



National Audit Office

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## **Report**

by the Comptroller  
and Auditor General

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## **Department of Health**

# Care services for people with learning disabilities and challenging behaviour

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Department of Health

# Care services for people with learning disabilities and challenging behaviour

Report by the Comptroller and Auditor General

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Sir Amyas Morse KCB  
Comptroller and Auditor General  
National Audit Office

2 February 2015

This report examines the challenge faced in delivering key commitments in the Winterbourne View Concordat, the extent to which these have been achieved, and the barriers to transforming care services for people with learning disabilities.

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## Key facts

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**2,600**

inpatients with learning disabilities in mental health hospitals at September 2014

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**£557m**

NHS spending on inpatients with learning disabilities in mental health hospitals, 2012-13

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**13**

Winterbourne View commitments met, out of the 20 key commitments government set itself

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**£5.3 billion**

spent by local authorities on community services for adults with learning disabilities, in 2013-14

**1 June 2014**

date in the Winterbourne View Concordat when all people, for whom it was appropriate, should have transferred from mental health hospitals into the community

**920**

people in mental health hospitals who still had no date for planned transfer to the community, at September 2014 (for 691 of these, a clinician had decided that they were not ready)

**150**

unannounced Care Quality Commission inspections after the Winterbourne View scandal: 71 NHS trusts, 47 private services and 32 care homes

**83%**

of the 2,600 people in mental health hospitals were sectioned under the Mental Health Act, as of September 2014

**6 years and 9 months**

average length of continuous inpatient stay (including transfers between hospitals) in the 4 hospitals we visited

**17 years and 4 months**

average length of stay, including admissions and readmissions, in the 4 hospitals we visited

**50+ kilometre**

journey from hospital to home for 36.5% of inpatients in mental health hospitals

# Summary

**1** In May 2011, a *BBC Panorama* programme exposed staff abuse of patients with learning disabilities at Winterbourne View, a private mental health hospital. The government responded with a commitment to transform services for all people with learning disabilities or autism who had challenging behaviour or a mental health condition. The Department of Health (the Department) led the government's review.

**2** In December 2012, the Department published *Transforming care: A national response to Winterbourne View Hospital* and the accompanying *DH Winterbourne View Review – Concordat: Programme of Action* (the Concordat). The Concordat set out the government's pledge to work with others to meet the 63 Transforming care commitments (the commitments). There was one central commitment. By 1 June 2014, if anyone with a learning disability and challenging behaviour would be better off supported in the community, then they should be moved out of hospital. As a consequence, the government expected to see a dramatic reduction in hospital placements and large mental health hospitals closed, so a new generation of inpatients did not take the place of people then in hospital.

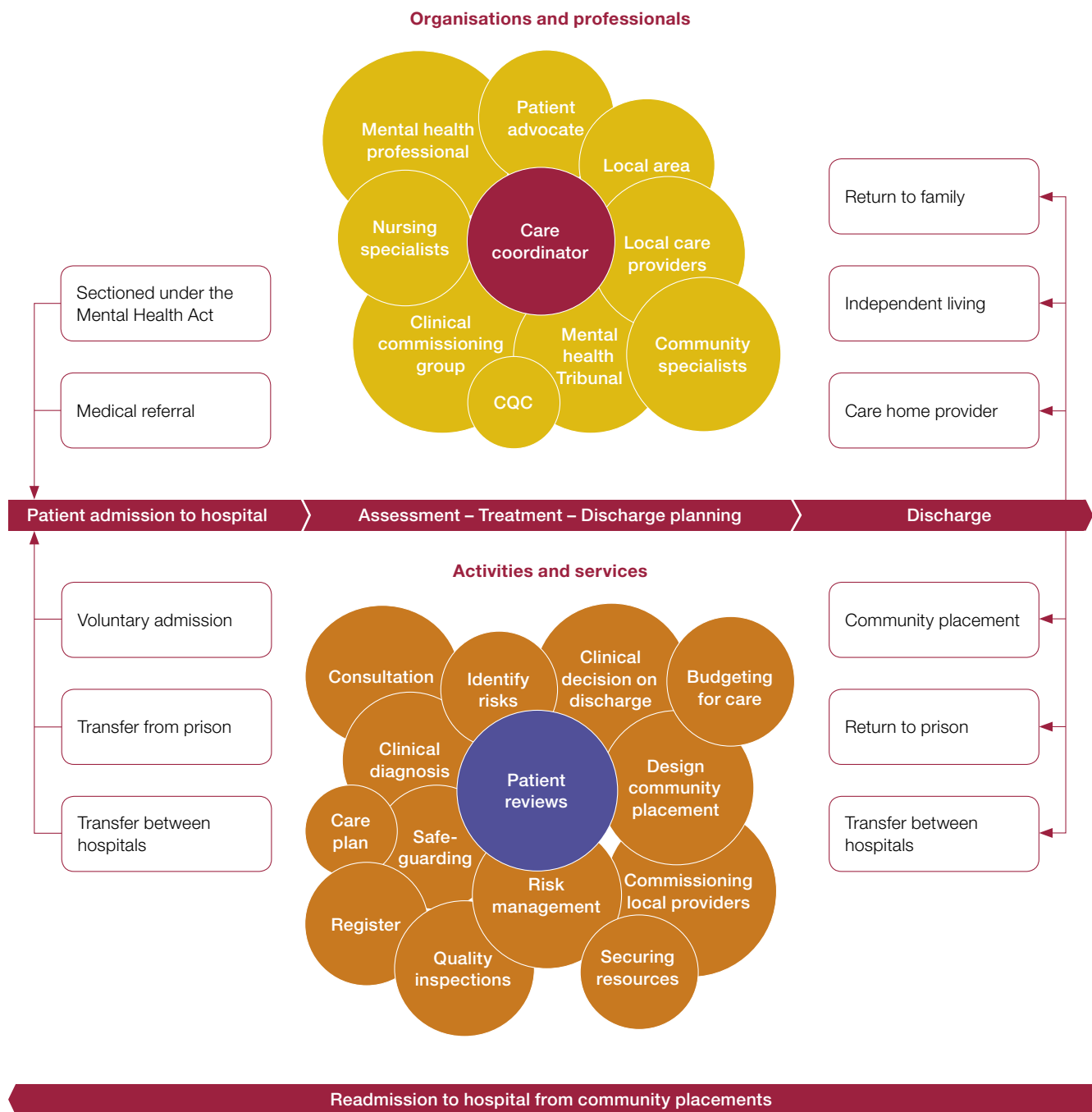
**3** The challenge of discharging people with learning disabilities and challenging behaviour dates back, at least, to the care in the community programme and associated hospital closure programme in the 1980s. It is a classic 'wicked issue' – that which defies simple solutions. As **Figure 1** overleaf shows, it involves complex interrelated events, processes and services for admitting, and assessing, treating and discharging patients. All of which must work together for the system to work as intended.

**4** The Department sets the strategy to improve quality and safety, enable change and measure and monitor progress. A cross-government Learning Disability Programme Board oversees the programme of transforming care services. The Department aimed to assure that the 51 organisations signed up to the Concordat's vision worked together to achieve the shared objectives. However, in line with the Health and Social Care Act 2012, NHS England, mental health hospitals, and local health and social care commissioners determined how to meet those commitments.

**5** We estimate that the NHS spent £557 million on services for inpatients with learning disabilities and challenging behaviour in 2012-13. In addition, local authorities with adult social services responsibilities spent £5.3 billion (2013-14) on services for adults with learning disabilities.

**Figure 1**  
Progress from hospital admission to discharge

**Integrated Care Programme Approach**



**Note**

1 'Clinical commissioning group register' was called the 'primary care trust register' in the Concordat.



## Scope of this report

**6** We have focused on the cohort of inpatients with a learning disability and challenging behaviour in mental health hospitals in England. A learning disability is a reduced intellectual ability and difficulty with everyday activities. A minority of people with learning disabilities exhibit challenging behaviour and can present a risk to themselves and to others. The report examines:

- the challenge the government faced, in meeting its commitments (Part One);
- performance against the commitments (Part Two); and
- barriers to transforming care services (Part Three).

**7** Our methods are set out in Appendices One and Two.

## Key findings

Understanding the scale of the challenge

**8 In December 2012, when agreeing the Concordat, the scope and the quality of data on patients with learning disabilities was poor.** Without an accurate picture of the scale of the task, remedial action may be misdirected, or not match the scale of the challenge. Early estimates of the size of the inpatient population were inaccurate and incomplete. The Health and Social Care Information Centre's census of mental health hospitals (September 2013) and NHS England's second census of commissioners (March 2014) eventually gave reasonable estimates of the inpatient population. They respectively estimated that there were 3,250 and 2,615 inpatients. The Department has asked the Health and Social Care Information Centre to develop the Mental Health and Learning Disabilities Data Set, to give sustained good-quality data (paragraphs 2.2 and 2.23).

**9 Only 73 of the 3,250 people in the 2013 census had been clinically assessed as posing such a risk to themselves, or others, that they needed to be in a high security hospital.** The government assumed there would be a dramatic reduction in hospital placements, large hospitals would close and there would be few new inpatients. Along with the expectations in the 2012 Concordat, families, carers and local stakeholders expected that almost all the 3,250 people in hospital would be discharged into more appropriate community settings, by 1 June 2014. However, 1,042 people were subject to restrictions under Part III of the Mental Health Act and related legislation. This may suggest a continued need for good-quality inpatient provision near where people live (paragraph 2.3).

**10 The government underestimated the complexity and level of challenge involved in meeting its commitments.**

When it published the Concordat, the government did not know the size of the challenge to increase the capacity of community placements. It had little information on whether local commissioners could put in place the bespoke community placements and personalised care plans required to manage risks and prevent readmissions. The government had not analysed why new patients were referred to hospitals (including the impact on the total inpatient population). It has not quantified the resources needed to accelerate patients' readiness for discharge, to meet the 1 June 2014 target date (paragraph 2.4).

Putting in place effective delivery mechanisms

**11 The government left it to mental health hospitals, NHS commissioners, and local authorities to decide how to meet the commitments.**

In line with the provisions of the Health and Social Care Act 2012, the Department did not have the traditional levers to implement the necessary changes, such as national monitoring, mandatory guidance, additional funding to build capacity, pooled budgets or dedicated funding. In addition, local authorities, primary care trusts (now clinical commissioning groups) and hospitals – those responsible for meeting the commitments – were not asked to sign up to the Concordat. The Department did, however, mandate NHS England to take forward key commitments and invested £5 million in the Transforming care programme, designed to support health and care commissioners (paragraphs 1.13, 1.15 and 2.15).

