

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.