

# Six Lives

## *Progress Report*

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# Foreword by the Minister for Care Services



'Six Lives: The provision of public services to people with learning disabilities' and the reports that preceded it, delivered a wake up call to the health and social care system. People with a learning disability were too often receiving sub-standard care that could lead to very poor outcomes for individuals and their families.

Since I came into post, I have made it a priority to drive change to meet the health needs of people with learning disabilities. I have been impressed to see the work of individuals and organisations who have taken innovative approaches, involving people with learning disabilities and their families in planning, assessing and delivering services, ensuring that their hospital ward, their GP surgery, their community service is fully accessible and is delivering high quality care to all.

It has been encouraging to see greater leadership throughout the NHS; providers and commissioners have been working with their frontline staff to ensure they are engaging people with learning disabilities and their families to ensure improvements are being delivered. The strengthened role of Learning Disability Partnership Boards is supporting engagement at a local level.

The Law is clear that public services must make reasonable adjustments to deliver equal outcomes and they must comply with the Mental Capacity Act.

However, there is still a long way to go before we can be confident that all health and social care organisations are meeting the needs of people with learning disabilities. Progress has not been fully embedded and is too often reliant on committed individuals rather than an every day part of how care and treatment is delivered.

People with learning disabilities and family carers still report experiences of care that fall well short of the standards we should all be able to expect.

The Government is consulting on proposals to free up the NHS and empower patients and carers. These plans will give greater power to people and their families to make choices about the care they receive and empower them to influence how services are delivered. Front line professionals will be freed to take innovative approaches to meeting the needs of all their patients, particularly those

for whom traditional models of care have not delivered. Local Government and local health services will work closely together, overcoming the artificial divides between which people with learning disabilities have too often fallen in the past.

I want to ensure health and care services ensure that the Government's vision of equity and excellence delivers for all people with learning disabilities.

All who work in health and care need to continue learning the lessons of 'Six Lives'. This is not a short term project. Achieving genuine equality and tackling disadvantage requires sustained, focused work continuing into the future. We must build on the progress made and challenge all parts of the health and social care system to judge their successes not just on how they meet the needs of the 'average population' but how they are overcoming inequalities and improving outcomes for people with learning disabilities and their families.

A handwritten signature in black ink, appearing to read 'Paul Burstow', written in a cursive style.

**Paul Burstow**  
**Care Services Minister**

# Summary



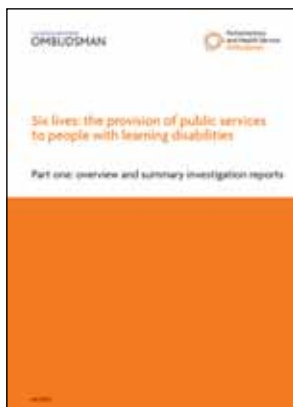
This is a report from the Department of Health for the **Parliamentary and Health Service Ombudsman** and **Local Government Ombudsman** to say what has happened since they wrote 'Six Lives'.



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 into complaints people make about local councils.



'Six Lives' is their report which looked at the services given to six people with learning disabilities who died. 'Six Lives' was published in March 2009. It said that:



- some organisations did not understand the laws about human rights and disability discrimination;



- some organisations needed to make big changes to the way they see people with learning disabilities and the way they work;



- the Department of Health should help make these changes and check they were happening.



This report says what has happened since 'Six Lives'.



To write this report we found out what lots of different people thought about how people with learning disabilities were being treated. We spoke to:



- people who work in the health service and in social care;



- people with learning disabilities and their families;



- Learning Disability Partnership Boards;





- organisations who provide support to people with learning disabilities;



- charities like Mencap.

## Doing what the Ombudsmen asked



To make things better the Ombudsmen said all health organisations and social care organisations (like hospitals, local doctors, and local authorities) needed to look at:

- how well they can meet the different needs of people with learning disabilities;





- how they can give the right care and treatment to people with learning disabilities.

We asked health organisations and local authorities if they had done what the Ombudsmen asked them to do in 'Six Lives'.



All health organisations said they did this, but many did this after the date the Ombudsmen said it should happen.

All Local Authorities told us they carried out the checks or had a clear plan when they would. Many did the checks after the date the Ombudsmen said it should happen.



The Ombudsmen asked three organisations who check health and social care services to say how well their rules work for people with learning disabilities. They are:



- Care Quality Commission, who check that health and social care services are good;
- Monitor, who check some kinds of NHS organisations are working well;
- the Equality and Human Rights Commission, who check people's human rights, are being respected.

**Equality and  
Human Rights  
Commission**

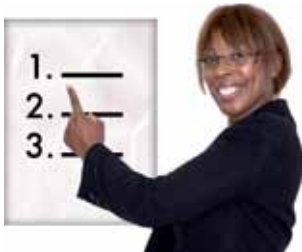


All three organisations have written to the Ombudsmen to say what they have done.

## What have we found out?



It is 18 months since 'Six Lives' was written.



Organisations have done lots of work to make care better for people with learning disabilities.



But we know there were lots of problems all over the country that meant people with learning disabilities were not getting the care they needed.



It will take time to make sure all places are giving the right care and treatment to all people with learning disabilities all the time.

Good things happening are not routine and part of everyday work in many places. When good staff move on to other jobs, the good work stops.

## Things that people told us are helping make a difference are:



- Leadership – people who are in charge making sure they think about people with learning disabilities in what they do.



- Annual health checks by GPs for people with learning disabilities.



- Including people with learning disabilities and their families when deciding how services are working for them and planning to make services better.



- Acute liaison nurses and health facilitators – people whose job is making health services work better for people with learning disabilities.



- “Reasonable adjustments” – changing how services are given to people with learning disabilities so they meet their needs. For example, longer appointment times and having information in ‘easy read’.



These good things need to be happening everywhere for all people with learning disabilities. More work is needed to make this happen.

## There were also things that people were worried about, like:



- Capacity and consent – following the law about capacity and consent and making decisions when people are not able to make them for themselves.

**Consent** means making your choice about treatment.

**Capacity** means being able to understand choices about treatment.



- Understanding of staff – making sure people who work in the health service understand about learning disability, how to communicate and how to make 'reasonable adjustments'.





- Complaints and advocacy – giving people the support they need to make choices about healthcare and making sure when things go wrong people are listened to and changes made.

## What happens next?



More work needs to be done by lots of organisations to make things better in all places for all people with learning disabilities.



Health will continue to be one of the three priorities in making sure that the Government plan 'Valuing People Now' happens.





The Government have said they want to make changes to how health services and social care services are organised.

People are being asked what they think of these changes.



It is important people with learning disabilities and their families are asked what they think.

It is important that what we have learnt about improving services for people with learning disabilities is included in these changes.



The Government wants to work with people with learning disabilities, families and their organisations to make sure things keep getting better.

# Introduction

This progress report has been written for the Parliamentary and Health Service Ombudsman and Local Government Ombudsman in response to the recommendations in their *'Six Lives'* report, published in March 2009.<sup>1</sup>

*'Six Lives'* investigated the deaths of six people with learning disabilities first highlighted by Mencap in their 2007 report *'Death by Indifference'*.<sup>2</sup> It looked not only in detail at what happened to those six people, but also the lessons that could be drawn for services as a whole to improve care for people with learning disabilities. *'Death by Indifference'* also prompted an independent inquiry into access to healthcare chaired by Sir Jonathan Michael.<sup>3</sup> The recommendations from this inquiry informed the actions set out for health in the *'Valuing People Now'* strategy.<sup>4</sup>

The recommendations in Six Lives to which this report responds were:

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 twelve months of the publication of this report.

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1 Six Lives, Parliamentary and Health Service Ombudsman and Local Government Ombudsman (2009)

2 Death by Indifference, Mencap (2007)

3 Healthcare for All: report of the independent inquiry into access to healthcare for people with learning disabilities, Sir Jonathan Michael, Department of Health (2008)

4 Valuing People Now: a new three-year strategy for people with learning disabilities HM Government (2009)

Secondly, that those responsible for the regulation 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 eighteen months of the publication of this report.

