



Department
of Health

Six Lives

Progress Report on Healthcare for People with
Learning Disabilities

Six Lives:

Progress Report on Healthcare for
People with Learning Disabilities

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Foreword by the Minister for Care and Support



It has been six years since Mencap's original report, *Death by Indifference*, shocked us all with its exposure of the unequal healthcare and institutional discrimination that people with learning disabilities can experience within the NHS. The report described the harrowing circumstances surrounding the deaths of six people with learning disabilities, people who died while in the care of the NHS.

While much has improved since then, we know there is still more that needs to be done to achieve the changes to the culture of care and compassion that we all want to see for people with learning disabilities.

Nowhere is the need to transform that culture, particularly for more vulnerable patients, more clearly demonstrated than by the shocking events at Winterbourne View Hospital. Our recent Confidential Inquiry into the premature deaths of people with learning disabilities report also showed that people with learning disabilities continue to have poor experiences and outcomes compared with people without learning disabilities.

We have learned from these that healthcare can still fall far short of the standards of care that we would expect our health and social care system to deliver. The events that occurred at Winterbourne View pointed not just to one rogue institution but also exposed widespread, systemic failings. For too long and in too many cases people with learning disabilities have received poor quality and inappropriate care.

So what are we doing about it?

We established and funded the Confidential Inquiry from April 2010 to March 2013 and now are working with NHS England, Public Health England and other partners on the Inquiry's recommendations. We have published our response to the recommendations alongside this report.

We have made safeguarding vulnerable people a key priority for NHS England. One of NHS England's objectives is to ensure that vulnerable people, particularly those with learning disability and autism, receive safe and appropriate high-quality care.

We will hold the NHS to account for the quality of services for people with learning disabilities through the NHS Outcomes Framework. This framework is meant to focus the NHS on improving outcomes for patients. One of the outcomes in this framework is to reduce premature mortality in people with learning disabilities.

The NHS is also taking steps to ensure that people with learning disabilities have exactly the same rights as anyone else. NHS England has a specific legal duty to tackle inequality and

advance equality, particularly for people who experience poor outcomes compared with the general population.

Public Health England's (PHE) priorities for 2013/14 include a focus on reducing premature mortality and on making nationally visible the health needs of those on the margins and otherwise overlooked. The Learning Disability Public Health Observatory is now established within Public Health England to provide high-quality data on learning disability.

We are taking steps to improve services for people with learning disabilities or autism and mental health issues or behaviour that challenges. People with learning disabilities or autism, who also have mental health conditions or behaviour that challenges, have a right to access the support and care they need in the community, near to family and friends. In line with our commitments outlined in *Transforming Care*, the Department of Health report into the Review of Winterbourne View Hospital, local health commissioners have developed their registers of people with learning disabilities and people's care plans should all have been reviewed. Details of actions taken by local commissioners in meeting this obligation will be published. As a result, anyone inappropriately in hospital will move to community-based support as quickly as possible.

Winterbourne View revealed weaknesses in the system's ability to hold the leaders of care organisations to account. We are tackling this gap in the care regulatory framework. The Care Quality Commission (CQC) is strengthening inspections and regulation of hospitals and care homes. This includes unannounced inspections involving people who use services and their families. CQC now includes reference to the best model of care in its guidance.

Every year more people are receiving an annual learning disability health check. This helps to identify a range of health needs and can allow people to access appropriate investigations and treatments for health conditions.

This report, the second of two progress reports that the Department has published at the request of the Local Government and Health Ombudsmen since the original *Six Lives* report was published in 2009, charts the progress that has been made in healthcare for people with a learning disability since 2010. Most importantly, it includes the very personal perspectives of people with learning disabilities and their families. They have been frank and fair with us, detailing both their positive and negative experiences of care. They have told us, loud and clear, that although there have been improvements, a lot more needs to be done to ensure that people are treated with the compassion and dignity that is their right, and that they receive the same quality of care and treatment as anyone else.

These fundamental messages need to be heard by everyone who works in the health and social care system, from Government to front-line staff, and we should all consider how we rise to this challenge.



Norman Lamb
Minister for Care and Support

Easy read summary



- This is a report from the Department of Health for the Parliamentary and Health Service Ombudsman and the Local Government Ombudsman.
- The report says what has happened since the Department of Health wrote the first progress report on 'Six Lives' in 2010.
- If you would like to see the easy read of the 2010 report click on this link:

www.gov.uk/government/publications/report



The Health Service Ombudsman has the power to look into complaints people make about the NHS.



The Local Government Ombudsman has the power to look at complaints about local councils.



'Six Lives' was the Ombudsmen's report looking at the care given to six people with learning disabilities who died. 'Six Lives' was published in March 2009.



This second report says what has happened to make things better for people with learning disabilities since the Department of Health's 'Six Lives' progress report in October 2010.

Who we asked about what had happened since 2010



To write this report we asked lots of different people for information about what has happened since 2010.

We asked the following people:



- People with learning disabilities and their families.



- People in health and social care organisations like NHS England and local councils.



- People who collect information about people with learning disabilities from Learning Disability Partnership Boards and other organisations.



- Charities like Mencap and the British Institute of Learning Disabilities (BILD) who helped us with a listening event for people with learning disabilities and family carers to talk about 'Six Lives'.



The Department of Health has published three other reports which will make a difference to people with learning disabilities:

1. The Francis Inquiry (Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry) which looks at putting patients first and improving the way we listen to them.
2. 'Transforming Care: A national response to Winterbourne View Hospital'.
3. A 'Concordat' or Agreement which is signed by 50 different organisations to say they agreed with the actions in the 'Transforming Care' report and would help to make them happen.



How we have listened to people with learning disabilities and their families



With the help of BILD and Mencap we asked people with learning disabilities and family carers about their experiences and if things had got better. We did this in two ways:

1. We held a listening event in April 2013 called 'Is healthcare "Getting Better" for people with a learning disability?', to hear from people with a learning disability and their families.
2. We also carried out a written survey in April to ask questions about what had got better for people with learning disabilities and their family carers.



What we found out:

People described some hospitals and GP practices as having improved their care and treatment of people with a learning disability a lot in recent years.

There are easy read copies of the report of the listening event and the survey on this link: www.mencap.org.uk/campaigns/take-action/death-indifference/six-lives-report

This is what many people told us:





Things going well in healthcare

1. Reasonable adjustments being made.
2. Staff having a positive attitude towards people with a learning disability.
3. Involving people with a learning disability and their families/carers.
4. Employment of learning disability nurses.
5. People in hospitals do what the law says in the Mental Capacity Act.



Things not going well in healthcare

1. It takes too long to find out what is wrong with someone and start treatment.
2. Annual health checks are not always done properly.
3. People with learning disabilities are not given information in a way they can understand.
4. People who work in hospitals do not always realise when someone is in pain.
5. People are not included in decisions about their care.

Doing what the Ombudsmen asked



Local Government
OMBUDSMAN



The Ombudsmen read the Department's 2010 progress report and said that it showed good progress had been made.

The Ombudsmen said there was a lot more to do to make sure health and social care services were good for everyone.

The Ombudsmen asked the Department to do another progress report to look at:

1. How health and social care organisations have carried on with the good work since 2010.
2. How good the organisations are that check services for people with learning disabilities. These are called the regulators.
3. How the big changes the Government has made to the health and social care system will affect people with learning disabilities. The changes are in the Health and Social Care Act 2012.

The report is in three parts to cover the things listed above.

PART ONE: How health and social care organisations have carried on with the good work since 2010?



We looked at the four most important things we reported on in October 2010. These are:



1. **Getting information from the Learning Disabilities Public Health Observatory.** This is an organisation that collects information about people with learning disabilities and puts it on their website to share with everyone.

We have lots of useful information like Partnership Board reports and annual health checks. The Observatory was set up for 3 years under 'Valuing People Now'. It will carry on as part of Government.



2. **Looking at the results of the Confidential Inquiry** which looked at why people with learning disabilities died earlier than other people.

The Government's answer to the report on the Confidential Inquiry is being published at the same time as this report. It shows that people with learning disabilities are still having poorer healthcare than others. There is an easy read copy available on this link:

[https://www.gov.uk/government/publications?department\[\]=department-of-health](https://www.gov.uk/government/publications?department[]=department-of-health).





3. Annual health checks.

Every year more people are getting health checks. GPs are getting better at making reasonable adjustments so that it is easier for people to have health checks.



4. Sharing good practice.

Good practice has been included in lots of reports. For example, the two reports on Winterbourne View.

There has been a good practice project as part of Winterbourne View led by the National Forum of People with Learning Disabilities and the National Valuing Families Forum. There will be an easy read report of the project published in summer 2013.

This report also includes progress since 2010 on the following:

Health self-assessments reports.

Learning Disability Partnership Boards reports.



From 2013 there will be a new report which puts the health self-assessment and the Learning Disability Partnership Board reports together.

The new report will cover health and social care for people with learning disabilities.



Learning disability liaison nurses in hospitals.

We heard from people with a learning disability and family carers that liaison nurses made a big difference to how health services work for them.

The Mencap survey showed that not all hospitals had a liaison nurse.

The Department of Health will be looking at collecting numbers of liaison nurses.

There has been a big report with information from the whole of the UK about learning disability nurses. It is called 'Strengthening the Commitment'. There is a lot of work to do from the report.

We also looked at other things which people said they were worried about in 2010:

Capacity and consent. This is about people being able to have a say and agree to important decisions like whether to have an operation.

The Mencap survey showed that some things were better. People were being asked to make decisions when they are able to. But this did not always happen.





Staff understanding the needs of people with learning disabilities.

We have lots of examples of good practice and 'reasonable adjustments'. This means changing the way you do things so that people with learning disabilities can take part or understand.



Advocacy and making complaints. This means giving people the support they need to make choices about healthcare and making sure when things go wrong that people are listened to and changes made.

From April 2013, local councils now decide about NHS advocacy services. They can make the best decisions for local people.

It is very important that people can complain if care is not good enough.

People at the Mencap listening event said there were lots of problems about making complaints. It is too soon to say if the new system will be better.

PART TWO: The regulators (government checkers)



The regulators – the Care Quality Commission (CQC), Monitor and the Equality and Human Rights Commission (EHRC) – were asked by the Ombudsmen about their progress since 2010.



The **CQC** checks health and care services.

Since the 2010 report, the CQC has included people with learning disabilities in their inspections. They are called ‘experts by experience’.



Monitor check some kinds of NHS organisations, called Foundation Trusts.

Monitor has a checking framework that includes learning disability as one of its checks.



The **EHRC** check people’s human rights are being respected.

There is joint guidance by CQC and EHRC on equality and human rights for CQC inspectors.



All three organisations have written to the Ombudsmen to say what they have done since 2010.

They say they are working together to make sure services for people with learning disabilities meet their needs.

PART THREE: Changes to the health and care system



The Government has made changes to how health services and social care services are organised.

The changes are now part of the law. The Health and Social Care Act 2012 made all the changes happen. But they did not happen until 1st April 2013.

There are new organisations like NHS England, Clinical Commissioning Groups (groups of GPs) and Public Health England.



One of NHS England's jobs is to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care.



The Department of Health is in charge of looking after the whole health and care system and making sure that the parts work together. Its job is to help people, including people with learning disabilities, to live better for longer.

The Department leads work for people with learning disabilities through the Learning Disability Programme Board.

The Board is chaired by the Minister for Care and Support, Norman Lamb. People with learning disabilities and family carers are on the Board.

Other things the Department of Health is doing to make things better



Health Equality Framework

- This is a framework that shows what leads to good health outcomes. It was drawn up by learning disability nurses.
- This means deciding what leads to some people having better health than others, like good housing and friends in the community.
- The framework is for people with learning disabilities and family carers, commissioners and providers to help decide what will help give good health outcomes.



Personal Health Budgets

- Personal Health Budgets are like personal budgets in social care. They give people more choice and control over their health.
- Everyone receiving fully funded Continuing Health Care will be offered a Personal Health Budget by 2014.





Safeguarding

- A new piece of law called the Care Bill is being discussed in Parliament. If it becomes law then every local council must set up a Safeguarding Adults Board.
- The Bill says that if councils think an adult with care and support needs is at risk of harm then they must consider what action is needed. This will keep people safer including people with learning disabilities.



Conclusion and next steps



There are messages in this report for government, commissioners and providers.



The Government will keep listening to the views of people with learning disabilities and their families to make more changes to improve their health and wellbeing.



Some things have got better, like more people having health checks, but there is more to be done.

We must all work together to make sure leadership is strong across the new health and care system.



The Department of Health will make sure that the National Learning Disability Programme Board continues to have a key role in policy for people with learning disabilities.



The Department of Health will work with NHS England to help them with their work to improve the lives of people with learning disabilities.



We will work with all the people who signed the Winterbourne View Concordat to make sure the actions happen and make a difference to people's lives.



We will make sure the things the Department of Health says in the report in reply to the Confidential Inquiry report happen.



The Department will make sure that the changes to health and care systems give a voice to people with learning disabilities and families.

Key learning from the listening event



It is important that everyone listens to people with learning disabilities and their families.



Things health professionals should ask when treating someone with a learning disability:

- Ask how you should communicate.
- Ask if there are any reasonable adjustments you can make.
- Ask if the individual would like additional support such as advocacy support.
- Ask if they have a health action plan and/or hospital passport.
- Ask if they understand what you have told them.



Things people with a learning disability and family carers should ask:

- Ask for an annual health check.
- Ask if there is a learning disability nurse.
- Ask for a hospital passport.
- Ask for a longer appointment time.
- Ask for information in easy read.

