

**BOARD PAPER - NHS ENGLAND**

**Title:**

Transforming Care for People with Learning Disabilities and/or Autism

**From:**

Jane Cummings, Chief Nursing Officer

**Purpose of Paper:**

To provide an update and assurance on NHS England's activity to transform care for people with learning disabilities and/or autism, following Sir Stephen Bubb's report on the issue

**Actions for the Board:**

The Board is asked to:

- Review, note and receive assurance on the plans put in place by NHS England to transform care for people with learning disabilities and/or autism

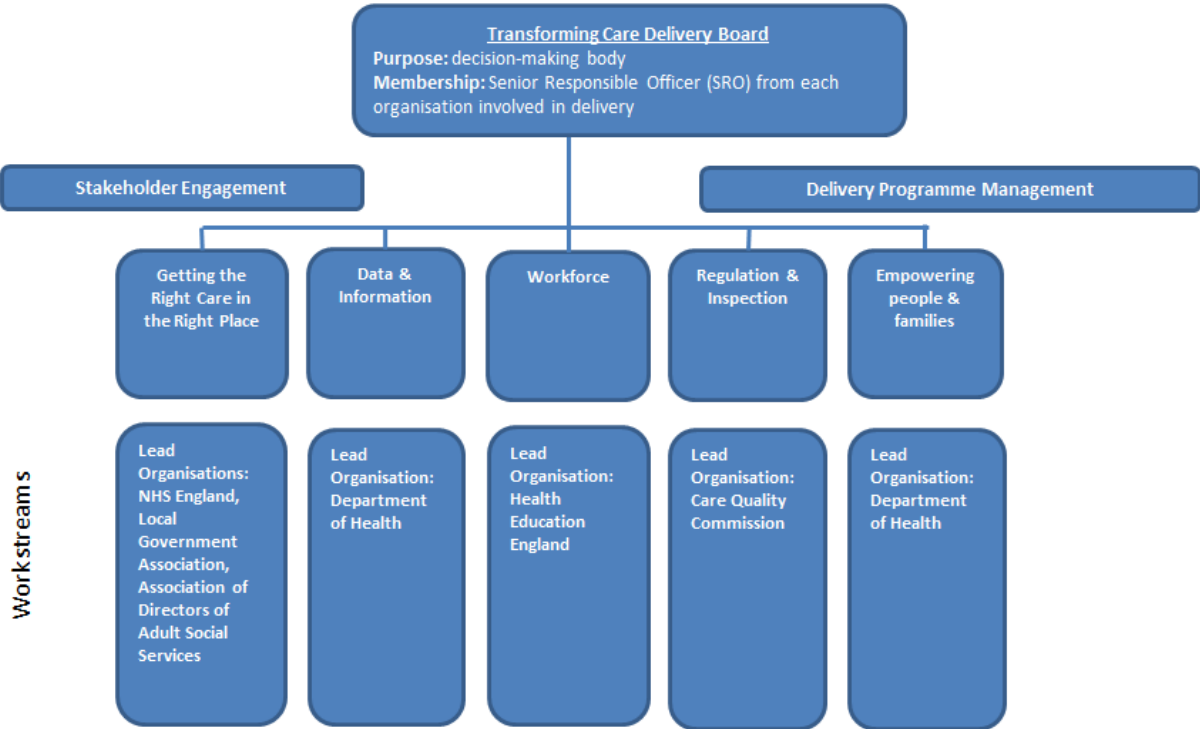
## **Context**

1. Following the scandal at Winterbourne View, a Concordat was published in 2012. Supported by 51 organisations including NHS England (as the NHS Commissioning Board), the Concordat those organisations to transforming care for people with a learning disability and/or autism and a mental illness or challenging behaviour (henceforth shortened to 'people with learning disabilities' for ease).
2. Recognising that not enough progress had been made, in summer 2014 NHS England commissioned Sir Stephen Bubb (CEO, the Association of Chief Executives of Voluntary Organisations) to produce a report on how to accelerate transformation.
3. Sir Stephen's report, *Winterbourne View – Time for Change*, was published at the end of November 2014, and contained recommendations for NHS England as well as for other organisations across the system. The recommendations are summarised in Annex A.
4. Following Sir Stephen's report, NHS England, the DH (Department of Health), LGA (Local Government Association), ADASS (the Association of Directors of Adult Social Services), CQC (the Care Quality Commission) and HEE (Health Education England) have agreed to strengthen the Transforming Care delivery programme and to take a number of steps in 2015 to empower people with learning disabilities and improve the quality of care they receive.
5. These actions are outlined in a document (*Transforming Care – Next Steps*) that we are publishing on 29 January, attached at Annex B.
6. The Board is asked to review, note and receive assurance on the plans put in place by NHS England.

## **Strengthening cross-system working**

7. We have agreed with the DH, LGA, ADASS, CQC and HEE to strengthen the Transforming Care delivery programme by creating a new delivery board, bringing together the senior responsible owners from all six organisations. NHS England will chair this delivery board, with ADASS providing the deputy chair. The workstreams we intend to pursue and the stronger governance structure are set out below.

**Transforming Care Assurance Board**  
 Purpose: hold delivery programme to account.  
 Co-Chairs: Minister & Gavin Harding MBE



8. The work to be taken forward through this programme will be complex and wide-ranging. Over the coming months we will continue to co-design and co-produce it in partnership with people with learning disabilities, their families, clinicians, commissioners, providers, other national organisations in the health and care system (such as Skills for Care, Skills for Health, Public Health England) and other stakeholders.
9. Engagement with people with learning disabilities and their families will be particularly important, and we intend to build on valuable engagement we have had to date (for instance, through the involvement of ‘experts by experience’ in Care and Treatment Reviews) to co-design and co-produce the activity set out below.
10. The actions set out below are therefore not an exhaustive list, but a set of immediate further steps we intend to take in 2015 (set out in more detail in Annex B).

**Empowering people and families**

11. The DH plans to consult on a range of potential future measures to strengthen people’s rights in the health and care system. This is likely to include options for ensuring people’s individual wellbeing is at the heart of decisions in both

health and social care, and issues around how the Mental Health Act is applied.

12. More immediately, NHS England will build on Sir Stephen Bubb's call for a 'right to challenge' by providing a Care and Treatment Review to any inpatient or inpatient's family who requests one, subject to certain limits.

