

Department of Health Review: Winterbourne View Hospital

Interim Report



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FOREWORD

life for people with major disabilities supported by good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management.

Prof Jim Mansell¹

Last year Winterbourne View hit the headlines with shocking scenes of abuse. Those events are still the subject of criminal proceedings. When they are concluded later this summer I expect to see South Gloucestershire's Serious Case Review and the Government will set out its full response then.

This interim report is not our last word on Winterbourne. This report actually looks beyond those events and draws on the inspection work of the CQC and the evidence gathered by the Department of Health inquiry team. It is a call to action.

The right to lead an ordinary life, to make decisions for yourself, to be part of the community able to take part and contribute is the essence of what the late Professor Jim Mansell proposed and advocated during much of his career. His reports to the Department of Health have profoundly changed policy and practice affecting the lives of people with learning disabilities and their families. His vision is still at the forefront of our minds today.

Living in the community, not kept isolated, institutionalised and apart. That was the goal of the closure of long stay hospitals and the campus closure programme. And for many people with learning disabilities and their families it has made a huge difference to their quality of life.

But with the closure of long stay hospitals and the campus closure programme, a new form of institutional care developed: what we now know as assessment and treatment units. Not part of current policy, and certainly not recommended practice, these centres have sprung up over the past thirty years. Containment rather than personalised care and support has too easily become the pattern in these institutions.

Even now, without the Winterbourne View Serious Case Review, there is compelling evidence that some people with learning disabilities and autism are being failed by health and care. Around the country there are excellent examples of personalised care, focused on supporting people in their community. But that excellence is not universal. There is insufficient focus on personalised care planning. And too often the care which people receive is poor quality.

This is not good enough. I am very clear that we must be taking action at a national and local level to support commissioners to redesign services towards the personalised model we expect, to commission for quality and outcomes and to improve the quality and safety of services.

That is why I have published this interim report on the review, so that we can ensure the excellent examples of personalised and supportive care that do exist are spread right across the country. So as much as this report sets out a road map for making sure that people with learning disabilities receive the support and care they need, it is just the beginning.

I hope that people will read this report and offer their views and ideas on what we propose to do. Once the criminal proceedings have been concluded and the Serious Case Review published I will make a full and final report from this review – setting out firm actions at a national level to ensure that these very vulnerable people receive the personalised care and support they need and deserve. And through the Learning Disability Programme Board, which I chair, we will maintain focus and follow up with a report a year later, to make sure that real progress is being made.

The NHS Constitution sets out the rights of patients to be allowed to make choices and be involved in decisions about their NHS care. The goal of the Coalition Government’s health and care reforms is to promote quality, putting the individual at the heart of their care.

Shortly the Coalition will publish a White Paper that sets out our plans to transform care and support so that everyone is treated with dignity and respect – ensuring people exercise genuine choice and control over their care.

I am grateful to the expert panel of Mark Goldring, Anne Williams and Tony Holland – as well as the late Jim Mansell – who have offered an independent perspective to the work of the Department’s Review Team.

The numbers of people with what is described as challenging behaviour are small – there will only be a handful in any local authority. Getting services and care right for them within the wider set of services and support for all those with learning disabilities or autism is achievable. It will require everyone involved to work together and to listen to the people that know best – people with learning disabilities themselves and the families with experience of this every single day.

A handwritten signature in black ink, appearing to read 'Paul Burstow'.

**Paul Burstow MP
Minister of State for Care Services**

June 2012

JOINT FOREWORD:

This interim report following the events at Winterbourne View hospital has highlighted the importance of health and care working in partnership at both a national and a local level to improve outcomes for people with learning disabilities or autism with behaviour which challenges.

Our shared objective is to see the health and care system get to grips with past failings in meeting the needs of this group of people and working together to commission the range of services and support which will enable them to lead fulfilling and safe lives in their communities.

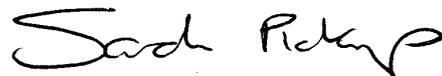
We commit to leading action at a national level to set the strategic direction and to measure progress in delivering key outcomes. This requires real system leadership across all sectors, including elected councillors as well as across health and care to reduce inequalities for those people with behaviour which challenges.

It is encouraging to see how well many health and care bodies are already working together to respond so positively to the issues raised by the CQC inspections. This needs to continue.

The new health and care system brings a greater opportunity for people to work together more creatively to develop local innovative solutions. Healthwatch and health and well-being boards will ensure that the voice of people with learning disabilities and autism and their families has proper place within that.



**Sir David Nicholson
Chief Executive of the
NHS Commissioning
Board Authority**



**Sarah Pickup
President
Association of Directors of
Adult Social Services
(ADASS)**

EXECUTIVE SUMMARY

1. At any one time around 15,000 people in England have learning disabilities or autism and behaviour that challenges.² Most of these people are supported by their family carers or live independently in the community, often with complex packages of support. But at any one time, around 1,200 of these people may be in hospital services for assessment and treatment. This review is about the quality of health and care services they receive.
2. This report does not cover what happened at Winterbourne View hospital as criminal proceedings are ongoing. We will publish a full report, including what happened at Winterbourne View, when criminal proceedings have concluded. However, we have already found strong evidence that the health and care system is not meeting the needs of people with learning disabilities or autism and behaviour that challenges. There is a vast gap between policy and practice. This report sets out the actions that we are taking now to address the serious issues we have already identified
3. This report is based on:
 - the reports of the Care Quality Commission's (CQC) focussed inspection of 150 hospitals and care homes for people with learning disabilities and the national summary report, published alongside this report;³
 - widespread engagement with people with learning disabilities, people with autism, family carers voluntary groups, with health and care commissioners, providers and professionals, as well as the regulators; and
 - other evidence submitted to the review team.
4. While only local action brings best practice, this report identifies 14 actions we will take at a national level so that the focus is on improving the lives of people with learning disabilities or autism and behaviour which challenges.

Our initial findings

5. The main initial findings are:
 - i. Too many people are placed in in-patient services for assessment and treatment (A&T) and are staying there for too long.
 - ii. This model of care goes against government policy and has no place in the 21st century. People should have access to the support and services they need locally – near to family and friends – so they can live fulfilling lives within the community.
 - iii. Winterbourne View was an extreme example of abuse, but we have found evidence of poor quality of care, poor care planning, lack of meaningful activities to do in the day, and too much reliance on restraining people.
 - iv. All parts of the system – those who commission care, those who provide care and individual staff, the regulators and government – have a duty to drive up standards. There should be zero tolerance of abuse.
6. We found examples of good practice - such as Tower Hamlets, Salford and Cambridgeshire – with good local services which mean very few people use in-

patient services for assessment and treatment. We want all people to benefit from local personalised services which will mean:

- no one is sent inappropriately into in-patient services for assessment and treatment
- people can move on from these services quickly to more appropriate care ,
- for the small number of people for whom in-patient services may be needed for a short period, the focus is on providing good quality care, and moving on to more appropriate settings as quickly as possible.

Making change happen

7. **Only local action can guarantee good practice**, stop abuse and transform local services.
8. Local health and care services must take action to:
 - listen to people with learning disabilities and their family carers in developing person-centred approaches across commissioning and care;
 - build understanding of the reasonable adjustments needed for people with learning disabilities who have a mental health problem so that they can make use of local generic mental health beds;
 - commission the right model of care to focus on the needs of individual people, looking to avoid the factors which might distress people and make behaviours more challenging, building positive relationships in current care settings;
 - focus on early detection, prevention, crisis support and specialist long term support to minimise the numbers of people reaching a crisis which could mean going into hospitals;
 - work together to plan carefully and commission services for the care of children as they approach adulthood to avoid crises; and
 - commission flexible, community-based services.
9. And **we will take action at a national level to make this happen**. We will:
 - set the strategic direction, outcomes and measure progress;
 - create the policy and legal framework within which local action should operate;
 - consider what longer term changes may be needed to the way in which services are monitored and inspected; and
 - ensure that commissioners, providers and the workforce are clear about their roles and accountabilities, and understand good models of care.

Objectives

10. The key objectives are to:
 - improve the capacity and capability of commissioning across health and care for people with behaviour which challenges with the aim of reducing the number of people using in-patient assessment and treatment services;
 - improve the quality of services which empower people with learning disabilities and their families to have choice and control;

- clarify roles and responsibilities across the system whilst ensuring better integration;
- promote innovation and positive behavioural support and reduce the use of restraint to a last resort; and
- establish the right information to enable local commissioners to benchmark progress in commissioning services which meet individuals' needs, improve the quality of care, and reduce the numbers of people in in-patient services for assessment and treatment.

The 14 national actions

11. We have **identified 14 actions at a national level** to help achieve these objectives and to drive good practice and focus on improving outcomes for individuals with learning disabilities or autism and behaviour which challenges.
12. If these actions happen, more people with learning disabilities will be supported to live at home, fewer people will develop behaviour that challenges and those that do can be kept safe in their communities, far fewer people will be sent away to hospitals and where that happens, proper planning will mean that their stay will be as short as possible, because hospitals should not be places to live in. And we will be able to measure progress in doing this.

Improve the capacity and capability of commissioning across health and care

- i. **Contracts:** The Department will work with the NHS Commissioning Board Authority to agree by January 2013 how best to embed Quality of Health Principles in the system, using NHS contracting and guidance. These principles will set out the expectations of service users in relation to their experience.

We will also work with the Towards Excellence in Adult Social Care (TEASC)⁴ to agree how Quality of Life principles should also be adopted in social care contracts to drive up standards.

