



House of Commons  
House of Lords

Joint Committee on Human  
Rights

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# The detention of young people with learning disabilities and/or autism

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**Second Report of Session 2019**

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

*Ordered by the House of Commons  
to be printed 23 October 2019*

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## Joint Committee on Human Rights

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## Summary

We regard ourselves as a civilised society with a respect for human rights. Most people would say we should take extra care to support young people and those who are disabled. But the brutal truth is that we are failing to protect some of the most vulnerable young people - those with learning disabilities and/or autism. And indeed, we are inflicting terrible suffering on those detained in mental health hospitals and causing anguish to their distraught families. The recent BBC Panorama programme showing taunting and abuse of patients at Whorlton Hall exposed the horrific reality for some.

Too often the pathway to detention is predictable. It begins from before diagnosis. A family grows worried about their child. They raise concerns with the GP, and with the nursery or school. It takes ages before they get an assessment and yet more time passes before they get a diagnosis of autism. All that time they struggle on their own with their worries and without help for their child. This pattern continues throughout childhood as families are under-supported and what little help they have falls away when the child reaches the age of 18. Then something happens, perhaps something relatively minor such as a house move or a parent falls temporarily ill. This unsettles the young person and the family struggles to cope. Professionals meet to discuss what should happen, but parents are not asked for their views. Then the child is taken away from their home and the familiarity and routine which is so essential to them. They're taken miles away and placed with strangers. The parents are desperately concerned. Their concerns are treated as hostile and they are treated as a problem. The young person gets worse and endures physical restraint and solitary confinement - which the institution calls "seclusion". And the child gets even worse so plans to return home are shelved. The days turn into weeks, then months and in some cases even years.

This is such a grim picture, yet it has been stark in evidence to our inquiry into the detention of young people with learning disabilities and/or autism. We have lost confidence that the system is doing what it says it is doing and the regulator's method of checking is not working. It has been left to the media, notably the BBC, Sky News and Ian Birrell in the Mail on Sunday, to expose abuse. No-one thinks this is acceptable. There has been a succession of compelling reports including that from the Children's Commissioner for England, Anne Longfield OBE.

Our proposals for change are urgent and they are not complicated. They include:

- The establishment of a Number 10 unit, with cabinet level leadership, to urgently drive forward reform to minimise the number of those with learning disabilities and/or autism who are detained and to safeguard their human rights.
- A review to be carried out by the Number 10 unit of the framework for provision of services for those with learning disabilities and/or autism. At a minimum Government should introduce:
  - a legal duty on Local Authorities and Clinical Commissioning Groups to ensure the availability of sufficient community-based services.

- a legal duty on Local Authorities and Clinical Commissioning Groups to pool budgets for care services for people with learning disabilities and/or autism.
- Stronger legal entitlements to support for individuals. The Government must act on legislative proposals put forward by the Equality and Human Rights Commission, as well as those made by the Independent Review of the Mental Health Act 1983 and campaign groups.
- Care and Treatment Reviews and Care, Education and Treatment Reviews to be put on a statutory footing.
- The criteria for detention under the Mental Health Act must be narrowed to avoid inappropriate detention. Those with learning disabilities and/or autism must only be detained in situations where:
  - treatment is necessary;
  - treatment is not available in the community and only available in detention (i.e. the last and only resort);
  - treatment is of benefit to the individual and does not worsen their condition; and
  - without the treatment, there is a significant risk of harm to the individual or others.
- Families of those with learning disabilities and/or autism must be recognised as human rights defenders, and other than in exceptional circumstances, be fully involved in all relevant discussions and decisions. This should include:
  - On every occasion that anyone is restrained or kept in conditions amounting to solitary confinement their families must be automatically informed.
  - Young people must not be placed long distances from home as it undermines their right to family life under Article 8 ECHR. Financial support must be made available to ensure that families are able to visit their loved ones.
- Substantive reform of the Care Quality Commission’s approach and processes is essential. This should include unannounced inspections taking place at weekends and in the late evening, and the use, where appropriate, of covert surveillance methods to better inform inspection judgements.

Our country is prosperous and values human rights. We cannot turn away from the reality of the lives of these young people and their families. It’s time to act.

# 1 Introduction

## Background to the inquiry

1. In the autumn of 2018, we were conducting an inquiry into the use of restraint and solitary confinement among children in detention settings.<sup>1</sup> Whilst our inquiry was ongoing, the issue of inappropriate or long-term placement of children and young people with learning disabilities and/or autism in mental health hospitals and the threat that such placements pose to their human rights, became the subject of media and parliamentary attention.<sup>2</sup> The catalyst for this was a BBC Radio 4 “File on 4” programme which featured Bethany, a 17-year-old who had, at that point, been a patient at St. Andrew’s Hospital in Northampton for nearly two years.<sup>3</sup> During her time at St Andrew’s, Bethany had been repeatedly restrained and spent most of her time in conditions that amounted to solitary confinement, with no access to treatment or therapy.

2. Given our focus on these matters, we invited Bethany’s father, Jeremy, and other witnesses with lived experience of detention to give evidence to us. What was clear from their testimony, some extracts from which are in the box below, is that the detention of young people with learning disabilities and/or autism not only threatens their rights to private and family life [Article 8 European Convention on Human Rights] and their right to freedom from inhuman and degrading treatment [Article 3 ECHR] but also their right to liberty and security [Article 5 ECHR] and in some cases their right to life [Article 2 ECHR].

“I did not know what was happening. Looking back at it now, it does not feel real. It feels like some sort of nightmare. It was not a safe place. It was not a treatment room. I got no assessment or treatment done. There was no care. I was just put in this room, and I lay there and went to sleep.”<sup>4</sup>

*Witness A, a young man with learning disabilities*

“They restrained me by using a hand against me. They would hold it and twist it in places it should not go. They threw me into my cells and it hurt. I was not allowed to go to the bathroom when I wanted, so I had to ring a bell to let them know. Sometimes they would answer it but sometimes they did not. This made me feel uncomfortable and upset. I really did not like it. It denied us our basic human needs.”<sup>5</sup>

*Witness B, who has a learning disability and who was detained as a young woman*

“A child with my daughter’s sensory issues is placed in a seclusion cell, which is a horrific environment [ ... ]. She then witnesses another person in distress carried past her by a group of staff, with that person kicking, screaming, shouting and crying. The sensory overload that that creates is torture for my daughter. It is absolute, utter torture.”<sup>6</sup>

*Jeremy, whose daughter Bethany was detained at St. Andrew’s Hospital Northamptonshire*

1 The report of that inquiry [Youth detention: restraint and solitary confinement](#) was published in April 2019

2 See for example HC Deb, 6 November 2018, [col 1389](#)

3 BBC Radio 4 File on 4 [Transforming Care - Is it Working?](#) 2 October 2018

4 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q. 2 [Witness A]

5 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q.2 [Witness B]

6 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q. 11 [Jeremy]

“He had his arm broken in a restraint, the right humerus bone. His arm was wrenched up behind his back until the bone snapped. He was then not taken to accident and emergency for 24 hours, even though his arm was completely swollen.”<sup>7</sup>

*Julie Newcombe whose son Jamie was detained for 19 months*

“His arm was broken in three places. He has had black eyes, wrist burns and bruises all over his body. Carpet burns have taken the skin off his face and chin.”<sup>8</sup>

*Anonymous parent quoted by Julie Newcombe in oral evidence*

“He has lost so much weight in there. His primary nurse said they were not concerned. He told me he was scared, because he was not getting any food and he thought they were never going to feed him again.”<sup>9</sup>

*Anonymous parent quoted by Julie Newcombe in oral evidence*

“My son was kept in seclusion for up to nine hours at a time. The rule was that he could not leave until he was quiet. With his anxiety and sensory presentation, there was no way this was possible. He started to bang his head against the wall and would bite the wood in the doorframe out of desperation.”<sup>10</sup>

*Anonymous parent quoted by Julie Newcombe in oral evidence*

3. Fundamental questions needed to be asked about why these young people were being detained, often for long periods, causing their situation to worsen rather than improve. To this end we launched our inquiry on 10 January 2019 and sought views on the following issues:

- Whether the Government’s Transforming Care programme, which aims to significantly reduce the number of those detained inappropriately, has been successful and if not, why not.
- If it has not been successful what needs to be done to ensure that the numbers detained are reduced more rapidly.
- Whether the human rights of children and young people with learning disabilities and/or autism who are detained in mental health hospitals are being breached.
- If, so how are they breached and what needs to be done to better protect them?<sup>11</sup>

4. This inquiry has focused on the situation in England as health and social care matters are devolved to Wales, Northern Ireland and Scotland.

5. In response to our call for evidence we were very grateful to received 50 written submissions, 39 of which have been published on our website, several anonymously. We also received a significant amount of material that we were asked to keep confidential, so although it has influenced our thinking, we have refrained from publishing it. We are grateful to all those who provided information and evidence.

7 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q.14 [Julie Newcombe]

8 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q.18 [Julie Newcombe]

9 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q.18 [Julie Newcombe]

10 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q.18 [Julie Newcombe]

11 [Detention of young people with learning disabilities and/or autism - call for evidence](#)

6. As noted above, we initially held a one-off oral evidence session in the context of our inquiry into the use of restraint and solitary confinement in youth detention. At this session we were very grateful to hear from several witnesses with lived experience of detention; Paul Scarrott, Jeremy, Julie Newcombe and two witnesses with learning disabilities who gave evidence anonymously. The evidence they provided was invaluable in informing this inquiry and we are deeply indebted to them.

7. The evidence we heard in the first session convinced us that we could not leave the matter there and we needed to look further. We held a series of five further oral evidence sessions at which we heard from NGOs, lawyers, regulators, MPs and Government Ministers. We are grateful to them for giving up their time to assist us in this work.

## Scope and terminology

8. The institutions where those with learning disabilities and/or autism are detained are often referred to as Assessment and Treatment Units (ATUs). These are specialist units which are often situated within larger mental health hospitals. They are designed to be short-term secure placements for people with learning disabilities to receive assessment and treatment before moving back into the community. However, in some cases people live in them for years. People with learning disabilities and/or autism are also detained in non-specialist mental health hospitals. In this report when we refer to young people who are detained it should be read as including those in any institution registered by the Care Quality Commission as a hospital, operated by either an NHS or independent sector provider and providing mental or behavioural healthcare in England.<sup>12</sup>

9. We are acutely aware that many of the concerns raised in this report are shared by those who live, or whose loved ones live, in a range of other settings such as residential special schools and supported living arrangements. These are beyond the scope of this inquiry, but we have taken on board the message from those who submitted evidence that it must not be assumed that because people are discharged from hospitals to community settings, that they are free from human rights abuses and we urge those with responsibility for these other institutions to be alert to this fact.<sup>13</sup>

10. We recognise that not all those young people living in ATUs and mental health hospitals are formally detained under mental health or mental capacity legislation. However, we have serious concerns about the treatment of ‘informal’ patients some of whom have told us that they fear challenging their situations for fear of being ‘sectioned’. Therefore, we use the term ‘detained’ in a broad sense to refer to all those young people with learning disabilities and/or autism in ATUs and other mental health hospitals.

11. This inquiry has focused on younger people, but we recognise that there are many older adults in similar situations, some of whom are now detained because of failures to provide adequate support for them when they were younger. Many of the recommendations made in this report apply to all those with learning disabilities and/or autism regardless of age.

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12 This is the definition used by NHS Digital to compile the [Assuring Transformation](#) data collection

13 See for example Anonymous 16 ([YDA0026](#))

## 2 Transforming Care

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### Background

12. It has long been apparent that many people with a learning disability and/or autism are placed in secure settings inappropriately. In July 2011 a BBC ‘Panorama’ programme revealed abuse of patients with learning disabilities and autism at Winterbourne View. The Department of Health’s national policy response, “Transforming Care: A National response to Winterbourne View Hospital” stated that “hospitals are not where people should live” and pledged that everyone inappropriately in hospital would move to community-based support as quickly as possible and no later than 1 June 2014.<sup>14</sup>

13. When this target was missed, NHS England commissioned Sir Stephen Bubb to consider how a new national framework for learning disability services could be implemented. His report, “Winterbourne View - Time for Change”, again found that people with learning disabilities and/or autism in England were being placed inappropriately in long-term institutional care rather than being supported in the community.<sup>15</sup>

14. Further to this, in October 2015, NHS England published “Building the right support” which set a target to reduce the number people with a learning disability and/or autism in hospitals by 35% to 50% by March 2019.<sup>16</sup> Key elements of the plan to achieve this included:

- Care and Treatment Reviews (CTRs): introduced to bring together the person with a learning disability and/or autism, their families/carers, independent expert advisors—one clinical and one expert by experience, the multi-disciplinary team involved in their care, and commissioners. Their aim is to look at whether someone’s care is safe, effective, whether they need to be in hospital and whether there is a plan in place for the future. Care, Education & Treatment Reviews (CETRs) perform a similar function for a child or young person but include education.
- Transforming Care Partnerships (TCPs): 49 local partnerships comprising Clinical Commissioning Groups (CCGs), NHS England’s specialised commissioners and local authorities were set up across England. The partnerships were tasked to develop implementation plans covering a three-year period from 2016–2019.
- A national service model: this was developed with the help of people with lived experience, clinicians, providers and commissioners. It set out the range of support that should be in place no later than March 2019.<sup>17</sup>
- A new financial framework to underpin delivery of the new care model: was introduced. This included asking local TCPs to use the total sum of money they spend as a whole system on people with a learning disability and/or autism to deliver care in a different way that achieved better results. As part of this CCGs were encouraged to pool their budgets with local authorities.

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

15 Sir Stephen Bubb, [Winterbourne View - Time for Change](#), 2014

16 NHS England, [Building the right support](#), October 2015

17 NHS England, [Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition](#), October 2015

## Progress to date

15. Over the period in which Transforming Care has operated some limited progress has been made but the number of people in inpatient care remains stubbornly high.

### Key statistics: July 2019

- In July 2019, 2,270 people remained in institutions.<sup>18</sup> This represents a net reduction of just 125 people over the lifetime of ‘Transforming Care’.<sup>19</sup>
- Of the 2,270 over half (57%) had a total length of stay of over 2 years.
- The number of children in these settings has more than doubled from 110 in March 2015 to 255 in July 2019.<sup>20</sup>
- The number of children and young people in these settings aged 0–24 stands at 680.<sup>21</sup>
- 625 (28%) of those with learning disabilities and/or autism in such institutions have a care plan which states that they do not need inpatient care.<sup>22</sup>

16. When we asked Ray James, National Learning Disability Director at NHS England, about the steep increase in the number of children with learning disabilities and/or autism who are in these hospitals he told us:

“In part, there have been changes to the way in which the numbers are recorded and counted. In particular, autistic young people who receive treatment in mental health in-patient beds are now counted in the current number; they were not consistently counted that way when the number was 110. I do not want to give the impression that I am trying to explain away changes in data due to the way in which the data is collected and presented, but that is a helpful point of understanding.”<sup>23</sup>

17. Evidence from the National Autistic Society highlights that there has been a 24% rise in autistic people without an accompanying learning disability being admitted to mental health hospitals since 2015. More than one in four of the autistic inpatients had been in these hospitals for five years or more and 30% had been identified as no longer needing inpatient care. The organisation contends that this is because Transforming Care did not fully consider the needs of autistic people.<sup>24</sup>

18. Ray James from NHS England noted that the proportion of patients who currently have a diagnosis of autism and no learning disability is high among children at 70%. He felt that this was “a clear signal that, across public service, we need to ensure that we

18 [Learning Disability Services Monthly Statistics AT: July 2019 MHSDS: May 2019](#) Reference Data Tables, Table 2.

19 [Learning Disability Services Monthly Statistics AT: July 2019 MHSDS: May 2019](#) Reference Data Tables, Table 2. In March 2015, 2395 people were in inpatient facilities.

20 [Learning Disability Services Monthly Statistics AT: July 2019 MHSDS: May 2019](#) Reference Data Tables, Table 2.

21 [Learning Disability Services Monthly Statistics AT: July 2019 MHSDS: May 2019](#) Reference Data Tables, Table 2.

22 [Learning Disability Services Monthly Statistics AT: July 2019 MHSDS: May 2019](#) Reference Data Tables, Table 6.

