



Department  
of Health



# People with learning disabilities dying too young.

## A report about what is changing.



**Easy Read version of:**  
Premature deaths of people with learning disabilities: Progress update

# What is in this paper



What this paper is about

1.



What needs to change

3.



What we found out

5.



1. Find out who has a learning disability and what support they need

7.



2. Make sure services work together

13.



3. Stick to the law and rules **20.**



4. Plan ahead **23.**



5. Give good care to people who are dying **25.**



6. Keep checking why people die **27.**



What happens next **29.**

# What this paper is about



In 2007 Mencap wrote a report called **Death by indifference**. It was about 6 people with learning disabilities who should not have died.



A group of experts looked at why people with learning disabilities sometimes die younger than other people.

This was called a **Confidential Inquiry**.



Last year the government wrote 2 reports:

- one report was called **Six lives** and said what was happening to make healthcare better for people with learning disabilities
- the other report was a reply to the **Confidential Inquiry**.







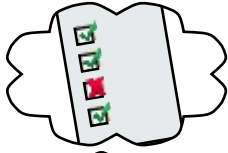
This paper is about what has happened since then.



In April 2013 there were lots of changes to the way health care is run.



Organisations like NHS England, public health and social care must check that the ideas from the Inquiry happen all over the country.



# What needs to change



The **Inquiry** said too many people with learning disabilities live shorter lives than other people because:



- it can take too long to find out what is wrong with them



- they might not get treated quickly enough



- they might not get the healthcare they need.



Local and national health and care services must show how they will have better **outcomes** for people with learning disabilities.



This means thinking about how the things they do will help people with learning disabilities live longer, healthier lives.

# What we found out



- things are better in some parts of the country or for some groups, but not for everyone

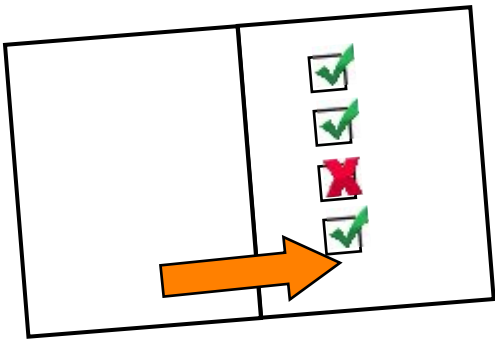


- services must work together to make sure everyone with a learning disability has the same chance to be healthy



- services need to find the right healthcare for different people and groups.





The rest of this paper looks at each of the things that need to change and says:



- what has happened so far



- what some services are doing well.



# 1. Find out who has a learning disability and what support they need



People with learning disabilities often die from illnesses that could be treated.



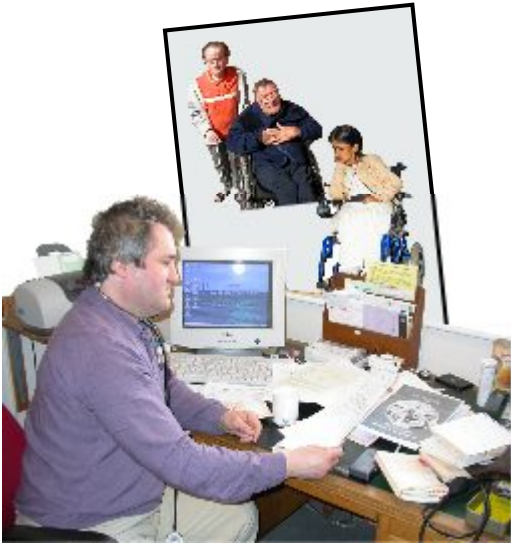
A law called the Equality Act says services must make **reasonable adjustments**.

This means changing things that stop people using a service or make it difficult for them.



Services need to know if someone has a learning disability and what changes they need.

## What is happening now



- from this year GPs should **register** or list all their patients with a learning disability. This includes children and young people



- services are better at finding out how many people have learning disabilities and sharing this information



- people who run services for the NHS must show how they change things so people with learning disabilities can use them



- Public Health England has a list of ideas for changes that help people with learning disabilities get the same health care as other people



- Monitor checks healthcare services. They will ask whether patients with learning disabilities get the right care and support



- we will check community health services give people with a learning disability the right care



- Public Health England's website shows where there are **acute liaison nurses** and how to contact them. Acute liaison nurses understand how to work with patients with a learning disability



- local areas have to do a **self-assessment** to check the care they give. This includes changes so people with learning disabilities have the same chance as other people to get good healthcare





- NICE is an organisation that helps make health and social care better. They are writing new advice about healthcare and support when people with learning disabilities:



- have challenging behaviour



- have mental health problems



- get older



- we are finding out how many people with learning disabilities die from more than one illness

**NICE** National Institute for Health and Care Excellence



- NICE will involve people with learning disabilities when they write advice and information.

## Doing things well

### In Plymouth



A computer tells staff and community health services when someone with learning disabilities goes into hospital or is an out-patient.



This means they get the support they need from staff who understand them.



They will check if patients do not turn up for appointments so they can make sure everything is ok.



## In Sheffield

The local council has a list of people with a learning disability that is linked to GPs and hospitals.



This helps them see if people with a learning disability are getting the same health checks and care as other people.



They are looking at better ways to plan with people and stop them needing lots of emergency care.



## 2. Make sure services work together



Good healthcare should look at the different health problems a person has. Not just one thing at a time.



Too many people with learning disabilities die from things that could be treated.