**12 As funding did not follow the patient, there was no financial incentive for local areas to bring patients home.**

Around half of inpatients are funded directly by NHS England. There can be substantial extra costs to local health and care commissioners to meet discharged patients' community care needs when their hospital care was previously funded by NHS England. This was not a hospital closure programme. However, previous commitments to discharge large numbers of inpatients had associated funding to build and maintain community services. However, there was neither funding for patient transfers, nor pump-priming money, available for this programme (paragraphs 2.15, 2.24, 2.25 and 3.1).

## Performance against key Concordat commitments

**13 NHS England has regularly reviewed the status for the 48 patients who had been at Winterbourne View when it closed.** The latest review, between January and June 2014, showed that (paragraph 2.14):

- 10 people were still in hospital;
- 20 were in residential care;
- 5 were in supported housing with their own tenancies;
- 12 had their own general needs tenancy; and
- one had died.

**14 Despite progress on most main commitments, the government did not dramatically reduce hospital placements or new admissions.** Out of 20 key commitments that the government set, 6 were met by the target date, 7 were met but not by the target date, and 7 have not yet been met. Most progress has been made on commitments to publish guidance, best practice and standards. Data at June 2014, the date for meeting the key Concordat commitment, shows the following (paragraphs 2.6 to 2.9, Figures 3 and 4):

- The number of people with learning disabilities and challenging behaviour in hospital was broadly stable at 2,615 in March 2014 and 2,601 in June 2014.
- Over the three quarters ending December 2013 to June 2014, there were 902 hospital admissions compared with 600 discharges, a net gain of 302. However, this data does not distinguish between discharges to community settings, or transfers to other hospitals.
- At June 2014, 2,024 of the 2,601 inpatients had no planned transfer or discharge date and 1,614 of these had received a clinical decision not to transfer. This was despite an NHS England requirement that commissioners should ensure that when someone is admitted to hospital they have a planned transfer or discharge date.
- At June 2014, for 1,296 of the 2,601 inpatients, their local authority did not know they might transfer to their area on discharge from hospital.
- In addition, the September 2013 census of hospitals showed that 36.5% of inpatients were in hospitals over 50 kilometres from their home area.

**15 The Health and Social Care Information Centre did not give the information we needed, to validate the quality of their annual inpatient census data.** Consequently, we primarily analysed NHS England's quarterly census data, which we validated (Appendix Two paragraph 10).

**16 The Care Quality Commission made unannounced inspections at 150 services after the Winterbourne View scandal.** The Commission was responsible for inspecting, regulating and ensuring that services met the agreed model of care. It focused on two standards: care and welfare; and, protecting health and well-being and enabling inpatients to live free from harm. Excluding 5 pilot inspections, the Commission found 69 failed to meet one or both standards, some hospitals admitted people for long periods, and discharges took too long to arrange (paragraph 2.13).

**17 NHS England lacks adequate and reliable data to monitor progress.**

In 70% of the 281 case files we reviewed at visits to 4 hospitals, there was at least one error in the June 2014 quarterly census data submitted to NHS England. Official data for our cohort of 281 patients showed an average stay of 3 years and 10 months. The actual length of stay was 4 years and 3 months in their current hospital. The census reports only the length of stay in any given hospital ward. It does not include total continuous inpatient stay – in the same or another hospital. Also, the data does not show how many times a patient is admitted to hospital or the total time they spent there. NHS England needs both to effectively understand and manage discharges and to stem the flow of people into hospital. Our cohort of 281 cases had a total average length of continuous inpatient stay (including transfers between hospitals) of 6 years and 9 months. For admissions and readmissions, the average total inpatient stay was 17 years and 4 months, although this was not a statistically significant sample (paragraphs 2.20, 2.21 and Figure 7).

#### Response to missing key commitments

**18 The Department and NHS England have acknowledged the slow progress in meeting the key Concordat commitments.** In April 2014, NHS England identified the need for plans to ensure that people have effective care and treatment reviews and set a level of ambition for discharges which the NHS, working with local partners, could deliver. The Department asked NHS England, in May 2014, to put together an action plan and publish it by the end of August. The plan was presented to the Transforming Care Assurance Board in September 2014. NHS England commissioned Sir Stephen Bubb to review how best to increase local community care provision and move people with learning disabilities out of hospital. He concluded that “we make it too hard for stakeholders across the system to make change happen, and too easy to continue with the status quo” (paragraphs 2.26 to 2.28).

**19 NHS England set a new ambition in August 2014 to transfer 50% (around 1,300) of people who were inpatients on 1 April 2014 to more appropriate care settings by 31 March 2015.** In November 2014, NHS England clarified that it meant discharges from mental health hospitals and not transfers between them. NHS England said that around 400 of this cohort of inpatients had been discharged in the first 7 months of 2014-15. The ambition requires a further 900 to be discharged in the remaining 5. However, the figures do not separately identify transfers to other hospitals or readmissions, so overstate progress to an unknown degree. When we met with local authorities, clinical commissioning groups and hospitals (those to be tasked with delivery) in October 2014, they were unaware of NHS England's ambition. However, although there was no central implementation plan, risk assessment or mitigation plans, NHS England told us that during our work (paragraphs 2.29 to 2.31):

- each of its regional directors was accountable for progress with the new ambition;
- the national learning disability programme team developed protocols for care and treatment reviews to identify patients with no clinical need for inpatient care; and
- it has worked with the Local Government Association and the Association of Directors of Adult Social Services to address gaps in communication to clinical commissioning groups and local authorities.

**20 There is no timetable or ambition to reduce the inflow of inpatients with learning disabilities or close hospitals.** The 2012 Concordat stated that the commitments would mean a new generation of inpatients did not take the place of people then in hospital. The mental health hospitals we visited all had waiting lists for admission. So simply discharging existing patients would not reduce their overall numbers, if these patients were all replaced by new admissions. Some people will, however, continue to need high-quality local inpatient services because of a crisis in their community care or serious offending behaviour (paragraphs 1.13, 2.8 to 2.10).

## Building sustainable community based care services

**21 Joint work between health and social care commissioners is vital to make discharges from mental health hospitals sustainable.** Discharges are more likely to succeed where local multidisciplinary teams work closely with hospital clinicians and hospital outreach teams to design and commission bespoke care plans and intervene quickly to prevent readmissions. We found cases of significant delays in decision-making on funding for bespoke community based care packages. Mental health hospitals have the advantage of economies of expertise for treating mental ill health, such as personality disorder. And they understand best how to apply psychiatric, psychological, linguistic and occupational therapeutic treatments, specifically built around the needs of people with a learning disability. This is an underused resource and should be available locally (paragraphs 2.24 and 3.5).

**22 Developing robust community services for people with a learning disability and challenging behaviour takes time.** Salford local authority and clinical commissioning group (previously the primary care trust) is often identified as a beacon of good practice. It has a joined up health and social care management and commissioning structure with a pooled budget. This supports a co-located and multidisciplinary team, committed to keeping people out of mental health hospitals by supporting them in the community. However, this single service has taken over a decade to introduce (paragraph 3.10).

## **Conclusion**

**23** Moving people with learning disabilities and challenging behaviour out of hospital, where appropriate, is a complex process which defies short-term solutions. Unless all parts of the health and social care systems work effectively together, it is unlikely to happen. Despite government efforts, and the key commitments it has met, it did not achieve this central goal by the target date. This was partly because there are no mechanisms for systematically pooling resources to build sufficient capacity in the community for this to happen.

**24** The government faces 3 challenges in improving the care for people with learning disabilities and challenging behaviour. First, to determine the most appropriate place for people's assessment and treatment. Second, to reduce the number of people with learning disabilities in inappropriate settings. And third, to create a sustainable system that minimises the need for inpatient care settings. While NHS England has made a disappointingly slow start to this task, there are signs of progress in documenting people's readiness for discharge, if not yet in reducing admissions. The nature and pace of joint-working between health and social care commissioners must change if they are to meet their commitments.

## Recommendations

**25** Our recommendations are interdependent, and would be unlikely to maximise performance against the government's commitments if taken only in isolation.

**26 The government must improve data, ensure there are discharge plans for inpatients, and introduce a readmissions performance indicator:**

- a** improve data quality and coverage, by including the numbers and flows of patients through the health, social care and criminal justice systems (using the Mental Health and Learning Disability Data set);
- b** through NHS England, ensure that every inpatient, who does not pose such a risk that they need to be in a high-security hospital, has a discharge plan by 31 January 2016; and
- c** through the Mental Health and Learning Disability Data set, introduce a readmissions performance indicator to assess how sustainable care packages for discharged patients are.

**27 The government should use the mechanisms offered by the Better Care Fund to mandate pooled budgets for care services for people with learning disabilities from April 2016.** Local areas should work with NHS England and pool budgets to make joint decisions on care, which would incentivise the joining up of health and social care services. This should be underpinned by:

- a** funds that follow the person with learning disabilities from hospital to the community;
- b** co-locate multidisciplinary teams of learning disability specialists to plan and support discharges and train providers; and
- c** having a named coordinator for each inpatient who attends every biannual review meeting, primarily focusing on planning their discharge.

**28 Clinical commissioning groups, local authorities and NHS England should better use the economies of expertise within mental health hospitals in the ongoing care of people discharged from hospital.** This should include designing discharge and care plans. This would help prevent the mental ill health of people with learning disabilities and challenging behaviour deteriorating to the point that they become a risk to the public, or themselves, and require readmission.

# Part One

## Transforming care

### **People with learning disabilities**

**1.1** A learning disability is a reduced intellectual ability and difficulty with everyday activities, which affects someone for their whole life. The condition may be identified in childhood, but will be present from birth. Treatment programmes for people with learning disabilities are not a cure. Treatment includes helping the person to understand and manage their behaviour and their relationships with others; reducing any risks they pose to themselves and others; and improving their communication skills and independence.

### **Referral to mental health hospitals**

**1.2** A minority of people with learning disabilities show challenging behaviour. They can present a risk to themselves, and others such as their families and the public. Challenging behaviour can include self harm, violence and aggression. Their families, or those supporting them in the community, might ask that the person be admitted to a mental health hospital. Some people with learning disabilities commit criminal acts, and their condition means they might be unaware of the significance and consequence of their actions.