23 [Q2 \[Ray James\]](#)

24 [The National Autistic Society \(YDA0044\)](#)

keep having more work to develop our understanding of what is needed in community settings in order to reduce the likelihood of those admissions particularly for autistic young people.”<sup>25</sup>

19. The Centre for Welfare Reform warned that even the apparent progress that has been made, may in fact be less than it seems:

“ [T]he targets set to reduce adult placements have not been met and there seems a strong likelihood that even the very modest progress that is reported is highly exaggerated. It seems likely that people are being moved - not back home - but into moderately less institutional services.”<sup>26</sup>

20. Mencap and the Challenging Behaviour Foundation are similarly concerned that many who are discharged under the Transforming Care programme are later readmitted. They point to a 2018 report from the Voluntary Organisations Disability Group (VODG) which found that people discharged from inpatient units are often readmitted within months due to community placements failing.<sup>27</sup>

21. The latest phase of the Transforming Care programme officially came to an end at the end of March 2019. In the House of Commons on 23 May, Caroline Dinenage MP, Minister for Care, confirmed that it will continue.<sup>28</sup> On 10 October 2019, NHS England announced the establishment of a new taskforce to “improve current specialist children and young people’s inpatient mental health, autism and learning disability services in England.” It was also announced that Anne Longfield OBE, the Children’s Commissioner for England, will chair an independent board to scrutinise the work of the taskforce.<sup>29</sup>

## NHS Long Term Plan

22. The NHS Long Term plan, published in January 2019, set a revised target for reducing the number of those with learning disabilities and/or autism in inpatient units:

“By March 2023/24, inpatient provision will have reduced to less than half of 2015 levels (on a like for like basis and taking into account population growth) and, for every one million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit. For children and young people, no more than 12 to 15 children with a learning disability, autism or both per million, will be cared for in an inpatient facility.”<sup>30</sup>

23. Those making written submissions to this inquiry expressed concern that this is an unambitious target which lacks clear policies to resolve the systemic problems that leave people in inpatient care for extended periods of time.<sup>31</sup> Rt Hon Norman Lamb MP, who was Minister for Care and Support under the Coalition Government between September 2012 and May 2015, told us:

25 [Q2](#) [Ray James]

26 Centre for Welfare Reform ([YDA0036](#))

27 Challenging Behaviour Foundation and Mencap ([YDA0014](#))

28 HC Deb, 23 May 2019, [col 817](#)

29 NHS England, [NHS taskforce to drive improvements in young people’s hospital mental health, learning disability and autism care](#), (10 October 2019)

30 NHS England [NHS Long Term Plan](#) January 2019

31 Dimensions ([YDA0012](#)), Challenging Behaviour Foundation and Mencap ([YDA0014](#))

“The target that has been set is not challenging enough. You alluded to the target and the deadline of March 2019 for reducing the numbers by between a third and a half. We fell well short of a third. Twenty-something per cent was achieved. To shift that to 2023 just sends the signal to the system: “Take your foot off the pedal”.”<sup>32</sup>

Anne-Marie Trevelyan MP agreed that the target needs to be more ambitious:

“The target is the wrong way round. The target should be zero and the exception should be justified. Norman is exactly right: the vast majority of these young people should not be there in the first place and, if given the appropriate assessment and care packages pulled together, do not need to be in that environment at all. We need to turn it on its head”<sup>33</sup>

## Other relevant policy developments

24. The Independent Mental Health Act (MHA) Review was published on 6 December 2018. Its recommendations include making changes to the criteria for detention under the Mental Health Act 1983, giving health and social care commissioners a duty to collaborate to ensure provision of community-based support and treatment for people with a learning disability, autism, or both and putting Care and Treatment Reviews on a statutory footing.

25. At the end of 2018, in response to the media and parliamentary attention about the treatment of those with learning disabilities and/or autism in detention, the Government asked the Care Quality Commission (CQC) to review the use of restrictive interventions on those with mental health problems and learning disabilities and/or autism in hospitals and care homes. On 21 May 2019 the CQC published its interim report which focused on 39 people who are cared for in segregation on a learning disability ward or a mental health ward for children and young people. It found that for many:

“[t]heir world is narrowed to a highly restricted existence in a single room, or small suite of rooms. For many, their interactions with other people are characterised by distress and sometimes by the use of force by staff who consider this necessary to protect the person or others from harm.”<sup>34</sup>

26. Also, in May 2019 the Children’s Commissioner for England produced a highly critical report on the experiences of children with learning disabilities and autism detained in mental health hospitals.<sup>35</sup>

27. In April 2014 the Government published ‘Think Autism’, a strategy for meeting the needs of autistic adults in England.<sup>36</sup> The strategy supports the Autism Act 2009. On 14 March 2019 the Department of Health and Social Care, working with the Department for Education, launched a review of the strategy. As part of this review, there are plans to extend the strategy to cover children as well as adults.<sup>37</sup>

32 [Q33](#) [Rt Hon Norman Lamb MP]

33 [Q33](#) [Anne-Marie Trevelyan MP]

34 Care Quality Commission, [Interim report: Review of restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability and or autism](#), 21 May 2019

35 Children’s Commissioner, [Far less than they deserve](#), May 2019

36 HM Government, [Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#) April 2014

37 HM Government, [Review of the National Autism Strategy ‘Think Autism’](#), March 2019

## Political accountability

28. The list of reviews, reports and policy initiatives above testifies to the fact that this issue 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. Rt Hon Norman Lamb MP considered this was because:

“It does not have enough priority within government, bluntly. It is fair to say that this issue was the most frustrating issue I dealt with as Minister up to 2015. I saw complete inertia in the system, a system that was refusing to change. Bear in mind that in December 2012 we published Transforming Care, which was a concordat. In other words, NHS England, the Local Government Association and all the key players signed up to a commitment to change, and then they failed to do it. [ ... ] You need national leadership and a sense of mission to drive through changes, to change this scandalous practice, because we are simply not achieving change fast enough.”<sup>38</sup>

29. Bethany’s situation shows the human impact of the inertia that persists. On 17 October 2019, more than a year after her case was brought to public attention by the BBC, her father Jeremy released a public statement agreed by all the parties involved in the legal action he took challenging his daughter’s detention and treatment:

“At mediation on 25 September 2019, agreement was reached which has resolved matters, including the claim for damages, without the need for further litigation. St Andrew’s Healthcare and NHS England have accepted that the care provided to Bethany did not always comply with the Mental Health Act Code of Practice and the NICE Guidelines on managing violence and aggression. This affected her wellbeing and made it harder for her to return to live in the community.”<sup>39</sup>

In a blog post accompanying the statement Jeremy revealed that, despite these admissions and the media attention on her case, Bethany remains in “seclusion” and that as we write, her situation is in fact worse than ever. Having left St. Andrew’s in late 2018, she was in two other placements before moving to a medium secure hospital in summer 2019 where she is now detained. Jeremy describes her life in this institution:

“And that is where she remains. Locked away again in a cell. No daily access to fresh air. [ ... ] This time there isn’t even a hatch to hold her hand through. When I phone her the staff put a phone on the floor in the corridor and Beth lies on the floor to talk to me under the door. [ ... ] Investigations into abuse by staff have had to begin, some have been removed after shouting at her and calling her names. Beth reported they mimic her rocking and her speech. A safeguarding investigation was stopped after Beth was unable to specify the dates the alleged abuse occurred. [ ... ] When I visited Beth the other day, I went into her cell and as I approached her as she sat on the thin mattress on the floor that serves as her bed, I asked her if she wanted to stand up for a hug. She sat there mournfully and flatly replied “I can’t

38 [Q33](#) [Rt Hon Norman Lamb MP]

39 Jeremy, [The System is broken. The update on Beth’s journey and the legal action](#), 17 October 2019

... I'm not allowed to stand up if the door is open." This type of control is brutal and unnecessary. She is more restricted with the door open than with it shut."<sup>40</sup>

**30. Given the limited progress to date, we have no confidence that the target to reduce the numbers of people with learning disabilities and/or autism in mental health hospitals, set out in the NHS Long Term plan, will be met. We welcome the recent establishment, by NHS England, of a taskforce to drive improvements in inpatient care and an independent oversight board to be chaired by the Children's Commissioner for England to oversee the taskforce's work. However, this will not address the biggest barrier to progress - a lack of political focus and accountability to drive change. *To urgently minimise the number of those with learning disabilities and/or autism who are detained and to safeguard their rights, a Number 10 unit, with cabinet level leadership, must be established to ensure reform is driven forward.***

### 3 Ending harmful detention

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31. Although it is government policy to significantly reduce the number of children, young people and adults with learning disabilities and/or autism who are detained, it remains far too high. In this chapter we look in more detail at the reasons for this and make proposals for change.

#### Why are people detained?

##### *Failure to support young people and families*

32. Dame Christine Lenehan, Director of the Council for Disabled Children, told us that when young people are detained it is usually the result of a long and predictable series of failures to appropriately support them and their family.<sup>41</sup> The first failure is often delay in diagnosis. Dimensions, a not-for-profit support provider for adults with learning disabilities and autism, explained:

“Importantly, for many young people with a learning disability and/or autism, a diagnosis should be made in childhood. On this basis, local authorities should be able to effectively plan services that meet the needs of young people and their families long in advance, so that there is never, or very seldom, a need for admission. The current backlog for diagnosis, particularly for autism, limits opportunities to plan for individuals as they grow up.”<sup>42</sup>

33. The Minister for Care, Caroline Dinenage MP, recognised that delays in diagnosis were a significant problem. She told us that the Government was setting a clear target of three months from referral to diagnosis and for the first time would be collecting data so that NHS Trusts could be held to account where there were delays. This is very welcome.<sup>43</sup>

34. Even after diagnosis, families told us that they faced a constant battle with the system to access the services to which they were entitled. One mother told us:

“Our experience with our (central London) LA [local authority] is that there is institutionalised, systematic refusal to meet statutory obligations as a routine matter in all aspects of education, health and social care provision. [ ... ]

Our experience [ ... ] is that they are reactive (if there is a reaction at all) and preventative help is largely a myth. It has been said to me on a number of occasions that help might be more readily available if Rachel was actively self harming (she has severely self harmed in the not too distant past with a serious suicide attempt in 2016) or if her levels of self harm escalated to another suicide attempt. This is frankly unbelievable. But, again, sadly I suspect, not unusual.”<sup>44</sup>

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41 [Q13](#) [Dame Christine Lenehan]

42 [Dimensions](#) ([YDA0012](#))

43 [Q28](#) [Caroline Dinenage MP]

44 [Anonymous 14](#) ([YDA0047](#))

35. In her evidence to us the Minister for Care, Caroline Dinenage MP accepted that failure to support young people and their families at an early stage was often a reason for detention later on:

“All too often, what you have heard is right: young people end up in an in-patient setting as a result of a number of failed opportunities to intervene earlier, provide the right support and maybe diagnose them from an early stage.”<sup>45</sup>

36. In part, this dearth of support is a result of reduced funding. The Centre for Welfare Reform notes:

“In principle Transforming Care did recognise that investing in local services was essential. However, the nature of austerity means that it has been those very services, the most local, preventive and flexible services, the ones that help people avoid institutional care, that were the first to be cut.”<sup>46</sup>

**Routes into detention**

37. Because support for many families is so limited, when something, perhaps quite small, goes wrong, admission to inpatient care is used as a first rather than last resort.<sup>47</sup> Dimensions gave the following examples:

“[ ... ] the parent as the primary carer falls ill and can’t deliver care for a week or so; or renovations to their house means a change in the pattern of living at home and unsettles their loved one. These instances show how very minor events can have life changing consequences where care and support is hanging on a thread.”<sup>48</sup>

38. This diagram, submitted in written evidence from the Centre for Welfare Reform, shows how a pattern of institutionalisation develops for many young people.<sup>49</sup>

Why people end up in ATUs and private ‘hospitals’...



[Source: Duffy S (2013) Returning Home. Sheffield, The Centre for Welfare Reform]

<http://bit.ly/returnhome>

45 [Q20](#) [Caroline Dinenage MP]  
 46 Centre for Welfare Reform ([YDA0036](#))  
 47 [Q13](#) [Simon Duffy]  
 48 Dimensions ([YDA0012](#))  
 49 Centre for Welfare Reform ([YDA0036](#))

## Impact of detention

39. Once detained, young people's situations can worsen rather than improve. The effects of trauma experienced in detention make it increasingly difficult for someone to go home.

“Think about somebody going through all those things—violence, abuse, other things that happened to him in these places—for 19 months. When he comes out, he is not just going to carry on as normal. Forget that. He was damaged. He still is damaged and it is three years later.”<sup>50</sup>

*Julie Newcombe whose son Jamie was detained for 19 months*

“I was told that he would be admitted for a 12 week assessment period where he would access a variety of therapies to help him. In fact he ended up being there for 2 years. He was restrained, overmedicated and was not treated with respect or understanding. [ ... ] At one point he became so anxious due to hearing the shouting and screaming of other service users who were acutely unwell that he shut himself in his bathroom and smashed the toilet. As a result he broke his finger and had to have surgery. [ ... ] On discharge he lived in the community for 2 and a half years but the provider could not meet his needs as he had been so traumatised from the ATU and ended up just sleeping most days.”<sup>51</sup>

*Mother whose 17 year old son was detained in an ATU for over 2 years*

## Lack of alternative community provision

40. A major barrier preventing successful discharge is the lack of flexible support in the community.<sup>52</sup> In a joint submission Inclusion London, People First (Self Advocacy) and Changing Perspectives told us:

“Young people end up in the psychiatric system because of local authorities’ and clinical commissioning groups’ systematic failure to fund well-coordinated education, health and care services.”<sup>53</sup>

41. The quality of support services is a barrier even if they are available. We were told by the campaign group Rightful Lives that:

“Services are often too prescriptive and are not designed alongside the individual and their family. Without drawing on the valuable experience and expertise of loved ones, services end up delivering poor support that does not fulfil the person or meet their needs. It becomes far more likely that the person will then display behaviours that lead to inpatient admission.”<sup>54</sup>

50 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q. 14 [Julie Newcombe]

51 Mrs Lisa Cookson ([YDA0019](#))

52 See for example Mr Ian Penfold ([YDA0016](#))

53 Inclusion London, People First (Self Advocacy) and Changing Perspectives ([YDA0029](#))

54 Rightful Lives ([YDA0034](#))

42. Lack of appropriate housing has been highlighted as major issue. In some cases, people cannot leave hospital because there is simply nowhere for them to go.<sup>55</sup> Housing options for people across the autistic spectrum are needed but are not currently being developed.<sup>56</sup>

43. Many of those young people admitted to mental health hospitals do not have mental health problems but some do, and others may develop them as a result of being detained. If they are to be discharged successfully it is essential that access to specialist mental health and behavioural support services is available in the community. Dr Nell Munro from the University of Nottingham argues that an increase in such provision is the most vital change needed to reduce the number of people detained more rapidly than at present.<sup>57</sup>

### Funding disincentives

44. In large part the lack of community-based services is a result of disincentives operating in the funding framework. Jeremy explained this in the context of his daughter Bethany's situation:

“[Local authorities] love the fact that, when they place our children in these units, they are no longer paying the bill. My daughter's care in St Andrew's is approaching £15,000 a week. That is an awful lot of money, the best part of £800,000 a year or £1.6 million so far. A cash-strapped local authority does not want that bill. Actually, it would not cost them that much. There could be a massive saving. [ ... ] The money is going into the wrong part of the system. It is not going into prevention; it is going into the very top, when the failures have happened, and there is nothing else to do with our children but lock them away. That must be reversed. It must.”<sup>58</sup>

45. Transforming Care attempted to remedy this disincentive by encouraging local CCGs and local authorities to pool their budgets. However there has been limited success in achieving this. In March 2017 the National Audit Office published its assessment of the Transforming Care Programme. One of its conclusions was that money was not being released from mental health hospitals quickly enough to help pay for extra community support. This was in part because mechanisms to pool budgets within Transforming Care Partnerships were not yet working as intended. As of summer 2016, only one third of clinical commissioning groups had pooled their budgets with individual local authorities.<sup>59</sup> The Children's Commissioner for England Anne Longfield OBE, in her report on children with learning disabilities or autism living in mental health hospitals published in May 2019, confirmed that pooled budgets have still not become widespread.<sup>60</sup>

46. Witnesses to our inquiry were also concerned that private sector providers had a vested interest in maintaining occupancy rates and profits.<sup>61</sup> There are particular concerns about

55 Rightful Lives ([YDA0034](#))

56 The National Autistic Society ([YDA0044](#))

57 Dr Nell Munro ([YDA0020](#))

58 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q 16 [Jeremy]

59 National Audit Office, Department of Health, [Local support for people with a learning disability](#), Session 2016–17, HC 1053, March 2017

60 Children's Commissioner, [Far less than they deserve](#), May 2019

61 See for example: Penn Little ([YDA0009](#))

potential for conflicts of interest for clinical staff, employed by such private companies, who have responsibility for making assessments about whether a young person should be discharged.<sup>62</sup>

47. Jonathan Marron, Director General, Community and Social Care at the Department of Health and Social Care rebutted the idea that current financial arrangements give providers a perverse incentive for keeping people in detention:

“Our challenge is whether we have the right community services in place either to help people not go into in-patient services or, indeed, to allow a quicker discharge. That is our big problem. [ ... ]. That is what is holding us back, not an incentive problem.”<sup>63</sup>