Introduction

1. The Parliamentary and Health Service Ombudsman and Local Government Ombudsman's 2009 'Six Lives' report¹ investigated the deaths of six people with learning disabilities, first highlighted by Mencap in their 2007 report 'Death by Indifference'.² The Ombudsmen's 2009 recommendations can be found at Annex A.
2. The Department of Health published a first progress report responding to the Ombudsmen's recommendations in October 2010³ and this is the second follow-up progress report.
3. This report falls into **three main parts**:
4. **Firstly**, what has happened since the publication of the last report in October 2010 in the areas the Department of Health said it would give immediate priority to. These areas include:
 - early learning from the Learning Disabilities Public Health Observatory;
 - monitoring progress in the Confidential Inquiry into the premature deaths of people with learning disabilities;
 - supporting improvements in the take-up of annual health checks for people with learning disabilities; and
 - promoting good practice.
5. We have also included progress since 2010 on the following particular areas:
 - health self-assessments;
 - learning Disability Partnership Boards; and
 - liaison and facilitation staff in acute and primary care
6. And on the following issues which were of particular concern to people with learning disabilities and family carers in 2010:
 - capacity and consent;
 - staff understanding (including communications, information and reasonable adjustments); and

1 Parliamentary and Health Service Ombudsman and Local Government Ombudsman (2009). *Six Lives: The provision of public services to people with learning disabilities*.

2 Mencap (2007). *Death by Indifference. Following up the Treat me right! report*.

3 Department of Health (2010). 'Six Lives' Progress Report.

- complaints and advocacy.
7. **Secondly**, we have included in the report what the regulators – CQC, Monitor and the Equality and Human Rights Commission – have reported at the Ombudsmen’s request on what has happened in this area since 2010.
 8. **Thirdly**, we have included progress and key developments in other areas since the 2010 report, which we believe will be very important in continuing to improve the healthcare of people with learning disabilities. These include new responsibilities for improving the healthcare of people with learning disabilities following changes to the health system since 2010.
 9. There are also three other developments that will help to improve the health and wellbeing of people with a learning disability:
 - work on identifying the determinants of good healthcare, addressed in the *Health Equalities Framework for People with Learning Disabilities 2013*;⁴
 - the development of Personal Health Budgets, including the commitment that everyone receiving Continuing Health Care will be offered a Personal Health Budget by 2014; and
 - developments on safeguarding in the Care Bill, crucial for this vulnerable group not least in the context of Winterbourne View.
 10. Finally, we look to the future and set out actions in a number of key areas.
 11. These can be found in Part 3 of this report under Conclusion and Next Steps.

Who needs to read this report?

12. This second progress report has been written for the Parliamentary and Health Service Ombudsman and Local Government Ombudsman and responds to their recommendations (Table 1).

⁴ UK Learning Disability Consultant Nurse Network, Improving Health and Lives: Learning Disabilities Observatory and National Development Team for Inclusion (2013). *The Health Equalities Framework: An outcomes framework based on the determinants of health inequalities*. http://www.ndti.org.uk/uploads/files/The_Health_Equality_Framework.pdf

Table 1

The Ombudsmen wrote to the then Minister for Care Services in December 2010. The Ombudsmen welcomed the Department of Health's report which identified good progress in many areas whilst recognising that much remained to be done to achieve change across the whole system.

The Ombudsmen set out some further recommendations for the Department of Health to continue to promote and support progress:

- *to continue to promote and support the progress outlined in their 2010 report;*
- *to monitor progress and the impact of significant change within both health and social care organisations and publish a further progress report; and*
- *to review the level of assurance provided by performance monitoring regimes in relation to services for people with learning disabilities, which are put in place by relevant regulators.*

13. This report is also for people with learning disabilities, as defined in *Valuing People*, the 2001 White Paper on the health and social care of people with learning disabilities,⁵ their families and carers, advocates, providers and commissioners of services for people with learning disabilities, and everyone who cares about improving the healthcare of people with a learning disability.

Background

14. In October 2010 the Government published the first *Six Lives Progress Report* in response to the Ombudsmen's recommendations. That report showed that, while progress had been made, some serious issues remained. Progress often relied on individual staff or local groups, and was not embedded as established good practice across all organisations.
15. Following this, the Ombudsmen asked the Department of Health to continue to promote and support the progress outlined in their report, monitor the impact of significant change within both health and social care organisations and publish this further progress report.⁶

5 Department of Health (2001). *Valuing People: A new strategy for learning disability for the 21st century: implementation*.

6 The Department of Health and the Ombudsmen agreed that publication of this second follow-up report should take place in 2013 rather than 2012 (as originally agreed) so that it could reflect:

- (i) the outcome of the DH Review into Winterbourne View – which was published in December 2012;
- (ii) the new health and care system in place from April 2013 following the Health and Social Care Act 2012.

It has also enabled us to carry out greater consultation with people with learning disabilities and family carers and to take account of the Department's response to the Confidential Inquiry into premature deaths of people with learning disabilities. The Government Response to the Confidential Inquiry recommendations is being published alongside this response.

16. In writing this report, the Department of Health would also like to acknowledge the findings in Mencap’s report *Death by indifference: 74 deaths and counting. A progress report 5 years on* published in February 2012.⁷ The report noted that while there had been progress, there were still major problems with use of the Mental Capacity Act 2005, poor complaints procedures, failure to recognise pain, delays in diagnosis and treatment, poor communication and lack of basic care.

17. This report also refers to the findings of the Mid-Staffordshire Inquiry conducted by Robert Francis. It is worth reminding ourselves what was said at that time:

‘Although the Inquiry and this response focus primarily on NHS hospitals the core messages are applicable to all staff working throughout the health and care system, whatever the setting. The failures of care identified at Winterbourne View Hospital – a hospital far away from Mid Staffordshire NHS Foundation Trust both geographically and in the nature of its services – demonstrated that the interests of patients need to be foremost, whatever their individual needs and wherever they are cared for. This call for action is as applicable to staff working in an independent hospital or treatment unit for patients with mental health problems or learning disability as it is for staff in acute hospital.’⁸

18. It also reflects:

- the findings of the Department of Health’s Review on Winterbourne View *Transforming Care: A national response to Winterbourne View Hospital*⁹ with a programme of action to deliver change so that people with behaviour that challenges no longer live inappropriately in hospitals but are supported to live fulfilling and safe lives in their communities in line with best practice; and
- the Government’s Mandate to NHS England:¹⁰

‘The NHS Commissioning Board’s objective is to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high-quality care. The presumption should always be that services are local and that people remain in their communities: we expect to see a substantial reduction in reliance on inpatient care for these groups of people.’(para 4.5)

7 Mencap (2012). *Death by Indifference: 74 deaths and counting. A progress report 5 years on*.

8 Department of Health (2013). *Patients First and Foremost: The Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170701/Patients_First_and_Foremost.pdf

9 Department of Health (2012). *Transforming Care: A national response to Winterbourne View Hospital*.

10 Department of Health (2012). *The Mandate. A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015*.

How we gathered evidence for this progress report

19. To prepare this report, information and views have been gathered from a range of people and methods. These include an online survey, a listening event with people with learning disabilities and family carers and data, publications and reports published over the past three years.

How we have listened to people with learning disabilities and family carers

20. The Department of Health, working with Mencap and BILD held a joint listening event ‘*Getting Better?*’ in April 2013. It was aimed at people with a learning disability and their family carers to gain a fuller understanding of their views and experiences of healthcare since the 2010 report. The Department of Health also worked with Mencap and BILD to conduct a survey about the healthcare provided to people with a learning disability by the NHS. We have used quotes from people who attended the event and from those who completed the survey. Their thoughts and views are reflected throughout this report and we would like to thank all those who shared their experiences with us.
21. A copy of the report from the listening event called *Is healthcare “Getting Better” for people with a learning disability?* and the survey results are also being published alongside the report.¹¹ It is recommended that both reports should be read alongside this report.
22. Copies of these documents can be found on the [Gov.uk](http://www.gov.uk) website at: [www.gov.uk/government/publications?department\[\]=department-of-health](http://www.gov.uk/government/publications?department[]=department-of-health) and www.mencap.org.uk/campaigns/take-action/death-indifference/six-lives-report

¹¹ BILD, Department of Health, Mencap (2013). *Summary report: Is healthcare “Getting Better” for people with a learning disability?* and *Consultation questionnaire results: Is healthcare “Getting Better” for people with a learning disability?* <http://www.mencap.org.uk/campaigns/take-action/death-indifference/six-lives-report>

PART ONE – Progress since 2010

What we have heard from people about progress since 2010

23. We have information and data, for example from the Learning Disability Partnership Boards progress report 2011/12¹² and on health checks, which show that there have been areas of improvement for people with learning disabilities since 2010, for example:
- over a third of adults with a learning disability have personal budgets;
 - the proportion of adults living in their own homes or with family increased from 54% in 2010/11 to 62% in 2011/12;
 - the proportion of adults with a learning disability living in residential placements out of area is reducing – although still too high – from 9% in 2010/11 to 7.4% in 2011/12;
 - over 86,000 health checks were carried out for people with learning disabilities in 2011/12 – almost 20% more than the previous year, and 82% of those GPs identified as eligible in the Quality and Outcomes Framework – but this is only just over half of eligible people in the whole population.
24. However, we know that quantitative data only gives a partial picture and that the qualitative experiences people have are also an important indicator of progress.
25. With the help of the British Institute of Learning Disabilities (BILD) and Mencap, we gathered evidence on the experiences of people with learning disabilities and family carers on the progress made since 2010.
26. Overall, there were many examples of improvement identified.

‘Some good people, some good practices, some proactive families but we must have cultural change’

‘I have never received care like that before – they understood my son and they cared’

‘They understood she was special’

12 Improving Health and Lives: Learning Disabilities Observatory (2013). *Learning Disability Partnership Board Progress Reports for 2011/12*. <http://www.improvinghealthandlives.org.uk/projects/pbr201112home>

27. Participants identified several hospitals and GP practices as having significantly improved their care and treatment of people with a learning disability in recent years. There was strong praise for the role of learning disability liaison nurses in particular and evidence that many more health professionals had received some learning disability awareness training. There were many examples of the NHS making reasonable adjustments to the way healthcare is provided. However, the many good examples were also balanced with some very concerning ones. The areas in which people did not feel that as much progress was being made were: the way people were communicated with; that communication and information were poor; and that there was a lack of involvement of people with learning disabilities and family carers in decision making.
28. We have summarised below the most common messages we heard on progress since 2010:

Things going well in healthcare – good progress

- Reasonable adjustments being made across the board
- Staff having a positive attitude towards people with a learning disability
- Involvement of people with a learning disability and their families/carers
- Employment of learning disability nurses
- Following the Mental Capacity Act 2005

Things not going well in healthcare – less good progress

- Delays in diagnosis, care and treatment
- Poor quality health checks
- Inaccessibility or a lack of communication and information
- Failure to recognise or treat pain
- Not involving people in decisions about their care

29. In some areas, where we have data and information available to us, such as health checks, we have compared what the data says with what we heard from people to see if they are telling a consistent story.
30. In other areas we do not as yet have a robust, systematic set of data. Although we are making steps to improve the data that we have, we recognise there is more to do. In these areas, we have tried to reflect in this report what people with learning disabilities and their family carers have told us. At this time, this is our main source of evidence.

Section 1: Progress on the Department of Health's four 2010 priorities

31. The 2010 progress report sets out the Department of Health's four specific priorities for improving the healthcare of people with learning disabilities:
- i. To ensure early learning from the **Learning Disabilities Public Health Observatory (PHO)**.
 - ii. To ensure good progress in the **Confidential Inquiry into premature deaths of people with learning disabilities**.
 - iii. To support improvement in the take-up of **annual health checks** for people with learning disabilities.
 - iv. to promote **good practice**.
32. This section looks at what further progress has been made in these four areas.

(i) Improving Health and Lives Learning Disabilities Public Health Observatory

What was said in 2010?

33. A common theme from across the country (para 3.26 **Better data and information** in the 2010 report) was the need for access to good data to better understand and plan for the health needs of people with learning disabilities. The absence of good, reliable data was seen as a barrier to improving the quality of their healthcare. The Department of Health undertook to ensure early learning from data collated by the PHO. This would help support practical improvements in care and treatment to better inform commissioning decisions.

What has been achieved since 2010?

34. The Improving Health and Lives (IHaL) Learning Disabilities Public Health Observatory (PHO) was set up in April 2010 under a three-year contract.

Scope

35. Since its inception, the PHO has been gathering essential information and data collected at national and local level on the health and healthcare of people with learning disabilities. The PHO has been helping to make existing health-related data more accessible, allowing people to make better use of data, and improving the quality

and relevance of data. It has produced invaluable intelligence and has also served as a repository for locally generated information that can be shared nationally, such as:

- annual health checks;
- the National Learning Disabilities Health Self-Assessment Framework; and
- Partnership Board reports.

Usage

36. A survey of users conducted in September 2012 showed that the information is used regularly and valued highly by a wide range of people, including practitioners, managers, commissioners, people with learning disabilities and family carers. Sixty-seven per cent of respondents described the information available as 'very useful' and a further 24% 'quite useful', while 55% used the website at least once a month. 65% reported that they had used information from IHaL publications in their work. Examples ranged from presentations and policy papers for (former) Primary Care Trusts (PCTs) boards and Joint Strategic Needs Assessments (JSNAs), to teaching materials and study essays.

