

# Winterbourne View:

Transforming Care Two Years On

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# Winterbourne View:

## Transforming Care Two Years On

**A jointly produced document prepared by the Department of Health and its partners: the Association of Directors of Adult Social Services, Care Quality Commission, Health and Social Care Information Centre, Local Government Association, NHS England and Public Health England**

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Kayleigh spent almost 10 years of her life in assessment and treatment units across Britain, the closest of which was Winterbourne View where she spent 3 years. This was 120 miles away from home.

In January 2014 she moved into her own home in the community. We have faced some challenges over the last year as would be expected but on the whole it has been a successful and positive year with Kayleigh gradually learning the art of living back in the community without strict rules dictating when she must do the most simple things such as eat or smoke.

Getting Kayleigh home was not easy or straightforward. It took me many years of frustration and tears to achieve this final aim and without my determination and passion Kayleigh would not be where she is today.

As parents we struggle to have a voice that is heard by 'professionals' who believe themselves to be right and are not prepared to give the chance of normality to our most vulnerable people. Institutionalisation becomes the norm within assessment and treatment units and behaviour becomes a self-fulfilling prophecy with the treatment encouraging the behaviour and hence the ability to move on for our vulnerable relatives is limited or non-existent.

For Kayleigh, the move has been positive with her learning new social skills through being a part of the local community and neighbourhood. Everyday events that we take for granted.

Barriers to discharge that we had to overcome included the fact that the responsible clinician is not independent and therefore is not quick to want to permit release. Local services do not have the facilities or expertise in the local area to support discharge and are wary of accepting the responsibility back onto their patch (Kayleigh is still in a position whereby no-one in the local learning disability service is prepared to take overall responsibility for her even though this is a statutory requirement). Also, housing in appropriate areas may be difficult to locate.

I was able to purchase a house for Kayleigh through Joint ownership with Advance Housing so was able to find a property that would meet her living requirements in an area that was suitable to her needs and hence giving her a greater chance of success. This is not something that is available to everyone trying to be discharged into the community.

Kayleigh is one of the lucky ones who has been able, with my support to achieve her wish of living her life in the community. According to the Bubb report there are many who have not achieved this even though we are 2 years on. This outcome needs to be achieved for the majority and not just the few. All vulnerable people and their families need to have a voice that is heard. *From Wendy parent of Kayleigh.*

*This story underlines what the Transforming Care programme can do to ensure that individuals can, with the right support, live in community.*

# Foreword

- i. Winterbourne View was a scandal that shocked and appalled us all. Our review, [\*Transforming Care: A national response to Winterbourne View Hospital: Department of Health Review Final Report\*](#) (2012) looked at why this happened and set out a programme of work to take every step we can, to ensure this does not happen again.
- ii. The Department of Health committed in *Transforming Care* to produce a report two years on to account for progress<sup>1</sup>. This report is a collective account from partners across the health and care system to reflect the cross-system effort that has continued over the past year to tackle the root causes of the abuse and treatment of people at Winterbourne View.
- iii. This report sets out what has been done and recognises there is still much more to do. The summary includes a number of achievements, for example:
  - We know how many people are in inpatient settings, where they are and who is responsible for them.
  - We have strong accountability and corporate responsibility arrangements in place via the Duty of Candour and Fit and Proper Person Test to assure the quality and safety of care services that people receive.
  - We have new DH guidance on minimising restrictive interventions, complemented by a suite of information by Skills for Care and Skills for Health setting the foundation for a broader new programme Positive and Safe launched by the Department of Health in 2014. Work is underway to improve and report on data about the use of restraint.
  - A more rigorous registration, assessment and inspection approach is in place for learning disability services, involving experts by experience and ratings are being published from inspections taking place since October 2014.
  - The Care Act 2015 underpins and reinforces the importance of good quality, independent advocacy and will play an important part in supporting people, their families and carers to raise concerns when these arise.
  - There has been a step change in leadership within NHS England since April 2014.
- iv. It is also clear that we have not made as much progress as we intended, which is not good enough. The commitment to transfer people by 1 June 2014 from inappropriate inpatient care to community-based settings was missed. This commitment is still right but the process is clearly more complex than we anticipated and the system has not delivered what we expected to achieve when *Transforming Care* was published.

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<sup>1</sup> *Transforming Care: A national response to Winterbourne View Hospital:* (December 2012), Annex B – Timetable of Actions number 60: “The Department will publish a second annual report following up progress in delivering agreed actions”.

There are many people with very complex needs, in many different types of inpatient settings and we need to ensure the right decisions are made about their care, listening to the people who matter most: individuals, their families and carers.

- v. As part of our determination to step up the pace of change, all partners involved in *Transforming Care* have agreed the need for a single programme with a single plan. This will drive a better co-ordinated approach to achieve faster and sustainable progress. We understand that this is not easy which is why we are looking at what more we can do to strengthen the rights of people with learning disabilities and autism. This will also build on the recommendations of *Winterbourne View - A Time for Change* (2014) by Sir Stephen Bubb.
- vi. We will be clear about the priorities for further action in the single *Transforming Care* Programme. In an appendix to this report is a summary of the original actions set out in the *Transforming Care* report and accompanying Concordat. These actions have been reviewed in the light of what we know now and grouped into three categories: actions completed and closed or about to be completed, actions which have been completed but are now part of another ongoing programme for example, the ongoing inspection programme of the Care Quality Commission, and actions outstanding, which will be carried forward into the *Transforming Care* Programme.
- vii. Partnership working is key to success and we are clear that this cannot all be done from Whitehall. There has to be a change in culture and behaviour in local areas. Strong local leadership is critical to making change happen. Health and Wellbeing Boards have a key role in bringing together local organisations to work in partnership and ensure accountability. Health and care commissioners need to ensure that high quality community based services offer people the right care and support. The voluntary and community sector have an important role in challenging local decisions and advocating for people and their families, as well as people, their families and carers being supported to be involved at every level.
- viii. We are committed to working in co-production with people with learning disabilities and their family carers to ensure that people are not left in institutions when they can, and should be, living as equal and valued citizens in our communities.



A handwritten signature in black ink that reads "Norman Lamb".

Norman Lamb, Minister of State for Care and Support



A handwritten signature in black ink that reads "G. Harding MBE".

Gavin Harding, MBE

Leslie was diagnosed with autism at three but seemed to thrive at our village school in North Devon and later at a special unit for autistic children. In adolescence his behaviour became more challenging and at 18 he tried to take his own life. Provision in North Devon was inadequate for his needs so the local authority decided Winterbourne View was the nearest place that was equipped to look after him. We hoped it was the right place - we could not have been more wrong.

We don't think Leslie suffered the same experience as other patients but he was immediately unhappy. We could see that despite its outward appearance it was a terrible place. Leslie was 18 confused and frightened and needed a therapeutic environment but instead got Winterbourne View.

We set about convincing our local authority to move Leslie and after 14 weeks it was agreed he would go to a residential college. Leslie was identified as having post-traumatic stress disorder as a result of what he had witnessed and experienced at Winterbourne View. While the college was well resourced in many ways, it lacked staff who were properly qualified for work with autism. It was decided that he should live at home with a programme of support in place there.

One of our main fears is that during a crisis something will happen that puts our son's well-being into the hands of people who know very little about him. Recently Leslie has become involved in a pilot scheme to create a "Police Passport" which is a data base aimed at informing police, on the spot, about vulnerable people and reducing the risks to them.

Leslie lives at home with his mum, dad and brother. His programme is aimed at giving him the skills to have a place of his own with supported living. Because of his autism he lives in the moment and finds it difficult to visualize a time when things will be better for him. His brother is dedicated to Leslie's well-being but it is a terrific drain on him when we go from one crisis to another.

Media attention over Winterbourne View has enabled local authorities to justify the release of funding to help our son but the problem is there is no effective mechanism in place to help us cope in a crisis. I'm sure others who are in a similar situation to us share our fears and frustration when after all the promises from the government we see no real changes in the available help. *From Les Bonner, dad of Leslie.*

*This story shows what the Transforming Care programme needs to do to ensure that people can live in the community with the right support in place.*



# Chapter 1 – The right care in the right place

**Everyone inappropriately placed in hospital should be supported to move to community-based support where there are quality care support and housing services based on the model of good care.**

1. A central part of our plan for action set out in the Department of Health's (DH) review [\*Transforming Care: A national response to Winterbourne View Hospital: Department of Health Review Final Report\*](#) (2012) and accompanying Concordat<sup>2</sup> focused on stopping people with challenging behaviour being placed in hospital inappropriately to ensure that they only go into hospital if hospital care is genuinely the best option, and only stay in hospital for as long as it remains the best option. This builds on the model of care outlined by the 1993 Mansell report (updated and revised in 2007<sup>3</sup>) which emphasises:
  - the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers
  - a focus on personalisation and prevention in social care
  - that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour
  - that services/support should be provided locally where possible.
2. This chapter sets out work we have undertaken to understand the transformation needed to meet this challenge. Also, to use this understanding to ensure the right actions are being taken forward to ensure people with challenging behaviour are supported to live in the community, where that is the right setting for them, and with the right support in place.
3. In *Transforming Care*, our central ambition was to reduce the number of people with challenging behaviour inappropriately placed in hospitals by 1 June 2014. This has not been achieved. There has been some progress in discharging people with 923 discharges by consultant psychiatrists between December 2013 and September 2014. However, 1,036 people have been admitted in the same period.
4. We recognise that there is a need to provide specialist hospital placements in some circumstances where there is a genuine need and in some cases as an alternative to custody. However, we remain committed to seeing a substantial reduction in the number of people in inpatient settings. We now have a better understanding of the scale of the challenge and what action is needed to achieve this, including:

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<sup>2</sup> Refer to appendix 1 for an updated tracker of *Transforming Care* actions.

<sup>3</sup> Professor Jim Mansell, *Services for people with learning disability and challenging behaviour or mental health needs: (2007)*.

- 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.

## Understanding the transformation needed

5. While reviews of people in specialist hospital settings were carried out between June 2013 and June 2014, during this period clinicians identified fewer people than we anticipated for discharge. At the same time, people have continued to be admitted/re-admitted. It is recognised that we need a fundamental change in health and social care practice focused on prevention and on innovative approaches to working with people that are person centred, rather than requiring people to fit into existing services. People should be given more choice and control through personal budgets. Commissioners and providers need to work together to develop stable community placements, backed up by specialist community learning disabilities services and crisis support services to prevent admission to specialist hospitals.

The difference that having a Personal Health Budget makes is that both my family and daughter's lives have improved beyond all recognition. My daughter does not have mental capacity but is capable of letting us know if she dislikes someone or something that is happening to her. We now choose who works with her and how they work with her. Choice in all things is now available to us all.

We have a highly trained staff team of 8 that work to a very high standard of care. Everyone knows what he or she is doing and how to look after my daughter. This has been achieved by including the staff in setting up all routines and policies and writing the care plan. The care plan is a whole person care plan that is constantly updated and it under-pins the care package. All staff are able to come with suggestions and ideas that might improve my daughter's life.

My daughter has a happy life with many activities and outings; she is no longer ignored or comes last in anything we do. Everything revolves around meeting her needs and letting her have fun. With regard to meeting outcomes, my daughter's health has improved; staff know how to treat her ailments. We have reduced medication; we have reduced doctor's visits almost down to a flu jab.

Our hospital admissions have ceased and will now only be for major surgery when required. My daughter's anxiety has reduced dramatically and her well-being has been enriched. This is all due to 'bespoke training' of staff to meet my daughter's needs. If I had to sum up the reasons for her happiness and wellbeing it would be because that we now choose and control her care, and that training is appropriate to the her needs, a good staff team, and having a peer group to support, advise and help you, are all essential to the success of Personal Health Budgets. *From an anonymous parent.*

6. The latest data from NHS England shows us that commissioners identified 2,600 people in inpatient settings on 30 September 2014 which is almost unchanged from the 2,601 people in inpatient settings on 30 June 2014. However, there have been improvements in:

Figure 1

	30 March 2014	30 June 2014	30 September 2014
More patients with planned transfer dates	256 with/2358 without	577 with/2024 without	1680 with/920 without
More patients being recorded as being on a register	2096 on/519 without	2135 on/466 without	2426 on/174 without
More patients who had their last review within the last 26 weeks	2334	2303	2411
More patients experiencing reduced lengths of stay:			
Less than 1 year	865	935	978
1-2 years	522	490	486
2-5 years	731	686	671
More than 5 years	492	485	461
Fewer patients without a care co-ordinator	111 without/2503 with	96 without/2505 with	38 without/2562 with
Fewer patients who have had a care plan review in the last 12 weeks but do not have a planned transfer date	1170	1165	501

7. For a written description of the statistics presented in figure 1, refer to appendix 7.
8. Approximately a quarter of people are placed in these settings by the courts or prisons, including people placed on a Restriction Order. Some of these patients may not be suitable for discharge, where they pose a serious risk to the public or who may need to complete a prison sentence after treatment. However, there are a number of patients who could be discharged with the right kind of community support and we are working with a range of organisations to tackle these issues.

I have good news - I am going to be coming off my restriction order in 3 months' time! I was in and out of hospital for 15 years. I had some very hard times in my life. Hospital was so bad. I hated being given medication most of all. I hated the side room. I hated being controlled by other people. It was so hard, people think they have power over you.

Now I have my own flat and I come and go when I want. I have a job now and I enjoy it because I am helping other people. People rely on me. It makes me feel trustworthy. I am no longer on medication so no more injections!

When I was growing up I didn't trust anyone. I am learning to trust people now. I have really needed people to talk to and keep me safe. I was afraid when I first left hospital and it is hard to talk about. The hardest things when I got out were trusting people, trusting women and learning about relationships of all kinds.

I found drinking and drugs a problem but I stopped because I don't want to go back to hospital. I also had trouble with running away at first. I had 24 hour support at first and sometimes I just wanted to be alone and free to do what I wanted.

Now I have had my support hours reduced from 24 hours to 4 hours a day plus sleep ins, but I don't have sleep ins on Tuesdays and Fridays now! I really enjoy doing what I want without anybody telling me what to do. I am my own man now.

I wouldn't want to run away now. Why would I run away from my own life? I have way too much to lose. *From an anonymous self-advocate.*

9. In light of the need to achieve faster progress to change this pattern of care, Simon Stevens - CEO of NHS England commissioned Sir Stephen Bubb to understand the challenges and propose steps to put this right. This report, [Winterbourne View - A Time to Change](#), was published in November 2014 and NHS/System published its response in January 2015<sup>4</sup>. In the meantime, NHS England has produced an action plan aimed at making faster, sustainable progress to 'better care now' and has committed additional resources until March 2016 to deliver change.
10. Alongside this, DH and NHS England have each created a £7m capital fund to support people inappropriately placed in inpatient settings to move into community-based settings. For details of DH's capital scheme and how it is being used, see appendix 2.

### **Getting Care and Treatment Right: Personal Care Planning**

11. There were 48 patients resident at Winterbourne View at the time of its closure. In line with our commitment to this group of patients, NHS England established the Improving Lives team to review their care. This team has established a process of review that involves health and social care professionals and Experts by Experience (people with learning disabilities and family carers). The latest review between January and June 2014, showed that of the 48 people in Winterbourne View: 10 adults are still in hospital; 20 are living in residential care; five are living in supported housing with their own tenancies; 12 have their own general needs tenancy; and one has died.

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<sup>4</sup> <http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/transform-care/>

The National Valuing Families Forum were signatories to the original Concordat Document and members of the Forum have been active critical friends in monitoring and challenging progress in the last two years.

A positive opportunity for family involvement has been as Experts by Experience in The Improving Lives Team. Being team members on two day reviews for people who left Winterbourne View, co-producing with NHS Clinicians and Social Care Associates, has seen true sharing of professional expertise and lived experience. There have been many two way challenges to assumptions and a strong network of people who have learning disabilities, families and professionals has emerged.

As a parent supporting someone with significant needs to live an active life with community presence, the opportunity to be a review team member and to see first-hand the barriers preventing other people to do this, has strengthened my resolve to be part of the voice for immediate system change. *From Vicki Raphael, Christian's mum, Expert by Experience with the Improving Lives Team and Chair of the National Valuing Families Forum.*

12. NHS England is now building on the approach developed by the Improving Lives team to provide 'Care and Treatment Reviews' for everyone in inpatient settings, with the aim that a multi-disciplinary team from health and social care, alongside Experts by Experience will review all patients in hospital care. As at mid-January 2015, 1,032 reviews had been undertaken and NHS England expects to complete many more by the end of March. Of people in hospital for longer, 566 had been discharged by mid-January 2015 and NHS England envisages that Care and Treatment Reviews will continue to speed up discharges in the coming months.
13. NHS England is carrying out work in partnership with social care professionals to reduce the number of people with learning disabilities being admitted into inpatient beds. The work involves the development of a protocol to make sure that where somebody is at risk of being admitted to an inpatient bed an 'Alternative to admission' review is carried out. This is like a Care and Treatment Review and involves Experts by Experience and clinical experts, along with the current clinical team to look at what alternatives can be put in place for care and treatment in the community. If somebody needs an admission then the review process will identify the aims of admission, care pathway and planned discharge date. The protocol will ensure that commissioners are being made aware of people who are at risk of admission in their local area, have oversight of all admissions and that following an admission, there is a review of the care pathway and tracking of progress towards discharge.

### **Local planning and commissioning**

14. Local areas are expected to have locally agreed joint plans in place to support high quality care and ensure that a new generation of inpatients does not take the place of people currently in hospital. The Concordat highlighted that pooled budgets are likely to facilitate more integrated care arrangements.

*'Pooled budgets with shared accountabilities are likely to facilitate the development of more integrated care. They may help overcome the lack of strong financial incentives on a single commissioner to invest in community services (e.g. where the cost of investment in supported living in local communities falls to councils while savings from reduced reliance on hospital services go to NHS commissioners),'* *Transforming Care*, p. 25.

15. As part of the Department of Health's *Transforming Care* programme, the Joint Improvement Programme (JIP) is led by the Local Government Association (LGA) and NHS England. The JIP team have supported a series of regional workshops, including over 20 joint commissioning workshops bringing together local authorities, Clinical Commissioning Groups (CCGs) and Specialised Commissioners to identify the barriers to change and facilitate collaborative working and problem solving at a local and regional level. This joint approach is fundamental in ensuring the establishment of well-functioning systems of working and is something the programme will be building on going forward.
16. Whilst some CCGs and local authorities are making good progress on local joint commissioning arrangements, this is not consistent across the country and some parts of the country have a better range of community support options and less patients placed in hospitals than others. The Specialised Commissioning teams, located in NHS England, hold the budget and responsibility for about half of patients in hospital settings.
17. The work that has gone on means that there is now a much more detailed understanding of the barriers to progress, and there is continued work across the partnership to resolve ongoing 'national' issues, including looking at how the money can follow the person in order to equip localities to develop the community-based capacity needed. More locally, the critical steps are to develop person centred plans for people, in partnership with individuals, and get community provision right at the local level. NHS England will help to drive this change through the NHS England planning guidance 'The Forward View Into Action: Planning for 2015/16'<sup>5</sup>, which includes an expectation that CCGs (and Specialised Commissioning Teams) will improve their position in terms of the number of patients being admitted and discharged from hospital and the quality of care being provided.

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<sup>5</sup> <http://www.england.nhs.uk/wp-content/uploads/2014/12/forward-view-plning.pdf>. Technical guidance is published here: <http://www.england.nhs.uk/wp-content/uploads/2014/12/plan-guid-nhse-annx-231214.pdf>

This is a transformational programme: it's about changing a whole system and established way of working and embedding a completely new approach. That is taking time. There are challenges – finding ways to move money around the system, establishing the right skills base to support people with very complex needs in the community and unpicking a commissioning landscape that is currently very fragmented. We also want to work in a way that brings families and individuals with us, where we can build trust and ensure the right outcomes for individuals. To ensure sustainability in approach we need to be careful that we don't run to meet the target and completely miss the point.

To have a real high-level focus on people with learning disabilities in this way, locally and nationally, is one positive to come of out something so horrific. It has acted as a lever for change but the challenge will be how we ensure that we keep that pressure on. *From Lesley Singleton, Head of Mental Health & Learning Disabilities, Cheshire West & Chester Council & West Cheshire Clinical Commissioning Group.*

18. Health and Wellbeing Boards have a role to provide leadership by ensuring that there is strong integrated local health and care commissioning and housing support, and encourage the use of pooled budgets. The JIP has worked with the NHS Confederation to produce a guide for Health and Wellbeing boards [Health and wellbeing boards: leading local response to Winterbourne View](#). Alongside this, NHS England is encouraging Specialist Commissioning teams to work collaboratively with local commissioners to make change happen.