### **Getting the right care in the right place**

13. To ensure that people with a learning disability in hospital who could be supported in the community are discharged into a community setting as soon as possible, NHS England will work with partners to embed Care and Treatment Reviews into 'business as usual', reviewing the current process so that lessons are learned and improvements made.
14. In parallel, we will put in place robust admission gateway processes, so that where an admission to hospital is considered for someone with a learning disability and/or autism, a challenge process is in place to check that there is no available alternative – and where an individual does need to be admitted, they have an agreed discharge plan from the point of admission.
15. We will develop a clearer model for health and care services for people with a learning disability, describing outcomes to be achieved, with associated performance indicators, what kind of services should be in place (covering inpatient capacity and community-based support), and standards that services should meet. This will include a strong emphasis on personalised care and support planning, personal budgets and personal health budgets. The DH will also explore how additional rights to a personal health budget could be developed.
16. Having developed quality standards and outcome metrics as above, we will reflect them in the NHS Standard Contract, the assurance process for Clinical Commissioning Groups (CCGs), and, where appropriate, in data that we publish on how local areas are performing.
17. We will support local areas to adopt good practice at pace, test innovation, and 'get the basics right'. In parallel, we will establish a 'reconfiguration taskforce' to support local leaders to reshape services at pace in the North of England.
18. Our work to support innovation will include funding a detailed feasibility study on Sir Stephen Bubb's proposals for social investment models.

19. We will continue to promote joint working between health and social care commissioners: for instance, NHS England will support Clinical Commissioning Groups (CCGs) to co-commission specialised NHS services with NHS England, NHS England, the LGA and ADASS will continue to promote joint working and pooled budgets between CCGs and local authorities, and the DH plans to explore views on Sir Stephen Bubb's recommendation that the Government should look at applying the Better Care Fund model to this field.

### **Regulation and inspection**

20. The CQC will continue to apply rigorous standards to the registration of new services, and seek to ensure that inappropriate models of care are not registered.
21. The CQC will further refine its inspection methodology for mental health and learning disability hospital services, and ensure that regulatory action is taken when relevant. The CQC will work with partners to develop a clear approach for ensuring that unacceptable mental health and learning disability hospital services are closed through use of its enforcement powers.

### **Workforce development**

22. HEE, Skills for Care and Skills for Health will work in partnership with people who need care and support, carers and other partners to develop a workforce which provides person-centred care and support for people with a learning disability in their community that is needs-led, local and accessible. The first step will be to carry out scoping work with partners to identify current gaps in the provision of workforce development.

### **Conclusion**

23. The Board is asked to review, note and receive assurance on the plans put in place by NHS England in partnership with other organisations across the health and care system.

**Jane Cummings**  
**Chief Nursing Officer**

## Annex A

### Winterbourne View – Time for Change: summary of recommendations

#### A) Strengthening rights

- 1. The Government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning.** The Charter should clarify existing rights, and set out new rights we propose below. The mandatory commissioning framework later in our recommendations should require all commissioners to invest in services that make these rights ‘real’ and easily used.
- 2. The Government should respond to ‘the Bradley Report Five Years On’,<sup>1</sup>** to ensure that people with learning disabilities and/or autism are better treated by the criminal justice system
- 3. People with learning disabilities and/or autism and their families should be given a ‘right to challenge’ decisions to admit or continue keeping them in inpatient care.** They should receive independent expert support to exercise that right, including high-quality independent advocacy.
- 4. NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism,** including all those in inpatient care and appropriate groups living in the community but at risk of being admitted to inpatient care.
- 5. The Government should look at ways to protect an individual’s home tenancy when they are admitted to hospital,** so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.

#### B) Forcing the pace on commissioning

- 6. The Government and NHS England should require all local commissioners to follow a mandatory commissioning framework.** The funding and responsibility for commissioning services for this group should be devolved as much as possible from NHS specialised commissioning to Clinical Commissioning Groups. Learning from the strengths (and weaknesses) of the Better Care Fund, a mandatory framework should then require the pooling of health, social care and housing budgets, and mandate NHS and local government commissioners to draw up a long-term plan for spending that funding in a way that builds up community services, makes the Charter of Rights above real, and reduces reliance on inpatient services. NHS

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<sup>1</sup> G. Durcan, A. Saunders, B. Gadsby & A. Hazard, *The Bradley Report five years on: an independent review of progress to date and priorities for further development* (2014)

England, central Government and local government representatives such as the Local Government Association and Association of Directors of Adult Social Services should support and assure the drawing up of local commissioning plans, and unblock systemic barriers (including Ordinary Residence rules and eligibility for Continuing Health Care). There should be a named lead commissioner in each area, working collaboratively with a provider forum and people with learning disabilities and/or autism and their families.

- 7. Community-based providers should be given a 'right to propose alternatives' to inpatient care** to individuals, their families, commissioners and responsible clinicians.

#### **C) Closures of inpatient institutions**

- 8. The commissioning framework should be accompanied by a closure programme of inappropriate institutional inpatient facilities.** This active decommissioning should be driven by a tougher approach from the Care Quality Commission, local closure plans, and closures led by NHS England where it is the main commissioner. NHS England should come to a considered, realistic view on what is possible – but then it should set out a clear timetable not just for reductions in admissions or inpatient numbers, but for closures of beds and institutions.

#### **D) Building capacity in the community**

- 9. Health Education England, Skills for Care, Skills for Health and partners should develop a national workforce 'Academy' for this field, building on the work already started by Professors Allen and Hastings and others<sup>2</sup>.** The Academy should bring together existing expertise in a range of organisations to develop the workforce across the system.

- 10. A 'Life in the Community' Social Investment Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services.** The Investment Fund, seeded with £30 million from NHS England and/or Government, could leverage up to £200 million from other investors to make investment more easily accessible to expand community-based services.

#### **E) Holding people to account**

- 11. Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level.** Data on key indicators

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<sup>2</sup> Their proposal is outlined at [https://drive.google.com/file/d/0B\\_At2T3XSWfTd2VOcTRrOURMZW8/edit?pli=1](https://drive.google.com/file/d/0B_At2T3XSWfTd2VOcTRrOURMZW8/edit?pli=1)

(such as admissions rates, length of stay, delayed transfers, number of beds by commissioning organisation) should be collected and published. Both local commissioners and national bodies (including NHS England, DH, the LGA and others) should be held to account for implementing our recommendations above – local named lead commissioners by local people, NHS England and central Government, and national bodies through existing governance structures (such as the Transforming Care Assurance Board chaired by the Minister for Care and Support).



# **Transforming Care for People with Learning Disabilities – Next Steps**

**January 2015**

This document has been produced jointly by the following organisations:

- Association of Directors of Adult Social Services (ADASS)
- Care Quality Commission (CQC)
- Department of Health
- Health Education England (HEE)
- Local Government Association (LGA)
- NHS England

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## Executive summary

### Introduction and context

1. The Government and leading organisations across the health and care system are committed to transforming care for people with learning disabilities and/or autism who have a mental illness or whose behaviour challenges services. We have made progress, but much more needs to be done.
2. Recognising this, NHS England commissioned Sir Stephen Bubb to produce a report on how to accelerate the transformation that we, people with learning disabilities and their families are looking for.
3. Following Sir Stephen's report, we (NHS England, the Department of Health, the Local Government Association, the Association of Directors of Adult Social Care, the Care Quality Commission and Health Education England) are confirming our commitment to strengthen the Transforming Care delivery programme by creating a new delivery board, bringing together the senior responsible owners from all our organisations.
4. The work to be taken forward through this programme will be wide-ranging, and over the coming months we will continue to co-design and co-produce it in partnership with people with learning disabilities and/or autism, their families, clinicians, commissioners, providers, other national organisations in the health and care system (such as Skills for Care, Skills for Health, Public Health England) and other stakeholders.
5. This paper, however, sets out some early actions we will be taking in 2015 following Sir Stephen Bubb's report, and some of the issues we will want to engage further with stakeholders on as we work together to transform care. These early actions are set out below.