Publications

37. In addition to regular reports, the PHO has produced a substantial number of special reports on specific topics including:
- reasonable adjustments;
 - advocacy;
 - causes of death;
 - the extent of overlap of autism and learning disability, and variations in the number of school-aged children with a learning disability or autism; and
 - following the events at Winterbourne View Hospital, the patterns of use of assessment and treatment units, and other inpatient settings (as documented in the 'Count Me In' census).
38. All the PHO resources are freely available on the Observatory's website and are listed in Annex B of this report. This provides a first stop for a wide range of types of information and is heavily used, attracting around 40,000 user hits per month.
39. The Observatory's annual report 'People with Learning Disabilities in England', first published in 2011, brings together a wide range of information from health, education, social care and other sources, drawing out and commenting on important trends. From 2012, it has been accompanied by online health profiles which provide local authority level detail, where available, for key indicators. These are available on the IHaL website and widely used. Download counts for the annual report stand at 4,436 for the first annual report and 5,962 for the second. As of February 2012, the health profiles have been consulted more than 9,300 times.

Helping people make better use of the data

40. The Observatory's early work in this area focused on a major programme of 'Sharing the Learning' events to publicise its work, discuss its uses and get better understanding of how to maximise its applicability for people providing and commissioning services locally. This work also gave rise to a series of 'Evidence into Practice' briefings, aimed primarily at commissioners.
41. From the outset, the Observatory has worked with five local partner sites, sharing their experience of using information to improve care. Examples include work on improving access to cancer screening in Cornwall (which formed the basis of one of the Observatory's *Reasonable Adjustments* reports) and better engagement with social care providers regarding reducing the impact of the determinants of health inequalities in Sheffield.

Collaborative working with clinicians

42. The Observatory has also worked collaboratively with other groups, such as the Royal College of Nursing, the Access to Acute Hospitals Network (A2A Network) and Mencap to raise awareness of issues for people with learning disabilities in mainstream hospitals with mainstream hospital staff.
43. The Observatory worked with the Royal College of General Practitioners and the Royal College of Psychiatrists to produce commissioning guidance for the new Clinical Commissioning Groups (CCGs).¹³ This sets out how commissioners can reflect the needs of people with learning disabilities across the whole spectrum of the healthcare for which they are responsible. This work involved both a broad consultation exercise and work with three CCGs working as commissioning pathfinders. The guidance was published in October 2012 and is now being updated to take account of the final Department of Health report on Winterbourne View, the findings from the Confidential Inquiry and the revised joint health and social care assessment framework.

What happens next?

44. The Observatory has dramatically improved the quality of information available on the health of people with a learning disability and the health inequalities they experience. As a result, it has helped promote sustainable good practice, becoming a key source of evidence for local commissioning, benchmarking and accountability.
45. Provision of high-quality data and analysis is vital to inform local Health and Wellbeing Boards and local commissioners. Local Healthwatch and organisations for people with learning disabilities and family carers also need a reliable source of information that they can use to compare local performance and hold local commissioners and services to account. At a time when the new NHS and public health landscape is taking shape, the importance of continuing to improve data and information on the

13 Improving Health and Lives: Learning Disabilities Observatory (2012). *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups*. http://www.improvinghealthandlives.org.uk/publications/1134/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups

health and care of people with learning disabilities is reflected in the commitment to the continuation of a PHO function within Public Health England. This was set out in a recent interview given by Public Health England's Chief Knowledge Officer, Professor John Newton, to the health representative of the National Forum of People with Learning Disabilities, and a member of the National Valuing Families Forum.¹⁴

46. The Observatory will continue to deliver data to support system priorities for people with learning disabilities. It will be continuing with annual reports, the Self-Assessment Framework and health check reporting, and will be repeating the reasonable adjustments survey. In addition, this year the Observatory will be working on:
- a new census of people with learning disabilities and autism in inpatient settings, as part of the Transforming Care programme following Winterbourne View; and
 - the enhanced opportunities to report the care received by and mortality of people with learning disabilities as a result of the new constitutional arrangements for the Health and Social Care Information Centre.

(ii) Confidential Inquiry into premature deaths of people with learning disabilities

What was said in 2010?

47. In the 2010 report the **'Six Lives' recommendations (2.20)** noted the establishment of a new Confidential Inquiry into premature deaths of people with learning disabilities. The inquiry was set up to carry out a detailed investigation inquiry and share the lessons learned to prevent unnecessary deaths in the future.

What has been achieved since 2010?

48. The Department of Health established and funded the Confidential Inquiry into premature deaths of people with learning disabilities from April 2010 to March 2013 in response to a recommendation in *Healthcare for All*, the report of the independent inquiry into access to healthcare for people with learning disabilities (July 2008).
49. The Confidential Inquiry's final report was published in March 2013.¹⁵ It showed that people with learning disabilities continue to have poorer experience and outcomes compared with people without learning disabilities – see areas listed below:
- Men with learning disabilities died on average 13 years sooner than men in the general population. Women with learning disabilities died 20 years sooner than women in the general population. Overall 22% of people with learning disabilities were under 50 when they died, compared with 9% of people without learning disabilities.

14 Public Health England (2013). *The Future of the Learning Disabilities Observatory*. <http://www.ihal.org.uk/videos/future>

15 Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. and Russ, L. (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Final Report*. <http://www.bris.ac.uk/cipold/>.

- A total of 38% of deaths of people with learning disabilities were from causes that were potentially amenable to change with good-quality healthcare compared with 9% in the comparator group of people without learning disabilities.
 - People with learning disabilities who died had complex health and care needs and multiple medical conditions which meant they were a vulnerable group.
 - People with learning disabilities experienced delays in having their needs identified and addressed. Some 86% of those that died had been identified as being unwell prior to the diagnosis and treatment of their final illness and 84% of these had sought medical attention in a timely way. However, 41% had problems with investigations and 33% died with undiagnosed significant illness.
 - In many cases, GP and hospital systems did not identify people with learning disabilities so they did not get reasonable adjustments when needed. GP referrals for non-emergency hospital care sometimes did not mention a person had learning disabilities and hospitals did not routinely identify people with learning disabilities.
 - There was inappropriate use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders.
 - Families and carers were not listened to by professionals.
50. We heard similar messages in the joint Department of Health, Mencap and BILD 'listening event' and survey in April 2013. The survey showed that 53% of respondents reported that healthcare staff do not always listen when they tell them what they need. Worryingly, 43% of respondents to the survey said that they were unsatisfied at the length of time a person with a learning disability had to wait for a diagnosis. Management of pain remains a significant issue, with 44% of respondents reporting that healthcare staff do not always help them if they tell them they are in pain.
51. We heard about failures and delays in diagnoses resulting in delays in beginning appropriate treatment. This was associated in some cases with the assumptions made because someone had a learning disability, including a lack of understanding about how displays of behaviour that challenges could be a means of communicating that something is wrong.

'They missed diagnosis of a bladder stone'.

'The GP failed to diagnose that my ankle was broken and I had to go to hospital'.

What happens next?

52. The Department of Health is committed to addressing the issues identified by the Confidential Inquiry to improve the quality of care and outcomes for people with learning disabilities and family carers.

53. The Department is working with NHS England, Public Health England and other partners on the findings and recommendations of the Confidential Inquiry. We are publishing the response alongside this report. [www.gov.uk/government/publications?department\[\]:department-of-health](http://www.gov.uk/government/publications?department[]:department-of-health).

(iii) Annual health checks

What was said in 2010?

54. The Department of Health said it would support improvements in the take-up of annual health checks for people with learning disabilities and consider how best to sustain a system of annual health checks in the future. Annual health checks for people with learning disabilities were introduced in 2008 as part of a Directed Enhanced Service (DES) for GPs. They are a 'reasonable adjustment' to overcome known health inequalities faced by people with learning disabilities highlighted in a number of reports including *Death by Indifference* and the Ombudmen's Six Lives. GPs are paid a standard fee for each health check they undertake.

What has been achieved since 2010?

55. Since the last report in 2010, there has been marked progress in the number of health checks delivered. People with learning disabilities are entitled to an annual health check via the Learning Disability Directed Enhanced Service. GPs providing the DES are required to establish a specific LD DES register cross checked with the local authority and validated annually. The PHO has monitored the take-up of annual health checks and analysed and published annual reports. The PHO ran events to publicise its findings and the evidence for health checks. The Observatory believes this has resulted in more accurate data because of the higher level of public scrutiny.
56. Table 2 shows a summary of numbers of health checks done across two years. Those eligible for annual health checks are people with learning disabilities known to social services through a request for a social care assessment. These are likely to be people with moderate or severe learning disabilities or people with mild learning disabilities and additional complex needs.

Table 2 National health check figures

Year	2010/11	2011/12
Health checks done	73,068	86,023
Coverage (percentage of eligible people having checks)	48%	53%
Number of people identified as eligible	153,021	162,945
Eligible people as % of people that GPs report as known to have LD in the Quality and Outcomes Framework	81%	82%

57. We have heard from those in different areas around the country what they been doing to improve the process of providing and take-up of health checks.

Portsmouth

One good practice example is the Health Action Plan Champion training in Portsmouth which is offered to all provider services to further the progress made in delivering annual health checks for people with a learning disability. Paid carers are now feeling better equipped to identify health issues, support attendance at annual health checks and complete health action plans with the people with a learning disability they are supporting.

58. From the information we received from local NHS organisations about good local practice, and from people with a learning disability and family carers, there are some key messages regarding ways to improve the quality and take-up of health checks, including:
- health facilitation nurses;
 - reasonable adjustments;
 - communication; and
 - involvement of people with learning disabilities and family carers in training practitioners to give health checks.

Involvement of health facilitation nurses

59. Participants from the listening event reported that quality was improved by the involvement of a health facilitation nurse in training health staff and also attending some health checks to help develop good practice and identify health needs – in particular for people with more complex needs. Health facilitation nurses have a key role to play in helping to identify people with more complex needs and raising the profile of health checks among people with learning disabilities, family carers and local Health and Wellbeing Boards.

Overcoming barriers and reasonable adjustments

60. There were a number of ways that individual GP practices (and the former PCTs and Strategic Health Authorities (SHAs)) sought to remove the barriers to a higher take-up of health checks. We heard about flexibilities in the delivery of health checks – how they were sometimes undertaken in the person's own home for example. There were also examples of opticians and dentists also doing home visits. In the surgery, longer appointment times were allowed and sometimes as a first appointment to reduce waiting and the anxiety that might result. Some GPs made sure that they were not on the on call rota on the day allocated for health checks as they may be delayed getting to them.

Communication

61. Good communication was seen as vital to increasing the numbers receiving health checks as well as the usefulness of the check itself. This includes communication in an accessible way with patients – through accessible leaflets and DVDs, for example. Some invitations were sent out in an accessible format and followed up with a phone call the day before to check the particular needs of the individual patient.
62. Communicating with families and carers was also important so that they understood the purpose and importance of the health check. Finally, communicating between different parts of the health service was also highlighted in several areas.

What people with learning disabilities and families told us

63. Despite the examples we heard of good practice and the data showing improving take-up of health checks, people with learning disabilities and their families raised a number of concerns about the quality of annual health checks at the listening event. Some people had not been offered one at all, others questioned their quality and thoroughness. Although they recommended that everyone should have a health check, there were concerns that they are not being done well everywhere.

'My GP gets paid for these. My son never gets out of his wheelchair or has any kind of body check. It's money for old rope!'

'My annual health check was done on the phone'

What happens next?

64. In the future, NHS England plans to review the costs and benefits of the existing arrangements around the DES in light of the Confidential Inquiry and other evidence, with a view to assessing the effectiveness of the service in improving outcomes. This will form part of the work to review possible changes to GP contracts. NHS England will work collaboratively with NHS Employers and the British Medical Association's General Practitioners Committee to see how the DES could be improved for 2014/15.

(iv) Promoting good practice

What was said in 2010?

65. The Department of Health said that the PHO and *Valuing People Now* web pages would continue to host examples of good practice and tools to enable local areas to implement improvements.

What has been achieved since 2010?

66. Up to March 2011, the Valuing People Now (VPN) programme was the main vehicle for collecting and sharing good practice. The material made available on the VPN website

remains available in archived form.¹⁶ Since 2011, there has been a wealth of material on good practice developed across the country, which has been captured in a number of key reports and published on the DH website (now part of www.gov.uk).

67. This includes:

Public Health Observatory

68. One aspect of the work of the PHO has been to identify and promote good practice. Good practice examples are identified in many publications, but the best example of this is the Reasonable Adjustments Database.¹⁷ This provides access to over 200 examples of good practice categorised by type of service, type of adjustment, type of provider and location. Most have downloadable descriptions and many have further downloadable material.

Examples from NHS and The Association of Directors of Adult Social Services

69. As part of our information gathering for this progress report, we also specifically asked the LD leads in (former) SHAs and the Association of Directors of Adult Social Services to submit examples of good practice under the main headings in the Self-Assessment Framework. We have included some of these, as well as examples from other sources, in this report and will continue to look for opportunities to share and spread this learning with our partners.

Service specification

70. The draft service specification being developed by NHS England, ADASS and others included visits to a number of good practice examples in developing their work for adults. Key themes and issues identified on visits were collated and fed into the final specification. A similar process will be followed when the children's service specification is developed.