### Improving people's rights

19. Despite a huge amount of effort to try to transform the lives of people with learning disabilities and autism, the scale or pace of change for individuals that we all wanted to see has not yet been delivered. The report by Sir Stephen Bubb [Winterbourne View - A Time to Change](#) (2014) made clear that there is a need to ensure the rights that people have are made real in practice and are given effect in the processes and at the points when they matter most to people, for example, at the point of admission to inpatient settings. Many people with learning disabilities reported variable lived experience, lack of access to the rights they have, lack of access to the support needed to exercise rights and in some cases, doubts about whether rights are being respected as originally intended.
20. In response to these findings and, building on learning from work over the past two years, we are determined to make a difference for people and their families in the decisions about admission and discharge from hospitals. As a result, we are committed to exploring what else we can do to improve people's rights in these situations, with the aim of improving their inclusion and promoting their independence.
21. The JIP set up and facilitated an engagement strategy group of Experts by Experience, self-advocates, family carers and others in order to help ensure that people with direct experience are informing and shaping the agenda at a local and national level. We remain

committed, as a programme, to joint working with individuals and families, and strengthening the voice of people and families locally.



## Chapter 2 – Strengthening accountability and corporate responsibility

### **Stronger accountability and responsibility of providers, and their management, for quality of care**

22. When things go wrong it is recognised that individuals and families often do not know who to hold to account. This chapter sets out our arrangements to ensure accountability for delivering the programme and describes work we have done to support more robust accountability in organisations that provide care.

#### **Holding partners to account for *Transforming Care* delivery**

23. The cross-Government Learning Disability Programme Board (LDPB) has continued to provide an overview of delivery across learning disability-related activity with representation from senior representatives throughout Government and the health and care system. For a full list of the LDPB's membership, see appendix 3. To see a diagram of how the LDPB and TCAB work, see appendix 4.

24. Accountability has been strengthened by establishing the Transforming Care Assurance Board (TCAB), chaired by Norman Lamb, Minister of State for Care and Support and Gavin Harding MBE to oversee progress. The TCAB has self-advocates and family representatives to ensure that their perspectives are central to our work. For a full list of the TCAB's membership, see appendix 5.

25. Board papers for both the TCAB and the LDPB are available online and can be accessed at:

<https://www.gov.uk/government/groups/transforming-care-assurance-board>

<https://www.gov.uk/government/groups/learning-disability-programme-board>

26. Under the terms of the Health and Social Care Act 2012, DH agrees a mandate each year with NHS England. The mandate in 2013-14<sup>6</sup> included the objective for NHS England set out below and this continues in 2015/16:

*'to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high*

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<sup>6</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/256497/13-15\\_mandate.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256497/13-15_mandate.pdf)

*quality care in the community. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people.'*

27. DH also has a mandate with Health Education England (HEE) which sets out that HEE will work with the DH, providers, clinical leaders, and other partners to improve the skills and capability of the workforce to respond to the needs of people with learning disabilities and challenging behaviour. HEE will also work with partners to encourage and promote access to programmes of education and training which support the aims and objectives of the Positive and Safe programme which is focused on minimising the use of restrictive practices in health and care (see chapter 4, paragraph 61 for further information).

### **Holding organisations to account**

28. *Transforming Care* identified a key concern that leaders of organisations were not being fully held to account for poor quality or for creating a culture where neglect and abuse can happen. The Francis Inquiry report<sup>7</sup> also raised concerns about corporate accountability which apply to health and care settings. *Hard Truths*<sup>8</sup>, the final Government response to the Francis Inquiry report, noted that the public has the right to expect that people in leading positions in NHS organisations are fit and proper persons, and that where it is demonstrated that a person is not fit and proper, they should not be able to occupy such a position.

Transforming care is about a change in culture, not accepting failure, not accepting “good enough” but expecting more from ourselves as professionals, critically reflecting on our practice, and further reflecting on the impact of the organisations we work for on people with learning disabilities and autism and families. *From a local commissioner for learning disability.*

29. To strengthen powers for holding organisations to account for failures to provide quality care, **a new duty of candour** came into force for NHS bodies on 27 November 2014 and will be extended to all providers registered with the Care Quality Commission (CQC) from April 2015. The duty of candour has been designed to foster an open and transparent culture throughout organisations and to make providers accountable to patients and their families/carers for being open with service users when a specified safety incident has occurred. The CQC will be able to take enforcement action against the provider, and in certain circumstances its board and senior management<sup>9</sup>, where breaches of the duty of candour have been found.

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<sup>7</sup> *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*: (2013) London: The Stationery Office <http://www.midstaffpublicinquiry.com/report>. Also see <http://www.midstaffpublicinquiry.com/> for a range of information and links to documents.

<sup>8</sup> Department of Health, *Hard Truths: The journey to putting patients first*: (2014) London: The Stationery Office <https://www.gov.uk/government/publications/mid-staffordshire-nhs-ft-public-inquiry-government-response>

<sup>9</sup> Where a provider has not notified person of a relevant safety incident or has not done so in line with the process set out in the regulations, and a senior manager or director is proved to have consented or connived in that breach.

*'When failure occurs, repercussions should be felt at all levels of an organisation. Through proposed changes to the regulatory framework, we will send a clear message to owners, Directors and Board members: the care and welfare of residents is your active responsibility, so expect to be held to account if abuse or neglect takes place,'*  
*Transforming Care, p.5.*

30. Further, a **new fit and proper person's test** for Board-level appointments came into effect from November 2014 for NHS providers in NHS Trusts, foundation trusts and special health authorities. All other providers will be expected to comply with this by April 2015. The test includes the need for a Director to have a good character, to have a relevant employment history, to be capable of undertaking the relevant position, after any reasonable adjustments have been made, and to not have been involved in serious misconduct or mismanagement while undertaking a regulated activity. Where a Director is considered by the CQC to be unfit it can either refuse the provider's registration in the case of a new provider, including requiring them to apply the duty correctly, with the consequence that an unfit Director would be removed.
31. From April 2015, all providers of health and adult social care must meet new fundamental standards which set out the line below which care must never fall. The CQC will use the fundamental standards as part of its inspections of providers, and will take enforcement action where breaches are found. Where providers fail to meet some of the fundamental standards, and these failures lead to avoidable harm or the significant risk of such harm, the CQC can bring a prosecution without the need to issue an advance warning notice. In the most serious cases, an organisation could have its CQC registration removed and so effectively be shut down. Prospective providers who cannot demonstrate that they can meet the fundamental standards will not be granted registration.
32. The introduction of the forthcoming statutory offences of ill-treatment or wilful neglect will also send a clear message throughout the health and care system that intentionally poor care will never be tolerated. At present, prosecutions for a statutory offence of ill-treatment or wilful neglect can only occur in respect of certain cases, such as mental health care, where a person lacks mental capacity, and in relation to children in certain circumstances. These two new offences, one for individuals and one for organisations, will ensure that prosecutions can be followed for offences taking place across all healthcare settings. This is not about punishing healthcare staff who make honest mistakes; we are committed to promoting a learning culture across the NHS where staff and organisations are supported to learn from unintended errors to improve the safety of services for patients.

### **Quality of Care and Leadership of Boards**

33. Owners, Boards of Directors and senior managers of organisations which provide care are responsible for ensuring the quality and safety of their services. This includes safe recruitment practices, training for staff on how to support people with challenging

behaviour, good management and supervision, leadership, good governance systems and providing good information to support people making choices about care and support.

34. Alongside the changes to introduce the duty of candour and fit and proper person's test, the National Skills Academy for Social Care (NSA) has developed a number of resources<sup>10</sup> to support social care providers to improve their leadership skills, including:

- a one day programme for Boards based on the NSA's Leadership Qualities Framework for Adult Social Care which covers topics such as understanding and using financial information, a personal qualities self-assessment, quality assurance and social care values
- an on-line programme to address Board Member and Trustee development
- the NSA is planning to update its Leadership Qualities Framework for Adult Social Care in 2015 following a survey in 2014.

### **Criminal checks**

35. Following DH's commitment in *Transforming Care* to review registration requirements about criminal record checks, a new portable service for criminal record checking has been introduced by the Disclosure and Barring Service (DBS). This allows individuals to choose to register for a service which keeps their DBS certificate up-to-date and also makes it easier for people to move between regulated jobs or to work and volunteer at the same time, and allows employers to easily check for changes.

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<sup>10</sup> <https://www.nsocialcare.co.uk/programmes>

## Chapter 3 – Tightening regulation and inspection

### Tighter regulation and inspection of providers.

36. As the organisation responsible for the regulation and inspection of health and adult social care services specified by the Health and Social Care Act 2008, the CQC has a critical role in ensuring that registered providers deliver safe, high quality care to people with challenging behaviour and, where this is not happening, that swift enforcement action is taken to protect people. This chapter sets out the rigorous programme implemented by the CQC to change the way it inspects all registered health and social care services and improve systems and checks when providers apply to register for a service.

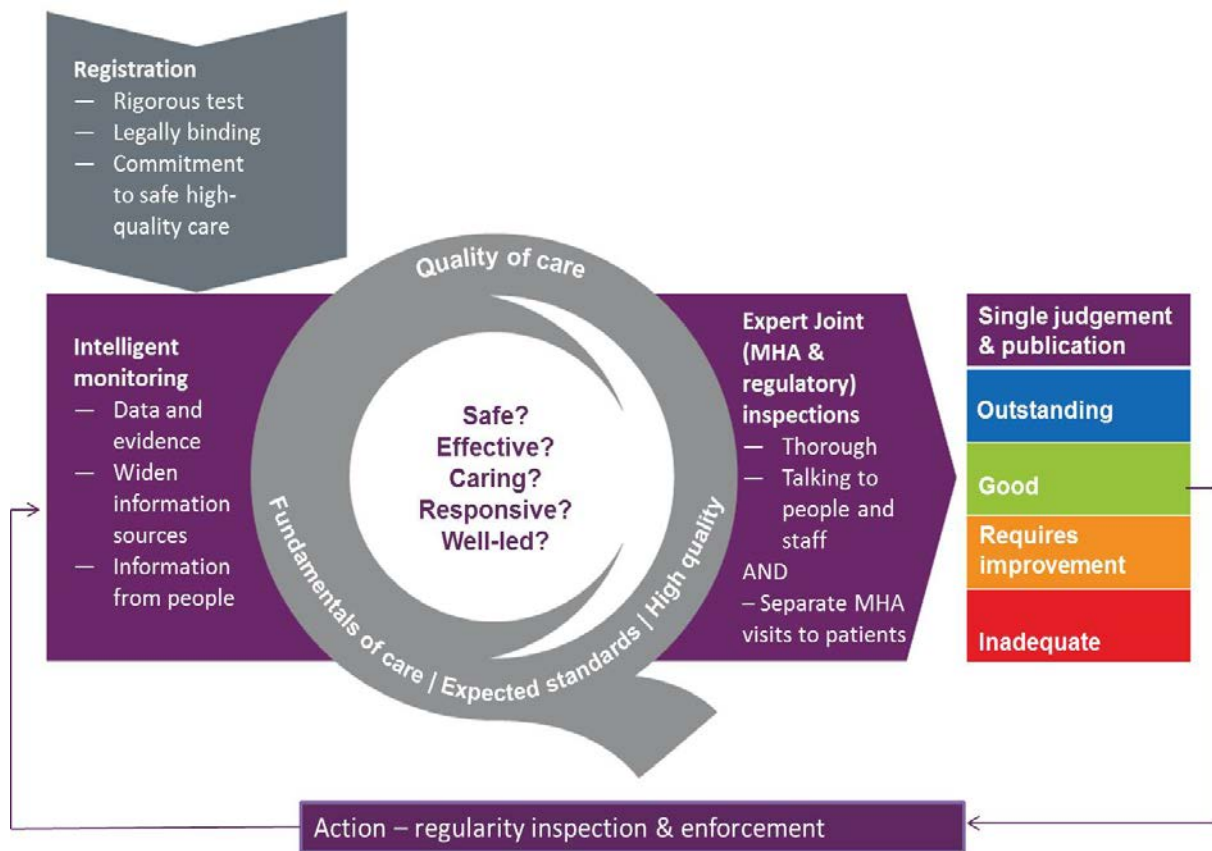
*'What happened at Winterbourne View raised profound questions about how regulation and inspection was working,' Transforming Care, p.36.*

### New approach to inspections

37. From April 2014, the CQC introduced a new approach to inspecting learning disability hospitals and specialist health services. From October 2014 all mental health hospital services will be judged and rated as either inadequate, requires improvement, good or outstanding. This approach was developed with professional bodies and regulators and through consultation with people with learning disabilities, family carers, clinical experts, voluntary support organisations, providers, professional bodies and regulators. Most inspections are announced but always include some unannounced and out-of-hours visits. The CQC continues to conduct unannounced, focused or comprehensive inspections of all service types to follow-up concerns, and in response to information from a wide range of sources including intelligent monitoring data, concerns raised by people using services and their carers, and whistleblowing.

38. CQC inspections of all health and social care services now ask five key questions: is the service safe, effective, caring, responsive and well-led? Evidence is gathered in a variety of ways to inform judgements about these five questions. Inspection teams use key lines of enquiry to organise evidence gathering and report their findings. After the inspection, a meeting is held between the CQC, the provider, partner organisations and commissioners to discuss the findings, agree actions and ensure that stakeholders are aware of any breaches of the regulations and that providers are held to account.

Figure 2 - Diagram of CQC's new approach to inspection:



39. For a written description of figure 2, refer to appendix 7.

40. In line with the CQC's strategy for 2013-16, the views of people using services including families and carers are central to all inspection activity. The CQC's fifth State of Care report<sup>11</sup> was published in September 2014 and describes how the CQC will look at how providers respond to whistle-blowers in every inspection as part of its consideration of whether the organisation is well led. The report includes case examples of regulatory action taken as a result of whistleblowing to the CQC.

41. The CQC has also reviewed the way it uses information about complaints and concerns. Embedding complaints and concerns in the CQC's regulatory model has two aims: to improve how it uses the intelligence from concerns and complaints to better understand quality and to look at how well providers handle complaints and concerns to encourage improvement. More detail is available in the December 2014 report 'Complaints Matter'<sup>12</sup>.

<sup>11</sup> <http://www.cqc.org.uk/sites/default/files/state-of-care-201314-full-report-1.1.pdf>

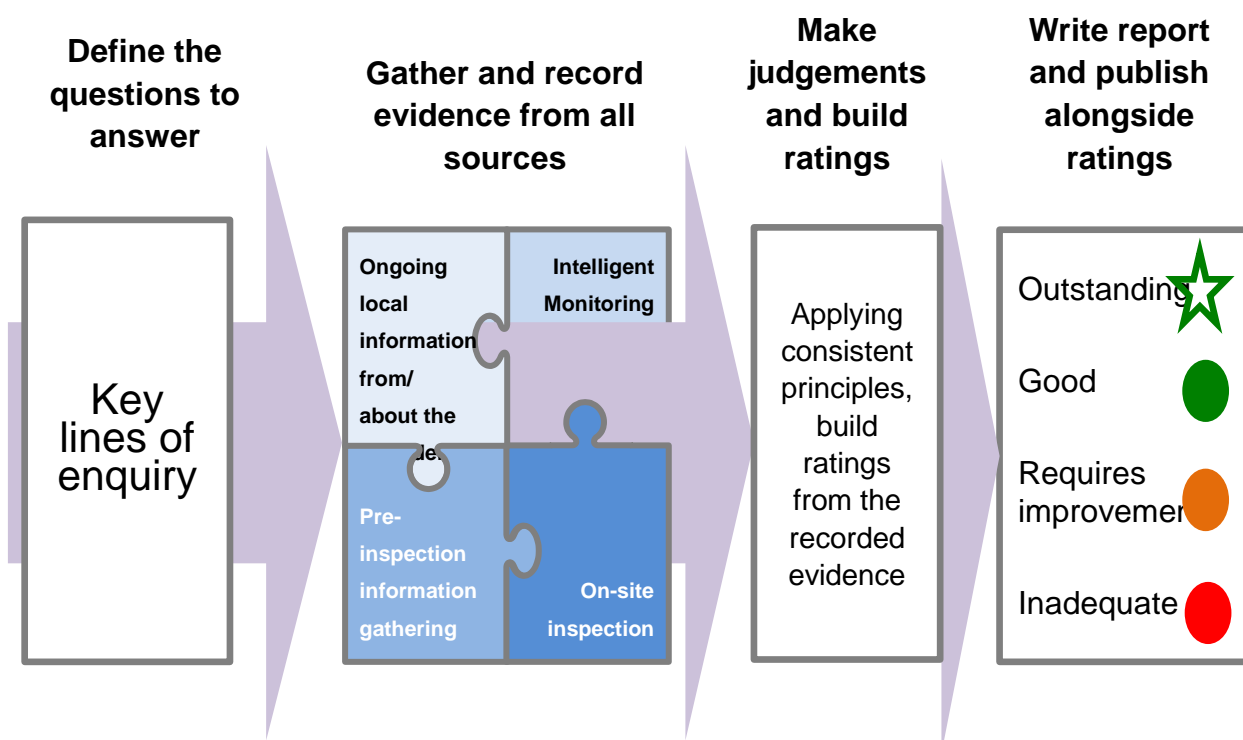
<sup>12</sup> [http://www.cqc.org.uk/sites/default/files/20141208\\_complaints\\_matter\\_report.pdf](http://www.cqc.org.uk/sites/default/files/20141208_complaints_matter_report.pdf)

42. Most inspection teams include Experts by Experience (including family members) and clinical experts as well as CQC inspectors. Clinical experts are recruited from a range of professional backgrounds and are selected on the basis of the relevance of their expertise to each inspection.

My opinion of the new ways of working on inspections is far better than when we used the old outcomes. This is because the 5 key question headings are easier to focus on and make better sense. I have found that I can get more real quotes from people and from my observations and I don't know why but people seem to be able to tell me more than they did with the questions we used with the old outcome.  
*From Stephen Merriman, an Expert by Experience.*

43. Since October 2014, the CQC has published ratings on a four-point scale covering outstanding, good, requires improvement or inadequate. The expectation is that these ratings will help to provide people with accessible information about the quality and safety of services allowing them to make informed choices.

Figure 3 - Diagram to show the ratings process:



44. For a written description of figure 3, refer to appendix 7.

45. The CQC has also worked with an expert group of professionals, people who use services, family carers and CQC staff to co-produce separate guidance for inspection teams looking at specialist health provision for people with learning disabilities. This requires inspection teams to ask questions about issues such as restrictive practices, discharge arrangements, the distance people using the service are from their home addresses, involvement of families and carers, and access to good quality independent

advocacy. A registration programme for the registration of new learning disability services has helped the CQC to make informed judgements about whether a service has the potential to deliver good quality, safe and effective care, and whether the overall model of care was consistent with that described in *Transforming Care*.

## **Enforcement action**

46. The CQC has a responsibility to take enforcement action where poor quality, unsafe care is provided and has powers to restrict the provision of these services or cancel the registration of these services. The range of sanctions available to the CQC will increase, affecting all registered providers from April 2015.

47. The role of the registered manager is an important one in making a difference to people's experiences of care. The CQC ran a project from November 2013 to April 2014 to reduce the number of locations operating without a registered manager. The CQC issued 590 fixed penalty notices to providers of locations where there had been no registered manager for six months or more and the provider had not submitted a reasonable explanation. A high proportion of these providers responded without the need for further action and 42% paid a fixed penalty notice. By May 2014, 57% of the 2439 targeted locations had put a registered manager in place and a further 20% had submitted applications to register. Post-May 2014, all cases (such as the 9% awaiting further reviews) were handed over to operations staff as part of 'business as usual' and are being tracked individually. A full evaluation of the project can be accessed at: [http://www.cqc.org.uk/sites/default/files/cm051406\\_item\\_6\\_asc\\_board\\_report.pdf](http://www.cqc.org.uk/sites/default/files/cm051406_item_6_asc_board_report.pdf)

48. The CQC also has a key role in sharing information, data and details it has about prospective providers with the relevant CCGs and local authorities. Registration inspectors may contact commissioners about new registration applications, especially if there are concerns that the care which is intended to be provided may not be consistent with best practice. The CQC reports that this has so far proven to be an effective approach; for example, in the case to refuse the registration for a new assessment and treatment unit, the CQC issued a notice of proposal to refuse a registration application for an in-patient facility for people with learning disabilities because of concerns that the model of care was not consistent with *Transforming Care*. The provider subsequently withdrew their application and the CQC accepted their withdrawal.