## Conclusion

48. **The detention of those with learning disabilities and/or autism is often inappropriate. It causes suffering and frequently makes their conditions worse. Nevertheless, their detention continues even when there is a consensus among families, professionals and Commissioners that individuals are not receiving appropriate medical treatment and do not need to be detained.**

49. **The right housing, social care and health services needed to prevent people being detained inappropriately are simply not being commissioned. Change is urgently needed. We therefore recommend that the Number 10 unit we propose, must review the framework for the provision of services for those with learning disabilities and/or autism. At a minimum the Government should introduce:**

- ***a legal duty on Local Authorities and Clinical Commissioning Groups to ensure the availability of sufficient community-based services.***
- ***a legal duty on Local Authorities and Clinical Commissioning Groups to pool budgets for care services for people with learning disabilities and/or autism.***

50. Alongside stronger legal requirements on public bodies to provide appropriate services, individuals also need stronger legal entitlements to the support they need to lead independent, positive lives in the community. Rt Hon Norman Lamb MP told us:

“I still feel very strongly that [new legal rights for individuals and for families] are needed. When you talk to families of people with learning disabilities or with autism, too often you just hear that they feel completely powerless. They have no voice in the system at all. No one listens to them. That is not to say that giving new legal rights suddenly changes the world, but it is part of changing the culture and shifting the balance of power towards individuals and away from the bureaucracy.”<sup>64</sup>

51. A number of organisations are currently looking at ways to strengthen individual rights:

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62 Rightful Lives ([YDA0034](#))

63 [Q28](#) [Jonathan Marron]

64 [Q38](#) [Rt Hon Norman Lamb MP]

- a) The Equality and Human Rights Commission is currently developing proposals for legislative change to strengthen disabled people’s right to live independently and be included in the community.<sup>65</sup>
- b) Rightful Lives, a parent-led campaign group has recently published an 8 Point Plan setting out changes they would like to make to the inpatient hospital system and the way in which people with learning disabilities and autistic people are supported. This plan calls for enhanced legal rights to “strengthen people’s right to independent living and a life free from the threat of detention, with community alternatives to hospital care.”<sup>66</sup>
- c) The Independent Review of the Mental Health Act 1983 suggested that Mental Health Tribunals should be given a power to require support in the community.<sup>67</sup>

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

53. In our “Enforcing human rights” report, published in 2018, we noted how difficult it often is in practice for individuals to enforce rights that are enshrined in law. This is due to a lack of access to justice for many and an underdeveloped and inconsistent culture of human rights in our public services.<sup>68</sup> ***In addition to strengthening rights it is imperative that more is done to ensure young people with learning disabilities and/or autism are able to enforce existing ones. To this end, we repeat here key recommendations made in our “Enforcing human rights” report:***

- ***Public authorities must comply with their duty under s.6 of the Human Rights Act in order to prevent breaches of individuals’ human rights.***
- ***The Government must revise the financial eligibility criteria for legal aid with a view to widening access to those who would otherwise be unable to enforce their human rights.***
- ***Families must be given non-means tested funding for legal representation at inquests where the state has separate representation for one or more interested persons.***

## Care and Treatment Reviews and Care, Education and Treatment Reviews

54. We have heard that Care and Treatment Reviews (CTRs) and Care, Education and Treatment Review (CETRs), when they work well can be instrumental in preventing detention. Dame Christine Lenehan told us that data on CETRs in the community before admission, or pre the possibility of admission, show that they prevent 80% of children who

65 Equality and Human Rights Commission ([YDA0045](#))

66 Rightful Lives, [8 Point Plan Consultation](#)

67 Wessely S and others, [Modernising the Mental Health Act: Increasing choice, reducing compulsion](#) (Final report of the Independent Review of the Mental Health Act 1983) December 2018, recommendation 47.

68 Joint Committee on Human Rights, Tenth Report of Session 2017–19, [Enforcing human rights](#), HC 669 / HL Paper 171

go through that process being admitted.<sup>69</sup> She urged NHS England to provide more data and analysis of the process so it could be better understood how the reviews are helping to prevent admissions. Are they coming up with positive solutions or are they avoiding or delaying addressing the situation?

55. Other witnesses had less positive experiences of these types of review. Julie Newcombe from Rightful Lives, told us:

“CTRs, which were the big flagship thing about transforming care, routinely do not get done properly, or if they are the recommendations are not followed up. They just get put in a drawer in cyberspace.”<sup>70</sup>

56. NHS England guidance says that CTRs or CETRs should take place at 3 monthly intervals for children in all hospital settings and for adults in non-secure settings at 6 monthly intervals and for adults in secure settings at 12 monthly intervals.<sup>71</sup> It is not clear that this is happening. Data collected at the end of July 2019 showed that 37% of inpatients last had a review over 6 months ago.<sup>72</sup>

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

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69 [Q15](#) [Dame Christine Lenehan]

70 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q.18 [Julie Newcombe]

71 NHS England, [Care and Treatment Reviews \(CTRs\): Policy and Guidance](#), March 2017

72 NHS Digital, [Learning Disability Services Monthly Statistics Data from the Assuring Transformation Collection - July 2019 Main Report](#), August 2019

## 4 The legal framework for detention

58. The detention of young people with learning disabilities and/or autism engages numerous human rights under the European Convention on Human Rights, incorporated into domestic law by the Human Rights Act 1998, as well as various rights provided by international conventions which are legally binding on the UK in international law.

### Convention rights

59. The following Convention rights are particularly relevant to the detention of young people with learning disabilities and/or autism in mental health hospitals:

- a) Article 2 places an obligation on public authorities<sup>73</sup> to protect the right to life, a prohibition on the taking of life, and a procedural obligation to investigate deaths. Where deaths occur in detention, or there is an imminent risk of death, Article 2 is engaged.
- b) Article 3 prohibits torture, inhuman or degrading treatment. Where conditions in detention reach a certain level of gravity, Article 3 may be engaged.
- c) Article 5 prohibits arbitrary deprivation of liberty. A person of “unsound mind”<sup>74</sup> may be lawfully deprived of their liberty if it is lawful, necessary and proportionate. Where a person is detained on the grounds of mental ill-health or mental incapacity, Article 5 is engaged.
- d) Article 8 provides the right to respect for a private and family life. This requires public authorities to protect the right to personal autonomy, physical and psychological integrity, and the maintenance of relationships with others. Where an individual’s autonomy or integrity is interfered with, or where individuals are removed from their families, Article 8 is engaged.
- e) Article 14 provides for the right not to be discriminated against in relation to the other Convention rights. Where young people with learning disabilities and/or autism are discriminated against in relation to the enjoyment of their Convention rights, Article 14 is also engaged.

### The Equality Act 2010

60. The Equality Act 2010 protects against discrimination on the grounds of protected characteristics, including disability. It requires reasonable adjustments to be made for disabled people.<sup>75</sup> It also requires public authorities to have due regard to the need to eliminate discrimination, to promote equality of opportunity for people with protected characteristics and to foster good relations between people who share a protected

73 This applies to ‘core’ public authorities, which includes all bodies that are obviously public in nature (e.g. NHS trusts, prisons, local authorities) and ‘functional’ public authorities which includes any person whose functions are of a public nature. Section 6(3) Human Rights Act 1998.

74 This term is used to reflect the wording of the Convention but is considered archaic and stigmatising and is not endorsed by this Committee.

75 Equality Act 2010, [Section 20](#)

characteristic and those who do not.<sup>76</sup> Where adverse impact for people sharing a particular protected characteristic is detected, having considered these three aims, public bodies need to consider whether there are ways they could reasonably mitigate that impact.<sup>77</sup>

## International human rights treaties

61. The UK is a signatory to a number of international human rights treaties which are legally binding in international law. Of particular relevance is Article 19 of the UN Convention of the Rights of Persons with Disabilities (UNCRPD), which provides for the right of disabled people to live independently in their communities.<sup>78</sup>

## Deprivation of liberty

### *When can a person be lawfully deprived of their liberty?*

62. Article 5 of the European Convention provides that no one shall be arbitrarily deprived of his or her liberty. The European Court has provided that a person is deprived of liberty for the purpose of Article 5 where the following three elements are present:

- a) Confinement in a particular place for a not negligible period of time (the objective element);
- b) Lack of valid consent (the subjective element);
- c) Attribution of responsibility to the State (i.e. where the State knows or ought to know).<sup>79</sup>

63. Case law has established that Article 5 provides procedural safeguards for persons deprived of their liberty on the ground of “unsound mind”. It requires:

- a) Objective medical evidence of a true mental disorder of a kind or degree warranting compulsory confinement, which persists throughout the period of detention;<sup>80</sup>
- b) Consideration of less restrictive alternatives;<sup>81</sup>
- c) Independence between those providing the care and treatment and those authorising the deprivation of liberty;<sup>82</sup>
- d) The right to a speedy determination by a court of the lawfulness of the detention and immediate release where the deprivation of liberty is found to be unlawful or no longer necessary;<sup>83</sup>

76 Equality Act 2010, [Section 149](#)

77 [Equality Act 2010](#)

78 UNCRPD, [Article 19](#)

79 *Storck v Germany* (Application No. 61603/00) at para 74; *Stanev v Bulgaria* (Application No. 36760/06) at para 117

80 *Stanev v. Bulgaria*, para. 145; *D.D. v. Lithuania* [2012] ECHR 254, para. 156; *Kallweit v. Germany*, App. No. 17792/07, para. 45; *Shtukaturov v. Russia*, Application No. 44009/05 [2008] ECHR 223, para. 114; *Varbanov v. Bulgaria*, Application No. 31365/96 [2000] ECHR 457, para. 45; and *Winterwerp v. the Netherlands* (1979–80) 2 EHRR 387 (Application No. 6301/73), para 39

81 *Stanev v Bulgaria* (2012) 55 EHRR 22 (Application No. 36760/06), para 43

82 *IN v Ukraine* (Application No. 28472/08), para 81

83 European Convention on Human Rights, [Article 5\(4\)](#)

e) Regular reassessment of whether detention criteria are met.<sup>84</sup>

64. There is an exhaustive list of circumstances in which a person can be lawfully deprived of his or her liberty. Article 5(1)(e) provides an exception for the lawful detention of persons of “unsound mind”.<sup>85</sup> There are three elements which must be satisfied to justify detention on this ground:

- a) The individual must be reliably shown to be of unsound mind;
- b) The mental disorder must be of a kind or degree warranting compulsory confinement;
- c) The mental disorder must be persisting.<sup>86</sup>

65. If the place or conditions of detention do not rationally connect with the reason for detention, Article 5 will be violated.<sup>87</sup>

## Deprivation of liberty on grounds of mental health or mental capacity

66. The law in England and Wales provides for the detention of individuals on the grounds of mental ill-health or mental incapacity in various ways, with the majority detained under one of the following regimes:<sup>88</sup>

### *The Mental Health Act 1983*

67. We understand that the majority of detentions for inpatient treatment for mental disorder are authorised under the Mental Health Act 1983 (MHA).<sup>89</sup> Individuals may be admitted and detained under section 2 of the Mental Health Act 1983 (MHA) if suffering a mental disorder that warrants detention for *assessment*, and if they “ought to be” detained for their own health/safety or the protection of others, for a period not exceeding 28 days.<sup>90</sup>

68. Individuals may be admitted and detained under section 3 MHA 1983 if detention is necessary for the purpose of assessment for *treatment* if suffering from a mental disorder which makes it appropriate for him/her to receive medical treatment in hospital; and it is necessary for his/her health or safety or the protection of others and it cannot be provided unless detained; and the appropriate medical treatment is available. This would only apply to individuals with a learning disability if associated with ‘abnormally aggressive

84 Winterwerp v. the Netherlands, (1979–80) 2 EHRR 387 (Application No. 6301/73). For a fuller discussion of these requirements, see Law Commission, *Mental Capacity and Deprivation of liberty*, HC 1079, March 2017, p 243; and European Court of Human Rights, *Guide on Article 5: Right to Liberty and Security*, April 2018.

85 This is an archaic and stigmatising term which is reproduced here for accuracy to reflect the exact wording of the Convention.

86 Winterwerp v Netherlands (1979) 2 EHRR 387; Johnson v UK (1997) 27 EHRR 296

87 Mayeka v Belgium App No 13178/03, para 102; R (Suppiah) v Secretary of State for the Home Department [2011] EWHC2 (Admin)

88 In addition, individuals may be detained in hospital by virtue of various hospital orders given by the Magistrates or Crown Court for patients involved in criminal proceedings. There may be emergency situations where the law will allow for short-term detention (e.g. life-saving treatment)

89 Statistics are unavailable. However, based on the evidence we received, and the samples used in the recent reports of the CQC and the Children’s Commissioner, we can infer that section 3 MHA is the legal mechanism by which the majority are detained in ATUs. Also, see Dr Lucy Series ([YDA0046](#))

90 Mental Health Act 1983, [Section 2](#)

or seriously irresponsible conduct'.<sup>91</sup> There is no such additional requirement for those with autism. Autism is currently defined as a 'mental disorder' under the Mental Health Act, which means that autistic people can be sectioned without having a treatable mental health condition. Organisations such as the National Autistic Society are therefore calling on the Government to set up an independent review of the 'mental disorder' definition under the Act.<sup>92</sup>

69. Section 3 MHA provides that "appropriate medical treatment" must be available. Medical treatment is defined in section 145 MHA 1983: "the purpose of [medical treatment] is to alleviate, or prevent a worsening of, the disorder or one or more of its symptoms or manifestations".

### *Lack of 'appropriate treatment'*

70. Based on the evidence we received in this inquiry, it is overwhelmingly clear that many placements in mental health hospitals are not meeting the needs of individuals with learning disabilities and/or autism. On the contrary, much of the evidence we have heard has indicated a significant increase in distress and a worsening of symptoms for those detained, particularly where segregation and restraint have been used.<sup>93</sup> We are concerned that a very broad approach has been taken to the "appropriate medical treatment" requirement in section 3 of the Mental Health Act 1983 and the approach appears to be that the most basic provision of care satisfies this test.

71. In an example that echoes that of Jeremy's daughter Bethany,<sup>94</sup> Mr Chris Rayner told us that his autistic daughter was first admitted to an ATU in July 2017 due to self-harm. He told us: "During the 9 months she was an in-patient, other than anti-depressant medication, the ATU was unable to offer any treatment - no therapy and little or no intervention. It was a prison holding cell, designed purely to medicate, stabilise and keep safe. Her underlying mental health issues were ignored."<sup>95</sup> He continued: "My daughter wasted 9 months of her life in an ATU that was not fit for purpose. She missed critical aspects of her education, was kept under lock and key and denied treatment making no progress towards recovery. She was denied her personal liberty and dignity, being watched 24x7 in every aspect of her daily life - in the shower, on the toilet and in her bedroom. It was utterly devastating and traumatising for her."<sup>96</sup>

72. Rightful Lives notes that "people are often subject to overly restrictive and inappropriate regimes that entail seclusion and restraint, both chemical and physical. This is largely because these units are not equipped to meet the individual's care and support needs, which are not psychiatric in nature."<sup>97</sup> The Centre for Welfare Reform states: "ATUs exist because we fail to support people in the right way [ ... ] ATUs are not about assessment and treatment, they are primarily about containment - imprisonment."<sup>98</sup>

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91 Mental Health Act 1983, [Section 3](#). Note that the MHA's definition of 'mental disorder' was amended in 2007 to include a specific provision stating that 'a person with learning disability shall not be considered by reason of that disability' to have a mental disorder in the meaning of the MHA 'unless that disability is associated with abnormally aggressive or seriously irresponsible conduct on his part. See Mental Health Act 1983, [Section 1\(2A\)](#).

92 The National Autistic Society ([YDA0044](#))

93 See para 39.

94 [Q11](#) [Jeremy]

95 Chris Rayner ([YDA0008](#))

96 Chris Rayner ([YDA0008](#))

97 Rightful Lives ([YDA0034](#))

98 Centre for Welfare Reform ([YDA0036](#))

73. The evidence to our inquiry indicates that mental health hospitals are not providing young people with learning disabilities and/or autism with treatment which is individualised and therapeutic. On the contrary, the evidence points in a number of cases to a worsening of conditions and further traumatising of the detained young people.