# Chapter 1: Evidence Sources

1.1 To prepare this report, information and views have been gathered from a range of people and groups.

Source	Information collected
Strategic Health Authorities (SHAs)	Provided assurance and exception reporting on NHS bodies receiving report in accordance with the first 'Six Lives' recommendation.
Health Self Assessment Framework	The regional health self assessment framework enabled detailed information on where progress was being made to improve healthcare for people with learning disabilities, where more work needed to be done and examples of good practice. All regions are using this Framework. (An example is included in Annex A).
Learning Disability Partnership Boards	All 152 local Learning Disability Partnership Boards produced an annual report for their area in March 2010. These annual reports were used to produce a regional report which included a section on how each region had responded to 'Six Lives', including local authority reporting in line with the first recommendation.
Local Authorities	Local Authorities provided assurance that they had received reports in accordance with the first 'Six Lives' recommendation and reported on progress made.
Provider organisations	A survey was sent out via the Valuing People Now Provider Forum asking for their views on progress made.
People with learning disabilities and family carers	<p>Department of Health and Mencap jointly hosted a listening event – <i>Six Lives: what do you think?</i> – primarily for people with learning disabilities and family carers. Members of the National Forum for People with Learning Difficulties and the National Valuing Families Forum gave their views on progress made in primary and acute care since the report was published.</p> <p>The Health Sub Group of the National Forum for People with Learning Difficulties shared their responses to questions on progress made, changes still needed and the big priorities going forward.</p>

<b>Source</b>	<b>Information collected</b>
Voluntary Sector advocacy/ campaigning organisations	Voluntary sector organisations were invited to send representatives to the <i>'What do you think?'</i> event and share their views and experiences.  In addition, Mencap submitted their views on progress made since the publication of 'Six Lives'.

# Chapter 2: The 'Six Lives' Recommendations:

## Reviewing and reporting

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.

## Summary

- 2.1 All NHS bodies have confirmed that they have carried out a local review and reported to their Boards as recommended, but a number did this after the Ombudsman's deadline of 31st March 2010.
- 2.2 All 152 Local Authorities have confirmed that they have carried out a local review and reported as recommended, or have at least set a date to do this. The majority of reports were received after 31st March 2010.

## NHS bodies

- 2.3 To check progress against this recommendation, Strategic Health Authorities were asked to seek assurance that they, their PCTs and NHS provider organisations (specifically acute trusts, mental health trusts, ambulance trusts and learning disability trusts) had received a report in line with the recommendation.
- 2.4 Some SHAs went directly to their provider organisations to ensure this had taken place, some asked their PCTs to provide the assurance for those providers they commissioned. Data received showed how many organisations had received reports by March 2010, how many had (or had a date set) by the time of publication and any exceptions.

- 2.5 In most areas, the report received was based on data gathered during the Regional Health Self Assessment Framework (see p. 23). This information was presented at Board Level.
- 2.6 A number of organisations, particularly provider organisations, had not reported to their boards by the end of March. SHAs and PCTs had to remind them of their responsibilities to ensure reports were received.

<b>SHA</b>	<b>Organisations receiving a report in line with 'Six Lives' recommendation before March 2010</b>	<b>Number of organisations receiving a report before the end of September 2010</b>
South West	13 PCTs (and their provider trusts)	1 PCT (and their provider trusts)
South Central	7 PCTs (and their provider trusts)	2 PCTs (and their provider trusts)
East Midlands	8 PCTs (and their provider trusts)	1 PCT (and their provider trusts)
London	18 PCTs and 17 provider trusts	13 PCTs and 23 providers
West Midlands	All PCTs and their provider trusts	
Yorkshire and Humber	All PCTs and all but 4 provider trusts	All remaining provider trusts
North East	3 PCTs (and their provider trusts)	1 PCT (and their provider trusts)
North West	17 PCTs and 15 provider trusts	7 PCTs and 28 provider trusts
South East Coast	11 PCTs (and their provider trusts)	14 PCTs (and their provider trusts)
East of England	3 PCTs (and their provider trusts)	10 PCTs (and their provider trusts)

### Social care organisations

- 2.7 Through regional and local Learning Disability Partnership Board reports, it was possible to gather information about how local authorities were responding to the recommendation. It was not possible to track compliance with all social care providers.

- 2.8 All local authorities provided assurance they had received a report in line with the recommendation, or had set a date to do so. The level of response to the 'Six Lives' recommendation was slower in local authorities than in NHS organisations.
- 2.9 It was less clear for local authorities which body they should be presenting their review findings to. Bodies reported to included:
- Learning Disability Partnership Boards
  - Joint commissioning boards
  - Safeguarding boards
  - Local Authority Cabinet
- 2.10 Although some good practice examples from local authorities were shared, the focus of work arising from "Six Lives" has been in the NHS.
- 2.11 People with learning disabilities often have complex needs which cross the boundaries between health and social care and so a joined up approach is essential.
- 2.12 Without providers and commissioners of care engaging with this agenda it will not be possible to ensure that people with learning disabilities can receive equal health outcomes.

<b>Region</b>	<b>Local authorities confirming they have received a report in line with the 'Six Lives' recommendation</b>	<b>No. of Local Authorities who have set a date for receiving a report</b>
Eastern	9	2
East Midlands	8	1
London	28	4
North East	12	
North West	13	10
South East	12	7
South West	14	1
West Midlands	14	
Yorks and Humber	15	



## The Regional Health Self Assessment Framework

- 2.13 An important way for organisations to carry out the review has been the Regional Health Self Assessment Framework (SAF). All but one region were able to use their results to inform the reports delivered in line with the 'Six Lives' recommendation.
- 2.14 Initially developed in Yorkshire and Humber, this process brings local people with learning disabilities and their families together with those who plan and deliver healthcare services.
- 2.15 They assess where healthcare services are against a framework of measures, and together rate whether they are operating at red (still a lot of work needed), amber (progress made, but work remains to be done) or green (outcome is achieved). These results are used to inform commissioning decisions and plan future improvements.

*"The self assessment helped really senior people understand this is their agenda"*

– PCT experience

- 2.16 Yorkshire and Humber have recently completed their third year of the SAF process. They have made much progress and are still highlighting where they want to make improvements, for example in offender health, transition from child to adult services and delivery of annual health checks. Annex A includes an extract from their year three report to demonstrate the detail, evidence and impact of the SAF.
- 2.17 The engagement of people with learning disabilities and their families has been a crucial part of making the SAF work.

*"The team made a big effort to make things accessible for me. They used Easy Read, pictures, traffic light cards and spoke slowly and clearly..."*

*During the Assessment it felt good when I was able to ask questions. It made me feel my view and opinion was valuable to people..."*

*I was surprised when some of the PCTs who said that they were doing good work did their presentations using lots of jargon, complicated words and spoke very fast. Actions are more important than words."*

– Self advocate's experience of the SAF

*"It's often the people with learning disabilities and their families who ask the important questions and get people providing services to really think."*

– SHA experience of the SAF

- 2.18 The Department of Health (DH) has encouraged the use of the SAF and funded support for regions in setting up and running the process. But the SAF is not a performance management tool for DH. All SHAs have chosen to undertake it, and worked with their PCTs, providers and local people to deliver it. It provides a practical framework for local areas to assess their own progress alongside those who use services so properly informed local and regional plans for improvement can be developed.

*"The process gave a framework to look at the situation and know what to do first."*

– PCT commissioner

## Regulatory bodies

Those responsible for the regulation 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.

- 2.19 The Care Quality Commission, Monitor and the Equality and Human Rights Commission have written to the Ombudsmen outlining what they have done in response to this recommendation in 'Six Lives'.

## Role of the Department of Health (DH)

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.