DH Review of Winterbourne View – interim and final reports

71. The interim report on the DH Review into Winterbourne View Hospital published a separate document setting out in detail three areas of excellent practice in Tower Hamlets, Salford and Cambridgeshire.¹⁸ *Transforming Care: A national response to Winterbourne View Hospital, the DH Review final report*, set out a programme of action that included good practice as a key part of several strands of work. A good practice guide was published alongside the report.¹⁹

16 HM Government. *Valuing People Now*. <http://webarchive.nationalarchives.gov.uk/20101111063951/valuingpeoplenow.dh.gov.uk/>

17 Public Health England (2013). *Reasonable Adjustments Database*. <http://www.ihal.org.uk/adjustments/>

18 Department of Health (2012). *Department of Health Review: Winterbourne View Hospital – Interim Report*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141591/Department-of-Health-Review-Winterbourne-View-Hospital-Interim-Report1.pdf

19 Department of Health (2012). *Winterbourne View Review: Good practice examples* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127314/good-practice-examples.pdf.pdf

Transforming Care – Good Practice Project

72. Some of the examples in this report came from a Good Practice Project jointly led by key stakeholders in the National Forum of People with Learning Disabilities and the National Valuing Families Forum working with ADASS, Local Government Association (LGA) and Think Local Act Personal (TLAP) to identify good practice that met certain indicators, including co-production, personalisation and integrated care.
73. This project was undertaken as part of the Department's work following *Transforming Care*. Its report will be published in the summer 2013. The Minister for Care and Support, Norman Lamb, hosted an event on 30 April 2013 where the six projects selected by people with learning disabilities and family carers were presented.
74. Building on this event, there will be a further good practice event in autumn 2013 with the NHS England and the LGA Joint Improvement Programme set up as a result of *Transforming Care*.

Mencap, BILD and the Department of Health listening event

75. At the listening event, people with learning disabilities and their families shared with us many examples of good practice. They shared services working collaboratively with people with a learning disability and family carers in driving change. They told us about a number of arrangements that had been set up to share experiences. For example, one local GP practice had set up a patient forum that included people with a learning disability. Some talked about how partnership boards and advocacy groups had been involved in training health staff and auditing services. Many comments stated that there were clearly some strong champions for change, with the actions of some individual health professionals given high praise.
76. For example:

'NHS funding was provided to pay for easy read information to be given to chemists and pharmacists'

'The learning disability nurse runs a focus group for people with a learning disability and their families'

Quality checking in Gloucestershire – *(one of the six projects selected as part of the Transforming Care – Good Practice Project.)*

A quality checking project in Gloucestershire co-produced by Gloucestershire Joint Commissioning Team and Gloucestershire Voices, a user-led organisation, has been running successfully for 18 months. There are three parts to the quality checking process. First, there is a Q360 online survey for people who use care and support services. The survey is aimed at the people involved in the person's life. This can be family members, friends, relevant service staff, people they meet in the community and so on. In this way, feedback can cover the different aspects of a person's life from varying perspectives. Second, there is a programme of quality checking visits run by Gloucestershire Voices, who have trained people with learning disabilities who use support themselves to be experts by experience. They ask people in residential services about their lives and report on what could be improved. Sometimes small things make a big difference. The third part of the process is unannounced visits by the Joint Commissioning Team, to check whether people are being supported and cared for properly at all times, including at night.

Access to public health services in Norfolk – *(one of the six projects selected as part of the Transforming Care – Good Practice Project.)*

This example illustrates people with learning for disabilities working with professionals and others to make sure that disabled people get equal access to services. It was selected because it addresses a very common issue for people with learning disabilities needing easy-to-access information on local health services. With responsibility for public health services passing to local authorities, it is an issue that would benefit from being addressed in all local authorities.

The project support staff spoke to people with learning disabilities and used their stories and ideas to advise professionals about the barriers that people with learning disabilities face in accessing public health services.

The aim of the project was to provide action-based recommendations, information and advice leaflets, good practice guides on accessibility and recommendations for training/development. In this way, the project would make a difference to the way in which information about health services is designed and delivered to people with learning disabilities.

Speakup Self Advocacy Ltd 'Healthy Surfers' project (*this good practice example is currently supported by the Department of Health Voluntary Sector Investment Programme Innovation, Excellence and Strategic Development Fund.*)

Self-advocates are trained to become 'Healthy Surfers' so that they can train others to use the internet to access healthcare information. Speakup has produced a DVD and other material to reach out across England to support people to log on and surf the internet safely to find health and fitness sites. Forty-one self-advocates have been trained so far.

'I wanted to find information on high blood pressure; for my mum to understand high blood pressure, as she didn't know which foods she could eat. I found it helpful for myself because it helped me understand more things about how to keep Mum calm and help her stop panicking.'

What happens next?

77. The Department of Health will also continue to seek out and share good practice working with partners including the Joint Improvement Programme, the National Forum of People with Learning Disabilities and the National Valuing Families Forum.
78. In summer 2013, the Department will publish the Good Practice Project report completed under *Transforming Care: A national response to Winterbourne View Hospital*. There will be a wider good practice event hosted by the Joint Improvement Programme (set up by the LGA and NHS England following Transforming Care and the Concordat) and the Department of Health in the autumn to build on this work and pull together and share examples from many sources.

Section 2: Progress on the Department of Health's wider 2010 commitments

79. In addition to the four areas covered above, in our last progress report the DH said it would maintain and build on progress in local health and social care services through use of the following:
- (a) **The Health Self-Assessments**
 - (b) **Learning Disability Partnership Boards**
 - (c) **Liaison and facilitation staff in acute and primary care**
80. This part of the report looks at these areas and how they are being used to support improvements.

(a) The Health Self-Assessments

81. The annual National Learning Disability Health Self-Assessment Framework was developed as a way of bringing people together to discuss, and decide, how well they think their local and regional health organisations are working to improve the health of people with a learning disability. Many people, including the members of Learning Disability Partnership Boards, and health and social care organisations agreed it was a really good way of working. It was undertaken by all 10 former Strategic Health Authorities (SHAs). Information on the Health Self-Assessment is available on the Improving Health and Lives (IHAL) Public Health Observatory website.²⁰

What has been achieved since 2010?

82. Health Self-Assessment data has been gathered from around England.
83. The link below provides the latest available data from regions that completed the 2011/12 exercise
http://www.improvinghealthandlives.org.uk/projects/self_assessment/regions/
84. There are currently no published summaries of the findings available.

What happens next?

85. A new Joint Health and Social Care Learning Disability Self-Assessment Framework will be introduced from 2013/14 which identifies specific priorities for improvement in

20 Improving Health and Lives: Learning Disabilities Observatory (2013). *Self Assessment 2011/12 database*.
http://www.improvinghealthandlives.org.uk/projects/self_assessment/regions/

each area of the country. These reports will give vital information for the new, developing organisations such as Healthwatch and Health and Wellbeing Boards to help support better health outcomes for people with learning disabilities. NHS England and the Department of Health are currently looking at the implementation of the process to take this forward. The Joint Framework combines the former Health Self-Assessment and the Learning Disability Partnership Board reports into a single document, which has been widely consulted on and agreed. Learning disability leads in the former SHAs played a central role in developing, disseminating and collating information for the Health Self-Assessments and the new joint framework.

(b) Learning Disability Partnership Boards

What has been achieved since 2010?

86. *Valuing People* (2001) introduced Learning Disabilities Partnership Boards, which all areas were encouraged to establish as a local partnership through which local statutory and non-statutory partners engage self-advocates and family carers in co-production of their self-assessments and commissioning plans. All Learning Disability Partnership Boards in England produced reports about their work every year. These reports show the numbers of people known to local services, and issues relating to social care and healthcare.

Partnership Board report 2011-12

87. In March 2013, the Public Health Observatory published the third annual *Learning Disability Partnership Board Progress Reports* covering the period 2011/12. The report includes both statistical information and descriptive details of local priorities and initiatives regarding the numbers of people known to local services, and issues relating to social care and healthcare. Some 79% (122/154) of local partnership boards returned a report.

Headline figures from Learning Disability Partnership Board Progress Reports

	2010/11	2011/12
Partnership boards submitting annual reports	126	122/154*
Number of people reported as known to have LD per 1,000 working-age adults	3.8	4.5
Total reported health and social care spend per person with LD**	£42,227	£41,667
Proportion of adults with LD having personal budgets	28%	38%
Proportion of PB areas offering personal budgets for children and young people with LD	39%	55%
Completed Health Self-Assessment Framework	76%	93%
Proportion of adults with LD living in their own home or with family	54%	61%
Proportion of adults with LD living in residential placements outside the area	9%	7.4%
Proportion of adults with LD in some paid employment (full or part time)	7%	6.9%

* There are 151 upper tier local authorities – but one area had three Partnership Boards.

** 66 authorities providing usable data for both years. Because of the striking increase in numbers of individuals reported as having learning disabilities between the years (which we believe is attributable more to improved data than to real change) 2011/12 figures for the numbers with learning disability used for both years in this calculation.

What the reports tell us

88. There are a multitude of examples showing what has changed in the lives of people with learning disabilities as they have moved from residential settings to supported living in the community. For example, the proportion of adults living in their own homes has gone up from 54% in 2010/11 to 61% in 2011/12; and the proportion of adults having a personal budget has increased from 28% in 2010/11 to 38% in 2011/12. Full details of the *Progress Reports* can be found at: <http://www.improvinghealthandlives.org.uk/projects/pbr201112home>

What happens next?

89. The Health and Social Care Act 2012 introduced Health and Wellbeing Boards. These Boards do not replace the need for local partners to have a forum where they engage with people with learning disabilities and family carers, and co-produce JSNAs, commissioning plans and assurance of the quality of care provided to meet the needs of people with learning disabilities in the local population.
90. Although they are not a statutory requirement, local leaders in councils and Clinical Commissioning Groups (CCGs) are strongly encouraged to continue to support learning disability partnership board arrangements that can support and contribute to the Health and Wellbeing Board. In this way they can be confident that it is engaging

with people with learning disabilities, meeting their needs through a strong commissioning plan and making sure it has a robust plan to respond to, for example, the post-Winterbourne View action plan.

91. As mentioned above, the new Joint Health and Social Care Learning Disability Self-Assessment Framework is replacing both the former Health Self-Assessment Framework and the Learning Disability Partnership Board reporting system. This will reflect changes to the health and care system and identify how the Framework can support and align with the focus on improving outcomes. The Public Health Observatory will continue to be centrally involved in collating, analysing and publishing results.

(c) Liaison and facilitation staff and learning disabilities nursing

What was said in 2010?

92. Liaison and facilitation staff in acute and primary care was seen as an area that had improved in bringing about improvements to patient experiences and building capacity in mainstream health services to deliver improvements for people with learning disabilities. The Department of Health said it was important that this approach be maintained in health and social care services.

What has been achieved since 2010?

Review into learning disabilities nursing

93. In 2011 the UK Chief Nursing Officers initiated a review into learning disabilities nursing to ensure that the health and social care systems are prepared for the changing health needs of people with learning disabilities called *Strengthening the Commitment: The report of the UK modernising learning disabilities nursing review (2012)*.²¹ The aims of the review were to provide focus and direction for the development of the profession, enhance its image, profile and contribution, and, importantly, ensure that people with learning disabilities have access to the expert nursing care they need.

The role of specialist learning disabilities nurses in the community

94. Learning disability nurses work with people, families and carers with a wide range of abilities and needs and within a diverse range of settings, providing both generalist and specialist nursing care. Most people with learning disabilities live in the community and for those who require specialist health interventions, these are often provided by community learning disability teams. While the constitution of teams varies from area to area most teams include a significant number of learning disability nurses.

Acute liaison nurses

95. A review of acute liaison nurses was carried out in March 2013 by the Access to Acute Hospitals Network (a2a Network), which was established in 1999 as a national forum

21 Scottish Government (2012). *Strengthening the Commitment: The report of the UK Modernising Learning Disabilities Nursing Review*. <http://www.scotland.gov.uk/Resource/0039/00391946.pdf>

to improving access to acute hospital care for people with learning disabilities. Further information can be found on their webpage is <http://a2anetwork.co.uk>.

96. We heard from people with a learning disability and family carers that liaison nurses and health facilitators continue to make a significant difference to how health services work for people with learning disabilities. People with learning disabilities and their families were particularly supportive of the role.

‘The consultant learning disability post has made an enormous difference – cuts red tape and makes things happen’

‘The learning disability liaison nurse runs a focus group for people with a learning disability and their families’

‘Learning disability nurses in acute hospitals work well – but only if you know about them’

Good practice example

A patient attended a hospital out-patient department for pre-admission for a possible eye operation. One carer supported the patient. The patient was anxious and physically aggressive to hospital staff, and the appointment was abandoned. Carers were contacted and it was agreed that two carers would support the patient through pre-admission and surgery. A quiet side room was made available on the day. One individual nurse was allocated to support the patient and carers throughout hospital admission and no other ward staff were involved to ensure a consistent approach and relationship building. The patient was first on the list for surgery. The patient wore their own night dress to theatre as requested by carers. All went smoothly, with no incidents.

97. Whilst there was strong praise for these nurses where and when they were available, the survey results showed that most people had not had access to one.

The majority of respondents (73%) said they had not been offered the support of a learning disability liaison nurse in hospital for the person with a learning disability.

Independent National Collaborative

98. Many learning disability nurses work in the independent sector although little is known about the numbers employed currently or future workforce demands. To enable a better understanding of the situation, and planning for a high-quality and sustainable learning disabilities nursing workforce across all sectors, there is now a national collaborative. Following two successful collaborative conferences, the Independent National Collaborative was launched in February 2013.

99. The Collaborative will respond to the recommendations in *Strengthening the Commitment* relating to the independent sector, including workforce planning, educational requirements and career opportunities.

Strengthening evidence-based practice

100. The Chief Nursing Officers' review also found that learning disability nurses needed mechanisms to share best practice and develop the evidence base to advance the profession. Research in learning disabilities nursing is now increasing slowly, although many areas remain under-researched. There is a need to develop robust evidence, which can then inform practice, particularly into the efficacy of interventions, health promotion and prevention approaches.
101. The UK Learning/Intellectual Disability Nurse Academics Network²² was asked to look at areas that would benefit from collaborative research and larger scale and comparative studies that would make a real difference to the health and wellbeing of people with learning disabilities. It would also bring a greater focus, extend research activities, strengthen education and training, and implement research findings in practice. In response the UK Learning/Intellectual Disability Nurse Academics Network has developed an action plan. It has surveyed all learning disability nurse lecturers to establish their areas of research. Currently it is identifying priorities for research, taking into account the views of people with learning disabilities, and funding opportunities.