### *Deprivation of liberty under the Mental Capacity Act 2005*

74. Individuals who lack mental capacity may be detained under the Mental Capacity Act 2005 (MCA) either under a ‘Deprivation of Liberty Safeguards’ (DoLS) authorisation for adults<sup>99</sup> or by decision of the Court of Protection for those aged 16 or 17.<sup>100</sup> We understand that there is a minority of people with learning disabilities and/or autism deprived of their liberty under the MCA.<sup>101</sup> The interface between the Mental Capacity Act and the Mental Health Act causes particular difficulties. The MCA is entirely distinct from the MHA. As explained in the MHA Review Interim Report, “the MCA relates to a person’s ability (capacity) to function and to make a particular decision. This is different to the status of someone diagnosed with a mental disorder as defined in the MHA and who is subject to its powers. The MCA covers all decision-making, whereas the MHA 1983 is largely limited to decisions about care in hospital and medical treatment for mental disorder.” The two regimes interact when authorising the deprivation of a person’s liberty in hospital arises from their care and treatment for a mental disorder.

75. Under the current system, an individual is ineligible for DoLS and must be detained under the MHA if that individual falls within the scope of the MHA<sup>102</sup> and is objecting to psychiatric treatment.<sup>103</sup> If the individual falls within the scope of the MHA but is not objecting to psychiatric treatment, then the assessor has a choice as to detaining under the MHA or under DoLS. If the individual falls at the interface between the two schemes, the assessors must consider what is the least restrictive way of achieving the proposed treatment.<sup>104</sup>

76. There are, however, weaker legal safeguards for individuals detained under the MCA compared to the MHA. For example, when a person is detained for treatment under the MHA, their ‘nearest relative’ can exercise powers of discharge, or they can object to an application for admission for treatment.<sup>105</sup> Although the hospital can seek to override this, the ‘nearest relative’ would retain the right to trigger a tribunal hearing.<sup>106</sup> By contrast, a detained individual’s family member does not have any power to object to admission or powers of discharge under the MCA; only the right to be consulted.<sup>107</sup> Furthermore, a person who is detained for treatment under the MHA is entitled to a tribunal hearing

99 Mental Capacity Act 2005, [Schedule A1](#)

100 Mental Capacity Act 2005, [Section 16\(2\)\(a\)](#). Note that once the 2019 amendments to the MCA are in force, the Liberty Protection Safeguards (LPS) scheme will apply. See Joint Committee on Human Rights, Seventh Report of Session 2017–19, [The Right to Freedom and Safety: Reform of the Deprivation of Liberty Safeguards](#), HC 890 / HL Paper 161

101 Dr Lucy Series ([YDA0046](#))

102 A person (P) is within the scope of the MHA (A) if P could be detained under the powers in s.2 or 3 of the MHA (i.e. compulsory admission for assessment or treatment of a mental disorder) and (B) if P would be accommodated in hospital for the purpose of being given medical treatment for mental disorder. (Conversely, if ‘but for’ P’s physical needs, P would not be detained, then P would not be within the scope of the MHA and would therefore be eligible under DoLS). See Mental Capacity Act 2005, Schedule 1A. Ineligible Persons, Case E.

103 Determined by taking into account all the circumstances (wishes, feelings, behaviour etc).

104 *AM v South London and Maudsley NHS Foundation Trust* [2013] UKUT 0365 (AAC)

105 [Mental Health Act 1983](#)

106 [Mental Health Act 1983](#)

107 Dr Lucy Series ([YDA0046](#))

within six months of their initial detention, or sooner if they, their nearest relative, or the hospital managers request an earlier hearing. The appeal is generally heard within weeks and the detained person will participate in the hearing. A person detained under the MCA must apply to the Court of Protection to challenge their detention. There is no automatic hearing. The court application process is complicated, appeals can take several months, and the detained person may participate in the hearing, but this is not guaranteed.<sup>108</sup>

77. However, Dr Lucy Series notes that “because of the restrictions on the use of the MHA for people with learning disabilities [see paragraph 68 above], in some cases the MHA cannot be used to authorise detention, so the MCA will be used even if the person is objecting. In effect, this means that people with learning disabilities, far from being better protected against arbitrary detention in ATUs, are more at risk.”<sup>109</sup>

### Deprivation of liberty on a “voluntary” basis

78. Individuals may be detained on a voluntary basis (‘informal admission’). Children aged 16 and 17 with capacity, or those under 16 who are considered to be ‘Gillick competent’,<sup>110</sup> can give consent to their assessment and treatment. In other cases, parents or guardians will usually have responsibility for providing consent on behalf of children.

79. If detained as a “voluntary” patient, an individual does not have the legal safeguards provided under the MHA or MCA. We heard evidence that some individuals are threatened with the prospect of being ‘sectioned’ if they try to leave, meaning their detention is “voluntary” in name only. One witness was told: “We will not section you. We will keep an eye on you. Could you please stay safe with our support?” I said yes and stayed safe. “When we find a bed, we will get you into a unit. If you carry on with what you are doing, you will be sent to Dundee. You will be sectioned and you will have nothing”. I said, “Okay”.<sup>111</sup>

### The lawfulness of deprivation of liberty where appropriate treatment is unavailable

80. In the recent case of *Rooman v Belgium* in January 2019, the Grand Chamber of the European Court of Human Rights clarified the obligations on states to provide treatment to persons in detention whilst considering the alleged failure to provide psychiatric and psychological treatment in the facility where the applicant (a sex offender) was detained.<sup>112</sup> Whilst detained in Belgium, the applicant had been unable to receive psychiatric treatment in his native language of German. He alleged this was a breach of his Article 5 and Article 3 rights.

81. In relation to Article 5 (right to liberty) the Court held that the applicant’s deprivation of liberty had not taken place in an appropriate institution which was capable of providing him with treatment adapted to his condition, as required by Article 5 (1). In particular, the Court clarified the following principles:

108 Dr Lucy Series ([YDA0046](#))

109 Dr Lucy Series ([YDA0046](#))

110 Gillick competence is a term referring to the principle that children under the age of 16 can consent to their own treatment if they have enough intelligence, competence and understanding to fully appreciate what is involved in their treatment.

111 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) [Paul Scarrott] Q.6

112 *Rooman v Belgium* [2019] ECHR 105

- a) There is a close link between the *lawfulness* of the detention of persons suffering from mental disorders and the *appropriateness of the treatment* provided for their mental condition;
- b) Any detention of mentally ill persons must have a *therapeutic purpose*, aimed specifically, and in so far as possible, at curing or alleviating their mental-health condition, including, where appropriate, bringing about a reduction in or control over their dangerousness;
- c) Mere access to health professionals, consultations and the *provision of medication does not suffice* for a treatment to be considered appropriate and thus satisfactory under Article 5.<sup>113</sup>

82. The Court emphasised that its role was not to analyse the content of the treatment that was offered and administered, rather, it must verify whether an *individualised programme* has been put in place, taking account of the specific details of the detainee's mental health with a view to preparing him or her for possible future reintegration into society. The Court highlighted the "*therapeutic aspect of the aim referred to in Article 5 § 1 (e)*" concluding that "*there exists an obligation on the authorities to ensure appropriate and individualised therapy*".<sup>114</sup>

83. In its consideration of Article 3 (prohibition on torture, or inhuman or degrading treatment or punishment) the Court found that, in this case, the national authorities had failed to provide treatment for the applicant's health condition from the beginning of his detention and that his continued detention without a realistic hope of change and without appropriate medical support for a period of about thirteen years had amounted to particularly acute hardship, causing him distress of an intensity exceeding the unavoidable level of suffering inherent in detention.<sup>115</sup> In order for treatment to fall within the scope of Article 3 ECHR all the facts and circumstances of the case must be considered.<sup>116</sup>

84. The Court further held that whilst measures depriving persons of their liberty inevitably involve an element of suffering and humiliation, Article 3 requires the State to ensure that persons are detained in conditions which are compatible with respect for their human dignity, that the manner of their detention does not subject them to distress or hardship of an intensity exceeding the unavoidable level of suffering inherent in such a measure and that, given the practical demands of imprisonment, their health and well-being are adequately secured by, among other things, providing them with the requisite medical assistance.<sup>117</sup>

85. The case law is clear that the detention of a person in inappropriate physical and medical conditions may amount to treatment contrary to Article 3. Conditions of detention must under no circumstances arouse in the person deprived of his liberty feelings of fear, anguish and inferiority capable of humiliating and debasing him and possibly breaking

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113 Rooman v Belgium [2019] ECHR 105, para 209

114 Rooman v Belgium [2019] ECHR 105, para 205

115 Rooman v Belgium [2019] ECHR 105

116 Stanev v Bulgaria [2012] ECHR 46 (Application No. 36760/06)

117 Stanev v Bulgaria [2012] ECHR 46 (Application No. 36760/06)

his physical and moral resistance.<sup>118</sup> Where young people are detained with a lack of appropriate medical care, and treated in a way which is humiliating and debasing, there is a risk that such conditions may amount to “degrading treatment” in violation of Article 3.

## Conclusion

86. If young people and adults with learning disabilities and/or autism are being detained under the Mental Health Act 1983, the law requires that medical treatment must be necessary, appropriate and available. In spite of these safeguards the default position is to continue to detain. Those admitted on a ‘voluntary basis’ have even fewer safeguards and may fear challenging their ongoing detention due to the threat of being ‘sectioned’.

87. We consider that the human rights of many of those with a learning disability and/or autism are being breached in mental health hospitals. The detention of individuals in the absence of individualised, therapeutic treatment risks violating an individual’s Article 5 right to liberty and security. In some cases, detention may even reach the threshold of degrading treatment contrary to Article 3.

88. The current legislation governing admission, treatment, and discharge from mental health hospitals is failing to protect the Article 5 rights of those with learning disabilities and/or autism. In particular, the requirement of “appropriate medical treatment” contained within the Mental Health Act is constructed far too broadly. *We endorse the recommendation of the Mental Health Act Review that the criteria for detention under the Mental Health Act must be narrowed.*<sup>119</sup> *Those with learning disabilities and/or autism must only be detained under the Mental Health Act, in situations where:*

- a) *treatment is necessary;*
- b) *treatment is not available in the community and only available in detention (i.e. the last and only resort);*
- c) *treatment is of benefit to the individual and does not worsen their condition; and*
- d) *without the treatment, there is a significant risk of harm to the individual or others.*

We acknowledge that tightening the criteria for detention under the Mental Health Act 1983 could increase the number of detentions under the Mental Capacity Act 2005, with its weaker safeguards. We emphasise that the legal principles set down by the European Court of Human Rights apply irrespective of which regime applies. All persons detained in mental health settings are entitled to individualised, therapeutic treatment. Where this is not happening, the detention of individuals is a violation of Article 5 and may, in some severe cases, violate Article 3. Persons detained under the Mental Capacity Act, and those admitted informally, must be afforded equal protection of their Article 3 and Article 5 rights.

118 *Selmouni v. France* [1999] ECHR (Application no. [25803/94](#))

119 See Department of Health and Social Care, [Modernising the Mental Health Act, Final report of the Independent Review of the Mental Health Act 1983](#), December 2018, page 301, recommendation 42

## 5 Families as human rights defenders

### Denial of young people and families' voices

89. During our inquiry we were told time and time again that young people and their families and carers are excluded from decision-making processes concerning young people's lives.

"Where has my parent voice been? I am the expert on my daughter. Two months ago, I had to fight to be included in what they called a professionals' meeting. I am the professional about my daughter. Bethany has no voice."<sup>120</sup>

*Jeremy, whose daughter Bethany was detained at St. Andrew's Hospital Northamptonshire*

"I can remember going to one meeting when 20 professionals had had their professionals' pre-meeting, like they do, and made all the decisions without me even being there. I was allowed to go in afterwards, sit and listen to their decision, which was actually to recommend a move to St Andrew's. I spoke through clenched teeth with tears pouring down my face: "He's not going to St Andrew's. People die there", so we managed to avoid it, luckily, and he was shipped off somewhere else, where they just broke his arm. It is so scary. You are constantly fighting and it takes over your lives."<sup>121</sup>

*Julie Newcombe whose son Jamie was detained for 19 months*

"We were marginalized and powerless to protect our son—even at the most basic level. Matthew thought he was in prison, and to us, it felt like he was being punished for being autistic and having a learning disability."<sup>122</sup>

*Isabelle Garnett whose son Matthew was detained for 18 months in an ATU*

### Breakdown of relations between professionals and families

90. On some occasions families are even vilified by professionals with the result that their expertise is not used to inform decisions.

"It takes huge effort and resilience to continually battle for assistance. Many families are simply unable to do so and collapse. [ ... ] One particularly noxious consequence is that, even if assistance is eventually conceded, the relationship has broken down before it has even started. This is in no-one's interest, but it is, in many cases, an unfortunate and entirely foreseeable by-product of the pressures of the way, in our experience, the system operates. [ ... ] our recent experience is that our LA is suspicious and distrustful, without any supporting evidence, of parents' representation of their child's wishes. This is not an auspicious start."<sup>123</sup>

*Mother of an autistic daughter who gave evidence anonymously*

120 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) [Jeremy] Q.15

121 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) [Julie Newcombe] Q.15

122 Mrs Isabelle Garnett ([YDA0018](#))

123 Anonymous 14 ([YDA0047](#))

## Attempts to silence families

91. It is wholly unacceptable that professionals should attempt to prevent parents from speaking out when they disagree with the way that their children are being treated. Julie Newcombe described some of the ways that her family experienced this:

“The hospitals like to punish parents if they speak out, and they have a clever way of doing that. They will take away Section 17 leave and restrict your visits, so do not speak out, because that is what will happen to you, as it did to us. At one point, we were threatened with transfer to a secure hospital a long way away, because we were causing trouble. We were denigrated to other professionals orally and in writing, and we were repeatedly accused of lying. Nobody should have to go through that, especially when it is their child”<sup>124</sup>

92. In the worst cases public bodies have applied for injunctions to prevent parents from speaking publicly about their children’s situation. Walsall Council sought such an injunction against Bethany’s father Jeremy in October 2018 when he began a campaign on social media to highlight the situation she faced. The application was only withdrawn when Jeremy received legal assistance from Mencap, the charity for people with learning disabilities, and two barristers working pro bono, to fight the case.<sup>125</sup>

93. Evidence received in our inquiry suggests that Jeremy’s is not an isolated experience. Several parents have told us how they have been “gagged” by the courts.<sup>126</sup>

94. When we asked Minister for Care, Caroline Dinenage MP about the use of injunctions she told us:

“We are very clear that we do not support injunctions that set out to gag families who are looking to expose poor patient care—quite the opposite. [ ... ] The best thing is to maintain good relationships with parents, keep them engaged and keep them informed. If it does not happen, that is where you get a friction and end up with the adversarial relationships that we too often hear about, which are very negative.”<sup>127</sup>

95. In correspondence from the Minister following the evidence session, she confirmed that NHS England has not taken out any such injunctions against families and that it has not been notified of any taken out by local NHS organisations. She did however recognise that anecdotal evidence suggests that some NHS organisations may have done so. Finally, she confirmed that her Department had been advised by the Ministry of Justice that information on such injunctions is not collected centrally.<sup>128</sup>

124 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q. 15 [Julie Newcombe]

125 [“Father beats legal bid to silence him over autistic girl in hospital ‘cell’”](#) The Times, 13 October 2018

126 Anonymous 5 ([YDA0033](#)) and Anonymous 16 ([YDA0026](#))

127 [Q25](#) [Caroline Dinenage MP]

128 Department of Health and Social Care ([YDA0056](#))

## Young people without family support

96. It is vital that those young people with learning disabilities and/or autism are supported to have their own voices heard, especially if they do not have family support. In a joint submission, Inclusion London, People First (Self Advocacy) and Changing Perspectives reminded us of this:

“People with LD/A who have supportive and loving families have someone to fight for them to try and secure their release. The families can complain and visit. But there are many people who do not have family that can support them or visit them, or that are too old to do this. Then people with LD/A are very isolated and have limited opportunities to have their voices heard because of being detained. They are invisible to the outside world. Also there is a huge imbalance of power between the health professionals (HP) and people with LD/A which puts people at risk. So it is important that inquiries and inspections hear directly from people with LD/A in hospital units, especially those that do not have familial support.<sup>129</sup>”

## Conclusion

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

- *Families should, unless there are exceptional circumstances, be given new legal rights to attend Care, Education and Treatment Reviews and Care and Treatment Reviews and any meetings at which decisions are taken about whether to place a young person in detention. They must also receive relevant reports.*
- *The rights of individuals and their families to advocacy must be enhanced and enforced, including for those who are considered to be informal patients. Advocacy services should be funded entirely separately from care and support services.*
- *It is wholly unacceptable that injunctions should be sought to prevent families from speaking out when they disagree with the way that their child is being treated. The Ministry of Justice must work with other departments to collect data on the number of injunctions sought by public bodies, including Local Authorities and Clinical Commissioning Groups, against families of those with learning disabilities and/or autism.*
- *There should be guidance providing that no public authority should apply for an injunction which gags a parent of a child or young person with autism and/or learning disabilities who is either in or being considered for placement in a mental health hospital unless they have obtained the specific approval for such an application from the Secretary of State for Health and Social Care.*