2.20 The DH has been working to support the implementation of the 'Six Lives' recommendations, as well as those in 'Healthcare for All'.<sup>5</sup> Health remains one of the three priorities in the Government's strategy to improve outcomes for people with learning disabilities, 'Valuing People Now'. Some of the recent key activities are outlined here:

- **Clear leadership** has been established:
  - The Chief Executive of the NHS, the Director General for Social Care, the National Director for Learning Disabilities and the Director for Primary Care have all written to NHS and local authorities at different times to remind organisations of their responsibilities to people with learning disabilities, and the 'Six Lives' recommendations.<sup>6</sup>
  - The Director for Primary Care at DH has lead responsibility for delivering the learning disability healthcare agenda. He chairs the Valuing People Now Health Steering Group which reports to the national Learning Disability Programme Board, co-chaired by the Minister for Care Services and reports on progress in improving health outcomes for people with learning disabilities.
- DH established a Directed Enhanced Service to deliver **annual health checks** to people with learning disabilities. GPs are incentivised to offer health checks every year to their patients with learning disabilities who are known to social services. The checks pick up previously unmet health needs and increase GP practice awareness of the health needs of this population.

DH continues to monitor and support their implementation. The NHS Information Centre collects data on the number of checks delivered, documents to support implementation have been provided and DH has recently commissioned the Royal College of General Practitioners to produce an additional training and support pack to help GPs deliver successful health checks. This is due for publication in October 2010.

5 [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099255](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255)

6 [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_086604.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_086604.pdf)  
[www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH\\_111562](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_111562)

- DH has established a new **confidential inquiry** into premature and avoidable deaths of people with learning disabilities. A contract was let with the Norah Fry Research Centre on 23rd March 2010 to carry out a detailed inquiry, and share the lessons learnt to prevent unnecessary deaths in the future. This contract will run initially to end March 2011 with the option to extend for a further two years subject to initial outputs and availability of resources.<sup>7</sup>
- DH has also set up a new **Learning Disabilities Public Health Observatory**. A contract was let with the North East Public Health Observatory, working with the Centre for Disability Research at the University of Lancaster and the National Development Team for Inclusion on 23rd March 2010. This contract will run initially to end March 2011 with the option to extend for a further two years subject to initial outputs and availability of resources. The Public Health Observatory will use data and information to produce practical tools to support effective commissioning to improve the health and lives of people with learning disabilities.<sup>8</sup>
- DH has published **guidance** to support NHS and social care organisations to deliver improved healthcare for people with learning disabilities. This includes guidance on commissioning mainstream health services to meet the needs of people with learning disabilities; health action planning; and facilitation and inclusion in single equalities schemes.<sup>9</sup>
- DH commissioned the **Council for Healthcare Regulatory Excellence** (CHRE) to work with its member organisations and report on how they are ensuring healthcare professionals are able to meet the needs of people with disabilities, particularly learning disabilities.<sup>10</sup> CHRE has asked for updates on progress in this area as part of their performance reviews of their members. Their update report is included in Annex B.

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7 [www.bris.ac.uk/cipold/](http://www.bris.ac.uk/cipold/)

8 [www.improvinghealthandlives.org.uk/](http://www.improvinghealthandlives.org.uk/)

9 [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_109753](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109753)

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_109088](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109088)

10 Full report available: [www.chre.org.uk/satellite/164/](http://www.chre.org.uk/satellite/164/)

- DH has worked closely with key delivery partners to **monitor progress** and produce this report, including:
  - named learning disability leads in SHAs, as well as asking for updates on activity via the SHA Performance Delivery Unit.
  - Regional Valuing People leads have worked to ensure that all 152 Learning Disability Partnership Boards produced an Annual Report setting out progress in delivering Valuing People Now by March 2010 and that local authorities have complied with the Ombudsman's recommendations.

# Chapter 3: The Impact

## Overview of findings

- 3.1 Although there were examples of good practice prior to the publication of *'Death by Indifference'* and the reports which followed, the majority of health and social care organisations were not giving sufficient attention to the health needs of people with learning disabilities.
- 3.2 The view consistently given by different groups presenting evidence for this report is that progress has been made in improving healthcare for people with learning disabilities, but serious issues remain. They have emphasised the need for momentum to be maintained to ensure health and social care systems are meeting the needs of all people with learning disabilities all of the time.

### Provider organisations

- 100% of provider organisations who responded to the survey reported that more work is needed to improve healthcare for people with learning disabilities
- 60% reported improvements in healthcare overall in the last eighteen months
- 53% reported improvements in primary care
- 40% reported improvements in acute care

- 3.3 It is clear that good work is often not embedded and remains overly reliant on individual staff members or local groups. The challenge in all areas is to turn these examples of good practice from isolated pockets of work into consistent delivery.

*"Individual healthcare professionals have shown great insight, endeavour and tenacity in reconfiguring services around the needs of patients with a learning disability. Their efforts have underpinned wide ranging attitudinal shifts among their colleagues and led to improvements in health outcomes... change should not have to just rely on individual's efforts. The key question then is how to mainstream this activity."*

– View from Mencap

- 3.4 Quality of service for people with learning disabilities varies substantially, not just across regions and localities, but within organisations. Family carers reported moving from one ward to another in an acute trust and receiving very different levels of care. One ambulance trust was named twice in the evidence given for this report, once as an example of an excellent patient experience, once as quite the reverse.

*“Things remain patchy and good practice seems to be more down to the individual than any service wide improvements.”*

– Provider view

- 3.5 All ten SHAs shared the three areas where they, as a region, i) were making most progress, ii) still needed most work and iii) had good practice examples.
- 3.6 The issues most commonly mentioned as part of this information are shown in the below table:

<b>Theme analysis of the ten SHA responses</b>			
	Mentioned as an area of progress	Mentioned as a continuing challenge	Included in good practice examples
Annual health checks	6	4	1
Improvements in mainstream commissioning	4	2	4
Acute services, especially liaison nurses	4	4	2
Training of staff	5	1	4
Inclusion of people with learning disabilities and their families	4	0	5
Data collection/identification of learning disabilities in systems	3	3	3
Easy read information	2	1	4
Screening and disease prevention	1	3	3
Safeguarding/Capacity and Consent	1	4	0

## Issues arising – what seems to be making a difference?

### Leadership

- 3.7 All levels of DH and NHS have responded to the need for better leadership on these issues. This has been particularly supported by the Self Assessment Framework and the reporting requirement of 'Six Lives'. It has led to much greater strategic oversight of services for people with learning disabilities.
- 3.8 Partnership Boards have increased their oversight and influence. Their annual reports have demonstrated the focus given to local health outcomes for people with learning disabilities, and health remains a major priority for all regions for the current year.
- 3.9 Leadership is also required in provider trusts and across social care organisations. Examples include:
- In Kirklees a learning disability Modern Matron post has been put in place to train learning disability champions on every ward.
  - In the North West, a Health Equalities Group includes chief executive representation for the Mental Health and Acute Trusts.

### Involvement of people with learning disabilities and families

- 3.10 All SHAs reported progress in involving people with learning disabilities and family carers and the SAF has provided a clear route to deliver this. The involvement of people with learning disabilities and family carers in signing off 77% of Partnership Board Annual Reports this year shows their increasing engagement in local decision-making.
- 3.11 While people and families involved in the SAF reported it as a positive experience, there are still gaps in involvement. Self-advocates report mainstream routes like LINKs and membership of Foundation Trusts are not easily accessible to them, and 60% of provider organisations reported no involvement of those they support in local decision making.
- 3.12 Effective engagement of people with learning disabilities and their families is essential to delivering personalised, effective services and equal outcomes.

### Annual health checks

- 3.13 All SHAs included annual health checks in their responses, as either an area of progress, or a focus for further improvements.



- 3.14 All those taking part in the *'What do you think?'* event said annual health checks were important. There were concerns about numbers accessing the checks, and the quality of those checks in some places, but there was universal support for their continuation, not just for the checks themselves, but also the value of the training for GPs and practice staff that accompanies the checks.