### Empowering people and families

6. The Department of Health plans to consult on a range of potential future measures to strengthen people's rights in the health and care system. This is likely to include options for ensuring people's individual wellbeing is at the heart of decisions in both health and social care, and issues around how the Mental Health Act is applied.
7. More immediately, NHS England will build on Sir Stephen Bubb's call for a 'right to challenge' by providing a Care and Treatment Review to any inpatient or inpatient's family who requests one, subject to certain limits.

## **Getting the right care in the right place**

8. To ensure that people with a learning disability and/or autism in hospital who could be supported in the community are discharged into a community setting as soon as possible, NHS England will work with partners to embed Care and Treatment Reviews into 'business as usual', reviewing the current process so that lessons are learned and improvements made.
9. In parallel, we will put in place robust admission gateway processes, so that where an admission to hospital is considered for someone with a learning disability and/or autism, a challenge process is in place to check that there is no available alternative – and where an individual does need to be admitted, they have an agreed discharge plan from the point of admission.
10. We will develop a clearer model for health and care services for people with a learning disability and/or autism who have a mental illness or behaviour that challenges, describing outcomes to be achieved, with associated performance indicators, what kind of services should be in place (covering inpatient capacity and community-based support), and standards that services should meet. This will include a strong emphasis on personalised care and support planning, personal budgets and personal health budgets. The Department of Health will also explore how additional rights to a personal health budget could be developed.
11. Having developed quality standards and outcome metrics as above, we will reflect them in the NHS Standard Contract, the assurance process for Clinical Commissioning Groups (CCGs), and, where appropriate, in data that we publish on how local areas are performing.
12. We will support local areas to adopt good practice at pace, test innovation, and 'get the basics right'. In parallel, we will establish a 'reconfiguration taskforce' to support local leaders to reshape services at pace in the North of England.
13. Our work to support innovation will include funding a detailed feasibility study on Sir Stephen Bubb's proposals for social investment models.
14. We will continue to promote joint working between health and social care commissioners: for instance, NHS England will support Clinical Commissioning Groups (CCGs) to co-commission specialised NHS services with NHS England, NHS England, the LGA and ADASS will continue to promote joint working and pooled budgets between CCGs and local authorities, and the Department of Health plans to explore views on Sir

Stephen Bubb's recommendation that the Government should look at applying the Better Care Fund model to this field.

### **Regulation and inspection**

15. The Care Quality Commission (CQC) will continue to apply rigorous standards to the registration of new services, and seek to ensure that inappropriate models of care are not registered.
16. The CQC will further refine its inspection methodology for mental health and learning disability hospital services, and ensure that regulatory action is taken when relevant. The CQC will work with partners to develop a clear approach for ensuring that unacceptable mental health and learning disability hospital services are closed through use of its enforcement powers.

### **Workforce development**

17. Health Education England, Skills for Care and Skills for Health will work in partnership with people who need care and support, carers and other partners to develop a workforce which provides person-centred care and support for people with a learning disability in their community that is needs-led, local and accessible.
18. Our first step will be to carry out scoping work with partners to identify current gaps in the provision of workforce development.

### **Conclusion**

19. As a group of organisations, we recognise the scale of change required to transform care for people with learning disabilities and/or autism. Progress has been made, and with action like our programme of Care and Treatment Reviews, we are changing lives, one person at a time.
20. But we recognise there is much further to go - and we are committed to seeing this transformation through.

## Introduction and context

1. The Government and leading organisations across the health and care system are committed to transforming care for people with learning disabilities and/or autism and mental health problems or behaviour that challenges. Our shared vision and commitment were set out in the Concordat signed in the wake of the events at Winterbourne View.<sup>1</sup>
2. Since then we have made progress, some of which is outlined in a separate report, *Winterbourne View: Transforming Care Two Years On*.
3. However, we have not made as much progress as we should have. Too many people with learning disabilities are admitted to hospital when admission could have been avoided, too many remain in hospital too long, and instances of poor care remain too common.
4. Recognising this, NHS England commissioned Sir Stephen Bubb to produce a report<sup>2</sup> on how to accelerate the transformation of care for people with learning disabilities and/or autism with behaviour that challenges or a mental health problem. The report was published at the end of November 2014, and Sir Stephen made a number of recommendations to organisations across the health and care system, summarised at Annex A.
5. Since Sir Stephen's report was published, NHS England, the Department of Health (DH), the Local Government Association (LGA), the Association of Directors of Adult Social Services (ADASS), the Care Quality Commission (CQC) and Health Education England (HEE) have committed to strengthen the Transforming Care delivery programme, building on the work of the last few years and accelerating progress where it has been slow.
6. In particular, whilst we recognise that there is a need to provide mental health hospital placements in some circumstances where there is a genuine need and in some cases as an alternative to custody, we remain committed to seeing a substantial shift away from reliance on inpatient care. Our efforts will be focused on:

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<sup>1</sup> *Department of Health Winterbourne View Review: Concordat: Programme of Action* (2012)

<sup>2</sup> *Winterbourne View – Time for Change* (2014)

- a substantial reduction in the number of people placed in inpatient settings;
- reducing the length of stay for all people in inpatient settings;
- better quality of care for people who are in inpatient and community settings;
- better quality of life for people who are in inpatient and community settings.