## 6 Conditions in places of detention

98. On 22 May 2019 a BBC Panorama programme aired which showed adults with learning disabilities and autism at Whorlton Hall in County Durham experiencing horrific abuse at the hands of staff. Anne-Marie Trevelyan MP, who is the mother of a young autistic man, told us:

“It was incredibly difficult to watch. I had to force myself to keep watching it. [ ... ] To have to watch that sort of footage, where those families and those individuals have not been supported, as our family have been [ ... ] was a truly ghastly thing.”<sup>130</sup>

We agree. The scandal is compounded by the fact that it comes eight years after a similar pattern of abusive behaviour was uncovered at Winterborne View, after which it was vowed that more would be done to protect people from abuse.<sup>131</sup> There has been long-standing concern about the use of restrictive practices in care settings which will be examined in more detail in this chapter. We must be clear at the outset that the behaviour of some staff at Whorlton Hall, as seen on Panorama, went beyond anything that could ever be argued to be legitimate. It was abusive and torturous. We are extremely concerned that the evidence we have received, much of it provided on a confidential or anonymous basis, indicates that Whorlton Hall is not an isolated case. For example:

“Why are [these] so called safeguards put there to protect investigate only to fail my son over and over again? Insufficient evidence? Seriously? A carer sees another carer kick box my son on [his] genitals, leaving serious bruising, [ ... ] Or that they broke [his] clavicle. Or [his] arm or [his] hand or [his] ankle or they punched him on [his] face almost breaking [his] Cheekbone, or the bruising all over your child’s body without so much an explanation how it happened. Or when they throw your son across a room like he is a chicken, or when they tie your son to a bed. Or put him on straight jackets for up to 14 hours a day.”<sup>132</sup>

99. A lack of appropriately skilled staff in inpatient settings is a serious concern. In its “State of Care 2018/19” report the CQC notes that since October 2018 it has rated 14 independent mental health hospitals that admit people with a learning disability and/or autism as inadequate and put them in special measures. The 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.”<sup>133</sup>

**100. We are clear that the best way to prevent human rights abuses in institutions is to take urgent action to stop people with learning disabilities and/or autism being**

130 [Q30](#) [Anne-Marie Trevelyan MP]

131 [“Government condemns ‘shocking’ Winterbourne View abuse”](#), BBC online, 1 June 2011

132 Anonymous 12 ([YDA0025](#))

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

**inappropriately detained. But for as long as people are detained, it is imperative that steps are taken to safeguard their human rights and ensure redress when those rights have been breached.**

## Restrictive interventions

101. Restrictive interventions are 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.<sup>134</sup>

102. As part of its response to the Winterbourne View scandal the Coalition Government looked at the use of restrictive interventions in mental health hospitals and produced guidance aimed at reducing their use. In the forward to that guidance the then Minister for Care, Rt Hon Norman Lamb MP wrote:

“Investigations into abuses at Winterbourne View Hospital and Mind’s Mental Health Crisis in Care: physical restraint in crisis (2013) showed that restrictive interventions have not always been used only as a last resort in health and care. They have even been used to inflict pain, humiliate or punish. Restrictive interventions are often a major contribution to delaying recovery, and have been linked with causing serious trauma, both physical and psychological, to people who use services and staff. These interventions have been used too much, for too long and we must change this.”<sup>135</sup>

103. Statistics indicate that this guidance has not achieved its aims. Figures from NHS Digital show that in June 2019 11% of people with learning disabilities and/or autism in inpatient units/wards experienced some form of restrictive intervention (430 out of 3,845 people).<sup>136</sup> This number has been increasing in recent years.

104. It is especially concerning that young people aged under 18 are the age group most likely to be subject to restrictive interventions. 26% of those in inpatient units/wards have been subject to restrictive interventions. In June 2019 a total of 3,565 restrictive interventions were carried out, 1,190 of them on under 18 year-olds and 1,120 on those age 18–24.<sup>137</sup>

105. In our report “Youth detention: solitary confinement and restraint”, published in April 2019, we have already examined some of these issues and made recommendations.<sup>138</sup> Here we summarise the additional evidence we have received to this inquiry and make some further recommendations.

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

135 Department of Health, [Positive and Proactive Care: reducing the need for restrictive interventions](#), April 2014

136 NHS Digital, [Learning Disability and Autism Monthly Statistics from Mental Health Services Dataset June 2019](#). Reference Tables 1 & 17 (19 September 2019)

137 NHS Digital, [Learning Disability and Autism Monthly Statistics from Mental Health Services Dataset June 2019](#). Reference Tables 1 & 17 (19 September 2019)

138 Joint Committee on Human Rights, Nineteenth Report of Session 2017–19, [Youth Detention: Solitary confinement and restraint inquiry](#), HC 994 / HL Paper 343

## Solitary Confinement

106. The CQC published the interim report of its review into restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability or autism in May 2019. The report focuses on 39 people who are cared for in segregation on a learning disability ward or a mental health ward for children and young people. Among those young people is Adam:

“Adam has been confined to a seclusion room with dimmed lighting. [ ... ] The walls of the seclusion room are padded because Adam often throws himself at the walls and bangs his head on them. He is not permitted to use the adjoining lounge room routinely because this had not been fitted with padding. If Adam wants to use the lounge, staff use physical restraint—for example, staff hold Adam’s lower arms and guide him away from the entrance to the lounge. He had only left the seclusion room 16 times in the 12 months before we visited him. [ ... ] Staff sit in the corridor behind a locked door observing Adam. Because there is no equipment that enables staff to communicate with him, they have to shout at him through a window. Adam sometimes watches television with staff. When this happens, the television is placed at the seclusion room window, with staff outside in the corridor. Education consists of a book held to the window.”<sup>139</sup>

107. Under the Mental Health Act Code of Practice staff in mental health hospitals are permitted to ‘segregate’ and ‘seclude’ patients in certain circumstances:

- Seclusion refers to the supervised confinement and isolation of a patient, away from other patients, in an area from which the patient is prevented from leaving, where it is of immediate necessity for the purpose of the containment of severe behavioural disturbance which is likely to cause harm to others.<sup>140</sup>
- Long-term segregation refers to a situation in which “a patient is not allowed to mix freely with other patients on the ward or unit on a long-term basis in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation”.<sup>141</sup>

108. The term ‘solitary confinement’ is generally associated with custodial settings and does not appear in the Mental Health Act Code of Practice. It is defined in the Istanbul Statement on the Use and Effects of Solitary Confinement as the “physical isolation of individuals who are confined to their cells for twenty-two to twenty-four hours a day. [ ... ] Meaningful contact with other people is typically reduced to a minimum. [ ... ]”<sup>142</sup> **In our “Youth Detention: solitary confinement and restraint” report we concluded that “Some cases in hospitals amount to solitary confinement, which is not compliant with human rights standards for children”. We reiterate that conclusion here.**

139 Care Quality Commission, [Review of restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability or autism Interim report](#), May 2019

140 Department of Health, [Mental Health Act 1983 Code of Practice](#) (2015) p.300

141 Department of Health, [Mental Health Act 1983 Code of Practice](#) (2015) p.412

142 [Istanbul Statement on the Use and Effects of Solitary Confinement](#), 9 December 2007 at p 1

### Physical restraint

109. We have heard from parents and staff about the harrowing impact of physical restraint on young people.

“Between 11th June and 8th November 2018, she was physically and forcibly restrained 18 times, including use of prone restraint on a hard floor. Brutal, frightening and traumatic for a vulnerable autistic child (clearly in fight or flight response). During the use of prone restraint, she sustained physical injuries that were neither reported to me or raised as safe guarding concerns to the [Local Authority Designated Officer].”<sup>143</sup>

*The father of an autistic child who has been an in-patient in two psychiatric Assessment and Treatment Units (ATUs).*

“During his time in the ATU AP was frequently restrained. Supine restraint was common and it appears that he was also occasionally prone restrained. [ ... ] In the community we use an approach that aims to support individuals in distress. This uses no static holds and takes into account the emotional and sensory needs of the individual. In the years we have been using this approach with AP we have never felt the need to use tight, restrictive restraints or floor restraint.”<sup>144</sup>

*Parent of 19 year old son with severe autism and learning disabilities who spent 16 months detained in an ATU.*

“As a current nurse I have come across the continued demonisation of vulnerable patients in care. You get the group culture then taking off in forms of office negativity, fear tattle and this becomes more fear and next it’s a rush job into another traumatic restraint. [ ... ] It is imperative to make managers accountable (similar to sales targets) to drastically reduce the number of restraints imposed on most vulnerable children [ ... ]. Would they like their own child with learning difficulties and autism to be rough handled as it is so scary and intimidating for the patient and all they can do is lash back and become more aggressive if they see a gang coming to jump them. It is horrid to behold.”<sup>145</sup>

*A nurse*

### Medical restraint

110. The use of psychotropic medication in mental health hospitals is a recurrent theme across the many submissions to our inquiry.

“The doctors said Matthew needed to take anti-psychotic medication, a medicine that is formulated for people with psychosis, a serious mental health illness. But Matthew was not mentally ill. He didn’t want the medication so he was prone restrained, face down, by up to 6 adults and forcibly injected with a high dose of anti-psychotics at least every two weeks. Matthew hasn’t taken any anti-psychotic medication since leaving ATU.”<sup>146</sup>

*Isabelle Garnett whose son Matthew was detained for 18 months in an ATU*

143 Chris Rayner ([YDA0008](#))

144 Anonymous 4 ([YDA0015](#))

145 Ita O’Donnell ([YDA0023](#))

146 Mrs Isabelle Garnett ([YDA0018](#))

“[ ... ] autism is a lifelong neurological condition which is not capable of remedy, nor should it be. What is needed is support and the development of strategies to enable the individual to cope. I accept that there may be cases where medication is appropriate e.g. beta blockers to assist in dealing with sensory overload or meds which have been shown to reduce the frequency and severity of challenging behaviours in autistic people (e.g. aripiprazole) in particular circumstances. But our experience is that medication does not assist Rachel, and we have trialled a number of options over the years. It is, in my view, dangerous and irresponsible to think that medication is the answer. It is not. Often I suspect, medications are given to assist the carer rather than the individual.”<sup>147</sup>

*Mother of an autistic daughter who gave evidence anonymously*

111. Psychotropic medicines affect how the brain works and include medicines for psychosis, depression, anxiety, sleep problems and epilepsy. Sometimes they are also given to people because their behaviour is seen as challenging. People with a learning disability and/or autism are more likely to be given these medicines than other people.<sup>148</sup>

112. In 2016 the Department of Health launched a national project called ‘Stopping over medication of people with a learning disability, autism or both’ otherwise known as STOMP. The project aims to stop the over medication of people with a learning disability, autism or both with psychotropic medicines.<sup>149</sup>

## Conclusion

113. **The evidence presented in our inquiry reinforces the recommendations and conclusions we made in our report “Youth detention: solitary confinement and restraint.” We highlight two of those recommendations in the context of this inquiry:**

- a) ***“that the use of separation in hospitals be more rigorously regulated. Each institution in the health sector must report data on extension of separations to the responsible Minister on a monthly basis, who will certify the information and lay it before each House for publication.” In its response to the report the Government accepted that that the regulation of hospitals that use separation could be improved and noted that the Care Quality Commission’s review into the use of restrictive interventions will be looking further at this area. The Government also drew attention to the fact that that NHS Digital is now reporting data on restrictive interventions on a monthly basis. While we welcome this, we continue to believe that our recommendation should be implemented in full and we urge the CQC to take it up in the final report of its review which is due to be published in spring 2020.***
- b) ***that while “there may be there may be exceptional circumstances in which prone restraint is preferable to alternatives, it must be more rigorously regulated by governing health bodies and regulators, including by annual publication of statistics for each institution (broken down by patients’ diagnoses, age and justification for not using an alternative method).” In its response to the report***

147 Anonymous 14 ([YDA0047](#))

148 NHS England, [Stopping over medication of people with a learning disability, autism or both \(STOMP\)](#)

149 NHS England, [Stopping over medication of people with a learning disability, autism or both \(STOMP\)](#)

*the Government highlighted recent improvements that have been made in the area of data collection including requiring that services include in the records they provide the duration of any use of prone restraint. This is a positive step forward and we hope that improved data collection will lead to more rigorous regulation.*

114. Additionally, we believe that more must be done to ensure that families are kept informed when restrictive interventions are used on their loved ones. Anne-Marie Trevelyan MP raised this important point:

“families have no automatic right to be informed of restraint or medical use, in either the school or the medical environment, they have no access.”<sup>150</sup>

She argued that if this were to be a requirement it would increase transparency in the system and make it easy for the regulator to identify poor practice.<sup>151</sup>

115. The Mental Health Units (Use of Force) Act 2018 received Royal Assent on 1 November 2018. The Act places new statutory obligations on inpatient mental health units. These include a requirement to keep a record (for 3 years) of any use of force by staff which is more than ‘negligible’. This record must include whether any notification regarding use of force was sent to the person (if any) to be notified under the care plan.<sup>152</sup> While it is very positive that records will now be kept, in our view this does not go far enough. ***We recommend that on every occasion that anyone is restrained or kept in conditions amounting to solitary confinement their families must be automatically informed.***

## Family contact during detention

116. Article 8 ECHR provides a right to respect for private and family life. It specifies that:

- i) Everyone has the right to respect for his private and family life, his home and his correspondence.
- ii) There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.<sup>153</sup>

117. When a young person with learning disabilities and/or autism is detained, their rights under Article 8 ECHR and those of their family are engaged. Detention entails inherent limitations on private and family life. However, the European Court of Human Rights has held that it is an essential part of a detainee’s right to respect for family life that the authorities enable detainees or, if need be, assist detainees in maintaining contact with close family.<sup>154</sup>

150 [Q31](#) [Anne-Marie Trevelyan MP]

151 [Q31](#) [Anne-Marie Trevelyan MP]

152 The Mental Health Unit (Use of Force) Act 2018, [Section 6 \(5\) \(p\)](#)

153 European Convention of Human Rights, [Article 8](#)

154 Horych v Poland (Application no. 13621/08), April 2012 para 123

118. It is clear from evidence to this inquiry that placing young people long distances away from their families poses a threat to their right to family life:

“[ ... ] my son has been taken into a therapeutic unit against our wishes 202 miles away from our home, this was a last resort not a first option for him in May 2019. [ ... ] I know from experience that my sons human rights have been breached, from arrival he has had his mobile phone confiscated and locked away, he has not been allowed to contact any family or friends since May, [ ... ] we as parents have had no contact with him and are becoming distraught at having no contact with our son.”<sup>155</sup>

*Mother of a son with autism who was detained in an ATU in May 2019*

“The profound effect on close family and especially siblings in their vulnerable loved one being incarcerated so far away from home. In our case a 320mile round trip (160miles each way) made by either parents and sometimes brother each and every Sunday to visit our son, over a 2 year period.”<sup>156</sup>

*Parents whose son was detained*

“The distance and geographic position of the ATU in (a rural county) made visiting very difficult. My husband and I travelled to see our son every other week. It was an eight-hour drive in each direction. Our usual routine was to drive to (\*\*\*) on a Sunday, stay overnight in a Travelodge in (\*\*\*), drive to the ATU on the Monday morning, visit our son for approximately two hours and then drive home. [ ... ] There was also a large financial impact. Each trip cost around £250–(£100 car hire, £100 fuel, £50 Travelodge). I recently made a request to (local CCG) for support to visit under as recommended under the MHA Code of Practice (paragraphs 14.85 and 17.4), but this was refused.”<sup>157</sup>

*Parent of 19 year old son with severe autism and learning disabilities who spent 16 months detained in an ATU.*

119. Evidence from the Challenging Behaviour Foundation and Mencap highlighted that 29% of 0–18 year olds were being treated 100km or more from home.<sup>158</sup> It also noted a finding from their “Keeping in Touch with Home” report that “many families are discouraged from visiting their children, [local authorities] often fail to fund travel and telephone/ digital contact is rarely used as it might be in schools, e.g., through video diaries / photos.”<sup>159</sup>

**120. *Placing young people a long way from their home reduces their support from their families and undermines their right to family life under Article 8 ECHR. It must stop. Until it is stopped, families must be given the financial support they need to be able to visit their loved ones.***

155 Miss Leann Bailey ([YDA0053](#))

156 Anonymous 5 ([YDA0033](#))

157 Anonymous 4 ([YDA0015](#))

158 Challenging Behaviour Foundation and Mencap ([YDA0014](#))

159 Challenging Behaviour Foundation and Mencap ([YDA0014](#))

## Deaths in Assessment and Treatment Units

121. On 30 October 2018 Sky News revealed findings from a FOI request which showed that at least 40 had died in an ATU in the previous two and a half years. Nine of these people were under 35 years old.<sup>160</sup> The Equality and Human Rights Commission (EHRC) drew our attention to a 2018 legal case in which Southern Health NHS Trust accepted it was responsible for the deaths of two patients at a short-term assessment and treatment unit in contravention of Article 2 ECHR.