- ii. **Service specification:** The Department will work with the NHS Commissioning Board Authority and the Association of Directors of Adult Social Care (ADASS) to develop a clear description of all the essential components of a model service by March 2013.
- iii. **Resources:** NICE will develop Quality Standards on learning disabilities and the autism Quality guidelines will be published in July 2012. Draft guidance for Clinical Commissioning Groups (CCGs) developed by the Learning Disability Observatory, the Joint Commissioning Panel and the Royal College of General Practitioners is available on the Observatory website.⁵ This is being reviewed and revised guidance will be published in October 2012.
- iv. **Collaborative commissioning:** The NHS Commissioning Board Authority will support CCGs to work together in commissioning services for people

with learning disabilities and behaviour which challenges. Health and Wellbeing Boards (HWBs) will bring together local commissioners of health and social care in all areas, to agree a joined up way to improve services.

Improve the quality of services which empower people with learning disabilities and their families to have choice and control

- v. **Voice:** The Department is establishing HealthWatch both locally and nationally. It will act as a champion for those who use services and for family carers, ensuring that the interests of people with learning disabilities are heard and understood by commissioners and providers of services across health and social care.
- vi. **Personalisation:** The Department expects the NHS and local authorities to demonstrate that they have taken action to assure themselves and the public that personalised care and choice and control is available in all settings, including hospitals.
- vii. **Providers:** The Department expects providers to deliver high quality services and prevent abuse. This includes:
 - actively promoting open access for families and visitors, including advocates and visiting professionals
 - making sure recruitment practices recruit the right people.

The Department will also discuss with providers developing and promoting a voluntary accreditation scheme.

The Department is working with the *Think Local, Act Personal* group⁶ and providers to identify the barriers in the housing market to increasing the availability of different housing options for people with learning disabilities with behaviour which challenges and to encourage and facilitate local solutions. This work should be completed by April 2013.

- viii. **Quality:** By autumn the National Quality Board⁷ will publish a report setting out how the new system architecture will identify and take action to correct potential or actual serious failure. This will provide clarity on the distinct roles and responsibilities of different parts of the system.
- ix. **Care Quality Commission:** The Department will look at how CQCs registration requirements could be changed to drive up the quality of services on offer and ensure that unannounced inspections can take place any day and any time of the week. CQC will review their on-going inspection of learning disability services, including the 150 hospitals and care homes recently inspected.

Clarify roles and responsibilities and promote better integration

- x. **Integrated workforce:** The professional bodies that make up the Learning Disability Professional Senate will carry out a refresh of *Challenging Behaviour: A Unified Approach* to support clinicians in community learning disability teams to clearly describe how different services fit together to deliver the best outcomes by December 2012.
- xi. **Professional standards:** The Academy of Royal Colleges and the professional bodies that make up the Learning Disability Professional Senate will develop core principles on a statement of ethics to reflect wider responsibilities in the new health and care system by April 2013.
- xii. **Concordat:** The Department is working with key national partners including the Association of Directors of Adult Social Services, the Local Government Association, the NHS Confederation, professional bodies including the Royal Colleges, health and care regulators, the Association of Supporting Living and the NHS Commissioning Board Authority to sign up to a concordat in the autumn committing each signatory to the actions they will take to deliver the right model of care and better outcomes for people with learning disabilities or autism and behaviour which challenges.

Promote innovation and reduce use of restraint

- xiii. **Restraint:** The Department will work with the Department for Education (DfE), Care Quality Commission (CQC) and others to drive up standards and promote best practice in the use of positive behavioural support and ensure that physical restraint is only ever used as a last resort.
- xiv. **Measuring progress:** The Department of Health will work with the NHS Commissioning Board Authority to agree what information and data we need to collect to measure progress – whether that is how long people stay in assessment units, how far they are from home, the experience of people who use care and support and their carers or other information that supports commissioners and providers to benchmark their activities.

Conclusions

- 13. The events at Winterbourne View were an extreme and unacceptable example of abuse. Our initial findings are that they are not widespread or systemic, but there is evidence of poor quality care, people staying in assessment units for too long and people being placed too far from friends and family.
- 14. Everyone has a duty to drive up standards. Local action will drive up good practice, but we are taking action at a national level too.
- 15. Our final report will be published when criminal proceedings have concluded and we will publish a follow up report one year later to make sure that progress has been made.

1. BACKGROUND AND CONTEXT

- 1.1 The Minister for Care Services, Paul Burstow, set up this review in response to the BBC Panorama programme on 31 May 2011, which showed serious abuse by staff of patients living in Winterbourne View Hospital, Bristol. Winterbourne View (which has now closed) was an independent sector hospital owned by Castlebeck Care Ltd.
- 1.2 The review is about the care of people with learning disabilities and/or autistic spectrum conditions who may have mental health conditions and/or behaviour which challenges (estimated as around 15,000 people in England), and their families/informal carers.
- 1.3 The aim of the full review will be to make sure that a rigorous and objective enquiry has taken place which:
 - establishes what happened at Winterbourne View;
 - identifies any wider issues about the care of these very vulnerable people;
 - learns lessons for the future; and
 - commits the Government to action.
- 1.4 This interim report of the review:
 - sets out the strategic direction, outcomes and how the Department of Health and the NHS Commissioning Board will measure progress;
 - ensures that commissioners, providers and the workforce are clear about their roles and accountabilities, and understand good models of care.
 - creates the framework within which local action should take place;
 - sets out proposed actions at a national level to drive good practice and focus on improving outcomes for individuals with learning disabilities or autism and behaviour which challenges.
- 1.5 The interim report will **not** directly cover what happened at Winterbourne View hospital. This will be included in the final report of the review which will draw on a number of investigations including:
 - police investigations and criminal proceedings against staff at the hospital;
 - reviews commissioned by the Castlebeck Care Board and shareholders;
 - inspections by the Care Quality Commission (CQC) of all Castlebeck Care units and a wider review of 150 learning disability hospitals and care homes (NHS, independent healthcare and social care facilities);
 - the report of the NHS Review of commissioning of care and treatment at Winterbourne View; and
 - the Serious Case Review (SCR) established by South Gloucestershire Council and chaired by Margaret Flynn.
- 1.6 The SCR will be published after the completion of criminal proceedings which is expected in August. The DH review will then formally consider the findings of these investigations and make a final report to Ministers who will share the report's findings and action plan with Parliament.

1.7 Even without the detailed findings of what happened at Winterbourne View which will be laid out in the SCR, we can clearly see from the CQC targeted inspections, and information from a wide range of stakeholders (including people who have used such services and their families), that the health and care system is not meeting the needs of people with learning disabilities or autism and behaviour which challenges, and there is a vast gap between national policy and practice on the ground. This must change.

Principles, policy, practice

1.8 A core right of all NHS patients is to be treated with dignity and respect and this is set out in the NHS Constitution.⁸ The Government is committed to the principle that people with learning disabilities or autism are people first, with the right to lead their lives like anyone else, with the same opportunities and responsibilities, and to be treated with the same dignity and respect.⁹ This applies just as much to those who also have behaviour which challenges.¹⁰

1.9 Professor Mansell's reports for the Department of Health in 1993 and revised in 2007¹¹ set out the established good practice on services for people with behaviour which challenges and there is a wide range of other good practice guidance available (See **Annex A**).

1.10 Despite this good practice, evidence to the Department's review shows that:

- Many people with behaviour which challenges – especially those living in assessment and treatment units - have little independence or choice and control.
- Health and care staff and providers do not always understand fully the legal framework for placing people into hospital settings where their liberty is constrained. Commissioners and providers should act to ensure they are fully compliant with the law including:
 - The NHS and Community Care Act 1990;
 - The Health and Social Care Act 2008;
 - The Mental Capacity Act 2005 and consequent Deprivation of Liberty Safeguards;
 - The Mental Health Act 1983; and
 - The Equality Act 2010.

1.11 Some people in assessment and treatment units are detained there under the Mental Health Act 1983, but others in locked wards, and with their freedom and movement constrained, are not. All patients are entitled to good quality care which respects their human rights. Some of the people we met, and their families, complained that they were given little say in where they were sent, which fails to meet the requirement safeguarded in the NHS Constitution that patients be allowed to make choices and be involved in decisions about their NHS care. This does not fit with the principles of personalisation. Nor does it fit with the principles of the Mental Health Act - least restriction, respect, participation, effectiveness, efficiency and equity. In the final report this autumn we will set out how we ensure these rights and principles are reflected in practice.

Numbers

- 1.12 There is poor quality of data available about numbers of people with learning disabilities or autism and behaviours that challenge, and about length of stay in in-patient services for assessment and treatment. There is no clear definition of what assessment and treatment means. As a result people are often lost in the system. The Department will work with the NHS Commissioning Board Authority to bring greater transparency to measure progress in providing this group with better quality health and care.
- 1.13 Challenging behaviour is not a diagnosis. Some people will have periods of behaviour which challenges. For others it may be more of a long-standing problem and may have been evident from childhood. Understanding the issues and providing good care and support may minimise the incidence of challenging behaviour. Nevertheless, we estimate that at any one time there are about 15,000 people with learning disabilities or autism and behaviour which challenges. Most of these are supported by their family carers or live independently in the community, often with complex packages of support.
- 1.14 At any one time, around 1,200 of these people may be in in-patient services for assessment and treatment. Some of the 1,200 are in hospital because of a break-down of community support. Others are there because they may need compulsory treatment, because of the risk they present to themselves or other people, or following diversion from the criminal justice system. However, there is no clarity about what assessment and treatment means.¹² The number of units providing assessment and treatment services is also hard to pin down. **Annex B** sets out available data in more detail.
- 1.15 Strategic Health Authorities collected data at 31 October 2011 to benchmark numbers of people in in-patient assessment and treatment services and give local commissioners evidence of current provision to enable effective planning. This is being analysed by the Learning Disabilities Observatory and will be available for the final report of this review.
- 1.16 The Department is working with CQC and the Health and Social Care Information Centre to improve data collection through the Hospital Episode Statistics for people with learning disabilities in in-patient services for assessment and treatment services and to develop a Learning Disability Minimum Dataset by 2014/15.