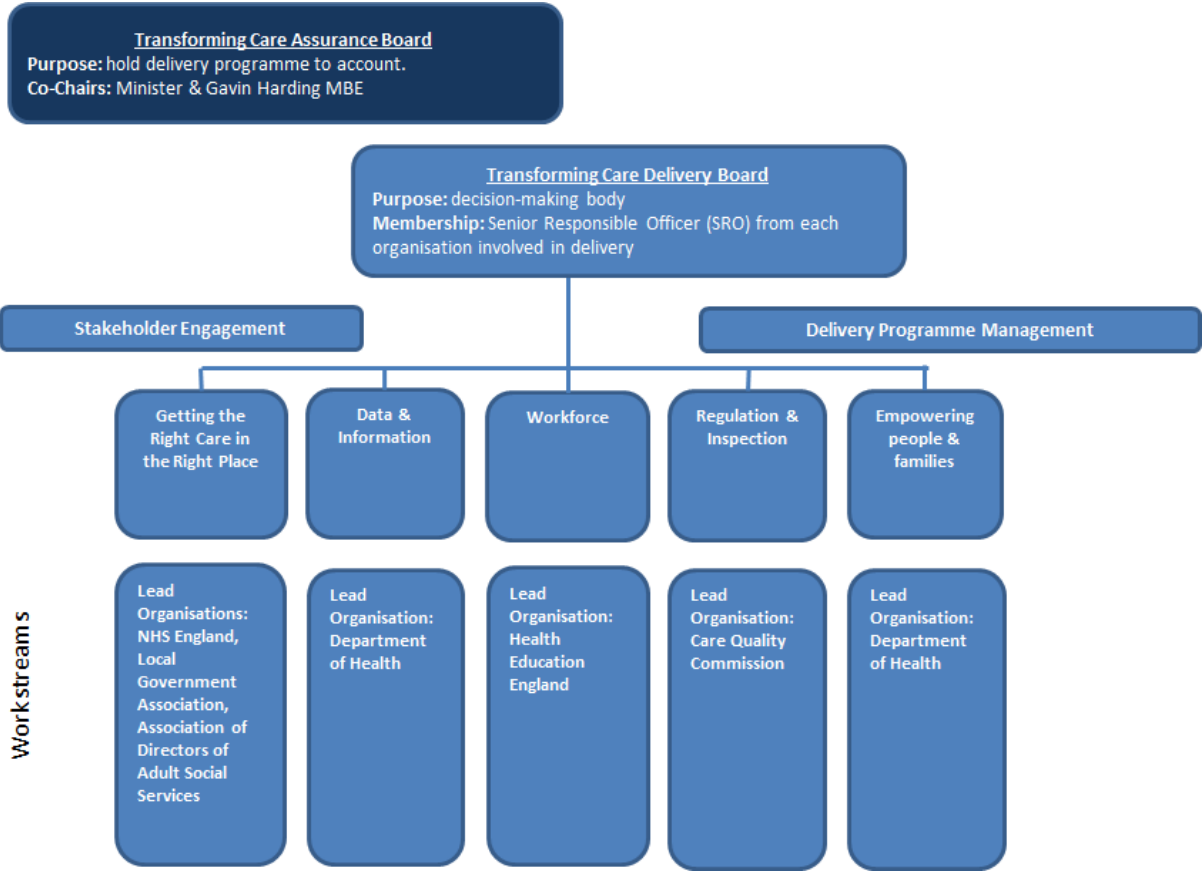
7. To achieve those ambitions, we will pursue a number of streams of work:

- Empowering people and families
- Getting the right care in the right place – both by ensuring that the current care system works for patients and families, and by designing and implementing changes for the future
- Regulation and inspection: tightening regulation and inspection of providers, strengthen providers' corporate accountability and responsibility, and their management, to drive up the quality of care.
- Workforce: improving care quality and safety through raising workforce capability.
- Data and information: underlying all the workstreams above will be a focus on making sure the right information is available at the right time to the people who need it.

8. As a group of organisations, we recognise the scale of change required, and we are committed to working together to ensure that we succeed in transforming care for people with learning disabilities and/or autism. To enable that, we will establish a stronger delivery programme governance structure. As organisations we have different legal structures and accountabilities, which will not change. However we are committed to making this delivery programme work, and to that effect are creating a new delivery board, bringing together the senior responsible owners from all our organisations. NHS England will chair this delivery board, with ADASS providing the deputy chair.

9. The workstreams we intend to pursue and the stronger governance structure are set out below.





- The work to be taken forward through this programme will be wide-ranging, and over the coming months we will want to co-design and co-produce it in partnership with people with learning disabilities and/or autism, their families, clinicians, commissioners, providers, other national organisations in the health and care system (such as Skills for Care, Skills for Health, Public Health England) and other stakeholders.
- This paper, however, sets out some early actions we will be taking in 2015 following Sir Stephen Bubb’s report, and some of the issues we will want to engage with stakeholders on as we work together to transform care.

## Empowering people and families

13. As Sir Stephen Bubb said in his report:

*“People with learning disabilities and/or autism and their families have an array of rights in law or Government policy - through human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, the UN Convention on the Rights of Persons with Disabilities, and so on... [but] the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored.”<sup>3</sup>*

14. Having looked at the data and evidence and listened to what people have said about how it can feel in the health and care system, how they want more choice and a stronger say in their own or their families’ care and to be closer to their family, the Department of Health is planning to consult shortly on a range of potential future measures. These will include what legal changes might be possible, which are designed to strengthen rights in the system for people to have more choice and say in their care, to live independently and be included in their community.

15. This is likely to include options around how the views and wishes of people and their families can be made more central to decision-making, and options for ensuring people’s individual wellbeing is at the heart of decisions in both health and social care, building on the changes due to be introduced by the Care Act (2014) in April 2015. This should be from individual care planning to admission and discharge. This will include those patients who are admitted under the mental health act and how they are supported and enabled, including by family and advocates, to have their and their family’s voice heard in what happens to them (for example, during renewals of detention). It is also likely to explore issues around how the Mental Health Act applies to people with learning disability or autism.

16. More immediately, Sir Stephen Bubb’s report called for people with learning disabilities and/or autism to be given a ‘right to challenge’ their admission or continued placement in inpatient care. To put this into practice, NHS England intends to provide a Care and Treatment Review (CTR) for any inpatient or inpatient’s family who requests one (subject to certain limits, for instance on the number of CTRs any one individual can request in a certain period of time). This will be established as CTRs are embedded into normal business (as we describe in paragraphs 18-20).

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<sup>3</sup> Winterbourne View – Time for Change: transforming the commissioning of services for people with learning disabilities and/or autism (2014)

**Care and Treatment Reviews (CTRs)**

CTRs are designed to support the individual patient and their family to have a voice, and to support the team around them to work together with the person and their family to support a discharge into community. The review process, carried out by independent expert advisers (including one clinician, one 'expert by experience'<sup>4</sup> and the responsible commissioner), asks whether the person needs to be in hospital and, if there are care and treatment needs, why these cannot be carried out in the community. The individual and their family are at the heart of the process, and the review team will meet with them to understand the individual as a central part of the review. If the resources and support are not in place to support someone's discharge, the CTR team can make recommendations to address what needs to be done to get to the point of a safe discharge into a community setting.

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<sup>4</sup> Experts by experience can be family carers or people with learning disabilities who have had relevant personal experiences of inpatient services, or of managing to find alternatives to admission themselves, and can use these experiences as expert advisors on a care and treatment review team.

