Department of Health

Winterbourne View:

Transforming Care One Year On

Winterbourne View:

Transforming Care One Year On

Department of Health Update

Contents

Ministerial Foreword 5
Simon's Story 8
Chapter 1 - Right Care, Right Place, Right Time 9
Chapter 2 - Regulation; Inspection; Corporate Accountability 13
Chapter 3 - Quality and Safety: Good Practice, Standards and Advocacy 18
Chapter 4 - Information and Data 21
Chapter 5 - Quality and Safety: Medication, Positive Behaviour Support and Physical Interventions. 25
Chapter 6 - Quality and Safety: Workforce 28
Chapter 7 - Children and Transition 31
Appendix 1: Summary of progress on actions from Transforming Care & Concordat 34
Appendix 2: Joint Health and Social Care Self-Assessment Framework 2013 72
Appendix 3: Investment Summary 80

Ministerial Foreword

WINTERBOURNE VIEW: TRANSFORMING CARE – ONE YEAR ON

i. Winterbourne View was a scandal which shocked and appalled us all. The systemic failings there are as bad as those uncovered by Robert Francis in his report into Mid Staffordshire. We are not looking at one or two poorly-trained or malicious members of staff but at something much more insidious. That is why we need this full programme of work to address all the different aspects and underlying causes which allowed this to happen. We must take every step to be as sure as we possibly can be that this will not happen again.

ii. One key aspect to this is transparency, at every level. This report is a part of that transparency. It does not pretend that we have solved every problem, or even met every milestone in the extensive programme of work we put in place. We are involved with a wide range of partners across the health and care sectors and making full use of the expertise of people with learning disabilities themselves, and family carers. But the report is able to summarise an impressive array of the products of many people's commitment and effort.

iii. This report is a chance to remind ourselves how important it is that we get care right for people with learning disabilities and whose behaviour challenges. Reading through it you will see what looks like a lot of process – legislation, consultation, data collection and the rest - which can seem a long way from the people we are trying to care for. We need to get those processes right in order to get the care right, but we must never forget the real reason we're doing all of this, which is people.

iv. We have set ourselves, and the system, a series of major challenges with this programme. This report sets out how far we have come in a short time, and over a period of major upheaval as the NHS reforms have been implemented. A great many people have worked extremely hard to achieve this. Appendix 1 summarises progress across all the Concordat commitments, and provides links to all the products associated with them. These provide the springboard for the next phase of the programme.

v. In particular, we have between us

- Completed the Learning Disabilities Census;
- Published the Joint Improvement Programme's stocktake report, including information at local level;
- Established an Enhanced Quality Assurance Programme to pursue the June 2014 deadline;
- Developed a new planned approach to Care Quality Commission (CQC) inspection of mental health and learning disabilities services from next year, to be led by Professor Sir Mike Richards;
- Developed new fundamental standards, which we will set out in regulations;
- Ensured Adult Safeguarding Boards will be written into law.

December 2013

vi. However, while we take heart from all of this, we cannot begin to sit back. There is still a great deal to do. We still cannot point to routine evidence of the quality of outcomes from care – let alone demonstrate better outcomes. We know that there are individuals from Winterbourne View itself who are still not in the right care setting for them. We need to pick up the pace in order to meet our June 2014 milestones.

vii. We are all hugely impatient to see improved outcomes for the patients and families who need these services, and it is right that we should be. Our impatience and determination are what have driven this programme so quickly, and will take it to the next level. However we must also be patient if our changes are to be sustainable. Without the right preparation and groundwork we shall be wasting our time. Worse, we might end up actually causing harm.

viii. Our starting point for this work is the 48 former residents of Winterbourne View. Sadly, one has since died so we are now tracking progress for the remaining 47.

ix. For now, NHS England is keeping a track of where those residents are. One thing they do not need is media intrusion so we cannot identify them individually. We know that in June this year 24 of them were in residential care homes, 10 in supported living and 13 still in an NHS setting.

x. Of those 13, 5 were in assessment and treatment centres, 3 in medium secure and 5 in low secure settings. Sadly, 12 of these people were being cared for out of area.

xi. NHS England has established an Enhanced Quality Assurance programme (EQAP) which will be responsible for future collection of information about these patients, including – if the individuals consent to this – additional assurance that they have had high-quality reviews, have clear care plans and are receiving the best possible support.

xii. While we must not lose sight of the Winterbourne View residents themselves this programme of work goes much wider. *Transforming Care* estimated that there were 3,400 people altogether in NHS-funded learning disability inpatient beds. We now have data from the Learning Disabilities Census, commissioned as part of this programme, which found that on 30 September provider organisations reported that there were 3,250 service users meeting the inclusion criteria. From the commissioning side, NHS England and Clinical Commissioning Groups have identified 2,677 individuals. These data need now to be reconciled, using common definitions, but they tell us for the first time with some confidence the number of people we are talking about. They also show us that:

- Many people are spending a long time in inpatient care. 60% of service users had been inpatients for a year or more while around one in six had been inpatients for five years or longer. Older people were more likely to have these long lengths of stay.

- Patterns of care vary enormously across the country. More than half of inpatients with home postcodes in the South West were in placements more than 100 km from home, but fewer than one in ten from the North East were so far from home.

- Strikingly, providers could not supply a valid residential postcode for 28% of inpatients. Some providers were unable to supply this information for most of their inpatients.

xiii. This sort of information underlines, yet again, the scale of the task – as well as pointing out some clear areas for attention. One of these is to get behind the data and understand what is happening locally, as well as for individuals. While we expect the total inpatient numbers to come down over time, there will always be people who need this care and there will be some who need it for the long term. Always, our focus must be on what is right for individuals.

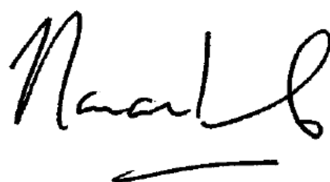
xiv. The target date for everyone to be in appropriate care is June 2014. This is one of the chief areas for impatience. The right care is more important than the exact date – but there is no excuse for delay.

xv. To get us to that point as quickly as possible we need to accelerate progress on the Concordat commitments. I have identified five key actions for the next six months. They are:

- Meet the commitment to ensure that individuals have moved or are moving to settings closer to family by June 2014.
- Establish robust systems for service users, their supporters and clinicians to feed into and challenge the initiatives being taken forward.
- Drive concerted effort to ensure that services are provided to a 21st century standard, including Positive Behaviour Support and guidance on minimising the use of restraint.
- Establish Key Performance Indicators, using data from the Single Assessment Framework and the census.
- Disseminate the model service specification to both children's and adults' services to that it can be used to drive up quality.

xvi. I do not pretend that this will be easy. The agenda is crowded and resource is tight. But we are spending public money, putting many people inappropriately in institutionalised care. This is intolerable.

xvii. We all remember the shock we felt when we first discovered what had been happening at Winterbourne View, and none of us wants to read that story happening again somewhere else.



NORMAN LAMB
Minister of State for Care and Support

Simon's story – by his mum

Once more I find myself recounting Simon's story but this time I do it with an element of hope.

Simon's story of his adult life starts when we were extraordinarily lucky to find a new, small care home just 10 minutes away from us. Simon was proud to be the first one in and he got first choice of bedrooms! Aged 18 he was to spend the next fifteen happy years here. His life was stable, he was close to his friends and family and had a rich, social life balanced with a community-based work placement.

But Simon also had unpredictable and sometimes challenging behaviour. The home put on an additional staff member to help Simon cope . This worked reasonably well with some extra funds from social services. But not for long.

We were told that Simon had to go away for assessment: this would "give him the best chance of obtaining that funding". Our objections were ignored: if we failed to agree "he would be sectioned and physically removed in an ambulance". It was to be over three years before Simon came home.

The new home was unable to deal with Simon. He was locked in the home, which made him behave worse and they resorted to using restraint. His psychiatrist (despite little day to day contact with him) said "he was too dangerous ever to return home."

He was moved again and the same things happened. We later learned that Simon had on at least three known occasions been subjected to illegal restraints. Simon was sectioned and sent to Winterbourne View where he endured 15 months of systematic and sustained torment both emotional and physical.

Simon has a phobia about toilets: the staff held his head down the pan and flushed it. They locked him overnight in an empty room with just a duvet. Sometimes they locked him out at mealtimes.

Uniquely, Simon was able to return to his original home where he was welcomed with open arms. But the staff noticed how he had changed, and how his life was now limited. His anger and frustration caused them huge problems but not once have they had to restrain him. Simon now self-harms quite badly at times. His anxiety has reached new heights so that his day has to be filled from start to finish.

Many things have changed for Simon but I strongly believe that being in a familiar place amongst family and friends has gone a long way towards healing some – though not all - of the damage. Amazing staff have cared for him and loved him. This shining example of care at its best has enabled Simon to manage his life in the community though at times the ability to do so has seemed very fragile.

This is Simon's story. And this is why Transforming Care is so badly needed.

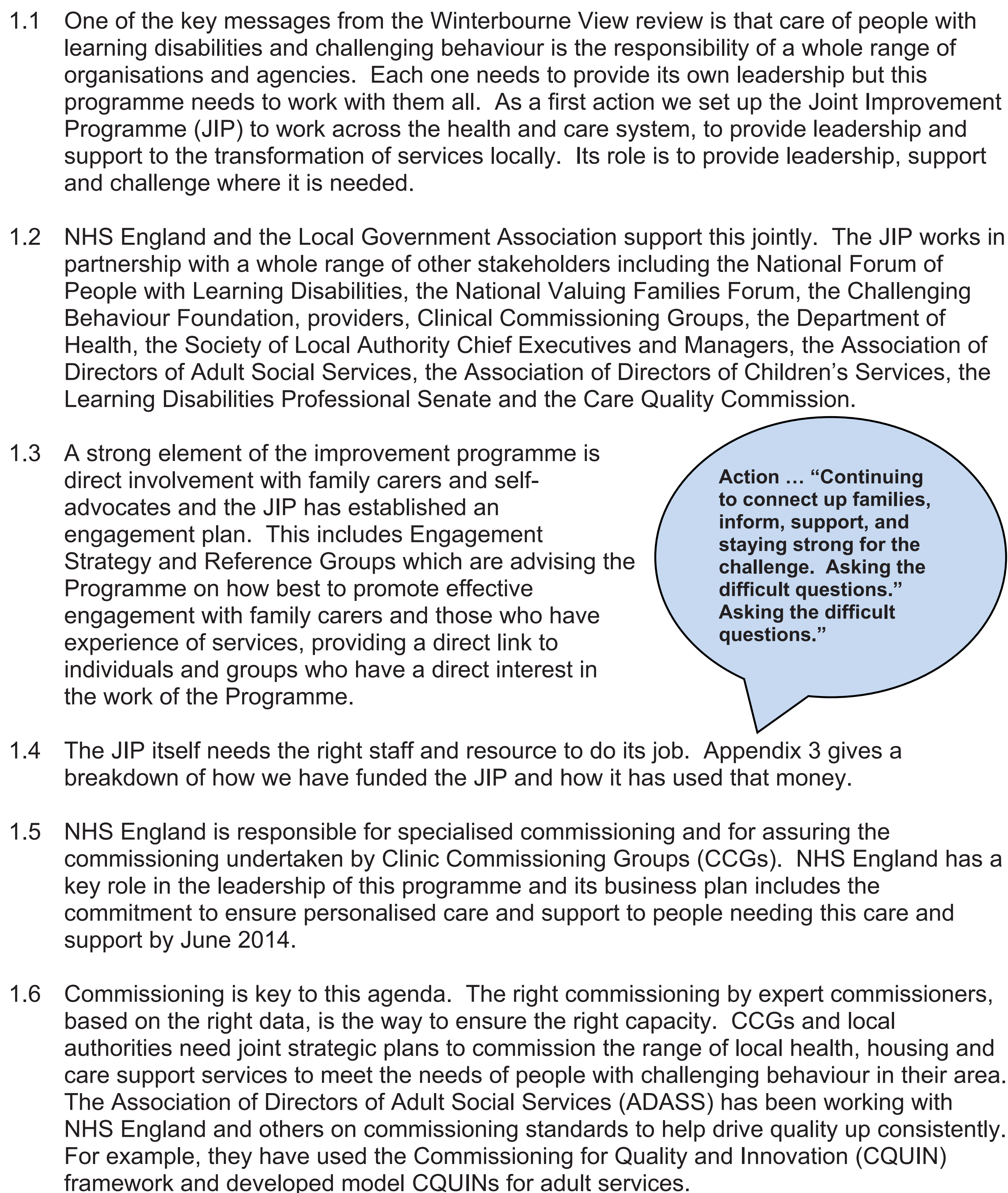
Chapter 1 - Right Care, Right Place, Right Time.

Reviewing placements and supporting everyone who is 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.

1.1 One of the key messages from the Winterbourne View review is that care of people with learning disabilities and challenging behaviour is the responsibility of a whole range of organisations and agencies. Each one needs to provide its own leadership but this programme needs to work with them all. As a first action we set up the Joint Improvement Programme (JIP) to work across the health and care system, to provide leadership and support to the transformation of services locally. Its role is to provide leadership, support and challenge where it is needed.

1.2 NHS England and the Local Government Association support this jointly. The JIP works in partnership with a whole range of other stakeholders including the National Forum of People with Learning Disabilities, the National Valuing Families Forum, the Challenging Behaviour Foundation, providers, Clinical Commissioning Groups, the Department of Health, the Society of Local Authority Chief Executives and Managers, the Association of Directors of Adult Social Services, the Association of Directors of Children's Services, the Learning Disabilities Professional Senate and the Care Quality Commission.

1.3 A strong element of the improvement programme is direct involvement with family carers and self-advocates and the JIP has established an engagement plan. This includes Engagement Strategy and Reference Groups which are advising the Programme on how best to promote effective engagement with family carers and those who have experience of services, providing a direct link to individuals and groups who have a direct interest in the work of the Programme.

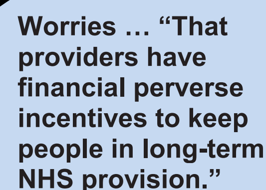


1.4 The JIP itself needs the right staff and resource to do its job. Appendix 3 gives a breakdown of how we have funded the JIP and how it has used that money.

1.5 NHS England is responsible for specialised commissioning and for assuring the commissioning undertaken by Clinic Commissioning Groups (CCGs). NHS England has a key role in the leadership of this programme and its business plan includes the commitment to ensure personalised care and support to people needing this care and support by June 2014.