ACTION

- 1.17 The Department will work with the Information Centre and the NHS Commissioning Board Authority to agree what information and data we need to collect to measure progress – whether that is how long people stay in assessment units, how far they are from home, the experience of people who use care and support and their carers or other information that supports commissioners and providers to benchmark their activities.**

2. SUMMARY OF EVIDENCE

- 2.1 In October 2011, CQC began a targeted inspection programme of 150 hospitals and care homes for people with learning disabilities. CQC completed all visits in February 2012. Reports for all inspections are on the CQC website¹³ and a national summary report was published on 25 June 2012.
- 2.2 Inspections were led by CQC inspectors joined by two “experts by experience” - people who have experience of using services, either first hand or as a family carer and who can provide the patient perspective - and a professional advisor. Unannounced visits usually lasted two days. Inspections focused in particular on 2 key outcomes:
- Outcome 4 - Care and welfare; and
 - Outcome 7 - Safeguarding adults from abuse.
- 2.3 CQC inspected 71 NHS facilities, 47 Independent Healthcare providers and 32 adult social care facilities. Details of the findings are in the CQC summary report, but key findings were that:
- Across all the 150 NHS, Independent Healthcare and adult social care facilities inspected the overall levels of compliance with both outcomes were low with 48% of all locations inspected being non compliant with care and welfare of people who use services and safeguarding people who use services from abuse;
The majority of the assessment and treatment services were compliant with both outcomes (51%).
 - Of the assessment and treatment services, NHS locations were nearly twice as likely to be compliant with both of the outcomes compared to Independent Healthcare Service providers (68% and 33% respectively);
 - Of the adult social care services less than half (47%) of the residential care homes were compliant with both of the outcomes;
 - However, the majority of people (63%) were living in residential care homes that were compliant with both outcomes;
The majority of assessment and treatment services were compliant with both outcomes (51%).
- 2.4 The key issues where there were concerns included:
- limited person-centred care;
 - limited appropriate activities; and
 - a lack of monitoring and learning from incidents of restraint.
- 2.5 The Department’s review also draws on an extensive engagement with key stakeholders (see **Annex C**).

3. THE MODEL OF CARE

- 3.1 **There are too many people with learning disabilities/autism and behaviour which challenges living in in-patient services for assessment and treatment and they are staying there for too long. This model of care has no place in the 21st century.**
- 3.2 The closure of most long-stay hospitals in the 1980s and 1990s, and the recent closure of NHS campuses, means most people with learning disabilities, including those with behaviours that challenge now live in the community with support. But some still live (for short or longer periods) in NHS funded settings. Assessment and treatment units emerged as the most likely solution to meeting the needs of people with learning disabilities and complex mental health/behavioural issues post-institutional closure.¹⁴ However, there were opposing views between ‘building based’ services and increasing support to people in their natural communities as the preferred option.¹⁵
- 3.3 Good practice guidance on supporting people with learning disabilities, autism and those with behaviour which challenge includes the 1993 Mansell report, updated and revised in 2007¹⁶ (see **Annex A**). Both emphasise:
- the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers;
 - a focus on personalisation and prevention in social care;
 - that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour; and
 - that services/support should be provided locally where possible.
- 3.4 Evidence shows that community-based housing enables greater independence, inclusion and choice and that challenging behaviour lessens with the right support. The Association of Supported Living’s report *There is an Alternative* describes how 10 people with learning disabilities and challenging behaviour moved from institutional settings to community services providing better lives and savings of around £900,000 a year in total.¹⁷
- 3.5 The CQC *Count me in 2010* census showed only 2 learning disabled patients on Community Treatment Orders compared to over 3,000 mental health patients – suggesting a greater reliance on in-patient solutions for people with learning disabilities than for other people needing mental health support.¹⁸
- 3.6 CQC found some people were staying many years in assessment and treatment units. Annex B estimates that, in March 2010, at least 660 people were in A&T in Learning Disability wards for more than 6 months.
- 3.7 This report sets out how the model of care set out in the Mansell reports fits with the new health and care system architecture focusing on key principles, desired outcomes for individuals, and a description of how the model should work in practice.

Key principles

3.8 The key principles of high quality services for people with learning disabilities and behaviour which challenges are set out below:

For people

- i. I and my family are at the centre of all support – services designed around me, highly individualised and person-centred.
- ii. My home is in the community – the aim is 100% of people living in the community, supported by local services.
- iii. I am treated as a whole person.
- iv. Where I need additional support, this is provided as locally as possible.

For services:

- v. Services are for all, including those individuals presenting the greatest level of challenge.
- vi. Services follow a life-course approach i.e. planning and intervening early, starting from childhood and including crisis planning.
- vii. Services are provided locally.
- viii. Services focus on improving quality of care and quality of life.
- ix. Services focus on individual dignity and human rights.
- x. Services are provided by skilled workers.
- xi. Services are integrated including good access to physical and mental health services as well as social care.
- xii. Services provide good value for money.
- xiii. Where in-patient services are needed, planning to move back to community services starts from day one of admission.

Outcomes

3.9 A high quality service means that people with learning disabilities or autism and behaviour which challenges will be able to say:

- i. I am safe.
- ii. I am treated with compassion, dignity and respect.
- iii. I am involved in decisions about my care
- iv. I am protected from avoidable harm, but also have my own freedom to take risks I am helped to keep in touch with my family and friends.
- v. Those around me and looking after me are well supported.
- vi. I am supported to make choices in my daily life.
- vii. I get the right treatment and medication for my condition.
- viii. I get good quality general healthcare.
- ix. I am supported to live safely in the community.
- x. Where I have additional care needs, I get the support I need in the most appropriate setting.
- xi. My care is regularly reviewed to see if I should be moving on.

- 3.10 This is about personalisation, starting with the individual at the centre, living in the community. The first level of support for that individual includes the people, activities and support all people need in their every day lives – family, friends, circles of support, housing, employment and leisure.
- 3.11 Most people with learning disabilities or autism will need more support from a range of sources: their GP or other primary care services, advocacy, a care manager or support worker and could include short breaks. That support may change as needs change, and this will involve assessments of physical or mental health needs or environmental needs (such as loss of a parent, a relationship breakdown, unemployment) to identify what support should be provided.
- 3.12 For people who need further support – including where they have behaviour which challenges – the intensity of support should increase to match need. That should include intensive support services in the community, assessment and treatment services (which could be provided in a safe community setting), and, where appropriate, secure services. But the aim should always be to look to improvement, recovery, and returning a person to their home setting wherever possible.
- 3.13 Responsibility for safety and quality of care depends on all parts of the system working together:
- i. **providers** have a duty of care to each individual they are responsible for, ensuring that services meet their individual needs and putting systems and processes in place to provide effective, efficient and high quality care;
 - ii. **commissioners** (NHS and local authorities) are responsible for planning for local needs, purchasing care that meets people’s needs and building into contracts clear requirements about the quality and effectiveness of that care;
 - iii. **workforce**, including health and care professional and staff who have a duty of care to each individual they are responsible for; and
 - iv. **system and professional regulators** who are responsible for assuring the quality of care through the discharge of their duties and functions.
- 3.14 To achieve these outcomes a revised model of care as set out below needs to be delivered.

Model of care - Roles and responsibilities

Good services meeting the needs of everybody must include:

Information

- **Councils, elected councillors, health bodies, voluntary sector, care providers** should provide good quality, transparent, information, advice and advocacy support for individuals, families and carers.

Community based support

- **Councils and health commissioners** should ensure that general services (GPs, hospitals, libraries, leisure centres etc) are user-friendly and accessible to people with learning disabilities/autism so they can access what everyone else can access.
- **Community based mental health services** for this group should offer assertive outreach, 24-hour crisis resolution, a temporary place to go in crisis and general support to deal with the majority of additional support needs at home.
- **Housing** authorities should include a wide range of community housing options - shared, individual, extra care, shared lives scheme, domiciliary care, keyring, respite.
- **Social care commissioners** should ensure the availability of small-scale residential care for those who would benefit from it (eg because they have profound and multiple disabilities).
- **Councils and employment services** should offer support into employment.
- **Councils, voluntary and independent sector providers** should enable a range of daytime activities.
- **Councils** should roll out personal budgets for all those who are eligible for care and support including those with profound and multiple disabilities and/or behaviours seen as challenging.
- Where appropriate, **health commissioners** should fund continuing health care.
- **Health and social care commissioners** should focus on early intervention and preventive support to seek to avoid crises (eg behavioural strategies). Where crises occur, they should have rapid response and crisis support on which they can call quickly.