## Getting the right care in the right place

17. Transforming care for people with a learning disability and/or autism will require commissioners from local government and the NHS to work together to reshape services, with oversight and support from Health and Wellbeing Boards. NHS England, the Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS) will work together to support them to do so in a coordinated way – providing support jointly in some instances, and in separate but complementary ways in others.
18. Our work will include immediate action to support people in hospital to be discharged when they are ready to be supported in the community and to prevent inappropriate admissions, and longer-term work to reshape the provision of care and support services.

### Supporting discharges

19. We want to ensure that anyone with a learning disability and/or autism in hospital who could be supported in the community is discharged into a community setting.
20. In the last few months, NHS England has undertaken a major programme of Care and Treatment Reviews for people who were inpatients on 1 April 2014 (i.e. those who had been inpatients for longest) and who did not have a discharge plan and date. As at mid-January, we had undertaken 1,032 reviews, and expect to complete many more by the end of this financial year (2014/15). Of this group of people in hospital for longer, 566 had been discharged by mid-January 2015 and we envisage that CTRs will continue to speed up discharges in the coming months.<sup>5</sup>
21. The evidence from CTRs completed to date is that they are an effective lever for change and we therefore intend to embed them as ‘business as usual’ in the coming months. We are reviewing the current process to ensure any lessons are learned and improvements made. The review will include:
  - evaluation by a user-led organisation of the experiences of ‘experts by experience’, patients, and their families/carers
  - a review of processes to ensure that commitments made following a CTR are implemented, and insight from CTRs fed into broader commissioning plans
  - work with the Ministry of Justice, the Department of Health, ADASS, the LGA and other partners to make any necessary adjustments to the CTR process so that it can be ‘rolled out’ in Medium and High Secure services, explicitly reflecting the requirements of the relevant legal frameworks.

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<sup>5</sup> Figures are based on internal NHS England management information

- strengthening the CTR process to ensure requirements for education and 'looked after children' are explicit where the care of people under 18 is being reviewed.

22. An updated CTR protocol that takes account of lessons learned and improvements will be issued to take effect in the first half of 2015.

### **Preventing inappropriate admissions**

23. In parallel to our work on supporting people in hospital to be discharged into the community, in 2015/16 we will also take further steps to prevent children and adults with a learning disability and/or autism being admitted inappropriately in the first place.

24. Building on existing good practice in some local areas, we will support Clinical Commissioning Groups (CCGs) and local authorities to draw up registers identifying those individuals most at risk of being admitted to hospital, so that the right support can be made available to them to prevent the need for admission.

25. We will also put in place robust admission gateway processes, building on the principles underpinning Care and Treatment Reviews and learning from gateway processes elsewhere in the NHS, so that:

- where admission is considered, a robust challenge process is in place to check that there is no available alternative; and
- where individuals are admitted, they have an agreed discharge plan from the point of admission – with monitoring processes put in place to ensure that that discharge plan is followed

26. Our intention is to develop these gateway processes with partners, including people with learning disabilities and/or autism and their families, and then pilot them, prior to putting them in place nationally in the spring.

27. We recognise that admission for short-term assessment and treatment will be necessary in some cases – including, in the immediate term, where there is currently an absence of the required community-based services. The information from this challenge process will be useful in informing the scale and nature of community services we need, and our longer-term work on reshaping provision.

28. The Department of Health is also looking at options around whether some of these process - for example, the checks and requirements at admission and the requirements for discharge planning from admission - could be strengthened or supported in statute, and will be looking to consult on these issues in future.

## Reshaping services

29. In addition to immediate steps to support discharges and prevent inappropriate admissions, we also want to see a more fundamental and long-term reshaping of services.
30. The Concordat set out the goal of reshaping provision for people with a learning disability and/or autism who have mental health conditions or behaviour that challenges. It envisaged the development of personalised, local, high-quality services alongside the closure of large-scale inpatient services.
31. Building on the work already undertaken by the Joint Improvement Programme, in 2015/16 we will take a number of steps to better enable local commissioners to undertake that transformation.

## A clearer service model for commissioners to implement

32. Despite the considerable work that has been done to describe 'what good looks like' in terms of services for people with learning disabilities and/or autism and a mental illness or challenging behaviour, many commissioners remain unclear as to what kind of services (inpatient and community-based) they should commission or decommission.
33. As Sir Stephen Bubb's report recognised, stakeholders have differing views as to what inpatient provision we need or no longer need:

*"Some... argued that all hospitals for people with learning disabilities and/or autism should be shut. Others believe some hospitals should remain open, providing a high-quality, locally-integrated service more clearly focused on assessment, treatment and discharge – but they want the number reduced. Some suggested that it is learning disability-specific mental health facilities which should be closed, with universal mental health services making the necessary adjustments to be inclusive of people with learning disabilities alongside others."*

34. Similarly, although a good deal of work has been done to describe what community-based services for people with learning disabilities and/or autism should look like (from Professor Mansell's work to more recent good practice guidance from the NHS England/LGA Joint Improvement Programme), we have heard from many commissioners a desire for this to be drawn together more clearly into service models and quality standards.
35. Engaging with people with learning disabilities and/or autism, their families, carers, clinicians, providers and other experts, and building on the body of

existing work in this field, we will therefore set out a model for health and care services for children and adults with a learning disability and/or autism who have a mental illness or behaviour that challenges. This will describe:

- outcomes to be achieved, with associated performance indicators,
- what kind of services should be in place (covering inpatient capacity and community-based support), and
- standards that those services should meet.

36. This service model will include a strong emphasis on personalised care and support planning, personal budgets and personal health budgets, building on a range of recent moves by the Government, NHS England and local government:

- From April 2015, the Care Act comes into force and this will place personal budgets into law for the first time. This will ensure that everyone with care and support needs will receive a personal budget as part of a care and support plan, regardless of the setting they are in.
- The Department of Health is currently testing the use of direct payments in residential care, with the intention to roll this out across all local authorities in 2016.
- A right to have a personal health budget for people in receipt of NHS Continuing Health Care (NHS CHC) was introduced in October 2014. In addition, clinical commissioning groups are able to offer them on a voluntary basis to others who may benefit. The *Forward View into action: Planning for 2015/16*<sup>6</sup> requires CCGs to set out their local personal health budget offer and include this in their Joint Health and Wellbeing Strategy. There is a requirement that their local offer specifically includes people with learning disabilities.
- Under the Children and Families Act 2014, children who have special educational needs should have a single assessment, an Educational, Health and Care Plan and the option of a personal budget
- From April 2015, the Integrated Personal Commissioning (IPC) programme, jointly led by NHS England and local government representatives, will for the first time, blend health and social care funding for some of the people with the highest care needs and allow them to direct how it is used through personalised care and support planning and personal budgets. We know that 4 out of 9 areas plan to include people with learning disabilities.

37. As part of their planned consultation to strengthen the rights of people to live independently and be included in their community, the Department of Health is also exploring how additional rights to a personal health budget could be developed to facilitate the discharge of people from inpatient settings and help to prevent further inappropriate admissions.