1.6 Commissioning is key to this agenda. The right commissioning by expert commissioners, based on the right data, is the way to ensure the right capacity. CCGs and local authorities need joint strategic plans to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area. The Association of Directors of Adult Social Services (ADASS) has been working with NHS England and others on commissioning standards to help drive quality up consistently. For example, they have used the Commissioning for Quality and Innovation (CQUIN) framework and developed model CQUINs for adult services.

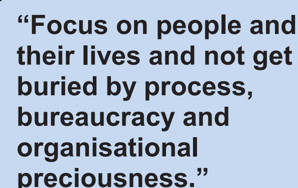
1.7 In addition, ADASS and the Care Provider Alliance published *Finding Common Purpose*[1], developing strategic commissioning relationships to support people with learning disabilities in November 2013. It suggests how commissioners can build on what works and avoid the "short term, adversarial relationships which can harm valuable services – and the people who depend on them".



CCG registers

1.8 A first step for the programme was to be sure that all local NHS commissioners knew who they were responsible for who fell within the scope of this programme. Data issues are a question in their own right and are covered in Chapter 4: *Transforming Care* recognised the challenges and Appendix 1 shows how much work has been going on to address them, but there is still more to do. By April 2013 all Primary Care Trusts had developed registers of all people with learning disabilities or autism who have mental health conditions or behaviour that challenges in NHS-funded care. These were handed over to CCGs. With the local authority, they have also undertaken reviews of care plans for all the people on the registers, and have identified someone who should be the first point of contact for each individual. CCGs identified 1,317 individuals for whom they had commissioned care. All of these people had had reviews by 31 July 2013.

1.9 In addition, NHS England undertook to monitor progress for specialised commissioners. This work identified 1,360 patients in specialised services. 46 of those people were either discharged or had transferred into a care setting (usually home) so an in-patient review was no longer required, and 10 more were found by the Area Teams not to need one for other reasons – for example, 4 were confirmed as not having a learning disability. The remaining 1,304 have all now had their care reviewed.



1.10 NHS England has - subject to formal approval by the Health Research Authority Confidential Advisory Group - established quarterly monitoring for NHS commissioners to ensure delivery of the June 2014 commitment. It will also ensure that all future reported figures are robust. It has also set up an Enhanced Quality Assurance Programme (EQAP) to ensure that that people are safe and to assure the quality of reviews. EQAP is looking at:

- Reviews of the former patients of Winterbourne View and others of concern;
- Assessment of the quality of reviews completed by NHS England and CCGs;
- Reviews of patients in providers (NHS and Independent Sector) where CQC has concerns.

1.11 The next – and most important – step is to put the newly agreed plans into action for each of these 2,621 individuals. This will be the test of the quality of the reviews and is now underway. At the same time, we must use the new Learning Disability Census information to make sure that we identify anyone who has been missed so far, and make sure that they too have plans in place.

[1] http://www.vodg.org.uk/news/316/111/Report-breaks-down-barriers-to-better-commissioning-of-learning-disability-services.html

1.12 The milestone date for all people with care and support needs to be receiving personalised care and support is June 2014. This is likely to prove challenging and is why the programme needs to pick up the pace. People with care and support needs and their families are at the centre of this and their needs are paramount. We have set the deadline to concentrate minds. We have learned from the Francis report that targets must not be allowed to take priority over good care. But neither can this be used as an excuse for not moving as swiftly as possible for the benefit of people with care and support needs.

1.13 This programme of work does not finish at the June 2014 deadline. We are aiming for sustainable improvements, not a quick fix. To meet our aims of delivering personalised care closer to people's homes and communities for the future means maintaining our focus on this work beyond the immediate timetable. Many of the people with care and support needs who have been in hospitals as in-patients for disproportionately long periods of time will need proper psychological support when they relocate to their home areas. This means that there are requirements for appropriate housing to be available, and teams with the skills needed to help people with institutionalisation and post traumatic issues based on their hospitalisation. These teams will also need the necessary support from professionals who can provide the continuing supervision, training and advice to enable them to respond to ongoing and new risks and challenges.

1.14 Work on the registers also showed that there was more to do to be sure that they were comprehensive. In particular, they need to capture people in secure services and those in the care of Child and Adolescent Mental Health Services (CAMHS). There are also a number of children and young people in residential schools away from home who need support to move back to community-based personalised care where that is the right setting for them.

The Housing Learning and Improvement Network has kept its members updated with key housing and safeguarding information through its newsletter and on its website. They have run learning and improvement workshops at regional "look and learn" events on safeguarding. With 46,000 members, 94% of whom read the newsletter, this is an effective way of communicating to a key audience.

Local planning

1.15 The JIP conducted a detailed stocktake with all Local Authorities, CCGs and Health and Wellbeing Boards. Every locality returned the questionnaire. The local work to complete the stocktake itself created much of the discussion and decision making needed to meet the Concordat requirements.

1.16 The stocktake returned some very encouraging information. It showed that all localities were engaged and working on the Concordat commitments and that there is a bedrock of skilled and committed staff at commissioner, care management and provider levels, and in leadership roles supporting change.

1.17 It also found significant variations between localities. Although the programme emphasises the importance of joint ownership across health and social care, only 49% of returns had clearly been completed jointly. For the remainder, in 18% of returns it was unclear whether they were a shared effort and the rest had evidently been handled by one or other part of the system. This suggests that there are still issues of leadership to be addressed and the JIP will be dealing with this as a priority, working with partners to develop options. However, if this work finds continuing underperformance, there is backstop provision in regulation to support local authorities, while NHS England has powers which it can use as appropriate.

Pooled budgets

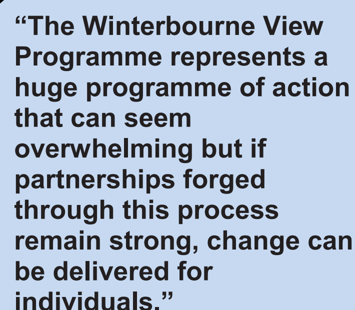
1.18 Shared funding arrangements go alongside shared leadership in ensuring that people's care is determined by their needs rather than by bureaucratic processes. The Concordat highlights pooled budgets as the way to achieve this. The stocktake showed that these are still not widely used, although some localities use other mechanisms to support the flow and flexibility of resources. This is another area for further work by the JIP.

1.19 Where this flexibility is not available, it appears that rigid and sometimes arbitrary division between areas of commissioning are acting as a brake on progress. This clearly needs attention and the JIP will develop this when it undertakes local in-depth reviews as part of its development programme.

Chapter 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.

2.1 Transforming Care is high on the agenda for the Department of Health. The Learning Disability Programme Board leads on delivery of this programme of change by measuring progress against the Concordat's milestones, monitoring the risks to delivery and publishing regular updates. The Board is chaired by the Minister of State for Care and Support and by Jon Rouse, Director General for Social Care, Local Government and Care Partnerships. The Board includes people with learning disabilities and representatives of family carers to keep it honest and grounded in the reality of what it is trying to achieve.



2.2 The Board's papers are available online to ensure full transparency. This report has been published to meet a specific commitment in the Concordat. The Department of Health has held two Concordat events to share progress and invite feedback. Throughout this report there are quotations from some of those who attended the event on 5 November, including people with learning disabilities themselves.

2.3 This report begins with a case study – Simon's story. It reminds us powerfully why this programme was, and is, needed.

> **Mencap and the Challenging Behaviour Foundation** have campaigned with the families of people who were at Winterbourne View, and others, to keep these issues high on the national and local agendas.
>
> They have ensured that families have a voice with Ministers and key decision makers. Their involvement is greatly appreciated.

Regulation

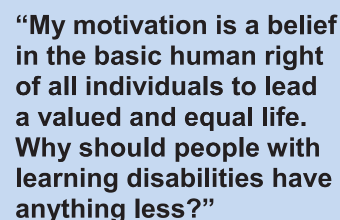
2.4 The Care Quality Commission (CQC) has undertaken a rigorous process of development and consultation to change the way it inspects services for people with learning disabilities and improve systems and checks when providers apply to register a service.

2.5 These changes improve the statement of purpose, and provide guidance for registration assessors on site visits and interviews with registered managers. These raise the bar and require that providers set out in their statement of purpose how values-based recruitment is handled and how care staff are inducted, trained and supervised against appropriate standards and best practice. Aspirant registrants must also indicate how their proposed service fits with the model of care as set out in the Concordat. Organisations must now

identify individuals at Board level who have day to day accountability and responsibility for quality, safety and compassionate care.

Inspection

2.6 The CQC has set out its strategy for inspections over 2013-16. Its inspections of hospitals, including those with learning disabilities services, will be led by Professor Sir Mike Richards, the Chief Inspector of Hospitals. There will be a pilot wave of some of these services, using the new methods, in January 2014. However, where there is information and evidence of concerns about quality and safety CQC will continue to respond and inspect services as part of their programme of work.



2.7 Inspections of adult care learning disability services will be led by Andrea Sutcliffe, the Chief inspector of Adult Social Care. The new approach to adult care inspections will be trialled from spring 2014. In the meantime CQC will continue to inspect adult care services as part of its on-going programme.

2.8 This programme involves unannounced inspections of providers of learning disability and mental health services. CQC will be asking about issues such as the length of time people have been in assessment and treatment units. As well as the professional staff involved in this, CQC is using experts by experience: service users and their families are part of the inspection team to ensure that their perspective is not lost in the formalities of standards and paperwork.

The Helsey Group – an independent service provider and a member of the Adults with Learning Disabilities Services (ALDS) Forum – has taken action where they felt most attention was needed without waiting for further national guidance.

Their Non-Executive Board members are each taking personal responsibility for visiting each of their services every two months. This is in addition to quality monitoring visits from the arm's length quality team. The Chief Executive Officer is undertaking fortnightly walkabouts of services.

Quality indicators and outcomes provided at Board meetings include physical intervention, complaints, quality assessments, and health and safety information. The company has facilitated full and frank discussion with the Non-Executive board if there are concerns.

Corporate Accountability

2.9 The previous accountability arrangements failed to detect the true picture at Winterbourne View hospital. The Department of Health committed to examine how corporate bodies and their Boards of Directors can be held to account for the provision of poor care and harm.

2.10 In July 2013 the Government issued a consultation on *Strengthening Corporate Accountability in Health and Social Care*. This proposed a new requirement that all Board

Directors (or equivalents) of providers registered with the Care Quality Commission must meet a new fitness test. This will apply to providers from the public, private and voluntary sectors.

2.11 The failings at Winterbourne View centred on abuse and assault, while those at Mid Staffordshire involved neglect. Although the symptoms differ there are similarities in the underlying causes. The Francis report of the inquiry into Mid Staffordshire NHS Foundation Trust published in February 2013 raised concerns about corporate accountability which apply to both care settings. *Hard Truths*,[2] the final Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry, published in November 2013, 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.

2.12 *Hard Truths* announced that the Government will establish a new fit and proper person's test for Board-level appointments, which will mean that the Care Quality Commission is able to bar Directors who are unfit from individual posts at the point of registration. Where a Director is considered by the Care Quality Commission to be unfit it could either refuse registration, in the case of a new provider, or require the removal of the Director on inspection, or following notification of a new appointment.

2.13 Further details will be set out in the response to the consultation on corporate accountability which will be published shortly. The Government plans to publish the draft regulations for consultation at the same time and to introduce the new regulations during 2014.

Golden Lane Housing (Mencap's housing arm) has successfully launched a £10 million bond which they have used to invest in housing across the country for people with a learning disability.

They have provided new tenancies in community-based settings for over 137 people with a learning disability in the first six months of this financial year. This is through a combination of housing acquired through the bond resources and housing leased form other landlords. We are exploring how this model might be used more extensively.

Fundamental Standards

2.14 The Care Quality Commission (CQC) has consulted on its approach to regulating providers of health and care services. When inspections are carried out in any care setting, teams will ask five key questions - is a service safe, effective, caring, responsive and well led?

2.15 The Department of Health has been working with the CQC to develop a set of fundamental standards and will consult on these in due course.

2.16 These will set a clear bar for the safety, effectiveness and compassion below which standards of care should not fall. There will be immediate and serious regulatory consequences for services where care falls below these levels, including services going

[2] *Hard Truths: the Journey to Putting Patients First*

into special measures, being prosecuted, or having their registration and licensing withdrawn.

2.17 The CQC published the responses to its public consultation on 17 October 2013, which showed that there is agreement with the new approach.[3] The Department will consult shortly on the draft regulations which will set in legislation the fundamental standards of care that providers must meet. The new regulations will come into effect during 2014 and 2015 and will apply to all providers of health and social care that are required to register with the CQC.

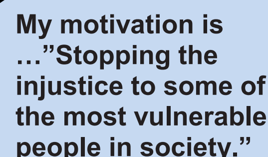
United Response has reviewed its whistle blowing policy and is implementing a full review of its Quality Assurance system.

They have set up a trustees' ethics committee to sign off case studies and photos of people who cannot demonstrate capacity to consent under the mental capacity Act but whose stories will help raise awareness of people with profound disabilities in a positive way. They are finalising a checklist for managers to use when supporting people moving from an institutional setting to the community.

They are revising Challenging Behaviour and Physical Intervention Standards to clarify responsibilities and develop standardised local and national reporting procedures for the use of physical interventions.

Duty of candour

2.18 The Government will introduce an explicit, statutory duty of candour as a Care Quality Commission registration requirement. The duty will apply to health and adult social care providers of regulated activities and will be enforced using the CQC's powers. This duty will ensure that providers are open with patients and service users about failings in care and provide an explanation and, where appropriate, an apology. As a further incentive for Trusts to promote a culture of openness across their organisations, the Government will consult on proposals about whether Trusts should reimburse a proportion or all of the NHS Litigation Authority's compensation costs when they have not been open about a safety incident.



2.19 Similarly, the General Medical Council, the Nursing and Midwifery Council, the Health and Care Profession Council and others will be working to agree consistent approaches to candour and reporting of errors, including a common responsibility across doctors and nurses and other health professionals to be candid with patients when mistakes occur whether serious or not, and clear guidance that professionals who seek to obstruct others in raising concerns or being candid would be in breach of their professional responsibilities. The Department of Health will ask the Professional Standards Authority to advise and report on progress with this work. The professional regulators will develop new guidance to make clear professionals' responsibility to report 'near misses' or errors that could have led to death or serious injury, as well as actual harm, at the earliest available opportunity and will review their professional codes of conduct to bring them into line with

[3] http://www.cqc.org.uk/public/news/support-our-inspection-changes

this guidance. The professional regulators will also review their guidance to panels taking decisions on professional misconduct to ensure they take proper account of whether or not professionals have raised concerns properly and openly.