49. The CQC has also taken enforcement action against providers that do not operate effective recruitment procedures to ensure staff are suitably skilled, of good character and legally entitled to do the work in question. The CQC issued 141 compliance actions in 2014 in relation to the regulation covering recruitment and selection of staff in learning disability services. 11 warning notices were served.



## Chapter 4 – Improving quality and safety

**Improved quality and safety so that there is better understanding of good practice on positive behaviour support and the environment so that challenging behaviour and the need for physical restraint are reduced. There is an emphasis on not over-using antipsychotic and antidepressant medicines for the patient.**

I think I talk for a lot of the parents when I say that nothing has improved since the Winterbourne View scandal. A small sum of money was given to Respond for the families to get help but this came far too late and people couldn't afford to attend the family support days for long, if at all.

The people that resided at Winterbourne were not properly monitored after they left, I know, my Son went into another abusive placement which is now another police investigation. Only a very sporadic weekly music therapy session has been what my Son has been offered to help him deal with the trauma of both of these placements.

The only positive thing I can say has happened has been the fact that the families themselves feel they have a deep understanding of each other's feelings and they have been there for each other since they were able to get to know each other, some through the support days that they could make. *From Claire, mum of Ben.*

*This case shows that for some individuals and families, there are still challenges in making sure they are getting the right support.*

50. Responsibility for providing good quality care rests with providers. However, we recognised in *Transforming Care* that there were a number of national and local actions needed to ensure better quality of care. This chapter covers work delivered by a range of partners to ensure this happens.

### Best practice

51. The JIP has shared learning and good practice across area partners through peer-to-peer learning and support, and the publication and dissemination of tools and guidance. This includes a core principles guide to commissioning services [Ensuring quality services for children and adults with behaviour that challenges](#) and publication of case studies outlining area approaches to *Transforming Care*<sup>13</sup>.

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<sup>13</sup> [http://www.local.gov.uk/place-i-call-home/-/journal\\_content/56/10180/6445827/ARTICLE](http://www.local.gov.uk/place-i-call-home/-/journal_content/56/10180/6445827/ARTICLE)

52. The National Institute of Clinical Excellence (NICE) published a quality standard on the mental wellbeing of older people in care homes in December 2013<sup>14</sup> and is planning to publish a quality standard on challenging behaviour and learning disabilities in October 2015. NICE is currently developing new clinical guidelines on challenging behaviour and learning disabilities for publication in May 2015 and on mental health problems in people with learning disabilities for publication in September 2016. These guidelines will provide clarity about what constitutes good practice and should provide a helpful and influential source for health and care staff, providers and commissioners.

### **Improving safeguarding**

53. The Care Act which comes into force this April places Safeguarding Adults Boards on a statutory footing. This is to strengthen accountability, information sharing and a framework for action by all partners to protect adults from abuse. Local authorities, NHS and police (and any other agency deemed appropriate) will need to work together to develop and implement adult safeguarding strategies and conduct safeguarding adult reviews in serious cases. Local authorities will have a lead role in co-ordinating safeguarding activity with a responsibility to ensure enquiries are made into cases of abuse and neglect.

54. The Department for Education (DfE) has recently launched a consultation on certain revisions to the statutory guidance, [Working Together to Safeguard Children](#), to provide advice for organisations, agencies and individuals working with children to safeguard and promote their welfare. DfE plans to publish the revised guidance in March this year.

### **Applying protections of the Mental Health Act and the Mental Capacity Act**

*'Some of the people we met said they and their families were given little say in where they were sent. This does not fit with the principles of personalisation in the NHS Constitution or the principles of the Mental Health Act 1983 and Mental Capacity Act 2005,' Transforming Care, p.43.*

55. The CQC has aligned its statutory monitoring of the Mental Health Act 1983 with its comprehensive inspection of mental health and learning disability services. The Key Lines of Enquiry, developed as guidance for inspection teams and providers, include specific lines of enquiry about the provider's compliance with the Mental Health Act 1983 and the Mental Capacity Act 2005. This ensures every inspection considers how people's liberty is being restricted and checks that providers are acting within the law. The CQC's judgements about how effective and well-led an organisation is are directly affected by how well the provider protects people using the Acts.

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<sup>14</sup> <http://www.nice.org.uk/guidance/qs50>

56. The proposed Mental Health Act 1983: Code of Practice currently before Parliament has been updated to reflect changes in legislation, policy, case law and professional practice. A number of the changes are part of our approach to addressing concerns for individuals subject to the Mental Health Act 1983, including those who have a learning disability. These include:

- updating the guidance on supporting individuals with learning disabilities and autism and on the learning disability qualification
- five new Guiding Principles for ensuring people are placed in the least restrictive setting, care and treatment is focused on recovery and is therapeutic, and service users and their families are involved in decisions about their care and treatment and are treated with dignity and respect
- clarified what professionals need to do to be compliant with the Code;
- confirmed that the CQC will inspect against the Code about what good practice is (see chapter 3 paragraph 37)
- clarified what individuals can do if they feel the Code is not being applied appropriately
- ensuring patients can be more involved in decisions that affect them, including having information in formats that they understand (e.g. easy read), having access to independent mental health advocates (IMHAs), ensuring staff, including IMHAs, those on tribunals and on hospital managers panels are trained in supporting individuals with a learning disability, autism or behaviour that can be considered challenging;
- enabling patients and their families to have a greater say in where they wish to be located e.g. close to home or family
- clarified when the Mental Health Act 1983 should be used and when the Deprivation of Liberty Safeguards (DoLS) should be used
- confirmed that blanket restrictions should not be applied at ward or hospital level, or to particular groups of patients, unless these can be justified
- promoted the maintenance of family and carer relationships e.g. through visits and use of mobile phones, electronic devices and the internet
- included a new chapter and additional guidance throughout the Code to promote human rights and equality
- updating guidance on the use of restraint, seclusion and long term segregation, including supporting the approach in DH's guidance *Positive and Proactive Care* (see paragraph 64) to promote the use of positive behaviour support and de-escalation techniques, and reconfirming that any form of restraint should only be a last resort, not involve pain and be for the shortest possible period
- providing additional guidance on the involvement of service users, their families, carers and advocates in reviews and decisions about discharge, continued detention or community treatment, including in 'uncontested cases'
- including additional safeguards in relation to decisions about discharge to promote greater transparency and accountability and to enable greater scrutiny by hospital managers of clinical decisions

- making it clear that reviews must take place and that not having these in the required time frame before a period of detention expires (often called 'defacto detention') can be considered an illegal deprivation of liberty.

57. In relation to mental health services, the CQC has committed that the proposed Mental Health Act 1983: Code of Practice will be the starting point for the CQC's rating system and will help identify what constitutes good practice in the care and treatment of people subject to the Mental Health Act 1983. Where the principles and guidance of the Code are not implemented, the CQC may use its regulatory powers to facilitate change and improvement in local services as a failure to apply the Act and the Code may show a breach of one of the registration requirements.

58. We are committed to embedding the Mental Capacity Act (MCA) 2005 across work programmes as the MCA is central to providing safe care and improving quality. We have drawn up a programme of work: *Valuing every voice, respecting every right* which sets out a system-wide programme of work in 2015 to see a real improvement in implementation of the MCA.

59. In November 2014, DH and the Ministry of Justice (MoJ) announced a national forum with an independent chair to advocate for, and raise awareness of, the MCA. It will make the links between different sectors where better implementation of the MCA will realise real benefits for individuals.

60. DH has commissioned the Social Care Institute of Excellence (SCIE) to undertake a review of current guidance and tools to determine what represents the 'gold standard' that can then be widely disseminated to professionals working with individuals who may lack capacity so that they can familiarise themselves with the provisions of the MCA.

61. We will take a comprehensive approach to promoting implementation. Professional training is a priority and the Government, together with HEE and the Royal College of General Practitioners, have identified immediate actions. NHS England and the Association of Directors of Adult Social Services (ADASS) have committed to lead on work examining the important role that commissioning has to play in encouraging a culture in keeping with the principles of the MCA.

62. DH continues to work closely with the CQC to agree how best to raise awareness of, and ensure compliance with, the MCA and the Deprivation of Liberty Safeguards (DoLS) provisions to protect individuals and their human rights. Updates on DH/CQC activity on DoLS were reported via the annual CQC Monitoring Report on DoLS<sup>15</sup> (January 2014) and through the Government response to the House of Lords (June 2014)<sup>16</sup>. The CQC

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<sup>15</sup> [http://www.cqc.org.uk/sites/default/files/documents/dols\\_2014.pdf](http://www.cqc.org.uk/sites/default/files/documents/dols_2014.pdf)

<sup>16</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/318730/cm8884-valuing-every-voice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/318730/cm8884-valuing-every-voice.pdf)

has greatly increased the emphasis on MCA-DoLS in its new inspection regime. Better training of CQC inspectors on the MCA is well underway.

63. The JIP has, in partnership with the Care Provider Alliance, commissioned guidance for providers of community services and a briefing paper aimed at members of care providers' boards to support providers to apply the MCA in the right way. These documents are aimed at helping to ensure that the legal rights of those who may lack capacity are upheld and that the individual is at the heart of decision-making. They can be accessed at:

*Mental Capacity Act 2005: a brief guide for providers of Shared Lives and other community services:*

[http://www.local.gov.uk/documents/10180/6869714/L14-393+MCA+guides\\_09.pdf/e95b1230-88b3-44dc-8cb9-4672c5d1ce3d](http://www.local.gov.uk/documents/10180/6869714/L14-393+MCA+guides_09.pdf/e95b1230-88b3-44dc-8cb9-4672c5d1ce3d)

*Care Providers and the Mental Capacity Act 2005: advice for members of care providers' boards:*

[http://www.local.gov.uk/documents/10180/6869714/L14-491\\_Care+providers+and+the+MCA+2005\\_09.pdf/42453612-dcf4-4287-ae2f-7d38df8f98d4](http://www.local.gov.uk/documents/10180/6869714/L14-491_Care+providers+and+the+MCA+2005_09.pdf/42453612-dcf4-4287-ae2f-7d38df8f98d4)

*Mental Capacity Act 2005: An easy read guide:*

<http://www.local.gov.uk/documents/10180/12137/ntal+Capacity+Act+2005+easy+read+guide/38683f88-4b96-49d6-86ab-89b2404d2e7a>

## **Positive behavioural support and the minimisation of restrictive practices**

*'The CQC inspections revealed widespread uncertainty on the use of restraint, with some providers over-reliant on physical restraint rather than positive behaviour support and managing the environment to remove or contain the triggers which could cause someone to behave in a way which could be seen as challenging. In Winterbourne View, bullying, punishment and humiliation were disguised as restraint,' Transforming Care, p.44.*

64. Following a commitment in the Concordat, DH published [Positive and proactive care: reducing the need for restrictive interventions](#) in April 2014. As part of their inspections, CQC considers how providers are taking account of this guidance. The guidance will be complemented by specific guidance for children and young people, due to be published this year. The guidance is part of a suite of information setting the foundation for a broader new programme *Positive and Safe* which the DH started in 2014, focused on strengthening other levers to effect change. Other key documents which complement this have already been published by NHS Protect or are forthcoming by NICE and others. Skills for Care and Skills for Health also published a complementary guide for workforce development: [A Positive and Proactive Workforce](#).

65. At the moment we are not able to routinely collect data on the use of restraint. We are working with the Health and Social Care Information Centre (HSCIC) to agree a single definition of restraint and to expand the detail of what is routinely published in this area from 2016. In the meantime DH intends to publish a snapshot report on data about use of restraint in spring 2015.

### **Addressing the use of medication**

66. The Winterbourne Medicines Programme was formally launched in April 2014 by Dr Keith Ridge (Chief Pharmaceutical Officer) and is made up from three initiatives which was agreed by a wide range of stakeholders. Firstly, NHS England and NHS Improving Quality worked in partnership to launch the Winterbourne Medicines Programme (collaborative), with the aim to ensure safe, appropriate and optimised use of medication for people with learning disabilities whose behaviour can challenge. NHS Improving Quality are currently working with six project sites and other interested parties and a "community of practice" to improve care. Secondly, NHS England asked CQC to audit medication data related to the "Second Opinion Authorised Doctor" requirement. Thirdly, NHS England commissioned research using Clinical Practice Research Datalink to examine use of antipsychotic, antidepressant, and anxiolytic medication in people with learning disabilities in primary care. The results and learnings from this overview of current practice provides an evidence base and will be shared and built into an ongoing programme of action to optimise use of medication in people with learning disabilities, as part of the *Transforming Care* Programme. More information can be found on the Winterbourne Medicines Website at: [www.nhs.uk/winterbourne](http://www.nhs.uk/winterbourne). The community of practice can be accessed at: [www.6cs.nhs.uk](http://www.6cs.nhs.uk).

### **Improving information, advice and advocacy**

*'It is clear that there is a wide variety in the quality and accessibility of information, advice and advocacy, including peer advocacy and support to self-advocate,' Transforming Care, p.45.*

67. DH committed to working with advocacy organisations to drive up the quality of advocacy organisations and ensure that advocacy is person centred. A third edition of the Advocacy Quality Performance Mark (QPM) was launched in 2014. The QPM works in conjunction with the Advocacy Code of Practice<sup>17</sup>, enabling providers to demonstrate how they are meeting the different standards set out in the code. 39 organisations currently hold the QPM and 92 organisations are working towards QPM in its new guise.

68. In February 2014, the CQC hosted the Three Lives event. The event invited colleagues, including family carers to hear the experiences of three individuals with learning

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<sup>17</sup> <http://www.qualityadvocacy.org.uk/wp-content/uploads/2014/03/Code-of-Practice.pdf>

disabilities who were failed by services. The report<sup>18</sup> by the CQC and the Challenging Behaviour Foundation outlines the actions identified at the meeting and describes how it fits with the wider programme of work under way, including *Transforming Care*.

69. A follow-up legal focus group was held in September 2014 and considered what legal opportunities may have been missed in the Three Lives case studies and made recommendations for action to include legal advice for people with learning disabilities and their families. We are looking at their findings alongside other proposals for legislative reforms.
70. The Care Act 2014 and its associated Regulations<sup>19</sup> and Statutory Guidance<sup>20</sup> aims to strengthen the voice of people who use services and their carers in their care and support arrangements. From April 2015, local authorities will be required to arrange an independent advocate to facilitate the involvement of a person in their assessment, in the preparation of their care and support plan and in the review of their care plan, if the following two conditions are met:
- the person has substantial difficulty in being fully involved in these processes
  - there is no one appropriate available to support and represent the person's wishes.
71. DH has commissioned the SCIE to develop a range of resources to help local authority staff and commissioners to expand and commission effective independent advocates and advocacy services, which can be accessed on the SCIE's website:  
<http://www.scie.org.uk/>.
72. Local Healthwatch are now up and running across England and examples of how they are engaging with people with learning disabilities to understand their experiences of health and care include training people to undertake 'enter and view' visits to local services, as well as working with local partners that represent this population group to ensure their views are captured and reflected. Healthwatch England is continuing to support local Healthwatch in engaging with people with learning disabilities by ensuring that these examples are shared across the network. It is working with Mencap to produce a new toolkit that will enable local Healthwatch to draw on best practice and encourage those that have not yet engaged with this group to consider doing so. This will be available shortly.

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<sup>18</sup> CQC and Challenging Behaviour Foundation (2014) *3 Lives: what we have learned, what we need to do*, CQC.  
<http://www.cqc.org.uk/content/3-lives-report>

<sup>19</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/376204/2903119\\_Care\\_Act\\_Negative\\_Regulations\\_Master.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/376204/2903119_Care_Act_Negative_Regulations_Master.pdf)

<sup>20</sup> <https://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation>

*'While stronger regulation and inspection, quality information and clearer accountability are vital, so too is developing a supportive, open and positive culture in our care system,' Transforming Care, p.5.*

## Workforce

*'The events at Winterbourne View highlighted that there are too many front-line staff who have not had the right training and support to enable them to care properly for people with challenging behaviour. This is a theme which has been reinforced by many of the families we have heard from,' Transforming Care, p.39.*

73. During 2014, we have seen a great deal of activity to provide guidance and support for local providers and health and care professionals to improve practice and a number that are specifically aiming to support working with people with challenging behaviour.

74. HEE continues to play its part in fulfilling *Transforming Care* and Concordat commitments. HEE has worked with DH, providers, clinical leaders, and other partners to improve the skills and capability of the workforce to respond to the needs of people with learning disabilities and challenging behaviour. Also, with partners to encourage and promote access to programmes of education and training which support the aims and objectives of the Positive and Safe programme. Examples include:

- as recommended by Camilla Cavendish in her independent review into healthcare assistants and social care workers, and following extensive debate during the passage of the Care Bill, a care certificate for support workers in health and social care will be rolled out from April 2015, replacing the National Minimum Training Standards and the Common Induction Standards<sup>21</sup>
- an E-Learning resource to support all health and care staff in providing compassionate care and modules for mental health assessors to apply the DoLs safeguards<sup>22</sup>
- a values based recruitment framework published in October 2014 for all universities that deliver NHS-funded programmes to ensure that individual values and behaviours align with that of the NHS Constitution.<sup>23</sup>

75. However, we recognise that delivering high quality care means we need to recruit and retain staff in specialist health and care teams, as well as ensuring staff working across all health and care settings are well trained across the range of providers providing care for people with challenging behaviour in the community and hospitals. We are inviting HEE to help lead this work.

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<sup>21</sup> <http://hee.nhs.uk/work-programmes/the-care-certificate/>

<sup>22</sup> <http://www.e-lfh.org.uk/programmes/deprivation-of-liberty-safeguards/>

<sup>23</sup> <http://hee.nhs.uk/wp-content/blogs.dir/321/files/2014/10/VBR-Framework.pdf>



76. The Learning Disability Professional Senate (LDPS) has worked to develop a collaborative approach across the professions and has published or supported the development of the following guides:

- The Royal College of Speech and Language Therapy document: [Five good communication standards - reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital or residential settings](#)
- The *Statement of Ethical Practice*<sup>24</sup>
- The Joint Commissioning Panel Guidance *Mental Health Services for people with learning disabilities* with the Royal College of Psychiatrists<sup>25</sup>
- The Royal College of Psychiatry report *People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services*<sup>26</sup>

77. In addition to the above, the LDPS has drafted and is seeking views on specifications of community teams which should help commissioners to achieve consistent high standards for the future and reduce reliance on institutional care. The final version is due to be agreed at the next LDPS meeting on 3 March this year.

78. In September, in partnership with Skills for Care and Skills for Health, the JIP launched a series of action learning sets to allow people with direct responsibility for supporting people with a learning disability and behaviour that challenges – either in supporting them to move home from an inpatient setting or to prevent admission in the first place – to learn from each other's experiences and to work together to put into place solutions for the individuals they are working with.

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<sup>24</sup> [http://www.rcn.org.uk/development/nursing\\_communities/rcn\\_forums/learning\\_disabilities/links/?a=600451](http://www.rcn.org.uk/development/nursing_communities/rcn_forums/learning_disabilities/links/?a=600451)

<sup>25</sup> <http://www.jcpmh.info/good-services/learning-disabilities-services/>

<sup>26</sup> <http://www.rcpsych.ac.uk/pdf/FR%20ID%2003%20for%20website.pdf>

# Chapter 5 – Monitoring and reporting on progress

**Transparent information and robust monitoring to deliver transformed care and support and to make sure the public, people with challenging behaviour and families know whether we are making progress.**

79. At the start of the *Transforming Care* programme the data about numbers of people with challenging behaviour in inpatient settings was weak. It has taken commitment from across a number of organisations including DH, NHS England, the CQC, the HSCIC, and Public Health England (PHE) to provide a baseline of data to understand what is happening nationally and locally. These are discussed in this chapter as well as further work we need to do to help commissioners to drive change at a local level and provide assurance at a national level that the work underway is having the right impact.

