



Department
of Health

Government response to the Confidential Inquiry into premature deaths of people with learning disabilities

Easy read

July 2013

Easy read summary

What this report is about



In 2008, a report called *Healthcare for All* looked at how people with learning disabilities get healthcare services.

The report said that people with learning disabilities could die earlier than they should.

The report also suggested a Confidential Inquiry should look at this and give advice to doctors, nurses and other professionals about how to stop this happening.

We set up and gave money to a Confidential Inquiry to do this work.

The Confidential Inquiry produced a report in March 2013.

The report shows that people with learning disabilities have a poor experience of healthcare services. They also die very early compared to other people.





We want to make things better for people with learning disabilities.

We want them to have good care, be healthier, and live longer than they do at the moment.

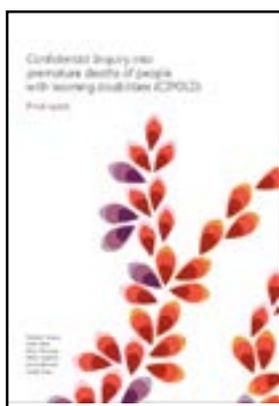
We also want to support their families and other people who care for them.

We have written this report to say how we will work with others to do this.



There have been some big changes in how the National Health Service (NHS) and Social Care decide what care is available to people.

There are lots of new organisations. They are all responsible for making sure that what we say here happens.



The Confidential Inquiry suggested how we could improve things in 18 areas.

We have said what we will do in each of these areas.

In some of these areas we can do things quickly. In others, we need to do more work to see what we can do.



There is another important document, which will tell us how well the NHS is doing to make things better for people with learning disabilities.

It is called the Mandate. We will use this to ask NHS England what they have done for people with learning disabilities.

These are the 18 things the Confidential Inquiry suggest



1. We need to make sure that all NHS organisations know about everyone who has learning disabilities and what reasonable adjustments they need.

We think this is a good idea. At the moment things are not very good. We need to make this better.

We have a strategy called *The power of information*. It says what we will do to improve information in the NHS and Social Care.

We will work with our partners and use the strategy to make sure that we know more about people with learning disabilities, and what their needs are.



2. We need to make sure that people who provide services make reasonable adjustments where people with learning disabilities need them.

Every year we need to look at all the reasonable adjustments that have been made and let everyone know about good examples so that more people can do those things.



The people who say which services should be available (commissioners) use a contract to make sure that people who deliver those services (providers) do what they are supposed to.

A contract says what a provider should do.

The NHS standard contract already asks providers to make reasonable adjustments for people who find it difficult to communicate.

We will see if we can use the contract to make sure that providers look at all the reasonable adjustments made over a year.



3. NICE guidelines should include information on how to manage people's care when they have more than one condition or illness

We think this is a good idea.

The National Institute for Health and Care Excellence (NICE) produces information on good quality care.

NICE already makes sure that it thinks about the needs of people with learning disabilities.

NICE will make sure that people with learning disabilities and family carers are able to help it get things right.

4. There should be one named person who can help people who have many or difficult health needs

We agree that this is important.

NHS England will make sure that people who have needs that are difficult to manage get the right support.

This will include one person who can:

- make sure they get all the care they need.
- talk to other health and care professionals.
- work with people to plan their care for the future.





5. People with learning disabilities who have more than one condition should have their own health record which they keep.

We agree that this is important.

People with learning disabilities are the most important people. They should have control over their records.



NHS England will have a person later this year whose job will be to look at how this can happen for people with learning disabilities.



6. Annual Learning Disability Health Checks should be the same across the country

The learning disability health check scheme is designed to ensure that health workers look at people's physical and mental health needs.

It also asks professionals to make sure that the health check links to a person's health record or action plan.



7. People with learning disabilities should get the same tests and treatments as anyone else especially for cancer

We agree this is important. We know that many people with learning disabilities do not access the right care at the right time.



We will use the Mandate to make sure that NHS England is doing better for people with learning disabilities.

NHS England will work with the organisations who decide what services are available and check they are doing the things they need to.

There is easy read information about how people with learning disabilities can get checks for breast, cervical and bowel cancer.



8. We should remove things which stop people getting access to specialist learning disability services

General practitioners (GPs) need to have a register of people with learning disabilities, who are over 18 years old. This will help doctors provide better services for these people.

Doctors also have information about when people with learning disabilities might need to see a specialist service. They need to work with social services and others to make this happen.

When NHS England looks at what GPs need to do, it will see if they can do more for people with learning disabilities



NHS England will also make sure that people who say what services should be available know about and help to deliver the suggestions in this report.



9. Adults with learning disabilities to be considered a high risk group for deaths from respiratory problems

We have asked a group of people who produce information on what medicines people should get to protect them from flu, pneumonia and other respiratory problems to look at this report.