**1.3** Some people with learning disabilities receive a civil or criminal section under the Mental Health Act. Some might be sent directly from court to mental health hospitals or transferred from prison if the person can be managed and treated better in a secure hospital. In September 2014, of the 2,600 people in mental health hospitals, 83% had been sectioned under the Mental Health Act, with 46% receiving a civil section and 37% receiving a criminal section. A further 11% were admitted under normal referral procedures, and 5% fell into various 'other' categories for placement in a mental health hospital.



**1.4** For this examination, we have focused only on those 2,600 people with learning disabilities or autism, or both, who have mental health problems or challenging behaviour, in mental health hospitals. For brevity, we refer to those people within the scope of our examination as ‘people with learning disabilities’. We intend to examine community services for the estimated 908,000 adults and 236,000 children with a learning disability in a future study.<sup>1</sup>

### **Inpatient treatment services**

**1.5** We used the 2013 published learning disability census data to estimate the cost of treating people in inpatient hospital services. In 2012-13, the NHS spent £557 million on this care for people with learning disabilities within the 58 NHS and 49 independent hospitals, with assessment and treatment centres. These are designed to give tailored assessment, treatment and rehabilitation to improve the patient’s ability to understand, and manage, their behaviours. Specialist mental health staff, such as clinical psychiatrists, psychologists and nursing staff, assess the patient to identify their treatment and care needs. They are required to prepare the patient’s care plan, in consultation with the patient. Mental health hospitals must also carry out biannual formal reviews of, and updates to, each inpatient’s care plan as they continue their treatment. These include deciding who would be better cared for in the community.

**1.6** After admission, mental health staff should begin to develop a discharge plan with the patient and where appropriate their family, and health and social service representatives from the patient’s home area. The discharge plan aims to enable the person to progress from receiving specialist treatment in hospital to living with their family or in a community placement appropriate to their needs and risks. Planning a patient’s discharge can be lengthy and complex. The community support required can include bespoke and secure housing, and around-the-clock care.

### **Winterbourne View hospital**

**1.7** On 31 May 2011, a *BBC Panorama television programme* showed staff abusing inpatients with learning disabilities at Winterbourne View, a private mental health hospital in South Gloucestershire. In June 2011, the hospital closed and its patients were transferred to alternative services. The police investigation resulted in 11 criminal convictions of staff at the hospital.

<sup>1</sup> Public Health England, *People with Learning Disabilities in England 2012*, Improving Health and Lives Team, July 2013.

## Transforming care and support services

**1.8** The Department of Health (the Department) led the government's review to examine how to prevent abuse, and recommended actions to improve service quality and safety. The government intended that this transformation would prevent people from being placed in hospitals inappropriately and improve care and support. In December 2012, the government published its response to Winterbourne View, concluding that:<sup>2</sup>

- there was a widespread failure to design, commission and provide services that followed best practice, which gave people the support they needed close to home;
- too many people were placed inappropriately and for long periods in hospital assessment and treatment centres;
- people had a right to care in community settings, near to family;
- there was a widespread failure to assess care quality or outcomes achieved for the very high cost of hospital care; and
- there were too many examples of poor-quality care.

## Transforming care and the Winterbourne View Concordat

**1.9** In December 2012, the Department published *Transforming care: A national response to Winterbourne View Hospital (Transforming care)*<sup>3</sup> and the *DH Winterbourne View Review - Concordat: Programme of Action (the Concordat)*.<sup>4</sup> The reports outlined around 100 commitments of which the Departments tracked 75 (63 of 63 in *Transforming care* and 12 of around 36 in the Concordat). The Concordat set out the government's pledge to work with others to meet all the commitments:

- by 1 April 2013, the NHS Commissioning Board (now NHS England) would ensure that all primary care trusts (now clinical commissioning groups) would have local registers of those with challenging behaviour in NHS-funded care;
- by 1 June 2013, any adult in a specialist autism or learning disability hospital would have had their care reviewed and a care plan agreed;
- by April 2014, every area would have a locally agreed joint plan for high-quality care and support services for people with learning disabilities that followed a model of care; and
- by 1 June 2014, if any person would be better off supported in the community, then they should have been moved out of hospital.

2 Department of Health, *Winterbourne View: Summary of the Government Response*, December 2012. Available at: [www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/Winterbourne%20View%20Summary%20Document%20final%2010.12.12.pdf](http://www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/Winterbourne%20View%20Summary%20Document%20final%2010.12.12.pdf)

3 Department of Health, *Transforming care: A national response to Winterbourne View Hospital*, Department of Health Review: Final Report, December 2012. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf)

4 Department of Health, *DH Winterbourne View Review Concordat: Programme of Action*, December 2012, available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213217/Concordat.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf)

**1.10** The Department included the model of care within its national response to Winterbourne View, *Transforming care*, in December 2012, based on the Mansell report.<sup>5</sup> The model included core principles for transferring people from hospital to the community:

- health and social care commissioners should start to plan from day one of admission for the move back to the community;
- social care services should be responsible for individual people, even when they are in NHS-funded services, including working with all partners to develop and work towards making a discharge plan; and
- health and social care commissioners should regularly review hospital admissions, and focus on moving the person on to more appropriate community services, as soon as it is safe to do so.

### **Leadership and responsibilities**

**1.11** The Department took the lead role in setting the strategic direction for transforming care and led work to measure and monitor progress. However, a complex structure of organisations has joint responsibilities for meeting the commitments. The cross-government Learning Disability Programme Board is responsible for monitoring delivery, supplemented by a Transforming Care Assurance Board. The main accountability arrangements are in **Figure 2** overleaf.

**1.12** The Department tracked the programme of actions in Annex B of *Transforming care* to monitor progress and risks to delivery. Other partners developed their own delivery plans. Individual key delivery partners reported the overall programme of actions to the Learning Disability Programme Board. The partners include NHS England, CQC and the Joint Improvement Programme team who reported on patient discharges, registers, care plan reviews and inspections.

**1.13** NHS England and the Local Government Association (LGA) co-sponsored the Joint Improvement Programme, with £5 million Department funding. The Programme was to support health and care commissioners through new guidance, and identify and share best practice. The government required NHS England to ensure that clinical commissioning groups worked with local authorities in providing care services. Its presumption was that people would remain in their communities, receiving local services. Two key expectations of the 2012 Concordat were that the plans would ensure:

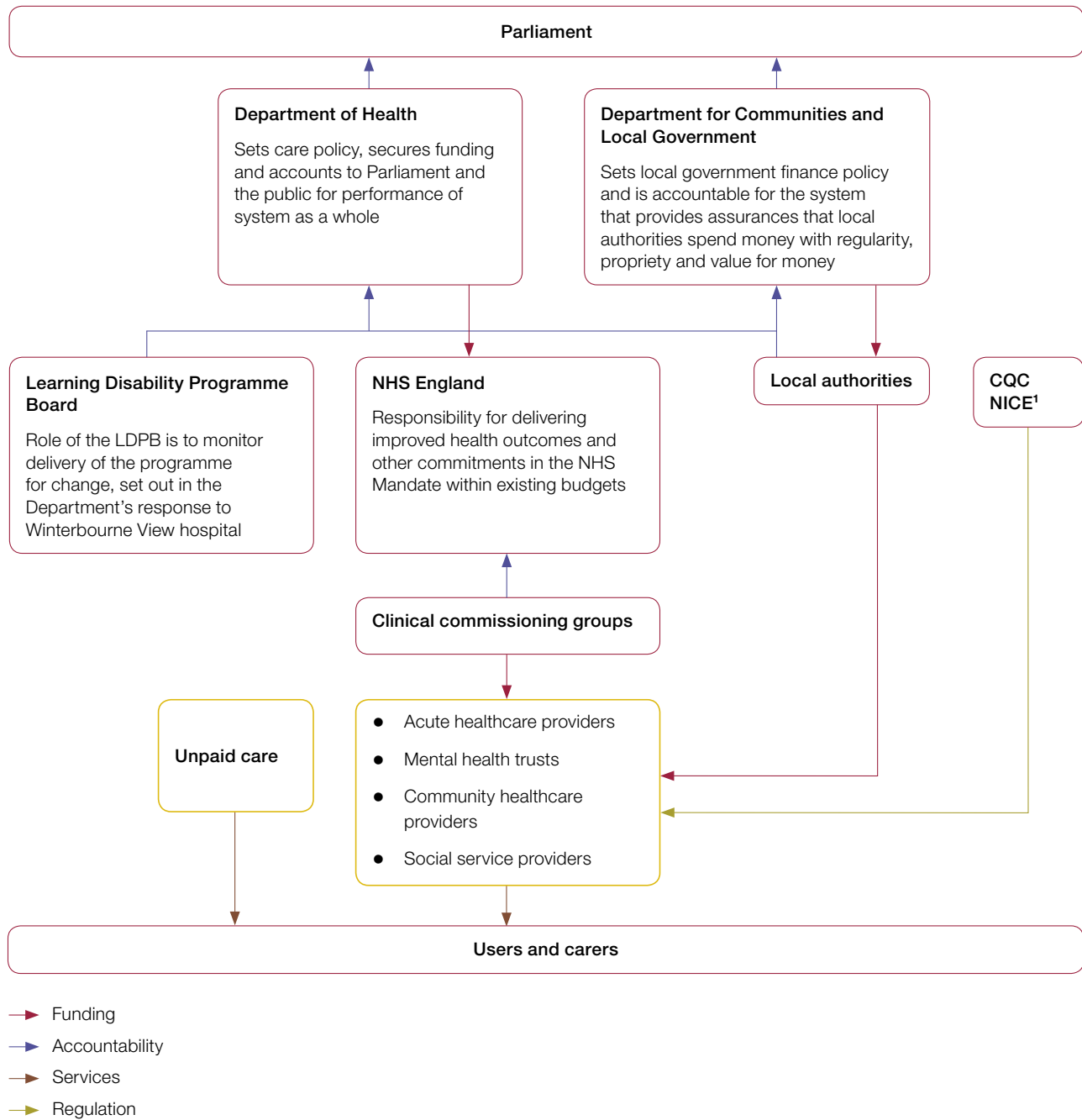
“...a dramatic reduction in hospital placements for this group of people and the closure of large hospitals”; and;

“... that a new generation of inpatients does not take the place of people currently in hospital.”