## Learning Disability Census

80. In *Transforming Care*, DH committed to commission an audit of current services for people with challenging behaviour to provide a snapshot of provision to enable a better understanding about what is happening. The Learning Disability Census has been established as a mandated collection under the Health and Social Care Act 2012 to provide information for the first time on people with learning disabilities and the outcomes they experience when using learning disability services. The Learning Disability Census 2013 established a baseline to monitor long term change and improvement. It was repeated in 2014. The published report can be accessed at:

<http://www.hscic.gov.uk/pubs/ldcensus14>

81. Key headline findings from the 2014 census are set out below<sup>27</sup>:

- The 2014 Learning Disability Census reported on 3,230 patients who met the inclusion criteria. The 2013 Learning Disability Census reported on 3,250 patients who met the inclusion criteria
- Figure 1 shows that 1,975 patients were receiving care at the time of both census collections. Of these, calculations suggest that 1,830 patients (57% of the 2014 head count) were receiving continuous inpatient care between both census collections. Analysis of admission dates for the 2014 Learning Disability Census indicated that there were 370 patients who had a first admission date (as part of a continuous period of

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<sup>27</sup> Note: all figures for 2014 are subject to suppression rules. All data less than 5 is replaced by \* and all numbers are rounded to the nearest 5. Due to rounding, some totals may not add up. Data for 2013 does not follow these rules as it was previously published in the unsuppressed format, prior to the new HSCIC suppression rules coming into force.

inpatient care) prior to the 2013 census. This suggested that they would have been receiving in-patient care at the time of the 2013 census and therefore that they were likely to have been eligible for inclusion in the census, but were not included by data providers

- Figure 2 shows that on census day, 2,585 patients (80%) were subject to the Mental Health Act (MHA), of which 1,460 patients (45%) were detained under Part II, 425 patients (13%) were detained under Part III without a restriction order; whilst 635 patients (20%) were detained under Part III and subject to Ministry of Justice restriction order
- The 2014 census asked a new question about the main treatment reason for a person remaining in inpatient care. Table 1 shows the results; the three most common reasons were:
  - Continuing need for inpatient care of mental illness (1,365 patients, 42%)
  - Continuing behavioural treatment programme (695 patients, 21%)
  - Current behaviour assessed as too risky for Ministry of Justice to agree any reduction in security level (485 patients, 15%)

These categories accounted for 2,545 patients (79%), all indicating some ongoing need for inpatient care

- Table 2 shows that on census day, 2,775 patients (86%) were recorded as being at risk of at least one of six behaviour traits. The behaviour with the most people recorded as displaying this behavioural risk was violence or threats of violence to others (2,310 patients, 72%)
- Between 2013 and 2014, there was a slight fall in the overall number of incidents recorded in the three months prior to census day. 1,450 patients (45%) did not have any incidents in the three months prior to census day in 2014 compared to 1,377 patients (42%) in 2013. Table 3 shows that during the three months prior to census day 2014, 64% of females (535) experienced at least one incident compared to 52% of males (1,245)
- Table 4 shows that the use of antipsychotic medication appears to have risen since 2013. There were 2,345 (73%) patients in 2014 receiving antipsychotic medication either regularly or through PRN ('Pro Re Nata' meaning 'as and when needed') or both in the 28 days prior to the census collection compared to 2,220 (68%) patients in 2013
- On census day in 2014, 2,320 patients (72%) were making use of an independent advocate, 715 patients (22%) did not use an advocate. For the remaining 190 patients (6%) the use of an independent advocate was unknown
- Length of stay looks at the amount of time spent in the current hospital from admission to census day on 30<sup>th</sup> September 2014. Figure 3 shows that in general the length of stay remained unchanged between the two censuses. Median length of stay for 2013 was 542 days and in 2014 it was 547 days
- The distance from home of a patient is calculated from their residential and hospital postcodes and in 2014, 570 patients (19%) were calculated to be more than 100km from home. Figure 4 shows that the profile of distances remained unchanged between 2013 and 2014
- The average weekly charge to the commissioner of the inpatients recorded in the 2014 census was £3,246. CCGs paid for 1,575 patients (49%); whilst NHS England paid for

1,395 patients (43%) directly through specialist commissioned services. Local authorities paid for 150 patients (5%); and just 20 patients were paid for by a pooled budget (1%). The remainder were paid for by either private funding, non UK commissioning or NHS commissioner outside England.

82. For the diagrams referred to above, see appendix 6.

### **Assuring Transformation data**

83. NHS England introduced the 'Assuring Transformation' quarterly data collection for all NHS Commissioners from January 2014. Each CCG and NHS Area Team responsible for specialised commissioning of secure mental health and child adolescent mental health services are asked to submit information. The data covers a range of key areas to track progress including the number of patients currently in inpatient care, whether they have been transferred, whether there is a planned date to transfer and the number of people that have been admitted to inpatient care in the last quarter. Refer to chapter 1, paragraph 6 for a summary of key messages from the latest available Assuring Transformation data.

84. It is important to recognise the following important differences between the datasets:

- the census is an annual collection which provides a snapshot of the number of people in a bed at midnight on 30 September irrespective of who has commissioned their care
- the census does not include residents of England who may be receiving care in other countries
- Assuring Transformation data is a quarterly collection presenting data
- Assuring Transformation data covers people whose care is commissioned by the NHS in England (CCGs and NHS England). It includes residents of England receiving care in other countries.

85. Further improvements to data collection are required and there are plans to move from a manual data collection to an on line data collection system run by HSCIC. This change will enable local commissioners to have an accurate record to drive performance and quality improvements, as well as enabling us to aggregate the data to understand the trends at a national level.

### **Learning Disability minimum data set**

86. In *Transforming Care*, DH committed to develop a new learning disability minimum data set to be collected through the HSCIC from 2014/15. The Mental Health Minimum Data Set (MHMDS) data set has been expanded to include services for people with learning disability and autistic spectrum disorders. The first version of this expanded dataset was mandated for collection from 1 September 2014. The HSCIC is planning to introduce a second version of this dataset from April 2016 and is working with stakeholders on a number of proposed changes to meet the monitoring needs of learning disability services.

### **Joint health and social care self-assessment framework**

87. The joint health and social care self-assessment framework (SAF) which monitors progress of key health and social care inequalities at local and national levels has an important role in enabling commissioners and providers to compare how they are performing against the average and against their peers<sup>28</sup>.
88. Work on the SAF during 2014 has shown that self-assessment by local partnership boards has been reassuring about the extent to which learning disability liaison functions were in place in general hospitals. However, most local partnership boards reported themselves as weak in awareness of levels of access people for people with learning disabilities to wider primary care services including dentistry, optometry, podiatry and community pharmacy services, and oversight of the numbers of people with learning disabilities in the criminal justice system and the extent to which their health needs are being met.
89. In relation to health care commissioning, between a quarter and a third of local partnership boards have been unable to obtain statistical information about key health issues such as mortality and common long term conditions like epilepsy and diabetes and cancer screening coverage for people with learning disabilities and are therefore not able yet to judge the success of local initiatives in these areas.
90. It is especially important in this context that physical health needs are addressed as unmet needs can themselves be a root cause of challenging behaviour. This point has been reinforced in the proposed Mental Health Act 1983: Code of Practice. More broadly steps are being taken to improve the coverage and consistency of health checks provided to people with learning disabilities, and this scheme (provided under a designated enhanced service) has been expanded to include young people from the age of 14, and to link more closely to health action plans.

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<sup>28</sup> <http://www.improvinghealthandlives.org.uk/projects/jhscsaf2014>

## Chapter 6 – Children and Young People in Transition

**Deliver integrated support to vulnerable children and young people with behaviour that challenges. This should include early and effective intervention with care co-ordinated around and tailored to the needs of the individual child or young person.**

Ian is a young man with learning disabilities, autism and behaviour that can be challenging. Ian was sectioned under the Mental Health Act and had been in an assessment and treatment unit for several years.

A 'moving on' plan was developed by the Community Learning Disabilities Health team. Potential options for Ian's living arrangements were identified based on Ian's needs and preferences. Ian's parents and an independent advocate were involved in sourcing the options to ensure that this was done in Ian's best interests.

Whilst Ian was eligible for 100% funding from the NHS, there was close involvement from a social worker throughout the process. A Section 117 discharge meeting took place with representatives from the local community team and new staff team (from Ian's new provider) all present. A core group of support staff at the provider organisation were identified so that Ian would have a consistent staff team.

Leading up to his move, lots of additional meetings with Ian's family, all the relevant professionals, the Charge Nurse at the ATU and Ian's new provider took place to carefully plan his transition and agree a transition plan. The aim was to introduce Ian to his new support team and environment in a structured way over a period of 4-6 weeks. Each time Ian visited his new home, he brought a few personal items to leave in his new room and was supported to prepare something to eat in the kitchen of his new home

Ian successfully made the transition to his new home, and his family have said they are "very happy". Ian's unsettled behaviours have significantly reduced and he has settled in well. *From London Borough of Newham.*

91. The right care for people with challenging behaviour includes care that is age-appropriate, in particular for early years children and for young people transitioning to adults' services. This chapter sets out work that has been undertaken during the last year covering special educational needs, children and adolescent mental health services (CAMHS) and work with local areas.

### **Special educational needs and disability**

92. The new statutory framework for joint working between local authorities and CCGs to secure services for children with special educational needs and disability (SEND)<sup>29</sup>, introduced from September 2014, provides a structure for reaching a multi-agency consensus on the needs of a child with learning disability. This includes planning for young people up to the age of 25, across education, health and social care, focusing on the outcomes which make a real difference to them, and specifically including planning for their transition to adulthood, including future employment and independent living. Involving and working with the child or young person and their family is fundamental to the process of developing the Education, Health and Care plan, and ensuring its focus on the outcomes which will make the most difference to the individual.

### **Children and adolescent mental health services**

93. NHS England conducted a rapid review of Tier 4 CAMHS services<sup>30</sup>, which looked at current provision, level of demand, admission criteria and areas of best practice. The review outlines particular issues which impact on CAMHS Tier 4 inpatient services, as well as the overall care pathway for children and young people, which covers the transition from children and young people mental health services to adult mental health services. The report identified specific improvements that are required as an immediate and urgent priority through national commissioning. This includes a shortage of tier 4 beds in some regions, allowing children in crisis to be treated in age specific contexts" in description of NHS England's review of Tier 4 CAMHS.

94. We know that many young people face a 'cliff-edge' in transitioning from CAMHS when they reach 18, and it is vital that mental health care remains consistent and uninterrupted as children and young people reach 18. In August the Minister of State for Care and Support set up the Children and Young People's Mental Health and Wellbeing Taskforce. The Taskforce is looking specifically at improving the experience of transition from child

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<sup>29</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/342440/SEND\\_Code\\_of\\_Practice\\_approved\\_by\\_Parliament\\_29.07.14.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/342440/SEND_Code_of_Practice_approved_by_Parliament_29.07.14.pdf)

<sup>30</sup> <http://www.england.nhs.uk/wp-content/uploads/2014/07/camhs-tier-4-rep.pdf>

and adolescent to Adult Mental Health Services, as well as other challenges facing child and adolescent mental health services. We are supporting NHS England's work to develop a service specification for transition from CAMHS. CCGs and local authorities will be able to use the specification to build the best measurable, person-centred services that take into account the developmental needs of the young person as well as the need for age appropriate services.

## Local areas

95. The JIP team have worked with key partners through a Children and Young People Partnership Group and with a range of partners including DfE, Ofsted, the Association of Children's Services (ADCS), the CQC, PHE, leading children's disability charities and parents of disabled children to ensure the needs of children and young people with challenging behaviour are picked up across the *Transforming Care* programme, and to influence relevant children's policy to help ensure that the needs of children and young people with behaviour that challenges are incorporated and that sustainable change is embedded in system approaches (e.g. through the Special Educational Needs reforms). Examples of work include:

- a focus on lifelong planning as part of the JIP's commissioning workshops and through its wider support to local area partners
- 9 regional planning workshops to help promote and share approaches in early 2015
- work with the JIP's in-depth review areas has included a focus on children and young people and the inclusion of relevant children's services
- promoting the use of personal health budgets for children and young people with complex needs.

96. However, we recognise that there is more to do in this area and will be ensuring that there is an integrated approach across the NHS and local Government to delivery of change for children.

Our son who has a learning disability and complex needs is well cared for by dedicated staff in his care home in Sunderland. He has many opportunities for activities that we never thought possible such as visits to the theatre, museums and eating out in city centre restaurants. (However places to go to when behaviour is less settled and where the needs of individuals with challenging behaviour are understood such as his weekly disco are very rare.)

The one certainty in our lives is that regulations surrounding the care of our son will always be changing and with that the hard won stability of good care could be snatched away.

These anxieties have been greatly reduced by being a member of a Carers' Management Board (CMB). The CMB has regular meetings with the Director of the Company Sunderland Care and Support Limited (SCSL) set up by Sunderland Council to run homes for people with Learning Disability in Sunderland. Members of the CMB are relatives of the residents of



homes run by this not for profit Company and during meetings can bring up any concerns about the care of their loved ones. This has led to many improvements in the care in homes and a greater understanding of how changes in regulations will affect the delivery of this care. More information about the CMB can be found on the web site of Sunderland Carers' Centre: [www.sunderlandcarers.co.uk](http://www.sunderlandcarers.co.uk). *From Gaynor Mitchell, Family Carer and member of Sunderland Carers' Management Board.*

# Conclusion

97. Two years on since *Transforming Care* was published, it is clear from this report that whilst we have made some progress, the system has not delivered what we set out to achieve. There has to be much faster and more sustainable progress if we are to achieve a model of care that is focused on prevention and a high level of person centred support and care to people with complex needs that is provided locally wherever possible. People should only be in hospital care when that is genuinely the best option, and only stay in hospital care for as long as it remains to be the best option.
98. Up to now, we have focused on trying to drive delivery through existing systems and legislation but, increasingly the evidence on progress is suggesting that this has simply not been enough. Over the past two years there have been growing calls from multiple sources – from national experts and statutory agencies to individual families - that the current statutory framework is simply not sufficient to drive through the culture shift we need to see which will result in a transformation of care for people. We are therefore exploring whether we can consult on a package of future measures designed to deliver greater change for people: strengthening their voice and inclusion.
99. To drive through further progress, we also working on establishing a re-calibrated, strengthened *Transforming Care* programme based on clearly defined actions which we can measure progress by, and be held account for delivery. As noted in the foreword, we need a better co-ordinated approach to achieve faster and sustainable progress. As part of our determination to step up the pace of change all partners involved in *Transforming Care* have agreed the need for a single programme. These actions are set out in the NHS/system response<sup>31</sup> which sets out the future direction for the *Transforming Care* programme. As part of taking this forward, we will ensure that Concordat commitments not yet achieved set out in appendix 1 form part of this.
100. The views of the people who matter most – individuals, their families and carers – are key and we are committed to working in co-production to ensure meaningful engagement and to support openness and transparency as we take this new single programme forward.

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<sup>31</sup> <http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/transform-care/>

## Appendix 1 – Tracker of Transforming Care Actions

### SUMMARY OF PROGRESS ON ACTIONS FROM TRANSFORMING CARE (DECEMBER 2014)

All actions have been reviewed and grouped into one of two categories:

- **COMPLETE:** Actions completed, or imminently to be completed, which will now be managed in organisations' normal business
- **CONTINUING:** Incomplete actions which will continue in the Transforming Care Programme

Ref. no.	Action	Status
	<p><b>WORKSTRAND 1: RIGHT CARE, RIGHT PLACE</b>            Reviewing placements and supporting everyone inappropriately in hospital to move to community based support. Locally agreed plans to ensure quality care and support services based on the model of good care.</p>	
13	<p>The Local Government Association (LGA) and NHE England will establish a joint improvement programme (JIP) to provide leadership and support to the transformation of services locally. They will involve key partners including the Department of Health (DH), the Association of Directors of Social Services (ADASS), the Association of Directors of Children's Services (ADCS) and the Care Quality Commission (CQC) in this work, as well as people with challenging behaviour and their families. The programme will be operating within three months and Board and leadership arrangements will be in place by the end of December 2012. DH will provide funding to</p>	<p><b>COMPLETE</b></p> <p>JIP was established and its agreed programme to March 2015 is nearing completion. Building on this work, a joint Transforming Care programme is now planned across NHS England, LGA and ADASS from April 2015.</p>

	support this work.	
18	<p>NHS England will work with ADASS to develop:</p> <ul style="list-style-type: none"> <li>practical resources for commissioners of services for people with learning disabilities, including new NHS contract schedules for specialist learning disability services;</li> <li>models for rewarding best practice through the NHS Commissioning for Quality and Innovation (CQUIN) framework; and</li> <li>a joint health and social care self-assessment framework to support local agencies to measure and benchmark progress.</li> </ul> <p>NHS England will work with DH to set out how to embed Quality of Health Principles in the system, using NHS contracting and guidance.</p>	<p><b>COMPLETE</b></p> <p>NHS England published the following in 2013 and 2014:  <a href="http://www.commissioningboard.nhs.uk/nhs-standard-contract/">http://www.commissioningboard.nhs.uk/nhs-standard-contract/</a>  <a href="http://www.england.nhs.uk/nhs-standard-contract/">http://www.england.nhs.uk/nhs-standard-contract/</a>  <a href="http://www.local.gov.uk/place-i-call-home-/journal_content/56/10180/5971490?_56_INSTANCE_0000_templateId=ARTICLE">http://www.local.gov.uk/place-i-call-home-/journal_content/56/10180/5971490? 56 INSTANCE 0000 templateId=ARTICLE</a>  NHS England and LGA published the Core Principles Commissioning Tool giving examples of best practice (see action 19 below). NHS England Planning guidance for 2015/16 includes a section on Learning Disability.</p>
19	<p>NHS England and ADASS will develop service specifications (now called core principles) to support Clinical Commissioning Groups (CCGs) in commissioning specialist services for children, young people and adults with challenging behaviour built around the model of care in Annex A to Transforming Care.</p>	<p><b>COMPLETE</b></p> <p>In February 2014 NHS England and LGA published the document '<i>Ensuring quality services: core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges</i>':  <a href="http://www.local.gov.uk/place-i-call-home-/journal_content/56/10180/5971490?_56_INSTANCE_0000_templateId=ARTICLE">http://www.local.gov.uk/place-i-call-home-/journal_content/56/10180/5971490? 56 INSTANCE 0000 templateId=ARTICLE</a></p>
20	<p>The Joint Commissioning Panel of the Royal College of General Practitioners and the Royal College of Psychiatrists will produce detailed guidance on commissioning services for people with learning disabilities who also have mental health conditions.</p>	<p><b>COMPLETE</b></p> <p>Commissioning guidance on Mental Health Services for People with Learning Disabilities was published in June 2013  <a href="http://www.jcpmh.info/resource/guidance-for-commissioners-of-mental-health-services-for-people-with-learning-disabilities/">http://www.jcpmh.info/resource/guidance-for-commissioners-of-mental-health-services-for-people-with-learning-disabilities/</a></p>
22	<p>NHS England will ensure that all Primary Care Trusts develop local registers of all people with challenging behaviour in NHS-funded care.</p>	<p><b>COMPLETE</b></p> <p>All local areas now use registers. Work continues to refine their quality and coverage.</p>

