

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

Easy read report



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Chapter 1: What is this report about?



Mencap wrote a report called 'Death by indifference' in 2007. The report was about 6 people with learning disabilities who should not have died.



The **Health Service and Local Government Ombudsman** looked into the complaints of all 6 families.



An **Independent Inquiry** also looked at what we can learn from what happened to these 6 people.



That Inquiry had some ideas about what to do to make sure people with learning disabilities get better healthcare.



One idea was to set up a **Confidential Inquiry** to look at why people with learning disabilities sometimes live shorter lives than other people.



This report is about what this Confidential Inquiry has found.

Chapter 2: How did we do this?



We were told about the death of a person with learning disabilities.



We were usually told by phone or email.



We sent out forms to the professionals who worked with the person who had died.



An investigator found out as much as possible about the care that the person was given.



A nurse visited and talked to the family or friends of the person if possible. The nurse asked about the life of the person who had died.



For each person who died we held a meeting to talk about everything we had found out.

A report was written about what we had found out about the health and social care that person got.



We had a team of experts who met about every 2 weeks. They looked at the report of each person's death.

They checked to see if they agreed with what was written in the report.



The experts thought about all the deaths they had checked.

Then they decided what we can do to stop people with learning disabilities dying earlier than they should.

They also thought about what helps people with learning disabilities to live longer, healthier lives.



We compared deaths of people with learning disabilities with the deaths of people who did not have learning disabilities.



This has helped us to learn more about how to make services better for people with learning disabilities.



We worked in 5 health areas in the South West of England.

We looked at the deaths of people with learning disabilities over the age of 4 who lived in these areas.



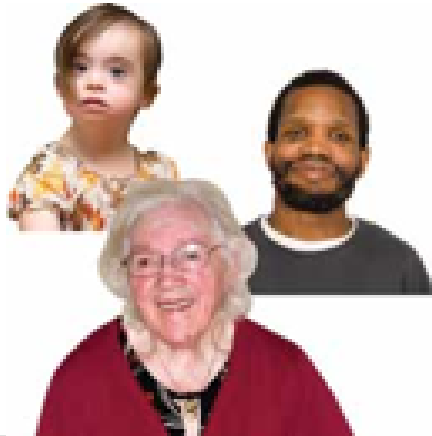
In 2 years we looked at the deaths of 247 people with learning disabilities. This was everybody that we were told had died in the 5 areas.

We also looked at the deaths of 58 people who did not have learning disabilities.

Chapter 3: What do we know about the people who died?



Here are some facts about the people with learning disabilities whose deaths we looked at.



The youngest person was 4 years old.

The oldest person was 96 years old.



We looked at the deaths of 142 men with learning disabilities.

We found that on average these men died 13 years sooner than men in the general population.



We looked at the deaths of 105 women with learning disabilities.

We found that on average these women died 20 years sooner than women in the general population.



Most of the people whose deaths we looked at were white British.



We think there should be more work done to look at why people with learning disabilities from **Black and minority ethnic groups** may die earlier than they should.



Most of the people had a doctor who knew they had learning disabilities.



Most people with learning disabilities lived in a residential care home.



Some people with learning disabilities did not live in a home that met their needs.



Most people with learning disabilities had some support every day.



People needed support with lots of different things. This included housework and personal care.

Chapter 4: What do we know about the deaths of people with learning disabilities?



The most common **underlying cause of death** for people with learning disabilities was problems with their heart.



The most common **immediate cause of death** was a chest infection.



The most common place for people with learning disabilities to die was in hospital.



A lot of the deaths we reviewed were unexpected. This means that the day before the person died, no-one thought they were about to die.



Our team of experts thought about every person who had died and if they had died earlier than they should have done. We called this a **premature death**. We thought that some of the deaths were premature.

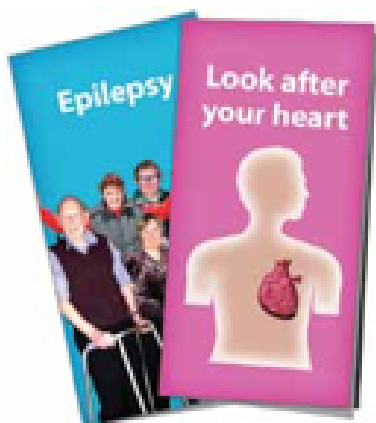


The main reason for someone dying earlier than they should was a delay or problem with their treatment.