<sup>5</sup> Professor Mansell, *Services for people with learning disabilities and challenging behaviour or mental health needs*, Department of Health, 1993. Available at: [http://webarchive.nationalarchives.gov.uk/20130107105354/www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_080128.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_080128.pdf)

**Figure 2**  
Accountability arrangements

Transforming care programme accountability arrangements



**Notes**

1 CQC: Care Quality Commission; NICE: National Institute for Health and Care Excellence.

**1.14** The Department secured commitment to deliver its goals from 51 organisations which signed up to the Concordat (Appendix Three), the vision to transform services for people with learning disabilities, and to working together to achieve the shared objectives. The Concordat also set out the commitments made by individual organisations, or smaller groups of organisations, for specific actions, alongside the broader actions the Department itself had committed to take. Signatories committed to working collaboratively with clinical commissioning groups, local authorities and the mental health hospitals, to meet the objectives within the Concordat.

**1.15** In line with the Health and Social Care Act 2012, the Department could not direct mental health hospitals to prepare patients with learning disabilities for discharge by 1 June 2014, or to reduce the number of inpatient beds. However, the timetable of actions in its final report stated that by 1 June 2013, health and care commissioners, working with service providers, and service users and their families, would review the care of all inpatients, and they would agree a personal care plan for each individual based on their, and their families', needs and agreed outcomes.<sup>6</sup> The Department's focus for the mental health hospitals was principally to provide high-quality and appropriate care and prevent abuse, which included strengthening CQC's inspection regime.

<sup>6</sup> Department of Health, *Transforming care: A national response to Winterbourne View Hospital*, December 2012. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf)

## Part Two

### Performance against the commitments

**2.1** This part of the report covers:

- how well the government understands the scale of the challenge;
- performance against the commitments;
- why commitments were not met; and
- the government's response to missing key commitments.

#### **Scale of the challenge**

**2.2** In 2010, CQC estimated that there were 3,376 inpatients in mental health hospitals with learning disabilities and challenging behaviour. In December 2012, the Department estimated that there were around 3,400 people with a learning disability and challenging behaviour in hospital at any one time. Of these, 1,200 were in mental health hospitals. However, the Department and NHS England recognised that there was poor-quality data on the numbers of people with challenging behaviour. Subsequently, NHS England's census of commissioners, and the Department-funded Health and Social Care Information Centre (HSCIC) led census of mental health hospitals, respectively found 2,577 (December 2013) and 3,250 (September 2013) inpatients with a learning disability or autism, or both, and a mental health condition or challenging behaviour. These data also have quality and coverage issues, which we discuss in Appendix Two. This makes the December 2013 quarterly data incompatible with subsequent quarters reported in Figure 6.

**2.3** In addition, only 73 of the 3,250 people in the 2013 census were placed in one of 3 high secure hospitals.<sup>7</sup> This low number and the commitment in the Transforming care and accompanying Concordat contributed to the expectation that almost all the 3,250 people in hospital would be discharged into more appropriate community settings, by 1 June 2014. Overall, 1,042 people were restricted under Part III of the Mental Health Act and related legislation.

<sup>7</sup> Broadmoor Hospital, Rampton Secure Hospital and Ashworth Hospital.

**2.4** In 2012, the Department did not know how long the cohort of inpatients had spent in hospital or how many were likely to be ready for life in the community – in terms of receiving a clinical decision to discharge. Some commitments concerning clinical commissioning group registers and care plan reviews were designed to provide some of this information. However, it is still unknown how long patients have spent in hospital, or how many times each patient has been readmitted. Treatment programmes can take a long time to affect the patient’s behaviours and risks. The government did not have a detailed analysis of the scope to accelerate patients’ treatment programmes or to hasten their readiness for discharge. Without this data on the cohort of inpatients covered by the commitments, the government and NHS England did not know the scale of the task, and the hospital resources required, in preparing to discharge patients by 1 June 2014.

**2.5** In December 2012, when the commitments were made, the government set a goal for every local area to have, by April 2014, a locally agreed joint strategic plan, and a review of funding arrangements to commission local health, housing and care support services to meet people’s needs when discharged. However:

- the Department had no detailed analysis of the cost of expanding community services, to provide places for all those expected to be transferred from hospital;
- the Department had not assessed the availability of skilled staff or the tailored accommodation required to support community placements; and
- the Department for Communities and Local Government, and individual local authorities and clinical commissioning groups, did not sign up to the Concordat’s commitments.

## **Performance against the commitments**

**2.6** We examined performance against the main commitments to transform care for people with learning disabilities, which we summarise in **Figure 3** overleaf. See our website for more detailed findings.<sup>8</sup>

**2.7** Most progress against the commitments was on changes to processes, rather than outcomes. For example, the commitments to publish guidance, best practice and standards were met. Establishing better intelligence on the scale of the task, through registers and reviews was also reported. However, no evaluation exists on how extensively these outputs have been distributed, or what impact they have had on care quality or outcomes.

**Figure 3**

## Progress in meeting commitments

Area of the Concordat	Achieved	Achieved, but not by target date	Not achieved	Examples of progress against key commitments
Right care, right place, right time	1 (out of 7)	3 (out of 7)	3 (out of 7)	<p>All commissioners have registers of people with learning disabilities and the large majority of people had a personal care plan in place by the target delivery date. However, NHS England recognises that registers are not complete and more work is needed to provide assurance over the quality of plans.</p> <p>There has been little progress with commitments to improve joint working or with the main objective to move people with learning disabilities in inpatient care into an appropriate community setting.</p>
Regulation	1 (out of 3)	2 (out of 3)	0 (out of 3)	<p>The Care Quality Commission has started using experts and people with learning disabilities as part of its inspection team and 150 unannounced inspections were carried out following the Winterbourne View scandal.</p> <p>The Department of Health introduced legislation aimed at strengthening the Care Quality Commission's ability to hold corporate bodies and individuals to account, although the powers remain untested.</p>
Information and data	2 (out of 3)	0 (out of 3)	1 (out of 3)	<p>NHS England collected and reported data on the number of inpatients to monitor progress, although our work suggests the data are poor and lack the details required to identify and share best practice.</p> <p>The Learning Disability Programme Board was established in November 2012 to oversee progress with the commitments. However, it is our view that the Board did not provide effective leadership given that the main commitment to move inpatients into appropriate community settings was not met.</p>
Good practice and standards	1 (out of 2)	1 (out of 2)	0 (out of 2)	<p>Progress has been made with publishing best practice guidance and standards, such as on commissioning, providing quality care and advocacy. However, no evaluation exists on whether guidance and standards are being used, or have had the desired impact.</p>
Medication and positive behaviour support	0 (out of 2)	0 (out of 2)	2 (out of 2)	<p>A number of steps have been taken to strengthen the effectiveness of safeguarding boards, such as by publishing guidance, but no systematic evidence exists on whether boards are operating effectively.</p> <p>The Department has published statutory guidance to reflect Care Act 2014 changes to local authority responsibilities for protecting people with care and support needs from abuse. It has established a working group to help develop good practice guidance, which it plans to publish by the target delivery date of April 2015.</p>
Children and the transition to adulthood	1 (out of 3)	1 (out of 3)	1 (out of 3)	<p>The Children and Families Bill introduced a new single way to assess children with education, health and care plans.</p> <p>The Department of Health reported that the Children and Young People's Health Outcomes Forum – an advisory group of professionals – is supporting improved outcomes for children and young people with challenging behaviour. But the commitments did not include any outcome based targets to measure whether it is driving improvements on the ground.</p>

**Note**

1 Main commitments include those identified by the government.

Source: National Audit Office analysis of the Learning Disability Programme Board's self-assessment of their performance



**2.8** More importantly, the target to discharge all inpatients by 1 June 2014 who would be better cared for in the community (**Figure 4**) was not met. As a result, the government did not dramatically reduce the number of large hospitals, or stem the flow of a new generation of people into hospital.

**2.9** In December 2012, the Concordat had expected that most inpatients, inappropriately placed in hospital, would be discharged into community placements in less than 12 months. The most recent data available, at September 2014, indicated that there were 2,600 inpatients. This is virtually unchanged from the numbers at March and June 2014, indicating no overall progress against the target to reduce the number of people in hospitals.<sup>9</sup> Data from the September 2013 and September 2014 HSCIC census<sup>1</sup> also show little change with respective inpatient numbers of 3,250 and 3,230.

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## **Figure 4**

### Measuring performance in discharging inpatients

#### **Key performance indicators for discharging inpatients to community settings by 1 June 2014**

- The number of people with learning disabilities and challenging behaviour in hospital was broadly stable at 2,615 in March 2014 and 2,601 in June 2014. In September 2014, the total was 2,600.<sup>1</sup>
- Over the quarters ending December 2013 to June 2014, there were 902 hospital admissions compared with 600 discharges, a net increase of 302. Between June and September 2014, the equivalent figures were a further 404 admissions and 323 discharges, a net gain of 81. However, this data does not distinguish between discharges to community settings, or transfers to other hospitals.<sup>1</sup>
- At June 2014, 2,024 of the 2,601 inpatients still had no planned transfer or discharge date and 1,614 of these had received a clinical decision not to transfer. This was despite an NHS England requirement that commissioners should ensure that when someone is admitted to hospital, they have a planned transfer or discharge date. By September 2014, 920 of the 2,600 inpatients had no planned transfer or discharge date. For 691 of these patients, a clinician had decided that they were not ready to leave.<sup>1</sup>
- At June 2014, for 1,296 of the 2,601 inpatients, their local authority was unaware of their potential future transfer to their area on discharge from hospital. At September 2014, this number had reduced to 965 of the 2,600 inpatients for that quarter.<sup>1</sup>
- 36.5% of patients were admitted to hospitals over 50 kilometres from their home area.<sup>2</sup>

#### **Note**

1 NHS England's December 2013 data had missing returns from 42 clinical commissioning groups, which alongside other data quality issues render it incomparable with subsequent quarters.

Sources: NHS England's census of commissioners<sup>1</sup> and September 2013 HSCIC census of mental health hospitals<sup>2</sup>

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9 NHS England considers that the quarterly census of commissioners is only comparable between the three quarters of March, June and September 2014.

**2.10** Between December 2013 and September 2014, NHS England reported that 923 inpatients were discharged. But, as it recognises, these figures do not distinguish between people transferred between security settings, within and between hospitals.<sup>10</sup> NHS England recognises that these discharges did not reduce the total inpatient population, despite the Concordat emphasising the importance of ensuring that a new generation did not take their place. Between December 2013 and September 2014, there were 1,306 hospital admissions compared with 923 discharges, a net increase of 383.<sup>11</sup> A forum of clinical commissioning groups is investigating the reasons behind this. However, some people may still need high-quality local inpatient services because of a crisis in their community care, or serious offending behaviour.