*"Health action planning has improved considerably with GPs' improved knowledge of learning disability needs."*

– Provider experience

- 3.15 There has been marked progress in the numbers of checks delivered, but even so figures show that last year only 41% of eligible people received a check, so much work remains.

Annual health check data <sup>11</sup>		
	Year one 2008/9	Year two 2009/10
Number of people eligible for a health check	118,230	145,130
Number of people receiving a health check	27,011	58,919
Percentage of eligible people receiving a health check	23%	41%

- 3.16 To have the greatest impact, health checks need to be linked to effective health action planning. This requires engagement of people with learning disabilities, their families and supporters. Provider organisations shared examples of their work with local GPs and PCTs to ensure all those they supported had an up to date and useful Health Action Plan which GPs contribute to.

In the North East, they are developing a regional annual health check template for all GPs to use. This generates a Health Action Plan, hospital passport and, if needed, a referral to acute services with required reasonable adjustments clearly identified.

*"All service users have received a check from their GP... this has led to follow up for conditions which had been undiagnosed in the past, e.g. diabetes."*

– Provider view

<sup>11</sup> From NHS Information Centre Omnibus data collection. For full data and analysis, please visit [www.ihal.org.uk](http://www.ihal.org.uk)

3.17 Evidence shows:

*"introduction of health checks for people with learning disabilities typically leads to: (1) the detection of unmet, unrecognised and potentially treatable health conditions (including serious and life threatening conditions such as cancer, heart disease and dementia); and (2) targeted actions to address health needs."*<sup>12</sup>

3.18 They are a practical 'reasonable adjustment' for the NHS to make to meet the increased healthcare needs of people with learning disabilities.

### Acute care

3.19 The ability of hospitals to provide a consistently good service to people with learning disabilities continues to be an area of concern, particularly for those with the most complex needs.

*"In acute settings [there is] poor understanding of the needs of those with additional support and communication requirements."*

– Provider view

3.20 Where progress was reported, it was frequently linked to the work of acute liaison staff. Their numbers are increasing, for example all acute foundation trusts across the North East have either recruited learning disability liaison nurses or have committed resources to enable to this to happen immediately.

*"The creation of a specific learning disability liaison nurse has been a welcome addition."*

– Provider view

3.21 Activity carried out by these staff members includes:

- training and capacity building mainstream staff;
- developing effective care pathways;
- direct intervention and support for those with most complex needs;
- developing resources, e.g. easy read information.

3.22 In some Trusts, work has been done to demonstrate the benefits of this work, including reduced length of stay, reduced readmission rates and better reported patient experience.

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<sup>12</sup> Robertson, Roberts, Emerson 'Healthchecks for People with Learning Disabilities: A Systematic Review of Evidence', September 2010, Improving Health and Lives Observatory

- 3.23 Meeting the needs of patients with learning disabilities, as well as other patients with additional needs, must be something all acute trusts are able to do.

In the South West, a project is underway to peer review 18 acute hospitals, specifically looking at how they are meeting the needs of patients with learning disabilities.

The review teams will be led by a commissioner and include health and social care professionals as well as people with learning disabilities and their families. The result of the review will include a benchmark for each hospital and recommendations for further action required. This information will be available for commissioners of acute hospital services in order to monitor progress.<sup>13</sup>

- 3.24 Both provider organisations and family carers mentioned problems of responsibility for providing additional care for patients with learning disabilities whilst in hospital. Carers are often expected to provide round-the-clock support, but responsibility for funding this is unclear and basic things like offering food and drinks is not always happening.
- 3.25 Protocols need to be established to ensure that where family and paid carers want to provide support in hospitals this is facilitated, but that assumptions are not made that extra support will be made freely available.

Worcestershire County Council worked with a provider organisation (HFT) and local health organisations in their region. They produced a guide to improve support for people with learning disabilities when they are in hospital, particularly addressing the role of paid support staff from social care.<sup>14</sup>

## Better data and information

- 3.26 A common theme for the majority of regions, accessing and effectively using data remains a challenge across England.

*“Only a minority of PCTs are able, or have plans, to capture information about people on GPs registers electronically to monitor their use of the range of health services and ensure equality of access. Only 2 hospitals currently have the ability to accept electronic ‘flags’ from GPs so that people with learning disabilities are recognised at the point of referral.”*

– SHA experience

<sup>13</sup> For more information, see [www.swacutehospitalreview4ld.org.uk/](http://www.swacutehospitalreview4ld.org.uk/)

<sup>14</sup> [www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf](http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf)

- 3.27 Identifying people with learning disabilities within existing data both to better understand and plan for their health needs, and to share information about the adjustments an individual requires as they move through the health system are potentially very powerful tools to improve the quality of healthcare for people with learning disabilities. Some areas have done some focused work to overcome difficulties but this remains a barrier to improving care in the majority of places.

Healthcare for All Task and Finish Group, led by University Hospitals Birmingham with South Birmingham PCT:

- Created a mechanism to allow information from GPs around reasonable adjustments required for patients to be collated by the Informatics Team;
- Informatics also worked closely with Operation to examine ways to flag patients with learning disabilities using existing technology and develop a centralised approach in ensuring medical and nursing staff are made aware of any additional requirements that a patient may have.

## Reasonable Adjustments

- 3.28 All the groups at the 'What do you think' event quoted examples of reasonable adjustments they had seen in primary care; e.g. longer appointment times, shorter waiting times, appropriate involvement of families (although examples of failures to provide these adjustments were also reported).

*"My GP gave me a longer time... she explained things to me well."*

– Patient experience, 'What do you think' event

- 3.29 Reasonable adjustments were less commonly mentioned in relation to acute care, though provision of easy read information was frequently sighted. Websites like [www.easyhealth.org.uk](http://www.easyhealth.org.uk) make accessing easy read materials easier for health professionals and people with learning disabilities, their families and carers. In the South West, a library of easy read materials has been gathered and shared via CD and website with mainstream health staff to support them in their work.

Doncaster has produced a breast screening photo journey and trained relevant staff. This ensures people with learning disabilities understand what will happen when they attend for screening and staff make reasonable adjustments to accommodate them.

- 3.30 Supporting staff to understand the law and take practical steps to make reasonable adjustments is an important task. Often taken on by health facilitators in primary care and acute liaison staff in hospitals, appropriate adjustments can hugely improve patient's experience and outcomes.

*"Across the NHS, changes are being made that are helping deliver better healthcare outcomes for patients with a learning disability. Taking the time to really get to know patients, through double length appointment times, has been an important reasonable adjustment, at limited extra cost, that many people known to Mencap have appreciated when offered."*

– Mencap view

- 3.31 However, there is clearly a need for further work to ensure staff assess patients' needs and make adjustments in their work to meet them. Failure to do so can have far reaching negative consequences for patients.

*"My son was admitted due to problems managing his epilepsy. We told staff he needed a side room as he has set routines and is unable to take medication when others are watching him. Staff refused to let him use a vacant side ward, saying it was reserved for infectious patients.*

*My son became increasingly agitated, but they still refused. Eventually he became so distressed he disrupted the whole ward and all the other patients and had to be restrained. He was then moved to the side ward, held down and sedated.*

*His service providers witnessed his aggressive behaviour and insisted that he was prescribed an antipsychotic medication, otherwise they would no longer support him when he was discharged. My son has no diagnosed mental health condition, but the psychiatrist prescribed haloperidol. We are now in the process of weaning him off it as he developed side effects and was very subdued."*

– Family carer experience

- 3.32 Making reasonable adjustments to deliver equal outcomes is a legal requirement of public services.<sup>15</sup> The Chief Executive of the NHS, Sir David Nicholson, wrote to his colleagues on 29th June 2008 to remind them of their obligations to make these adjustments. There is more to do to ensure organisations are consistently delivering reasonable adjustments for people with learning disabilities.