Commissioning, Assessment and care planning

Health and social care commissioners should develop personalised services that meet people's needs. Key factors include:

- involving individuals - with support where needed - and families at all stages
- planning for the whole life course, from birth to old age, starting with children's services
- developing expertise in challenging behaviour
- developing partnerships and pooling resources to work together on joint planning and support with integrated services – including:
 - multi-disciplinary teams to perform assessments, care planning, care assessment, care management and review,
 - joint commissioning – ideally with pooled budgets, and
 - shared risk management.
- **Health and social care commissioners** should use all available information from joint strategic needs assessments (JSNAs) and local health and wellbeing strategies to

commission strategically **for innovation** and to develop person-centred community based services

- **Health and social care commissioners** should commission personalised services tailored to the needs of individuals, ensuring a focus on improving that individual's health and well-being and agreed outcomes. Progress towards delivering outcomes should be regularly reviewed.
- **Health and social care commissioners** should start to plan from day one of admission to in-patient services for the move back to community.
- **Health and social care commissioners** should ensure close coordination between the commissioning of specialised services including secure services, and other health and care services.
- **Social care bodies** have ongoing responsibility for individuals, even where they are in NHS-funded acute or mental health services, including working with all partners to develop and work towards delivering a discharge plan.
- **Health and social care commissioners should** audit provision to assess which services are good at supporting people with challenging behaviour (the Health Self Assessment Framework is an effective way to monitor outcomes).
- **Health and social care commissioners** should develop effective links with children's services to ensure early planning at transition and joint services. The SEND Green Paper proposal for an integrated health, education and care plan from 0-25 will also help to ensure that children's services are similarly thinking about a young person's transition to adult services at an early stage.

Service Providers

- **All service providers** (community, residential, health, care, housing – public sector, independent sector, voluntary sector) have a duty of care to the individuals for whom they provide services. This includes ensuring that:
 - people are safe and protected from harm,
 - their health and well-being are supported,
 - their care needs are met,
 - people are supported to make decisions about their daily lives,
 - people are supported to maintain friendships and family links.

Providers should:

- provide effective and appropriate leadership, management, mentoring and supervision. Good leadership is essential in setting the culture and values.
- have a whole organisation approach to Positive Behaviour Support training.
- recruit for values and ensure that staff have training for skills - mandatory training which can include training on value bases when working with people with learning disabilities, positive behaviour support, types of communication including non-verbal communication, active support and engaging in meaningful activities and Mental Capacity requirements. Best practice includes involving people with learning disabilities and families in the training.
- operate good clinical governance arrangements.
- monitor quality and safety of care.
- Work with commissioners to promote innovation – new and different ideas , especially for the most challenging.

Assessment and treatment services

- **Health and care commissioners** are responsible for commissioning assessment and treatment services where these are needed. The focus should be on services (which can be community based) rather than units. Where a person is at risk (or is putting others at risk) in a way that community support cannot help and needs to be moved to a safe place, **commissioners** should focus on this being provided close to home.
- **Health and care commissioners** should look to review any placement in assessment and treatment services regularly, and focus on moving the individual on into more appropriate community based services as soon as it is safe for the individual to do so.
- **Social care services** should be closely involved in decisions to admit to assessment and treatment services.
- All **assessment and treatment services providers** must comply with statutory guidance on the use of physical restraint.

Prisons and secure services

- **Social care services** should work closely with prison and secure services to ensure person centred planning and health action planning and to plan for appropriate provision when people move on from prison or secure services.
- **Offender management processes** should include health screening programmes that identifies an offender's learning disability and any physical and/or mental health issues.

Workforce should demonstrate that they are providing quality care and support which includes:

- personal and professional accountability,
- training in working with people with complex needs and behaviour which challenges,
- developing good communication and involving advocates and families,
- monitoring individual's progress and reviewing plans, and
- good understanding of the legislative framework and human rights.
- Taking action to report any concerns identified.

System and professional regulators

As a regulator, the Care Quality Commission (CQC) should:

- monitor whether services are meeting essential standards,
- take enforcement action if a provider is not compliant,
- monitor the operation of the Mental Health Act 1983.

Professional regulators such as the Nursing and Midwifery Council (NMC) and General Medical Council (GMC), have a role to play to protect and promote public safety. They do this by:

- setting and maintaining professional standards and
- investigating and taking appropriate action where concerns are raised about registrants, which can include the registrant being removed from the register and where appropriate being referred to the Independent Safeguarding Authority (ISA) if it is considered to be in the best interests of the public.

Together the professional regulators have produced a leaflet¹⁹ to help the public to ensure that they receive the care and treatment from professionals who meet the right standards.

Making the model of care happen

3.15 The review found that:

- People with learning disabilities and their families and services are not clear about roles and responsibilities across the system;
- There is ignorance about best practice and even where best practice is; known, people do not know how to make it happen;
- There are perverse incentives in the system;
- There are barriers to developing the market to ensure there is a wide range of housing support and options available.

3.16 To make change happen the following need to be in place:

- A clear vision of what we want to offer, a shared value base and a commitment to see it delivered;
- The voice of users and families is heard and acted on;
- All parts of the system understand and apply the law;
- There is good understanding and application of positive behavioural support – and that physical restraint is only ever a last resort.
- Providers, commissioners, the workforce and regulators are clear about their roles and act on their responsibilities;
- Incentives in the system to ensure good models of care which give the best care and outcomes for individual people.

3.17 The key is a redesign of services to invest in flexible good quality local services and away from sending people away from home. The use of in-patient services for assessment and treatment varies hugely across the country in terms of numbers of people and length of stay. There are robust examples of good practice where the focus is on providing intensive community support as far as possible with only limited use of in-patient services. Developing the capacity and capability of local services is critical in this.

Tower Hamlets, Salford and Cambridge have provided examples of good practice in:

- i. reducing the numbers of people using in-patient services for assessment and treatment
- ii. developing good local services across health and care
- iii. developing multidisciplinary teams to provide intensive support in the community.

These examples have been published separately at:

www.dh.gov.uk/learningdisabilities

4. VOICE OF PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

- 4.1 The NHS and Social Care Act 2012²⁰ principle of *no decision about me without me* applies to all people who use services, including those with behaviour which challenges. But the experience of people who have contributed to the DH Review is that their voice is still too often not heard and that they are not sufficiently involved in decisions about their health and care.
- 4.2 The Mental Capacity Act 2005 makes clear that providers of services must start from the presumption that people have capacity to make decisions about their care – and so should be consulted on all aspects of their care including what they eat, what they wear, and the activities they take part in. All people receiving care and support should have personalised care plans which should include supporting them to maintain close relationships with families and friends. Hospitals need to be very clear that assessments of capacity must be decision specific; and that assessments of capacity which are about 'diagnosis' are insufficient for decisions about how a person is being cared for.
- 4.3 The NHS Constitution states that patients have the right to be involved in discussions and decisions about their healthcare. Where people lack capacity to make decisions, then providers should ensure that others are able to speak on their behalf, whether families or advocates. Good information and advice is important in helping people with learning disabilities and their families to understand the care available to them and to make informed choices, another right set out in the NHS Constitution.
- 4.4 However, CQC found that people (and carers) were not always given appropriate and accessible information and advice. CQC found that people often had to request advocacy, and were not always given appropriate and accessible information on how to access independent advocacy. The Care and Support White Paper will set out actions to improve the quality and availability of information, advice and advocacy support that will help people to understand their rights and what advocacy services are available locally. People with learning disabilities and family carers also raised concerns about the availability of independent advocacy and the quality of advocacy services.
- 4.5 People detained under the Mental Health Act 1983 are entitled to an advocate (Independent Mental Health Act Advocate) to support them to access the safeguards they are entitled to (such as a Tribunal to review the decision to continue to detain them). Service providers have a duty to inform patients about this service and enable them to access it. Some people who may lack capacity to make decisions about serious medical treatment or care moves may be entitled to an Independent Mental Capacity Advocate (IMCA).
- 4.6 CQC found that some services had insufficient information available to explain to people using the service and their relatives how to report abuse or raise a

concern or complaint. The Care and Support White Paper will set out our plans to ensure that local authorities provide clear information on how people can raise a concern about abuse, or a complaint.

- 4.7 Following the financial difficulties of Southern Cross in 2011, the Government is considering whether current consumer protection arrangements are sufficient to support care residents and their families, in the event of the financial distress of a care provider. The Government will set out the direction of travel on market oversight in the forthcoming Care and Support White Paper.
- 4.8 From April 2013, new local Healthwatch organisations will have the powers to enter and view services where there are concerns about a particular provider to scrutinise and comment upon it. The provider will have to respond in writing to any recommendations for improvements made by local Healthwatch. If appropriate, information can also be passed to the local authority or the CQC to consider if further action is needed. Training will be provided for local Healthwatch organisations.
- 4.9 Health and Well-being Boards should engage with people with learning disabilities and their family carers, to ensure their voice is heard in commissioning services.

ACTION

- 4.10 The Department is establishing HealthWatch both locally and nationally. It will act as a champion for those who use services and for family carers, ensuring that the interests of people with learning disabilities are heard and understood by commissioners and providers of services across health and social care.**
- 4.11 Providers need to actively promote open access for families and visitors, including advocates and visiting professionals. This is about increasing transparency.**

5. Personalisation

- 5.1 Personalisation is at the heart of transforming care and support for people with learning disabilities or autism and behaviour which challenges. But the CQC inspections identified real concerns about the quality of person-centred planning for people in those units. Involvement of people in developing their care plan was limited. Care plans were not person centred and unable to inform the delivery of care in a way that met individual needs and ensured patient welfare and safety.
- 5.2 Commissioners and providers need to review care plans to ensure that:
- they involve the individual and their families in developing plans;
 - plans are accessible to service users and in a format they can understand.
 - planning starts from childhood;
 - plans are not just for when things are going well but also for when things may go wrong so as to avoid spot-purchasing in times of crisis;
 - discharge planning is built into care plans from day one when people go into hospital settings.

Examples of good practice include:
'Liberty Care Plans' where people are helped to be as included in their families and in the local community as possible.