**2.11** Although the number in hospital is stable, there have been recent improvements:

- In September 2014, 65% of inpatients with learning disabilities had a date for a planned transfer to the community, a marked improvement on the 22% who had a transfer date in June 2014. This was partly because NHS England has started a programme of reviews for those patients with no planned discharge date. It is collecting data every 2 weeks to track progress of these reviews.
- The proportion of inpatients with a transfer date, or a clinical decision to transfer them to the community when capacity allows, rose from 38% for the June 2014 cohort of inpatients to 73% for the September 2014 cohort.
- In September 2014, 93% of inpatients were on a clinical commissioning group register, up from the 82% who were on a register in June 2014.
- In September 2014, the local authority was unaware of a potential future discharge from hospital for 37% of inpatients, an improvement on the 50% in June 2014.

**2.12** When the government published its response to Winterbourne View in December 2012, one of its main findings was a failure to design, commission and provide services to support people near to their homes and family.<sup>12</sup> Over a third of patients were admitted to hospitals over 50 kilometres from their home area (**Figure 5**).

<sup>10</sup> NHS England has not validated this data. It is not designed to meet statistical standards and cannot be reconciled to the other data sets on the population of inpatients with a learning disability.

<sup>11</sup> It is important to note that admission and discharge figures do not distinguish between people transferred between security settings within and between hospitals. Therefore, admissions and discharges are likely to be overestimated.

<sup>12</sup> Department of Health, *Winterbourne View: Summary of the Government's response*, December 2012, available at: [www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/Winterbourne%20View%20Summary%20Document%20final%2010.12.12.pdf](http://www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/Winterbourne%20View%20Summary%20Document%20final%2010.12.12.pdf)

**Figure 5**

## Service users by distance from home

Distance from home	Number of service users	Percentage of service users (%)
All service users with known postcodes of residence and ward stay	3,129	100
With the same postcode for residence and ward stay	240	7.7
Up to 10km	612	19.6
10 to <20km	415	13.3
20 to <50km	719	23.0
50 to <100km	573	18.3
100km or more	570	18.2

**Notes**

- 1 Service users are included here, if there is both a recorded postcode for home (either supplied by the provider or traced through the NHS number) and a postcode of ward stay.
- 2 Nine service users with postcodes of residence differing from postcodes of ward stay are included in this row, as both postcodes are allocated to the same hospital, and the distance calculated between the differing postcodes was 0 metres.

Source: Health and Social Care Information Centre, *Learning Disabilities Census Report – England*, September 2013

**2.13** The government did meet its commitment to strengthen the CQC inspection regime. Between December 2011 and May 2012, CQC published 150 reports based on the completed inspection programme of 71 NHS Trusts, 47 independent hospitals and 32 care homes for people with learning disabilities in England. Inspectors were supported by 51 professional advisers and 53 people with learning disabilities or their carers, or both. Excluding 5 pilots, CQC found that 69 failed to meet one or both of 2 standards: care and welfare; and protecting health and well-being, and enabling inpatients to live free from harm. Many failings resulted from care not being centred on the individual patient, or tailored to their needs. Inspectors found that some patients were admitted for long periods, and that discharge plans were taking too long to arrange.

**2.14** NHS England has regularly reviewed the status of the 48 patients at Winterbourne View Hospital at the time of its closure. The most recent review, for January to June 2014, showed that: 10 people were still in hospital; 20 were living in residential care; 5 were in supported housing with their own tenancies; 12 had their own general needs tenancy; and one had died.

### **Why key commitments were not met**

#### Undeveloped delivery mechanisms

**2.15** The Department and other organisations signed up to commitments in the Concordat, in line with the Health and Social Care Act 2012. It devolved how the commitments would be met to NHS England, and local health and social care commissioners. The government did not, therefore, have the traditional levers to achieve the commitments. It had no national monitoring, mandatory guidance, pump-priming, pooled budgets, dedicated funding, or accountability arrangements from providers to the government. The government did not ask clinical commissioning groups, local authorities and mental health hospitals to sign up to the Concordat. This further weakened the government's ability to meet the commitments. These are the main bodies upon which discharging patients, and expanding and operating community placements, depends.

**2.16** The Concordat (see footnote 4) also presumed that introducing pooled budgets would minimise overlaps in service delivery and speed up discharges. It stated that:

“The strong presumption will be in favour of supporting this (delivery of the commitments) with pooled budget arrangements, with local commissioners offering justification where this is not done.”

**2.17** However, as of June 2013, pooled budgets remained the exception, with only 27% of local areas reporting a pooled or aligned health and social care budget. This limited the discharge rate of inpatients into community placements. The Department said that it had not received justification from (or challenged) local authorities or clinical commissioning groups where learning disability related health and social care budgets had not been pooled. However, the Minister of State for Care and Support wrote to health and well-being boards in May 2013 referring specifically to the Transforming care commitments and the need to pool budgets.

## Data quality and coverage

**2.18** In 2013, NHS England acknowledged that data quality was insufficient to manage delivery of the commitments. Since September 2013, NHS England has gathered data on progress through a quarterly data collection process for NHS commissioners called 'Assuring Transformation' (the census of commissioners). NHS England collects quarterly data from 211 clinical commissioning groups, and 10 NHS England specialised commissioning teams, to track the numbers of patients admitted to, and discharged from, hospital into community services.

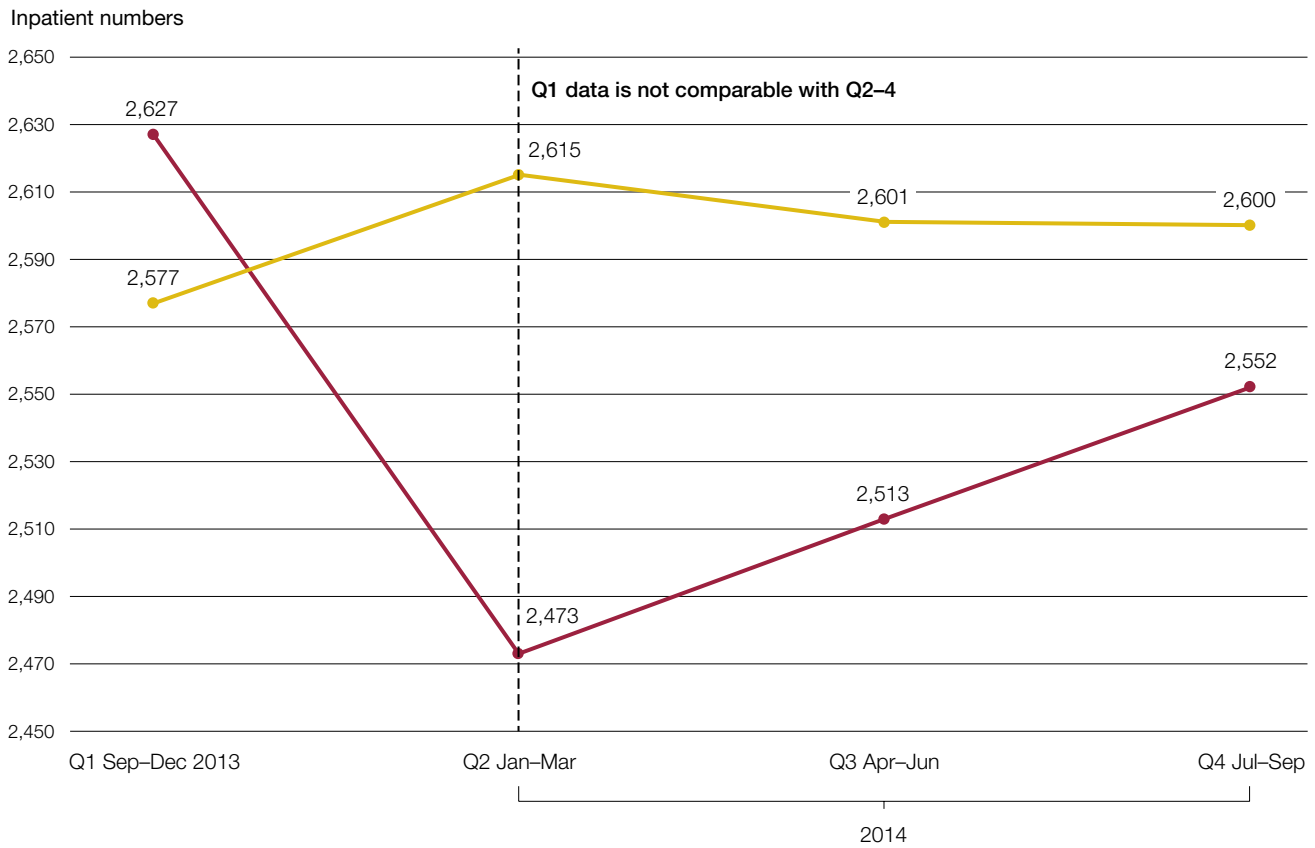
**2.19** Our analysis found that the reported number of discharges to community services included transfers between hospitals and within the same hospital. For example, from a medium to a low secure setting. Therefore, the data do not represent the true numbers going into and out of hospital. Including duplicate returns, the inpatient population is increasing (**Figure 6** overleaf). NHS England has acknowledged, however, that there are quality issues, including duplicate returns, in its published data. It acknowledges it has a way to go to improve data quality and is developing a dashboard of performance measures.

**2.20** Our review of patient records in the 4 hospitals we visited found errors in the data that commissioners submitted to NHS England. We examined 281 patient records against NHS England's reported data for the patient. In 70% of the case files, there was at least one error. The highest proportion of errors (47%) was for the period since the patient's most recent formal review of their care plan (**Figure 7** on page 29). We also found differences in the reported time patients had been in hospital. Official data for our cohort showed an average stay of 3 years and 10 months, whereas we found an actual length of stay of 4 years and 3 months in their current hospital.

**2.21** The census reports only the length of stay in any given hospital ward. It does not include total continuous inpatient stay whether in the same, or another hospital, or both. In addition, the data does not include the number of times a patient is admitted to hospital, or the total time spent there. NHS England needs both to effectively understand and manage discharges, and stem the flow of people into hospital. We found that the total average length of continuous inpatient stay for our cohort (including transfers between hospitals) was 6 years and 9 months. Including admissions and readmissions, the average total inpatient stay was 17 years and 4 months. Although this was not a statistically significant sample, it is enough to prompt a systematic review of data quality and coverage.

