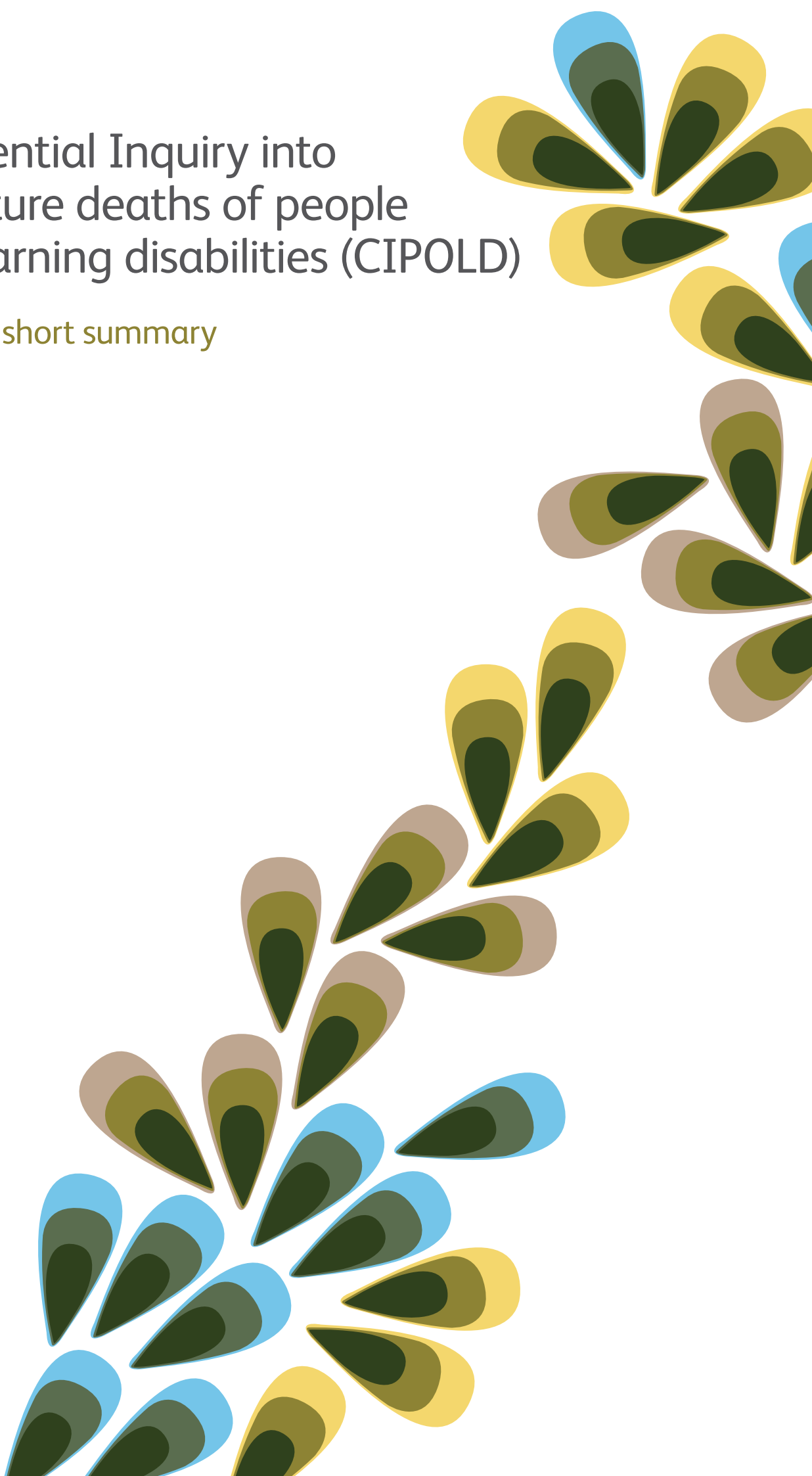


# Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

Easy read short summary

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# Why did we do this work?

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

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Following this a Confidential Inquiry was set up. This has been looking at why people with learning disabilities sometimes live shorter lives than other people.

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# How did we do this work?

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We were told about the deaths of 247 people with learning disabilities. We looked at what happened to these people before they died.



We compared deaths of people with learning disabilities with the deaths of 58 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.

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# What did we find out about the people who died?

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



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



The most common reason why people with learning disabilities got very ill and died was problems with their heart.



The most common reason for people with learning disabilities eventually dying was a chest infection.



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.



We thought that some of the deaths were premature deaths. This means we thought some people died at a younger age than they should have done and they could have lived for longer.



The main reason for someone dying earlier than they should was a delay or problem with finding out why they were ill and treating them.

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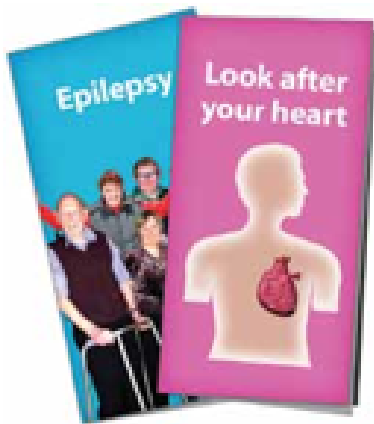
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# What were their health needs?

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



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

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# Why did they die earlier than other people?

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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 people did not have the right investigations.



Some people with learning disabilities need changes made to services so they can use these as easily as other people. This did not always happen.



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



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



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





Professionals did not always follow the Mental Capacity Act. This is a law about decision making. If people cannot make their own decisions this law should be used to help them.



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



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

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# What needs to be done now?

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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.



Some people with learning disabilities have lots of different 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 needs to be kept up to date.



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



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 long-term planning for people's health needs. This needs to look at the whole person.

There should also be a plan to 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. This will help us to learn more about the reasons why people with learning disabilities die.

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

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A full copy of the report, an easy read version, and an executive summary are available on the CIPOLD website [www.bristol.ac.uk/cipold](http://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](http://www.photosymbols.co.uk)

Prepared by the CIPOLD Team, March 2013.

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This is the easy read short summary 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.



Improving Health and Lives:  
Confidential Inquiry



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