ACTION

- 5.3 **The Department expects the NHS and local authorities to demonstrate that they have taken action to assure themselves and the public that in ensuring personalised care and support with choice and control in all settings – including hospitals..**
- 5.4 A key part of personalisation is about increasing user choice and control. The Department is working with the LGA and ADASS, the National Valuing Families Forum and the National Forum of People with Learning Difficulties to identify good practice in local authorities who have developed innovative solutions to maintain and improve people's outcomes and access to services. These will focus on:
- Co-production - involving people who use services in designing and planning them;
 - Community building - and moving towards community based support;
 - A capabilities approach to disability - looking at people's strengths and promoting what they can do;
 - Integrated services, covering health, care, housing and leisure; and
 - Personalisation as a foundation on which other strategies build.

6. PROVIDERS AND ENSURING QUALITY OF CARE

- 6.1 Supporting people with learning disabilities or autism and behaviour which challenges is a skilled and complex job. All NHS patients have a right under the NHS Constitution to be treated with a professional standard of care by appropriately qualified and experienced staff. Providers have a duty to fulfil this requirement and demonstrate that they are providing good quality care.
- 6.2 Provider organisations have a critical role in providing good leadership, setting the right cultures and behaviours to prevent systemic abuse, and acting quickly where concerns are identified. Internal management and assurance is key to quality outcomes. Providers need to ensure clear lines of accountability in their governance arrangements. The role of provider boards is critical here. Providers need to demonstrate that they govern themselves well and focus on good quality assurance.
- 6.3 Good quality services are those where providers state clearly what you will find in these services; and there is genuine openness to families and communities.

ACTION

- 6.4 The Department expects providers to deliver high quality services. The Department will also discuss with providers action to develop a voluntary accreditation scheme.**
- 6.5 Examples include schemes such as My Home Life, UK Home Care Association Code of Practice, or the Dementia Compact. The Social Care Institute for Excellence (SCIE) is shortly to publish *Making it Real* outcomes with a generic quality framework that providers of all shapes, sizes and specialisms might wish to adopt. The Department will build on this to ensure additional requirements for this highly vulnerable group are included.
- 6.6 Recruitment of the right staff at all levels– and providing appropriate training - is critical to providing safe, good quality care. Providers are accountable for the staff they employ and should be creative in recruiting. Practice leadership plays a key role in monitoring day to day practice and driving up standards. **CQC registration requirements on providers include having appropriately trained and qualified workers.**
- 6.7 **Providers should make sure their recruitment practices select people who are suitable for working with people with learning disabilities or autism and behaviour which challenges.** Best practice includes:
- Peer monitoring of the interview process
 - Involvement of people and families in interviews
 - Using profiling to weed out unsuitable candidates.
- 6.8 Providers need to ensure that staff have the right incentives to create and maintain the right culture in services. This includes setting clear expectations and accountabilities. In particular, providers need to ensure that training includes value bases when working with people with learning disabilities,

positive behaviour support, types of communication including non-verbal communication, and particularly Mental Capacity Act requirements. Best practice includes involving people with learning disabilities and families in the training. The Nursing and Care Quality Forum has also highlighted the importance of making sure nurses are recruited for their caring nature and compassion as well as their knowledge and skills and the importance of leadership and accountability.

- 6.9 CQC inspections found that though suitable activities were in place at many services, some had only a limited choice or access to activities that would support and promote independence. Activities were not always tailored to meet individuals' needs and wishes. Providers need to ensure that they offer person-centred care and support with a broad range of meaningful activities.
- 6.10 Providers are key partners in working with commissioners to drive up the quality and availability of different housing options and to develop creative solutions to support more people to live in community settings.

ACTION

6.11 DH is working with the *Think Local, Act Personal* group and providers to identify the barriers in the housing market to increasing the availability of different housing options for people with learning disabilities with behaviour which challenges and to encourage and facilitate local solutions. The project should be completed by April 2013.

- 6.12 Improving the quality of health and care is a key objective for DH and is at the heart of this review. The National Quality Board (NQB) provides leadership for quality across the health system including where it links with social care.

ACTION

6.13 The NQB will publish in late summer a report setting out how the new system architecture will identify and take action to correct potential or actual serious failure. This will provide clarity on the distinct roles and responsibilities of different parts of the system in relation to quality failure, and emphasise the importance of all parts of the system operating within a culture of open and honest transparency and working together in the best interests of patients and service users.

- 6.14 The NQB will also consider its continuing role in light of the new system architecture over coming months, with a view to ensuring it is best placed to align different parts of the system across health and social care around a central focus on quality.

7. COMMISSIONING AND CONTRACTING

7.1 Commissioners have a key role:

- at a strategic level in planning and designing services to meet the needs of their local populations and shaping the market; and
- at a local level in collaborative approaches and in good procurement and contract, care and case management.

But it is clear that many commissioners are unaware of good practice in commissioning for people with learning disabilities or autism and behaviour which challenges.

7.2 Commissioning should be based upon the need identified in Joint Strategic Needs Assessments (JSNAs) and joint health and well-being strategies. From April 2013, local authorities and clinical commissioning groups (CCGs) will each have duties to contribute to these. Joint health and well-being strategies set priorities for collective action based on the needs identified within JSNAs and should form the basis for commissioning plans.

7.3 Health and well-being boards will be required to involve local people in preparing JSNAs and health and wellbeing strategies, ensuring that local needs and priorities are represented.

ACTION

7.4 **DH will provide statutory guidance to support health and well-being boards to develop joint health and well-being strategies, and will revise statutory guidance for the JSNA to reflect the needs and circumstances of the new system.**

7.5 For the future:

- **CCGs** will have specific duties to secure improvements in the quality of services, reduce inequalities in access to – and outcomes from – health services, promote involvement of patients and carers in decisions about individual care, secure advice from a range of health professionals, and cooperate with local authorities including participation on Health and Wellbeing Boards.
- **The NHS Commissioning Board** will support CCGs in commissioning services and hold them to account for the outcomes they achieve. The Board will publish commissioning guidance and provide practical tools and resources to support CCGs.
- **Clinical senates** will have a supporting and enabling role, acting as a source of advice for CCGs. They will be available to provide expertise and advice on a range of health and care perspectives and will include public health specialists, allied health professionals and adult and social care experts.
- **Clinical networks** will support commissioners in the implementation of evidence based care for specific conditions or groups of patients.

7.6 There is good guidance on the characteristics of services that best meet the needs of people with learning disabilities and behaviour which challenges, but

commissioners have said they would welcome practical tools to support them in commissioning more effectively for these services and to improve outcomes.

ACTION

7.7 The Department is working with the NHS Commissioning Board Authority and ADASS to develop a model service specification by March 2013.

7.8 NICE is developing Quality Standards on learning disabilities and the autism Quality guidelines will be published in July 2012.

7.9 Three emerging CCGs are working with the NHS Commissioning Board Authority and the Learning Disabilities Observatory in a project to look at commissioning services for people with learning disabilities.²¹ The project aims to support CCGs as they begin to commission community, hospital and specialist health services for people with learning disabilities. It will build on recent work to improve care and provision for people with learning disabilities and enable sharing of the learning with the wider clinical commissioning community. **Draft guidance for CCGs developed by the Learning Disability Observatory, the Joint Commissioning Panel and the Royal College of General Practitioners is available on the Observatory website.²² This is being reviewed and revised guidance will be published in October 2012.**

7.10 Effective local partnerships and pooled resources are crucial in work to improve outcomes for people with behaviours that challenge. This includes effective partnership working across CCGs and across health and social care commissioners, with local providers and with children's services to identify and support young people in transition to adult services.

7.11 This will include ensuring clear commissioning responsibilities to prevent the loss of focus on individuals which can arise where providers receive referrals from a number of different commissioners.

7.12 Local collaborative commissioning arrangements could, for instance, be based on a co-ordinating commissioner for a provider of specialist services to people with behaviour which challenges where there is more than one commissioner. This would ensure a single coordinated approach to assessing needs, specifying contractual requirements and reviewing quality of services.

7.13 This will not replace the responsibilities of individual commissioners in relation to ensuring high-quality assessment and placement decisions for individuals and active review of placements, including out of area placements.

ACTION

7.14 The NHS Commissioning Board will support CCGs to work together collaboratively in commissioning services for people with learning disabilities and behaviour which challenges.

- 7.15 For people with behaviour which challenges whose care is funded through NHS Continuing Healthcare (CHC) arrangements, family carers expressed concerns about individuals' access to direct payments and how local authorities engage with individuals funded under CHC.
- 7.16 Personal health budgets, including direct payments, are currently being piloted across England. The final evaluation report is due in October 2012 and subject to this evaluation, they will be rolled out more widely.
- 7.17 Assessments for NHS CHC need to be undertaken by professionals who have clear knowledge of NHS CHC domains and with understanding of learning disabilities. There is anecdotal evidence that commissioning of care packages could be improved, looking at more innovative models often commissioned by local authorities. NHS commissioners can make arrangements for local authorities to commission on their behalf. Local authorities need to stay engaged with CCGs about people with learning disabilities accessing CHC.