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<sup>6</sup> [www.england.nhs.uk/ourwork/forward-view/](http://www.england.nhs.uk/ourwork/forward-view/)

## **Implementing the new service model**

38. Our intention is to put the service model outlined above into practice through:

- Support for local areas: in 2015/16, we will offer support to all local areas to adopt good practice at pace, test innovation, and ‘get the basics’ right. In parallel, we will establish a ‘reconfiguration taskforce’ to support local leaders to start reshaping services at pace in the North of England, where commissioners who want to transform services face a particular challenge.
- Giving the quality standards in the service model ‘teeth’: we will reflect the quality standards in the service model in NHS contracts, use the performance indicators in the service model in the CCG assurance process, and where appropriate, publish data against those indicators
- Supporting commissioners from across the health and social care system to work together to transform care
- The Department of Health, building on this operational work, will also look at whether there are further statutory changes which could be introduced to strengthen the commissioning of community services, ensure clarity over responsibilities in the system, including in relation to the mental health act and support commissioners to work together jointly for individuals

39. We set out more detail on each of these steps below.

### **Support for local areas**

40. Reliance on inpatient care varies across the country, meaning that some areas will need to go harder and faster to meet the needs of this vulnerable group in providing integrated care, close to home. As the charts at Annex B suggest, it appears that commissioners in the North of England who want to transform services face a particular challenge, and we are therefore committing to providing intensive support in the North to accelerate change.

41. Building on local commissioners’ existing plans, and through extensive engagement with people with a learning disability and/or autism, their families and carers, clinicians, providers, the voluntary sector and Health and Well Being Boards, a ‘reconfiguration taskforce’ will test the forthcoming national standards and service models set out above, build momentum for change and accelerate the pace of transformation.

42. This taskforce will act as an enabler to local commissioners, providing additional support to harness local endeavour and bring about a radical shift in commissioning. It will involve close cooperation between NHS England and regional ADASS, people with learning disabilities and/or autism, their families, providers, clinicians and other stakeholders.



43. In parallel to that intensive support in the North of England, we will provide support to other local areas across the country, building on the work of the Joint Improvement Programme. We have heard that:
- good practice is happening in individual local areas across the country, and spreading that good practice can have a rapid impact;
  - many local areas are interested in applying relatively new approaches to services for people with learning disabilities (such as Sir Stephen Bubb's proposals for using social investment to build the capacity of community-based support, or expanding the availability of personal health budgets), but will need support to do so;
  - in some local areas, core building blocks of good commissioning which will be fundamental to more far-reaching service reconfiguration (such as having an in-depth understanding of current and future need) are missing.
44. Building on the work of the Winterbourne View Joint Improvement Programme, in 2015/16 we will therefore put in place a package of support for local areas to adopt good practice at pace, test innovation, and 'get the basics' right to enable them to undertake long-term service reconfiguration.
45. NHS England, the LGA and ADASS will work together to design and put in place this package of support for local councils and NHS commissioners, and we will be engaging with stakeholders on what that support should look like over the coming weeks. The support we provide will build on existing activity (such as the work that the Joint Improvement Programme has been undertaking with 'in-depth review areas') and align with existing national and regional networks. NHS England will also encourage CCGs to take stock of their commissioning capability in this field through CCG assurance discussions.
46. As part of our support to test innovation, NHS England and the Department of Health, working closely with the LGA and ADASS, will advance the important work that Sir Stephen Bubb did on social investment models as a potential tool to enable commissioners and providers to improve community support. Building both on the work of Resonance and of other groups, including the Housing and Support Alliance, to outline possible social investment fund models, we are in the process of identifying a region, locality or cluster of localities to work in partnership with us to test the feasibility of different models. It is essential that we base this work on a strong understanding of different service costs, potential savings, numbers and needs of the population and other important factors like the local property market. The Department of Health are looking as the first step to commission and fund expert detailed feasibility work on the investment models proposed, working closely with NHS England, the LGA, ADASS and

commissioners in the identified local area or region to ensure we can take forward effective models as rapidly as possible.

47. We will also work with local commissioners to explore Sir Stephen Bubb's recommendation of a 'right to propose' alternatives to inpatient care for community-based providers, looking at whether there are ways we could make it easier for providers to work with commissioners on developing community-based support packages for people currently in hospitals.

### **Giving the standards in the new service model 'teeth'**

48. Over time, we will support commissioners to contract with providers in a way that reflects the service model and associated quality standards that we intend to set out. The way we do that is likely to vary from the NHS to local government, with a 'sector-led improvement' approach across health and social care, and national assurance processes and mandatory tools also playing a complementary role in the NHS.
49. All NHS commissioners are expected to use the NHS Standard Contract with the providers they secure services from (other than primary care providers). The Standard Contract for 2015/16 will contain provisions requiring all providers of NHS-funded services for people with learning disability and/or autism to comply with standards for admission and discharge which we intend to set out shortly, following consultation with current providers among other stakeholders. For instance, we will consider setting standards at the point of admission (such that providers can only admit individuals who have been approved as needing hospital treatment by the admission gateway set out above, or must be able to evidence discharge planning starting for each patient from the point of admission).
50. Providers will be expected to move quickly to implement the standards set out in the service model. NHS commissioners will monitor progress closely during 2015/16, and NHS England will consider the introduction of specific mandatory financial sanctions into the Contract from 1 April 2016, subject to consultation.
51. In the longer term, we expect the contracting of NHS services for this group of people to change, moving away from non-specific block contracts and towards contracting for specific outputs or outcomes, and giving individuals and their families greater control over how the money is spent. We will support this long-term shift by helping local areas to test innovative approaches (such as Integrated Personal Commissioning), and increasing the quality and availability of data to allow for the development of new forms of contracting.

52. We intend that the service model outlined above will describe outcomes that local areas should be seeking to achieve, and associated performance indicators. NHS England will then make use of these performance indicators in the CCG assurance process, and where appropriate, we will explore publishing them.

### **Supporting commissioners to work together**

53. We know that providing high-quality support for people with learning disabilities and/or autism who have a mental illness or behaviour that challenges will require health and social care commissioners – local authorities, CCGs and NHS England as commissioner of specialised health services – to work together effectively.

54. NHS England, the LGA and ADASS will continue to promote joint working and pooled budgets between CCGs and local authorities.

55. In addition, in the light of Sir Stephen Bubb's recommendations that the Government should look at the Better Care Fund model (which mandated pooled budgets between local government and the NHS) and see what learning could be applied to this area, the Department of Health will look to explore views on this further. In line with Sir Stephen's recommendations, this could include how we can move further on local pooled budgets and joint commissioning plans, building on the development of the Integrated Personal Commissioning Programme (as described above).