25	DH will work with key partners to agree how Quality of Life principles should be adopted in social care contracts to drive up standards.	<p><b>COMPLETE</b></p> <p>The Minister of State for Care and Support launched Quality of Life standards and a toolkit on 10 June 2014  <a href="http://changingourlives.org/index.php?option=com_k2&amp;view=item&amp;id=446:national-launch-of-quality-of-life-standards&amp;Itemid=357">http://changingourlives.org/index.php?option=com_k2&amp;view=item&amp;id=446:national-launch-of-quality-of-life-standards&amp;Itemid=357</a></p>
26	NHS England will make clear to CCGs in their handover and legacy arrangements what is expected of them in maintaining local registers, and reviewing individuals' care with the Local Authority, including identifying who should be the first point of contact for each individual.	<p><b>COMPLETE</b></p> <p>The (then) NHS Commissioning Board wrote to Regional Directors in January 2013  <a href="http://www.improvinghealthandlives.org.uk/uploads/doc/vid_18799_Letter%20to%20Regional%20Directors%20re%20Winterbourne%20view%2024.1.13.pdf">http://www.improvinghealthandlives.org.uk/uploads/doc/vid_18799_Letter%20to%20Regional%20Directors%20re%20Winterbourne%20view%2024.1.13.pdf</a></p> <p>NHS England wrote again to CCGs in June 2013  <a href="http://www.improvinghealthandlives.org.uk/uploads/doc/vid_18800_130603%20Barbara%20Hakin%20WV.PDF">http://www.improvinghealthandlives.org.uk/uploads/doc/vid_18800_130603%20Barbara%20Hakin%20WV.PDF</a></p> <p>NHS England quarterly data collection provides up to date information on the number of people on registers.</p>
27	NHS England will hold CCGs to account for their progress in transforming the way they commission services for people with learning disabilities/autism and challenging behaviours.	<p><b>CONTINUING</b></p> <p>Initial work is complete. NHS England published guidance in 2014 and Learning Disability sections of 2015-16 Planning Guidance sets expectations of CCGs. Further work is required.</p>
33	The strong presumption will be in favour of pooled budget arrangements with local commissioners offering justification where this is not done. NHS England, ADASS and ADCS will promote and facilitate joint commissioning arrangements.	<p><b>CONTINUING</b></p> <p>Initial work is complete. JIP has developed a series of collaborative commissioning workshops aimed at supporting local area partners across health and social care to identify challenges and share solutions to enable joined up approaches to commissioning services, including funding. These have shown that existing arrangements are variable and therefore the focus has been to support integrated models of funding appropriate to the area. Learning Disability sections of NHS England 2015-16 planning Guidance sets expectations of CCGs. Further work is required.</p>
34	NHS England will ensure that CCGs work with local authorities to ensure that vulnerable	<p><b>CONTINUING</b></p>

	people, particularly those with learning disabilities and autism receive safe, appropriate and high quality care. The presumption should always be for services to be local and that people remain in their communities.	Further work is required. This is the purpose of the NHS England work programme, which is led by the Chief Nursing Officer, working with other system partners.
35	Health and care commissioners should use contracts to hold providers to account for the quality and safety of the services they provide.	<b>COMPLETE</b>  The new NHS standard contract was implemented from April 2014. That included a requirement for providers to undertake annual audit of reasonable adjustments under the Service Conditions section paragraph 13.2 <a href="http://www.england.nhs.uk/wp-content/uploads/2013/12/sec-b-cond-1415.pdf">http://www.england.nhs.uk/wp-content/uploads/2013/12/sec-b-cond-1415.pdf</a>  NHS England and the LGA published core principles in February 2014 (see action 19 above).
42	Health and care commissioners, working with service providers, people who use services and families, will review the care of all people in learning disability or autism inpatient beds and agree a personal care plan for each individual based around their and their families' needs and agreed outcomes.	<b>COMPLETE</b>  Initial work is complete. Further work is required – this is a core element of the NHS England work programme, working with other system partners.
57	CCGs and local authorities will set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area. This could potentially be undertaken through the Health and Wellbeing Board and could be considered as part of the local Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategy (JHWS) processes.	<b>COMPLETE</b>  The Minister for Care and Support wrote to all Health and Wellbeing Boards chairs in May 2013. <a href="https://www.gov.uk/government/news/norman-lamb-highlights-role-of-health-and-wellbeing-boards-in-reforming-care-following-winterbourne-view">https://www.gov.uk/government/news/norman-lamb-highlights-role-of-health-and-wellbeing-boards-in-reforming-care-following-winterbourne-view</a>  See action 67 (Workstrand 1) for link to NHS Confederation guidance for Health & Wellbeing Boards.  JIP's work with 34 in-depth review areas has focussed on developing joint local plans as a priority. Examples of good practice around effective joint planning will continue to be shared and local areas will be encouraged to share plans.
58	Health and care commissioners should put plans into action as soon as possible and all	<b>CONTINUING</b>

	individuals should be receiving personalised care and support in appropriate community settings no later than 1 June 2014.	Further work is required. This is the purpose of the NHS England work programme, which is led by the Chief Nursing Officer, working with other system partners.
65	The national market development forum within the TLAP partnership will work with DH to identify barriers to reducing the need for specialist assessment and treatment hospitals and identify solutions for providing effective local services.	<p><b>COMPLETE</b></p> <p><i>'Be Bold, developing the market for the small numbers of people with very complex needs'</i> was published on 12 December 2012  <a href="http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=9412">http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=9412</a></p> <p>TLAP are now working regionally to ensure that this and other resources are being used.</p>
66	The Developing Care Markets for Quality and Choice (DCMQC) programme will support local authorities to identify local needs for care services and produce market position statements, including for learning disability services.	<p><b>COMPLETE</b></p> <p>The Institute of Public Care DCMQC programme now offers support to all local authorities to help develop market position statements (MPS) and provides a support toolkit.  <a href="http://ipc.brookes.ac.uk/dcmqc.html">http://ipc.brookes.ac.uk/dcmqc.html</a>  126 authorities have now either published, or are about to publish, an MPS.</p> <p>Building on the DCMQC programme, a new DH-funded programme supports local authorities commissioning services more effectively. A set of commissioning standards has been co-produced with the sector, led by LGA and ADASS, delivered by the Health Services Management Centre at the University of Birmingham. The prototype framework of standards <i>Commissioning for Better Outcomes: a roadmap</i> launched in October 2014 will be piloted, refined and then join LGA materials that support sector-led improvement in 2015. The standards facilitate self and peer review to evaluate the extent that a local authority is using best practice, covering areas including market shaping, integrated health and care and personalisation.</p>
67	DH will work with sector leaders on co-produced resources to support health and wellbeing boards on specific aspects of Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs). As part of this work, we will explore how, in responding to the issues raised in the Winterbourne View review, we will ensure that health and wellbeing boards have support to understand the complex needs of people with	<p><b>COMPLETE</b></p> <p>NHS Confederation, with JIP, the LGA, NHS England and Regional Voices, published guidance for Health and Wellbeing Boards in July 2014.  <a href="http://www.nhsconfed.org/resources/2014/07/health-and-wellbeing-boards-leading-local-response-to-winterbourne-view">http://www.nhsconfed.org/resources/2014/07/health-and-wellbeing-boards-leading-local-response-to-winterbourne-view</a></p>

challenging behaviour.



## **WORKSTRAND 2: REGULATION, INSPECTION, CORPORATE ACCOUNTABILITY**

Strengthen corporate accountability and responsibility of providers, and their management, for quality of care. Tighten regulation and inspection of providers.

1

CQC will continue to make unannounced inspections of providers of learning disability and mental health services employing people who use services and families as vital members of the team.

### **COMPLETE**

CQC has implemented its new methods of inspection and scheduled inspections of all NHS and independent sector learning disability services through to 2016.

2

CQC will take tough enforcement action including prosecutions, restricting the provision of services, or closing providers down, where providers consistently fail to have a registered manager in place.

### **COMPLETE**

In September 2013, CQC's board agreed to address the unacceptably high number of locations operating without registered managers. CQC required all providers with locations without a manager for more than six months to resolve that immediately, or a fixed penalty notice would be issued. A number of penalty notices (£4,000) were issued to providers as a result.

[http://www.cqc.org.uk/sites/default/files/documents/chief\\_executive\\_report\\_to\\_board\\_12\\_sept.pdf](http://www.cqc.org.uk/sites/default/files/documents/chief_executive_report_to_board_12_sept.pdf)

In March 2014 the Minister of State for Care and Support met senior CQC staff to discuss enforcement. New regulations will increase CQC's ability to take action on providers of poor quality care, including bringing prosecutions and closing down providers.



3	CQC will take enforcement action against providers who do not operate effective processes to ensure they have sufficient numbers of properly trained staff.	<p><b>COMPLETE</b></p> <p>NHS England, CQC and JIP have been working together on areas of concern. <i>The Hard Truths</i>, Francis response has set out additional requirements for staffing.</p> <p>In October 2014, CQC fully rolled out an approach to ratings of mental health and learning disability services. CQC will rate both at service and Trust levels, across five domains (safe, effective, caring, responsive, well-led) and a four point rating scale: outstanding, good, requires improvement and inadequate.</p> <p>Regulations to put in place new fundamental standards and fit and proper person requirements will come into effect in April 2015. CQC takes regulatory action across all services where staff recruitment, induction, training supervision and numbers in settings compromise care delivery.</p> <p>CQC's Key Lines of Enquiry (KLOE) are being used for learning disability inspections and address issues about the number of staff as well as their skills, capability and effectiveness. CQC has issued warning notices four times since April 2013 about staffing concerns.</p>
29	CQC will take action to ensure the model of care is included as part of inspection and registration of relevant services from 2013. CQC will set out the new operation of its regulatory model, in response to consultation, in Spring 2013.	<p><b>COMPLETE</b></p> <p>CQC has implemented registration changes and now look closely at all aspirant registrants to see if they are proposing services that are consistent with the model set out in the Concordat.</p> <p>CQC refused the only application to register a new Assessment and Treatment Unit (ATU) received in 2014. The provider withdrew the application and no longer intends to provide the proposed service for patients with a learning disability.</p>

30	CQC will share the information, data and details they have about providers with the relevant CCGs and local authorities.	<p><b>COMPLETE</b></p> <p>CQC is delivering this through registration inspections and inspections of hospitals using new methodology, which includes a quality summit at the end of the inspection process attended by the local authority and CCG. CQC's links to local authorities for adult care learning disability services are well established both for registration and inspections. CQC's new approach for inspecting primary medical services will include people with a learning disability as a core group.</p> <p>All information about providers, including about registration and inspection, is available on CQC's website.</p>
31	CQC will assess whether providers are delivering care consistent with the statement of purpose made at the time of registration.	<p><b>COMPLETE</b></p> <p>CQC link inspections to the commitments set out in a provider's statement of purpose.</p> <p>CQC is applying a more rigorous test to new registrants which is legally binding and contains a commitment to safe, high-quality care. Experts by experience are involved in this process. The fit and proper persons test will also be used.</p> <p>CQC agrees it needs to ensure that the statement of purpose is reviewed as part of the core data set in its new inspection programme. It acknowledges more needs to be done to ensure that providers keep their Statement of Purpose updated and notify CQC of relevant changes.</p>
32	Monitor will consider in developing provider licence conditions, the inclusion of internal reporting requirements for the Boards of licensable provider services to strengthen the monitoring of outcomes and clinical governance arrangements at Board level.	<p><b>COMPLETE</b></p> <p>Licence condition FT4 for NHS Foundation Trust governance arrangements is contained in: <a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/285009/Annex_NHS_provider_licence_conditions_-_20120207.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/285009/Annex_NHS_provider_licence_conditions_-_20120207.pdf</a></p> <p>This includes establishing and implementing clear reporting lines and accountabilities. Since April 2014 non-Foundation Trust providers - who are not exempt under the regulations made by DH - have for the first time had to comply with a set of licence conditions in order to deliver NHS-funded services.</p>

36	<p>Directors, management and leaders of organisations providing NHS or local authority funded services to ensure that systems and processes are in place to provide assurance that essential requirements are being met and that they have governance systems in place to ensure they deliver high quality and appropriate care.</p>	<p><b>COMPLETE</b></p> <p>Providers have undertaken a range of actions to meet this commitment. The Driving up Quality Code (see action 43, workstrand 3) developed and signed up to by a range of learning disability providers includes guidance and good practice on developing a good culture in organisations and on leading and running an organisation well. The code also includes a self-assessment guide to help organisations assess their own performance.</p> <p>CQC has been changing the way it assesses leadership and corporate responsibility in providers for this sector.</p> <p>In July 2014, the Government published its response to the consultation on the fit and proper person requirement, duty of candour and fundamental standards, and laid draft regulations which are expected to be in place by April 2015.  <a href="https://www.gov.uk/government/news/fundamental-standards-improving-quality-and-transparency-in-care">https://www.gov.uk/government/news/fundamental-standards-improving-quality-and-transparency-in-care</a></p> <p>The “Well led” section in CQC's KLOE is about organisations' leadership. If CQC is not assured about leadership capacity and capability, it will determine whether or not the service should go into special measures.</p>
40	<p>DH will immediately examine how corporate bodies, their Boards of Directors and financiers can be held to account for the provision of poor care and harm, and set out proposals during Spring 2013 on strengthening the system where there are gaps. We will consider both regulatory sanctions available to CQC and criminal sanctions. We will determine whether CQC's current regulatory powers and its primary legislative powers need to be strengthened to hold Boards to account and will assess whether a fit and proper persons test could be introduced for board members.</p>	<p><b>COMPLETE</b></p> <p>In July 2014 the Government published its response to the consultation on the fit and proper person requirement, duty of candour and fundamental standards, and laid draft regulations (see action 36 above).</p> <p>From 27 November 2014, the regulations put in place two new requirements applying to NHS bodies: the duty of candour and the fit and proper person requirement: directors. Provider guidance was published on 20 November 2014. The requirements will be extended to all registered providers from April 2015.</p> <p>Regulations approved by Parliament change the legislative basis for CQC's registration of health and social care providers, and provide CQC with additional tools to hold corporate bodies to account. The regulations have now been approved by Parliament and will come into force as set out above (action 36).</p> <p>From 1 April 2015, all registered providers will have to meet new registration requirements that set new fundamental standards of care. Importantly, these will allow CQC to bring a</p>

		prosecution in the most serious cases of poor care without having to issue an advance warning notice.
41	CQC will take steps now to strengthen the way it uses its existing powers to hold organisations to account for failures to provide quality care. It will report on changes to be made from Spring 2013.	<p><b>COMPLETE</b></p> <p>Fundamental standards were published on 7 July 2014  <a href="https://www.gov.uk/government/news/fundamental-standards-improving-quality-and-transparency-in-care">https://www.gov.uk/government/news/fundamental-standards-improving-quality-and-transparency-in-care</a></p> <p>The new fundamental standards regulations, and CQC's new enforcement powers linked to these, will apply from April 2015. From 27 November 2014, CQC have implemented two of the new standards for NHS providers, including Mental Health and Learning Disability NHS Trusts and NHS Foundation Trusts - see action 40(a) above.</p> <p>CQC continues to use its existing enforcement powers across NHS and independent health sector services where there are breaches of the current regulations.</p>
55	CQC will also include reference to the model in their revised guidance about compliance. Their revised guidance about compliance will be linked to the DH timetable of review of the quality and safety regulations in 2013. However, they will specifically update providers about the proposed changes to their registration process about models of care for learning disability services in 2013.	<p><b>COMPLETE</b></p> <p>CQC's requirements guide for those applying to be a new provider is on their website  <a href="http://www.cqc.org.uk/content/step-step-guide-applying-new-provider">http://www.cqc.org.uk/content/step-step-guide-applying-new-provider</a></p> <p>In the past year, CQC has received a single application to register a new ATU which it refused (see action 29 above). CQC's new regulatory model for inspection of existing inpatient services allows for comment on the model of care. If the model of care is deemed inappropriate, that must be addressed by commissioners and others in the system.</p>
68	DH will review the regulatory requirements in respect of criminal records checks and whether providers should routinely request a criminal record certificate on recruitment from 2013 once the impact of the new service is understood.	<p><b>COMPLETE</b></p> <p>The review found no need to change the CRB check regulations. Applicants can now subscribe to an update service when they make a new application for a certificate. This service keeps the certificate up to date, meaning that employers can make instant online checks. Once they have subscribed, individuals can take their certificate with them from role to role where the same type and level of check is required. Disclosure and Barring (DBS) checks are only one part of ensuring effective and safe recruitment processes. Providers should also be using other mechanisms, including checking employment history and gaps, and reviewing references.</p>

<p>69</p>	<p>CQC will use existing powers to seek assurance that providers have regard to national guidance and the good practice set out in the model of care at Annex A.</p>	<p><b>COMPLETE</b></p> <p>This now features in the new approach to registration for learning disability providers published in July 2013.  <a href="http://www.cqc.org.uk/organisations-we-regulate/services-people-learning-disabilities">http://www.cqc.org.uk/organisations-we-regulate/services-people-learning-disabilities</a></p> <p>CQC's new inspection methodology and KLOE focus on what good care looks like. As part of that determination CQC asks about a range of things including training in and implementation of positive behaviour support programmes and use of non-verbal communication techniques, skills and tools.</p>
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**WORKSTRAND 3: GOOD PRACTICE, STANDARDS AND ADVOCACY**

Improve quality and safety so that best practice in learning disability services becomes normal practice. Ensuring good information and advice, including advocacy, is available to help people and their families.


<p>49</p>	<p>DH will work with independent advocacy organisations to drive up the quality of independent advocacy.</p>	<p><b>COMPLETE</b></p> <p>From April 2015, the Care Act 2014 introduces a new duty on local authorities to provide independent advocacy targeted to people who have substantial difficulty in being involved in assessment, planning and review, and have no appropriate individual(s) – carer, family or friend – who can support their involvement. This will widen accessibility to independent advocacy particularly to people who are not provided with an advocate under the Mental Health Act or Mental Capacity Act. DH is continuing regular meetings with advocacy groups and others interested in Care Act implementation and how it links with other advocacy provision to ensure better advocacy is delivered.</p> <p>The National Development Team for Inclusion (NDTi) developed the 3rd edition of the Quality Performance Mark (QPM) in 2014 with funding from DH. The NDTi worked with providers, users and commissioners of advocacy services to review and revise the QPM and supporting Code of Practice. The QPM provides an innovative assessment of the quality of advocacy through a system of inspection and review including observation. It collects systematic evidence on the quality of advocacy and many commissioners require</p>
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		<p>and rely on it.</p> <p>In October 2014, Regulations were laid before Parliament:  <a href="https://www.gov.uk/government/consultations/updating-our-care-and-support-system-draft-regulations-and-guidance">https://www.gov.uk/government/consultations/updating-our-care-and-support-system-draft-regulations-and-guidance</a>  and Statutory Guidance to support implementation of part 1 of the Care Act had been consulted on and published:  <a href="https://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation">https://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation</a></p> <p>In October 2014 the Social Care Institute for Excellence published resources to help local authority staff and commissioners expand and commission effective independent advocates and advocacy services:  <a href="http://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/">http://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/</a></p> <p>Skills for Care and the National Skills Academy for Social Care in partnership with The College of Social Work have developed a suit of training materials on the Care Act, including independent advocacy, designed to be adapted and used by leaders, managers, self-directed learners and learning and development professionals:  <a href="http://www.skillsforcare.org.uk/Standards/Care-Act/Learning-and-development/First-contact-and-identifying-needs.aspx">http://www.skillsforcare.org.uk/Standards/Care-Act/Learning-and-development/First-contact-and-identifying-needs.aspx</a></p>
7	<p>DH will work with independent advocacy organisations to identify the key factors to take account of in commissioning advocacy for people with learning disabilities in hospitals so that people in hospital get good access to information, advice and advocacy that supports their particular needs.</p>	<p><b>COMPLETE</b></p> <p>Inclusion North is working with commissioners, providers, people and families to share the outcomes from the North East advocacy project. This offers learning on the broader role of advocacy and 'looking out for' as well as a commissioning framework and exploring commissioning advocacy models that provide more than paid professional advocacy.  <a href="http://inclusionnorth.org/projects/what-we-are-doing-now/advocacy-project/">http://inclusionnorth.org/projects/what-we-are-doing-now/advocacy-project/</a></p> <p>DH funded and contributed to sharing the work with people, families and commissioners across the country, and to develop Top Tips guidance on delivering advocacy in specialist services. The work included national and regional meetings with the National Forum of People with Learning Disabilities and the National Valuing Families Forum; 10 'driving up quality' events; and a workshop and stall at the National Advocacy Conference.</p>

		The work was also shared with ADASS, as part of the QPM's refresh, and all of the advocacy resources are available on the QPM website. This work is also informing advocacy workshops supported by JIP. It has led to development of a further project, funded by DH to support self-advocacy groups to create local change.
8	DH will work with independent advocacy organisations to drive up the quality of independent advocacy, through strengthening the Action for Advocacy Quality Performance Mark and reviewing the Code of Practice for advocates to clarify their role.	<p><b>COMPLETE</b></p> <p>NDTi launched the revised QPM on 3 April 2014:  <a href="http://www.ndti.org.uk/major-projects/current/advocacy-quality-performance-mark/">http://www.ndti.org.uk/major-projects/current/advocacy-quality-performance-mark/</a></p> <p>The Code of Practice has been revised and published:  <a href="http://www.qualityadvocacy.org.uk/wp-content/uploads/2014/03/Code-of-Practice.pdf">http://www.qualityadvocacy.org.uk/wp-content/uploads/2014/03/Code-of-Practice.pdf</a></p> <p>For the majority of providers the application/assessment process takes in excess of six For the majority of providers the application/assessment process takes six months from initial registration to completion, split into four distinct stages.</p> <p>The QPM website currently houses a 'QPM Map' which shows all providers accredited with the QPM in England and Wales. New organisations will be included as they achieve the Award. The site also has a downloadable PDF with an up-to-date, printable list of all accredited organisations:  <a href="http://www.qualityadvocacy.org.uk/our-organisations/">http://www.qualityadvocacy.org.uk/our-organisations/</a></p>
24	The National Quality Board will set out how the new health system should operate to improve and maintain quality.	<p><b>COMPLETE</b></p> <p>The National Quality Board updated its guidance in January 2013 in the light of the Winterbourne View report:  <a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213304/Final-NQB-report-v4-160113.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213304/Final-NQB-report-v4-160113.pdf</a></p>