Chapter 3 - Quality and Safety: Good Practice, Standards and Advocacy

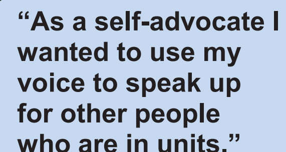
Improve quality and safety so that best practice in learning disability services becomes normal practice. Ensuring good information and advice, including advocacy, is available to help people and their families.

Advocacy

3.1 The complexities of the health and care systems, and the complexity of the needs of individuals, mean that people with learning disabilities and their families have a particular need for well trained and independent advocates. These services can be invaluable in negotiating a path through the options, ensuring that everyone understands what is happening and why.

3.2 The Joint Improvement Programme (JIP) covered advocacy in its stocktake and the results were encouraging. 85% of localities reported that advocacy services were 'routinely available', and 76% said that they had confidence in the quality of advocacy support. Some areas were also able to describe how they evidenced the availability and quality of advocacy. However, the overall figures in the responses do not match the experience reported by third sector organisations and family carers. Their reports fit better with the smaller number of places who say that they have inclusive reviewing arrangements in place. In some places there are problems with the quality of advocacy services, while in many others there are problems around easy access to advocacy services.

3.3 This mismatch means that this is a significant area for follow-up by the JIP, which plans now to explore further the availability and quality of advocacy services both locally and regionally.



3.4 The Department has been working with independent advocacy organisations such as Inclusion North to improve the quality of the services available. The Department also works with Independent Mental Capacity Advocate (IMCA) services in some of the regional networks, with discussions of recent case-law. IMCA services have been active in considering which people need access to the Court of Protection, and have started acting as Litigation Friends, enabling people to have access to courts where there is no one else to bring a case in front of a judge.

3.5 Underlining the importance of advocacy, the Care Bill has been amended to introduce a duty on local authorities from 2015 to provide independent advocacy in certain circumstances where it is considered that a person would otherwise experience substantial difficulty in being involved in their social care assessment, support planning or review. This will apply to adults and carers as well as children and young people at points of transition. The next step is to develop draft regulations and guidance to flesh this out. These will be ready for consultation in Spring 2014.

3.6 As part of the work to improve quality, the Department has been supporting work to strengthen the Action for Advocacy (A4A) Quality Performance Mark (QPM) and review

the Code of Practice for advocates to clarify their role. The QPM is the only national advocacy-specific quality assessment system which applies to all forms of one to one advocacy. Organisations can be awarded the QPM if they meet specified quality standards which demonstrate their commitment and ability to provide high quality independent advocacy. The Department of Health entered into an agreement with A4A to take this work forward. However, A4A have ceased all operational activity and, following an interview with its trustees, its acting Chief Executive and representatives from Department of Health, the responsibility for taking forward the future of the QPM national advocacy accreditation scheme, has been passed to the National Development Team for Inclusion (NDTi) in order that the commitment given in *Transforming Care* can be delivered.

3.7 NDTi will aim to undertake a review of the Quality Performance Mark (QPM) and Code of Practice (CoP), alongside associated materials, within this financial year. Their aim is that the revised tools will be ready for re-launch by April 2014.

3.8 At a local level, Inclusion North have developed a scope of work to provide people with learning disabilities with good access to information, advice and advocacy in hospital.

Inclusion North
The North East advocacy project aimed to develop thinking around advocacy in specialist services that was more than a paid professional role. This example shows what can happen when people are supported to come together to explore rights and speak up on more than an individual basis.

Mr F had lived at home with family for all of his life. He came into hospital for a period when he was very unhappy and unsettled and his behaviour was challenging to the family. Mr F was asked if he was interested in coming along to the self-advocacy group and, with time and support to understand what it all meant, he agreed. Mr F came along to the group every week for the 12 weeks. He grew in confidence from week to week and became a vocal member of the group. It was noticed on the ward that he had more to contribute on a day to day basis. Mr F said being part of such a group had been great for helping him speak up and learn about his rights. He said that he has now spoken up about what he wants for his future and people are listening. He said he would come back to hospital to share his story and tell people it's not that scary after all.

3.9 The Department is committed to work with the Local Government Association (LGA), Healthwatch England and the NHS to embed the importance of involving people with learning disabilities and their families in all planning and decision making which affects them. The LGA and Local Healthwatch England has agreed a joint work programme to address this. There is a national Healthwatch implementation team in place and working with local commissioners.

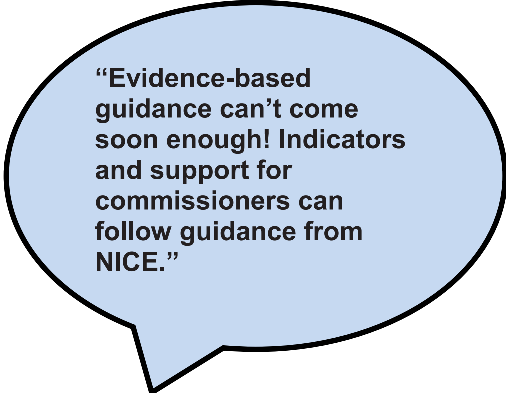
Healthwatch England has agreed with the National Valuing Families Forum that local Healthwatch should be supported to engage and work with people with learning disabilities. They are finalising the approach to producing tools to support this, with guidance from NVFF. This will help people with learning disabilities to hold local commissioners and providers to account. Healthwatch England will be seeking out feedback from people with learning disabilities and learning disability partner organisations about their engagement with local Healthwatch.

3.10 On the provider side, in September the Driving Up Quality Alliance launched a code for organisations to follow, based on Think Local Act Personal Making It Real Principles. This

aims to translate the high level vision into practical terms which will engage individuals on a personal level. It recommends that providers take responsibility for improving their services. Providers need to make a commitment first to listen to the people they support and then to support them to build lives that have meaning for them.

NICE Quality Standards

3.11 National Institute for Health and Care Excellence (NICE) Quality Standards are helpful and influential to both commissioners and providers, setting out evidence-based definitions and measures of quality. Clinical guidelines set out clearly and in detail what good practice should look like. NICE's collaborative and inclusive production process means that key organisations are involved in developing these materials.



3.12 The Concordat includes commitments that NICE will publish quality standards and clinical guidelines on challenging behaviour and learning disability. This is well under way. The clinical guideline will ready for publication in May 2015. They will be doing the same for mental health and learning disability but this work is not due to start yet. Winterbourne View stakeholders, including representatives of carers and families, have been involved. while Mencap are a stakeholder on NICE quality standards.

Chapter 4 - Information and Data

Ensure transparent information and robust monitoring to deliver transformed care and support and make sure the public, people with challenging behaviours and families know if we are making progress

4.1 *Transforming Care* reported that there was a major intelligence gap in this area. There was little clarity on the number of people with behaviour that challenges in hospital settings, or on who was responsible for them. Since then there has been a great deal of activity to improve the situation which has itself uncovered a series of challenges. In particular, we need to agree on the definitions we use for both the individuals and the care settings. This is not simply a technical issue. While there is scope for misunderstanding on the current scale we shall struggle to state with confidence that we understand the position fully, either nationally or locally.

Learning Disability Census

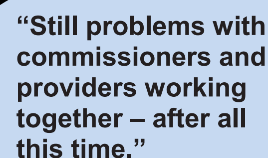
4.1 In *Transforming Care* the Department committed to commission “an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and length of stay”. This is a provider-based exercise, covering mental health and learning disability providers in the statutory, voluntary and private sectors. The Health and Social Care Information centre (HSCIC) collected and analysed the data. The full results published on 13 December can be found on their website.[4]

4.2 The census date was 30 September 2013. All localities provided data.

4.3 3,250 services users met the inclusion criteria for the 2013 Learning Disabilities Census. This is larger than the total of 2,677 identified by Clinical Commissioning Group’s (CCGs) as people in services they commission, and by NHS England for specialist commissioning. It is smaller than the 3,400 estimated in *Transforming Care*. This is a moving population, with people entering and leaving it, which complicates the picture, but commissioners will be anxious to use this information to triangulate with their own, so that they can be certain about numbers of people for whom they are commissioning care – and this is not always as simple as it might seem: Chapter 2 describes how NHS England’s monitoring of progress by specialised commissioners almost immediately found 56 people out of their initial 1,360 who no longer met the criteria. Complexities of definition – such as the understanding of “challenging behaviour” - and complexities of care commissioning are likely to be the other main reasons for the discrepancies, and the Joint Improvement Programme (JIP) and NHS England have been waiting for the census results to be able to work to reconcile the numbers. We know that the data in this area present significant challenges and a great deal of work has already gone on to resolve them. More is still needed and the census is a major contribution.

[4] http://www.hscic.gov.uk/ldcensus

4.4 The Local Government Association (LGA) and NHS England are today publishing local status reports which will be an important step in resolving these issues. These follow up the JIP stocktake published in October. Status reports show the numbers of people who are currently funded by CCGs, though where CCGs and local authorities do not share boundaries this can be less straightforward. Specialist and forensic commissioning is more complex and works to different boundaries. For each of the ten specialist areas it is now urgent that local areas (CGG and local authority) working with specialist commissioners and area teams, agree the local numbers and then work together from the reviews on the commissioning and funding challenges.



4.5 There are key findings from the census which will help to direct this work. Overall, providers could not supply a valid residential postcode for 28% of inpatients. Some providers were unable to supply this information for most of their inpatients. This clearly needs to be resolved before we can be confident that systems are joining up to provide the best care for these people, and in particular that everything is being done to maintain contacts with family, friends, advocates and commissioners.

4.6 On out of area placements, the census found that just over one in five inpatients were staying in wards 100km or more from their residential postcode. About the same proportion were within 10 km of their home postcode.

4.7 There were wide regional variations in how close to home people were cared for. More than half of those with home postcodes in the South West were in placements more than 100 km from home, while this was the case for fewer than one in ten of those from the North East. Almost 40% of service users who lived in London received inpatient care within 10 km of home, while in the South East this applied to almost 20% - reflecting the difference between urban centres and more rural areas. Appendix 2 illustrates the variation at Local Authority level between people from that location known to have a learning disability and people known to be receiving inpatient treatment in that location.

4.8 On length of stay, 60% of service users had been inpatients for a year or more while around one in six had been inpatients for five years or longer. Length of stay varied with age: around 40% of patients aged 65 and over had been inpatients for five years or more, around twice the proportion for all inpatients. Service users aged 18 and under were much more likely to have been inpatients for three months or less: more than 45% of them were in this position compared with almost 19% overall.

4.9 This audit provides baseline data so that we can track progress for the future. We shall be repeating the census next year.

Self-assessment framework

4.10 The Concordat included a commitment that NHS England and Association of Directors of Adult Social Services (ADASS) would implement a joint health and social care self-assessment framework to monitor progress of key health and social care inequalities from April 2013. These data would be published at local as well as national level, so that commissioners and providers can see how they are performing against the average and against their peers. The framework has been implemented and data from local areas have been collected by Public Health England's Learning Disabilities Observatory. Data collection finished only on 6th December, so there has not been time to report the findings in detail here. A full analysis will be published early in the New Year. Appendix 2 provides an overview of the coverage of the exercise and a number of key results with direct relevance to the Joint Improvement Programme.

Local Stocktake

4.11 The Joint Improvement Programme stocktake captured a wide range of information from all localities. It was designed to provide comprehensive, detailed and helpful feedback to both commissioners and providers about strengths and development needs. It is not a formal data collection like the census. The analysis was undertaken to regional level, providing a high level picture. However, for full openness and transparency – and to make it as practically useful as possible - it has now been developed to show details on a place by place basis. This shows progress in commissioning, funding and work to meet the June 2014 deadline set out in the Concordat. This material has been published at the same time as the One Year On report, and gives local areas the information they need to identify the real, practical steps they need to take from here.

Key Performance Indicators

4.12 Key Performance Indicators (KPIs) are essential to allow both the Learning Disabilities Programme Board and local areas to get a firm grip on how services are working locally. However it is also critical to choose the right KPIs. The Francis Report underlines the danger of perverse incentives, with the risk that organisations will concentrate on hitting the target while missing the point.

4.13 This means that the process of developing KPIs is necessarily longer than we would like. We have to be certain that we are using the right definitions, that everyone understands them in the same way, and that we are not inadvertently building in problems for the future. Department of Health, Health and Social Care Information Centre (HSCIC) and NHS England have been working together to produce initial draft KPIs. The areas under consideration are:

- Proportion of inpatients with stays of 6 months / 1 year / 2 years whose discharge has been delayed due to a lack of appropriate discharge destination.
- Total number of incidents of challenging behaviour and physical restraints per inpatient per year
- Proportion of inpatients with Care Programme Approach (CPA) review and care plan (or other assessment and review) within the last 6 months.
- Total number of safeguarding alerts / serious untoward incidents per in patient per year.
- Total number of people moved from inpatient to community settings in a given number of months
- Total number of complaints over a given number of months
- Achievement of person centred planning outcomes
- Number of in-patient days in all mental and behavioural in-patient care in all sectors (NHS and independent) in the quarter for people with learning disabilities and /or autistic spectrum conditions
- The number of children in residential special schools with learning disabilities
- The number of current in-patients, at the end of each quarter who have been in hospital throughout the quarter, in all mental and behavioural in-patient care in all sectors (NHS and independent) with learning disabilities and / or autistic spectrum conditions
- The number of current in-patients who have had a face to face clinical review with the psychiatry of learning disabilities team for their home area within the quarter.

4.14 This range shows the challenge of finding forms of data which actually measure outcomes and quality. We must remember, for example, that for some people residential care is the right care. The Health and Social Care Information Centre (HSCIC) indicator development team is now checking underpinning data sources and the robustness of the draft KPIs themselves. The next step will be to test the drafts with stakeholders, including engaging with family carers and self-advocates and we are anxious to ensure that people have a full opportunity to contribute views and suggestions. The final KPIs will be ready for implementation from April 2014.

Chapter 5 - Quality and Safety: Medication, Positive Behaviour Support and Physical Interventions

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.

The Mental Health Act 1983

5.1 Winterbourne View raised very serious concerns that the principles and safeguards of the Mental Health Act 1983, and the Mental Capacity Act 2005 were not being correctly applied to individuals. People were having their freedom and movement constrained without clear justification. The principles of personalisation in the NHS Constitution were also being ignored.