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<sup>15</sup> Disability Discrimination Act 1995 and 2005

## Training

*“We feel Trust staff are willing to change and want the involvement, they just haven't been given the skills or knowledge to do it.”*

– Provider view

3.33 Consistently mentioned was a need for better training of mainstream healthcare staff. Commonly cited areas for development included:

- basic understanding of learning disabilities;
- mental capacity, consent and best interest decision making;
- effective communication, including with those who have limited or no verbal communication;
- responding appropriately to challenging behaviour;
- understanding and making appropriate reasonable adjustments.

3.34 Whilst some work has been done to improve the skills and understanding of mainstream staff, there clearly remains a need for further development in this area, creatively delivered to a variety of healthcare staff.

The East Midlands Ambulance Service, in conjunction with regional health facilitators, has developed a comprehensive training package for ambulance staff at two levels. The Level 1 basic awareness element provides a booklet of accessible information for the station, individual staff and the vehicle. This has been provided to just under 3,000 staff. The Level 2 element delivers a 70 minute taught session covering a range of issues including diagnostic overshadowing.

In the North West an anticipatory care calendar is being introduced. Behavioural changes do occur in some people with learning disabilities when they are ill. The calendar has been developed to provide social care staff with a system for recording a person's normal behaviour and any changes in it. It also provides guidance on what actions they should take as a result of these recordings, using a traffic light system.<sup>16</sup>

3.35 People at the *'What do you think'* event particularly stressed the importance of people with learning disabilities and family carers being involved in delivering the training to help overcome the attitudes and assumptions that some people still have.

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16 For more information, see [www.mccn.nhs.uk/about/projects/acc.php](http://www.mccn.nhs.uk/about/projects/acc.php)

Advocacy organisation My Life, My Choice from Oxfordshire have carried out training with a range of health professionals, including:

- Oxfordshire's GP surgeries;
- Doctors and nurses from the Oxford Radcliffe Hospital;
- Oxfordshire's salaried Primary Care Dentists;
- Oxford Brookes' University students.

*"Brilliant and well planned; it makes a real and powerful difference to be trained by people with learning disabilities."*

– Oxfordshire GP

3.36 Apart from the training component of the Annual Health Check Directed Enhanced Service, there has not been a strategic approach taken to tackling the training needs of staff to enable them to effectively meet the healthcare needs of people with learning disabilities. Responsibility for ensuring staff are fully equipped to do this is spread across a variety of organisations, professional and public bodies and all areas have struggled to untangle these responsibilities to create a coherent, effective approach.

## Commissioning

3.37 Examples of including the needs of people with learning disabilities in commissioning relationships have been shared, but are by no means universal.

3.38 Commissioners need to have a clear expectation that providers will meet the additional needs of people with learning disabilities, and manage contracts accordingly.

- In London, some PCTs are using Service Improvement Targets in contracts with Mental Health Provider Trusts linked to CQUIN.<sup>17</sup> These aim to ensure equality of service for people who have learning disabilities and experience mental health problems.
- In Bristol, CQUIN is being used to improve services in an acute trust. A target of 70% of those admitted with learning disabilities, and a stay of longer than 48 hours, will have a learning disability assessment completed. The information will be audited and evaluated for future years.

<sup>17</sup> Commissioning for Quality and Innovation (CQUIN) – a payment framework which makes a proportion of providers' income conditional on quality and innovation



- In the North West, a Learning Disability Partnership Board has developed a robust three year commissioning strategy, clearly identifying commissioning intentions to reduce inequalities in health outcomes for people with learning disabilities.

3.39 Local Authorities are central to commissioning learning disability services. Examples of good partnership working across local authorities and PCTs in joint commissioning services for learning disabilities have been shared.

- Essex County Council have taken steps to ensure effective joint working with five local PCTs . This includes a joint Learning Disability Commissioning Group attended by senior commissioning managers from both health and social care services across the county. This reports to a joint meeting of Commissioning Directors from Social Care and all five PCTs. They have also put into place an Operational Commissioning Delivery Plan to ensure that they make the best possible use of existing capacity and resources.
- East Sussex has a joint commissioning strategy and implementation plan that has been approved by the Learning Disability Partnership Board, County Council's Cabinet and Primary Care Trusts in the county. This includes a set of priorities across health and social care to address the full range of needs and has been developed from a comprehensive joint strategic needs assessment and from full engagement of people who use services. The delivery of the plan is monitored through the Learning Disability Partnership Board and by the County Council's Cabinet and the Adult Social Care Scrutiny Committee.

## Issues arising – what is causing the most concern?

### Capacity and consent

- 3.40 Examples of failures by healthcare staff to comply with the Mental Capacity Act and its Code of Practice were among the most worrying evidence received. It was one of the key issues for those attending the '*What do you think?*' event, and also raised as a serious concern by providers.
- 3.41 Family carers reported regularly being asked to sign consent forms on behalf of their relatives and having to talk staff through their legal obligations. There were even reports of 'Do Not Resuscitate' orders being placed on patients' records without any conversation with the individuals concerned, or their families.



*"My son has a severe learning disability and challenging behaviour. I arrived at the hospital where he needed tests. I was asked 'how many people should I get? four or five?'. It took a moment to realise the doctor meant the number of people required to hold my son down and force treatment on him. There was no question of speaking to him or me about the best way to explain the treatment or keeping him as calm as possible. I had to explain best interest decision making to her, and to her manager, before even the most basic principles of the law were followed."*

– Family carer experience, from the 'What do you think?' event

- 3.42 DH continues to provide annual allocation for health and social care services to support the successful implementation of the Mental Capacity Act.<sup>18</sup>
- 3.43 Currently, a number of organisations are using some of that resource to audit their compliance with the Act's requirements.

Guys and St Thomas' NHS Foundation Trust have developed a comprehensive, Trust wide implementation plan for the Mental Capacity Act. This includes an audit tool to check compliance with the Act. The tool is designed to cover all adult patients who may lack capacity.<sup>19</sup>

North Yorkshire County Council ensures safeguarding and mental capacity are regularly discussed in local provider forums. This stresses the need for communication across organisations and the transparent recording of best interest decision making.

- 3.44 Failure to follow the law is very serious and all organisations should be checking their staff are meeting requirements under the Mental Capacity Act and its Code of Practice.

## Complaints

- 3.45 Those sharing their views at the '*What do you think?*' event stressed that complaints procedures remained difficult to understand and access, took too long and did not show what was going to change as a result of investigations.

<sup>18</sup> [www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/AllLocalAuthority/DH\\_117056](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/AllLocalAuthority/DH_117056); [www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH\\_117412](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_117412)

<sup>19</sup> For more information, visit [www.scie.org.uk/publications/mca/audits/list.asp](http://www.scie.org.uk/publications/mca/audits/list.asp)

*“Mencap's Death by Indifference report identified that for parents, carers and support networks, the complaints process was slow, bureaucratic and defensive. In her report the Ombudsman agreed. Unfortunately over the past year, the situation has not improved. Hospitals still fail to act in a timely fashion. Complaints still take a huge amount of time.”*

– Mencap's view

- 3.46 Transparency about complaints and the lessons learnt is vital to improving services and increasing patient confidence.

Rotherham Neighbourhoods and Adult Services has looked at the way in which it can improve the way complaints are dealt with by offering a personalised complaint service. It has developed an easy read complaint booklet in consultation with service users to improve access to the complaint procedure.

## Advocacy

- 3.47 Self advocates also stressed the need for advocacy support for people with learning disabilities to support good health outcomes. Independent advocacy can enable people with learning disabilities to fully exercise choice and control in health services.
- 3.48 Advocacy is also important for those who do not have the capacity to make certain decisions about their healthcare. The number of referrals to Independent Mental Capacity Advocates for serious medical treatment decisions has risen for people with learning disabilities (221 in year one to 387 in year two),<sup>20</sup> but such referrals are only made under very specific circumstances<sup>21</sup> and provision of independent advocacy for the majority of people with learning disabilities is very patchy across the country.