39	<p>DH will work with LGA and Healthwatch England to embed the importance of local Healthwatch involving people with learning disabilities and their families. A key way for local Healthwatch to benefit from the voice of people with learning disabilities and families is by engaging with existing local Learning Disability Partnership Boards. LINKs (local involvement networks) and those preparing for Healthwatch can begin to build these relationships with their Boards in advance of local Healthwatch organisations starting up on 1 April 2013.</p>	<p><b>COMPLETE</b></p> <p>Local Healthwatch are now up and running across England. They are engaging with people with learning disabilities to understand their experiences of health and care including training people to undertake 'enter and view' visits to local services, as well as working with local partners who represent this population group to ensure their views are captured and reflected. Healthwatch England is continuing to support local Healthwatch in engaging with people with learning disabilities by ensuring that these examples are shared across the network. It has also worked with Mencap to produce a new toolkit that will enable local Healthwatch to draw on best practice and encourage those who have not yet engaged with this group to consider doing so. The toolkit is due for publication in early 2015.</p>
43	<p>Provider organisations will set out a pledge or code model based on shared principles - along the lines of the Think Local Act Personal (TLAP) Making it Real principles.</p>	<p><b>COMPLETE</b></p> <p>The Driving Up Quality Code is now live. To sign up to the code or get more information visit <a href="http://www.drivingupquality.org.uk">http://www.drivingupquality.org.uk</a></p> <p>By 18 November 2014 there were 198 providers signed up to the Driving Up Quality Code and actively working with it.</p>
44	<p>DH, with the National Valuing Families Forum, the National Forum of People with Learning Disabilities, ADASS, LGA and the NHS will identify and promote good practice for people with learning disabilities across health and social care.</p>	<p><b>COMPLETE</b></p> <p>The final report can be found here: <a href="https://www.gov.uk/government/publications/learning-disabilities-good-practice-project-report">https://www.gov.uk/government/publications/learning-disabilities-good-practice-project-report</a></p> <p>Examples JIP has collected of detailed local areas approaches and 'what good looks like' are on their website and disseminated in many different ways including across the partnership to inform ongoing work, such as commissioning practices.</p>
62	<p>NICE will publish quality standards and clinical guidelines on challenging behaviour and learning disability.</p>	<p><b>COMPLETE</b></p> <p>Work is well underway: clinical guidelines are expected to be published in May 2015, and the quality standard in October 2015.</p>



63	NICE will publish quality standards and clinical guidelines on mental health and learning disability.	<p><b>COMPLETE</b></p> <p>NICE has started to develop a clinical guideline on mental health and learning disabilities involving stakeholders, including representatives of carers and families. The guideline is due to publish in September 2016. Work on the quality standard will start in March 2016 and it will publish in December 2016.</p>
 <p><b>WORKSTRAND 4: INFORMATION AND DATA</b></p> <p>Ensure transparent information and robust monitoring to deliver transformed care and support and make sure the public, people with challenging behaviour and families know if we are making progress</p>		
4	The cross-government Learning Disability Programme Board will measure progress against milestones, monitor risks to delivery and challenge external delivery partners to deliver to the action plan of all commitments. CQC, NHS England and the head of the LGA, ADASS, NHS England development and improvement programme will, with other delivery partners, be members of the Programme Board, and report on progress.	<p><b>COMPLETE</b></p> <p>DH's Learning Disability Programme Board (LDPB) oversees all key actions relating to learning disabilities. Since September 2014 updates on progress on Transforming Care actions have been made to the new Transforming Care Assurance Board. There is a separate Autism Programme Board. LDPB will continue to receive a high level overview update on the Transforming Care programme.</p>
17	DH will commission an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and lengths of stay. The audit will be repeated one year on to enable the LDPB to assess what is happening.	<p><b>COMPLETE</b></p> <p>Initial analysis of data from the Learning Disability Census on 30 September 2013 was published on 13 December 2013, and secondary analysis in April 2014.</p> <p><a href="http://www.hscic.gov.uk/article/2021/Website-Search?productid=14640&amp;q=learning+disability+census&amp;sort=Relevance&amp;size=10&amp;page=1&amp;area=both#top">http://www.hscic.gov.uk/article/2021/Website-Search?productid=14640&amp;q=learning+disability+census&amp;sort=Relevance&amp;size=10&amp;page=1&amp;area=both#top</a></p> <p>The second Learning Disability Census on 30 September 2014 followed extensive engagement with over 100 provider organisations. Data from the census will be published in January and April 2015.</p>

37	DH, the Health and Social Care Information Centre (HSCIC) and NHS England will develop measures and key performance indicators to support commissioners in monitoring their progress.	<p><b>CONTINUING</b></p> <p>A set of key measures based on NHS England's Assuring Transformation data was shared with the Transforming Care Assurance Board in September 2014. Early development work was done on key performance indicators by DH, HSCIC, NHS England and other partners.</p> <p>Strategic data requirements to support the programme and drive improvements in quality of services for people with learning disabilities generally are being reviewed, including looking at requirements for KPIs.</p> <p>It is important that these do not duplicate existing measures and can be supported by a stable data source, such as the new Mental Health and Learning Disability Data Set.</p>
38	NHS England and ADASS will implement a joint health and social care self-assessment framework (SAF) to monitor progress of key health and social care inequalities from April 2013. The results of progress from local areas will be published.	<p><b>CONTINUING</b></p> <p>The joint Health and Social Care SAF 2013 was published in June 2014.</p> <p><a href="http://www.improvinghealthandlives.org.uk/projects/hscldsaf">http://www.improvinghealthandlives.org.uk/projects/hscldsaf</a></p> <p>NHS England is leading work with ADASS, HSCIC and Public Health England (PHE) to review the process and ensure the SAF is embedded robustly in business as usual for 2015 and beyond (see also action 18, workstrand 1).</p>
52	DH will work with the improvement team to monitor and report on progress nationally, including reporting comparative information on localities. We will publish a follow up report by December 2013.	<p><b>COMPLETE</b></p> <p>The One Year On report was published on 13 December 2013:</p> <p><a href="https://www.gov.uk/government/publications/winterbourne-view-progress-report">https://www.gov.uk/government/publications/winterbourne-view-progress-report</a></p>

60	The Department of Health will publish a second annual report following up progress in delivering agreed actions.	<p><b>COMPLETE</b></p> <p>This is the second progress report. Publication early in 2015 has allowed an inclusive approach, engaging with stakeholders including people with learning disabilities and family carers, and inclusion of the most up to date data from the Learning Disability Census and other sources.</p>
61	DH will develop a new learning disability minimum data set to be collected through HSCIC.	<p><b>CONTINUING</b></p> <p>The Mental Health Minimum Data Set has been expanded to include people with learning disabilities. Version 1 of the new Mental Health and Learning Disability Data Set was mandated from 1 September 2014. Version 2 of the Data Set is expected to be mandated from 2016.</p>
64	DH will continue to collate a suite of information and evidence relating to people with learning disabilities and behaviour which challenges and the health inequalities they experience and report on these to the LDPB.	<p><b>CONTINUING</b></p> <p>DH and its partners are working to understand the strategic data and information requirements to sustain improvements in services over the long term and will develop proposals in early 2015. This will build on data and information already collected and published by the HSCIC and the Learning Disabilities Observatory in PHE. PHE publish data on all people with learning disability  <a href="http://www.improvinghealthandlives.org.uk">http://www.improvinghealthandlives.org.uk</a></p>



#### **WORKSTRAND 5: MEDICATION, POSITIVE BEHAVIOUR SUPPORT AND PHYSICAL INTERVENTION**


Improved quality and safety to give a better understanding of good practice on positive behaviour support and the environment so that challenging behaviour and the need for physical restraint are reduced. Antipsychotic and antidepressant medicines are used to ensure the best course of action for the patient and not over-used.

5	<p>DH will work with CQC to agree how best to raise awareness of and ensure compliance with Deprivation of Liberty Safeguards (DoLS) provisions to protect individuals and their human rights and will report by Spring 2014.</p>	<p><b>COMPLETE</b></p> <p>CQC now has a dedicated role working with inspectors and others on DoLS implementation and assessing use of DoLS through inspections. CQC has prioritised the Mental Capacity Act (MCA) and DoLS in the fundamental revision of its regulation and inspection model.</p> <p>In October 2013 DH set up the MCA Steering Group, which brings together the main national health and social care partner organisations responsible for implementing the MCA and DoLS.</p> <p>In <i>Valuing every voice, respecting every right: making the case for the Mental Capacity Act</i>, published in June 2014, the Government and partners responded to a House of Lords Select Committee report by setting out a system-wide programme of action to improve awareness of the MCA:  <a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/318730/cm8884-valuing-every-voice.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/318730/cm8884-valuing-every-voice.pdf</a></p> <p>A Supreme Court judgement in March 2014, which clarified the test for what constitutes a deprivation of liberty, has highlighted the importance of compliance and has led to a significant increase in DoLS applications. DH and CQC issued advice notes in light of the judgement.</p>
6	<p>DH will, together with CQC, consider what further action may be needed to check how providers record and monitor restraint.</p>	<p><b>COMPLETE</b></p> <p>DH published <i>Positive and Proactive Care: reducing the need for restrictive interventions</i> in April 2014:  <a href="https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-restrictive-interventions">https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-restrictive-interventions</a></p> <p>DH also published joint guidance with Skills for Health and Skills for Care for commissioners and employers seeking to minimise the use of restrictive practices in social and health care:  <a href="http://www.skillsforcare.org.uk/Skills/Restrictive-practices/Restrictive-practices.aspx">http://www.skillsforcare.org.uk/Skills/Restrictive-practices/Restrictive-practices.aspx</a></p> <p>The NHS Benchmarking Network has completed the first collection of data on restraint commissioned by DH. In December 2014 DH hosted a data workshop to assess accuracy, robustness, and comparability of data returns from both NHS and independent organisations. DH will contact those organisations reporting particularly high and low incidents of restraint to investigate concerns about data quality and practice. Data will</p>

		<p>inform CQC inspections and DH is considering appropriateness of data publication. The collection exercise will be repeated in January 2015, permitting a more reliable assessment of apparent trends and data accuracy.</p> <p>In the longer term, DH are considering with HSCIC the best options for recording and monitoring restraint, including by improving definitions used in the next iteration of the Mental Health and Learning Disability Data Set. It is likely that data from this source would be available earliest from 2016. Once available, data will be used to triangulate evidence with restrictive intervention reduction programmes and CQC findings.</p>
9	<p>A specific workstream has been created by the police force to identify a process to trigger early identification of abuse. The lessons learnt from the work undertaken will be disseminated nationally. All associated learning from the review will be incorporated into training and practice, including Authorised Professional Practice (APP).</p>	<p><b>COMPLETE</b></p> <p>Avon and Somerset Constabulary have designed a process that is working well for identifying early patterns and trends of abuse.</p> <p>Some police forces nationally have systems to identify abuse; others do not. Difficulties in imposing one system on all forces arise because they are autonomous and use different IT systems. Nevertheless, as part of the College of Policing APP process, the Association of Chief Police Officers (ACPO) expects in early 2015 to issue guidance to all forces to use in adults at risk investigations and enquiries and including guidance on early identification of patterns and trends.</p>
11	<p>The British Psychological Society, to provide leadership to promote training in, and appropriate implementation of, Positive Behavioural Support across the full range of care settings.</p>	<p><b>COMPLETE</b></p> <p>The Learning Disability faculty of the Society has enrolled thirteen experienced psychologists on the South Wales Advanced Professional Diploma in Positive Behavioural Support. The British Psychological Society has revised the accreditation criteria for clinical psychology and is identifying additional core competencies in this area.</p>
45	<p>The Department of Health will explore with the Royal College of Psychiatrists and others whether there is a need to commission an audit of use of medication for this group. As the first stage of this, we will commission a wider review of the prescribing of antipsychotic and antidepressant medicines for people with challenging behaviour.</p>	<p><b>CONTINUING</b></p> <p>Three initiatives, agreed by a wide range of stakeholders, are addressing these actions:</p> <ol style="list-style-type: none"> <li>1. NHS England and NHS Improving Quality worked in partnership to launch the Winterbourne Medicines Programme (collaborative), with the aim to ensure safe, appropriate and optimised use of medication for people with learning disabilities whose behaviour can challenge. NHS Improving Quality are working with six project sites and other interested parties and a "community of practice" to improve care.</li> <li>2. NHS England asked CQC to audit medication data related to the "Second Opinion</li> </ol>

51	The Royal College of Psychiatrists, the Royal Pharmaceutical Society and other professional leadership organisations will work with ADASS and ADCS to ensure medicines are used in a safe, appropriate and proportionate way and their use optimised in the treatment of children, young people and adults with challenging behaviour. This should include a focus on the safe and appropriate use of antipsychotic and antidepressant medicines.	Authorised Doctor" requirement. 3. NHS England commissioned research using Clinical Practice Research Datalink, to examine use of antipsychotic, antidepressant, and anxiolytic medication in people with learning disabilities in primary care. The results and learnings from this overview of current practice will be built into an ongoing programme of action to optimise use of medication in people with learning disabilities as part of the Transforming Care programme.
53	DH with external partners will publish guidance on best practice around positive behaviour support so that physical restraint is only ever used as a last resort where the safety of individuals would otherwise be at risk and never to punish or humiliate.	<b>COMPLETE</b>  DH published Positive and Proactive Care in April 2014: <a href="https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-restrictive-interventions">https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-restrictive-interventions</a>  along with joint guidance with Skills for Health and Skills for Care for commissioners and employers seeking to minimise the use of restrictive practices in social care and health: <a href="http://www.skillsforcare.org.uk/Skills/Restrictive-practices/Restrictive-practices.aspx">http://www.skillsforcare.org.uk/Skills/Restrictive-practices/Restrictive-practices.aspx</a>  All of this is now the foundation for a new Positive and Safe programme of work to embed culture change. This action is complete for adults (see workstrand 7 about guidance for children).
59	DH will update the Mental Health Act Code of Practice and will take account of findings from this review.	<b>COMPLETE</b>  Subject to Parliamentary approval, the new code will come into force by 1 April 2015. It will sit alongside other materials such as an updated reference guide, accessible materials, and a more interactive and better-searchable website. DH are working with a range of partners on promoting awareness and ensuring that key professionals are trained effectively.

70	ADASS and ADCS will produce guidance notes and simple key questions to raise awareness, ensure visibility and action at a local level and to empower members of Safeguarding Adults Boards, Health and Wellbeing Boards and Learning Disability Partnership Boards.	<p><b>COMPLETE</b></p> <p>ADASS published guidance on their website in December 2012, available at: <a href="http://www.adass.org+AA72.uk/AdassMedia/stories/Policy%20Networks/Learning%20Disability/Key%20Documents/Winterbourne%20View%20Compendium_Dec12.pdf">http://www.adass.org+AA72.uk/AdassMedia/stories/Policy%20Networks/Learning%20Disability/Key%20Documents/Winterbourne%20View%20Compendium_Dec12.pdf</a></p> <p>This is supplemented by NHS Confederation guidance (see action 67, workstrand 1).</p>
71	DH have already committed to putting Safeguarding Adults Boards on a statutory footing (subject to parliamentary approval). DH will revise statutory guidance and good practice guidance to reflect new legislation and address findings from Winterbourne View, to be completed in time for the implementation of the Care Bill.	<p><b>COMPLETE</b></p> <p>The Care Act was passed in May 2014. Detailed statutory guidance published on 23 October 2014 makes clear that all practitioners need to be trained in recognising signs of potential abuse or neglect and how to respond: <a href="https://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation">https://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation</a></p> <p>The guidance includes regulations underpinning the duty of local authorities to provide independent advocacy (in certain circumstances) for people who are the subject of a safeguarding enquiry or a safeguarding adult review.</p> <p>DH has commissioned a range of tools and products from Skills for Care and the Social Care Institute for Excellence (SCIE) to support implementation of the safeguarding elements of the Act. These include guidance on Safeguarding Adults Reviews and on information sharing. SCIE is also using the work of task and finish groups, its own evidence and work with users and carers, to produce good practice guidance by 31 March 2015.</p> <p>DH continues to support the Making Safeguarding Personal (MSP) programme led by Towards Excellence in Social Care (TEASC). MSP has take-up in every local authority. Partnership and prevention are core, recurring themes in all the guidance. It tackles the need for cultural change as well as the practical steps to respond to issues identified by Winterbourne View, including the roles of practitioners, multi-agency training, planning and information sharing.</p>

72	Safeguarding Adults Boards should review their arrangements and ensure they have the right information sharing processes in place across health and care to identify and deal with safeguarding alerts.	<p><b>COMPLETE</b></p> <p>The Care Act was passed in May 2014, and detailed statutory guidance in October (see action 71(a) above).</p> <p>DH has commissioned SCIE to produce guidance for Safeguarding Adults Boards to ensure they are fit for purpose across all their functions and duties. LGA have a process for peer-led review on adult safeguarding.</p>
 <p><b>WORKSTRAND 6: WORKFORCE</b></p> <p>Improve quality and safety through improving the capability of the workforce. Staff are properly trained in essential skills supported by good clinical and managerial leadership. Health and care professionals understand and are supported in achieving minimum standards and aspire to best practice. Members of staff should feel it is safe to raise concerns when things go wrong and be listened to.</p>		
10	The College of Social Work, working in collaboration with BASW and other professional organisations and with service user led group, to produce key points guidance for social workers on good practice in working with people with learning disabilities who also have mental health conditions.	<p><b>COMPLETE</b></p> <p>A Brief guide to good practice standards for commissioners and providers was published in August 2013  <a href="http://www.tcsw.org.uk/uploadedFiles/TheCollege/Social_Work_Practice/WinterbournViewGuidanceAugust2013.pdf">http://www.tcsw.org.uk/uploadedFiles/TheCollege/Social_Work_Practice/WinterbournViewGuidanceAugust2013.pdf</a></p> <p>The College of Social Work commissioned a survey of research evidence about effective social work interventions with learning disabled people and their families. This work has been undertaken by the Open University. Publication is due in December 2014. The report was completed in December 2014 and will be published on The College of Social Work website early in 2015.</p>
12	The Royal College of Speech and Language Therapists to produce good practice standards for commissioners and providers	<p><b>COMPLETE</b></p> <p>These standards cover good communication for commissioners and providers together with</p>



	to promote reasonable adjustments required to meet the speech, language and communication needs of people with learning disabilities in specialist learning disability or autism hospital and residential settings.	a guide to "what does good look like and how will you know". <a href="http://www.rcslt.org/news/good_comm_standards">http://www.rcslt.org/news/good_comm_standards</a>
14	The professional bodies that make up the Learning Disability Professional Senate will refresh <i>Challenging Behaviour: A Unified Approach</i> to support clinicians in community learning disability teams to deliver actions that provide better integrated services.	<b>COMPLETE</b> A short key messages refresh of the NICE challenging behaviour guidelines is due to be published in May 2015. A full report published as a book including a chapter on the NICE guidelines is due to be published in August 2015.
15	Skills for Health and Skills for Care will develop national minimum training standards and a code of conduct for healthcare support workers and adult social care workers. These can be used as the basis for standards in the establishment of a voluntary register for healthcare support workers and adult social care workers in England.	<b>COMPLETE</b> Skills for Health and Skills for Care have delivered the minimum training standards and code of conduct for healthcare support workers and adult care workers in England. That was published in March 2013 to coincide with the Francis report: <a href="http://www.skillsforhealth.org.uk/about-us/news/code-of-conduct-and-national-minimum-training-standards-for-healthcare-support-workers/">http://www.skillsforhealth.org.uk/about-us/news/code-of-conduct-and-national-minimum-training-standards-for-healthcare-support-workers/</a> Skills for Care, Health Education England (HEE) and Skills for Health are developing a Care Certificate to be launched in Spring 2015 to replace the National Minimum Training Standards.
16	Skills for Care will develop a framework of guidance and support on commissioning workforce solutions to meet the needs of people with challenging behaviour	<b>COMPLETE</b> Skills for Care and NDTi published guidance for employers to 'Develop a framework of guidance and support on commissioning workforce solutions to meet the needs of people with challenging behaviour' in February 2013. <a href="http://www.skillsforcare.org.uk/challengingbehaviour/">http://www.skillsforcare.org.uk/challengingbehaviour/</a> Active dissemination has been in progress through both bodies. Provider groups have been circulating the framework among members. Skills for Care and Skills for Health have built on this work to contribute to action 53, workstrand 5 on restraint.
21	The Royal College of Psychiatrists will issue guidance about the different types of inpatient services for people with learning	<b>COMPLETE</b> The report ' <i>People with learning difficulty and mental health, behavioural or forensic</i>