**Figure 6**  
Number of people with learning disabilities in hospital

The number of people with learning disabilities in hospital has not significantly reduced



- National Audit Office estimates
- Data from NHS England

**Notes**

- 1 NHS England's December 2013 (Q1) data had missing returns from 42 clinical commissioning groups, which alongside other data quality issues render it incomparable with quarters 2, 3 and 4.
- 2 Duplicates arise primarily because clinical commissioning groups and NHS England's specialised commissioners' report on the same patient when only one should do so.

Source: National Audit Office analysis

**Figure 7**

## National Audit Office review of patient records

Of patient records reviewed, 70% had at least one error

	Errors in NHS England census data	Sample of cases reviewed	Incomplete data entries	Incorrect (%)
Date of birth	22	280	11	8
Sectioned under the Mental Health Act	31	235	46	13
Admission date	58	279	2	21
Review date (pre 30 June 2014)	132	278	3	47
Any of the above	198	281	N/A	70

**Notes**

- 1 Date of birth: we did not review this.
- 2 Sectioned under the Mental Health Act: we did not confirm status of section at St Andrew's Hospital.
- 3 Admission date: provider could not confirm admission date.
- 4 Review date: we did not review the date for 3 cases.

Source: National Audit Office analysis

**2.22** In 2013-14, local authorities spent £5.3 billion on services for all adults with learning disabilities. However, there is no separate cost breakdown for community services for those with a learning disability and challenging behaviour. These costs can be extremely high because challenging behaviour requires bespoke community placements to meet intensive treatment and support needs. These are essential to manage the risks that people can present to themselves and others.

**2.23** The government does not track people with learning disabilities as they move between community and inpatient care settings. Doing so could have provided data to analyse the impacts of different models of care on patient outcomes. The Health and Social Care Information Centre (HSCIC) and NHS England have not yet linked their data sets using patient NHS numbers. This would show length of stay, track readmissions from the community, and monitor transfers between hospitals. NHS England said it expects to transfer data collection and reporting to the HSCIC from January 2015. It believes this will reduce data errors. The Department said that there are plans to link the 2013 and 2014 census of providers and the HSCIC and NHS England data in early 2015. It has required the HSCIC to develop the Mental Health and Learning Disabilities Data Set with the aim of providing sustained good-quality data.

## Slow progress in developing local commissioning strategies

**2.24** Clinical commissioning groups and local authorities have been slower to develop local commissioning strategies to reduce reliance on inpatient services. Clinical commissioning groups commission around half of hospital admissions for people with learning disabilities. NHS England commissions the rest. Meeting the needs of people in the community, who NHS England previously funded in hospital, is a material cost to local commissioners. This can affect their ability to provide appropriate and sustainable care packages. Hospitals subsequently experience significant delays in discharging patients while complex negotiations continue between NHS England, clinical commissioning groups and local authorities to develop joint funding arrangements for community placements.

**2.25** Previous programmes to discharge large numbers of inpatients had associated funding to build and maintain community services. However, the Local Government Association (LGA) told us that:

“Even with the best intentions from all parties, it will remain difficult to make very rapid progress when there is no additional funding, NHS and local government are facing very tough financial challenges, and the funding does not follow the person who needs the support.”

## Response to missing the key commitments

**2.26** The government and NHS England recognised that performance has been slow and have changed the delivery, accountability and monitoring systems. In April 2014, NHS England identified the need for plans to ensure that people have effective care and treatment reviews and set a level of ambition for discharges which the NHS, working with local partners, could deliver. In addition, the Department asked NHS England, in May 2014, to put together an action plan and publish it by the end of August. The plan was presented to the Transforming Care Assurance Board in September 2014.

**2.27** The Department replaced the Post Winterbourne View Project Board with the Joint Improvement Programme Board. When it became clear the central objective would not be achieved, it established a Senior Sponsors Group in May 2014. The group is chaired by its senior responsible officer and includes representatives from NHS England, the LGA, CQC and the Association of Directors of Adult Social Services. It aims to strengthen governance by replacing the Joint Improvement Programme Board with the Transforming Care Assurance Board. The new board first met in September 2014, and will give feedback to the Learning Disabilities Programme Board.



**2.28** In July 2014, NHS England commissioned Sir Stephen Bubb to assess how they might implement a national commissioning framework, delivered locally. The framework would help to increase the community provision needed to move people with learning disabilities or autism out of inappropriate hospital care. The November 2014 Bubb report recommended:<sup>13</sup>

- introducing a Charter of Rights for people with learning disabilities;
- giving people with learning disabilities and their families a right to challenge decisions and request a personal budget;
- that local decision-makers follow a mandatory framework showing who is responsible for which services, and how they will be held to account, including improved data collection;
- introducing a planned closure programme of inappropriate institutional inpatient facilities;
- better training and education for NHS, local government and provider staff; and
- setting up a social investment fund to build community service capacity.

**2.29** In August 2014, NHS England had set a new ambition, to be delivered by 31 March 2015. The ambition was to ‘transfer’ more than half of the 2,615 people who were inpatients on 1 April 2014 to more appropriate care settings. NHS England communicated the ambition to its regional directors in late September 2014. In October 2014, NHS England appointed a programme director and programme leaders to address slow progress. Local commissioners queried whether the 50% ambition was specifically discharges from mental health hospitals, or transfers to a more appropriate inpatient setting or a combination of the two. NHS England confirmed in November 2014 that the ambition was for discharges from mental health hospitals.

**2.30** We found no evidence that the clinical commissioning groups, local authorities or mental health hospitals that we visited knew of the ambition. It can take up to 18 months to plan a patient’s discharge. There are therefore limited prospects for significantly increasing the rate of sustainable discharges by 31 March 2015. The LGA said that, even with adequate funding and good local relationships, it takes time to plan and deliver support for those with challenging behaviour in the community. It was concerned about balancing well-intentioned plans, with ensuring the right community provision is in place.

<sup>13</sup> Transforming care and commissioning steering Group. *Winterbourne View: time for change*, November 2014. Available at: [www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf](http://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf)

**2.31** NHS England said that around 400 of these inpatients had been discharged in the first 7 months, and it expects to discharge a further 900 in the remaining 5. However, NHS England has not provided comparative discharge or readmission rates. Nor has it said why it thinks the number of inpatients has remained unchanged. The expectation in the 2012 Concordat was that a new generation of inpatients did not take the place of people then in hospital. Without comparative discharge and readmission rates, this ambition may simply be continuing the normal turnover rate in the patient population.

**2.32** There was no central implementation plan, risk assessment or mitigation plans for NHS England's new ambition. However, NHS England said that during our work:

- regional directors have been made accountable for progressing the new ambition and ensuring that it is delivered in a planned manner;
- the national learning disability programme team has developed protocols for care and treatment reviews used to identify patients for whom there is no clinical need for inpatient care; and
- it worked with the LGA and the Association of Directors of Adult Social Services to address gaps in communication to clinical commissioning groups and local authorities.

**2.33** NHS England had also requested monthly data returns from its commissioners between July and September 2014. Since October, it has increased the frequency of returns to fortnightly to monitor progress against its new ambition. NHS England told us that the data is based on management information and soft intelligence. They told us that it is not as robust as the quarterly data and is not validated or published, but used to show NHS England's Management Board the indicative transfer position of patients in between the quarterly published data. For this reason, we have not used this data in our report.

## Part Three

### Barriers and solutions to transforming care services

**3.1** Discharging people with learning disabilities and challenging behaviour from hospital is a long-standing issue. It dates back at least to the care in the community programme, and associated mental health hospital closure programme, in the 1980s. It is a classic 'wicked issue' (an intractable problem) which defies simple solutions. Using our fieldwork, we identified several obstacles, and some local approaches addressing these, for discharging patients sustainably.

#### **Developing local pooled budgets**

**3.2** The Concordat presumed that local commissioners would develop pooled budget arrangements, and justify where they had not done so. Pooled budgets minimise service overlaps, reduce bureaucracy and improve productivity. However, the Winterbourne View Joint Improvement Programme found that agreeing shared funding is one of the hardest aspects of local joint working. In June 2013, only 27% of local authorities had pooled budgets and 20% had other risk sharing agreements.

**3.3** The Department recognised that changing the financial flow is necessary to enable clinical commissioning groups to invest in specialist community services, to support people in the community, and invest less in inpatient services. The Department and NHS England have each committed one-off capital funding of £7 million to support the programme in 2014-15. The Department had, by January 2015, allocated around £3.7 million to a number of local authorities who are working with providers to support local discharge arrangements through the provision of appropriate housing. NHS England has invited clinical commissioning groups to apply for capital funding and it has received bids. Although NHS England has yet to allocate any funds, it is currently considering the bids and told us that it will allocate funds to successful applicants by the end of 2014-15.

**3.4** In July 2014, NHS England (with the LGA, Think Local Act Personal (TLAP))<sup>14</sup> and the Association of Directors of Adult Social Services) announced plans for a new Integrated Personal Commissioning (IPC) programme. This aims to combine health and social care funding for individuals with learning disabilities (and other high-need populations) for them to say how it is used. The IPC is a voluntary scheme. Third sector organisations will be commissioned to act as partners to existing local structures, determined locally, to support personal care planning, advocacy and service 'brokerage' for those enrolled in the programme. The scheme is due to be launched in April 2015, after the 31 March 2015 delivery date for the new NHS England ambition to discharge 1,300 patients. Its success will partly depend on the level of voluntary take-up, and on the flexibility it gives people with learning disabilities to direct their care.

### **Preventing delayed discharges and readmissions**

**3.5** During our visits, we observed that inpatients are more likely to have a successful discharge when a local multidisciplinary specialist learning disability team has worked closely with hospital clinicians and hospital outreach teams. Effective joint working between local health and social care commissioners, community care providers and hospitals requires early, and continuous dialogue during the inpatient stay. It involves close communications on commissioning bespoke care plans for the patient. There are further benefits from ongoing links between the mental health hospital and the community care provider after a discharge. For example, short rapid specialist intervention in response to a sudden behavioural change can improve the outcome of an ex-patient's condition and prevent costly readmissions.

**3.6** We held focus groups with clinicians, and they agreed with the principle that people, who would be better off supported in the community, should be discharged from hospital. Clinicians' main concerns were about getting assurances about the risks in preventing any deterioration in the patient's mental health after their discharge. These included:

- low confidence in how placements are managed and if they are sustainable;
- providing suitably skilled and experienced staff to respond to the person's needs (especially in a crisis);
- the quality standards of some community service providers; and
- how robust the risk management is, in the discharge plan.