122. While it has not been a focus in the context of this inquiry, this information is nonetheless profoundly troubling. We endorse the view of the EHRC that “it is critical that the health and social care system routinely identifies, investigates and learns from the preventable deaths and serious patient safety incidents of people within its care. This must include people detained in psychiatric hospitals.”<sup>161</sup> ***We note the Government’s proposal to establish an independent body to investigate serious healthcare incidents. We urge the Government to work with the Equality and Human Rights Commission to ensure that it is fulfilling its obligations under Articles 2 and 3 ECHR in relation to independent investigations of deaths of those with learning disabilities and/or autism in detention settings.***

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160 Paul Kelso, [40 people died in ‘barbaric’ secure hospitals the government pledged would close](#), 11 April 2019, Sky News

161 Equality and Human Rights Commission ([YDA0021](#))

## 7 The Care Quality Commission

123. The Care Quality Commission (CQC), as the regulator, should be a bulwark against human rights abuses of those detained in mental health hospitals. On its website the CQC asserts that it “protects the rights of vulnerable people including those restricted under the Mental Health Act.”<sup>162</sup> However, evidence examined in this chapter suggests that the CQC’s ability to carry out this function is impaired and its approach and processes are in need of urgent reform.

### Whorlton Hall

124. On 22 May 2019 a Panorama documentary aired on BBC1 showing reporter Olivia Davies working undercover at Whorlton Hall, an independent mental health hospital. It revealed patients with learning disabilities and/or autism being mocked, taunted and intimidated by abusive staff.<sup>163</sup> They were deliberately provoked by staff who then physically restrained them.

125. In the years preceding these events the CQC carried out a number of inspections of Whorlton Hall:

- August 2015: An inspection team led by Barry Stanley-Wilkinson carried out a routine inspection of Whorlton Hall. A draft report, rating the establishment as ‘Requires Improvement’ was prepared but not published.<sup>164</sup>
- March 2016: a further inspection was carried out. A report of this inspection, which states that it also covers the findings of the August 2015 inspection visit, was published in June 2016. Whorlton Hall was rated as ‘Good’ but ‘Requires Improvement’ for safety.
- August and November 2016: further inspections were carried out to check improvements had been made. The inspection in August was prompted by concerns about the quality of care that were brought to the CQC’s attention since June. Following the November inspection Whorlton Hall was rated as ‘Requires Improvement.’
- September 2017: a routine inspection took place. The report published in December 2017 rated Whorlton Hall as ‘Good’.
- March 2018: an inspection took place in response to whistleblowing concerns received by CQC. These highlighted issues in staffing and patient safety, culture and incident monitoring. No rating was given as part of this inspection. In the report published in May 2018 some concerns about safe staffing levels were flagged but the inspection picked up no signs of the kinds of abuse revealed in the secret filming.

162 Care Quality Commission, “[who we are](#)”

163 Olivia Davies worked at Whorlton Hall for a period of 2 months at the beginning of 2019

164 On 5 June 2019 the Committee, having been made aware of the draft report, made a request to the CQC for a copy of it. On 10 June 2019 the CQC provided us with five versions of the report and published them on its website.

### ***The '2015' draft report***

126. In response to the broadcast of the BBC Panorama programme, Barry Stanley-Wilkinson, a former CQC inspector, came forward and revealed that he had led an inspection of Whorlton Hall in August 2015. This had raised significant concerns but the report from the inspection was never published.<sup>165</sup> We contacted him, and he provided us with correspondence relating to the decision not to publish the report which we made available on our website.<sup>166</sup>

127. In response to Mr Stanley-Wilkinson's comments the CQC posted this statement on its Twitter account on 22 May 2019:

“A CQC inspection of Whorlton Hall was carried out between 4–6 August 2015. The draft report from this did not identify any concerns about abusive practice. All CQC reports go through a rigorous peer review process conducted by inspection colleagues; during this process it became apparent that the inspection team in 2015 had not collected evidence that was robust enough to substantiate a rating of Requires Improvement. A new comprehensive inspection was undertaken in March 2016, which rated the Hospital Good overall, but Requires Improvement, for Safety. We are clear however that no CQC inspection of Whorlton Hall, whether the report of that inspection was published or not, raised any concerns about abusive practices among staff. [ ... ]”<sup>167</sup>

128. Ahead of our oral evidence session on 12 June we requested a copy of the unpublished 2015 report from the CQC. On 10 June the CQC provided us with five versions of the report and posted them on their website.<sup>168</sup> These versions had been commented upon, including by a peer reviewer, report writing coaches and a management reviewer.

129. The chief reason given by CQC management for the decision not to publish the report was the perceived failure of the inspection team to collect sufficiently robust evidence to substantiate the rating of 'Requires Improvement' that was proposed.<sup>169</sup> However, our examination of the draft report revealed that it did contain evidence of serious failings that in our view could justify the 'Requires Improvement' rating recommended by the inspector. In particular, the draft report recorded accusations of bullying and inappropriate behaviour by staff, use of “seclusion” without proper processes, under-staffing, neglect of the needs of patients and low levels of staff training.<sup>170</sup> Some examples of comments made in the draft report include:

“Patients had accused staff of bullying and using inappropriate behaviour. [ ... ] We did note in one patient's records it stated, where they made allegations against staff the first step was to “ignore” the allegation.”<sup>171</sup>

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165 [Barry Stanley-Wilkinson, LinkedIn messages](#)

166 [Evidence published](#) from former Whorlton Hall Inspector, Mr Stanley Wilkinson

167 [Twitter statement](#) 22/05/19

168 Care Quality Commission, [CQC shares previously unpublished findings of 2015 inspection of Whorlton Hall](#), 10 June 2019

169 [Q42](#)

170 Care Quality Commission, [CQC shares previously unpublished findings of 2015 inspection of Whorlton Hall](#), 10 June 2019

171 [Draft Inspection Report 'Post IM Review'](#) 16 December 2015 p.18

“The service used a low stimulus room without any protocols or procedures for its use and essentially secluded patients without proper processes in place.”<sup>172</sup>

The fact that allegations about bullying and inappropriate behaviour had been made was not questioned or commented on in any of the versions of the draft report that the CQC provided us with.

130. In August 2015 the management of Whorlton Hall made a lengthy complaint to the CQC listing several concerns about the conduct of the inspection. For example, they complained about the size of the inspection team which they believed to be disproportionate and to have placed staff under undue pressure.<sup>173</sup> The inspection team comprised of seven people; a lead inspector, an inspection manager, a psychiatrist, a psychologist an occupational therapist, a pharmacist, and an expert by experience.<sup>174</sup> To us this does not appear excessive, as each person has a distinctive role in the team. However, in its response to the complaint (made nearly three months after it had been received), the CQC Inspection Manager agreed that the team was too big and when the service was next inspected in 2016 there were only three people on the inspection team; two CQC inspectors and one learning disability nurse specialist advisor.<sup>175</sup>

131. In January 2016, prior to his departure from the CQC Mr Stanley-Wilkinson made an internal complaint to CQC management setting out his belief that inspection reports were not being published despite significant findings that compromised the safety, care and welfare of patients. With specific reference to Whorlton Hall he wrote:

“I am concerned about the relationship managers have had with the service in that they are all familiar with the provider. [ ... ] I was also told the complaint that was made about the inspection team made things difficult [in relation to the report being published].”<sup>176</sup>

132. While these concerns and the handling of the complaint from Whorlton Hall do not prove that the CQC management had an overly close relationship with the provider, taken together they do offer another potential explanation for the decision not to publish the 2015 report.

133. In response to the complaint made by Mr Stanley-Wilkinson an internal investigation was undertaken within the CQC. Internal emails provided to us suggest that in March/April 2016 Dr Paul Lelliot, Deputy Chief Inspector of Hospitals (lead for mental health) at the CQC, accepted a recommendation from the internal investigation to publish the report of the 2015 inspection. However, Dr Lelliot told us that he received the 2015 investigation report on or around 2 March 2016 and that in light of the new inspection of Whorlton Hall beginning the next day, he took a decision to include the findings of the 2015 report in the report of the 2016 inspection.<sup>177</sup>

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172 [Peer review of draft Whorlton Hall report](#) 25 November 2015 p.2

173 A (redacted) letter from the CQC to Whorlton hall, [responding to a complaint from them after the 2015 inspection](#)

174 Two inspectors in training and a support worker were also in attendance.

175 A (redacted) letter from the CQC to Whorlton hall, [responding to a complaint from them after the 2015 inspection](#)

176 Email correspondence from Mr Stanley Wilkinson to HR, and Senior Management at the CQC, [explaining his decision to resign](#)

177 [Q42](#) [Dr Paul Lelliot]

134. We strongly question the proposition that the 2015 report was elided into the report of the 2016 inspection. Despite a number of references made to the earlier report, key information was left out of the 2016 report. For example, the 2016 report concluded that “The hospital did not have a seclusion room. Following discussions with staff and review of care records we were satisfied that seclusion was not taking place in any other rooms.”<sup>178</sup> This seems to have overridden the evidence found in the 2015 inspection that patients were being essentially secluded in a low stimulus room without proper processes in place. These more favourable judgments allowed an overall rating of ‘Good’ to be awarded to Whorlton Hall.

135. We expect that the ongoing investigation into the events surrounding the 2015 inspection of Whorlton Hall commissioned by the CQC and being conducted by David Noble QSO will provide a thorough examination of all these issues.<sup>179</sup> If the propositions laid out here, on the basis of the evidence we have seen, are found to be correct, it is hard to see the 2016 inspection report on Whorlton Hall as anything other than a cover up. The suppression of the 2015 report was a catastrophic mistake which could potentially have prolonged the abuse experienced by patients at Whorlton Hall.

### **‘Closed cultures’**

136. In her evidence Anne-Marie Trevelyan MP questioned why the CQC does not employ covert surveillance methods so that they can see what it truly going on in these places: “If a journalist going undercover as a staff nurse can identify this, why on earth did the CQC not do what I would call secret shopper activity as part of its inspection programme?”<sup>180</sup>

137. In oral evidence Dr. Paul Lelliot, told us: “I would repeat what I said on the “Panorama” programme, which was that clearly we did not detect what was going on. I am deeply sorry about that because we could have saved people from continuing abuse.” The reason the CQC gives for this failure is that it is difficult to get under the skin of this type of ‘closed culture’.<sup>181</sup> Ian Trenholm, CQC’s Chief Executive, told us that the perpetrators of abuse at Whorlton Hall “appeared to collude in a way that deliberately thwarted our methodology. We need to reflect on that. We must change our methodology to think differently about these things.”<sup>182</sup>

138. We are astonished that the CQC does not appear to have considered the possibility that abusers would “collude in a way that thwarted” its inspection methodology. We agree it essential that the CQC changes the way it conducts inspections and does so urgently.

### **St. Andrew’s**

139. As far back as at least 2013 serious concerns have been raised in successive CQC inspection reports about the treatment of patients at St Andrew’s Healthcare Adolescents Service in Northampton (St Andrew’s):

178 Care Quality Commission, [Whorlton Hall, Quality Report](#), 17 June 2016, p.10

179 On 16 October 2019 David Noble QSO published a [letter](#) updating the CQC Board about progress with his review and outlining his preliminary conclusions

180 [Q31](#) [Anne-Marie Trevelyan MP]

181 Care Quality Commission - [Statement on Panorama: “Sickening abuse of vulnerable people”](#), 22 May 2019

182 [Q42](#) [Ian Trenholm]

- November 2013: an inspection report highlighted that patients being kept in conditions amounting to solitary confinement had been denied access to toilet facilities, food and drink.<sup>183</sup>
- December 2016: Helen Hayes MP made a complaint to St. Andrew's about the treatment of one of her young constituents who was detained there. Following a visit to the hospital she was very concerned for his welfare and did not feel that he was receiving appropriate treatment. The complaint was upheld by the hospital, but no further action was apparently taken.<sup>184</sup> In the same year the CQC inspected St. Andrew's and rated it as 'Requires Improvement'.<sup>185</sup>
- October 2018: the Secretary of State requested that the CQC carry out an investigation into conditions at St. Andrew's in response to the publicity surrounding Bethany's case. The CQC's report of that investigation, published in February 2019, again noted a number of areas that needed to improve.<sup>186</sup>
- June 2019 a further report on St. Andrew's following an inspection in March and April this year was published, which rated it as 'Inadequate'.<sup>187</sup> It has now been placed in special measures. This means that the service has been given six months from June to improve and if it does not it may then be deregistered.

140. Given the long-standing concerns about St. Andrew's we asked the CQC senior managers why is it still open nearly nine years after concerns were first raised. In response Dr Paul Lelliot told us:

“Your central premise that there have been long-standing concerns about the use of restrictive practices at St Andrew's is true. My recollection is that we go in there and inspect. After we pick up on issues, things get better. Then either they slip back or there are problems in another part of this big organisation. We find that they have sorted out something in this part, but not in another. That seemed to be the pattern. That is the pattern in my head, but over the last six months or so we have taken very decisive action against two important parts of this provider.”<sup>188</sup>

While we accept this contention that a service may change, sometimes rapidly, over time, it leaves us very concerned about the degree of trust that can be placed in inspection reports. We also question whether the CQC is responsive enough where a clear pattern of complaints and poor inspection reports, albeit with periodic improvements, emerges.

## A wider problem?

141. Whorlton Hall and St. Andrew's are not isolated cases. In written evidence to this inquiry, including in a number of submissions made on a confidential basis, other institutions have been named as places where young people have experienced abuse.

183 Care Quality Commission, [Inspection Report, St Andrew's Healthcare - Adolescents Service](#), November 2013

184 Helen Hayes MP shared copies of this correspondence with the Committee but we have not published it.

185 Care Quality Commission, [St Andrew's Healthcare: Women's, Men's, Adolescent and Neuropsychiatry services. Quality Report](#), 16 September 2016

186 Care Quality Commission, [St Andrew's Healthcare - Adolescents Service](#), Quality Report, 27 February 2019

187 Care Quality Commission, [St Andrew's Healthcare Adolescents service](#), Quality Report, 6 June 2019

188 [Q43](#) [Dr Paul Lelliot]

142. Since the Whorlton Hall scandal in May 2019, very serious concerns have also been raised publicly about a number of other hospitals. For example, West Lane Hospital in Middlesbrough was closed by the CQC in August 2019 after an inspection report found that “[p]atients were not safe and were at high risk of avoidable harm at West Lane Hospital.”<sup>189</sup> CQC had previously inspected the service in June 2018, rating it “Good”.<sup>190</sup>

143. In its written evidence the Centre for Welfare Reform questioned whether regulation can ever prevent abuse of the kind witnessed at Whorlton Hall:

“There is no empirical evidence that regulation even increases quality, in more ordinary care settings. Worse, we know that regulators constantly fail to spot extreme abuse. In the case of Winterbourne View it was Panorama - not the CQC - that discovered the abuse. And when I met with families whose children had been at Winterbourne View they said that Winterbourne View was the “least bad” institution that their children had been placed in. In other words Winterbourne is not an exception - it is the norm - and CQC is not changing this and cannot change this. In fact, regulating services effectively normalises them - it institutionalises the institution as an acceptable offer.”<sup>191</sup>

### ***Analysis of information provided by CQC and NHS Digital***

144. In order to look at the scale of concerns raised about providers, we requested data on a sample of inpatient services, from the CQC and NHS England. The services were purposively sampled to represent a range of NHS and independent sector provider organisations and a range of CQC overall ratings. We appointed Professor Chris Hatton, Professor of Public Health and Disability, at Lancaster University, as Specialist Adviser to the Committee and asked him to analyse the information. This analysis examined the information available to the CQC on 20 services; whistle-blowing contacts, safeguarding alerts and concerns, notifications, data on restrictive interventions, assaults and self-harm, and looked this information is related to inspections carried out by CQC. The full analysis is available on our website.<sup>192</sup>

145. A key conclusion we have drawn from this research is that there is a lack of an obvious relationship between the information that CQC has available to it about a service and its inspection ratings or regulatory actions relating to that service. Most inspections are scheduled and occur approximately every 18 months–2 years, with focused inspections tending to follow up specific aspects of scheduled comprehensive inspections. Beyond routine inspections, there seems to be little relationship between the information presented in the analysis and the timing of inspections, even when notifications of abuse or allegations are at very high levels, prone restraints are being recorded or police incidents in the service occur regularly. Across the 20 services analysed, 18 of them had at least one whistleblowing contact over the time period, but of the 136 whistleblowing contacts only 7% resulted in an earlier than planned inspection (see Graph 1 below). The analysis