	disabilities and how they should most appropriately be used.	<p><i>problems: the role of in-patient services</i>' was published in July 2013:</p> <p><a href="http://www.rcpsych.ac.uk/pdf/FR%20ID%2003%20for%20website.pdf">http://www.rcpsych.ac.uk/pdf/FR%20ID%2003%20for%20website.pdf</a></p>
23	The Academy of Medical Royal Colleges and the bodies that make up the Learning Disability Professional Senate will develop core principles on a statement of ethics to reflect wider responsibilities in the health and care system.	<p><b>COMPLETE</b></p> <p>The Statement of Ethics has been completed. The Professional Senate has asked all professional bodies to promote on their websites.</p> <p><a href="http://www.rcn.org.uk/development/nursing_communities/rcn_forums/learning_disabilities/links/?a=600451">http://www.rcn.org.uk/development/nursing_communities/rcn_forums/learning_disabilities/links/?a=600451</a></p>
28	HEE will take on the duty for education and training across the health and care workforce and will work with DH, providers, clinical leaders and other partners to improve skills and capability to respond the needs of people with complex needs	<p><b>CONTINUING</b></p> <p>HEE has been represented on the LDPB since June 2013. Their refreshed mandate includes Winterbourne View commitments at chapter 4, paragraph 4.10:</p> <p><a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/310170/DH_HEE_Mandate.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/310170/DH_HEE_Mandate.pdf</a></p>
54	There will be a progress report on actions to implement the recommendations in <i>Strengthening the Commitment</i> the report of the UK Modernising learning disability Nursing Review.	<p><b>COMPLETE</b></p> <p>A progress report on actions to implement recommendations in <i>Strengthening the Commitment</i> was published in April 2014:</p> <p><a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/309153/Strengthening_the_commitment_one_year_on_published.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/309153/Strengthening_the_commitment_one_year_on_published.pdf</a></p>
73	Through the Whistleblowing Helpline, DH aims to increase awareness of whistleblowing for staff within the health and social care sectors. The helpline will advise employers on embedding best practice policy and procedure and staff on how to raise concerns and what protection they have in law when they do so.	<p><b>COMPLETE</b></p> <p>The Helpline is run by Mencap. Helpline Number: 08000824825. <a href="http://www.wbhelpline.org.uk">www.wbhelpline.org.uk</a>  <a href="mailto:enquiries@wbhelpline.co.uk">enquiries@wbhelpline.co.uk</a></p>



## WORKSTRAND 7: CHILDREN AND TRANSITION

To deliver integrated support to vulnerable children and young people with challenging behaviours. This should include early and effective intervention with care co-ordinated around and tailored to the needs of the individual child or young person.

19	Shared with workstrand 1 - see action 19 there for children and young people service specification.	<p><b>COMPLETE</b></p> <p>See action 19, workstrand 1</p>
46	DH and the Department for Education (DfE) will work with the independent experts on the Children and Young People's Health Outcomes Forum to prioritise improvement outcomes for children and young people with challenging behaviour and agree how best to support young people with complex needs in making the transition to adulthood.	<p><b>COMPLETE</b></p> <p>The Children and Young People's Health Outcomes Forum is supporting this through its forward work programme.</p> <p>Guidance on integrated transition to adulthood has been developed for the Forum by the National Network of Parent Carer Forums, and the Forum is considering additional recommendations.</p> <p><a href="http://www.nnpcf.org.uk/what-good-integrated-care-looks-like-in-transition/">http://www.nnpcf.org.uk/what-good-integrated-care-looks-like-in-transition/</a></p> <p>Children's disability continues to be a significant issue in the ongoing core work programme of the Children and Young People's Health Outcomes Forum.</p>
47	DH and DfE will develop and issue statutory guidance on children in long-term residential care.	<p><b>COMPLETE</b></p> <p>DfE is leading this review and update of guidance linked to sections 17–19 of the Children and Young People's Act 2008.</p> <p>Publication was delayed while DfE considered any possible Deprivation of Liberty implications arising from the 'Cheshire West' and 'Barnsley' legal cases. Now that consideration is concluded, DfE will publish this guidance in early 2015.</p>
48	DH and DfE will jointly explore the issues and opportunities for children with learning	<p><b>COMPLETE</b></p>

	disabilities whose behaviour is described as challenging through both the special educational needs (SEN) and disability reform programme and the work of the Children's Health Strategy.	The Children and Young People's Health Outcomes Forum will cover this in its forward work programme. SEN reforms in the Children and Families Act have been granted Royal Assent and statutory guidance to support the implementation of the SEN reforms has been laid in Parliament.  DH, the Council for Disabled Children and DfE are developing guidance on minimising the use of restraint in health settings where children have behaviour described as challenging.
50	DfE will revise the statutory guidance <i>Working together to safeguard Children</i> .	<b>COMPLETE</b>  Guidance was published in March 2013: <a href="http://www.education.gov.uk/aboutdfe/statutory/g00213160/working-together-to-secure-good-outcomes-for-children-and-young-people">http://www.education.gov.uk/aboutdfe/statutory/g00213160/working-together-to-secure-good-outcomes-for-children-and-young-people</a>  Early intervention continues to be key in securing good outcomes for children and young people.
53	DH with external partners will publish guidance on best practice around positive behaviour support so that physical restraint is only ever used as a last resort where the safety of individuals would otherwise be at risk and never to punish or humiliate.	<b>COMPLETE</b>  Building on the DH-published <i>Positive and Proactive Care</i> in April 2014, guidance for reducing the need for restrictive practices on children, young people and those in transition in healthcare settings is being developed with key stakeholders. This will be published by March 2015 subject to clearance—(See workstrand 5 for guidance for adults.)
56	DH will work with DfE to introduce a new single assessment process and Education, Health and Care Plan to replace the current system of statements and learning difficulty assessments for children and young people with special educational needs; supported by joint commissioning between local partners (subject to parliamentary approval). The process will include young people up to the age of 25, to ensure they are supported in making the transition to adulthood.	<b>COMPLETE</b>  A Code of Practice was approved by Parliament on 28 July 2014: <a href="https://www.gov.uk/government/publications/send-code-of-practice-0-to-25">https://www.gov.uk/government/publications/send-code-of-practice-0-to-25</a>
74	Ofsted, CQC, Her Majesty's Inspectorate of Constabulary, Her Majesty's Inspectorate of Probation and Her Majesty's Inspectorate of Prisons will introduce a new joint inspection of multi-agency arrangements for the	<b>COMPLETE</b>  A consultation was published on integrated inspections in September 2014: <a href="http://webarchive.nationalarchives.gov.uk/20141124154759/http://www.ofsted.gov.uk/">http://webarchive.nationalarchives.gov.uk/20141124154759/http://www.ofsted.gov.uk/</a>

	protection of children in England.	<a href="#">resources/consultation-integrated-inspections-of-services-for-children-need-of-help-and-protection-children-lo</a> Pilot visits took place in Autumn 2014, and the next steps for integrated inspections will be announced in February 2015.
75	Ofsted will make judgements on the overall effectiveness, outcomes for children and young people, quality of care, safeguarding as well as leadership and management.	<b>COMPLETE</b> Ofsted are consulting on a new inspection framework for the inspection of children's homes which will be introduced in April 2015: <a href="https://www.gov.uk/government/consultations/childrens-homes-framework">https://www.gov.uk/government/consultations/childrens-homes-framework</a>

## **Appendix 2 – DH capital funding scheme**

### **Barnet**

- Grant funding will be used to pay for alterations in the grounds of a property (high-slip fence).
- DH is allocating £10,000.
- 1 person who is at risk of admission to an inpatient setting will be able to remain safely at home with his family.

### **Bexley**

- Grant funding will be used to adapt a property (to provide transitional accommodation for young adults with learning disabilities who are coming through Bexley's Local Colleges First programme).
- DH will allocate £43,000.
- A number of young adults have been identified as preparing to transition and at risk of admission to inpatient settings and will use this property to enable them to develop independence.

### **Birmingham**

- Grant funding will be used to pay for adaptations to a property.
- DH is allocating £262,158.
- 3 people in inpatient settings will move to this property.

### **Bristol**

- Grant funding will be used to make adaptations (an annex) to a property owned by Golden Lane Housing?.
- DH will allocate £104,000.
- 1 person in an inpatient setting will move to the property.

### **Bury**

- Grant funding will be used to adapt a property (to provide an environment for people with learning disabilities to obtain the necessary life and domestic skills needed to manage a property).
- DH will allocate £35,000.
- A number of young people in residential settings preparing to transition to adult services and at risk of admission to inpatient settings will benefit from this facility.

### **Camden**

- Grant funding will be used to make adaptations to a property.
- DH will allocate £120,000.
- 1 person at risk of admission to an inpatient setting will move to this property.

### **Cheshire West**

- Grant funding will be used to make adaptations to a property.
- DH will allocate £373,168.
- A mixture of 6 people in inpatient settings or at risk of admission to inpatient settings will move to this property.

### **Darlington**

- Grant funding will be used to pay for adaptations to a property in Darlington.
- DH is allocating £60,000.

- 1 person who has been in an inpatient setting for over 10 years will move to this property.

### **Derby**

- Grant funding will be used to make adaptations to 2 3-bedroomed properties in the council's existing stock or already under construction.
- DH will allocate £36,100.
- 3 people in inpatient settings, 2 people at risk of admission to inpatient settings and 2 people at risk of re-admission to inpatient settings will move to these properties.

### **Devon**

- Grant funding will be used to pay for a housing deposit, adaptations, mortgage arrangement and legal fees to properties in Devon.
- DH is allocating £800,000.
- 6 people in inpatient settings or currently not suitably housed within the community will move to these properties.

### **Dorset**

- Grant funding will be used to develop a 2 bed safe haven in partnership the local Housing Trust.
- DH will allocate £120,000.
- 20-30 people are on the Council's list of named individuals at risk of admission to inpatient settings should their current placement break down and are most likely to use a safe haven.

### **Gateshead**

- Grant funding will be used to make adaptations to properties managed by Gateshead Housing Company.
- DH will allocate £52,000.
- A mix of 10 people in inpatient settings, or at risk of admission to inpatient settings, or at risk of re-admission to inpatient settings will move to these properties.

### **Gloucestershire**

- Grant funding will be used to pay for adaptations to properties.
- DH will allocate £200,000.
- 8 people preparing to transition into adult services at risk of admission to inpatient settings will move to these properties.

### **Greenwich**

- Grant funding will be used to pay for adaptations to properties in Greenwich.
- DH is allocating £100,000.
- 5 people currently in inpatient settings or at risk of admission will move to these properties.

### **East Riding**

- Grant funding will be used to make adaptations to 2 properties.
- DH will allocate £113,561.
- 2 people in inpatient settings will move to these properties.

### **Hammersmith and Fulham, Kensington, Chelsea and Westminster**

- Grant funding will be used to support shared ownership of bespoke housing in the locality.

- DH will allocate £900,000.
- 6 people in inpatient settings identified as ready for discharge and suitable for this approach to housing will be supported to become shared ownership candidates.

### **Hampshire**

- Grant funding will be used to build 2 properties.
- DH will allocate £800,000.
- A mix of 6 people either in inpatient settings or at risk of admission to inpatient settings will move to these properties.

### **Hertfordshire**

- Grant funding will be used to make adaptations to a property identified by the person below and his family as a place they are happy to move to.
- DH will allocate £26,000.
- 1 person in an inpatient setting will move to this property.

### **Hull**

- Grant funding will be used to make adaptations to a property.
- DH will allocate £200,000.
- The property will provide a respite facility for people identified in the locality as at a high risk of admission to inpatient settings.

### **Islington**

- Grant funding will be used to make adaptations to a property.
- DH will allocate £50,000.
- The adaptations are focused on additional flexible space within an existing specialist support accommodation scheme. These will enable the space to be turned into sensory rooms in line with sensory profiles for each tenant. Funding will also be used to install 2 garden studios to provide more space for tenants (in particular those with autism who find community-based accommodation challenging).

### **Kensington and Chelsea**

- Grant funding will be used to make adaptations to properties.
- DH will allocate £10,000.
- 2 people currently being supported at a locally commissioned crisis bed unit at high risk of admission to inpatient settings will move to these properties.

### **Leicestershire**

- Grant funding will be used to purchase a property (to provide step down transitional support accommodation for up to 6 people a year and permanent accommodation for a further 2 people with learning disabilities) and a further 2 bedroomed property.
- DH will allocate £391,700.
- 16 people either in inpatient settings, at risk of admission to inpatient units or at risk of re-admission to inpatient units will move to these properties.

### **Newcastle**

- Grant funding will be used to pay for adaptations to properties.
- DH will allocate £60,000.
- 5 people at risk of admission to inpatient settings will move to these properties. A further 7 people at risk of re-admission to inpatient settings will also move to these properties.



### **Newham**

- Grant funding will be used to make adaptations to 2 properties.
- DH will allocate £130,000.
- 2 people in inpatient settings will move to these properties.

### **Norfolk**

- Grant funding will be used to pay for adaptations to a property (convert to 2 self-contained units of 2-bed and 1-bed accommodation).
- DH is allocating £50,000.
- 3 people at risk of admission to inpatient settings will move to this property.

### **North Lincolnshire**

- Grant funding will be used to make adaptations to 10 properties.
- DH will allocate £25,000.
- 10 people at risk of admission to inpatient settings will move to these properties.

### **Nottinghamshire County**

- Grant funding will be used to pay for adaptations to properties (350k for bungalows and adaptations to a step up/step down interim residential care home for service users to avoid or leave hospital early whilst the Council finds them suitable supported housing, and 65k for a scoping exercise to look at the potential to use land owned by the Council for supported housing).
- DH will allocate £415,000.
- 20 people in inpatient settings will move to these properties with a further 3 identified as benefitting from bespoke accommodation in the future.

### **Richmond**

- Grant funding will be used to contribute to the capital build development of a supported living scheme (4 apartments and 2 additional communal areas).
- DH is allocating £250,000 which will add to matched funding from the Mayor's Care and Support Specialised Housing Fund and £100,000 from the Recycled Capital Grant Fund.
- 3 people in transitional phases from in-patient settings to more local or more individualised services will move to this development.

### **Shropshire**

- Grant funding will be used to make adaptations to properties.
- DH will allocate £25,000.
- 2 people in inpatient settings will move to these properties.

### **Southend**

- Grant funding will be used to make adaptations to properties.
- DH will allocate £165,000.
- 3 people either in inpatient settings or at risk of admission to inpatient settings will move to these properties.

### **Waltham Forest**

- Grant funding will be used to make adaptations to properties.
- DH will allocate £385,000.

- 3 people at risk of admission to inpatient settings will be supported to remain living with their families and/or in community supported housing. 6 people being cared for out of the borough at risk of admission/re-admission to inpatient settings will move to one of the adapted properties.

### **Warwickshire**

- Grant funding will be used to pay for alterations to a property.
- DH is allocating £39,914.
- 1 person who is in a residential college as an emergency placement will move to this property.

### **Wiltshire**

- Grant funding will be used to purchase and adapt a property.
- DH will allocate £580,000.
- 1 person at risk of admission to an inpatient setting will immediately move to the adapted property, which will also be used to support 2 or 3 individuals at any one time who are at risk of admission as well.

### **Worcestershire**

- Grant funding will be used to pay for adaptations to a property (convert to 2 self-contained units).
- DH is allocating £60,000 which will add to £20,000 invested by Worcestershire County Council's capital funding resources.
- 3 people at risk of admission to inpatient settings will move to this property.

**TOTAL - £6,991,601**

### **Appendix 3 – Cross-Government Learning Disability Board Membership**

#### **Chair**

Norman Lamb, Chair, Minister for Care and Support

#### **Stakeholders**

Karen Flood - Co-Chair National Forum of People with Learning Disabilities (Supported by Paula Camborne)

Craig Hart - Co-Chair National Forum of People with Learning Disabilities (Supported by Catherine O'Byrne)

Vicki Raphael - National Valuing Families Forum

Julia Erskine - National Valuing Families Forum

Dan Scorer - Mencap

Ciara Lawrence – Mencap (Supported by Ailis Hardy)

#### **External Delivery Partners**

Alan Rosenbach – Care Quality Commission

Karen Dodd - The LD Professional Senate

Jane Cummings - NHS England

Dominic Slowie – NHS England

Rupert Nichols - NHS Confederation

Andrea Pope-Smith / Rosy Pope – Association of Directors of Adult Social Services learning disability lead

Katie Hall – Local Government Association

Sally Burlington – Local Government Association

David Sallah – Health Education England

Gyles Glover – Public Health England

Peter Kinsey – Care Management Group (representing providers)

#### **Other Government Departments**

Nicolette Divecha/ Berenice Napier / Jill Lindley - Department for Business, Innovation and Skills

Helen Nix - Department for Education

Yacoob Woozeer – Department Work & Pensions

#### **Department of Health**

Jon Rouse – Director General, Social Care, Local Government and Care Partnerships

Sarah McClinton – Director, Mental Health and Disability

Frances Smethurst - Deputy Director, Learning Disabilities and Autism

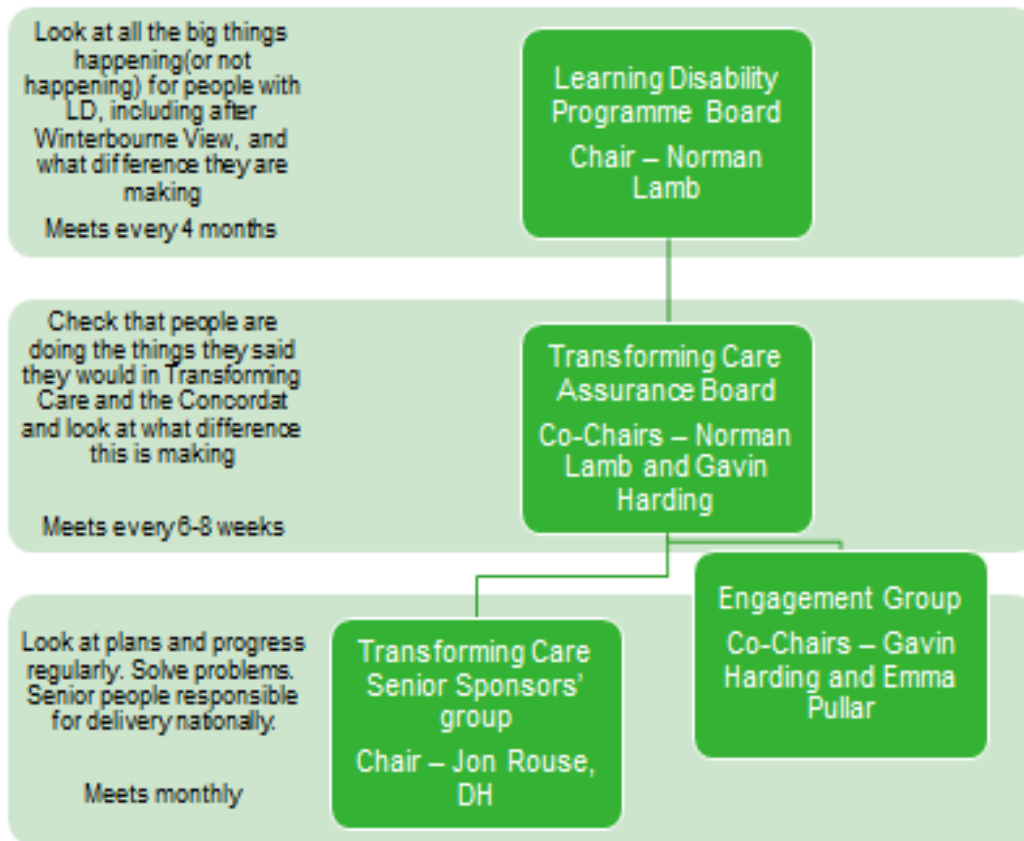
Ben Thomas - Professional Lead Nursing Mental Health and Learning Disability

Secretariat provided by Department of Health Learning Disability policy team

## Appendix 4 – Diagram of high-level governance of Transforming Care

Figure 4

### Assuring progress – High level governance



8

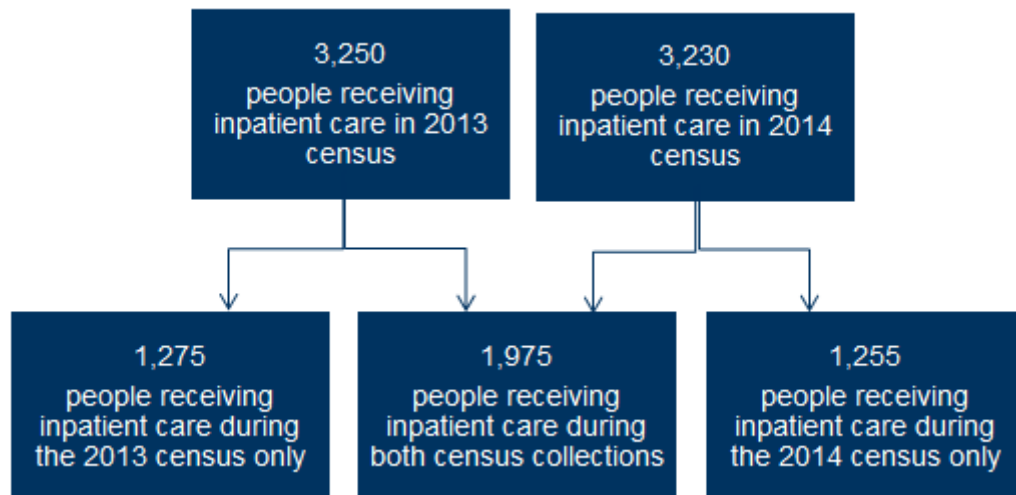
Refer to appendix 7 for a written description of this flowchart.