20 [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_110523](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110523)

21 [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_095891](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_095891)

## Chapter 4: Conclusion

### From the 'What do you think?' event; the five most important things to focus on now

- Training for mainstream staff – particularly making reasonable adjustments and improving communication
- Annual health checks – improving quality and number of people getting them
- Capacity and consent – making sure the law is followed
- Advocacy – support to people to make choices and speak up when they're not happy
- Complaints procedures – more accessible, quicker and with transparent outcomes

### Next steps

- 4.1 In the immediate future, the Department's priorities for healthcare for people with learning disabilities are to:
- **ensure early learning from the Learning Disabilities Public Health Observatory:** the Observatory is currently gathering data and making it available to support practical improvements in care and treatment. Basic data to inform commissioning decisions are already available on its website and further practical tools are being developed with commissioners. The Observatory is also carrying out a project on how the NHS makes reasonable adjustments. It will survey the kinds of adjustments made, how they are included in policy and practice, and how their implementation is monitored. Findings and resources will be available by the end of December 2010.
  - **ensure good progress in the Confidential Inquiry into premature and avoidable deaths of people with learning disabilities:** the Inquiry will improve the information available to frontline clinicians and commissioners to help prevent premature deaths and keep people healthier for longer.
  - **support improvement 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.

- **promote good practice:** the Learning Disabilities Public Health Observatory and Valuing People Now web pages will continue to host examples of good practice and tools to enable local areas to implement improvements for themselves.

## Maintaining progress

- 4.2 Where work has been successful in bringing about improvements, these approaches need to be maintained in health and social care services.
- The **Health Self Assessment** has helped bring about successful collaboration between local people with learning disabilities, their carers, health and care professionals, commissioners and healthcare providers. SHAs plan to continue with the process over the next year (see example in annex A).
  - **Learning Disability Partnership Boards** will continue to bring together local health and social care decision makers with users of services and their families to oversee improvements.
  - **SHA Learning Disability Leads** will help strengthen and sustain leadership and share expertise through the transitional period (up to April 2013) for the White Paper reforms discussed below. A strong focus on people with learning disabilities needs to underpin leadership across health and social care.
  - **Liaison and facilitation staff in acute and primary care** are demonstrating their worth in improving patient experience and building capacity in the mainstream health service to deliver improvements for people with learning disabilities. Maintaining their roles will enable them to continue their huge contribution to improvements in care and treatment.

## Future plans

- 4.3 The White Paper, *Equity and Excellence: Liberating the NHS*, sets out the Government's proposals for long-term transformation in healthcare services to put patients and the public first, focus on improvements in quality and healthcare outcomes, increase autonomy, accountability and democratic legitimacy, and cut bureaucracy and improve efficiency.
- 4.4 Following the White Paper, the implementation and approach to achieve these purposes has been subject to consultation, and the Government will respond to this consultation in due course. Moreover, many of the proposals require primary legislation, so are subject to Parliamentary approval.

- 4.5 As set out in the White Paper, the Government's vision is for an NHS that:
- is genuinely centred on patients and carers;
  - achieves quality and outcomes among the best in the world;
  - refuses to tolerate unsafe and substandard care;
  - eliminates discrimination and reduced inequalities in care;
  - puts clinicians in the driving seat and sets hospitals and providers free to innovate, with stronger incentives to adopt best practice;
  - is more transparent, with clearer accountability for quality and results;
  - gives citizens a greater say in how the NHS is run;
  - is less insular and fragmented, and works much better across boundaries, including with local authorities and between hospitals and practices;
  - is more efficient and dynamic, with a radically smaller national, regional and local bureaucracy;
  - is put on a more stable and sustainable footing, free from frequent and arbitrary political meddling.
- 4.6 In the White Paper we have said that the Department will have a progressively reducing role in overseeing education and training. The system will be designed to ensure that education and training commissioning is aligned locally and nationally with the commissioning of patient care.
- 4.7 Improving the experience of people with learning disabilities and reducing the inequalities they face will be a litmus test for the success of the reforms proposed in the White Paper. In developing and implementing those reforms, the Government is committed to ensuring that people with learning disabilities and their families and carers have greater control over their health and care, that there is greater accountability for the outcomes that the NHS achieves for people with learning disability, and that health and care professionals are encouraged and supported to work more effectively across boundaries to achieve these better outcomes.

- 4.8 The Department will consider carefully how to sustain effective leadership in this area throughout and beyond the transition to the new arrangements set out in the White Paper. This will include promoting strong roles for:
- emerging **GP commissioning consortia** in working effectively with local government, advocacy groups and Learning Disability Partnership Boards to promote equality for people with learning disabilities;
  - **local authorities** in identifying the health needs of people with learning disabilities through their key proposed role in the Joint Strategic Needs Assessment and in working with NHS commissioners to promote more integrated and personalised care and support for people with learning disabilities;
  - **local HealthWatch** organisations, which it is proposed will evolve from Local Involvement Networks to become the new consumer voice in health and social care and will be able to represent their local communities in reviewing the services available to people with learning disabilities and their inclusion in decisions about service development;
  - the proposed **national HealthWatch**, based in the Care Quality Commission (CQC), which will provide leadership and support to local HealthWatch organisations and be a source of intelligence for the NHS Commissioning Board, the CQC and Monitor – and enable the CQC to identify, and if necessary, act on, issues raised by local HealthWatch organisations.
- 4.9 The Government plans to publish its vision for public health later this year.
- The public health white paper will set out further details for the new public health service, which will bring together the key professionals involved in public health, from national to local level. It will have a mission to protect and help improve the nation's health and wellbeing.
  - Public health is all our business. The public health white paper will set out how the public health service will encourage and support people and communities to take greater responsibility for their own health. We will work in partnership with the rest of government, businesses, charities and communities to do this, and we will use and promote innovative and evidence-based approaches in everything that we do.

4.10 The Government plans to publish its vision for adult social care in Autumn 2010.

- The Vision will set the context for the future of social care, following the publication of the NHS White Paper and the outcome of the spending review in October, and provide context for the work of both the Commission on the Funding of Long Term Care and the Law Commission – expected in Spring and Summer 2011.
- We will bring together the conclusions of the Law Commission and the Commission on the Funding of Care and Support with the Vision for Adult Social Care into a White Paper in 2011.

*“We want to be treated with human and civil rights – as equals.”*

– From the ‘What do you think’ event

# Annex A – Extract from the Yorkshire and Humber Regional Health Self Assessment Framework

## Report on Year Three Health Assessment Framework

### Introduction

The Yorkshire and the Humber regional learning disabilities health programme was launched in November 2007, and since last year has been included in the region's 'Healthy Ambitions' programme of work. Yorkshire and the Humber was the national pilot site for the first learning disabilities health self assessment process, and the region has been widely commended for its work in this regard.

The annual self assessment process informs the agenda of the regional Health Programme Board, as well as shaping local strategic planning. The report below not only records the key findings from the recently completed Year three self assessment, but also offers comparative comment on progress achieved in these past three years.

### Three years on...how are we doing?

In the past three years people feel that the region's learning disability programme and its annual self assessment process, has been of great benefit in a number of ways. In terms of how people work it has:

- clearly articulated PCT and SHA commitment to improving the health and wellbeing of people with a learning disability;
- created the expectation of sustained progress in this work in all areas across the region;
- enhanced partnership work, involvement and communication across health organisations and with Partnership Boards and other groups;



- reaffirmed the vital central role in this work of Learning Disability Partnership Boards and their health sub groups, and
- generated a systematic collection of information and identification of priorities. Such information has offered a sound rationale for business cases for further resources, and numerous posts have been appointed to, to take vital work forward.

In terms of benefits to people, their families and those working in health organisations, it has:

- got more people involved in discussing their views about health services, as well as in decisions about strategic health plans;
- raised people's awareness, and brought more skills and resources into a good number of local areas and health organisations;
- helped to create more information about health services and issues in easy read format;
- led to a better experience for people when they visit the GP or go to hospital;
- made sure that patients and staff providing services all know a lot more about how laws like Mental Capacity Act protect people and also what they mean for how NHS staff work with people with learning disabilities.