**3.7** Clinicians said that preventing readmissions could be a major challenge, especially where a provider had been unable to manage the patient's risks, or respond effectively to their needs. They considered that readmission was often not best for the patient. And more resilient community placements, with clinical and trained care support, would prevent inappropriate hospital readmissions.

<sup>14</sup> TLAP sets out what people who use services and carers expect to see and experience if support services are truly personalised.

**3.8** The clinicians noted that delays in discharging people were often because of: delays in funding decisions; a lack of suitable accommodation; and insufficient capacity and capability among community providers to provide the required care package. The clinicians also noticed disparities between local strategies, their ability to deal with challenging behaviour and the degree of development of community and health services.

### **Developing and operating community placements**

**3.9** In the areas we visited, establishing enough appropriate housing provision for people with learning disabilities, who are ready for discharge from hospital, is problematic. At September 2014, 92 inpatients did not have a transfer date because of a lack of suitable housing provision. The reasons included difficulties in finding properties that were suitable for people with associated security needs, or mobility issues. The Winterbourne View Joint Improvement Programme is leading several projects, such as the 'Finding Common Purpose' programme, designed to find solutions to barriers to discharging patients. This includes getting capital funding for housing providers, to meet accommodation needs.

**3.10** Salford local authority and clinical commissioning group is often identified as good practice. Salford has developed a holistic community based model of care, drawing upon the principles in the Mansell guidance – first issued in 1993 and updated in 2007. Developing robust local services for people with a learning disability and challenging behaviour takes time. Salford local authority and clinical commissioning group (previously the primary care trust) have worked together for over a decade to develop a single service. They:

- developed a shared culture, with the service user at the centre of their delivery model, based upon mutual support and a commitment to giving people meaningful lives, rather than just getting them out of hospital;
- implemented a joined-up health and social care management and commissioning structure with a pooled budget;
- co-located health and social care commissioners and a multidisciplinary specialist learning disability community team of social workers, occupational therapists, speech therapists, nurses, psychologists, psychiatrists, physiotherapists and trained carers (community teams work with providers at short notice to maintain placements, when a service user's behaviour might otherwise lead to hospital admission or readmission); and
- ensured that people with learning disabilities are supported to communicate their views and reduce challenging behaviour, through accessing mainstream leisure, health and social services, but supported by the multidisciplinary team.

### **Developing specialist skilled community teams**

**3.11** Budget pressures on clinical commissioning groups and local authorities have resulted in pressures on resources for mental health hospitals and on community based learning disability teams. Some have reduced posts, either through recruitment freezes, or restructuring. Some specialist learning disabilities teams in the community have been run down, which has contributed to delays in introducing appropriate care packages. This has also increased the risk of hospital admissions, and readmissions, and the pressures on hospital resources.

**3.12** The clinical commissioning groups and local areas emphasised the importance of monitoring providers of community placements closely, and scrutinising the quality of support, care and security provided. These are essential to maintain mental health and reduce the person's risk of harm to themselves, to provider's staff, and the wider community. Holding providers to account is fundamental in ensuring that the person has a sustained and successful community placement.

# Appendix One

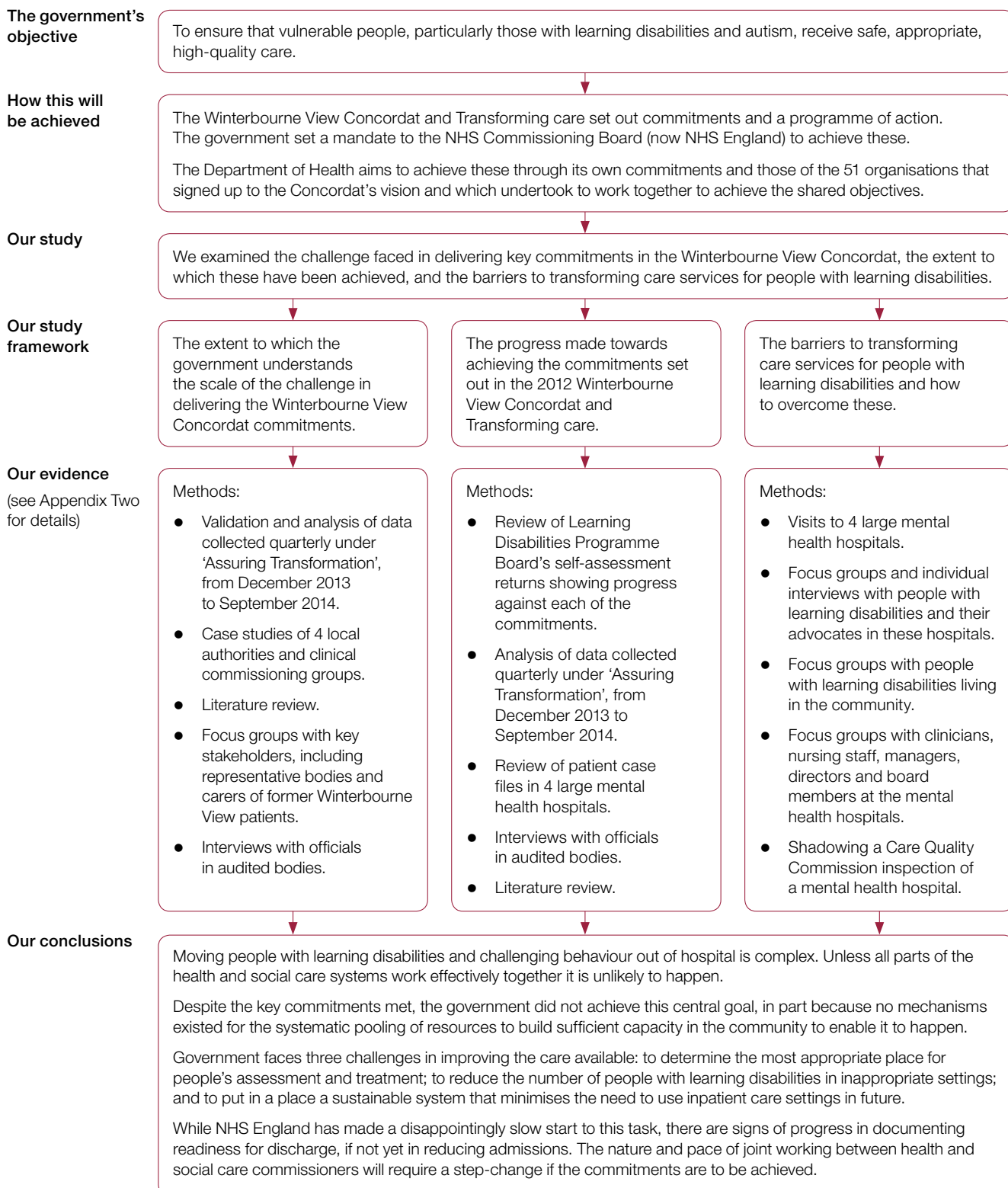
## Our audit approach

**1** This report examined the government's progress towards the key commitments in the Winterbourne View Concordat and in 'Transforming care' focused on the goal of moving people with learning disabilities, including people with autism, and who also have challenging behaviour, from mental health hospitals into cost-effective, high-quality care services in the community. We examined:

- the extent to which the government understood the scale of the challenge in delivering the Winterbourne View Concordat commitments;
- performance against the commitments set out in the Winterbourne View Concordat and Transforming care; and
- the barriers to transforming care services for people with learning disabilities and how these could be overcome.

**2** We applied an analytical framework with evaluative criteria, to determine the reasons for the failures to achieve the expected progress against the key commitments in the Winterbourne View Concordat, to identify the existing barriers to success, and to gather good practice on how local areas are addressing these. We consulted people with learning disabilities, and their carers and advocates, representative stakeholder organisations, and the professional mental health staff treating and supporting people with learning disabilities to gain all perspectives.

**3** Our audit approach is summarised in **Figure 8** overleaf. Our evidence base is described in Appendix Two.

**Figure 8****Our audit approach**



# Appendix Two

## Our evidence base

**1** We reached our independent conclusions on the government's progress towards improving the provision of cost-effective care services for people with learning disabilities, after analysing the range of evidence which we gathered from across our fieldwork which took place between September and October 2014. Our audit approach is outlined in Appendix One.

**2 We held focus groups with clinicians, nursing staff, senior managers, directors and board members at 4 large NHS and independent mental health hospitals.** We explored the arrangements to assess patients on arrival at hospital, to consult the patient and involve patients in their care, to develop and provide a programme of treatment to meet the patients' needs, and to plan for their discharge into the community, through joint working with representatives from local areas and clinical commissioning groups. We aimed to develop a greater understanding of the objectives of inpatient specialised care; the characteristics of effective risk management, treatment and discharge planning; the barriers and reasons for delays in transferring patients into the community; and how to reduce the risks of patient readmissions.

**3 We conducted interviews and focus groups with key stakeholders** (Figure 9 overleaf). We consulted people with learning disabilities in the community about their involvement in their care, their safety, and the treatment and support they received. We also consulted people with learning disabilities in the 4 large mental health hospitals we visited (Figure 10 on page 41). We consulted carers and patient advocates to obtain their views on the Concordat commitments, the progress made towards achieving these, to gain insights from personal experiences of the types of treatment and support services provided, and the degree of consultation on treatment, care and discharge plans. We also spoke to families of patients who had been resident at Winterbourne View to understand what had happened following the closure of Winterbourne View, and the follow up communications and support received from the 'Improving Lives' team. We held a focus group with a broader range of stakeholder organisations, providing support to people with learning disabilities, on progress against the Winterbourne View commitments and the assessment, treatment and support of people with learning disabilities in hospitals and in the community. We also engaged in bilateral consultation with stakeholder bodies for those unable to attend.

**Figure 9**

<b>People with learning disabilities in the community</b>		<b>Date of NAO visit</b>
Carers Centre	Tower Hamlets	22 September 2014
CHANGE	Leeds	25 September 2014
<b>Carers of people with learning disabilities</b>		<b>Date of NAO visit</b>
Carers Centre	Tower Hamlets	22 September 2014
<b>Stakeholders' focus group and consultation</b>	<b>London</b>	<b>9 September 2014</b>
British Institute of Learning Disabilities	Challenging Behaviour Foundation	
Housing and Support Alliance	Mencap	
People First England	National Family Carers Network	
The Disabilities Trust	Think Local Act Personal	
VoiceAbility		

Source: National Audit Office

**4 We reviewed the Learning Disability Programme Board's self-assessment against the Transforming care and Winterbourne View Concordat commitments.**

These commitments set out the government's action plan in improving care services for people with learning disabilities (Appendix 4, published on our website<sup>15</sup>).