## **Appendix 5 – Transforming Care Assurance Board Membership**

- Norman Lamb, Co-Chair (Minister of State for Care & Support)
- Gavin Harding, Co-Chair (National Forum of People with Learning Disabilities)
- Jon Rouse (Department of Health)
- Sarah McClinton (Department of Health)
- Sally Burlington (Local Government Association)
- Jane Cummings (NHS England)
- Hazel Watson (NHS England)
- Juliet Beal (NHS England)
- Martin McShane (NHS England)
- Dr Dominic Slowie (NHS England)
- Alan Rosenbach (Care Quality Commission)
- Karen Flood (National Forum of People with Learning Disabilities)
- Andrea Pope-Smith (Association of Directors of Adult Social Services)
- Viv Cooper (National Valuing Families Forum)
- Terry Parkin (Association of Directors of Children's Services)
- Kate Shethwood (Association of Directors of Children's Services)
- Dr Katie Armstrong (Clinical Commissioning Groups)
- Professor Gyles Glover (Public Health England)
- Professor Eric Emerson (University of Lancaster)
- Professor Tony Holland (University of Cambridge)
- Dave Williams (Salford Council)
- Lynne Winstanley (NHS Improving Quality)
- Sir Leonard Fenwick (NHS)
- Beverley Dawkins (Challenging Behaviour - National Strategy Group)
- Sarah Carter (Department for Education)
- Ann Earley (Winterbourne View family member)
- Emma Pullar (Winterbourne View Joint Improvement Programme, Engagement Strategy Group)

## Appendix 6 - Learning Disability Census 2014 Visual Diagrams

Figure 1: Census counts for 2013 and 2014

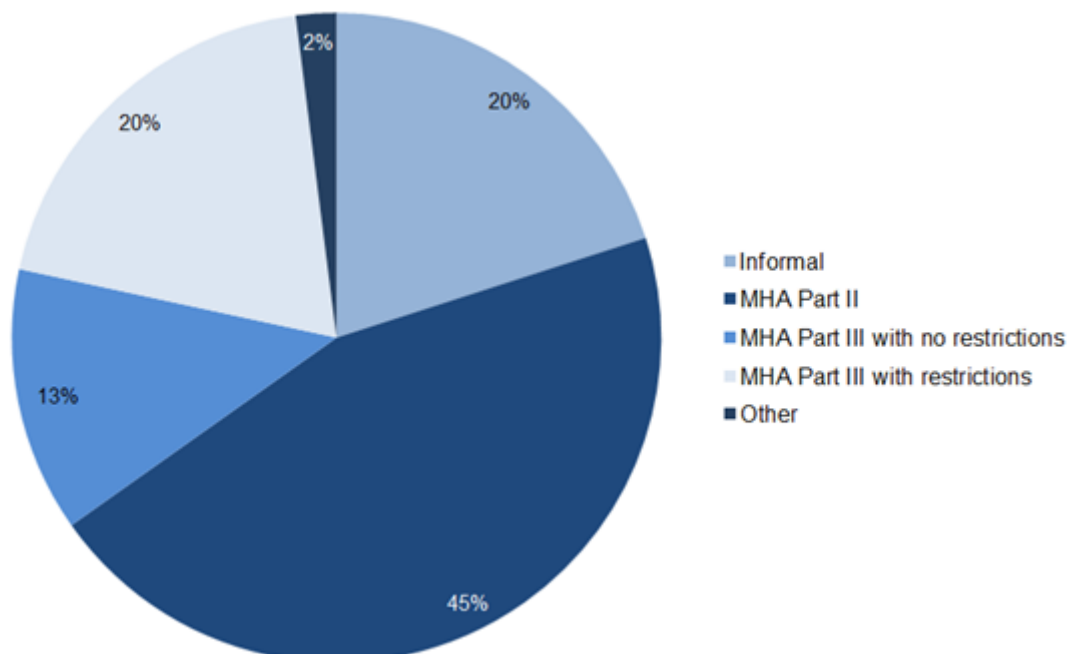


Source: HSCIC Learning Disability Census 2014 <http://www.hscic.gov.uk/pubs/lcensus14>

Base: All patients (3,250 in 2013 & 3,230 in 2014)

Note: Analysing 'first admission' date information for returns to the 2014 census identified 370 patients who had an admission date prior to the 2013; this suggests that they would have been receiving inpatient care at the time of the 2013 census. This group of people fall within the group receiving care in the 2014 census only (1,255 patients)

Figure 2: Percentage of patients detained under the Mental Health Act on census day 2014



Source: HSCIC Learning Disability Census 2014 <http://www.hscic.gov.uk/pubs/lcensus14>

Base: All patients (3,230)

**Table 1: Number and percentage of patients by main treatment reason for being in inpatient care on census day 2014**

	Number	Percent
<b>Total</b>	<b>3,230</b>	<b>100%</b>
<b>Need inpatient care for treatment reason</b>	<b>2,545</b>	<b>79%</b>
of which:		
Current behaviour assessed as too risky for Ministry of Justice to agree any reduction in security level	485	15%
Continuing need for inpatient care of mental illness	1,365	42%
Continuing behavioural treatment programme	695	21%
<b>Do not need inpatient care for treatment reason</b>	<b>440</b>	<b>14%</b>
of which:		
Local step-down placement in inpatient psychiatric unit preparatory to community resettlement being actively sought	200	6%
New community placement actively being sought as previous placement no longer viable	230	7%
Residential care placement funding dispute	10	0%
<b>Other</b>	<b>245</b>	<b>8%</b>

Source: HSCIC Learning Disability Census 2014 <http://www.hscic.gov.uk/pubs/ldcensus14>

Base: All patients (3,230)

**Table 2: Number of patients with each behavioural risk on census day 2014**

	Any risk	Violence risk	Sexual risk to others	Sexual risk to self	Fire risk	Self-injury risk	Property risk
<b>Total</b>	<b>3,230</b>	<b>3,230</b>	<b>3,230</b>	<b>3,230</b>	<b>3,230</b>	<b>3,230</b>	<b>3,230</b>
Absent	455	920	2,050	2,420	2,775	1,635	1,675
Present	2,775	2,310	1,180	810	455	1,595	1,555
Of which:							
Present only	1,990	1,795	955	715	395	1,390	1,375
Severe enough to require hospital treatment	785	515	225	95	60	210	185

Source: HSCIC Learning Disability Census 2014 <http://www.hscic.gov.uk/pubs/ldcensus14>

Base: All patients (3,230)

Note: Figures for 'present' aggregated 'present only' and 'severe enough to require hospital treatment' at source, these were rounded for this table. Reference data table 5 shows un-aggregated data, due to rounding; summing the reference data table figures may give slightly different results.

**Table 3: Number and percentage of patients by gender with at least one incident grouped into adverse experiences and/or restrictive measures three months prior to census day 2014**

	Total	Number		Percent	
		Male	Female	Male	Female
<b>All patients</b>	<b>3,230</b>	<b>2,400</b>	<b>830</b>	<b>100%</b>	<b>100%</b>
<b>No incidents</b>	<b>1,450</b>	<b>1,155</b>	<b>295</b>	<b>48%</b>	<b>36%</b>
<b>At least one incident</b>	<b>1,780</b>	<b>1,245</b>	<b>535</b>	<b>52%</b>	<b>64%</b>
<i>of which:</i>					
Adverse experiences only	660	495	170	21%	20%
Restrictive measures only	295	240	55	10%	7%
Incidents of both type	820	510	310	21%	37%

Source: HSCIC Learning Disability Census 2014 <http://www.hscic.gov.uk/pubs/ldcensus14>

Base: All patients (3,230)

Note: 'At least one incident' is shown here rounded from raw data. This can be calculated from the reference data table 20 but due to suppression the totals may not add up

Adverse experiences (accidents, physical assault and self-harm) Restrictive measures (hands on restraint and seclusion), Adverse experiences include accidents, physical assault and self-harm; restrictive measures include hands on restraint and seclusion.

**Table 4: Number and percentage of patients by use of antipsychotic medication in the 28 days prior to census day 2013 & 2014**

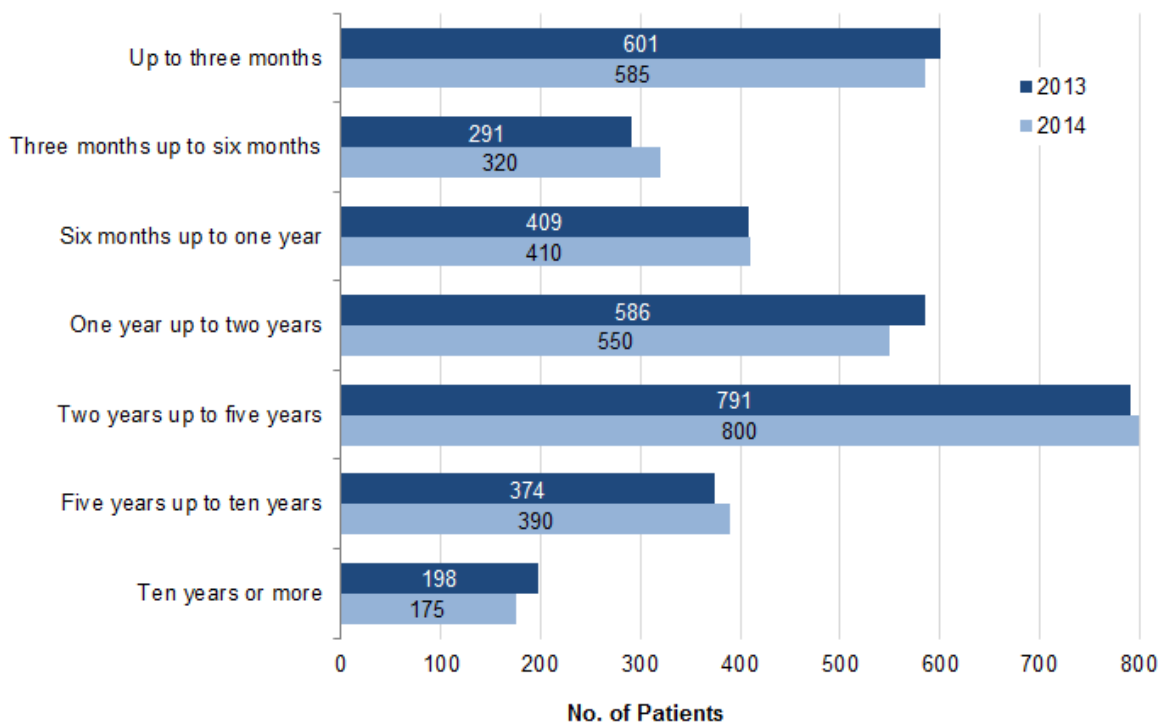
	Number		Percent	
	2013	2014	2013	2014
<b>All Service Users</b>	<b>3,250</b>	<b>3,230</b>	<b>100%</b>	<b>100%</b>
<b>None</b>	1,030	885	32%	27%
<b>Yes</b>	2,220	2,345	68%	73%
<i>of which:</i>				
Regularly	1,316	1,680	40%	52%
PRN	156	150	5%	5%
Both Regularly and PRN	748	515	23%	16%

Source: HSCIC Learning Disability Census 2014 <http://www.hscic.gov.uk/pubs/ldcensus14>

Base: All patients (3,250 in 2013 & 3,230 in 2014)

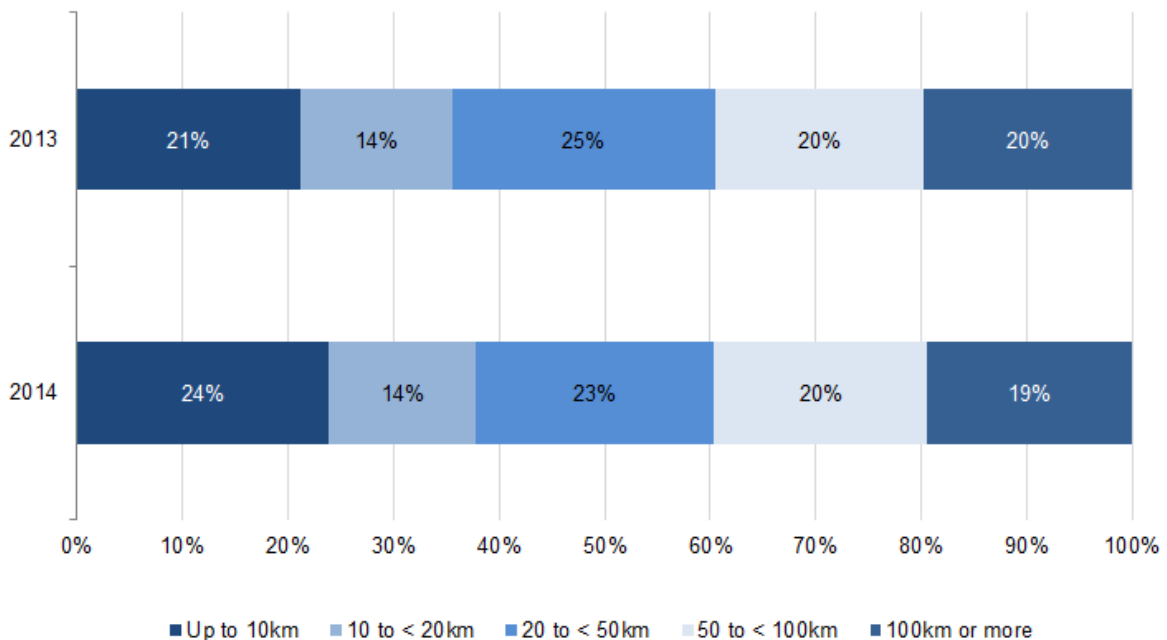


**Figure 3: Length of stay on census day 2013 & 2014**



Source: HSCIC Learning Disability Census 2014 <http://www.hscic.gov.uk/pubs/ldcensus14>  
 Base: All patients (3,250 in 2013 & 3,230 in 2014)

**Figure 4: Distance from home on census day 2013 & 2014**



Source: HSCIC Learning Disability Census 2014 <http://www.hscic.gov.uk/pubs/ldcensus14>  
 Base: All patients except for where distance from home is unknown or the same as the hospital (2,889 in 2013 & 2,950 in 2014)

## **Appendix 7 – Written descriptions of statistics and visual diagrams**

### **Figure 1**

This shows latest data from NHS England of numbers of people in inpatient settings and highlights improvements in the following areas:

More patients with planned transfer dates: 256 with/2358 without as at 30 March 2014; 577 with/2024 without as at 30 June 2014; 1680 with/920 without as at 30 September 2014.

More patients being recorded as being on a register: 2096 on/519 without as at 30 March 2014; 2135 on/466 without as at 30 June 2014; 2426 on/174 without as at 30 September 2014.

More patients who had their last review within the last 26 weeks: 2334 as at 30 March 2014; 2303 as at 30 June 2014; 2411 as at 30 September 2014.

More patients experiencing reduced lengths of stay for:

Less than a year 865 as at 30 March 2014; 935 as at 30 June 2014; 978 as at 30 September 2014.

1-2 years 522 as at 30 March 2014; 490 as at 30 June 2014; 486 as at 30 September 2014.

2-5 years 731 as at 30 March 2014; 686 as at 30 June 2014; 671 as at 30 September 2014.

More than 5 years 492 as at 30 March 2014; 485 as at 30 June 2014; 461 as at 30 September 2014.

Fewer patients without a care co-ordinator: 111 without/2503 with as at 30 March 2014; 96 without/2505 with as at 30 June 2014; 38 without/2562 with as at 30 September 2014.

Fewer patients who have had a care plan review in the last 12 weeks but do not have a planned transfer date: 1170 as at 30 March 2014; 1165 as at 30 June 2014; 501 as at 30 September 2014.

### **Figure 2**

This is a flowchart which describes the CQC's new approach to inspection.

On the top left of the flowchart is 'registration' under which is listed the following elements: rigorous test, legally binding and commitment to safe high-quality care.

Under 'registration' is 'intelligent monitoring' which lists the following elements: data and evidence, widen information sources and information from people.

At the other side of 'intelligent monitoring' is 'Expert Joint (MHA & regulatory) inspections' which lists the following elements: thorough, talking to people and staff and separate MHA visits to patients.

In between 'intelligent monitoring' and 'Expert Joint (MHA & regulatory) inspections' is a circle which links the two and is headed 'Quality of Care' with the 5 key questions – Safe? Effective? Caring? Responsive? Well-led?

The results of all the above feed into the single judgement and publication which is listed at the end of the flowchart with the following categories: outstanding, good, requires improvement and inadequate. These judgements inform action – regularity inspection and enforcement.

### **Figure 3**

This is a diagram to show the CQC's ratings process.

The first stage is to define the questions to answer – key lines of enquiry.

The second stage is to gather and record evidence from all sources. There is a jigsaw puzzle underneath this stage to show the four elements: ongoing local information from/about the provider, intelligent monitoring, pre-inspection information gathering and on-site inspection.

The third stage is to make judgements and build ratings. This involves applying consistent principles, build ratings from the recorded evidence.

The fourth stage is to write the report and publish alongside the ratings. These comprise either outstanding, good, requires improvement or inadequate.

### **Figure 4**

There are three parts to this flowchart which describes the high level governance arrangements for the Transforming Care programme.

At the top of the flowchart is the Learning Disability Programme Board chaired by Norman Lamb, Minister of State for Care and Support. The purpose of this group is to look at all the big things happening (or not happening) for people with learning disabilities, including after Winterbourne View, and what difference they are making. The group meets every 4 weeks.

In the middle of the flowchart is the Transforming Care Assurance Board which is co-chaired by Norman Lamb, Minister of State for Care and Support and Gavin Harding MBE. The purpose of this group is to check that people are doing the things they said they would do in Transforming Care and the Concordat and to look at what difference this is making. The group meets every 6-8 weeks. It feeds into the Learning Disability Programme Board.

At the bottom of the flowchart are two groups which feed into the Transforming Care Assurance Board. The Transforming Care Senior Sponsors' group chaired by Jon Rouse, Director General for Social Care, Local Government and Community Care Partnerships at the Department of Health, looks at plans and progress regularly and to solve problems. Senior people responsible for delivery nationally are members of this group. The group meets monthly. There is also the Engagement group which is co-chaired by Gavin Harding MBE and Emma Pullar.

### **2014 Learning Disability Census statistics:**

A written description about data presented in appendix 6 is described at paragraph 81 on pages 34-36.