It is important as we now approach a period of organisational change and increasing financial rigour, that we work hard to sustain and build on this work, and the good progress made.

## 2010 Self Assessment

### Progress made

People have worked hard again in the past year to make progress on the priorities they identified in 2009. Even more people have been involved in helping with the self assessment – and members of Health Sub Groups and Action Groups are to be especially congratulated for the work they are doing to drive progress in their local areas.

It is good to see that as a region we have almost finished our work to help people move out of campus places. Three years ago almost half of the areas in this region had people living in campus homes – and we now only have two people in one area, and they are due to move very soon. We decided to now pay particular attention this year and next to people who are still receiving treatment in NHS or private hospitals. This is so that we can make sure that they benefit from all the support and good practice that is developing for others in this region.

In the past year, impressive and commendable progress has been made across the region on many of the objectives in Top Target 2. The first self assessment in 2007-08 identified as regional priorities: the need to have much better information about people's health, and to improve people's access to mainstream health services. Since that time the hard work people have done means that both these important objectives have been met.

Last year it was concluded that despite positive work happening in some secondary care settings, there was still a marked need for some of the region's acute hospitals to further focus on the learning from Six Lives, and to improve the experience people and family carers have in hospital. This year has shown real progress made by many general hospitals and/or by their directorates, and a number of hospitals are to be commended for the leadership and commitment they are increasingly showing in this regard.

The past three years have also seen considerable work done to raise staff and patient awareness of the impact of key policies and legislation; to apply learning from Healthcare for All and Six Lives; to systematically report progress on this at NHS organizational board level; and to involve people with learning disabilities and carers much more in Safeguarding Boards and a range of training activity.

The past year has seen further progress across the region on many of the objectives in Top Target 4 – though, as last year, progress on individual objectives varies considerably between localities. Marked improvement is noted in improving planning for young people approaching transition. More self advocates and parents are getting involved with the work of health action groups and other mainstream health initiatives. People are gradually reviewing and in some cases re-modelling how their specialist services can work best in community settings, and many areas are using better information to develop their future planning for people who need more support to be healthy and to lead fulfilling lives.

### Work ahead in the coming year

A number of common themes have emerged which may inform regional development priorities in the coming year. These include:

- Identifying and meeting the needs of people from black and minority ethnic communities;
- Building on work this year and continuing to develop the central role and responsibility of the GP and primary care teams with regard to annual health checks and follow up;

- Building on work this year, and continuing to make sure that transition planning for all young people is of a consistently high quality – ensuring timely multiagency planning and provision of services for those who need more specialised support to be healthy and achieve their potential;
- Further work with hospitals to ensure a consistent quality of service in all the region's hospitals;
- Having a clear vision in every area of the range of specialist services needed;
- Getting even more people involved in talking and deciding about health planning and commissioning locally.

## Yorkshire & Humber SHA

### Learning Disabilities Self Assessment 2010

Primary Care Trust														
	Barnsley	Bradford	Calderdale	Doncaster	East Riding	Hull	Kirklees	Leeds	NE Lincs	North Lincs	North Yorkshire & York	Rotherham	Sheffield	Wakefield
<b>TARGET 1</b> Plans are in place and resources identified to meet White Paper/DH learning disability targets for resettlement and campus closure														
1.1 Resettlement of identified people from long stay hospitals, is complete														
1.2 All NHS Campuses will be closed by 2010														
1.3 (formerly 4.1) Discharge planning is in place														
<b>TARGET 2</b> PCTs are working closely with local Partnership Boards and statutory and other partners, to address the health inequalities faced by people with learning disabilities														
2.1 Comprehensive recording in GP Registers														

Primary Care Trust														
	Barnsley	Bradford	Calderdale	Doncaster	East Riding	Hull	Kirklees	Leeds	NE Lincs	North Lincs	North Yorkshire & York	Rotherham	Sheffield	Wakefield
2.2 Primary Care Teams tackling health inequalities	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
2.3 Equal access to disease prevention, screening, and health promoting activities	Green	Green	Green	Green	Red	Green	Green	Green	Green	Green	Green	Green	Green	Green
2.4 Services in wider primary care community	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
2.5 Service Agreements secure a range of treatment choices and equity of access	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
2.6 National Service Frameworks and linked networks and projects apply equally to people with disabilities	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
2.7 Equal access to benefits from the development of computer technology	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Red	Green	Green	Green
2.8 Good local planning for people from ethnic minority groups, and their carers	Green	Red	Green	Red	Green	Green	Green	Red	Red	Green	Green	Green	Green	Green
2.9 Good local planning for people with profound disabilities and their carers	Green	Green	Green	Green	Green	Green	Green	Red	Green	Green	Green	Green	Green	Green
<b>TARGET 3</b>														
<b>People with learning disabilities who are in services that the NHS commissions or providers, are safe</b>														
3.1 NHS bodies taking action in light of Healthcare for All, HCC Audit etc	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green

Primary Care Trust														
	Barnsley	Bradford	Calderdale	Doncaster	East Riding	Hull	Kirklees	Leeds	NE Lincs	North Lincs	North Yorkshire & York	Rotherham	Sheffield	Wakefield
3.2 NHS bodies have robust key policies e.g. Consent, DED	Orange	Orange	Green	Orange	Green	Green	Green	Orange	Green	Orange	Orange	Green	Orange	Green
3.3 Review of complaints and adverse incidents leads to improved practice in services	Orange	Orange	Orange	Orange	Green	Green	Green	Orange	Green	Orange	Green	Green	Green	Orange
3.4 Coherent local partnership in ensuring protection of vulnerable adults from abuse	Green	Orange	Orange	Green	Green	Green	Green	Green	Green	Orange	Orange	Green	Green	Green
<b>TARGET 4</b>														
<b>Progress is being made in implementing the service reforms and developments described in 'Valuing People'</b>														
4.1 Discharge planning for all adults and young people (See 1.3)														
4.2 Good range of local specialist services	Orange	Green	Orange	Orange	Green	Green	Orange	Orange	Green	Orange	Orange	Green	Orange	Green
4.3 Plans for local specialist services for young people in transition	Orange	Orange	Orange	Red	Orange	Orange	Orange	Orange	Green	Orange	Orange	Green	Green	Orange
4.4 People and families well involved in planning and delivery of health services	Green	Orange	Green	Green	Orange	Green	Orange	Orange	Orange	Orange	Orange	Green	Green	Orange
4.5 Good partnership working across local organisations	Orange	Green	Green	Green	Orange	Green	Orange	Orange	Orange	Orange	Orange	Green	Green	Orange
4.6 Good plans made, for people with learning disabilities who are ageing	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Green	Orange	Red	Orange	Green	Orange
4.7 Local partners planning together on autism	Red	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Red	Orange	Green	Orange

Primary Care Trust														
	Barnsley	Bradford	Calderdale	Doncaster	East Riding	Hull	Kirklees	Leeds	NE Lincs	North Lincs	North Yorkshire & York	Rotherham	Sheffield	Wakefield
4.8 Services available to those who challenge services	Orange	Orange	Orange	Orange	Green	Green	Green	Orange	Green	Orange	Orange	Green	Green	Green
4.9 Mental health policy and best practice equally applied to people with learning disabilities	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Green	Orange
4.10 Robust local workforce planning	Green	Orange	Orange	Orange	Orange	Orange	Green	Orange	Orange	Orange	Red	Orange	Green	Orange
4.11 Health of people with learning disabilities in prison	Red	Orange	Red	Red	Orange	Orange	Orange	Orange	Red	Orange	Orange	Orange	Red	Orange

# Annex B



## Update on Healthcare for people with disabilities

### September 2010

CHRE completed our advice and recommendations on *Healthcare for people with disabilities* in November 2009.<sup>22</sup>

All of the regulators have reviewed their arrangements and the table below provides responses in respect of the *Healthcare for people with disabilities* project. Their activities cover:

- Education and training;
- Standards and guidance;
- Plans for revalidation;
- Engagement with people with disabilities and representative organisations.