ACTION

- 7.18 **Health and care commissioners need to work together to review funding arrangements for people with behaviour which challenges and develop local action plans to deliver the best support to meet individuals' needs.**
- 7.19 The NHS Commissioning Board's role in commissioning GP services and other primary care services will include taking forward from PCTs (subject to this year's GP contract negotiations) the responsibility for the Directed Enhanced Service for annual health checks for registered patients with severe or moderate learning disabilities.
- 7.20 Commissioning for Quality and Innovation (CQUIN) is an NHS commissioning tool which makes a proportion of the provider's income conditional on delivering quality and Innovation. It has been used successfully in some parts of the country to improve services for people with learning disabilities. We will explore this further in the final report.
- 7.21 There is evidence that using Quality of Health principles, such as those developed by Changing our Lives, in contracts can drive up standards of care. These principles have been developed by service users and set out the standards to be expected for good quality services.
- 7.22 It is important to monitor performance against contracts to assess outcomes for the individuals concerned – and to involve people with learning disabilities and their families in these assessments. Changing our Lives audits of Quality of Health Principles could drive up standards of care. Changing our Lives audits include people with learning disabilities, in the design of assessments of healthcare providers on a range of measures.

ACTION

- 7.23 **The Department will work with the NHS Commissioning Board Authority to agree by January 2013 how best to embed Quality of Health Principles**

in the system using NHS contracting and guidance. These principles will set out the expectations of service users in relation to their experience

We will also work with the Towards Excellence in Adult Social Care (TEASC)²³ to agree how similar Quality of Life principles should also be adopted in social care contracts to drive up standards.

- 7.24 Evidence shows that on occasions commissioners have only used contracts supplied by the provider. This is inappropriate. NHS commissioners are required to use the NHS standard contract for providers of NHS funded care and avoid “spot purchased” patient placements. The NHS standard contract requires that the commissioner is informed at the same time as CQC of any notification of a serious incident where this concerns a service user. The commissioner should monitor the quality and performance of the provider as a whole as set out in the NHS Contract. In addition, the commissioner is responsible for ensuring appropriate arrangements for reviewing progress of assessment and treatment as set out in individual person centred care plan and in co-ordinating discharge arrangements alongside local authority commissioners.

ACTION

- 7.25 Local authority commissioners should review existing contracts to ensure they include an appropriate specification to meet the needs of the individual and appropriate information requirements to ensure the commissioner is able to monitor the care being provided.**
- 7.26 A number of patients in assessment and treatment units have been detained under the Mental Health Act 1983. The needs of detained patients should inform local commissioning plans and placements should meet the same considerations of good quality, focussing on outcomes and close to home.

8. WORKFORCE

- 8.1 Evidence to the DH review has highlighted the importance of clarifying roles and responsibilities for workforce including professionals and ensuring better integration of services and multi-disciplinary working.

ACTION

- 8.2 **The Royal Colleges and Learning Disability Clinical Senate will carry out a refresh of *Challenging Behaviour: A Unified Approach* to support clinicians in community learning disability teams to develop effective local pathways by December 2012²⁴.**

Halton Borough Council alongside St Helens and Halton NHS have commissioned a specialist, peripatetic lifespan Positive Behaviour Support Service. Neighbouring authorities St Helens and Knowsley are also investing in the service. The service works collaboratively in four areas:

- Early intervention
- Crisis management
- Technical Support
- Placement Development – returning people who are out of borough to their local area

- 8.3 A recurring theme in stakeholder discussions, whether with professionals or particularly from families, is a concern about the role of some clinicians in referring individuals to the services where those clinicians are employed. The GMC has issued guidance to doctors on this.²⁵

ACTION

- 8.4 **The Academy of Royal Colleges and the professional bodies that make up the Learning Disability Professional Senate will work to develop core principles on a statement of ethics which will reflect wider responsibilities in the new health and care architecture.**

- 8.5 Detentions under the Mental Health Act entail many safeguards of patient's rights, including the guiding principles of purpose, least restriction, respect, participation and effectiveness, efficiency and equity. These principles and protections apply equally to people with learning disabilities and should be in place when deciding on detention under the Mental Health Act 1983.

- 8.6 Caring for people with behaviours that challenge requires a well-trained workforce with the right skills mix including specialist professionals trained in specific conditions. And a key issue is ensuring that the workforce are trained in positive behavioural support approaches which includes identifying the factors which trigger challenging behaviour and in attitude change interventions.²⁶

- 8.7 Training resources available to professionals include:
- The GMC published in April a new online resource to support GPs treating patients with learning disabilities.

- The RCN has published a suite of information to support better training of Learning Disability nurses including mindfulness training.
- 8.8 Skills for Care, the sector skills council for adult social care in England, is developing a framework of guidance and support on commissioning workforce solutions to meet the needs of people with behaviour which challenges. This will be consulted on and tested in action in summer 2012, and launched by the end of 2012.
- 8.9 The four chief nursing officers across the UK commissioned a review of learning disabilities nursing. The report, published in April 2012, aims to ensure that people with learning disabilities of all ages have access to expert Learning Disabilities nurses and that their families and carers get the best support and care.

ACTION

- 8.10 The Department is working with the other three UK health departments and key partners to establish a steering committee to consider and take forward the recommendations in *Strengthening the Commitment* the report of the UK Modernising Learning Disabilities Nursing Review.** ²⁷
- 8.11 The Department will update the Mental Health Act Code of Practice to take account of findings from the review and to reflect the changes to the new health and care system.
- 8.12 A substantial proportion of the workforce caring for this group of people is not subject to statutory professional regulation, including health and social care support workers. There are however, processes to assure quality of care and public safety including supervision of unregulated staff by regulated professionals, CQC registration and the vetting and barring scheme. The Government has legislated in the Health & Social Care Act 2012 for a system of external quality assurance for voluntary registers of professional and occupational groups not statutory regulated.
- 8.12 DH has already jointly commissioned Skills for Health and Skills for Care to accelerate production of a code of conduct and minimum induction/ training standards for healthcare support workers and adult social care support workers in England. We expect these to inform the establishment of a voluntary register for healthcare support workers and adult social care workers in England, which could be operational from 2013 onwards. This will allow unregulated workers to demonstrate they meet a set of minimum standards for training and are signed up to a code of conduct. It will also provide health & social care providers with tools to enable them to identify appropriately skilled and qualified workers.

Safeguarding and restrictive physical intervention

- 8.13 CQC found that although most services reported safeguarding appropriately some did not in all instances. And there were cases where the outcomes of safeguarding incidents were not documented and lessons learnt. This is unacceptable and services must prioritise improvements in these areas.

- 8.14 **Strengthening adult safeguarding arrangements is a key priority for this Government.** We are committed to preventing and reducing the risk of abuse and neglect to adults in vulnerable situations, whilst supporting individuals in maintaining control over their lives and in making informed choices without coercion. We will work with others to establish a significant and enduring culture shift where there is zero-tolerance of abuse and neglect at every level of the health and social care system.
- 8.15 The Queen's Speech in May 2012 announced publication of a draft Care and Support Bill which will set out the first legislative framework for safeguarding adults in England. We intend to legislate for Safeguarding Adults Boards. Legislation will put these boards on a stronger, statutory footing, better equipped both to prevent abuse and to respond when it occurs.
- 8.16 Legislation is only part of the solution. All parts of the health and care system need to reinforce consistently the message that this type of behaviour is unacceptable and that everyone has a responsibility to act to prevent and report abuse. The final report of the DH review will address this in more detail.

Restrictive physical intervention and restraint

- 8.17 CQC inspections found that only 73% of locations met requirements on physical intervention/restraint. There was ineffective monitoring of restraint data and learning from incidents. Staff were not always trained and restraint was not always being delivered in line with the care plan. **Physical restraint should only ever be used as a last resort to ensure the safety of the individuals or others and always employ the minimum force possible.**

ACTION

- 8.18 **The Department is working with DfE, CQC and other partners to drive up standards and promote best practice by the end of 2013 for those working in therapeutic or supportive roles to promote use of positive behavioural support and avoid use of restrictive physical interventions, except as a last resort.** We will do this by:
- developing a set of core principles across the health and social care sector, (children and adults) emphasising the need for positive behaviour support and the importance of reducing the use of restrictive physical interventions by April 2013;
 - providing an interim update to the guidance issued jointly by DH/DfE under Section 7 guidance on 'restrictive physical interventions: how to provide safe services for people with learning disabilities and Autistic Spectrum Disorder' to cover the Mental Capacity Act, Deprivation of Liberty Safeguards and Safeguarding by April 2013 before the full review of the guidance is complete by end 2013.
 - reviewing training so that restrictive physical interventions should only ever be used when all other reasonable alternatives have been considered and found to be ineffective or inappropriate (or in an emergency when the risks of not doing so are outweighed by the risks of using restraint in which case a full behaviour assessment should be undertaken and a support plan developed). Training should be delivered in a framework that takes account

of the level of risk within specific services – and we will give more detail on this piece of work in our final report.

- considering what additional guidance is needed for specific groups including people with learning disabilities and behaviour which challenges.

8.19 Restrictive physical interventions must be part of a broader strategy of positive behaviour support to meet the needs of children and adults whose behaviour poses a serious challenge with proper reference to the human rights of the individual and their dignity and respect.

Whistleblowing

8.20 Events at Winterbourne View highlighted the importance of whistleblowing in identifying concerns and in taking action to address these concerns swiftly. All parts of the system have a role:

- Government: in ensuring that the legislative framework in the Public Interest Disclosure Act is adequate;
- employers: in supporting staff to raise concerns by having a clear policy in place which makes it clear that staff who raise concerns will be supported and which provides ways to by-pass the immediate line management chain where necessary;
- CQC: in monitoring concerns about patient safety raised with it and ensuring that timely referrals are made to the professional regulators where necessary;
- professionals and other health and care workers: in raising concerns promptly.

8.21 Where a doctor has good reason to think that patient safety is or may be seriously compromised by inadequate premises, equipment, or other resources, policies or systems, s/he has a duty to put the matter right if possible.²⁸ Similar duties are laid on other professionals through their codes of practice. In all cases, professionals must consider the wider implications of failing to report such concerns and the risks to patient safety.