What happens next?

102. To capture information on service provision in the NHS and better understand the learning disabilities workforce, a survey questionnaire has been developed and will be sent to all Trust nurse directors. The survey will also seek information on the local implementation of the recommendations. The results of the survey will enable better understanding of, and planning for, a high-quality and sustainable registered learning disabilities nursing workforce across all sectors.
103. The Chief Nursing Officer's review also recommended that nurses in all fields of practice should develop the core knowledge and skills necessary to work safely and appropriately with people with learning disabilities who are using general health services. The Learning/Intellectual Disability Nurse Academics Network is currently investigating the input that learning disability lecturers have into other fields of nursing. The results will be fed back to the Council of Deans of Health and the Nursing and Midwifery Council for appropriate action.
104. *Strengthening the Commitment* recommends that commissioners and providers of health and social care ensure that learning disability nurses are able to collaborate effectively with general health services. Working with major stakeholders, there is an annual conference aimed at improving care and safety in acute hospitals. At the end of 2012 a very successful conference was held in Hull to address many of the inequalities

22 The UK Learning/Intellectual Disability Nurse Academics Network can be contacted via the Vice-Chair hazel.powell@nes.scot.nhs.uk

and care issues in acute hospital Trusts, including improving the use of the Mental Capacity Act, and making reasonable adjustments.

Acute liaison nurses

105. The Department of Health is also continuing to look at the systematic evidence base for acute liaison nurses. However, there is a clear message from people with learning disabilities and their families that these roles can and do make a significant difference to the quality of their experience, which is a key outcome.
106. To support delivery of best practice, the Department of Health will publish a progress report on the implementation of the recommendations in *Strengthening the Commitment* along with examples of good practice on the report's webpage.²³ In collaboration with other key stakeholders, it will hold the third annual conference on acute care for people with learning disabilities.
107. The PHO is also working with the a2a network to develop an updated online database of contact details that self-advocates, carers or other advocates can use to find the liaison nurse in any NHS hospital.

Other ongoing work to improve the capability of the workforce

108. The events at Winterbourne View highlighted that there are too many front-line staff without the right training and support to enable them to care properly for people with behaviour that challenges. This is a theme that has been reinforced by many families. It is crucial that staff who work with people with learning disabilities are properly trained in essential skills. Better skills and training are an important part of raising standards overall.
109. Since April 2013, Health Education England (HEE) had a duty to ensure that there is an education and training system fit to supply a highly trained and high-quality workforce. HEE will work with the Department of Health, providers, clinical leaders, and other partners to improve the skills and capability of the workforce to respond to the needs of people with learning disabilities and behaviour that challenges and will examine ways to ensure that skills including knowing when and how to raise concerns and on disability hate crime are covered in training.
110. HEE will expect that all new entrants are tested for their values and interpersonal skills, and will reach out to schools and colleges to ensure that young people with the right values consider a career in healthcare. HEE will ensure the values set out in the NHS Constitution²⁴ lie at the heart of all it does.

23 http://www.rcn.org.uk/development/communities/rcn_forum_communities/learning_disabilities/strengthening_the_commitment

24 Department of Health (2013). *The Handbook to the NHS Constitution for England*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170649/Handbook_to_the_NHS_Constitution.pdf

Section 3: Progress on other areas people with learning disabilities were worried about

What was said in 2010?

111. In the Department's progress report in 2010, we acknowledged a number of areas where people with learning disabilities had concerns:
- i. **Capacity and consent** – following the law about capacity and consent and making decisions when people are not able to make them for themselves (the Mental Capacity Act 2005).
 - ii. **Understanding of staff** – making sure people who work in health services understand about learning disability, how to communicate and how to make 'reasonable adjustments'.
 - iii. **Complaints and advocacy** – giving people the support they need to make choices about healthcare and making sure when things go wrong that people are listened to and changes made.
112. Through the listening event and the survey which we ran with our partners BILD and Mencap in 2013, we specifically explored people's experiences in these areas. The discussions showed some ongoing concerns and also highlighted a number of other issues, which are still worrying people with learning disabilities, their families and carers.
113. Positive comments about healthcare were countered by concerns that practice was still too reliant on outstanding individuals rather than indicative of an overall culture change.

(i) Capacity and consent

Compliance with the Mental Capacity Act 2005

What has been achieved since 2010?

114. There was some evidence in the survey we carried out that compliance with the Mental Capacity Act (MCA) is improving. However, this seemed confined to the technical aspects of consent such as who should sign the consent form rather than proper involvement in medical decision making (see next section).

The majority of people with a learning disability had not been asked to sign a form about their treatment without it first being explained to them (61%). This had happened to 20% of family member survey respondents who said that the person they care for had gone into hospital in the last 12 months. However, the majority reported they had not been inappropriately asked to sign a form on behalf of the person with a learning disability (81% combined response rate for 'No this hadn't happened' and 'No the person I care for is/was unable to do so themselves'). 19% of family member respondents reported this had happened.

Decision making – The Mental Capacity Act 2005

'Why should we think that education and health law is not as important as the laws on driving and killing?'

'Capacity is not respected at all'

'The MCA is used to overprotect people'

115. The most serious example we heard was that a Do Not Attempt Resuscitation notice had been put on the person's records without consulting the family. Other examples reflected a lack of understanding about how to properly involve individuals and their families in making decisions about care and treatment.

Some 46% of respondents with a learning disability said that healthcare staff include them in decisions about their care all the time, while a significant proportion reported this only happened sometimes (36%) and very few said this never happened (4%). This means 40% of respondents felt that healthcare staff do not always include them in decisions. When asked if they were included in decisions made about the care of the person with a learning disability, where this had been necessary, 44% of respondents in the family survey indicated that they were included sometimes, 40% said they were included all the time and only a small proportion said they were never included (8%). This means 52% felt they were not always included in decisions about the person with a learning disability's care where this was necessary.

116. The MCA underpins all decisions about the lawful treatment of patients who cannot consent to decisions about their care and treatment.
117. Some 2 million patients, including many with learning disabilities, cannot consent to treatment due to their lack of mental capacity. This means that health staff involved in the treatment and care of patients who cannot consent, whether in hospitals or the community, must have a good understanding of the MCA. This includes, for example, how to carry out an assessment of capacity; to determine whether a patient is able to give valid consent or whether treatment needs to take place within a 'best interests framework', and when and how to instruct an Independent Mental Capacity Advocate.

118. A number of reports, including the Confidential Inquiry into premature deaths of people with learning disabilities, the Francis Report, *Transforming Care* and the annual CQC report on Deprivation of Liberty Safeguards all identified problems with how the MCA is understood and applied. They identified the lack of MCA compliant practice as a barrier to effective NHS care. They also identified unlawful NHS practice.

What happens next?

119. As steward of the NHS and social care, the Department of Health, working with partners across the system, will seek assurance, that services are ensuring those who lack the capacity to make decisions, to complain and to challenge, nevertheless are listened to, heard and all receive high quality, personalised care and support. The Department will continue to work with partners such as CQC and NHS England to ensure that the system understand these issues and is complying with the law.
120. The House of Lords has recently announced a scrutiny committee to consider the MCA. The committee will report before the end of the 2013/14 session. The Department of Health will look carefully at the committee's findings.

(ii) Staff understanding

Reasonable adjustments

Progress since 2010

121. We have heard lots of reports that reasonable adjustments are continuing to make a difference to the lives of people with learning disabilities, their families and carers.
122. There were many examples of reasonable adjustments being made across primary care and acute settings, indicating an improved understanding of the needs of people with learning disabilities across the NHS.
123. Examples of the range of reasonable adjustments that people had found helpful included easy read information, accessible signage; allowing family members to stay with the person in hospital, being first on the surgery list, the way information was explained to people, providing a treatment at home instead of at the surgery, and the development of resources and ward packs to help NHS staff treat patients with a learning disability. The provision of a health passport was described as helpful and important when it was written with the involvement of the person with a learning disability and their family.
124. Participants from the listening event made the following comments:

GPs

'I have had a good experience with my new GP who is honest that he has not worked with people with a learning disability before so I am teaching him'

'They gave me a Dictaphone so I could listen back and check what they said'

'I get sent easy read letters'

Hospitals

'The nurse supported me and helped me to stay at the hospital'

'The learning disability nurse came to meet me'

'My family were allowed to stay with me'

Other NHS services

'The palliative care team have ensured that all health professionals are talking to each other to coordinate care'

The optician explained everything and took their time and reassured me'

'The specialist dentist is very special and she explains what is happening to me every step of the way'

125. In 2012, the Department of Health asked the then Learning Disability Strategic Health Authority leads for examples of best practice in the NHS to illustrate the continued difference reasonable adjustments are making at a local level to the lives of people with learning disabilities and their families. There were many examples, just two of which are highlighted below.

Access to ambulance services example of reasonable adjustment in Salford

Joint work undertaken with the North West Ambulance Service to produce a *Pictorial Communications Handbook*, to facilitate ambulance journeys for people with learning disabilities. The booklets can be used by other vulnerable patient groups; one booklet is for use by Patient Transport Service and the other for the Paramedic Emergency Service. The booklet was adapted for use during the Olympics.

Example of reasonable adjustment in Warrington

A patient with very complex learning disabilities and behaviour that challenges was seen in the outpatients department by a consultant ophthalmologist, who had closed the department to see the patient at lunch time to prevent him becoming distressed. A 'best interests' decision was made to explore the possibility of an operation to improve the patient's quality of life.

Prior to the planned operation the patient and his carers were invited to view the ward, to see the lay out and to inform the hospital staff of any reasonable adjustments required and/or environmental changes that would make the patient's stay safer and more comfortable e.g. a door to an adjoining ward was identified as a potential issue and dealt with, and the route through the hospital, which the patient would take on admission, was also planned to avoid any incidents.

The anaesthetist visited the patient in his home and took away a copy of the patient's hospital passport so that nursing staff could read the information prior to admission. The anaesthetist also arranged for diazepam that the patient could take on the day, prescribed in liquid form as he could not tolerate tablets. On the day of the operation the anaesthetist went to the patient's home at 7.00am to administer the diazepam; he then followed the patient to the hospital, met him there and escorted him to the ward.

Carers said that the ward was arranged with regard to the patient's comfort, with comfortable chairs and the patient's choice of music playing in the background; the nurse assigned to the patient on the day checked that the volume of music was pitched correctly and had read the patient's hospital passport. The consultant visited the patient prior to him being taken to theatre and it was obvious he too had read the hospital passport, as he spoke to the patient about his interests and hobbies. All the professionals involved worked in a very person-centred way and, following the operation, the patient's positive care continued. The carer wrote 'it was a truly remarkable experience and one I am glad I witnessed'.

126. Following an initial national survey, the Public Health Observatory (PHO) maintains online the Reasonable Adjustments Database searchable by area, type of service and type of approach, providing a ready source of examples for people thinking about how to tackle issues of accessibility, safety and quality in their locality. At the start of June 2013, this had been viewed over 17,000 times. In 2012, the Observatory also started a series of new reports on reasonable adjustments relating to specific healthcare situations. Four have already been completed concerning: cancer screening, dentistry, eye care and diabetes.

Continuing concerns

127. Despite the good examples of reasonable adjustments there was some concerning feedback from the listening event and those survey results indicating that while there

appears to be an increased understanding in some services about how to provide accessible information to people with a learning disability this is far from commonplace.

128. However, we lack consistent and reliable data to assess what reasonable adjustments are routinely being made.

What happens next?

129. Service providers and commissioners of services are encouraged to visit the PHO website and look at the online Reasonable Adjustments Database. The PHO will maintain the database and continue to produce reports for specific healthcare situations. The next digest report on reasonable adjustments will cover dementia.
130. As the Government response to the Confidential Inquiry sets out, the Department will work with NHS England and other organisations about better recording of reasonable adjustments in patient records.

Communication and Information

‘People with a learning disability were not believed about how serious the health emergency was and the ambulance service would not come out’

‘The families’ input was disregarded’

131. Event participants described examples of poor communication: staff not explaining what they are doing; not supporting people to help them understand the conditions or treatment; not communicating in the best way for the individual; and health professionals not communicating well with each other. In particular, it was concerning to hear that many families and people with a learning disability felt that they were not listened to.

Some 54% of respondents with a learning disability and 64% of respondents in the family survey stated that healthcare staff never asked them how they should communicate with the person with a learning disability. A total of 46% of respondents with a learning disability stated that staff sometimes listen to them when they tell them what they need, 38% said this happens all the time and 7% said this never happens. Some 66% of respondents to the family survey stated that staff sometimes listen to them when they tell them what the person with a learning disability needs, 20% said this happens all the time and 9% said this never happens.

‘Sending letters to people who can’t read is very frightening. They think you are telling them they are ill’

‘There was no easy read information to help you get to the different hospital departments’

132. Despite the good examples of reasonable adjustments given by event participants it was concerning to see the survey results indicated that this is far from commonplace.

Some 70% of respondents with a learning disability and 84% of respondents in the family survey stated that healthcare staff never ask the person with a learning disability how they like to receive their information. A total of 46% of people with a learning disability found information they get about their health hard to understand, while 34% found the information OK to understand and only 20% found it easy to understand.

