Lives and Mark Brown ([ADL0009](#))
- 7 Rightful Lives and Mark Brown ([ADL0008](#))
- 8 Royal College of Psychiatrists ([ADL0011](#))
- 9 The Challenging Behaviour Foundation ([ADL0013](#))
- 10 The Challenging Behaviour Foundation ([ADL0014](#))
- 11 The Challenging Behaviour Foundation ([ADL0007](#))

List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the [publications page](#) of the Committee's website.

Session 2021–22

Number	Title	Reference
1st	The Government's White Paper proposals for the reform of Health and Social Care	HC 20
2nd	Workforce burnout and resilience in the NHS and social care	HC 22
3rd	Pre-appointment hearing for the Chair of the Food Standards Agency	HC 232
4th	The safety of maternity services in England	HC 19