8.22 CQC has strengthened its arrangements for responding to concerns that are raised with it by whistleblowers. Whistleblowing concerns are now monitored to ensure they are followed up until completion and the information provided is included in regional risk registers, which list providers where 'major concerns' have been identified.

8.23 DH funds a free, confidential whistleblowing helpline for NHS staff and employers who need advice about raising concerns and for employers on best practice. The service, provided by the Royal Mencap Society, has been extended for the first time to staff and employers in the social care sector.

8.24 The NHS Constitution was updated on 8 March 2012 to include:

- an **expectation** that staff will raise concerns at the earliest opportunity;
- a **pledge** that NHS organisations will support staff when raising concerns;
- **clarity** around the existing legal right for staff to raise concerns about safety, malpractice or other wrong doing without suffering any detriment.

9. REGULATORS

9.1 There are already existing tiers of regulation that protect people and service users including:

- **The Vetting and Barring Scheme** managed by the Independent Safeguarding Authority (ISA). The ISA has the legal power to ban individuals from working with children or vulnerable adults.
- **The General Medical Council (GMC)** is the independent regulator of c. 240,000 doctors in the UK. The GMC's primary role is to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine. Their State of Medicine report has recognised the need for additional action to strengthen professionalism and leadership, crucial to good medical practice.²⁹
- **The Nursing and Midwifery Council (NMC)** is the statutory regulator of around 670,000 nurses and midwives in the UK. The NMC discharges its statutory duty to protect the public by:
 - Establishing standards of competence, ethics and conduct;
 - Establishing standards for education, training and continuing professional development;
 - Keeping a register of those who meet the standards; and, crucially,
 - Dealing with registrants who fall short of those standards through the taking of 'fitness to practise' action.

The Health Select Committee³⁰ recently welcomed steps that the NMC are taking in response to incidents such as events at Winterbourne View hospital in terms of greater proactivity in "opening...investigations into registrants without a formal referral from an employer, a member of the public or another professional".

- **The Health Professions Council will soon become the Health and Care Professions Council (H(C)PC)** when it does, in addition to the 15 professions it already registers (around 205,000) it will also become responsible for the registration of around 100,000 social workers in England. Just like the NMC and the GMC the HCPC will have a statutory duty to protect the public.
- **The Care Quality Commission (CQC)** has already reviewed and improved arrangements following the events at Winterbourne View:
 - It has strengthened its whistleblowing arrangements;
 - It is moving to a risk based approach to assessment and planning annual inspections;
 - It will build on the model of inspection for the LD review - in particular using experts by experience;
 - The Department of Health's Performance and Capability Review of the CQC³¹, published on 23rd February 2012, recommended that CQC should expedite plans to roll out safeguarding training to all front-line

staff and should continue to work with ADASS and local government to ensure all relevant staff are clear about protocols.

- **Monitor:** Monitor's overall objective is to protect and promote the interests of people who use health care services, by promoting health care services which are economic, efficient and effective and which maintain or improve the quality of services. It has a specific role in relation to continuity of services, and has existing oversight of social care providers who are also providing health services. Monitor will be consulting on its approach to application of the licensing scheme later in the summer.

ACTION

- 9.2 The Department supports CQC's suggestion that inspections of services should take place outside of normal office hours, and that weekend and evening visits could reveal additional information about the quality of care provided. We encourage CQC to take a flexible approach to the timing of inspections.**
- 9.3 The Department will, with CQC, consider options for revising the regulations that define the scope and requirements for providers' registration with CQC in order to drive up quality of provision.**
- 9.4 CQC will review their on-going inspection of learning disability services, including the 150 hospitals and care homes recently inspected.**

10. CONCLUSIONS

- 10.1 There are failings in the models and quality of care provided to people with learning disabilities or autism and behaviour which challenges.
- 10.2 This report has set out key actions for the Government to take forward in addressing the poor quality identified by the CQC inspections and improving outcomes for individuals with learning disabilities or autism and behaviour which challenges.
- 10.3 The Department is working with key national partners to develop a concordat committing each signatory to the actions they will take to deliver the right model of care and better outcomes for people with learning disabilities or autism and behaviour which challenges. We will publish that concordat in the autumn.
- 10.4 Key partners we are working with include:
- the National Forum of People with Learning Difficulties
 - the National Valuing Families Forum
 - the National Autistic Society
 - the Challenging Behaviour Foundation
 - the Association of Directors of Adult Social Services,
 - the Local Government Association,
 - the NHS Commissioning Board Authority
 - the NHS Confederation,
 - Royal Colleges and other professional bodies, including the Royal College of Psychiatrists, the Royal College of General Practitioners, the Royal College of Nursing, the Royal College of Occupational Therapists and the British Psychological Society
 - Skills for Care
 - health and care regulators,
 - provider groups, including the Association of Supported Living and
 - key voluntary sector partners, including Mencap.
- 10.5 The final report will set out progress in taking these actions forward as well as responding to the issues identified in the SCR report.
- 10.6 The Department will meet its public sector equality duty in formulating these actions and will demonstrate how we met the duty in detail when we publish the final report in the autumn. We will also publish an impact assessment alongside the final report.

Good practice guidance on commissioning for people with learning disabilities and challenging behaviour

1. These include:
 - **The Mansell reports:** The 1993 Mansell report, commissioned by DH, giving guidance on developing services for adults with learning disabilities whose behaviour or mental health problems present a challenge to services³². This was updated and revised in 2007.³³ Both reports emphasise:
 - the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers
 - a focus on personalisation and prevention in social care
 - that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour
 - that services/support should be provided locally where possible.
 - 2009 joint guidance by the Regulators for commissioning services and support for people with learning disabilities and complex needs³⁴.
 - DH 2007 good practice guidance for commissioning specialist adult learning disability health services³⁵.
 - DH 2009 guidance on World Class Commissioning to improve the health and wellbeing of people with learning disabilities³⁶
 - Royal Colleges' guidance on standards of clinical practice in supporting people with learning disabilities who present behavioural challenges.³⁷
 - *Raising our sights*, a report on adults with profound intellectual and multiple disabilities in March 2010³⁸. The Government response to this was published in February 2011.
 - 2010 statutory guidance to secure implementation of the autism strategy³⁹
 - NHS Continuing Healthcare practice guidance on implementing the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care.⁴⁰
 - the May 2011 Statement of Government Policy on Adult Safeguarding.
 - statutory guidance on Restrictive Physical Interventions for People with Learning Disability and Autistic Spectrum Disorder, in Health, Education and Social Care Settings.⁴¹
 - Three emerging CCGs are working with the NHS Commissioning Board and the Learning Disabilities Observatory in a project to look at

commissioning services for people with learning disabilities.⁴² The project has been set up to support CCGs as they begin to commission community, hospital and specialist health services for people with learning disabilities. It will build on recent work to improve the care and provision for people with learning disabilities and enable the groups to share the learning with the wider clinical commissioning community. Draft guidance for CCGs developed by the Royal College of General Practitioners is available on the Observatory website.⁴³ This is being reviewed and guidance will be published in October.

Numbers

1. We do not have definitive data on numbers of people with learning disabilities, but the Learning Disabilities Public Health Observatory estimated that in England in 2011, 905,000 adults aged 18+ had learning disabilities. However, the majority of adults with learning disabilities have mild learning disabilities and do not use specialised health or social care services for people with learning disabilities. In 2011, GPs identified 189,000 of their patients as having learning disabilities and 142,000 adults with learning disabilities were using specialised social care services for people with learning disabilities.⁴⁴
2. Research indicates that 10-15% of learning disabled users of educational, health or social care services show challenging behaviour; 64% of these show “more demanding” challenging behaviour; and approximately 50% of people with more demanding challenging behaviour live with their families.⁴⁵
3. This suggests that between 9,000 to 18,000 adults (ie approximately 15,000 people) can be described as having “more demanding” challenging behaviours of which around 7,000 live with their families. And around 10% (i.e. around 1,500 people) are, at any one time, living in a hospital setting, including in-patient services for assessment and treatment.
4. The review has heard evidence that if appropriate local services were developed then the number of in-patient beds required for assessment and treatment would be approximately 300-400 across England, translating to 2-3 beds per local authority area⁴⁶.
5. The actual number of assessment and treatment beds appears to be higher. However, there is little clarity on the number of assessment and treatment beds or units. The best available data is from the CQC:
 - the 2010 *Count me in* census suggests 1,252 occupied beds in assessment and treatment units (down from 1,521 in 2009) - however, this may include some people with mental health problems or personality disorders, but no learning disability⁴⁷
 - for the targeted inspection programme, CQC inspected 72 assessment and treatment units and 39 secure units for people with learning disabilities (34 residential care homes make up the 150 overall).
6. Mansell et al (2010) found that 25% of patients in assessment and treatment (A&T) units had finished treatment but had no plan for discharge. The equivalent figure for low secure units was 10% and 3% for medium secure units.
7. Unfortunately the *Count me in 2010* does not provide information on length of stay by different type of settings. The 2010 census counted 755 people with LD with a length of stay of less than six months. Even if they all were in A&T, which is not very realistic, there still would be about 500 patients (=1,251 – 755) in A&T for more than 6 months. An older study by Mackenzie and Mansell (2007) has reported a higher rate of 67% (equivalent to up to 840 patients in 2010).

The CQC summary report has also shown that the range of length of stay in NHS and Independent Healthcare Services assessment and treatment services and secure services ranged from 6 weeks to 17 years and were generally unacceptably long and inconsistent with the descriptions of assessment and treatment.