Taking pain seriously

'My son needed stitches and was not allowed pain relief'

133. Pain management has been a particular concern for some time. It was concerning that we heard people feel the management of pain remains a significant issue, given that there has been considerable awareness raising on this issue.

Some 49% of respondents with a learning disability stated that healthcare staff help them all the time if they are in pain, 40% said this happens sometimes and 4% said this never happens. This means 44% of respondents stated that health staff do not always help them if they tell them they are in pain. A total of 39% of respondents to the family survey stated that healthcare staff sometimes help the person with a learning disability they care for if they are in pain, 29% said this happens all the time and 11% said this never happens. This means 50% of respondents in the family survey stated that healthcare staff do not always help the person with a learning disability if they tell them they are in pain.

What happens next?

134. The Department of Health will continue to work with NHS England and other delivery partners to ensure these key messages are being heard appropriately through the health and care system.

Complaints and advocacy

What has been achieved since 2010?

135. Recent changes have been made to the complaints system.
136. **Independent Complaints Advocacy Service (ICAS)** From 1 April 2013 the commissioning of NHS advocacy services was transferred to local authorities. The ICAS service ceased to exist from 31 March 2013. Local authorities are free to determine the level and model of advocacy service need to meet the requirements of their local populations. Local authorities are better placed to know the needs of their populations.

137. **Patient Advice and Liaison Service (PALS)** PALS is a non-statutory body within the NHS available in most hospitals. PALS helps people who use NHS services to improve the NHS. It does this by listening to concerns, suggestions and experiences, and ensuring that people who design and manage services are aware of the issues raised.
138. The 'signposting function' of PALS has been transferred to local Healthwatch organisations. The Health and Social Care Act 2012 sets out that local Healthwatch will be established in April 2013 replacing the Local Involvement Networks (LINKs). A local Healthwatch is an independent organisation, able to employ its own staff and involve volunteers, so it can become the influential and effective voice of the public. The aim of local Healthwatch will be to give citizens and communities a stronger voice to influence and challenge how health and social care services are provided within their locality but the PALS function at hospitals remains unchanged. The role of PALS is different to that of local Healthwatch but it does overlap in the area of identifying concerns and making these known to the relevant bodies.
139. PALS staff may try to resolve a complaint but their role is mainly to help people get independent support from outside the NHS if that is what they need rather than manage the complaint itself. In some hospitals PALS is considered part of the overall patient satisfaction system which includes complaints; this is particularly evident in organisations with the best complaints handling systems.
140. It is too early to assess the impact the changes from 1 April 2013 are making but participants at the listening event made strong points about the difficulties that they felt they continued to experience when they needed to complain about their healthcare. One family reported having to make 18 complaints. Others were reluctant to complain because of the fear of a negative impact on the person receiving treatment. Many felt that the complaints system was not working well.

'Families do not have a clue how to complain and are scared that they will be punished'

'They just try to pull apart who said what and why'

'I am still waiting for the local hospital to reply'

141. These messages were supported by the survey results.

The majority of family members who had made an official complaint about the care of the person with a learning disability they care for found the complaints process very difficult (39%) or difficult (38%) (77% combined).

What happens next?

142. We heard strong messages about what people felt was still not working well and it is important that, across the health and care system we listen to these very real

concerns. DH will continue to work with NHS England and other partners on these issues.

143. Health and social care commissioners have a major role to ensure that services they commission have effective complaints processes in place and are delivered to a high standard. A key element is the extent to which providers implement change and service improvement in direct response to complaints. Information on complaints about providers will influence commissioning decisions.
144. Providers should take complaints seriously and their Boards (or equivalents within organisations) need to understand both the benefit of dealing with complaints effectively and the consequences if they do not. A vitally important element is that health and social care services should routinely learn from complaints, feeding into service improvement.
145. Following the Francis Inquiry, an independent review of NHS hospital complaints is currently being undertaken. The review aims to provide a holistic view of NHS complaints in hospitals and will gather experiences from NHS professionals, the public and stakeholders. The review of best practice on complaints will ensure that when problems are raised, they are heard, addressed and acted upon, and seen as vital information for improvement rather than irritations to be managed defensively.²⁵

25 Department of Health (2013). *Patients First and Foremost: The Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170701/Patients_First_and_Foremost.pdf

Section 4: Areas identified for further progress

146. There are a number of other related areas of concern which we have heard about where we need to make further progress with partners:

Compassionate care

'Ward care is non-existent – dignity suffers!'

'A member of (advocacy group) was left in hospital with little support, no support from hospital staff to eat meals, drink and get out of bed – she has complex needs'

147. Sadly, we heard from a number of people about poor quality experiences. Event participants gave many examples of poor care that included: getting pressure sores; neglect; that people felt staff were sometimes rough; and that care depended greatly on how much previous experience the nurses might have had caring for people with a learning disability.

A total of 46% of respondents with a learning disability felt that health staff are very caring towards them compared with 14% of respondents in the family's survey who felt healthcare staff are very caring towards them (family members). Families felt that healthcare staff are more caring towards the person with a learning disability they care for than to family members.

The majority of respondents (61%) had been required to carry out personal care themselves for the person with a learning disability they care for in hospital.

Diagnosis

'The GP failed to diagnose that my ankle was broken and I had to go to hospital'

'People have to go to hospital because their GP has got it wrong and does not understand'

'They missed the diagnosis of a bladder stone'

148. Event participants also gave many examples from their perspective of the problems associated with making a diagnosis and the assumptions made because someone had a learning disability. These included missing important symptoms, delayed diagnosis and misunderstanding when someone displayed behaviour that challenges, which is seen as problematic rather than communicating something that is wrong, such as being in physical pain.

Some 36% of family members found the length of time between meeting health staff and receiving a diagnosis moderately acceptable. However, a significant proportion felt that the length of time was not very acceptable or not acceptable (19% and 24% respectively).

149. It is clear, that there are many examples of good care and that, in some areas, people and their families feel good progress is being made. These areas include making reasonable adjustments, improving better communication amongst staff and improvements in practice around discussing consent and treatment. However, more involvement of people with a learning disability and their families will further help to improve the quality of care that the individual receives.

What happens next?

150. The Department of Health will continue to work with NHS England and other key partners to address these issues through other actions. These include actions in place following the Francis Inquiry, which also focus on putting patients first and improving the way we listen to them and their families, and those in *Transforming Care: A national response to Winterbourne View Hospital*.
151. It is also important that professionals should take note of all these comments to understand what good and bad healthcare looks like for people with a learning disability. If healthcare professionals listen to the comments and suggestions from people with a learning disability and family carers about what needs to change, they will be better equipped to meet the needs of people with a learning disability.

PART TWO – Progress and changes in the Regulatory Framework since 2010

What was said in 2010?

152. The Ombudsmen also specifically asked us to ensure that this progress report should cover and review the level of assurance provided by the regimes put in place by the regulators listed below in relation to services for people with learning disabilities:
- **Care Quality Commission (CQC)**
 - **Monitor**
 - **Equality and Human Rights Commission (EHRC)**

What progress has been made?

153. Following the last progress report the CQC, Monitor and the EHRC have been in direct contact with the Ombudsmen with updates on their work; they have copied their letters to the Department of Health to keep us informed.
154. A summary of work being undertaken by each of the regulators is set out below.

Care Quality Commission

155. The CQC continues to work closely with the EHRC. It has been holding quarterly meetings to review progress and has a detailed action plan setting out how it continues to work together to share and exchange information, particularly where there are breaches of human rights. It frames its work and relationships around a memorandum of understanding (MOU) and each year the chief executives of the respective organisations review the memorandum and the work programme.
156. CQC continues to work closely with Monitor and hold regular planning meetings to jointly manage the approach to registration and licensing, as well as the ongoing performance of Foundation Trust services. These meetings, both nationally and regionally, provide the opportunity for aspects of care that may be of concern including human rights, dignity and respect to be discussed and actions planned.

157. The CQC continues to carry out unannounced inspections of services for people with a learning disability. Generally 'experts by experience' are included in these inspections, which includes both people who have used the services and relatives/family members.
158. The CQC's model of risk now incorporates the institutional care of people with learning disabilities as high risk. The CQC has made clear to providers and commissioners that it is raising the bar on registration.
159. The CQC is working with the Health and Care Professions Council (HCPC), Skills for Care, Skills for Health and National Skills Academy to make sure that the newly revised guidance on common induction standards, core competencies and national minimum training standards and the role of the registered manager are incorporated into providers of learning disability services' statements of purpose.
160. In addition, after the BBC *Panorama* programme exposé of the horrors at Winterbourne View Hospital, the CQC carried out a themed inspection of 150 learning disability services across England. The inspection included 'experts by experience' and professional advisers as part of the team. The significant levels of non-compliance with outcomes for including people in planning their own care and the inappropriate use of seclusion and restraint led to a significant programme of ongoing follow-up inspections.
161. CQC commissioned Ipsos Mori to conduct a feasibility study on how to systematically capture the views of those with a learning disability and their families about their experiences of care in acute hospital settings. The data and information will form part of the evidence set for judgements about the effectiveness and responsiveness of the provider. The study will report in the autumn of 2013.

Monitor

162. Monitor continues to work closely with partner organisations, and in particular the CQC, to ensure that where health provision concerns relating to learning disabilities are identified, they are communicated to the right organisation on a timely basis and with appropriate evidence. Once communicated, regulatory action is taken in a coordinated manner between relevant partner organisations to ensure concerns are rapidly rectified.
163. In Monitor's direct regulation of NHS Foundation Trusts, Trusts' Boards of Directors have the primary responsibility for ensuring proper leadership and governance in all areas including learning disabilities. Monitor continues to give prominence to this area of concern through its regulatory framework with a specific indicator on learning disabilities. This means certification against compliance includes requirements about access to healthcare for people with a learning disabilities. Monitor has just completed a consultation on its 'Risk Assessment Framework', which is expected to come into effect from 1 October 2013 and will continue to include the indicator.

164. The EHRC, Monitor and the CQC will continue to ensure equality and human rights obligations are properly addressed through their statutory functions.

Equality and Human Rights Commission

165. In 2010, the EHRC and CQC agreed a memorandum of understanding (MOU). The MOU has been an effective framework for collaborative work and a robust conduit for intelligence exchange and candid discussions between the two organisations.
166. In 2011, EHRC and CQC published joint guidance on equality and human rights for CQC inspectors, which was disseminated alongside a bespoke training programme.
167. A well-established positive working relationship exists between the EHRC and CQC and the MOU has helped to engender a shared commitment to ensuring that the regulation of health and social care services focuses on equality and human rights.
168. Over the past two years, the EHRC has sought to work with Monitor to ensure that equality and human rights have a high priority. The EHRC has maintained regular dialogue with Monitor, particularly at a time when regulatory functions has expanded, to encourage the creation of effective systems to detect threats to equality and human rights in the health services.
169. The health and social care regulatory architecture has undergone a series of fundamental changes over the past 12 months, largely due to the Health and Social Care Act 2012. These will evolve further as a result of the Francis Inquiry. The EHRC, CQC and Monitor are undertaking a regulatory mapping exercise to understand where each organisation's regulator responsibilities for regulating equality and human rights lie.

What happens next?

170. The regulatory system will continue to protect the interests of people with learning disabilities using health and care services in the new health and care system. As the new system brings more freedom for those who plan, commission and provide services, new and existing health and care regulators will safeguard the interests of patients and the wider public. In particular:
- The CQC will measure whether services meet national standards of quality and safety, ensuring that people are treated with dignity and respect. Healthwatch England will work as part of the CQC.
 - Monitor will protect and promote the interests of people using health services by making sure that NHS services are effective and offer value for money. Licensing providers of healthcare will be one of the main tools Monitor will use to do this.
 - Most health and social care professionals must be registered with one of the independent regulators, such as the General Medical Council, which helps to protect patients and the public by ensuring that professional standards are met.

PART THREE – New developments and new responsibilities since 2010

Section 5: The new health and care system

171. The new health and care system became fully operational from 1 April 2013 to deliver the ambitions set out in the Health and Social Care Act 2012.
172. New and existing organisations, including NHS England, Public Health England and Health Education England, took on their full range of responsibilities from this date. More information on how the new structure and organisations will work can be found using the following link: <http://healthandcare.dh.gov.uk/guide-system/>
173. This report does not cover all the organisations in the system whose remit and responsibilities extend to people with a learning disability. We have focused on the roles of three key organisations who will provide national leadership across the system:
- The Department of Health
 - NHS England
 - Public Health England
174. NHS England and Public Health England also have particular roles in relation to local areas.

National leadership

(i) The role of the Department of Health in the new system

175. The Department of Health's purpose is to help people live better for longer. This applies as much to people with a learning disability as to any other member of the population. The Department will lead, shape and fund health and care in England, making sure all people – including those with a learning disability – have the support, care and treatment they need, with the compassion, respect and dignity they deserve. The new and changing health and care organisations work together with the Department to achieve this common purpose.
176. The Department of Health will enable health and social care bodies to deliver services according to national priorities and work with other parts of government to achieve this. It will set objectives and budgets and hold the system to account on behalf of the Secretary of State. The current priority programmes of the Department of Health in relation to learning disabilities are:
- to ensure that the actions in *Transforming Care*; the DH final report into the Review of Winterbourne View Hospital and the accompanying *Concordat* are delivered and make a difference to people's lives; and

- reducing premature mortality, through responding to the Confidential Inquiry into the premature deaths of people with learning disabilities and related work across the system.
177. The Secretary of State for Health has ultimate responsibility for ensuring the whole system works together to meet the needs of people with a learning disability and reflects their experiences. One of the ways it does this is through the Outcomes Frameworks for NHS, public health and social care which set the strategic framework for continued improvement in outcomes locally and nationally. Learning disabilities indicators are included in all three outcomes frameworks and the relevant areas are set out in full in Annex C for reference.
 178. National system leadership and partnership on policy for people with learning disabilities will continue to be provided at the Department of Health through the Learning Disability Programme Board, chaired by Norman Lamb, Minister for Care and Support.
 179. The Programme Board's role is to provide systems assurance and to oversee system changes and policies that affect the care, health and wellbeing of people with learning disabilities. The Board includes representatives from key stakeholders including the National Valuing Families Forum, the National Forum of People with Learning Disabilities and Mencap.
 180. The Board oversees the programme of change outlined in *Transforming Care: A national response to Winterbourne View Hospital* by measuring progress, monitoring risks to delivery and challenging external delivery partners.
 181. The Department of Health is committed to working in partnership with NHS England, Public Health England, local government, professional bodies and others, to continue to improve outcomes for people with a learning disability right across the health and care system.