We will continue to track the regulators' response to the recommendations we made in our report.

Regulator	
<b>General Chiropractic Council</b>	<p>All providers of chiropractic degree programmes are required to involve patients (including those with learning disabilities) and carers in the delivery of the programme. In consultation with the education providers and the Higher Education Equality Impact Unit the General Chiropractic Council has produced detailed guidance for disabled people who wish to train as chiropractors.</p> <p>The current Code of Practice requires chiropractors to promote equality consistent with human rights and anti-discrimination legislation. This includes a duty to tackle discrimination when it occurs in relation to age, disability, political beliefs, race and ethnicity, religion, sex and sexuality.</p>

<sup>22</sup> CHRE. 2009. *Healthcare for people with disabilities*. London: CHRE.  
Available at: [www.chre.org.uk/satellite/164/](http://www.chre.org.uk/satellite/164/)

Regulator	
<b>General Dental Council</b>	<p>Learning outcomes revision has focussed on treating patients with disabilities. We ensure that on registration all new registrants have been trained in the treatment of people with disabilities. Curriculum documents and learning outcomes emphasise this requirement. Recommendations in CHRE's report were taken into consideration when drafting the new learning outcomes for dentists and dental care professionals (DCPs). The outcomes relating to communication and professionalism now include a full awareness of disability and treatment of all patients with equal respect.</p> <p>We do not specifically require ongoing education and training programmes to include the skills and competencies necessary for meeting the healthcare needs of people with disabilities. This would largely be covered by continuing professional development (CPD) which is not quality assured by the GDC. CPD can comprise a range of activities that 'can reasonably be expected to advance a person's professional development' as a dentist or DCP. There are no compulsory subjects that must be covered in the current CPD scheme.</p> <p>We are in contact with disability groups to find out their needs and to develop ways of improving our work to ensure that patients with disabilities receive the best possible treatment. Patient feedback will be an integral part of the revalidation scheme. We intend to establish a baseline of information as part of revalidation to identify key risks to patients.</p> <p>Our current standards already make clear that registrants should not discriminate against patients, but we are planning a comprehensive review of our standards in 2011 and the recommendations made by CHRE will be fed into that review.</p>



Regulator	
<b>General Medical Council</b>	<p>Work is being taken forward within our standards team on a leading disabilities project designed to help doctors to help patients with learning disabilities. We are currently developing materials for an online learning resource, using Forum Theatre.</p> <p>We are also conducting a major review of our Equality Scheme this year, and will ensure that our revised scheme takes into account the recommendation that 'regulators disability equality schemes and action plans in the future should consider the regulators' indirect impact on the healthcare received by people with disabilities, and where possible this impact should be monitored and evaluated.'</p> <p>Since April 2010, we became responsible for the continuum of medical education and training, which covers undergraduate medical education, the Foundation Programme and specialty including GP training.</p> <ul style="list-style-type: none"> <li>• We are supporting medical schools as they prepare to implement the 2009 edition of 'Tomorrow's Doctors', the new curricular requirements which stress the importance of competences that cover the delivery of good medical practice to all patients, including those with learning disabilities and of involving carers where appropriate.</li> <li>• We have also been revising our guidance to medical schools 'Gateways to the Professions. Advising medical schools: encouraging disabled students'. The new edition reflects 'Tomorrow's Doctors' 2009 and the Equality Act 2010. It includes information from medical schools about reasonable adjustments provided to support disabled students. It will be published once the relevant provisions of the Equality Act come into force.</li> </ul>

Regulator	
<p><b>General Medical Council</b> continued</p>	<ul style="list-style-type: none"> <li>• We have approved the 2010 edition of the Foundation Programme Curriculum. In accordance with our guidance 'The New Doctor', the competences in the curriculum require that every Foundation Programme doctor 'in all interactions with both patients and colleagues takes account of factors pertaining to the patient's age, colour, culture, disability...' (paragraph 1.1). Also, the doctor 'takes accomplished, concise, targeted history and communicates in complex situations, which include...social and personal (e.g. English is not the patient's first language, impaired hearing/vision, learning difficulties)...' (paragraph 2.1).</li> <li>• We are now responsible for approving specialty including GP curricula (see our website for information such as: Curriculum Statement 14 from the Royal College of General Practitioners which covers 'Care of people with learning disabilities' as well as the curriculum from the Royal College of Psychiatrists relating to 'Psychiatry of learning disability').</li> </ul> <p>As part of the engagement activity for our revalidation consultation, we ran workshops with patient groups to get their feedback on our plans and proposals, which included patients with sensory impairment and learning disabilities.</p>
<p><b>General Optical Council</b></p>	<p>The Disability report went to Education and Registration Committees to ensure the recommendations are picked up in future work in respect of disabilities. The GOC competencies already include skills in respect of dealing with registrants with disabilities including those with learning disabilities. This is covered in the communication module for both optometrists and dispensing opticians.</p>

Regulator	
<p><b>General Osteopathic Council</b></p>	<p>CHRE's report on disability and health requirements will shape reforms to the standards of osteopathic care. The recommendations are receiving detailed consideration by committees of Council, including the Education Committee.</p> <p>Council will shortly conduct a review of the pre-registration curriculum content for osteopathic training, and in this we will take account of the CHRE recommendations.</p> <p>A review of quality assurance procedures for osteopathic education commences in Autumn 2010 and this also will embrace these recommendations.</p> <p>A major review of osteopathic standards and codes of conduct and competence currently underway aims to take account of the views of the public, patients and practitioners, including those with disabilities. The consultation exercise will specifically target disability representative groups. In common with all our public engagement activities and information provision, this consultation is designed to be as accessible as possible.</p> <p>Patient feedback is likely to be integral to our proposed revalidation scheme for osteopaths and we have sought input from disabled patients to identify the particular needs of these patients in the osteopathic clinical setting.</p>
<p><b>Health Professions Council</b></p>	<p>We will take forward the recommendations regarding considering changes to our standards and input from patients/clients as part of the next periodic review of the standards of conduct, performance and ethics – planned to commence in 2013/2014 according to our timetable for periodic review.</p> <p>We are not currently subject to the specific duties to publish an equality scheme, but do so anyway in excess of the requirement. We are due to update our scheme and republish at the beginning of next year and as part of this will consider the recommendation about reflecting indirect impact on disability equality for patients/service users.</p>

Regulator	
<b>Nursing and Midwifery Council</b>	<p>We are working with Mencap on their Learning Disability Week campaign for June 2010, which is focussing on health. We are contributing to their guidance for health professionals and will have information related to the week on our website.</p> <p>We continue to provide a specialist qualification specific to the care of people with learning disabilities. Our pre-registration nursing curriculum incorporates this topic and all programmes will consider issues of equality in healthcare generally and specifically in relation to people with disabilities.</p> <p>We continue to support Mencap's campaign "Getting it Right".</p>
<b>Pharmaceutical Society of Northern Ireland</b>	<p>We support the CHRE's recommendations that the PSNI's legislation should be brought into line with the reforms of other regulatory bodies and will continue to impress this need upon the DHSSPS and Northern Ireland Assembly e.g. clearly stating our role in protecting the public and ensuring registrants adhere to standards necessary for safe and effective practice.</p> <p>We will continue to work with the Royal Pharmaceutical Society of Great Britain / the General Pharmaceutical Council in relation to ensuring pharmacy education programmes provide students with the skills and competencies necessary for meeting the healthcare needs of people with disabilities.</p> <p>It is intended that the risk of poor care from a patient perspective form an appropriate part of our revalidation plans.</p> <p>Organisations representing the interests of disabled people form an important and active part of our Public Forum and we will strive to continue this, attracting the interest and engagement of additional such organisations where possible.</p>
<b>Royal Pharmaceutical Society of Great Britain</b>	<p>We reviewed all our guidance to registrants, along with the education and training requirements.</p>

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