Chapter 5: What are the health needs of people with learning disabilities?



We found that more people with learning disabilities were underweight than in the general population.



Lots of the people with learning disabilities had more than one medical problem.



Some of these were **long-term conditions**. The most common was epilepsy.



Some of these were **treatable conditions**. The most common was chest problems.



Most of the people with learning disabilities had been to the doctor for an **annual health check**.



We found that some people with learning disabilities found it difficult to take part in the bowel **screening programme**.

Chapter 6: Why did people with learning disabilities die sooner than other people?



We found a number of reasons why some of the people with learning disabilities in our study had died sooner than other people.



People with learning disabilities had more medical problems than people without learning disabilities.

They were more likely to have long-term problems like epilepsy or diabetes.



People with learning disabilities were more likely than people without learning disabilities to have problems due to their mobility or feeding difficulties.



People with learning disabilities did not always get treated quickly enough. There were lots of reasons for this.



Doctors need to find out what is wrong with a person before they can treat them.

Sometimes this did not happen quickly enough.

Sometimes they did not have the right investigations.



Some people with learning disabilities need **reasonable adjustments** so they can get good healthcare.



We found that there were often a lot of professionals involved in giving medical care to a person. They did not always know what the others were doing.



There were a lot of problems with planning for the healthcare and support that people needed.



We found that some people with learning disabilities needed someone to speak up for them.



People with learning disabilities sometimes had family or paid carers who did not feel that they were listened to.



Professionals did not always follow the **Mental Capacity Act**. Sometimes decisions were taken about medical care for someone without their consent.



There are guidelines about whether or not someone who is very ill should be **resuscitated**. These were not always followed.

Chapter 7: Why did some people with learning disabilities have a poor quality death?



People did not always have the chance to make choices about the end of their life. Sometimes this meant people died in a place that they did not want to.



Sometimes when someone is dying there are a lot of people involved.



It was a problem when people did not know what other people were doing.



Sometimes there were problems with people getting the right medicine to stop them being in pain.



There is special funding for people with ongoing health needs. It was not always clear who can get this money. The money was not always given in time to be useful.

Chapter 8: Was the quality of care good enough?



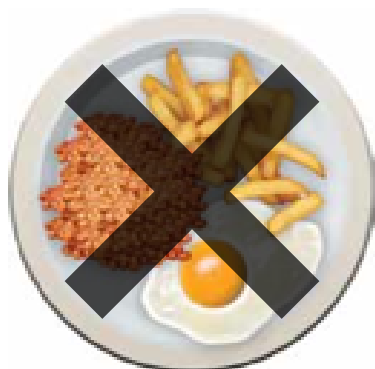
Sometimes no professionals knew anything about the past history of the person they were supporting. This could include their medical history.



Professionals did not always know what the person they were supporting liked and did not like.



Losing weight is often a sign of poor health. We found people with learning disabilities were often not weighed regularly.



Some people need to be fed through a tube into their stomach. It is important that these people still get enough food.



Most people in our study had been supported by a **Community Learning Disability Team** at some point. Some people needed this support and did not get it.

Some doctors did not know about Community Learning Disability Teams.



Most of the hospitals in our study had a **Learning Disability Liaison Nurse**. These nurses help to provide better care for people with learning disabilities in hospital.

Some of the hospitals did not have a special Learning Disability Liaison Nurse.



There is a need for more training about learning disabilities for hospital staff and care home staff.

Chapter 9: What difference has our work made so far?



Lots of professionals have taken part in the meetings we have held to review all these deaths.

They have told us they have learnt a lot from these meetings.



Some of the family members who spoke to a nurse said they had found this helpful.



We had serious concerns about some of the deaths we reviewed. Sometimes these concerns led to further investigations.

Chapter 10: What needs to be done now?



We need to know if people have learning disabilities. This is so services can make changes so that people with learning disabilities can use them as easily as everybody else.



Doctors should think about people as a whole, and all the different medical problems they have. They should not just think about one problem at a time.



Some people with learning disabilities have lots of people supporting them with their health. One of these people must take the lead in this.



People with lots of medical problems should have information recorded about these and the care they need. This should be kept up to date.



People with learning disabilities should get good quality annual health checks. These must lead to good healthcare.



People with learning disabilities should get the same investigations and treatments that other people get.



A lot of people with learning disabilities have serious chest infections. People with chest infections need to see a doctor quickly and get the right treatment.