5.2 To address this, the Department of Health is leading a cross-system review of the implementation of Mental Health Act 1983 and is due to consult on changes to the Code of Practice in early 2014. The Department is also reviewing implementation of the Mental Capacity Act 2005 and is committed to work with the Care Quality Commission (CQC) to agree how best to raise awareness of and ensure compliance with Deprivation of Liberty Safeguards provisions. This is a serious issue: it is unlawful to deprive someone of their liberty outside of these provisions. That work is under way and is due to report by Spring 2014.

5.3 Alongside this, the English Community Care Association (ECCA) undertook to produce extra support and explanatory material for its members on Deprivation of Liberty Safeguards and Human Rights. Those materials will be published, in conjunction with the Joint Improvement Programme, in April 2014.

Safeguarding Adults Boards

5.4 The Department of Health had an existing commitment to put Safeguarding Adults Boards on a statutory footing. This will be achieved through the Care Bill which has now reached its second reading in the House of Commons. The Department will revise both statutory and good practice guidance to reflect new legislation and, specifically, to address the findings from Winterbourne View. The Care Bill, and those supporting materials, will be implemented from 2015.

5.5 In the meantime, and to prepare for this, the Concordat sets out the need for Safeguarding Adults Boards to review their existing arrangements. In particular, they need to be sure that they have the right information sharing processes in place across health and care to enable them to identify and deal with safeguarding alerts.

5.6 Association of Directors of Adult Social Services (ADASS) has pursued this and found that many Safeguarding Adults Boards had considered Winterbourne View issues and looked at local arrangements. The Joint Improvement Programme (JIP) stocktake picked up

concerns expressed at the first Concordat event about assurance mechanisms, and was able to provide reassurance that there was reasonable evidence of local understanding and use of safeguarding processes.

Spotting abuse early

5.7 A major concern from Winterbourne View was the length of time individuals had been subject to abuse before anything was done about it. The police recognise that they have a role to play here. Avon and Somerset police have developed a process to trigger early identification of abuse, which they are now using. In January 2014 the police will plan how to disseminate this nationally. All associated learning will be incorporated into training and practice, including Authorised Professional Practice.

Positive Behavioural Support and the minimisation of restrictive practices

5.8 Positive Behavioural Support (PBS) is a technique to identify what environmental factors and other influences can be used to discourage problematic behaviour and encourage desirable behaviour. It can reduce the need for interventions such as physical restraint, chemical restraint, mechanical restraint and seclusion. It therefore has huge potential to improve the quality of life and outcomes for individuals across health and social care and in particular those treated in inpatient settings or in residential care.

5.9 The Concordat committed the Department of Health, with external partners, to publish guidance on best practice around positive behaviour support and the minimisation of restrictive practices across health and adult social care. The Royal College of Nursing agreed to take the lead role in producing this with a group of clinical professionals and experts by experience. They will publish a draft for consultation by the end of December 2013 and the Department of Health will publish a final version of the guidance by the end of March 2014. Aligned with this, Skills for Care and Skills for Health are developing a framework for commissioning training and other workforce development activities in positive behaviour support, including physical interventions as part of this approach.

5.10 In the summer Skills for Care published a framework for commissioning learning and development more generally in the context of support for people whose behaviour may challenge. Work now is focused on implementation of the workforce commissioning framework.

5.11 As part of the Concordat, the British Psychological Society (BPS) has undertaken to provide leadership to promote training in, and appropriate implementation of, Positive Behavioural Support across the full range of care settings.

5.12 To meet this commitment, 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. This work has the potential to contribute more widely to a programme to reduce restrictive practices and restraint.

5.13 Winterbourne View also raised questions about whether people were being given the right medications to improve their condition, or whether they were being over-medicated for the benefit of staff. The JIP has commissioned two reviews of current data held on the prescribing of antipsychotic and antidepressant medication for people with learning disabilities and challenging behaviour. These reviews are with the CQC and Medicines and Healthcare Products Regulatory Agency. In September 2013, NHS Improving Quality (NHSIQ) was commissioned to lead on scoping and establishing a collaborative to share learning and develop best practice to address these prescribing issues. It will launch in early 2014.

5.14 CQC is also carrying out an audit of use of medication for those patients with a learning disability detained under the Mental Health Act based on the Second Opinion Appointed Doctors (SOAD) data that they hold. It is a six month retrospective review. The output will give an insight into the way medications are used and the basis for their use. It will also set out how CQC can routinely capture the information.

5.15 All of this work needs to be effectively aligned and coordinated, including with the work by National Institute for Health and Care Excellence (NICE) to develop quality standards, and fundamental standards for CQC registration. In order to embed the required training, cultural and leadership changes required the Department is currently working with partners to develop a wider work programme to reduce restraint/restrictive practices across health and adult social care, including in particular learning disability and mental health services. This should allow us to maximise the benefits offered by synergies, avoid wasteful duplication and ensure that we do fundamentally transform services.

Chapter 6 – Quality and Safety: Workforce

Improve quality and safety through improving the capability of the workforce so that staff are properly trained in essential skills supported by good clinical and managerial leadership. Health and care professionals should understand and be supported in achieving minimum standards and aspire to best practice. Staff should feel it is safe to raise concerns when things go wrong and be listened to.

6.1 Workforce development is key to successfully changing the way in which people are supported. In the last year a range of different organisations have been involved in meeting the workforce challenges raised by Winterbourne View.

6.2 Appendix 1 sets out detailed progress on the different resources that are either in preparation or have been completed. Skills for Care has been working with the Department of Health, providers, clinical leaders, commissioners, carers and people with care and support needs to improve skills and capability to respond the needs of people with complex needs. The new resources in preparation include:

- Guidance for social workers on good practice in working with people with learning disabilities who are distressed or whose behaviour challenges those around them.
- Good practice standards for commissioners and providers to promote reasonable adjustments to meet the speech, language and communication needs of people with learning disabilities / autism in specialist hospital and residential settings.
- A refreshed “Challenging Behaviour: A Unified Approach” to support clinicians in community learning disability teams to provide better integrated services.
- Minimum standards of conduct and training for all healthcare workers and social care workers (published).
- A guide for social care employers on how good workforce development can aid positive behaviour support.
- A guide to different mental health inpatient services available for people with learning disabilities, mental health and or other needs.
- Core principles on a statement of ethics to reflect wider responsibilities in the health and care system.
- A progress report on implementation of the recommendations in *Strengthening the Commitment,* the report of the UK Modernising learning disability Nursing Review.
- Advice for employers on whistleblowing.

> **The Royal College of Nursing** highlights good practice in learning disability nursing.
> They provide support for the Learning Disabilities Academic network group.
> RCN has seen a year on year rise in Learning Disability forum membership.
> There is better awareness of learning disabilities career options, and better communication with the widest RCN membership.

6.3 Skills for Care is working with the Department of Health and partners on implementing the response to the Cavendish and Francis reports. A common theme is that all care workers need the right training, not just the traditional professionals such as doctors, nurses and social workers. That is behind the introduction of the Care Certificate. The Government has asked Health Education England to work with Skills for Care, Skills for Health and other stakeholders to consider how the ‘Certificate for Fundamental Care’ (now the Care Certificate) can be developed.

6.4 In addition to these activities other workforce development projects include a Skills for Care and Skills for Health workforce commissioning guide for social care and health employers on workforce development and the workforce development needs of workers who may need to carry out physical interventions, and a review of the curriculum for psychiatrists in training by the Royal Collage of Psychiatrists.

6.5 Social Care and Health employers have expressed a high degree of interest in using the workforce resources that have been developed.

6.6 Many of the workforce resources have sound advice and requirements.

6.7 Putting the resources into practice will require workforce development support and action that ensures that the reach and impact of the resources collectively can be measured. Most resources are aimed at one section of the workforce but their implementation requires changes to the workforce and organisational structure surrounding them as well as to the individual's practice.

6.8 Employers who provide services have suggested that working with commissioners can still be a challenge. An interest and commitment from commissioners in contracting to provide person-centred, effective and efficient, close to home support is not always evident. From a workforce development perspective this provides an opportunity to champion shared learning between commissioners, providers, people with care and support needs and family carers.

6.9 Commissioning and brokerage services should support families and individuals to find the right support and creatively build individual support packages. Families need to be supported to train individual support staff to work with their family member so the support is tailored. Workforce development support that enables these relationships to grow in the context of work in social care on assessment and eligibility will be important.

6.10 Ensuring that the workforce resources that have developed are widely shared, people and organisations know how to use them and know how the resources make an impact on how people are supported will be a key challenge over the next year.

6.11 *Hard Truths*, the response to the Francis Inquiry into Mid Staffordshire Foundation Trusts also set out a number of proposals which will help to improve services for people with learning disabilities. They are not aimed specifically at this group but people with learning disabilities should expect to benefit like anyone else from the range of developments including:

- **A new national safety website** which will publish all the information relevant to safety in every hospital in the country on a monthly basis, so that people with care and support needs have the same information about their hospitals that the system has.

- **A new national patient safety programme** across England to spread best practice and build safety skills across the country. NHS England will start the programme in April 2014 and will bring together frontline teams, experts, people with care and

support needs, commissioners and others to tackle specific patient safety problems, develop and test solutions, and learn from each other to improve safety.

- **A new criminal offence for wilful neglect**: the government will legislate at the earliest available opportunity to make it an offence to deliberately neglect patients - so that organisations and staff, whether managers or clinicians, responsible for the very worst failures in care are held accountable.

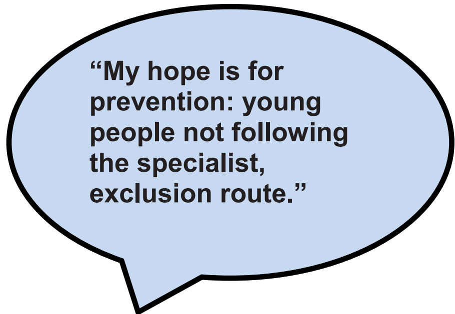
Chapter 7 - Children and Transition

To 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.

7.1 The Concordat's Programme of Action made clear that a life course approach needs to be adopted to transform health and care services and improve the quality of care offered to individuals with learning disabilities or autism who have mental health conditions or behaviour that challenges. If children and young people do not receive effective support at an early enough stage in life, it can set them on a path where their problems are exacerbated and their life chances affected. In responding to the terrible abuse which occurred at Winterbourne View a key issue has been to ensure that stakeholders representing children and young people, their families and carers, have been fully involved.

7.2 The Joint Improvement Programme has emphasised the commitment to this area by recently appointing a Special Advisor to lead on children and young people and life course planning, and recognising the development of the core service specification in line with the model of care in Transforming Care as a key piece of work yet to be completed.

7.3 The independent Children and Young People's Health Outcomes Forum has been asked to provide recommendations in relation to prioritising improvement outcomes for children and young people with behaviour that challenges and agree how best to support young people with complex needs in making the transition to adulthood. On behalf of the Forum, the National Network of Parent Carer Forums has issued guidance on integration of services for supporting children with complex needs in making the transition to adulthood, The Forum continues to be an advocate of supporting improved outcomes relating to the transition from children's to adult services and will recommend that supporting young people with complex needs, including autism or who exhibit challenging behaviour, is a significant element of the transition guidelines in development by the National Institute for Health and Clinical Excellence (NICE). The Department is working with NHS England in developing measures of the experience of care of children and young people, and the intention is that this will include meaningful measures of the effectiveness of transition. NHS England is developing a service specification for transition for the NHS.



7.4 Whilst progress has been slower than originally anticipated on the core service specification, there are now clear plans to produce a document for consultation in December 2013 which is focussed and practical and helpful and that will be used by commissioners. The all-age core specification will focus on how commissioners can ensure that high quality care and support are provided, with services designed around the needs of the individual and their family and provided as locally as possible. It will signpost how arrangements will change

with the passage of the Children and Families Bill, and provide clarity around the interface both with the commissioning of specialist health services and education. An Expert Advisory Group containing representatives from a number of key organisations bringing together their experience and expertise is supporting this work.

7.5 Work to align child health and learning disability data sets is underway and includes:

- a new learning disability measure was added to the Children and Young People's Improving Access to Psychological Therapies (IAPT) data set in October 2013;
- identification of those with learning disabilities in new large scale surveys of child health;
- a census of inpatient hospital beds for people of all ages with a learning disability or autism who may also have behaviour that challenges or a mental health condition;
- exploring and strengthening links between the availability of data on children and young people and adults through the work of the Child and Maternal Health Intelligence Network and the Learning Disability Observatory; and,
- developing links between data sets.

7.6 The Department of Health agreed funding in July 2013 for stage one of the two year development of a Disability E-Learning Portal by a Royal College of Paediatrics and Child Health (RCPCH) led Consortium. The Project Team for developing the e-learning portal were in post by early October 2013. This exciting project, which will specifically cover individuals with learning disabilities or autism who have mental health conditions or behaviour that challenges, will make available interactive online programmes to extend the skills and knowledge of

- NHS staff working with children and young people on evidence-based outcomes-focussed delivery;
- Staff working in universal settings, such as healthcare assistants, care home workers, teachers, social workers, police, probation, faith group workers, prison staff, to understand and recognise disability challenges and problems, particularly at the early stages, to provide simple strategies which staff can use to support children and young people where appropriate, and to help staff refer on where necessary.

7.7 In addition the Challenging Behaviour Foundation, in partnership with the Council for Disabled Children, is in receipt of three year project funding from the Department of Health to review and develop resources which support good practice in services for children and young people with learning disabilities and challenging behaviour and to work with stakeholder groups to increase the reach and access of these resources. The project started in July 2013.

7.8 The Children and Families Bill, which entered Committee Stage in the House of Lords on 6 October 2013, will extend the Special Educational Needs (SEN) system from birth to 25, giving children, young people and their parent's greater control and choice in decisions and ensuring needs are properly met. The Bill, in its current form, would introduce from September 2014:

- new joint-arrangements for assessing, planning and commissioning services for children and young people with special educational needs, which make it clear what will be offered, and who will deliver and pay for it, underpinned by a process to swiftly resolve local disputes between partners;

- a new local offer, so children, young people and their families are clear what is available locally, with a clear complaint process and redress system;
- local Education, Health and Care (EHC) Plans from 0 to 25 which set out in one place the support from education, health and care services children and young people will receive; with a new focus on helping to improve outcomes, including future employment and independent living;
- personal budgets for those families who want to have them; and,
- a duty on clinical commissioning groups (CCGs) (and in some cases, NHS England) as health commissioners to secure the provision of health services which they have agreed in the EHC plan, similar to the duty on local authorities in respect of special educational services.