They need the same health checks as other people so they can be treated quickly if they are ill.



## What is happening now



- local councils and the NHS are working together to plan good, safe care for people who are at risk of poor health



- NHS England says one person should **co-ordinate** or bring together different healthcare so people know who to talk to. This must happen for patients in hospital



- The Proactive Care Programme will help many people with very difficult health needs. Their GP will work with them to decide the best care and support to keep them safe and healthy



- many people already have health records that they keep themselves. These are sometimes called Health Passports



- when the NHS pays other services for healthcare the contracts (agreements) must talk about better health for people with learning disabilities



- from September there will be better planning for young people with learning disabilities up to 25 years old



- more people will be able to choose a **personal health budget** which is money to plan and pay for your own healthcare



- there will be better information about healthcare. Children and young people with learning disabilities will be able to say what they think about care



- the CQC check services. They will look at how services plan for young people with learning disabilities when they move to adult services



- yearly health checks will start when people with learning disabilities are 14 years old. These will link to a Health Action Plan



- we are looking at how many people with learning disabilities go for health checks and how to help them do this



- Public Health England has easy read information about things like cancer. They help services understand how to support people with learning disabilities to get checks





- NHS England will make sure Community Learning Disability teams support people to use the same health services as other people but have special services when they need them



- GPs are giving patients with lots of health needs more support to stop them going into hospital when they do not need to



- we are looking at the support people need to get good care from a dentist



- GPs will try to get more people with learning disabilities and their carers to have the flu jab to stop them getting chest infections.



## Doing things well



### In Humberside

Staff and his family use an i-Pad computer to support a man with learning disabilities and lots of health needs.



It uses photos, video and websites to explain who is involved in his care and how to support him properly.



### In Newcastle

Health Quality Checkers work with the CQC to see how well health services support other people with learning disabilities.



They are setting up a national Health Checkers service.



## In Derbyshire

GPs are looking at how to get more people with learning disabilities to have tests for cancer.



They have easy read information about tests and think about changes people might need.



## In South Devon

They are making health information easier to understand and have a drop in session in libraries for people who need help to communicate.



### 3. Stick to the law and rules



The **Mental Capacity Act (MCA)** is a law about what happens if someone cannot make a decision for themselves.



Workers must have good training so they understand this law and how to use it.



All health and care services should be able to talk to someone who understands how to use the law properly.

#### What is happening now

- the Department of Health is making sure health and care organisations know how to use this law



Department of Health



- GPs and other NHS staff will be trained about this law and how to use it



- there will be good, clear information on the internet for everyone to use



- the NHS will expect services it pays for to understand and use the Mental Capacity Act



- GPs will have extra training about mental health, learning disabilities and autism



- staff will be trained to **restrain** (hold) people safely and stop them hurting other people





- we are working with Health Education England on better training so staff understand the law about restraint and keeping patients away from other people



- sometimes people say they do not want to be **resuscitated** (brought back to life) if their heart stops. The Department of Health is looking at what the law says about this. We need to decide whether there should be national rules about this or local Health Trusts decide for themselves



- we will have a card to remind everyone about rights and people who cannot decide for themselves



- we are checking the information that tells people how to use the MCA.



## 4. Plan ahead



The inquiry said services should be better at thinking about problems that might happen.



This includes planning for when people need different care.



### What is happening now

- looking at ways to involve patients who are ill for a long time in planning the care they need
- helping services understand how to involve patients in writing their care plans and thinking about what they want to happen in the future.



## Doing things well

### In Peterborough

Nurses said it was difficult to explain things like taking blood pressure to people with learning disabilities.



They held a Big Health Day where people could learn about good health and health checks.



They also had the chance to try different sports and exercise.



## 5. Give good care to people who are dying



People with a learning disability who are dying often do not get the same support as other people.



This includes keeping you comfortable and trying to stop the pain.



### What has happened so far

- the government says patients with learning disabilities must have good care when they are dying



Other people must use the Mental Capacity Act if the person cannot make their own decisions about treatment and care





- staff will have better training about this law and how to use it



- there will be examples of how to change things to give people with learning disabilities good care when they are dying.



## Doing things well

Deciding Right helps doctors make decisions with patients who are dying and their carers.



It thinks about the law and making decisions with people with learning disabilities.



## 6. Keep checking why people die



The Inquiry said services should keep better information when people with a learning disability die.



### What is happening now



- NHS and social care services are looking at ways to collect and share this information
- we will also look at what happened when people nearly died. This will help us stop this happening so often
- there will be a project to look at why people with a learning disability die earlier than other people





- when they do their self-assessment, local areas say if they know how many people with a learning disability die each year



- NHS England is thinking about which groups could check what is happening in their area.

## What happens next



The **Learning Disability Programme Board (LDPB)** makes sure people with learning disabilities and their families have better health and better lives.



We will work with them to keep checking how things are going.



We will write reports about what is happening. These reports and all our papers for the Board will be on our website.







## Credits

This paper has been designed and produced for the Department of Health by the EasyRead service at Inspired Services Publishing Ltd. Ref ISL041/14. July 2014.



[www.inspiredservices.org.uk](http://www.inspiredservices.org.uk)

It meets the European EasyRead Standard.



Artwork is from the Inspired Photo collection and cannot be used anywhere else without written permission from Inspired Services Publishing Ltd.

[www.inspiredphotos.org.uk](http://www.inspiredphotos.org.uk)