**5 We analysed data on the population of people with learning disabilities in inpatient services across England.** We analysed data published by NHS England from the quarterly 'Assuring Transformation' data collections (census of commissioners) between December 2013 and September 2014, including length of stay in hospital, date of formal review, and section imposed. We also analysed the Health and Social Care Information Centre's (HSCIC) census of mental health hospitals to identify the inpatients sectioned under the Mental Health Act. The 2 different collections have different respondents: The census of commissioners is an NHS based return from English clinical commissioning groups and the 10 regional specialist commissioning teams. The HSCIC census is an NHS and independent sector return from English mental health hospitals.

<sup>15</sup> Available at: [www.nao.org.uk](http://www.nao.org.uk)

**6 NHS England has experienced difficulties in achieving robust reports on progress, which it attributed to the short turnaround times and from using an Excel based collection method.** NHS England depended on clinical commissioning groups to respond to feedback following basic data validations checks and to resubmit data. NHS England has acknowledged that there are quality issues, including duplicate returns, in its published data. It considered that there is a way to go in improving data quality and is developing a dashboard of performance measures. NHS England's December 2013 data had missing returns from 42 clinical commissioning groups, and; incomplete returns from many commissioners that submitted data. For example, 125 patients had no NHS number, compared to 2 in the September 2014 returns and 385 patients had no, or unusable information, about planned transfer dates compared to zero in September 2014. The HSCIC census includes 64 inpatients with a residential address in another United Kingdom country.

**7 We conducted case file reviews of a sample of inpatients at 4 large mental health hospitals.** We reviewed a sample of 281 case files for patients receiving secure inpatient care at 4 large NHS and independent mental health hospitals to validate NHS England's 'Assuring Transformation' data. **Figure 10** shows the mental health hospitals we visited, and at which we reviewed a sample of patient case files.

**8** We designed the case file reviews to collect evidence on:

- the length of time patients had been in any inpatient services and their lifetime duration of inpatient care;
- where applicable, the reasons why no date for transfer into the community had been agreed; and
- treatment programme reviews, and discharge planning arrangements.

**9** The case file reviews included discussion with the clinical staff for those patients for whom they were responsible.

**Figure 10**

Mental Health Hospital	Type	Date of NAO visit
St Andrew's Healthcare	Independent	23–24 September 2014
Calderstones Partnership NHS Foundation Trust	NHS	1–2 October 2014
St John's House, Partnerships in Care Ltd	Independent	7–8 October 2014
Tees, Esk, Wear Valleys, NHS Foundation Trust	NHS	9–10 October 2014

**Note**

1 We identified mental health hospitals for case studies based on a combination of the number of patients reported in the 2013 Learning Disability Census and a geographical spread across England. We selected 4 of the largest 10 hospitals.

Source: National Audit Office

**10** The Health and Social Care Information Centre was unable to comply with the National Audit Act (1983), which gives the Comptroller and Auditor General access to information required for statutory audit work. At the time of our work, the Centre was consulting on a new code of practice for protecting confidential information and was not able to provide the information we required to validate the quality of its census data within the timescale for our audit. Consequently, we focused our analysis on NHS England's Assuring Transformation quarterly census data.

**11 We conducted case study visits to 4 local authority areas and their associated clinical commissioning groups.** We designed the case studies to collect evidence on:

- the level of integration between inpatient care and community-based settings;
- how service capacity is developing in the community; and
- the potential barriers and facilitators in providing suitable community placements for people with learning disabilities and challenging behaviour.

**Figure 11** provides a list of our case study visits to local authorities and clinical commissioning groups in September and October 2014.

**12 We interviewed key stakeholders including the Department of Health, the Local Government Association and NHS England.** This work was designed to obtain evidence on:

- whether the scale of the risks and challenges of the Concordat commitments had been accurately understood, and appropriately managed and addressed;
- whether there were adequate levers and clarity of funding to direct delivery of the Concordat commitments and to pool resources;
- whether there was a robust structure for delivery, with clarity on individual roles and responsibilities for commitments made, and for joint working and support; and
- plans for achieving the outcomes committed to in the Concordat, for those that had failed to be achieved by the June 2014 deadline.

**13 We reviewed existing guidance and documents.** Our document review was designed to provide an overview of the sector, to understand national and local commitments to improving outcomes for people with learning disabilities, to gather insight and evidence from existing research, and identify known best practice.

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**Figure 11**  
Case study visits

<b>Local Authority</b>	<b>Clinical commissioning group(s)</b>
Tower Hamlets Council	NHS Tower Hamlets
East Sussex County Council	NHS High Weald Lewes Havens
South Gloucestershire Council	NHS South Gloucestershire
Salford City Council	NHS Salford

**Note**

- 1 We identified the areas for our case study visits by reviewing local area status reports and through our literature review to identify areas of good practice. We selected South Gloucestershire Council as this was the area where Winterbourne View Hospital was located.

Source: National Audit Office

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## Appendix Three

### Leadership and responsibilities for transforming care

**1** The Department of Health (the Department) has the lead role in transforming care for people with learning disabilities, in setting the strategic direction, and in proposals for legislation to reform health and social care. It also led in developing a framework to improve quality and to measure and monitor progress.

**2** A complex structure of other organisations also has responsibilities for delivering the Transforming care and Winterbourne View Concordat commitments. Key organisations with responsibility for transforming care services for people with learning disabilities are shown in **Figure 12** on pages 45 to 47. The Winterbourne View Joint Improvement Programme supports delivery and is itself supported by the NHS Mandate. The Learning Disability Programme Board has responsibility for monitoring overall delivery. In September 2014, the Department set up the Transforming Care Assurance Board to monitor outcomes.

**Figure 12**

## Key roles and responsibilities for transforming care services for people with learning disabilities and challenging behaviour

Organisations and boards	Role and responsibilities	Definition
Learning Disability Programme Board	<p>To work to improve health and well-being outcomes for people with learning disabilities and their families.</p> <p>To monitor delivery of the commitments in <i>'Transforming care: A national response to Winterbourne View Hospital'</i></p>	A cross-government board, which receives reports from NHS England, CQC and the Joint Improvement Programme.
Department of Health	<p>To set the strategic direction and proposals for legislation to reform health and social care.</p> <p>To provide a clear framework to improve quality, enable change and to measure and monitor progress.</p>	Department of State.
NHS England	<p>To ensure that NHS England and clinical commissioning groups work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high-quality care.</p> <p>To commission and secure treatment services for people with learning disabilities and/or autism and with challenging behaviour</p>	An executive non-departmental public body of the Department of Health.
Clinical commissioning groups	<p>Clinically led groups of all General Practitioners in their geographical area.</p> <p>To manage primary care commissioning, including commissioning care services for people with learning disabilities and/or autism, sectioned under the Mental Health Act, and for those people who meet the criteria for continuing NHS healthcare.</p>	Overseen by NHS England (including its regional offices and area teams).
Mental health hospitals	<p>To provide assessment of the patient's condition, their treatment and support needs, and risk management needs.</p> <p>To develop, and keep under review, a treatment programme, in consultation with the patient, aimed at providing the patient's treatment, support and risk management needs, while under their care.</p> <p>To develop a discharge plan for the patient, in consultation with the patient, their clinical commissioning group and local area, to prepare the patient for discharge into an appropriate, bespoke, community care package.</p>	NHS, independent, or private sector hospitals.

**Figure 12** *continued*

## Key roles and responsibilities for transforming care services for people with learning disabilities and challenging behaviour

<b>Organisations and boards</b>	<b>Role and responsibilities</b>	<b>Definition</b>
Winterbourne View Joint Improvement Programme	To support local area partners to work together to reduce the reliance on inpatient care for people with learning disabilities, by developing safe, appropriate and high-quality services, that aim to allow people with learning disabilities to receive necessary support to live in community settings.	Led by the Local Government Association and NHS England, and funded by the Department of Health.
Winterbourne View Joint Improvement Programme Board (since closed down)	To oversee the work of the Joint Improvement Team, to lead and support a transformation in the planning and delivery of care for people with learning disabilities, through a focus on best practice, assessment of the individual's needs, and listening to the person's preferences.	A non-statutory programme board, led by the Local Government Association and NHS England, and funded by the Department of Health.
Transforming Care Assurance Board	To take action and make sure progress is made on commitments in 'Transforming care: A national response to Winterbourne View' Hospital and 'DH Winterbourne View Review Concordat: Programme of Action'.  Reports to the Learning Disability Programme Board.	The overarching assurance board for the Transforming care programme.
Senior Sponsors Group	To examine plans and progress and solve any problems affecting progress in Transforming care  Includes senior responsible officers from NHS England, Local Government Association, Care Quality Commission and Association of Directors of Adult Social Services.	The Senior Sponsors Group is responsible for delivery nationally.
Improving Lives Team	To ensure that the former residents of Winterbourne View Hospital and others receive good quality care and support.  Works in partnership with family and carers.	Formed by NHS England to support the work of the Winterbourne View Joint Improvement Programme.
Local Government Association	To work with councils in England to support, promote and improve local government.	A politically-led, cross-party organisation that works on behalf of councils.



**Figure 12** *continued*

## Key roles and responsibilities for transforming care services for people with learning disabilities and challenging behaviour

Organisations and boards	Role and responsibilities	Definition
Care Quality Commission	<p>To make sure health and social care services provide people with safe, effective, compassionate, high-quality care and to encourage care services to improve.</p> <p>To monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety and to publish its findings, including performance ratings, with the aim of helping people choose care.</p> <p>The Commission inspects and regulates all mental health hospitals for people with learning disabilities.</p> <p>It ensures that services for people with learning disabilities are in line with the agreed model of care.</p> <p>It ensures that for people sectioned under the Mental Health Act, the powers of the Act are being used properly.</p> <p>The Commission's staff includes Mental Health Care Act reviewers.</p>	The independent regulator of all health and social care services in England.
Association of Directors of Adult Social Services	<p>To support the development of the national learning disability policy.</p> <p>To ensure individuals experience high-quality care and support, experience less inequality, and improved outcomes.</p>	Represents Directors of Adult Social Services across local authorities.

Source: National Audit Office

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