(ii) The role of NHS England

182. The main aim of NHS England is to improve the health outcomes for all people using NHS services but also to reduce inequalities in outcomes, giving the highest priority to the most vulnerable and marginalised groups.
183. One of the key drivers for NHS England in improving the quality of care is the NHS Mandate, including the NHS Outcomes Framework (see Annex C), which allows people to hold the NHS to account for improving outcomes.
184. The Mandate from the Government to the NHS covers the period from April 2013 to March 2015. It plays a vital role in setting out the strategic direction for NHS England and ensuring it is democratically accountable. NHS England is required to pursue the objectives in the Mandate. The objectives focus on areas identified as being of greatest importance to people.

185. The Mandate includes an objective for NHS England to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high-quality care.

The Government's Mandate to NHS England states that the objective 'is to ensure that clinical commissioning groups work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high-quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people'.

NHS England – response to Winterbourne View

186. Alongside the DH Review of Winterbourne View, a *Concordat: Programme of Action* was signed by a wide range of delivery partners including NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services. The Concordat sets out specific actions for NHS England working with others to transform health and care services offered to children, young people and adults with learning disabilities or autism who have mental health conditions or behaviour that challenges to ensure better outcomes for them. NHS England will:
- ensure that all Primary Care Trusts develop registers of all people with learning disabilities or autism who have mental health conditions or behaviour that challenges in NHS-funded care as soon as possible and certainly no later than 1 April 2013;
 - make clear to CCGs in its handover and legacy arrangements what is expected, including:
 - maintaining the local register from 1 April 2013; and
 - reviewing individuals' care with the local authority and identifying who should be the first point of contact for each individual.
187. NHS England is committed to ensuring progress is shared regularly with the signatories to the Concordat. The work to develop registers and ensure handover to the new CCGs has been completed.
188. Other key actions to follow will include:
- By June 2013, all current placements will be reviewed. Everyone inappropriately in hospital will move to community-based support as quickly as possible, and no later than June 2014.
 - By April 2014, each area will have a joint plan to ensure high-quality care and support services for all people with learning disabilities or autism and mental health conditions or behaviour described as challenging, in line with best practice.
189. As a consequence of these actions, there will be a dramatic reduction in hospital placements for people with a learning disability.

The Learning Disability Joint Improvement Programme

190. As part of the actions set in place following Winterbourne View, NHS England and the LGA have established a Joint Improvement Programme to provide leadership and support to transform services locally. The programme closely involves service providers, people with learning disabilities and autism and their families in their work and is leading a joint project to work with local health and social care commissioners to support the delivery of real service change in this area. A clear test of success will be the delivery of care which, where at all possible, allows people to live in their own communities supported by appropriate services resulting in a radical reduction in the need for assessment and treatment units and similar services by June 2014.

(iii) The role of Public Health England

191. Guidance, *Improving Outcomes and Supporting Transparency: A public health outcomes framework for England, 2013-2016* was published in January 2012. It focuses on the role of local government, the NHS and Public Health England, and their delivery of improved health and wellbeing outcomes for the people and communities they serve.
192. Public Health England will also have a key role to play for people with learning disabilities in the new system. Its main aim is to work with national and local government, industry and the NHS to protect and improve the nation's health and support healthier choices.
193. Its critical responsibilities most relevant to improving the health of people with learning disabilities include:
- making the public healthier by encouraging discussions, advising government and supporting action by local government, the NHS and other people and organisations;
 - sharing information and expertise with local authorities, industry and the NHS, to help them make improvements in the public's health;
 - researching, collecting and analysing data to improve understanding of health and come up with answers to public health problems;
 - reporting on improvements in the public's health so everyone can understand the challenge and the next steps; and
 - helping local authorities and the NHS to develop the public health system and its specialist workforce.
194. Public Health England's priorities for 2013 and 2014 include:
- helping people to live longer and more healthy lives by reducing preventable deaths and the burden of ill health associated with smoking, high blood pressure, obesity, poor diet, poor mental health, insufficient exercise, and alcohol;

- reducing the burden of disease and disability in life by focusing on preventing and recovering from the conditions with the greatest impact, including dementia, anxiety, depression and drug dependency;
- supporting families to give children and young people the best start in life, through working with health visiting and school nursing, family nurse partnerships and the Troubled Families programme; and
- promoting the development of place-based public health systems.

195. Public Health England has a particular role to play in supporting, through the Public Health Observatory function as part of their knowledge and intelligence work, the development of high-quality data and information on a learning disabilities. Most importantly they have a role in continuing to use that data and intelligence to support changes in practice which will improve the health of people with learning disability. They will also have a role to play in developing and spreading knowledge on what interventions help people with learning disability to lead healthier lives and look after their own health.

(iv) The continuing role of national clinical and professional leadership

196. National professional leadership is also vital. In NHS England, clinical leadership is being strengthened with a national clinical director for mental health, chronic disabilities and a national clinical director lead for learning disabilities currently being appointed. Strategic clinical networks are being established to support improved outcomes and quality for everyone with chronic neurological and learning disabilities.

197. The Learning Disability Professional Senate, a multi-disciplinary group of clinical professionals, is represented on the Learning Disability Programme Board and is a signatory to the Winterbourne View Concordat. The Senate is committed to providing clear professional leadership and developing guidance and core principles reflecting professional responsibilities in the new health and care system.

(v) How local health and care organisations will work together to improve care for people with learning disability

- CCGs are made up of doctors, nurses and other professionals who use their knowledge of the local health needs of people with learning disabilities to plan and buy services for their local community from any service provider that meets NHS standards and costs – these could be NHS hospitals, social enterprises, voluntary organisations or private sector providers. This means better care for patients, designed with knowledge of local services and commissioned in response to their needs.
- Health and Wellbeing Boards in every area should ensure that services work together to respond to people's needs and priorities. They will involve people and community organisations, including elected representatives, in deciding what services the community needs – this will inform CCGs and local authorities when

they commission services. We expect them to listen to people with learning disabilities and take account of their needs in planning services.

- Local Healthwatch, represented on Health and Wellbeing Boards, should give patients and communities a voice in decisions that affect them. Local Healthwatch will report its views and concerns to Healthwatch England so that issues can also be raised at a national level.
 - Local authorities commission care and support services and have a new responsibility to protect and improve health and wellbeing. They use their knowledge of their communities to tackle challenges such as smoking, alcohol and drug misuse and obesity for all groups. Working together with health and care providers, community groups and other agencies, they can help to prevent ill health by encouraging and supporting people with a learning disability to live healthier lives.
198. It is now the responsibility of NHS England to provide the framework of guidance in which CCGs operate.
199. In addition, in October 2012, in collaboration with the Learning Disability Public Health Observatory, the Royal College of General Practitioners and the Royal College of Psychiatrists produced good practice guidance²⁶ to support CCGs, with local authorities and Learning Disability Partnership Boards. It was written to help them to commission health services in ways that achieve better health outcomes and address the health inequalities of people with learning disabilities.
200. This guidance will assist CCGs to:
- commission high-quality, cost-effective general and specialist health services for people with learning disabilities;
 - jointly commission services for people who challenge services and those with complex needs; and
 - work with local authorities and others to address the social factors which can also adversely affect health outcomes of people with learning disabilities.
201. The guidance will help CCGs to think about the health inequalities when commissioning services for people with learning disabilities. These have been well documented in many reports and are to a larger extent avoidable.

26 Improving Health and Lives, (2012). *Improving the Health and Wellbeing of People with Learning Disabilities: An evidence-based commissioning guide for clinical commissioning groups*
http://www.improvinghealthandlives.org.uk/publications/1134/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups

Section 6: Other key developments

202. In addition to the major changes to the health system, this section highlights three other new or developing areas since 2010 which will help to improve the health and wellbeing of people with a learning disability:
- i. Health Equality Framework and work on social determinants
 - ii. Personal Health Budgets;
 - iii. Safeguarding and changes to legislation on adult social care

(i) Health Equality Framework for People with Learning Disabilities – determinants of health inequalities

203. The Health Equality Framework for People with Learning Disabilities published in March 2013²⁷ is an outcomes framework based around the determinants of health inequalities. It has been designed to help commissioners, providers, people with learning disabilities and family carers determine the impact and effectiveness of specialist health services for people with learning disabilities.
204. In 2011 the UK Learning Disability Consultant Nurse Network was asked to develop an outcomes framework that reflected the wide range of learning disabilities' nursing approaches, following Winterbourne View. The Network used the determinants of health inequalities to structure the framework, based on the information in the Public Healthy Observatory's health inequalities report.²⁸ The determinants are shown in Table 3.

Table 3 Health Equalities Framework for People with Learning Disabilities

• Social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness
• Physical and mental health problems associated with specific genetic and biological conditions in learning disabilities
• Communication difficulties and reduced health literacy
• Personal health behaviour and lifestyle risks such as diet, sexual health and exercise
• Deficiencies in access to and the quality of healthcare and other service provision

27 UK Learning Disability Consultant Nurse Network, Improving Health and Lives: Learning Disabilities Observatory and National Development Team for Inclusion (2013). *The Health Equalities Framework: An outcomes framework based on the determinants of health inequalities*. http://www.ndti.org.uk/uploads/files/The_Health_Equality_Framework.pdf

28 Improving Health and Lives: Learning Disabilities Observatory (2011). *Health Inequalities and People with Learning Disabilities in the UK: 2011*. http://www.improvinghealthandlives.org.uk/publications/978/Health_Inequalities_&_People_with_Learning_Disabilities_in_the_UK:_2011

205. The approach focuses on demonstrating reductions in the impact of exposure to these known determinants and thereby reducing the inequalities experienced by people with learning disabilities. By concentrating on the determinants of health inequalities the HEF proactively focuses on prevention and reduction rather than reactive approaches that merely address the symptoms of health inequalities.

Background

206. Originally conceived as a way of capturing the outcomes of learning disability nursing interventions, the model quickly generated interest and engagement from others with an interest in the health and wellbeing of people with learning disabilities – families, commissioners, other professions and people with learning disabilities themselves.
207. In 2012, with support from the PHO, and the National Development Team for Inclusion (NDTi), a working group of commissioners and providers, drawn mainly from the south west was set up to work alongside the Consultant Nurse Network to develop supplementary commissioning guidance, based on the HEF. Consultation, engagement and validation meetings were held with representatives from the National Valuing Families Forum, the Learning Disability Professional Senate and with local and national representatives of advocacy and groups of people who use services.

Using the HEF

208. The HEF has been developed into an electronic template (or eHEF) with step-by-step guidance, which organisations and individuals can use to collect and monitor health equality impact data, although this needs discussion with local data governance departments prior to implementation. There is a framework for commissioners and guidance to enable services to be commissioned around health equality. There is also a sample Commissioning for Quality and Innovation (CQUIN) template to support commissioners in driving the roll out of the HEF across provider organisations. There is information included for families and people with learning disabilities to further support the introduction of the HEF.

Purpose of the HEF

209. The HEF is not intended to replace existing outcome tools that are used in specific settings or for specific interventions; its purpose is to provide a clear and transparent overarching health-focused outcomes framework with a common language, which can aid understanding for everyone involved, particularly between commissioning and service provision and across health and social care settings.
210. The aim has been to provide a tool which makes sense to everyone, that is sensitive to outcomes at an individual level and which allows aggregation of data so that population trends at different levels can be better understood.
211. The HEF is available on the NDTi website, and has been widely promoted at a number of events. The NDTi provides support for the implementation of the HEF if requested.

(ii) Choice and control – Personal Health Budgets

212. One of the developments since the 2010 report is the introduction of Personal Health Budgets (PHBs). These sit alongside personal budgets in social care and increase the choice and control for individuals and their families.

What are Personal Health Budgets?

213. PHBs are aimed at improving outcomes and quality of life by giving people more choice and control over how their health needs are met. A PHB provides the chance to have a personalised care and support plan, linked with control over how the money in the budget is used. People have the option of a direct (cash) payment for healthcare. This can be held by an authorised representative if the individual lacks capacity to manage the budget.
214. PHBs build on personal budgets for social care and will facilitate greater integration across health and social care. They were successfully piloted between 2009 and 2012 and are now being gradually rolled out across England. The Government's Mandate to the NHS includes objectives to make personal health budgets available to adults and children who could benefit. People receiving NHS continuing healthcare will be the first to have the right to ask for a personal health budget from April 2014. People who could benefit include those with complex health needs and people with behaviour that challenges. The DH final report in response to Winterbourne View states that people should have 'access to personal budgets and personal health budgets, where appropriate.'

Evaluation

215. The evaluation of the pilot programme showed that PHBs worked particularly well for people with the highest needs; benefits include reduced hospital admissions and a reduction in the breakdown of support arrangements. A key success factor was good quality personalised care planning and having choice and control over support arrangements.