Some people with learning disabilities have difficulty using medical services. Community Learning Disability Teams should help these people.



There should be special advisers who know a lot about the Mental Capacity Act. They can help make sure that everyone follows this law.



There is a need for good quality training about the Mental Capacity Act. This must be regularly updated.



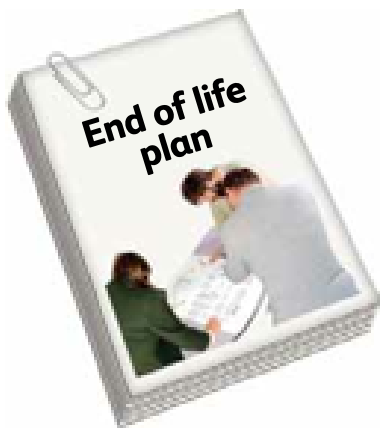
Sometimes people decide for themselves that they do not want to be resuscitated. This decision needs to follow the Mental Capacity Act and it must be written in their records.



Sometimes a decision about whether or not to resuscitate someone has to be taken in an emergency. If this happens the decision must be checked again after the emergency if that is possible.



There is a need for good long-term planning for people's health needs. This must look at the whole person.



When someone is near the end of their life they should get help from specialists. This can help make sure people with learning disabilities get good care when they are dying.



We need a system for recording the deaths of all people with learning disabilities. Some of the deaths would need to be investigated.

This will help us to learn more about the reasons why people with learning disabilities die.



We need to look at this information for everyone in the country. This will help us to learn more about the health and care needs of people with learning disabilities.

Thank you



**There are lots of people we need to say thank you to.
This includes family members, people with
learning disabilities and professionals.**

We would like to thank **everyone** who has helped us with this work.



We would especially like to thank the Bristol Health Trainers
who gave us advice about the work:

**Robert Absalom, Tracey Hyde, Beth Richards
Beth Sage and Tracy Smith – Manager, Bristol Health Trainers**

Difficult words used

Health Service and Local Government Ombudsman – these are organisations that have the power to look into complaints people make about the local council or the NHS.

Independent Inquiry – this is when a group of people who don't work for the Government look into why something went wrong.

Confidential Inquiry – this is a special type of study that collects evidence about the care that a group of people get.

Black and minority ethnic groups – this means people who, because of their race, colour, culture, language or nationality, are not the same as the majority of the population. For example, black Caribbean people, Pakistani people, Chinese people and Bangladeshi people.

Underlying cause of death – this is the reason that somebody gets very ill. It might be something like cancer.

Immediate cause of death – this is the reason that a person eventually dies. It might be a chest infection that stops them breathing.

Premature death – this is when we think someone has died at a younger age than they should have done and they could have lived for much longer.

Long-term conditions – these are medical conditions that cannot be made better but can be managed through medication and/or treatments.

Treatable conditions – these are medical conditions that can be made better.

Annual health check – this is a check every year for people with learning disabilities about their health.

Screening programmes – this is checking people to see if they have or will get health problems.

Reasonable adjustments – these are the changes people or services must make so disabled people can use services as easily as everybody else.

Mental Capacity Act – this is a law on decision-making. If people cannot make their own decisions this law should be used to help them.

Resuscitated – this is when first aid is used to help someone who is not breathing properly or their heart has stopped.

Community Learning Disability Team – this is a group of health and social workers. They are specially trained to help and support people with learning disabilities.

Learning Disability Liaison Nurse – this is a special nurse in a hospital who is there to make sure that people with learning disabilities get good support when they are in hospital.

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

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A full copy of the report, an executive summary and an easy read short summary are available on the CIPOLD website www.bristol.ac.uk/cipold

Should you require a hard copy, please contact the CIPOLD Team at the address above.

With thanks to Julian Goodwin for his help with this easy read report.

The pictures in this report are from Photosymbols: www.photosymbols.co.uk

Prepared by the CIPOLD Team, March 2013.

Designed by Thingswedo.

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This is the easy read report of the Confidential Inquiry into premature deaths of people with learning disabilities.

We looked at the deaths of 247 people with learning disabilities. We looked at what happened to these people before they died. We also looked at the deaths of 58 people who did not have learning disabilities.

We found that the health and social care given to people with learning disabilities could be better. We have made some suggestions about how services could be changed. These changes would help people with learning disabilities live longer, healthier lives.