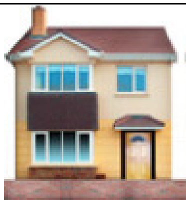
7.9 The Special Educational Need and Disabilities (SEND) pathfinder programme includes partnerships between local authorities and the health service to test out the new arrangements. This new approach has tremendous potential not only to ensure that children and young people who have extremely complex needs are supported with integrated packages of care planned and delivered according to their individual needs, but also to set an example to the wider NHS and social care of how to deliver integrated care co-ordinated around the patient.

7.10 The commitment to develop and issue statutory guidance on children in long-term residential care in 2013 is progressing well. The draft guidance has had input from external key stakeholders, and a revised draft will be shared between the Department for Education and the Department of Health at the start of December, which will then be sent for Ministerial approval.

Progress RAG: **RED** - Action significantly delayed
AMBER - Action delayed
GREEN - Action on track

APPENDIX 1

SUMMARY OF PROGRESS ON ACTIONS FROM TRANSFORMING CARE & CONCORDAT (DECEMBER 2013)



WORKSTRAND 1: RIGHT CARE, RIGHT PLACE, RIGHT TIME

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.

Ref No.	Action	Start Date	Finish Date	Progress RAG	Comments
13	The Local Government Association (LGA) and NHS Commissioning Board – (now NHE England) - will establish a joint improvement programme 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 support this work.	From Dec 2012	By March 2013		**COMPLETE** The Joint Improvement Programme (JIP) is in full operation. Chris Bull led as Programme Director, working part time, to November 2013. His successor is expected to be announced shortly.

Ref No.	Action	Start Date	Finish Date	Progress RAG	Comments
18A	The NHS England will work with Association of Directors of Social Services (ADASS) to develop practical resources for commissioners of services for people with learning disabilities, including new NHS contract schedules for specialist learning disability services		By March 2013		**ONGOING** An All Age Specification will be issued by the end 2013. This will replace the adult only specification.
18B	NHS England will work with Association of Directors of Social Services (ADASS) to develop practical resources for commissioners of services for people with learning disabilities, including models for rewarding best practice through the NHS; commissioning for Quality and Innovation (CQUIN) framework		By March 2013		**ONGOING** Model CQUINs for adults services are currently in draft and will be made available shortly.
18C	NHS England will work with Association of Directors of Social Services (ADASS) to develop practical resources for commissioners of services for people with learning disabilities, including a joint health and social care self-assessment framework (SAF) to support local agencies to measure and benchmark progress.		By March 2013		**COMPLETE** Data collection for the new SAF was completed in November 2013, working with Public Health England (PHE). http://www.improvinghealthandlives.org.uk/projects/hscldsaf. Analysis of the data can be found in Appendix 2 of this report
18D	NHS England will work with the Department of Health to set out how to embed Quality of Health Principles in the system, using NHS contracting and guidance.		By March 2013		**COMPLETE** NHS contract technical guidance includes the Quality of Life Principles at paragraph 9.38: http://www.commissioningboard.nhs.uk/nhs-standard-contract/

Ref No.	Action	Start Date	Finish Date	Progress RAG	Comments
19	NHS England and Association of Directors of Social Services (ADASS) will develop service specifications to support Clinical Commissioning Groups 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.		By March 2013		**ONGOING** An All Age Specification will be issued by the end 2013. This will replace the adult only specification.
20	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.		By March 2013		**COMPLETE** Commissioning guidance on Mental Health Services for People with Learning Disabilities was published in June. http://www.jcpmh.info/resource/guidance-for-commissioners-of-mental-health-services-for-people-with-learning-disabilities/
22	NHS England will ensure that all Primary Care Trusts develop local registers of all people with challenging behaviour in NHS-funded care.	From Nov 2012	By April 2013		**COMPLETE** All local areas are now using registers. Work continues to refine their quality and coverage.
25	The Department of Health will work with key partners to agree how Quality of Life principles should be adopted in social care contracts to drive up standards.		By 1 April 2013		**FINALISING TOOLKIT** Quality of Life standards have been written and tested and a toolkit to accompany the standards is in development. It will include a guide to “Quality Checking” which will outline underlying principles of quality checking work led by Experts by Experience. The toolkit describes some of the ways the Quality of Life standards are being used by commissioners to develop outcome based commissioning and by Council contracts departments to raise the quality of local support and provision. The standards and toolkit will be launched early in 2014.

Ref No.	Action	Start Date	Finish Date	Progress RAG	Comments
26	The NHS Commissioning Board will make clear to Clinical Commissioning Groups (CCG's) in their handover and legacy arrangements what is expected of them in maintaining local registers, and reviewing individual's care with the Local Authority, including identifying who should be the first point of contact for each individual.	From 1 April 2013	By June 2013		**COMPLETE** The NHSCB wrote to Regional Directors in January 2013. http://www.improvinghealthandlives.org.uk/uploads/doc/vid_18799_Letter%20to%20Regional%20Directors%20re%20Winterbourne%20view%2024.1.13.pdf NHS England wrote again to CCG's in June. http://www.improvinghealthandlives.org.uk/uploads/doc/vid_18800_130603%20Barbara%20Hakin%20WV.PDF
30	Care Quality Commission (CQC) will share the information, data and details they have about providers with the relevant Clinical Commissioning Groups (CCG's) and local authorities.		From April 2013		**ONGOING** CQC continue to provide information and data via the Joint Improvement Programme.
33	The strong presumption will be in favour of pooled budget arrangements with local commissioners offering justification where this is not done. The NHS Commissioning Board (now NHS England), Association of Directors of Social Services (ADASS), the Association of Directors of Children's Services (ADCS) will promote and facilitate joint commissioning arrangements.	From April 2013	Ongoing		**ONGOING** The stocktake showed that these are still not widely used, although some localities use other mechanisms to support the flow and flexibility of resources. This is another area for further work by the JIP.
34	NHS England will ensure that Clinical Commissioning Groups (CCGs) work with local authorities to ensure that vulnerable 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.	From April 2013	Ongoing		**ONGOING** The NHS England Business Plan includes a commitment to have achieved all the actions in the Concordat by June 2014. The Enhanced Quality Assurance Programme (EQAP) is working with CCGs and Area Teams.

Ref No.	Action	Start Date	Finish Date	Progress RAG	Comments
35	Health and care commissioners should use contracts to hold providers to account for the quality and safety of the services they provide.	From April 2013	Ongoing		**ONGOING** NHS England and the Joint Improvement Programme (JIP) are working with the Association of Directors of Social Services (ADASS) and the Association of Directors of Children's Services (ADCS) on information sharing. An all age core specification will be published alongside the NHS standard contract in December alongside other model specifications.
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.	From Nov 2012	By 1 June 2013		**COMPLETE** The main action is complete and work is ongoing by the Enhanced Quality Assurance Programme to understand and improve the quality of the plans.
57	Clinical Commissioning Groups (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.	From April 2013	By April 2014		**ONGOING** The Minister for care service Norman Lamb wrote to the chairs of all Health and Wellbeing Boards in May 2013. The Joint Improvement Programme (JIP) will be following this up as a priority, using the information from the stocktake. https://www.gov.uk/government/news/norman-lamb-highlights-role-of-health-and-wellbeing-boards-in-reforming-care-following-winterbourne-view

Ref No.	Action	Start Date	Finish Date	Progress RAG	Comments
58	Health and care commissioners should put plans into action as soon as possible and all individuals should be receiving personalised care and support in appropriate community settings no later than 1 June 2014.	From Nov 2012	By 1 June 2014		**ONGOING** NHS England through operational management arrangements is setting up quality monitoring to provide assurance. Their paper to the Learning Disability Programme Board in November sets out progress to achieving this by the June 2014 deadline. https://www.gov.uk/government/policy-advisory-groups/learning-disability-programme-board
65	The national market development forum within the Think Local Act Personal (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.	From June 2012	By 1 April 2013		**COMPLETE** Be Bold, developing the market for the small numbers of people with very complex needs, was published in December 2012. http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=9412 TLAP are now working regionally to ensure that this and other resources are being used.
66	The Developing Care Markets for Quality and Choice programme will support local authorities to articulate local needs for care services and produce market position statements, including for learning disability services.	From Dec 2012	By Dec 2014		**ONGOING** The Programme is being delivered by the Institute of Public Care, offering support to all English Local Authorities to help develop market position statements and provide a support toolkit. Work is progressing to plans with the expectation that almost all authorities will have received assistance by March 2014.

Ref No.	Action	Start Date	Finish Date	Progress RAG	Comments
67	The Department of Health 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 challenging behaviour.	Jan 2013	By Sep 2013		**ONGOING** NHS Confederation, with the Joint Improvement Programme, is producing guidance for Health and Wellbeing Boards.

SUMMARY OF PROGRESS ON ACTIONS FROM TRANSFORMING CARE & CONCORDAT (DECEMBER 2013)

WORKSTRAND 2: REGULATION, INSPECTION, CORPORATE ACCOUNTABILITY

Strengthen accountability and responsibility of providers, and their management, for quality of care. Tightening the regulation and inspection of providers.

Ref No.	Action	Start Date	Finish Date	Progress	Comments

Ref No.	Action	Start Date	Finish Date	Progress	Comments
1	Care Quality Commission (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.	From June 2012	Ongoing		**ONGOING** CQC published its fresh start approach to the regulation and inspection of mental health, learning disability and substance misuse services on 29/11/2013. The Chief Inspector of Hospitals will be responsible for the inspections of services for people with mental health needs, learning disabilities or autism, who are admitted to hospital to stay for assessment or treatment. This might include providing care, treatment and support for people detained under the Mental Health Act 1983 (MHA) or by an authorisation under the Mental Capacity Act Deprivation of Liberty Safeguards. The first wave of inspections will commence in January 2014.
2	Care Quality Commission (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.	From June 2012	Ongoing		**ONGOING** In September 2013 it was agreed by the CQC board that a project would be set up to address the unacceptably high number of locations operating without registered managers. CQC required all providers with locations that have been without a manager for more than 6 months to resolve that immediately or a fixed penalty notice would be issued. http://www.cqc.org.uk/sites/default/files/media/documents/chief_executive_report_to_board_12_sept.pdf

Ref No.	Action	Start Date	Finish Date	Progress	Comments
3	Care Quality Commission (CQC) will take enforcement action against providers who do not operate effective processes to ensure they have sufficient numbers of properly trained staff.	From June 2012	Ongoing		**ONGOING** NHS England, CQC and the Joint Improvement Programme (JIP) are working together on areas of concern. They are also working on an Enhanced Quality Assurance process. The *Hard Truths*, Francis response has set out additional requirements for staffing.
27	NHS England will hold Clinical Commissioning Groups (CCGs) to account for their progress in transforming the way they commission services for people with learning disabilities/autism and challenging behaviours.	From April 2013	Ongoing		**ONGOING** CCG's Winterbourne View action plans are included in NHS England's CCG assurance framework. http://www.england.nhs.uk/wp-content/uploads/2013/05/ccg-af.pdf

Ref No.	Action	Start Date	Finish Date	Progress	Comments
29	Care Quality Commission (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.	From April 2013	Ongoing		**ONGOING** Over the summer CQC consulted on their overall plans for inspection, and they are currently developing their models for inspecting, regulating and rating hospitals, GP and adult social care providers. In the coming year, CQC will produce guidance for each sector, and start to roll out their new inspection and ratings regimes, starting with Hospitals from January 2014. CQC published its Strategy for inspections over the period 2013-16 in April. It emphasises strengthening protection to those detained under the Mental Health Act. The link to the recently published fresh start for inspecting and regulating mental health services is here. http://www.cqc.org.uk/public/news/inspecting-and-regulating-mental-health-services
31	Care Quality Commission (CQC) will assess whether providers are delivering care consistent with the statement of purpose made at the time of registration.	From April 2013	Ongoing		**ONGOING** The registration changes that CQC have introduced include changes to the statement of purpose, guidance for registration assessors on site visits and interviews with registered managers. These raise the bar and require that providers set out in their statement of purpose that an organisation must name individuals at Board level who have day today accountability and responsibility for quality, safety and compassionate care. CQC will review existing statement of purpose. Future inspections will link the statement of purpose with fundamental standards.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
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.	From April 2013	Ongoing		**ONGOING** Monitor's licensing regime started in April 2013 for foundation trusts and it is anticipated that Monitor's full licensing regime will come into effect in April 2014. Monitor will review licensing in 2014, and will consider this issue as part of that review.
36	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.	From April 2013	Ongoing		**ONGOING** Providers have undertaken a range of actions to meet this commitment. The *Driving up Quality Code* (see action 43 for details) 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 organisation assess their own performance. The Care Quality Commission is changing the way they assess leadership and corporate responsibility in service providers for this sector.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
40	The Department of Health 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 Care Quality Commission (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.		By Spring 2013		**CONSULTATION COMPLETE, ONGOING WORK** In July 2013 the Government issued a consultation *on Strengthening Corporate Accountability in Health and Social Care.* https://www.gov.uk/government/consultations/improving-corporate-accountability-in-health-and-social-care The consultation proposed a new requirement that all Board Directors (or equivalents) of providers registered with the Care Quality Commission must meet a new fitness test. *Hard Truths*[5], the final Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry, published in November 2013, announced that the Government will establish a new fit and proper person's test for Board level appointments, which will mean that CQC is able to bar Directors who are unfit from individual posts at the point of registration. Where a Director is considered by the CQC to be unfit it could either refuse registration, in the case of a new provider, or require the removal of the Director on inspection, or following notification of a new appointment. Further details will be set out in the response to the consultation on corporate accountability which will be published shortly. The Government plans to publish the draft regulations for consultation at the same time and to introduce the new regulations during 2014.