56. In addition, from April 2015 NHS England will invite CCGs, working closely with local councils, to co-commission specialised services with NHS England, asking them to collaborate with us to transform services. As Sir Stephen Bubb's report argued, the current split in responsibilities can make that transformation harder. Under our plans, as part of ongoing discussions on ensuring that funding flows enable and incentivise transformation of services for people with learning disabilities and/or autism, from April 2015 CCGs will be able to co-commission specialised services with NHS England, and share in the gains if better preventative service result in reduced spending on specialised services.

57. We will encourage CCGs to make the transformation of services for people with learning disabilities a priority for their co-commissioning arrangements with NHS England, and where they do, they will be able to access extra support (as described above) to help them adopt good practice at speed, innovate, and plan for long-term service reconfiguration.

58. To support accelerated delivery in the North, we will also identify areas where there will be an offer of a gain-share arrangement specifically for learning disability specialised budgets. In those areas, CCGs will be able to share in any

gains to the specialised budget arising from their investment in improved community-based services, as part of a broader package of support to the region.

## Driving up quality through regulation and inspection

59. We know that the regulation and inspection of providers has a crucial role to play in driving up the quality of services available to people with learning disabilities and/or autism.
60. The Care Quality Commission (CQC) will continue to apply rigorous standards to the registration of new services, and seek to ensure that inappropriate models of care are not registered.
61. In 2015/16 the CQC will further refine its inspection methodology for mental health and learning disability hospital services and ensure that regulatory action is taken when relevant. This will include close working with partners when services are found to be delivering poor quality care. There will continue to be a programme of announced and unannounced inspections, and the CQC will work closely with NHS England on Care and Treatment Reviews, ensuring that this information guides us in our regulation and monitoring.
62. The CQC will work with DH, LGA, ADASS and NHS England to develop a clear approach for ensuring that unacceptable mental health and learning disability hospital services are closed through use of our enforcement powers. Closures must not lead to vulnerable patients being put at further risk. The responsibility for delivering alternative appropriate placements will be the responsibility of the commissioners.
63. The CQC also inspects community learning disability services, adult social care services and primary care services in relation to their ability to provide safe, effective, caring, responsive and well-led provision for those individuals who present the most challenges and the most complex needs.
64. The CQC will also continue to inspect acute hospitals in relation to how they meet the health care needs of patients with a learning disability across core services.

## Workforce development

65. We know that if we are to transform services for people with learning disabilities and/or autism, developing the workforce that delivers them will be essential.

66. Skills for Care, Skills for Health and Health Education England (HEE) will work in partnership with people who need care and support, carers and other partners to develop a workforce which provides person centred care and support for people with a learning disability in their community that is needs led, local and accessible. They will do this by:

- supporting the development of workforce awareness, knowledge and skills in recognised areas of health need including autism, mental illnesses, physical illnesses and physical ill health and social support needs to enable fulfilled lives;
- developing a good understanding of the links between these needs to ensure person centred care and support and support;
- developing personalised support and treatment approaches through holistic assessments and non-aversive treatment strategies using Positive Approaches;
- agreeing accreditation schemes for the training and delivery of these approaches of care;
- adopting national standards such as NICE guidelines and disseminating evidence-based practice;
- ensuring that there is a strong emphasis on developing leadership and management skills at all levels to promote innovation and change management; and
- ensuring that these changes have a positive impact on the lives of people with learning disabilities.

67. HEE is committed to working with partners to ensure that it meets its learning disability workforce development objectives in a timely manner. A newly formed Learning Disabilities steering group will manage the above programme of work in close collaboration with key stakeholders including people with learning disabilities and/or autism and carers.

68. HEE recognises that the workforce providing services to individuals with a learning disability and/or autism extends beyond the NHS to include the social care sector, the private and voluntary sector and the criminal justice system. HEE's aim is to ensure that the reach of its work programmes, particularly with regards to awareness raising, will impact across these key sectors. This will be best facilitated through working in partnership with key

stakeholders such as Skills for Care, whilst ensuring a regional focus by implementing many of the above projects through its Local Education and Training Boards.

69. Initial actions will include scoping and data collection to identify current gaps in the provision of workforce development. Knowledge and experience from examples of good practice will be identified and disseminated using HEE's national network of offices.

70. HEE anticipates that education and training for this workforce will be delivered using a three-tiered approach, replicating the approach which HEE recently used with its dementia strategy<sup>7</sup>. This is likely to include a first tier of awareness raising, a second tier incorporating more detailed learning and a third tier to enable the development of experts and leaders within the field. This would be delivered using a blended approach of delivery methods including e-learning, workplace based learning and face to face tuition.

## Conclusion

71. As a group of organisations, we recognise the scale of change required to transform care for people with learning disabilities and/or autism. Progress has been made, and with action like our programme of Care and Treatment Reviews, we are changing lives, one person at a time.

72. But we recognise there is much further to go - and we are committed to seeing this transformation through.

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<sup>7</sup> HEE, *Enabling through education and training: a strategy to support better care and better outcomes for people with dementia* (2013)

## Annex A - the Bubb report

1. Having missed the commitment to move all inpatients inappropriately placed in hospital to community settings by June 2014, and as part of our recognition that we needed to step up our efforts, NHS England commissioned Sir Stephen Bubb to produce a report on how to accelerate the transformation of care for people with learning disabilities and/or autism with behaviour that challenges or a mental health problem.
2. Sir Stephen was supported by a steering group of representatives from the voluntary sector, the NHS and local government, individuals with learning disabilities and/or autism, and family members of people with learning disabilities and/or autism. Over the course of its work, the group engaged with a range of stakeholders (from people with learning disabilities and/or autism and their families to commissioners, providers and academics).
3. Sir Stephen's report, published in November 2014, made a number of recommendations to organisations across the health and social care system, summarised below.
4. To **strengthen the rights of people with learning disabilities and their families**, the report recommended:
  - The Government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning.
  - The Government should respond to 'the Bradley Report Five Years On',<sup>8</sup> to ensure that people with learning disabilities and/or autism are better treated by the criminal justice system
  - People with learning disabilities and/or autism and their families should be given a 'right to challenge' decisions to admit or continue keeping them in inpatient care.
  - NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism
  - The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital, so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.

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<sup>8</sup> G. Durcan, A. Saunders, B. Gadsby & A. Hazard, *The Bradley Report five years on: an independent review of progress to date and priorities for further development* (2014)



5. To **improve commissioning**, the report recommended that the Government and NHS England should require all local commissioners to follow a mandatory commissioning framework, whereby:

- Commissioning of specialised services would be devolved as much as possible from NHS England to Clinical Commissioning Groups
- Pooling of health and social care budgets would be mandated
- Local NHS and local government commissioners would be mandated to draw up a long-term plan for building up community services and reducing inpatient provision
- Support and assurance of local plans would be provided by NHS England, central Government and local government representatives such as the Local Government Association and Association of Directors of Adult Social Services
- Community-based providers would be given a 'right to propose alternatives' to inpatient care to individuals, their families, commissioners and responsible clinicians.