189 Care Quality Commission, [Tees Esk Wear Valleys NHS Foundation Trust Child and adolescent mental health wards, Quality Report](#), August 2019 and Tees, Esk and Wear Valleys NHS Foundation Trust, [West Lane Hospital, Middlesbrough](#), updated 20 September 2019

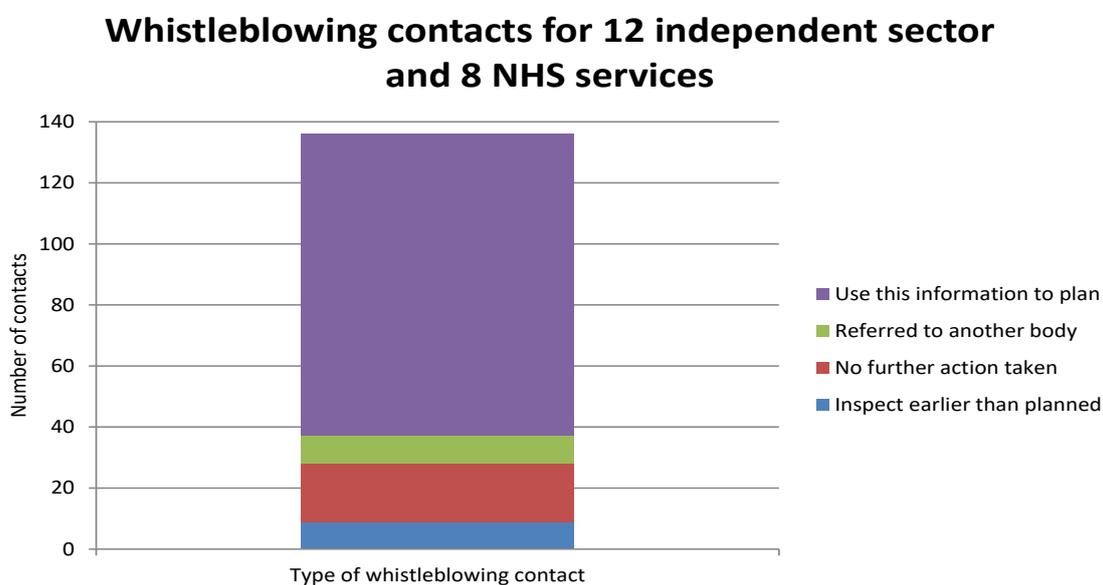
190 Care Quality Commission, [Tees, Esk and Wear Valleys NHS Foundation Trust, Inspection report](#), October 2018

191 Centre for Welfare Reform ([YDA0036](#))

192 [Analysis from Professor Hatton in support of the inquiry into the detention of children and young people with learning disabilities and/or autism](#)

does not include the timing of media reports or other external scrutiny. These may be more relevant in triggering inspections than the information reported to the CQC or whistleblowing contacts.

GRAPH 1



146. One of the CQC’s four strategic priorities for the period 2016 - 2021 is to “[d]eliver an intelligence-driven approach to regulation”. To achieve this it says it will “[l]ook at potential changes in quality by bringing together relevant information about a provider.”<sup>193</sup> The evidence from our analysis suggests that this is not happening, at least not consistently.

### *Responding to concerns from individuals and families*

147. It is unclear from the information provided for our analysis how the CQC records or responds to concerns raised by people in these services and/or their family members, if they are not recorded by the service provider or don’t reach the (rare) threshold of a safeguarding alert. The Challenging Behaviour Foundation felt that such concerns are not taken seriously enough by CQC:

“The reports of families and individuals (or from charities or advocates on their behalf) are not counted as “evidence” even where there are resulting injuries or clear changes to behaviour, mental health or emotional well-being, likely to be associated with trauma.”<sup>194</sup>

148. In its approach to “evidence” the CQC appears to be starting from a perspective of defending its judgments to service providers rather than that of responding to families and individuals. Ian Trenholm, Chief Executive of the CQC told us:

“A range of different providers will challenge our ratings process. That is why we have this quite complex quality assurance process[ ... ] It is why we make such a big deal out of making sure that we can triangulate evidence and all these things.”

193 Care Quality Commission, [Shaping the future: CQC’s strategy for 2016 to 2021](#), May 2016

194 Challenging Behaviour Foundation ([YDA0057](#))

149. Witnesses also argued that the CQC inspection process at points loses sight of those who it is supposed to be protecting. Dame Christine Lenehan, from the Council for Disabled Children, told us:

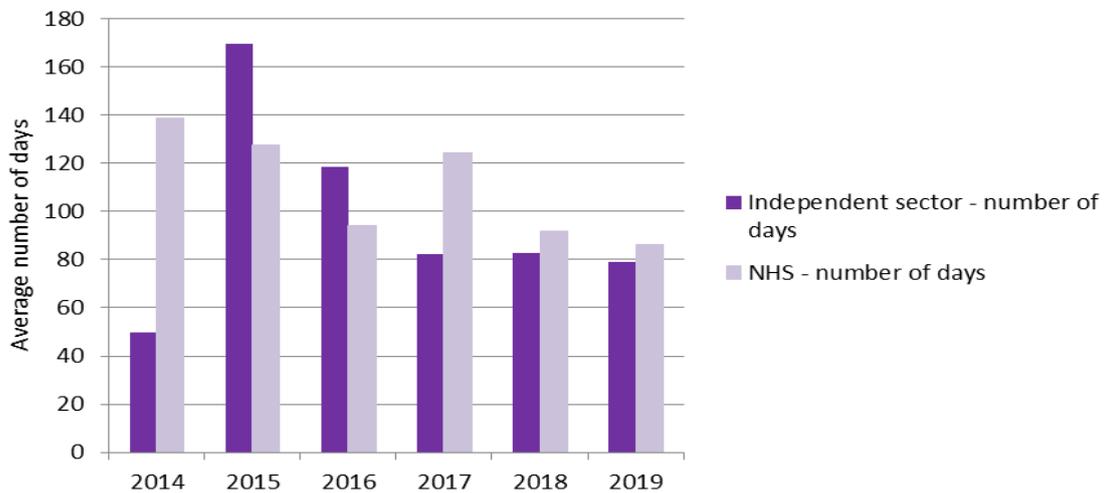
“[ ... ]the way the inspection process is set up, people inspect paperwork and processes; they do not inspect the lives of the people using services, they do not inspect context. “Do you have a book that says how often you have restrained people? Oh, yes, you have a book. Tick”.<sup>195</sup>

**A responsive regulator?**

150. The time from inspections to reports and/or regulatory actions being taken is a further issue of concern highlighted by the analysis. As Graph 2 below shows, the time from inspection to published report (with regulatory actions usually published on the same date as the report) has remained fairly steady at an average 80 days from 2017 through to 2019, a substantial improvement from 2015 and 2016 but still longer than under the previous framework in 2014. In some cases the delay is significantly longer than average. For example, a 2017 inspection report on wards for people with learning disabilities and autism at Brooklands Hospital, which is part of Coventry and Warwickshire Partnership NHS Foundation Trust, was not published until 8 November 2017, 137 days after the inspection took place.<sup>196</sup>

GRAPH 2

**Average number of days from inspection to published report by year**



151. In evidence Caoilfhionn Gallagher QC drew our attention to the CQC’s inspection of Lancaster Lodge where Sophie Bennett was living when she died in May 2016.<sup>197</sup> Sophie

195 [Q16](#) [Dame Christine Lenehan]

196 [Analysis from Professor Hatton in support of the inquiry into the detention of children and young people with learning disabilities and/or autism](#)

197 The Care Quality Commission (CQC) has informed Richmond Psychosocial International Foundation (RPFI), that it will be prosecuted over an alleged failure to provide safe care and treatment resulting in a service user being exposed to the significant risk of avoidable harm under regulations 12 and 221 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014; and that an individual will be prosecuted in this respect pursuant to section 91 of the Health and Social Care Act 2008.

was 19 and had diagnoses of Bipolar Affective Disorder, Social Anxiety Disorder, and atypical autism. An inquest which took place in 2019 found that “neglect” contributed to her death.<sup>198</sup> Caoilfhionn Gallagher QC told us:

“One concern I have is that, even when very serious problems are identified to the CQC, including with safety, there is a time lag before decisions are made and actions are taken. Although this is in a slightly different context, the recent inquest into the death of a young lady called Sophie Bennett is worth looking at on this point. The CQC had produced an incredibly damning report that resulted in most patients being moved out of the placement, with a small number of patients remaining in, one of whom ended up losing her life in an entirely foreseeable accident and in circumstances where the CQC had identified failings months previously. When the CQC identifies serious failings that relate to safety and fundamental breaches of human rights, what happens next?”<sup>199</sup>

152. While there must be quality assurance processes to guarantee the reliability of inspection reports we are concerned that these are preventing reports being published and regulatory actions being taken swiftly.

## Role of NHS Commissioners

153. Although we have focused here on the role of the Care Quality Commission there are others who must share responsibility for oversight of services where young people with learning disabilities and/or autism are detained. Most obviously this includes those who commission placements for young people; usually local Clinical Commissioning Groups (CCGs).

154. We are not confident that CCGs are doing enough to assure themselves that the care and treatment they fund in these settings is safe and appropriate. In the unpublished 2015 inspection report on Whorlton Hall it was noted that “The service did invite external agencies to the multidisciplinary meetings, such as commissioners. They often did not attend and subsequently did not contribute to the meetings but were sent the minutes.”<sup>200</sup>

155. On 18 June we wrote to Simon Stevens, Chief Executive of NHS England to ask whether he agreed that oversight of these institutions is a responsibility that his organisation shares with the CQC.<sup>201</sup> In response NHS England told us:

“the NHS will be improving its quality assurance process for specialist inpatient, care and treatment placements. Out of area inpatients with a learning disability and/or autism will regularly be visited onsite. The host Clinical Commissioning Group will also be given new responsibilities to oversee and monitor quality of care for hospitals in their local areas.”<sup>202</sup>

198 [“Jury find neglect contributed to self-inflicted death of teenager Sophie Bennett in care home”](#), Inquest

199 [Q16](#) [Caoilfhionn Gallagher QC]

200 [Draft Inspection Report ‘Post IM Review’](#) 16 December 2015 p.23

201 Letter from the Chair to Simon Stevens, Chief Executive, NHS England, regarding [requesting information on the Care Quality Commission](#), dated 18 June

202 Response from Ray James, National Director for Learning Disability, NHS England and NHS Improvement, to Chair, [regarding response to additional questions](#), dated 3 July

CCGs already have responsibilities to oversee and monitor the quality of care, for example in organising CTRs and CETRs. NHS England are also direct commissioners of inpatient placements for people with learning disabilities and/or autism and must take responsibility for overseeing and monitoring these. We urge NHS England to monitor closely to ensure that visits are in fact made to those in both locally and centrally commissioned placements and that they lead to improvements in care and treatment.

## Conclusion

156. Too often it is left to the media to be human rights defenders. In this case, were it not for the BBC, Sky News and Ian Birrell writing for the Mail on Sunday we would still be unaware of the extent to which those with learning disabilities and/or autism are being abused while being detained by the state. They are performing a hugely valuable role, but it should not be necessary for them to do so.

157. The failure to detect potential human rights abuses at Whorlton Hall and other hospitals detaining young people with learning disabilities and/or autism has exposed failings in the Care Quality Commission's inspection process. A regulator which gets it wrong is worse than no regulator at all. Substantive reform of its approach and processes are essential. *We hope that the independent review of CQC's regulation of Whorlton Hall between 2015 and 2019 being undertaken by Professor Glynis Murphy will make recommendations for such reform. In our view these should include:*

- *Measures to ensure that inspections are more fleet of foot. For example, unannounced inspections should take place at weekends and in the late evening.*
- *The use, where appropriate, of covert surveillance methods to better inform inspection judgements. In cases when tightly knit groups of staff seek to avoid scrutiny, whilst neglecting and abusing the most vulnerable people, inspectors should consider using the methods used successfully by journalists.*
- *Where concerns are raised by patients and family members about treatment these must be recognised by the CQC as constituting evidence and acted upon.*
- *Changes, including legislative changes if necessary, to make sure that the CQC is able to act more swiftly where concerns about a service are raised and substantiated.*
- *A review of the system which currently allows a service to be rated as 'Good' overall even when individual aspects, such as safety, may have a lower rating.*

## 8 The way forward

158. In this report we have made recommendations which are intended to minimise detention and prevent the abuse of young people's human rights. But what is needed most of all is a shared belief that this situation can and must change. The Centre for Welfare Reform told us:

“The gravest danger for people who end up inside these institutions is that people start to believe they must be there for a good reason for them and that it is the complex needs of the person that require these extraordinary measures, with such an extraordinary cost. However, just because an institution exists - and just people are sent there - does not mean the institution is necessary.”<sup>203</sup>

159. There is no better proof of this than the stories we have heard in the course of this inquiry about the positive, meaningful lives that many people with learning disabilities and/or autism are living outside detention. We will leave the final words of this report to them and their families:

“I live with two housemates. I have a job. Before, I just about existed, but today I can tell you that I now live my life the way I want to, with my support staff who treat me like a human being. That is all I have ever wanted, and that is all people with learning disabilities and/or autism want: to be treated equally, like everyone else.”<sup>204</sup>

*Witness A, a young man with learning disabilities*

“It is a lot better now than it was back then. I do my own things. I can go out on my own. I am independent. I have my own money. I go out and get shopping, cook my own food, take the dog for a walk, that sort of thing. It is really good now. I am really enjoying life.”<sup>205</sup>

*Witness B, who has a learning disability and who was detained as a young woman*

“Our son now has his personal budget, direct payments, his own housing association house with a lifetime tenancy for his independent living and 24 hour support in the village he grew up in with close proximity to family and friends and is at liberty to lead a life of his choosing at a fraction of the ATU figure of the finger in the pie costs.”<sup>206</sup>

*Father of an autistic son*

“I used to be in a bad place, I used to have injections... But now it's better because I do lots of nice things here. There are some nice people here. And my favourite is football man! There are lots of people I like here. We do lots of nice things. We do football. And I like Liverpool.”<sup>207</sup>

*Matthew who was detained for 18 months*

203 Centre for Welfare Reform ([YDA0036](#))

204 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q. 3 [Witness A]

205 [12 Dec 2018 - Conditions in learning disability inpatient units - oral evidence](#) Q. 3 [Witness B]

206 Richard Griffiths ([YDA0022](#))

207 Mrs Isabelle Garnett ([YDA0018](#))

## Conclusions and recommendations

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### Transforming Care

1. Given the limited progress to date, we have no confidence that the target to reduce the numbers of people with learning disabilities and/or autism in mental health hospitals, set out in the NHS Long Term plan, will be met. We welcome the recent establishment, by NHS England, of a taskforce to drive improvements in inpatient care and an independent oversight board to be chaired by the Children's Commissioner for England to oversee the taskforce's work. However, this will not address the biggest barrier to progress - a lack of political focus and accountability to drive change. *To urgently minimise the number of those with learning disabilities and/or autism who are detained and to safeguard their rights, a Number 10 unit, with cabinet level leadership, must be established to ensure reform is driven forward.* (Paragraph 30)

### Ending harmful detention

2. The detention of those with learning disabilities and/or autism is often inappropriate. It causes suffering and frequently makes their conditions worse. Nevertheless, their detention continues even when there is a consensus among families, professionals and Commissioners that individuals are not receiving appropriate medical treatment and do not need to be detained. (Paragraph 48)
3. The right housing, social care and health services needed to prevent people being detained inappropriately are simply not being commissioned. Change is urgently needed. *We therefore recommend that the Number 10 unit we propose, must review the framework for the provision of services for those with learning disabilities and/or autism. At a minimum the Government should introduce:*
  - *a legal duty on Local Authorities and Clinical Commissioning Groups to ensure the availability of sufficient community-based services.*
  - *a legal duty on Local Authorities and Clinical Commissioning Groups to pool budgets for care services for people with learning disabilities and/or autism.* (Paragraph 49)
4. *There is a consensus that people with learning disabilities and/or autism need stronger legal rights. We agree. Any legislative proposals put forward by the Equality and Human Rights Commission, as well as those made by the Independent Mental Health Act 1983 review and campaign groups, must be acted upon.* (Paragraph 52)
5. *In addition to strengthening rights it is imperative that more is done to ensure young people with learning disabilities and/or autism are able to enforce existing ones. To this end, we repeat here key recommendations made in our "Enforcing human rights" report:*
  - *Public authorities must comply with their duty under s.6 of the Human Rights Act in order to prevent breaches of individuals' human rights.*

- *The Government must revise the financial eligibility criteria for legal aid with a view to widening access to those who would otherwise be unable to enforce their human rights.*
  - *Families must be given non-means tested funding for legal representation at inquests where the state has separate representation for one or more interested persons. (Paragraph 53)*
6. *Care and Treatment Reviews and Care, Education and Treatment Reviews, when done well, can provide a crucial opportunity to develop viable alternatives to inpatient care. We recommend that they should be put on a statutory footing to strengthen their ability to perform this role. (Paragraph 57)*