[5] https://www.gov.uk/government/publications/mid-staffordshire-nhs-ft-public-inquiry-government-response

Ref No.	Action	Start Date	Finish Date	Progress	Comments
41	Care Quality Commission (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.	From Spring 2013	Ongoing		**ONGOING** The Department of Health has been working with CQC to develop a set of fundamental standards. These fundamentals will set a clear bar below which care must not fall. There will be immediate and serious regulatory consequences for services where care falls below these levels, including services going into special measures, being prosecuted or plans to withdraw registration and licensing. The CQC published the responses to its public consultation on 17 October 2013, which showed that there is agreement with the new approach[6]. In the new year, the Department of Health will consult shortly on the draft regulations which will set in legislation the fundamental standards of care that providers must meet. The new regulations will come into effect during 2014, and CQC will incorporate them in to their inspection and ratings regimes.
55	Care Quality Commission (CQC) will also include reference to the model in their revised guidance about compliance. Their revised guidance about compliance will be linked to the Department of Health 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.	From April 2013	By end 2013		**ONGOING** This change was introduced in July 2013. Work is now in hand on implementation. http://www.cqc.org.uk/organisations-we-regulate/services-people-learning-disabilities

[6] http://www.cqc.org.uk/sites/default/files/media/documents/cqc_newstartresponse_2013_14_tagged_sent_to_web.pdf

Ref No.	Action	Start Date	Finish Date	Progress	Comments
68	Department of Health 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.	Spring 2013			**COMPLETE** 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 will then keep the certificate up to date, meaning that instant online checks can be made by employers. Once subscribed the individual can take their certificate with them from role to role where the same type and level of check is required 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.
69	Care Quality Commission (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.	Jul-13			**COMPLETE** This now features in the new approach to registration for learning disability providers published in July 2013. http://www.cqc.org.uk/organisations-we-regulate/services-people-learning-disabilities

SUMMARY OF PROGRESS ON ACTIONS FROM TRANSFORMING CARE & CONCORDAT (DECEMBER 2013)

WORKSTRAND 3: GOOD PRACTICE, STANDARDS AND ADVOCACY

Improving 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.

Ref No.	Action	Start Date	Finish Date	Progress	Comments

Ref No.	Action	Start Date	Finish Date	Progress	Comments
49	The Department of Health will work with independent advocacy organisations to drive up the quality of independent advocacy.		In 2013		**ONGOING** The Care Bill, currently before Parliament will introduce a new duty on local authorities to arrange an independent advocate to be available to facilitate the involvement of an adult or carer who is the subject of an assessment, care or support planning or review if that local authority considers that the adult would experience substantial difficulty in understanding the processes or information relevant to those processes or communicating their views, wishes, or feelings Guidance will provide support to enable this to be translated into practice when the Bill becomes law in 2015.
7	The Department of Health 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.	From Dec 2012	March 2014		**COMPLETE** Inclusion North is working with commissioners, providers, people & families to share the outcomes from the North East advocacy project that offers learning on the broader role of advocacy & 'looking out for' as well as a commissioning framework and exploring commissioning advocacy models that provide more than paid professional advocacy. As well as regional workshops, all of the products are now on the Inclusion North website and there are reports and resources to help people, families and staff to think about advocacy and looking out for people. http://inclusionnorth.org/projects/what-we-are-doing-now/advocacy-project/

Ref No.	Action	Start Date	Finish Date	Progress	Comments
8	The Department of Health 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.	From Dec 2012	March 2014		**ONGOING** Action for Advocacy have ceased all operational activity. The responsibility for taking forward the future of the Quality Performance Mark (QPM) national advocacy accreditation scheme has been passed to the National Development Team for Inclusion (NDTi) in order that the commitment given in *Transforming Care* can be delivered.
24	The National Quality Board will set out how the new health system should operate to improve and maintain quality.	August 2012			**COMPLETE** The National Quality Board updated its guidance in January 2013 in the light of the Winterbourne View report. https://www.wp.dh.gov.uk/publications/files/2013/01/Final-NQB-report-v4-160113.pdf
39	The Department of Health will work with the Local Government Association (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.	From April 2013	Ongoing		**ONGOING** Healthwatch England has agreed with the National Valuing Families Forum (NVFF) that local Healthwatch should be supported to engage and work with people with learning disabilities and are finalising the approach to producing tools to support this. This is being guided by the NVFF's expertise.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
43	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.	Dec 2012	By Summer 2013		**COMPLETE** The *Driving Up Quality Code* is now live. To sign up to the code or get more information visit http://www.drivingupquality.org.uk
44	The Department of Health, with the National Valuing Families Forum, the National Forum of People with Learning Disabilities, Association of Directors of Social Services (ADASS), Local Government Association (LGA) and the NHS will identify and promote good practice for people with learning disabilities across health and social care.	Dec 2011	By Summer 2013		**COMPLETE** The final report can be found here: https://www.gov.uk/government/publications/learning-disabilities-good-practice-project-report. The next step will be effective dissemination, including making the right links to other good practice.
62	National Institute for Health and Care Excellence (NICE) will publish quality standards and clinical guidelines on challenging behaviour and learning disability.		By Summer 2015		**ONGOING** Work to develop a clinical guidance and a quality standard for challenging behaviour and learning disability are well under way; with the clinical guideline expected to be published in May 2015.
63	National Institute for Health and Care Excellence (NICE) will publish quality standards and clinical guidelines on mental health and learning disability.		By Summer 2016		**ONGOING** NICE will develop a clinical guideline and quality standard on mental health and learning disability; however, this work is not due to start yet. Winterbourne View stakeholders, including representatives of carers and families, have been involved, while Mencap are a stakeholder on NICE quality standards.

SUMMARY OF PROGRESS ON ACTIONS FROM TRANSFORMING CARE & CONCORDAT (DECEMBER 2013)

WORKSTRAND 4: INFORMATION AND DATA

Ensure 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.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
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, the NHSCB 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.	From Nov 2012	Ongoing		**ONGOING** DH's Learning Disability Programme Board (LDPB) oversees all the key actions relating to Learning Disabilities. It receives updates on progress against all key actions and reports from key delivery partners to provide assurance across programme of actions.
17	The Department of Health 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 learning disability programme board to assess what is happening.	Feb 2013	By March 2013		**COMPLETE** The Learning Disability Census took place on 30 September. Analysis of the submitted data is now in progress and was published on 13th December 2013.
37	The Department of Health (DH), the Health and Social Care Information Centre (HSCIC) and the NHS England will develop measures and key performance indicators (KPIs) to support commissioners in monitoring their progress.	From April 2013	Ongoing		**ONGOING** DH, HSCIC and NHS England have developed draft KPIs for testing with stakeholders. The final KPIs will be implemented from 2014.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
38	The 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.	From April 2013			**COMPLETE** The 2013/14 SAF is now complete. See also action 18C.
52	The Department of Health 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.		By Dec 2013		**COMPLETE** This is the promised report.
60	The Department of Health will publish a second annual report following up progress in delivering agreed actions.		By Dec 2014		For next year
61	The Department of Health will develop a new learning disability minimum data set to be collected through the Health and Social Care Information Centre.	Feb 2013	March 2014		**ONGOING** Mental Health Minimum Data Set to be expanded to include people with learning disabilities and data set to be renamed Mental Health and Learning Disabilities Data Set. Information Standards Board has approved this, however changes to information systems are required which means the new data set is now expected to be implemented from September 2014.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
64	The Department of Health 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 Learning Disability Programme Board.		part of action 4		A Data and Information Working Group has been set up to focus and provide technical advice on data and information related commitments in the Concordat and also wider learning disability data issues. This group reports to the Learning Disability Programme Board (LDPB). The group has focused on the Learning Disability Census, the development of the Mental Health and Learning Disabilities Data Set, key performance indicators, joint health and social care self-assessment framework which are detailed above. It is also looking at informing development of an indicator on reducing premature mortality in people with learning disabilities for the NHS Outcomes Framework. The link to LDPB papers is: https://www.gov.uk/government/policy-advisory-groups/learning-disability-programme-board. All data and information related progress reports and recommendations are discussed by the LDPB.

SUMMARY OF PROGRESS ON ACTIONS FROM TRANSFORMING CARE & CONCORDAT (DECEMBER 2013)

WORKSTRAND 5: MEDICATION, POSITIVE BEHAVIOUR SUPPORT AND PHYSICAL INTERVENTION

Improve quality and safety so that there is better understanding of how to use physical restraint properly and good practice on positive behaviour support and the environment so that challenging behaviour is reduced. Tackle over-use of antipsychotic and antidepressant medicines to ensure the best course of action for the patient.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
5	The Department of Health will work with the Care Quality Commission (CQC) to agree how best to raise awareness of and ensure compliance with Deprivation of Liberty Safeguards provisions to protect individuals and their human rights and will report by Spring 2014.	From Dec 2012	Spring 2014		**ONGOING** The Care Quality Commission has appointed a Mental Capacity Act lead. The English Community Care Association had produced further support and briefing for members of the Deprivation of Liberty Safeguards and human rights legislation.
6	The Department of Health (DH) will, together with Care Quality Commission (CQC), consider what further action may be needed to check how providers record and monitor restraint.	From Dec 2012	by end 2013		**ONGOING** DH set up a working group to find links with other work on data collection. This work is likely now to form a key part of a much wider programme on reducing restraint and restrictive practices in learning disability and mental health services.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
9	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.	From Dec 2012	Ongoing		**ONGOING** 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.
11	The British Psychological Society (BPS) to provide leadership to promote training in, and appropriate implementation of, Positive Behavioural Support (PBS) across the full range of care settings.	From Dec 2012	Ongoing		**ONGOING** 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.
45	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.		By Summer 2013		**ONGOING** This action is now being taken forward by NHS England. Three pieces of work are in action: (1) establishing a collaborative in partnership with NHS Improving Quality. The final scope will be produced by end December 2013 and it will launch in early 2014; (2) work with CQC on Second Opinion Appointed Doctors (SOAD) data on prescribing for antipsychotic and antidepressant medicines. (3) analysis of data held by Medicines and Healthcare products Regulatory Agency (MHRA) on prescribing for antipsychotic and antidepressant medicines.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
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.		In 2013		See comment on Action 45

Ref No.	Action	Start Date	Finish Date	Progress	Comments
53	The Department of Health 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.	Feb-13	By end 2013*		**ONGOING** The Department of Health commissioned a multi-professional team led by the Royal College of Nursing to develop new guidance on the use of positive behaviour support and the reduction in the use of restrictive practices. The Royal College will consult on draft guidance on ‘The minimisation of restrictive practices in health and adult social care’ by the end of December 2013 and the Department of Health will publish new guidance in March 2014. The Department of Health also commissioned Skills for Care, in conjunction with Skills for Health, to develop guidance for provider employers on the commissioning of training and workforce development activities on physical interventions as part of a positive behaviour support approach. Skills for Care and Skills for Health are finalising the draft guidance and will be testing it with providers in early 2014. The new guidance will be published alongside the guidance developed by the Royal College of Nursing in March 2014. The Department of Health is currently working with partners across the system to identify what further actions are required in order to embed implementation of these new practices and effect sufficient cultural and leadership change across the care system. * By end 2013 (Royal College of Nursing will lead consultation in December 2013 and DH will publish new guidance in March 2014)

Ref No.	Action	Start Date	Finish Date	Progress	Comments
59	The Department of Health will update the Mental Health Act Code of Practice and will take account of findings from this review.		In 2014		**ONGOING** The Department of Health, in conjunction with the Ministry of Justice, the National Offender Management Service, the Care Quality Commission and other partners is currently reviewing and updating the Mental Health Act 1983 Code of Practice. We are on track to consult on a revised version of the Code in spring 2014 and for a new version to come into force by the end of 2014. The Department of Health is also working with partners to make the Code more accessible and available to individuals subject to the Act, their families and carers, including those with a learning disability, autism or where English is not a first language.
70	The Association of Directors of Social Services (ADASS) and the Association of Directors of Children's Services (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.				**ONGOING** Guidance published in December 2012 on the ADASS website. Available at: http://www.adass.org.uk/images/stories/Policy%20Networks/Learning%20Disability/Key%20Documents/Winterbourne%20View%20Compendium_Dec12.pdf ADASS also published key questions for learning disability partnership boards, health and wellbeing boards and safeguarding adults boards which are being used, and which ADCS are exploring how best to adopt in relation to children. The key priority going forward, for both adults and children's services, is to ensure that local areas use the guidance effectively.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
71	The Department of Health 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.		Ongoing		**ONGOING** The Department of Health introduced new draft legislation as part of the Care Bill 2013. This has passed through the Lords and the next stage is 2nd Reading in the Commons.
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.		Ongoing		**ONGOING** The Care Bill currently in progress through Parliament contains a new “Supply of Information” clause which requires agencies and individuals to share information in order for Safeguarding Adults Boards to be able to carry out their duties and responsibilities. The ADASS Adult Safeguarding Policy Network are fully engaged with the improvement programme and continue to provide guidance and advice to Adult Safeguarding leads.

SUMMARY OF PROGRESS ON ACTIONS FROM TRANSFORMING CARE & CONCORDAT (DECEMBER 2013)

WORKSTRAND 6: WORKFORCE

Improve quality and safety through improving the capability of the workforce so that staff are properly trained in essential skills supported by good clinical and managerial leadership. Health and care professionals should understand and be 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.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
10	The College of Social Work, working in collaboration with British Association of Social Workers (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.		Apr-13		**COMPLETE** A brief guide to good practice standards was published in August. http://www.tcsw.org.uk/uploadedFiles/TheCollege/Social_Work_Practice/WinterbourneViewGuidanceAugust2013.pdf A more in-depth guide will be published later in 2013/14.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
12	The Royal College of Speech and Language Therapists, to produce good practice standards for commissioners and providers 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.		Nov-13		**COMPLETE** These standards cover good communication for commissioners and providers together with a guide to "what does good look like & how will you know". http://www.rcslt.org/news/good_comm_standards
14	The professional bodies that make up the Learning Disability Professional Senate will refresh *Challenging Behaviour: A Unified Approach* to support clinicians in community learning disability teams to deliver actions that provide better integrated services.		By end Dec 2013		**ONGOING** Each of the sections of the report has been drafted. We are now in the process of consulting more widely to ensure that the various stakeholders are signed up to the content. July 2014 is the anticipated date for the final draft to be available.
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.		By January 2013		**COMPLETE** 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. Published in March to coincide with the Francis report. http://www.skillsforhealth.org.uk/about-us/news/code-of-conduct-and-national-minimum-training-standards-for-healthcare-support-workers/