Supporting Personal Health Budgets

216. NHS England is actively supporting the NHS to develop the capacity and capability to deliver PHBs to more people with learning disabilities. This includes local work to develop good practice and examples such as Pete and Michelle's story. These stories and more information are available at www.personalhealthbudgets.england.nhs.uk

(iii) The Care Bill and safeguarding

217. The new Care Bill was launched as part of the Queen's Speech on 8 May 2013.
218. The purpose of the Bill is to modernise the previously fragmented law so that it prioritises the wellbeing of individuals and enables all those needing health and social care to get good care. It will also introduce a number of measures in response to the Francis Inquiry.

219. The main elements of the Bill include:

- modernising more than 60 years of care and support law into a single clear statute, built around the person not the service;
- enshrining a right for the millions of carers in England to receive support from their local council. For the first time, introducing a duty to meet carers' eligible needs for support and a new adult safeguarding framework;
- the creation of a cap on care costs. These changes will provide people with a new legal right to financial protection and prevent people facing huge care costs. Those who have care needs before they turn 18 will have their cap set at zero;
- creating a legislative framework that helps integrated care;
- ensuring people needing care can move between local authority areas without the fear that their care will be interrupted;
- providing a new legal entitlement for everyone to a personal budget; and
- clarifying how people will be protected from their care being disrupted if their care provider goes out of business; and introducing new oversight of the providers that would be the most difficult to replace if they were to fail.

220. Many of these proposed changes have the potential to make a significant difference to the lives of people with a learning disabilities.

Safeguarding

221. The Bill also creates a legal framework so key organisations and individuals with responsibilities for adult safeguarding can agree on how they must work together and what roles they must play to keep adults at risk safe.

222. The Bill requires local authorities to set up a Safeguarding Adults Board (SAB) in their area, giving these boards a clear basis in law for the first time.

223. The SAB must:

- include the local authority, the NHS and the police;
- develop shared plans for safeguarding; and
- publish this safeguarding plan and report to the public annually on its progress.

224. The Bill also requires local authorities to make enquiries, or ask others to make enquires, when they think an adult with care and support needs may be at risk of abuse or neglect in their area and to find out what, if any, action may be needed.

225. However, what the Bill does not give local authorities any new powers to enter a person's property. The Bill states that SABs must arrange Safeguarding Adult Reviews in some circumstances. The Reviews are about learning for the future.

Conclusions and next steps

226. The information gathered in this report can help shape the future of healthcare for people with learning disabilities. There are messages for national government, local commissioners, providers and organisations across the system. It can be used collectively not only to better understand what works well but also to determine what further improvements are necessary.
227. By listening to the views of people with a learning disability and their families, we will be able to create the culture and climate necessary for a healthcare system that is better equipped to meet their individual needs.
228. While some things have improved, for example, an increased number of health checks and people telling us that reasonable adjustments are making a difference to their lives, this report clearly also shows that there is more that needs to be done. We need to work together to change the culture and strengthen the leadership across the health and social care system to support better healthcare outcomes for people with learning disabilities, their families and carers.

What the Department of Health will do with its key delivery partners:

229. In the immediate future, the Department of Health's key actions will be to:
- ensure the National Learning Disability Programme Board continues to have a central role in system assurance, including shaping national policy working with key partners;
 - continue to support and work with NHS England in taking forward its programme of work to improve the lives of people with learning disabilities. We will continue to monitor progress through the Mandate and other system assurance mechanisms;
 - work with partners to ensure that the actions set out in the Department of Health's Report into Winterbourne View (including the commitments voluntarily made by a whole range of organisations in the accompanying Concordat) are carried through and that they make a difference to people's lives;
 - ensure the issues identified by the Confidential Inquiry into the premature deaths of people with learning disabilities are addressed as set out in the Government's response;
 - make sure that the reforms to health and care systems are giving greater voice and power to people with learning disabilities and their local communities to develop services for everyone, including those vulnerable and marginalised groups who have in the past not had their voice heard;

- ensure Health and Wellbeing Boards have guidance and information to support them to understand the complex needs of people with behaviour that challenges and to listen to what they tell them;
- ensure that the lessons learned from the Francis Report into the events that took place at the Mid Staffordshire NHS Foundation Trust apply equally to people with learning disabilities, whatever the setting;
- support the spread of Personal Health Budgets for people with a learning disabilities with greater integration across health and social care;
- support the changes to the Mental Capacity Act and Deprivation of Liberty Safeguards. The House of Lords has recently announced a scrutiny committee to look at the MCA and it will report before the end of the 2013/14 session. The Department of Health will look at the committee's findings; and
- continue to discuss with our system partners what people with a learning disabilities and their families have told us and the implications for service design and delivery. We will work with system partners to ensure we have a shared strategy to engage with and listen to people with a learning disability and family carers so that we use their insights to improve health and care.

Learning from the key messages we heard from people with a learning disability and family carers: Simple checks to make things better

230. The British Institute of Learning Disabilities (BILD), Mencap and the Department of Health worked together to consult with people with a learning disability and their families to gain an understanding of their views and experiences of healthcare.
231. On the basis of the findings from the listening event and survey, Mencap pulled together the following key questions people with a learning disability and their family carers should ask when accessing healthcare, and a list of key questions healthcare professionals should ask when treating someone with a learning disability.
232. The Department of Health agrees that if these simple questions are asked, it will help to improve good practice in the treatment of people with a learning disability. By getting healthcare right for people with a learning disability, we will also get it right for many other patients too.
233. We will promote and share this simple set of messages so that everyone can play their part in making further improvements – see Table 4.

Table 4 Key questions

Things health professionals should ask when treating someone with a learning disability:

- Ask how you should communicate.
- Ask if there are any reasonable adjustments you can make.
- Ask if the individual would like additional support such as advocacy support.
- Ask if they have a health action plan and/or hospital passport.
- Ask if they understand what you have told them.

Things people with a learning disability and family carers should ask:

- Ask for an annual health check.
- Ask if there is a learning disability nurse.
- Ask for a hospital passport.
- Ask for a longer appointment time.
- Ask for information in easy read.

Annex A: Ombudsmen's 2009 recommendations

Ombudsmen's recommendations from '*Six lives: The provision of public services to people with learning disabilities*' report 2009

First, that all NHS and social care organisations in England should review urgently:

- the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas; and
- the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities;

and should report accordingly to those responsible for the governance of those organisations within 12 months of the publication of this report.

Secondly, that those responsible for the regulation and inspection of health and social care services (specifically the Care Quality Commission, Monitor and the Equality and Human Rights Commission) should satisfy themselves, individually and jointly, that the approach taken in their regulatory frameworks and performance monitoring regimes provides effective assurance that health and social care organisations are meeting their statutory and regulatory requirements in relation to the provision of services to people with learning disabilities; and that they should report accordingly to their respective Boards within 12 months of the publication of this report.

Thirdly, that the Department of Health should promote and support the implementation of these recommendations, monitor progress against them and publish a progress report within 18 months of the publication of this report.

Annex B: Learning Disability Public Health Observatory publications

2010

GP Health Checks for People with Learning Disabilities

Working Definition of Learning Disabilities

Health Inequalities and People with Learning Disabilities in the UK: 2010

Health Checks for People with Learning Disabilities: A systematic review of evidence

Health Inequalities – Evidence into Practice

Health Inequalities – Easy Read

The Estimated Prevalence of Autism among Adults with Learning Disabilities in England

Health Checks for People with Learning Disabilities: Implications and actions for commissioners

How People With Learning Disabilities Die

Health Checks for People with Learning Disabilities – Easy Read

2011

Improving the Health and Wellbeing of People with Learning Disabilities: An evidence based commissioning guide for emerging clinical commissioning groups (draft)

Health Inequalities and People with Learning Disabilities in the UK: 2011. Implications and actions for commissioners and providers of social care. Evidence into practice report no. 4

Health inequalities and people with learning disabilities in the UK. Some things that people who buy social care services (commissioners) and provide social care services should do. Easy read

Health Inequalities and People with Learning Disabilities in the UK 2011. Implications and actions for commissioners. Evidence into practice report no. 1 (revised)

Health Inequalities & People with Learning Disabilities in the UK: 2011

Health Checks for People with Learning Disabilities: An audit tool – indicators of success

Health Checks for People with Learning Disabilities: An audit tool (easy read version)

Health Checks for People with Learning Disabilities: An audit tool

Health Checks For People With Learning Disabilities 2010-11

Variations in Numbers of School-aged Children with Learning Disability

Prevalence of Visual Impairments among People with Learning Disabilities

NHS Data Gaps for Learning Disabilities

Reasonable Adjustments for People with Learning Disabilities – Easy Read

Reasonable Adjustments for People with Learning Disabilities: Implications and actions for commissioners and providers of health care

Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An update

Reasonable Adjustments

People with Learning Disabilities in England 2010

What Learning Disability Registers Can Tell Us

2012

Autism Self-Assessment Framework, Preliminary Report

People with Learning Disabilities in England 2011

Having a Voice: Advocacy for people with learning disabilities (easy read)

Advocacy By and For Adults with Learning Disabilities in England. Evidence into practice report no. 5

Having a voice. Advocacy for people with learning disabilities (easy read)

Advocacy By and For Adults With Learning Disabilities in England

The Results of the CQC Inspection of Services for People with Learning Disabilities: Easy read

A Review of the Results of the 2011/12 Focused CQC Inspection of Services for People with Learning Disabilities

Learning Disability Partnership Board Progress Reports 2010/11: A thematic analysis

Learning Disability Partnership Board Progress Reports 2010/11: Easy Read Summary

IHAL 2012-06 Autism Self-Assessment 2010/11 Main Findings

Health Checks for People with Learning Disabilities in England, 2011/2012

Improving the Health and Wellbeing of People with Learning Disabilities: An evidence based commissioning guide for emerging clinical commissioning groups (CCGs)

Using Local Data to Monitor the Health Needs of People with Learning Disabilities

Making Reasonable Adjustments to Cancer Screening

Easy Read Presentation of the Commissioning Guidance

Presentation Summarising the Commissioning Guidance

Improving the Health and Wellbeing of People with Learning Disabilities (easy read version of commissioning guide)

Improving the Health and Wellbeing of People with Learning Disabilities: An evidence-based commissioning guide for clinical commissioning groups

Making Reasonable Adjustments to Dentistry Services for People with Learning Disabilities.

Have You Got a Learning Disability? Asking the question and recording the answer for NHS healthcare providers.

Autism Self-Assessment 2011

What You Thought About IHAL. Results of a survey of users, September 2012

A&T and Other Specialist Inpatient Care for People with LD in the Count-Me-In Census

Health Inequalities & People with Learning Disabilities in the UK: 2012

2013

Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities

Improving the Up-take of Health Checks for Adults with Learning Disabilities. Evidence into practice report no. 6

Hospital Admissions That Should Not Happen

Annex C: DH Outcomes Frameworks

What the Outcomes Frameworks say about people with learning disabilities

The NHS Outcomes Framework

The NHS Outcomes Framework for 2013/14 was published in November 2012. The purpose of the Framework is to:

- provide a national level overview of how well the NHS is performing;
- provide a way of ensuring accountability between the Secretary of State for Health and NHS England; and
- help to drive quality improvement and outcome measurement across the NHS.

The NHS Outcomes Framework includes a range of high-level national outcomes across five domains:

- Domain 1 – Preventing people from dying prematurely
- Domain 2 – Enhancing the quality of life for people with long-term conditions
- Domain 3 – Helping people to recover from episodes of ill health or following injury
- Domain 4 – Ensuring that people have a positive experience of care
- Domain 5 – Treating and caring for people in a safe environment; and protecting them from avoidable harm

Those that relate to people with learning disabilities include (under Domain 1): Reducing premature death in people with a learning disability which will be indicated by: Excess under 60 mortality rate in adults with a learning disability

Adult Social Care Outcomes Framework

The Adult Social Care Outcomes Framework (ASCOF) for 2013/14 was published in November 2012. The ASCOF includes a number of outcome measures across four domains:

- Domain 1 – Enhancing the quality of life for people with care and support needs
- Domain 2 – Delaying and reducing the need for care and support
- Domain 3 – Ensuring that people have a positive experience of care and support
- Domain 4 – Safeguarding adults whose circumstances make them vulnerable and protecting from them avoidable harm

The ASCOF is intended to give an indication of how well social care services nationally are doing in delivering better outcomes for people who use services. It will also help to benchmark and compare between areas.

Those that relate to people with learning disabilities include (under Domain 1):

- 1E.** *Proportion of adults with a learning disability in paid employment *** (PHOF 1.8, NHSOF 2.2)*
- 1G.** *Proportion of adults with a learning disability who live in their own home or with their family ** (PHOF 1.6)*

Public Health Outcomes Framework (PHOF)

Improving Outcomes and Supporting Transparency, A public health outcomes framework for England, 2013–2016 was published in January 2012. It focuses on the roles of local government, the NHS and Public Health England and their delivery of improved health and wellbeing outcomes for the people and communities they serve. The framework has two high level outcomes:

- i. Increased healthy life expectancy.
- ii. Reduced differences in life expectancy and healthy life expectancy between communities.

The PHOF has a wide range of other indicators covering public health activity, which can be measured into four domains:

- Domain 1 – Improving the wider determinants of health
- Domain 2 – Health improvement
- Domain 3 – Health protection
- Domain 4 – Healthcare public health and preventing premature mortality

Those that relate to people with learning disabilities include (under Domain 1):

*Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services *(i-NHSOF 2.2) ††(ii-ASCOF 1E) **(iii-NHSOF 2.5) †† (iii-ASCOF 1F)*

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