8. Some information on use of in-patient services for assessment and treatment is collected through Hospital Episode Statistics (HES) for NHS facilities, but independent hospital providers do not currently provide routine data. In addition, there is no standard way of tracking people with learning disabilities through the healthcare system.
9. Across health and social care, approximately £6.5 billion pounds is spent on care and support for people with learning disabilities and their families, around $\frac{2}{3}$ in social care. Use of these resources is very variable:
 - some localities have developed supported housing and community support activities for most people in their areas
 - for others residential care remains the predominant model
 - the most significant rises in unit costs are for residential care and nursing care⁴⁸
 - low spending on care management for people with learning disabilities is associated with high use of residential care.

Evidence from stakeholder engagement

1. The review team held a number of meetings with key external partners to consider emerging issues and developing recommendations. The aim was to ensure that people with learning disabilities and their families were at the heart of the review, and to enable the review to draw on the direct expertise of professionals working with people with learning disabilities and challenging behaviours. Key partners included:
 - the National Forum of People with Learning Difficulties
 - the National Valuing Families Forum
 - the Challenging Behaviour Foundation
 - the National Autistic Society
 - reference groups supporting the NHS Review
 - CQC Learning Disability Review Advisory Group
 - the Learning Disability Professional Senate
 - local authority commissioners.
2. The review also received submissions and correspondence from 396 people and organisations.

Notes

¹ Services for people with learning disabilities and challenging behaviour or mental health needs, October 2007, Prof Jim Mansell

² Some children and adults with severe learning disabilities typically display behaviour which may put themselves or others at risk, or which may prevent the use of ordinary community facilities or a normal home life. This behaviour may include aggression, self injury, stereotyped behaviour or disruptive and destructive behaviours. These behaviours are not under the control of the individual concerned and are largely due to their lack of ability to communicate. Challenging behaviour is defined as:

“Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.” *Emerson, 1995, cited in Emerson, E (2001, 2nd edition): Challenging Behaviour: Analysis and intervention in people with learning disabilities.* Cambridge University Press

See also Challenging Behaviour Foundation website:
<http://www.challengingbehaviour.org.uk/about-cbf/about-challenging-behaviour.html>

³ <http://www.cqc.org.uk/public/our-action-winterbourne-view/review-learning-disability-services/learning-disability-reports>

⁴ See IDEA <http://www.idea.gov.uk/idk/core/page.do?pagelId=4470092>

⁵ [http://www.improvinghealthandlives.org.uk/publications/1020/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence_Based_Commissioning_Guide_for_Emerging_Clinical_Commissioning_Groups_\(draft\)](http://www.improvinghealthandlives.org.uk/publications/1020/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence_Based_Commissioning_Guide_for_Emerging_Clinical_Commissioning_Groups_(draft))

⁶ <http://www.thinklocalactpersonal.org.uk/Browse/commissioning/developing/?parent=8567&child=7959>

⁷ Provides leadership for quality across the health system and where it links with social care.

<http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/Makingqualityhappen/NationalQualityBoard/index.htm>

⁸ <http://www.dh.gov.uk/health/category/policy-areas/nhs/constitution>

⁹ see *Valuing People Now: a new three- year strategy for people with learning disabilities* Department of Health (2009)

¹⁰ The Government is continuing to respond to the recommendations from Independent Inquiry into access to healthcare for people with learning disabilities *Healthcare for all*, Report of the Independent Inquiry into access to healthcare for people with learning disabilities, Sir Jonathan Michael, Department of Health (2009)

¹¹ *Services for people with learning disabilities and challenging behaviour or mental health needs* Report of a Project Group (Chairman: Prof J L Mansell). London HMSO (1993); *Services for people with learning disabilities and challenging behaviour of mental health needs* Report of a Project Group (Chairman: Prof J L Mansell). Revised edition Department of Health (October 2007).

¹² The CQC *Count me in census 2010* estimated that there were 1,252 occupied beds in learning disabilities wards. This includes some people with mental health problems or personality disorders.

¹³ <http://www.cqc.org.uk/public/our-action-winterbourne-view/review-learning-disability-services>

¹⁴ For example, reports like ‘Mental Handicap: Progress, Problems and Priorities’ (DHSS, 1980) and ‘Needs and Responses: Services for Adults with Mental Handicap who are Mentally Ill, who have Behaviour Problems or who Offend’ (DoH, 1989) contained sections referring to the potential development of services that we now describe as assessment and treatment units.

¹⁵ These polarised viewpoints were captured in chapter 2 of ‘Facing the Challenge’, a very influential report published by the King’s Fund Centre in 1987 that, with its follow-up report, was the predecessor of the Mansell Report.

¹⁶ *Services for people with learning disabilities and challenging behaviour of mental health needs* Report of a Project Group (Chairman: Prof J L Mansell). Revised edition Department of Health (October 2007).

¹⁷ *There is an alternative* Association of Supported Living (September 2011)

¹⁸ *Count me in 2010* (April 2011)

¹⁹ Who regulates Health and Social Care Professionals?

²⁰ Health and Social Care Act 2012 – see <http://www.dh.gov.uk/health/2012/06/act-explained/>

²¹ a partnership between Cambridgeshire and Peterborough; Gloucestershire; Nene Commissioning

²² [http://www.improvinghealthandlives.org.uk/publications/1020/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence_Based_Commissioning_Guide_for_Emerging_Clinical_Commissioning_Groups_\(draft\)](http://www.improvinghealthandlives.org.uk/publications/1020/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence_Based_Commissioning_Guide_for_Emerging_Clinical_Commissioning_Groups_(draft))

²³ See IDEA <http://www.idea.gov.uk/idk/core/page.do?pagelId=4470092>

²⁴ The Royal College of Psychiatrists and British Psychological Society and Royal College of Speech and Language Therapists: *A Unified Approach* (2007)

²⁵ GMC guidance -see http://www.gmc-uk.org/guidance/good_medical_practice/probity_conflicts_of_interest.asp

²⁶ A new training programme on challenging behaviour ‘Who’s Challenging Who?’ has been developed by Mencap Cymru and Bangor University. See www.mencap.org.uk/wales/projects/who-s-challenging-who

²⁷ ‘Strengthening the Commitment’ <http://cno.dh.gov.uk/2012/04/25/strengthening-the-commitment-the-report-of-the-uk-modernising-learning-disabilities-nursing-review>

²⁸ See *Good Medical Practice*; and other guidance: http://www.gmc-uk.org/guidance/ethical_guidance/raising_concerns.asp

²⁹ http://www.gmc-uk.org/State_of_medicine_Final_web.pdf 44213427.pdf

³⁰ <http://www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/1428/1428.pdf>

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- ³¹ <http://www.dh.gov.uk/health/2012/02/cqc-performance-review/>
- ³² *Services for people with learning disabilities and challenging behaviour or mental health needs*: Report of a Project Group (Chairman: Prof J L Mansell). London HMSO (1993)
- ³³ *Services for people with learning disabilities and challenging behaviour of mental health needs* Report of a Project Group (Chairman: Prof J L Mansell). Revised edition Department of Health (October 2007).
- ³⁴ Commission for Social Care Inspection, Mental Health Act Commission, Healthcare Commission. *Commissioning services and support for people with learning disabilities and complex needs: National report of joint review*. London: (2009)
- ³⁵ *Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance* Department of Health (2007).
- ³⁶ *The World Class Commissioning: Improving the health and wellbeing of people with learning disabilities*. Department of Health (November 2009)
- ³⁷ The Royal College of Psychiatrists and British Psychological Society and Royal College of Speech and Language Therapists: *A Unified Approach* (2007)
- ³⁸ *Raising our Sights: services for adults with profound intellectual and multiple disabilities* Professor Jim Mansell (March 2010)
- ³⁹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122847
- ⁴⁰ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_115133
- ⁴¹ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4068461.pdf
- ⁴² a partnership between Cambridgeshire and Peterborough; Gloucestershire; Nene Commissioning
- ⁴³ [http://www.improvinghealthandlives.org.uk/publications/1020/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence_Based_Commissioning_Guide_for_Emerging_Clinical_Commissioning_Groups_\(draft\)](http://www.improvinghealthandlives.org.uk/publications/1020/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence_Based_Commissioning_Guide_for_Emerging_Clinical_Commissioning_Groups_(draft))
- ⁴⁴ Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S., Evison, F., Glover, G. (2012). *People with Learning Disabilities in England 2011*. Stockton-on-Tees: Learning Disabilities Public Health Observatory, North East Public Health Observatory
http://www.improvinghealthandlives.org.uk/publications/932/People_with_Learning_Disabilities_in_England_2010
- ⁴⁵ Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Hatton, C., Mason, H., Swarbrick, R., Mason, L., Smith, K., Wright, K., Manion, R., Ferguson, B., & Hennessey, S. (1997). *The HARC Challenging Behaviour Project. Summary Report*. Manchester: Hester Adrian Research Centre, University of Manchester. Kiernan, C., Reeves, D., Hatton, C., Alborz, A., Emerson, E., Mason, H., Swarbrick, R., & Mason, L. (1997). *The HARC Challenging Behaviour Project*.
- ⁴⁶ CBF and Mencap: Winterbourne View - Background policy statement
- ⁴⁷ In the *Count me In* 2010 survey, these groups account for 10% of all in-patients. A further 20% have been admitted for multiple reasons (one of which may be a learning disability). It is not clear how these groups are distributed across different care settings.
- ⁴⁸ Adjusted for inflation, the compound annual growth rate for residential care from 2007/2008 to 2010/2011 is +3.8%, compared to +9.3% for nursing care over the same period. (See *People with learning disabilities in England 2011*)



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