They will give advice on this for people with learning disabilities to health professionals by the end of July.

NHS England will also look at what it can do to help people with learning disabilities with these problems.

10. Advice on the Mental Capacity Act should be easily available 24 hours a day

We agree that this is important. Everyone who works with people should know about the Mental Capacity Act and what they are expected to do.

The British Medical Association has produced a quick guide to help doctors and other health professionals.

There is also a Mental Capacity Lead in most hospitals and councils who can give advice.





11. We should be clear about what we mean by 'serious medical treatment' and give clear examples

We agree this is important. It is not always easy to do this. Getting it right could help doctors make sure that people get the right care.

It will help to make sure that people who cannot make decisions about their care, have the right support to make those decisions, or someone can make the decision for them.



We have asked NHS England and a group of professionals with an interest in learning disabilities to think about how this could be improved.



12. All health and social care staff should have training and regular updates on the Mental Capacity Act. This should be monitored.

Organisations that provide services are responsible for making sure their staff are trained in the Mental Capacity Act.



For people studying to be healthcare professionals, colleges, universities and professional organisations are responsible for making sure they get the right education and training.

A new organisation called Health Education England is now responsible for the healthcare workforce, education and training policy. We are working with them and other partners to make sure that professionals have the right skills to be able to work with people with learning disabilities.



We have asked another organisation called the Social Care Institute for Excellence to produce information on some parts of the Mental Capacity Act.



13. There should be clear guidance about whether or not someone who is very ill should be resuscitated. This should be the same across England

We know that it can be very difficult to make decisions about resuscitating someone who is very ill.



The British Medical Association, Royal College of Nursing and Resuscitation Council (UK) have produced guidance for professionals on this. They are reviewing the guidance to take account of this report and other things.

There is a court case looking at this issue at the moment. We cannot do anything until the court gives its decision. Once that happens, we plan to work with the professional organisations to see how we can improve things.



We have issued guidance to hospitals asking them to make sure that:

- they have policies in place about this.
- their staff understand the policies.
- people can access the policies.
- they monitor the policies regularly.



14. Advanced health and care planning should be prioritised. The complex needs of people with learning disabilities in managing their long-term conditions should be taken into account

We agree that this is important.

NHS England wants to make sure that people with long-term conditions, including those with learning disabilities can be involved in the care planning process. They should have a say in what services would benefit them.



NHS England is working with National Voices and Year of Care Partnerships to carry out care planning training and support. It will give more information about this later this year.

15. Decisions that a person with learning disabilities is to receive palliative care only should be supported by the Mental Capacity Act and the person referred to a specialist palliative care team

We agree with this. Decisions about people with learning disabilities only getting palliative care, need to be supported by the Mental Capacity Act.



We do not think everyone with a learning disability will need access to a specialist palliative care team. If they have a proper assessment of their needs and a care plan, other professionals like a GP might be able to look after them.



16. There should be a better way of collecting information on why people with learning disabilities die. There should be targets for reducing early deaths of people with learning disabilities with regular reporting of progress

We are looking at how to measure early deaths in people with learning disabilities in the NHS Outcomes Framework.



We also know there is lots of information the NHS collects on people with learning disabilities, their healthcare and deaths. We want to see if we can use this better to tell us what is happening.

We will have more information on this by the end of the year.



17. We should use information on deaths of people with learning disabilities to understand better what needs to happen locally

There are new organisations in local areas called Health and Wellbeing Boards. They are a partnership of the NHS, councils, public health and local communities.



Health and Wellbeing Boards try to understand the needs of local communities.

They produce a Joint Strategic Needs Assessment (JSNA).

They also try and address issues they find. They set their plans out in a Joint Health and Wellbeing Strategy (JHWS).

The aims of the JSNA and JHWS are to improve things for local people.

Organisations that decide what services are available locally need to include information from JSNAs and JHWSs in their decisions.



18. There should be one national organisation to look at deaths of people with learning disabilities

We need better information about why people with learning disabilities die, so that we can do something about it.

But, we need to do some more work before we decide if one national organisation is the right way of doing this.

The Confidential Inquiry has already told us some important things. We need to make sure we and everyone else address those things.

We need to make sure that everyone is doing this.



This tells you in brief what we will do

We will work with our partners to make sure that people with learning disabilities get better health and social care.

We want organisations to take this seriously.



We want people with learning disabilities to have the same health benefits as other people. We have said in this report that we will do lots of things to try and do this.

At the moment many people with learning disabilities are dying far too early when they should not be. We want members of staff to engage with people with learning disabilities and their families.



We want people with learning disabilities to be in control of their care and support.

We will measure if things are getting better. One way will be through the NHS Outcomes Framework.



You can find a copy of the report here:

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

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