### The legal framework for detention

7. If young people and adults with learning disabilities and/or autism are being detained under the Mental Health Act 1983, the law requires that medical treatment must be necessary, appropriate and available. In spite of these safeguards the default position is to continue to detain. Those admitted on a ‘voluntary basis’ have even fewer safeguards and may fear challenging their ongoing detention due to the threat of being ‘sectioned’. (Paragraph 86)
8. We consider that the human rights of many of those with a learning disability and/or autism are being breached in mental health hospitals. The detention of individuals in the absence of individualised, therapeutic treatment risks violating an individual’s Article 5 right to liberty and security. In some cases, detention may even reach the threshold of degrading treatment contrary to Article 3. (Paragraph 87)
9. The current legislation governing admission, treatment, and discharge from mental health hospitals is failing to protect the Article 5 rights of those with learning disabilities and/or autism. In particular, the requirement of “appropriate medical treatment” contained within the Mental Health Act is constructed far too broadly. *We endorse the recommendation of the Mental Health Act Review that the criteria for detention under the Mental Health Act must be narrowed. Those with learning disabilities and/or autism must only be detained under the Mental Health Act, in situations where:*
- a) *treatment is necessary;*
  - b) *treatment is not available in the community and only available in detention (i.e. the last and only resort);*
  - c) *treatment is of benefit to the individual and does not worsen their condition; and*
  - d) *without the treatment, there is a significant risk of harm to the individual or others.*

We acknowledge that tightening the criteria for detention under the Mental Health Act 1983 could increase the number of detentions under the Mental Capacity Act 2005, with its weaker safeguards. We emphasise that the legal principles set down by the European Court of Human Rights apply irrespective of which regime applies. All persons detained in mental health settings are entitled to individualised, therapeutic treatment. Where

this is not happening, the detention of individuals is a violation of Article 5 and may, in some severe cases, violate Article 3. Persons detained under the MCA, and those admitted informally, must be afforded equal protection of their Article 3 and Article 5 rights. (Paragraph 88)

### Families as human rights defenders

10. *Too often, the concerns raised by the families of those with learning disabilities and/or autism are considered to be hostile. The families are seen as a problem. This is unacceptable. They must be recognised as human rights defenders, and other than in exceptional circumstances, be fully involved in all relevant discussions and decisions. To ensure this we recommend:*
- *Families should, unless there are exceptional circumstances, be given new legal rights to attend Care, Education and Treatment Reviews and Care and Treatment Reviews and any meetings at which decisions are taken about whether to place a young person in detention. They must also receive relevant reports.*
  - *The rights of individuals and their families to advocacy must be enhanced and enforced, including for those who are considered to be informal patients. Advocacy services should be funded entirely separately from care and support services.*
  - *It is wholly unacceptable that injunctions should be sought to prevent families from speaking out when they disagree with the way that their child is being treated. The Ministry of Justice must work with other departments to collect data on the number of injunctions sought by public bodies, including Local Authorities and Clinical Commissioning Groups, against families of those with learning disabilities and/or autism.*
  - *There should be guidance providing that no public authority should apply for an injunction which gags a parent of a child or young person with autism and/or learning disabilities who is either in or being considered for placement in a mental health hospital unless they have obtained the specific approval for such an application from the Secretary of State for Health and Social Care. (Paragraph 97)*

### Conditions in places of detention

11. We are clear that the best way to prevent human rights abuses in institutions is to take urgent action to stop people with learning disabilities and/or autism being inappropriately detained. But for as long as people are detained, it is imperative that steps are taken to safeguard their human rights and ensure redress when those rights have been breached. (Paragraph 100)
12. In our “Youth Detention: solitary confinement and restraint” report we concluded that “Some cases in hospitals amount to solitary confinement, which is not compliant with human rights standards for children”. We reiterate that conclusion here. (Paragraph 108)

13. The evidence presented in our inquiry reinforces the recommendations and conclusions we made in our report “Youth detention: solitary confinement and restraint.” *We highlight two of those recommendations in the context of this inquiry:*
- a) *“that the use of separation in hospitals be more rigorously regulated. Each institution in the health sector must report data on extension of separations to the responsible Minister on a monthly basis, who will certify the information and lay it before each House for publication.” In its response to the report the Government accepted that that the regulation of hospitals that use separation could be improved and noted that the Care Quality Commission’s review into the use of restrictive interventions will be looking further at this area. The Government also drew attention to the fact that that NHS Digital is now reporting data on restrictive interventions on a monthly basis. While we welcome this, we continue to believe that our recommendation should be implemented in full and we urge the CQC to take it up in the final report of its review which is due to be published in spring 2020.*
  - b) *that while “there may be there may be exceptional circumstances in which prone restraint is preferable to alternatives, it must be more rigorously regulated by governing health bodies and regulators, including by annual publication of statistics for each institution (broken down by patients’ diagnoses, age and justification for not using an alternative method).” In its response to the report the Government highlighted recent improvements that have been made in the area of data collection including requiring that services include in the records they provide the duration of any use of prone restraint. This is a positive step forward and we hope that improved data collection will lead to more rigorous regulation. (Paragraph 113)*
14. *We recommend that on every occasion that anyone is restrained or kept in conditions amounting to solitary confinement their families must be automatically informed. (Paragraph 115)*
15. *Placing young people a long way from their home reduces their support from their families and undermines their right to family life under Article 8 ECHR. It must stop. Until it is stopped, families must be given the financial support they need to be able to visit their loved ones. (Paragraph 120)*
16. *We note the Government’s proposal to establish an independent body to investigate serious healthcare incidents. We urge the Government to work with the Equality and Human Rights Commission to ensure that it is fulfilling its obligations under Articles 2 and 3 ECHR in relation to independent investigations of deaths of those with learning disabilities and/or autism in detention settings. (Paragraph 122)*

### The Care Quality Commission

17. Too often it is left to the media to be human rights defenders. In this case, were it not for the BBC, Sky News and Ian Birrell writing for the Mail on Sunday we would still be unaware of the extent to which those with learning disabilities and/or autism are being abused while being detained by the state. They are performing a hugely valuable role, but it should not be necessary for them to do so. (Paragraph 156)

18. The failure to detect potential human rights abuses at Whorlton Hall and other hospitals detaining young people with learning disabilities and/or autism has exposed failings in the Care Quality Commission's inspection process. A regulator which gets it wrong is worse than no regulator at all. Substantive reform of its approach and processes are essential. *We hope that the independent review of CQC's regulation of Whorlton Hall between 2015 and 2019 being undertaken by Professor Glynis Murphy will make recommendations for such reform. In our view these should include:*
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  - *The use, where appropriate, of covert surveillance methods to better inform inspection judgements. In cases when tightly knit groups of staff seek to avoid scrutiny, whilst neglecting and abusing the most vulnerable people, inspectors should consider using the methods used successfully by journalists.*
  - *Where concerns are raised by patients and family members about treatment these must be recognised by the CQC as constituting evidence and acted upon.*
  - *Changes, including legislative changes if necessary, to make sure that the CQC is able to act more swiftly where concerns about a service are raised and substantiated.*
  - *A review of the system which currently allows a service to be rated as 'Good' overall even when individual aspects, such as safety, may have a lower rating. (Paragraph 157)*

## Declaration of interests

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Interests declared by Members during the Inquiry and / or consideration:

**Lord Brabazon of Tara (joined JCHR on 3 July 2019)**

- No relevant interests to declare

**Lord Dubs (joined JCHR on 3 July 2019)**

- No relevant interests to declare

**Baroness Hamwee (left JCHR on 3 July 2019)**

- No relevant interests to declare

**Baroness Lawrence of Clarendon (left JCHR on 3 July 2019)**

- No relevant interests to declare

**Baroness Ludford (joined JCHR on 3 July 2019)**

- No Interests declared

**Baroness Massey of Darwen (joined JCHR on 3 July 2019)**

- No interests declared

**Baroness Nicholson of Winterbourne (left JCHR on 3 July 2019)**

- No relevant interests to declare

**Baroness Prosser (left JCHR on 3 July 2019)**

- No relevant interests to declare

**Lord Singh of Wimbledon (joined JCHR on 3 July 2019)**

- No Interests declared

**Lord Trimble**

- No relevant interests to declare

**Lord Woolf (left JCHR on 3 July 2019)**

- No interests declared

# Formal minutes

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**Wednesday 23 October 2019**

Members present:

Fiona Bruce MP, in the Chair

Lord Brabazon of Tara	Baroness Massey of Darwen
Lord Dubs	Scott Mann MP
Ms Karen Buck MP	Lord Singh of Wimbledon
Joanna Cherry MP	Lord Trimble
Jeremy Lefroy MP	

Draft Report (*The detention of young people with learning disabilities and/or autism*), proposed by the Chair, brought up and read.

*Ordered*, That the Chair's draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 159 read and agreed to.

Summary read and agreed to.

*Resolved*, That the Report be the Second Report of the Committee.

*Ordered*, That the Chair make the Report to the House of Commons and that the Report be made to the House of Lords.

*Ordered*, That embargoed copies of the report be made available in accordance with the provisions of Standing Order no. 134.

[Adjourned till Wednesday 30 October 2019 at 3.00pm]

## Witnesses

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

### Wednesday 9 January 2019

**Dr Paul Lelliott**, Deputy Chief Inspector of Hospitals (and lead for mental health), Care Quality Commission, **Ray James**, National Learning Disability Director, and **Dr Jean O'Hara**, National Clinical Director, Learning Disabilities, NHS England

[Q1–12](#)

### Wednesday 27 March 2019

**Simon Duffy**, Director, Centre for Welfare Reform, **Dame Christine Lenehan**, Director, Council for Disabled Children, and **Caoilfhionn Gallagher QC**, Doughty Street Chambers

[Q13–19](#)

### Wednesday 3 April 2019

**Caroline Dinenage MP**, Minister of State for Care, and **Jonathan Marron**, Director General, Community and Social Care, Department of Health and Social Care

[Q20–29](#)

### Wednesday 5 June 2019

**Anne-Marie Trevelyan MP**, and **Rt Hon Norman Lamb MP**

[Q30–41](#)

### Wednesday 12 June 2019

**Ian Trenholm**, Chief Executive, and **Dr Paul Lelliott**, Deputy Chief Inspector of Hospitals (lead for mental health), Care Quality Commission

[Q42–50](#)

## Published written evidence

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

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

- 1 Affinity Trust ([YDA0013](#))
- 2 Anonymous 12 ([YDA0025](#))
- 3 Anonymous 1 ([YDA0001](#))
- 4 Anonymous 2 ([YDA0004](#))
- 5 Anonymous 3 ([YDA0006](#))
- 6 Anonymous 4 ([YDA0015](#))
- 7 Anonymous 5 ([YDA0033](#))
- 8 Anonymous 13 ([YDA0043](#))
- 9 Anonymous 14 ([YDA0047](#))
- 10 Anonymous 15 ([YDA0049](#))
- 11 Anonymous 16 ([YDA0026](#))
- 12 Article 39 ([YDA0028](#))
- 13 Bailey, Miss Leann ([YDA0053](#))
- 14 Buckingham, Mr Simon ([YDA0010](#))
- 15 Centre for Welfare Reform ([YDA0036](#))
- 16 Challenging Behaviour Foundation and Mencap ([YDA0014](#))
- 17 Cookson, Mrs Lisa ([YDA0019](#))
- 18 Costin, Mr James ([YDA0007](#))
- 19 Dimensions ([YDA0012](#))
- 20 Donohoe, Ms Abigail ([YDA0054](#))
- 21 Equality and Human Rights Commission ([YDA0021](#))
- 22 Equality and Human Rights Commission ([YDA0045](#))
- 23 Garnett, Mrs Isabelle ([YDA0018](#))
- 24 Griffiths, Richard ([YDA0022](#))
- 25 Hagan, Mrs Carole ([YDA0011](#))
- 26 Inclusion London, People First (Self Advocacy and Changing Perspectives) ([YDA0029](#))
- 27 Lawson, Mr Adam ([YDA0017](#))
- 28 Little, Penn ([YDA0009](#))
- 29 Munro, Dr Nell ([YDA0020](#))
- 30 The National Autistic Society ([YDA0044](#))
- 31 O'Donnell, Ita ([YDA0023](#))
- 32 Penfold, Mr Ian ([YDA0016](#))
- 33 People First Independent Advocacy ([YDA0030](#))

- 34 Rayner, Chris ([YDA0008](#))
- 35 Rightful Lives ([YDA0034](#))
- 36 Series, Dr Lucy ([YDA0046](#))
- 37 Stokes, Holly ([YDA0055](#))
- 38 Ward, Mr Andrew ([YDA0052](#))
- 39 YoungMinds ([YDA0032](#))

# 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 2017–19

First Report	Legislative Scrutiny: The EU (Withdrawal) Bill: A Right by Right Analysis	HC 774 HL 70
Second Report	Proposal for a Draft Human Fertilisation and Embryology Act 2008 (Remedial) Order 2018	HC 645 HL 86
Third Report	Legislative Scrutiny: The Sanctions and Anti-Money Laundering Bill	HC 568 HL 87
Fourth Report	Freedom of Speech in Universities	HC 589 HL 111
Fifth Report	Proposal for a draft British Nationality Act 1981 (Remedial) Order 2018	HC 926 HL 146
Sixth Report	Windrush generation detention	HC 1034 HL 160 (HC 1633)
Seventh Report	The Right to Freedom and Safety: Reform of the Deprivation of Liberty Safeguards	HC 890 HL 161
Eighth Report	Freedom of Speech in Universities: Responses	HC 1279 HL 162
Ninth Report	Legislative Scrutiny: Counter-Terrorism and Border Security Bill	HC 1208 HL 167 (HC 1578)
Tenth Report	Enforcing Human Rights	HC 669 HL 171
Eleventh Report	Second Legislative Scrutiny Report: Counter-Terrorism and Border Security Bill	HC 1616 HL 195 (HC 1827)
Twelfth Report	Legislative Scrutiny: Mental Capacity (Amendment) Bill	HC 1662 HL 208
Thirteenth Report	Proposal for a draft Jobseekers (Back to Work Schemes) Act 2013 (Remedial) Order 2018	HC 1451 HL 209
Fourteenth Report	Draft Human Fertilisation and Embryology Act 2008 (Remedial) Order 2018	HC 1547 HL 227
Fifteenth Report	Proposal for a draft Human Rights Act 1998 (Remedial) Order 2019	HC 1457 HL 228
Sixteenth Report	Immigration Detention	HC 1484 HL 279
Seventeenth Report	Human Rights Protections in International Agreements	HC 1883 HL 310 (HC 2199)

Eighteenth Report	Legislative Scrutiny: Immigration and Social Security Co-ordination (EU Withdrawal) Bill	HC 569 HL 324
Nineteenth Report	Youth detention: solitary confinement and restraint	HC 994 HL 343
Twentieth Report	Good Character Requirements: Draft British Nationality Act 1981 (Remedial) Order 2019 - Second Report	HC 1943 HL 397 (HC 120)
Twenty-first Report	Proposal for a draft Fatal Accidents Act 1976 (Remedial) Order 2019	HC 2225 HL 405
Twenty-second Report	The right to family life: children whose mothers are in prison	HC 1610 HL 411
First Special Report	Human Rights and Business 2017: Promoting responsibility and ensuring accountability: Government Response to the Committee's Sixth Report of Session 2016–17	HC 686
Second Special Report	Mental Health and Deaths in Prison: Interim Report: Government Response to the Committee's Seventh Report of Session 2016–17	HC 753
Third Special Report	Legislative Scrutiny: Counter-Terrorism and Border Security Bill: Government Response to the Committee's Ninth Report of Session 2017–19	HC 1578
Fourth Special Report	Windrush generation detention: Government Response to the Committee's Sixth Report of Session 2017–19	HC 1633
Fifth Special Report	Second Legislative Scrutiny Report: Counter-Terrorism and Border Security Bill: Government Response to the Committee's Eleventh Report of Session 2017–19	HC 1827
Sixth Special Report	Human Rights Protections in International Agreements: Government Response to the Committee's Seventeenth Report of Session 2017–19	HC 2199
<b>Session 2019–20</b>		
First Report	Democracy, freedom of expression and freedom of association: Threats to MPs	HC 37 HL 5
First Special Report	Good Character Requirements: Draft British Nationality Act 1981 (Remedial) Order 2019 - Second Report: Government Response to the Committee's Twentieth Report of Session 2017–19	HC 120
Second Special Report	Immigration detention: Government Response to the Committee's Sixteenth Report of Session 2017–19: Second Special Report of Session 2019–20	HC 216