Ref No.	Action	Start Date	Finish Date	Progress	Comments
16	Skills for Care (SfC) will develop a framework of guidance and support on commissioning workforce solutions to meet the needs of people with challenging behaviour.		By February 2013		**COMPLETE** Publication of Skills for Care/National Development Team for Inclusion (NDTi) guidance to 'Develop a framework of guidance and support on commissioning workforce solutions to meet the needs of people with challenging behaviour' for employers. Published in February. http://www.skillsforcare.org.uk/challengingbehaviour/ Active dissemination is in progress through SfC and NDTi. Provider groups are circulating the framework amongst members.
21	The Royal College of Psychiatrists will issue guidance about the different types of inpatient services for people with learning disabilities and how they should most appropriately be used.		By March 2013		**COMPLETE** The report *'People with learning difficulty and mental health, behavioural or forensic problems: the role of in-patient services' was* published in July 2013: http://www.rcpsych.ac.uk/pdf/FR%20ID%2003%20for%20website.pdf
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.		By 1 April 2013		**ONGOING** The Academy now has a framework in place for carrying out this work. A Statement of Ethics is in final draft and wider consultation will begin early in 2014.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
28	Health Education England will take on the duty for education and training across the health and care workforce and will work with the Department of Health, providers, clinical leaders and other partners to improve skills and capability to respond the needs of people with complex needs		Ongoing		**ONGOING** Professor Chris Welsh, Director of Education and Quality at Health Education England became a member of the Learning Disability Programme Board in June 2013. Health Education England's mandate is currently being refreshed and the Department of Health is working with them to ensure appropriate inclusion of Winterbourne View commitments.
54	There will be a progress report on actions to implement the recommendations in Strengthening the Commitment the report of the UK Modernising learning disability Nursing Review.		By end 2013		**FINALISING REPORT** Progress has been made on most of the 17 recommendations in Strengthening the Commitment the report of the UK Modernising learning disability Nursing Review and a full report will be published early in the New Year.
73	Through the Whistleblowing Helpline, the Department of Health 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.		Jan-12		**COMPLETE** Helpline run by Royal Mencap. Helpline Number: 0800 0824825 www.wbhelpline.org.uk enquiries@wbhelpline.co.uk

SUMMARY OF PROGRESS ON ACTIONS FROM TRANSFORMING CARE & CONCORDAT (DECEMBER 2013)

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.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
19	See with workstrand 1 for Children and Young People service specification.				
46	The Department of Health and the Department for Education 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.	Feb 2013	By Dec 2013		**COMPLETE** The Children and Young People's Health Outcomes Forum is supporting this through its forward work programme. 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 in relation to this. http://www.nnpcf.org.uk/news-and-consultations
47	The Department of Health and the Department for Education will develop and issue statutory guidance on children in long-term residential care.		In 2013		**FINALISING GUIDANCE FOR PUBLICATION** Statutory guidance on long-term residential care has been shared with Stakeholders and subject to approval; the guidance is expected to be published in January 2014.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
48	The Department of Health and the Department for Education will jointly explore the issues and opportunities for children with learning disabilities whose behaviour is described as challenging through both the SEN and Disability reform programme and the work of the Children's Health Strategy.		Sep-14		**ONGOING** The Children and Young People's Health Outcomes Forum will cover this in its forward work programme. SEN reforms in the Children and Families Bill are expected to gain Royal Assent in Spring 2014.
50	The Department for Education will revise the statutory guidance *Working together to safeguard Children.*		In 2013		**COMPLETE** The guidance, *Working to safeguard children was* published in March 2013. http://www.education.gov.uk/aboutdfe/statutory/g00213160/working-together-to-safeguard-children

Ref No.	Action	Start Date	Finish Date	Progress	Comments
56	The Department of Health will work with the Department for Education 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.	From 2014	Ongoing		**ONGOING** Special Educational Needs (SEN) reforms in the Children and Families Bill are now entering the Lord's report stage and are expected to gain Royal Assent in Spring 2014. Significant stakeholder interest in Education, Health and Care Plan. There is a continued need to ensure localities are thinking about this in life-course service planning - JIP to lead. The *Young People's Consultation on the Special Educational Needs Code of Practice* was published with a consultation closing date 20 December 2014. https://www.education.gov.uk/consultations/ The Pathfinders are developing new approaches to SEN and promoting them via Pathfinder champions and local engagement. There has been significant stakeholder engagement through targeted events with Pathfinders, nasen and the Council for Disabled Children (CDC). Implementation packs are due to be sent out to Local Authorities, Clinical Commissioning Group's and Health and Wellbeing Board's to support their implementation of the upcoming changes.
74	Ofsted, Care Quality Commission, Her Majesty's Inspectorate of Constabulary (HMIC), 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 protection of children in England.	From June 2013	Ongoing		**ONGOING** Ofsted has been working with HMIC, the Care Quality Commission, HMI Probation and HMI Prisons to develop a multi-agency inspection framework. The consultation for this closed in Oct 2013. Multi-agency inspections will take place from April 2015.

Ref No.	Action	Start Date	Finish Date	Progress	Comments
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.		Ongoing		**ONGOING** The multi-agency inspections from April 2015 will include judgements on leadership, management and governance, the quality of professional practice, the arrangements to help and protect children and the experiences and progress of the children and young people. Further details available at: http://www.ofsted.gov.uk/resources/framework-and-evaluation-schedule-for-inspection-of-services-for-children-need-of-help-and-protectio

Public Health England

Joint Health and Social Care Self-Assessment Framework 2013

Emerging findings from Responding Local Authorities

Introduction and background

This appendix provides a preliminary view of how far local Partnership Boards have been able to provide information about their work for this year's Joint Health and Social Care Self-Assessment Framework (SAF) exercise. The SAF process is a complex local stocktake. It covers a wide range of the physical and mental healthcare and the social care provided for people with learning disabilities in the geographic area covered by local learning disability Partnership Board. In almost all cases Partnership Board areas exactly match upper tier Local Authority areas. Following the action agreed in Transforming Care (Action 38), this year, for the first time, the regular local stocktakes undertaken by health and social care services have been fully integrated. This represents an amalgamation of the former Strategic Health Authority Self-Assessment Framework and the Local Authority based Partnership Board annual reports.

The Framework has two parts: key numbers and quality benchmarks. Partnership Boards are invited to set out numbers which describe the scale of the task they face in providing care and some indicators of how well they are performing. This is followed by a self-rating exercise to compare the local performance with some nationally agreed yardsticks. This part of the exercise is intended to be undertaken by Clinical Commissioning Group and Local Authority officers in collaboration with local care providers, self-advocates and family carers. It is recommended that the rating exercise should be finalised at a 'Big Health and Social Care Day' - a participatory planning exercise. This year the detail of the framework was developed by a group comprising former Strategic Health Authority learning disability leads and members of the Association of Directors of Adult Social Services. An independent consultant facilitated the process and members of the Learning Disabilities Observatory provided technical advice.

The collection of information relating to the framework started in August. The official closure date for submissions was the end of November. This reflected partly the fact that it involves a great deal of work, and partly the fact that it coincided with two other nationally inspired exercises (the Autism Self-Assessment Framework and the Stocktake of local services led by the Winterbourne View Joint Improvement Programme) requiring input largely from the same staff. In the event, as a result of technical difficulties, the closure date for submissions was extended to 5:00pm on the 6th December. Thus, given the publication deadlines for this report there has not been time to work through the data submitted in the depth required for detailed reporting. This brief summary focuses on four aspects:

- The number of authorities that responded
- How much of the Framework they were able to complete

- Further detail about the responses relating to in-patient psychiatric care for people with learning disabilities and how this compares with the findings of the recent in-patient census
- The numbers of individuals on Clinical Commissioning Group registers of individuals with challenging behaviour in the context of learning disability or autism, and the progress in reviewing their care needs

Responses

There are currently 152 upper tier local authorities. All of them registered to report their local conclusions. Responses reflected the geography of upper tier Local Authorities with one exception. In Lancashire Partnership Board areas were defined on the basis of former Primary Care Trust boundaries (Central, East, and North Lancashire). This year Lancashire continued to use this arrangement and produced three reports. So a total of 154 responses were received. All but 1 provided at least some details of local services.

Parts of the Framework covered

This section describes the reporting of the population of people with learning disability living in Partnership Board areas and the extent to which other sections of the Framework were covered. Coverage of population figures is reported in more detail since evaluation of almost all the other sections depends on understanding the size and structure of the population served.
The Framework asked about the number of people with learning disability by age group, disability and ethnic group. Age profiles could be given at three levels of detail: narrow age bands (0 to 13, 14 to 17, 18 to 34, 35 to 64 and 65 and older), broad age bands (0 to 17, 18 and older) or simply as a total figure. Respondents were asked for similar breakdowns of numbers of people with complex or profound learning disabilities (defined as learning disability complicated by severe problems of continence, mobility or behaviour, or severe repetitive behaviour with no effective speech) and with learning disabilities complicated by autism. They were also asked for numbers, aged 0 to 17 and 18 and older, of people in each of the three disability categories who are recorded as being from a minority ethnic group. Table 1 shows the numbers of respondents able to provide each set of figures.

Table 1. Numbers (and proportions) of respondents able to report figures for numbers in the population with learning disabilities (LD).

	All with LD	People with Complex or Profound LD	People with LD and Autism
Reported in narrow age bands	111 (72.1%)	102 (66.2%)	96 (62.3%)
Reported in broad age bands	28 (18.2%)	24 (15.6%)	30 (19.5%)
Reported totals only	6 (3.9%)	6 (3.9%)	7 (4.5%)
Respondents reporting any data	*145 (94.2%)*	*132 (85.7%)*	*133 (86.4%)*
Reported any ethnic minority data	102 (66.2%)	77 (50.0%)	77 (50.0%)

Table 2 gives an overview of all the sections of the Framework showing the proportion of Partnership Boards (out of the possible total of 154) responding to each. Not every Partnership Board would have people in every category in each section, so they would not necessarily be expected to respond to every question. In this table, they are scored as having responded to each Framework section if they made an entry in any part of it.

Table 2. Proportion (percentage) of respondents providing information about each section of the Framework

Framework Section	Proportion of respondents providing responses
Demography	94%
Complex or profound disorder	86%
Learning Disability with Autism	86%
Screening coverage	87%
GP observations	77%
Deaths	67%
Learning Disability Health Checks	97%
General hospital use	77%
Continuing Healthcare and Mental Health Act Section 117	95%
Local mental health in-patients	88%
Specialist commissioned mental health in-patients	92%
Stay legth of current mental health in-patients	90%
Challenging Behaviour registers and reviews	90%
Social Care statistics	84%
Employment and voluntary work	84%
Accommodation arrangements	82%
Adult safeguarding	98%
Mental Capacity Act / Deprivation of Liberty Safeguards	99%
Numbers with relevant Special Educational Needs in schools	97%
Staying Healthy ratings	95%
Being Safe ratings	96%
Living Well ratings	95%

The parts of the Framework with the weakest coverage were the number of deaths of people with learning disabilities (67%), the various GP-based observations, including blood pressure, body mass index, diabetes, epilepsy, asthma, dysphagia (difficulty swallowing) and coronary heart disease (77%), and the use of local general hospital care (77%). 87% of respondents were able to report to some extent about screening coverage, although only 80% reported about all three types. There were some parts of the Framework where it was a surprise that coverage was so low. These described issues which have been reported in national statistical returns for many years. They are the provision of social care packages (84%), work status (84%) and housing status (82%).

In-patient care for mental health problems or challenging behaviour

Respondents were asked to report the numbers of people in mental hospital in-patient care as at 31st March 2013. They were asked to break this down by commissioner type, location, primary reason for admission and broad length of stay.
Table 3 shows the numbers of respondents (out of the possible total of 154) providing information about the numbers of patients in locally commissioned and specialised commissioned services.

Table 3. Respondents providing numbers of mental hospital in-patients at 31st March by age band, commissioning arrangements and primary reason for admission

Primary reason for admission	Age 0 to 17	Age 18 or older
Locally commissioned services		
Challenging behaviour	103 (66.9%)	130 (84.4%)
Mental health problem	101 (65.6%)	131 (85.1%)
Complex physical health needs	100 (64.9%)	119 (77.3%)
Specialised commissioned - located locally		
Challenging behaviour	105 (68.2%)	132 (85.7%)
Mental health problem	107 (69.5%)	130 (84.4%)
Complex physical health needs	106 (68.8%)	127 (82.5%)
Specialised commissioned - distant		
Challenging behaviour	104 (67.5%)	133 (86.4%)
Mental health problem	101 (65.6%)	131 (85.1%)
Complex physical health needs	103 (66.9%)	120 (77.9%)

From table 3 it is clear that the overall numbers obtained give an incomplete picture of the numbers of in-patients Partnership Boards are aware are receiving mental hospital in-patient care. However some patterns emerge. A total of 3,213 people in hospital were reported. 6% of these were younger than 18, 94% were aged 18 or older. 45% of those reported were in local services, 57% in specialised commissioned services. Of those in specialised commissioned services, 67% were described as being in placements within the Partnership Board area or a neighbouring Clinical Commissioning Group.
31% of all patients were reported as being in hospital primarily because of challenging behaviour, 65% because of a mental health problem and 3% because of complex physical health problems. 56% of the people primarily in hospital because of challenging behaviour were in ordinary local services, as were 65% of those primarily in hospital because of complex physical health needs. In contrast only 39% of those primarily in hospital for mental health problems were in ordinary services whilst 61% were in specialised commissioned provision.

Respondents were asked how many of those currently in hospital at the end of March 2013 had been in-patients continuously for more than 3 months and more than two years. These responses were harder to analyse. 111 (72.1%) Partnership Boards provided a total year-end figure, but a larger number (120 (77.9%)) provided a three month figure. There was also evident inconsistency in how these data were recorded indicating that further consultation with sites submitting them will be needed before they can be reported in detail. 101 (65.6%) reported numbers in hospital two years or longer.
The figures reported in the SAF would not be expected to agree exactly with the findings of the recent Learning Disabilities Census[7] since only around 85% of SAF respondents reported in-patient numbers. Despite this the totals are strikingly similar The total number of in-patients reported in the SAF was 3,123, 99% of the census figure of 3,250. The split between local in-patients (SAF 1,441, census 1,470) and specialised commissioned patients (SAF 1,772, census 1,780) was also very close. In the SAF, 39 Partnership Boards did not provide local in-patient numbers and 28 did not provide specialised commissioned numbers. The census identified roughly 650 patients from these Local Authority areas; however the tabulation in the census report (table 10) is not sufficiently detailed to give a precise figure). This would suggest that the figures reported in the SAF are roughly 25% higher than the census findings. There is a further clear discrepancy in the proportion of in-patients reported as having been in hospital for two years or more. SAF respondents reported only 587 patients (18%) as having stayed this long. The census identified 1,363 (42%) patients in this position.