6. Sir Stephen also recommended **closures of inpatient institutions**, calling for:

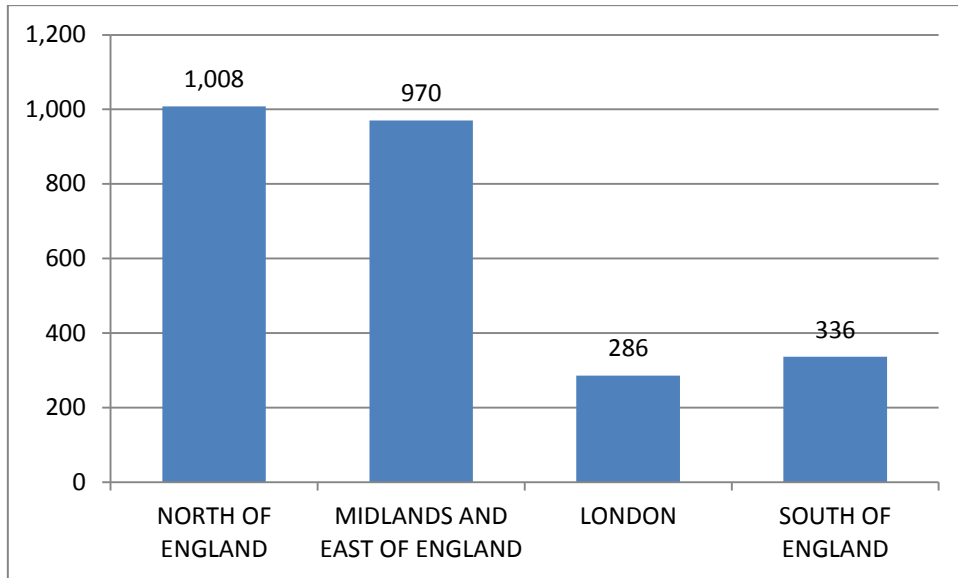
- a tougher approach from the Care Quality Commission,
- local closure plans, and closures led by NHS England where it is the main commissioner,
- NHS England to come to a considered, realistic view on what is possible and then set out a clear timetable for closures of beds and institutions.

7. To **build capacity in community services**, the report recommended:

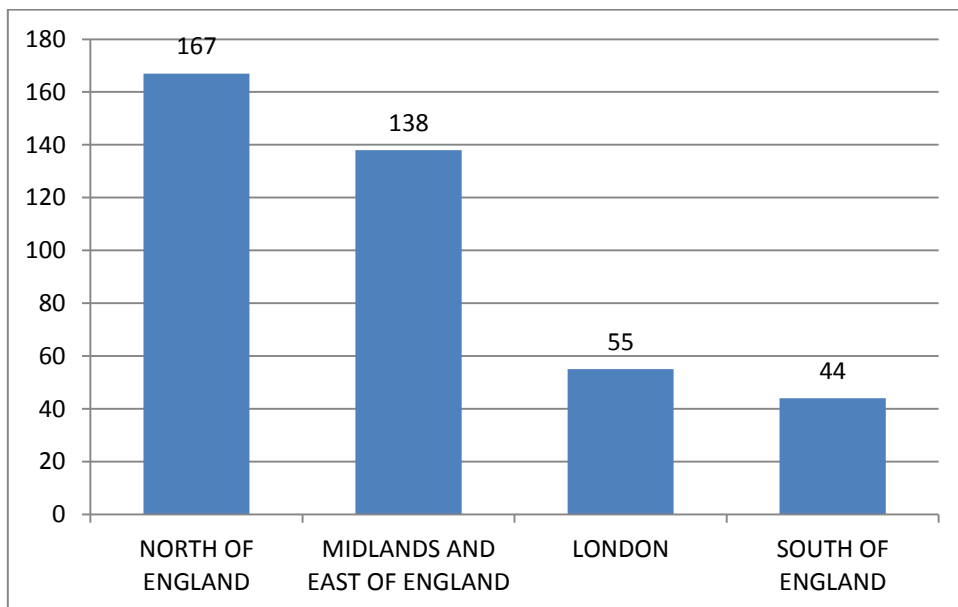
- Health Education England, Skills for Care, Skills for Health and partners should develop a national workforce 'Academy' for this field, which would bring together existing expertise in a range of organisations to develop the workforce across the system.
- A 'Life in the Community' Social Investment Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services.
- Sir Stephen also said that local and national organisations should be held to account for acting on these recommendations, through better collection and publication of data, and a monitoring framework at national and local level.

## Annex B – regional differences with regard to inpatient care

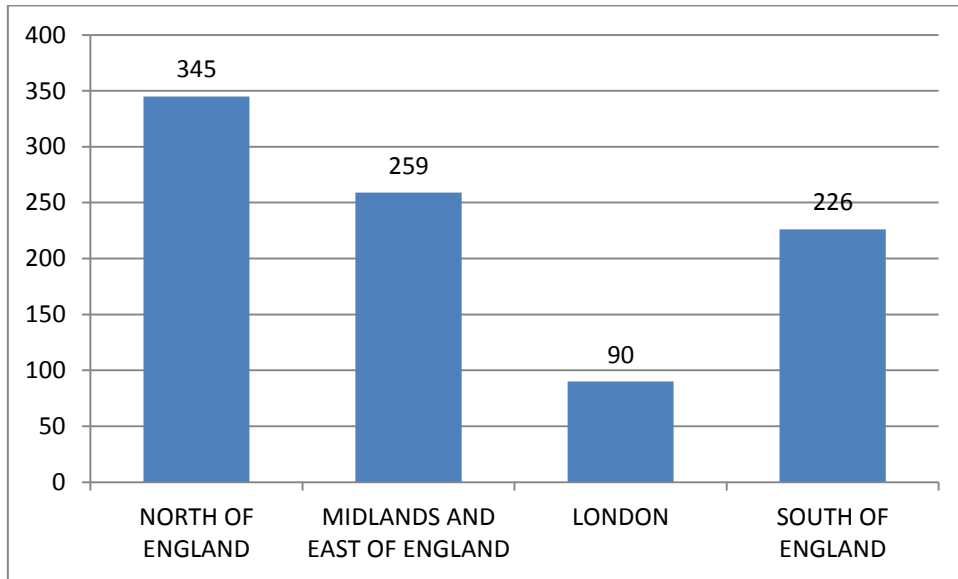
**Q2 2014/15 - LD Inpatient numbers (source: Assuring Transformation)**



**Q2 2014/15 - LD Admissions (source: Assuring Transformation)**



**Q2 2014/15 - Inpatients without a transfer date (source: Assuring Transformation)**



**Prevalence of inpatient care for adults with learning disability by region of residence (source: Learning Disability Census 2013)**