Challenging Behaviour Care Registers

In Transforming Care NHS England agreed to ensure that all Primary Care Trusts would set up registers of people with learning disability or autism who presented challenging behaviour for which they were receiving NHS-funded care, by 1st April 2013 (Action 22). Registers would be transferred to successor Clinical Commissioning Groups who would subsequently maintain them. Clinical Commissioning Groups were asked to ensure that all those registered had a review of their care by 1st June, with these reviews leading to a personal care plan agreed with the individual and based around their and their families' needs and agreed outcomes (Action 26). The Framework asked about numbers on the register at the handover point and at the end of June, and the number of these who had had a care review as specified by June 1st. Numbers were to be divided into those currently in hospital and those not.
123 (79.9%) Partnership Boards reported the number of patients in the registers handed over to Clinical Commissioning Groups at the start of April. 123 (79.9%) reported the number registered at 30th June, and a larger number (130 (84.4%)) reported the number whose care had been reviewed. Table 4 shows figures for the 115 Partnership Board areas answering all three questions.

[7] http://www.hscic.gov.uk/ldcensus

Table 4. Total number of patients reported by 115 respondents providing figures for all three questions (percentages are by row).

Measure	In hospital at index date	Not in hospital at index date	Total patients
On the PCT register at 31st March	1,156 (37.1%)	3,112 (72.9%)	4,268
On the CCG register at 30th June	1,124 (40.2%)	2,796 (71.3%)	3,920
Number whose care was reviewed by 1st June	1,163 (37.4%)	3,112 (72.8%)	4,275

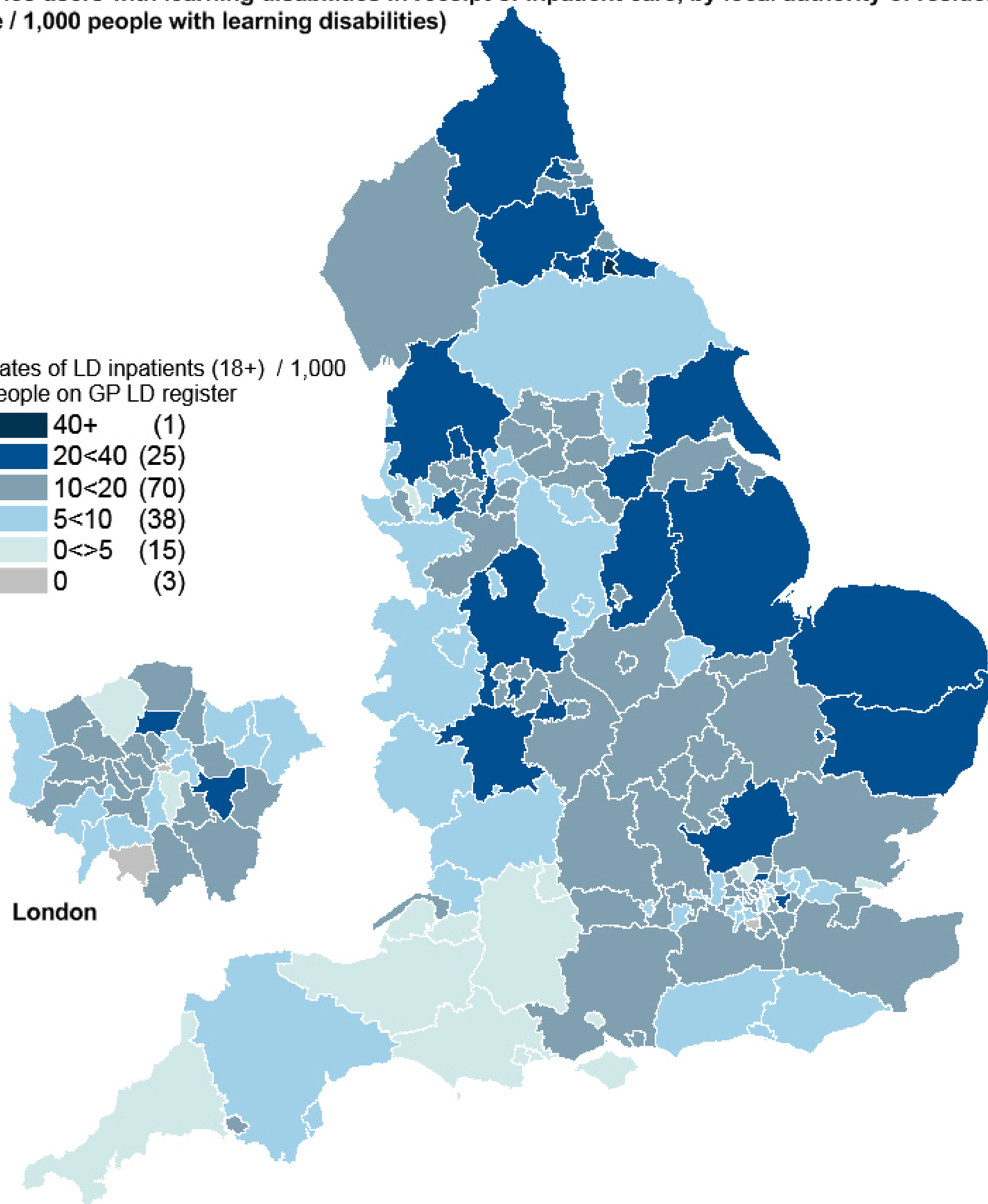
The numbers reported as being on challenging behaviour care registers and those reported as in-patients in the previous section differed somewhat. Only 80 Partnership Boards answered all the questions reported in table 4 as well as all the questions about numbers of in-patients by primary cause and commissioner type described above. This group of respondents reported a total of 894 in-patients on their registers at the end of March and 865 at the end of June. They reported having done care reviews for 905. However the numbers of in-patients they reported in response to the earlier questions, whose primary reason for being in hospital was challenging behaviour, were substantially lower: 346 in locally commissioned services and 271 in specialised commissioned services, a total of 617.

Conclusion

These are inevitably preliminary observations since data collection was only closed to entry on 6th December. This overview is intended mainly to indicate the extent to which the commitment to undertake self-assessment has been fulfilled.

The SAF is primarily intended to provide impetus, structure and comparative benchmarks for a local process of review and service improvement. A more detailed report on all of the findings of the exercise will be published by Public Health England early in the new year. This will be based on a thorough check and exploration of all the data from the SAF. It will include thematic analysis of the comments made in relation to the local quality ratings. Full responses from Partnership Boards and a summary spreadsheet designed to facilitate comparative study will be published alongside the final report.

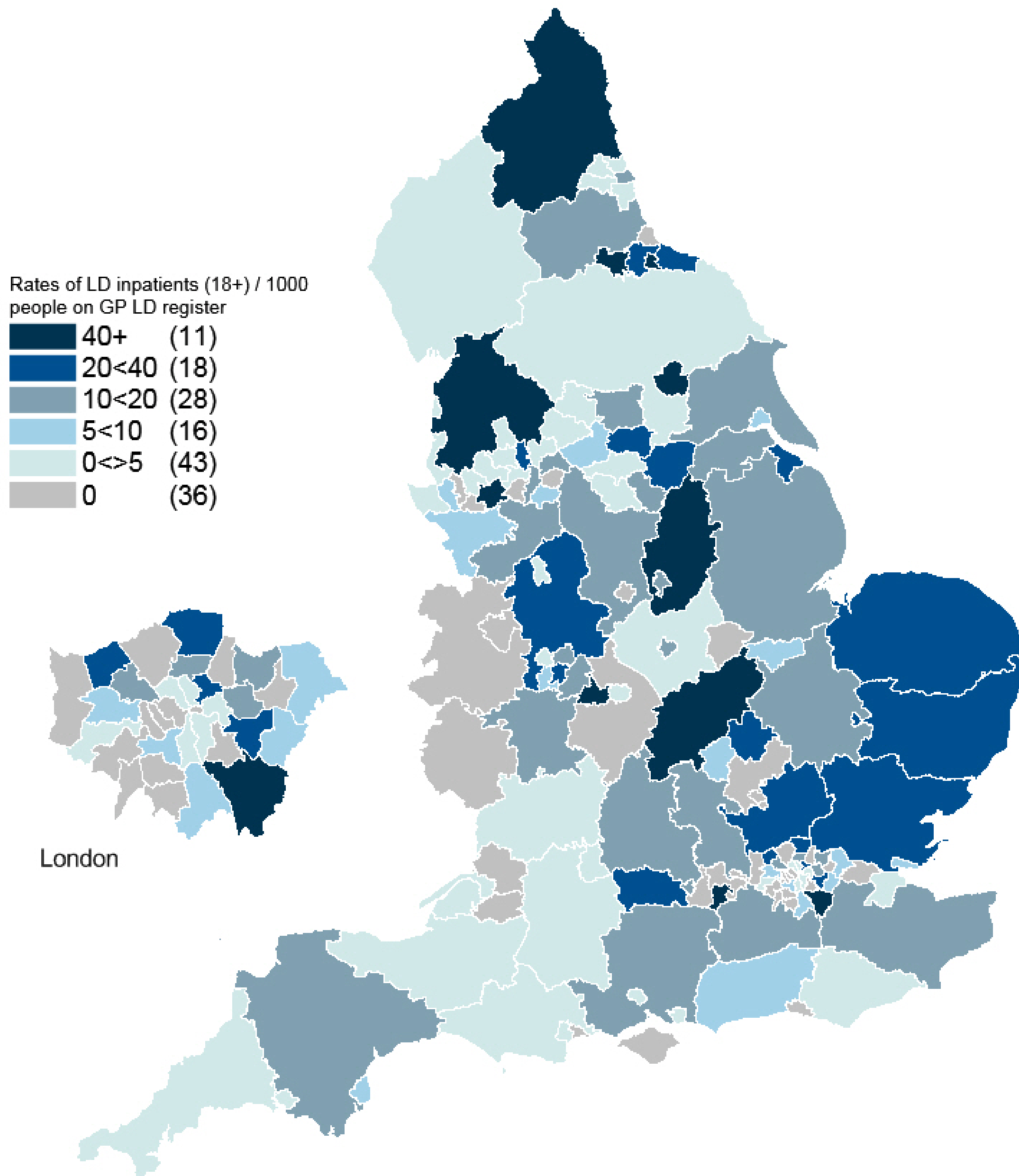
Service users with learning disabilities in receipt of inpatient care, by local authority of residence (rate / 1,000 people with learning disabilities)



Notes on interpretation:
The numerators for rates presented in these maps are the number of service users aged 18 and over, recorded in the 2013 Learning Disability Census, by local authority of residence and ward stay respectively. Local authority of residence is derived from the last known postcode of residence, whilst local authority of ward stay is derived from the postcode of the location of the service user's ward stay. Note that some Learning Disability Census service users receiving inpatient care had the same postcode recorded for both residence and ward stay (see Table 9, Reference data tables for the 2013 Learning Disability Census, http://www.hscic.gov.uk/pubs/ldcensusrep1213).
The denominator for rates presented in these maps is The Quality Outcome Framework (QOF) learning disability register, apportioned to local authority level.
The QOF business rules for learning disability may be found at the following location:
http://cdn.pcc-cic.org.uk/sites/default/files/articles/attachments/learning_disabilities_ruleset_v23.0.pdf.
Four GP practices could not be allocated to a local authority area as they had invalid postcodes.
The Isles of Scilly (not displayed) had a rate of 0 LD inpatients / 1,000 people on GP LD register, for both residence and ward stay.
Data sources:
HSCIC, Learning Disability Census, 2013: http://www.hscic.gov.uk/pubs/ldcensusrep1213
HSCIC, QMAS database - 2012/13 data as at end of June 2013

Copyright © 2013, Health and Social Care Information Centre, Community and Mental Health Team. All rights reserved.

Service users with learning disabilities in receipt of inpatient care, by local authority of ward stay (rate / 1,000 people with learning disabilities)



Notes on interpretation:
The numerators for rates presented in these maps are the number of service users aged 18 and over, recorded in the 2013 Learning Disability Census, by local authority of residence and ward stay respectively. Local authority of residence is derived from the last known postcode of residence, whilst local authority of ward stay is derived from the postcode of the location of the service user's ward stay. Note that some Learning Disability Census service users receiving inpatient care had the same postcode recorded for both residence and ward stay (see Table 9, Reference data tables for the 2013 Learning Disability Census, http://www.hscic.gov.uk/pubs/ldcensusrep1213).
The denominator for rates presented in these maps is The Quality Outcome Framework (QOF) learning disability register, apportioned to local authority level. The QOF business rules for learning disability may be found at the following location:
http://cdn.pcc-cic.org.uk/sites/default/files/articles/attachments/learning_disabilities_ruleset_v23.0.pdf.
Four GP practices could not be allocated to a local authority area as they had invalid postcodes.
The Isles of Scilly (not displayed) had a rate of 0 LD inpatients / 1,000 people on GP LD register, for both residence and ward stay.
Data sources:
HSCIC, Learning Disability Census, 2013: http://www.hscic.gov.uk/pubs/ldcensusrep1213
HSCIC, QMAS database - 2012/13 data as at end of June 2013

Copyright © 2013, Health and Social Care Information Centre, Community and Mental Health Team. All rights reserved.

APPENDIX 3

INVESTMENT SUMMARY

	JOINT IMPROVEMENT PROGRAMME 2013/2014 **Figures include apportioned staff costs**	**Budget**	**Expenditure to date (as at Dec. 2013)**	**Balance**
1	**Involvement and engagement work**	£128,000	£61,962	£66,038
2	**Communications activity**	£56,000	£30,101	£25,899
3	**Improvement projects and activity**	£1,144,000	£125,672	£1,018,328
4	**Programme support costs**	£640,000	£143,590	£496,410
5	**Other costs, including medication collaborative**	£400,000	n/a	£400,000
6	**VAT**	£492,000	£36,906	£455,094
	TOTAL EXPENDITURE TO DATE	**£2,860,000**	**£398,231**	**£2,461,769**
	Staff costs (total figure). These are included in the figures above apportioned across relevant activities			**£229,917**
	Notes ***Figures include apportioned staff costs***			
1	Including events, consultation etc.			
2	Publication costs, including easy read materials, briefings etc.			
3	Improvement programme/support to local areas, including resource development			
4	Including support to Joint Improvement Board activity & LGA charge			
5	Medication collaborative and CQC research project on medication data			
	Nb. Costs are profiled to increase substantially during 2013/14 and 2014/15. Some costs have been committed but not yet spent and are therefore not included in expenditure to date.			

You may re-use the text of this document (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit www.nationalarchives.gov.uk/doc/open-government-licence/

© Crown copyright

Published to gov.uk, in PDF format only.

www.gov.uk/dh