University of BRISTOL

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

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Improving Health and Lives: Confidential Inquiry

Number of reviews

We reviewed :

- All known deaths of people with learning disabilities
- From 5 PCT areas
- From 1st June 2010 – 31st May 2012.

233 adults with learning disabilities

14 children with learning disabilities

58 comparator cases.

The sequence of events in CIPOLD

1. Death of person with learning disabilities
2. Notification and investigation
3. Local Review Panel meeting and report
4. Overview Panel and final conclusions
5. Data entry and collation of findings.

The cohort of people with learning disabilities

- Age 4-96.
- Over half (58%) male.
- Most (93%) single.
- Most (96%) White British.

40% had mild learning disabilities
31% moderate learning disabilities
21% severe learning disabilities
8% had profound and multiple learning disabilities.

Age at death

Median age at death for males was 65 years

Men with learning disabilities died on average 13 years earlier than men in the general population.

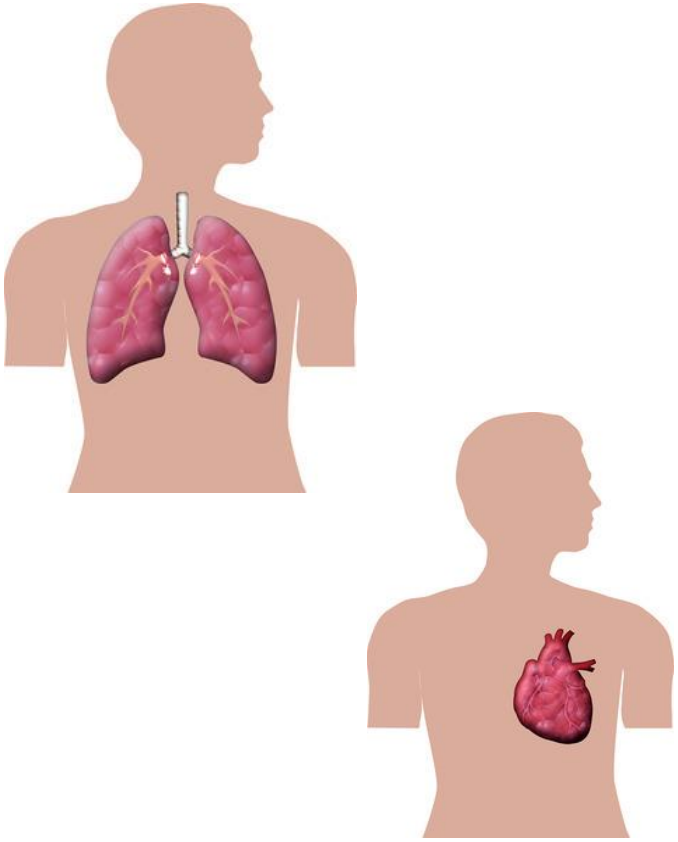
Median age at death for women was 63 years

Women with learning disabilities died on average 20 years earlier than women in the general population.

Causes of death

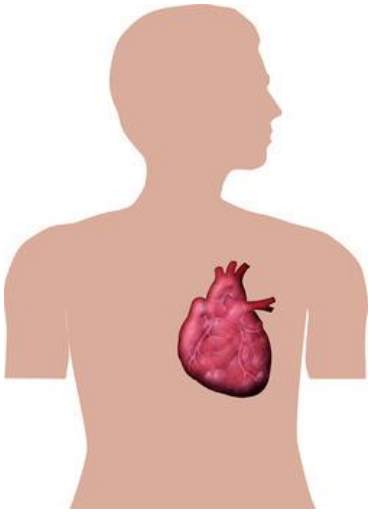
- Immediate cause of death
- Underlying cause of death
- Any other diseases, injuries, conditions or events that contributed to the death, but were not part of the direct sequence leading up to the death.

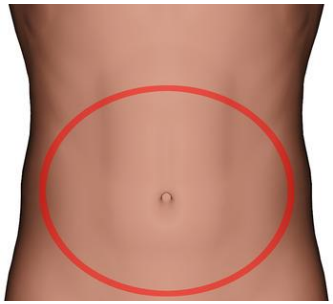
Immediate causes of death



- The most common immediate causes of death in people with learning disabilities were:
- Respiratory problems (34%)
- heart and circulatory disorders (21%).

Underlying causes of death



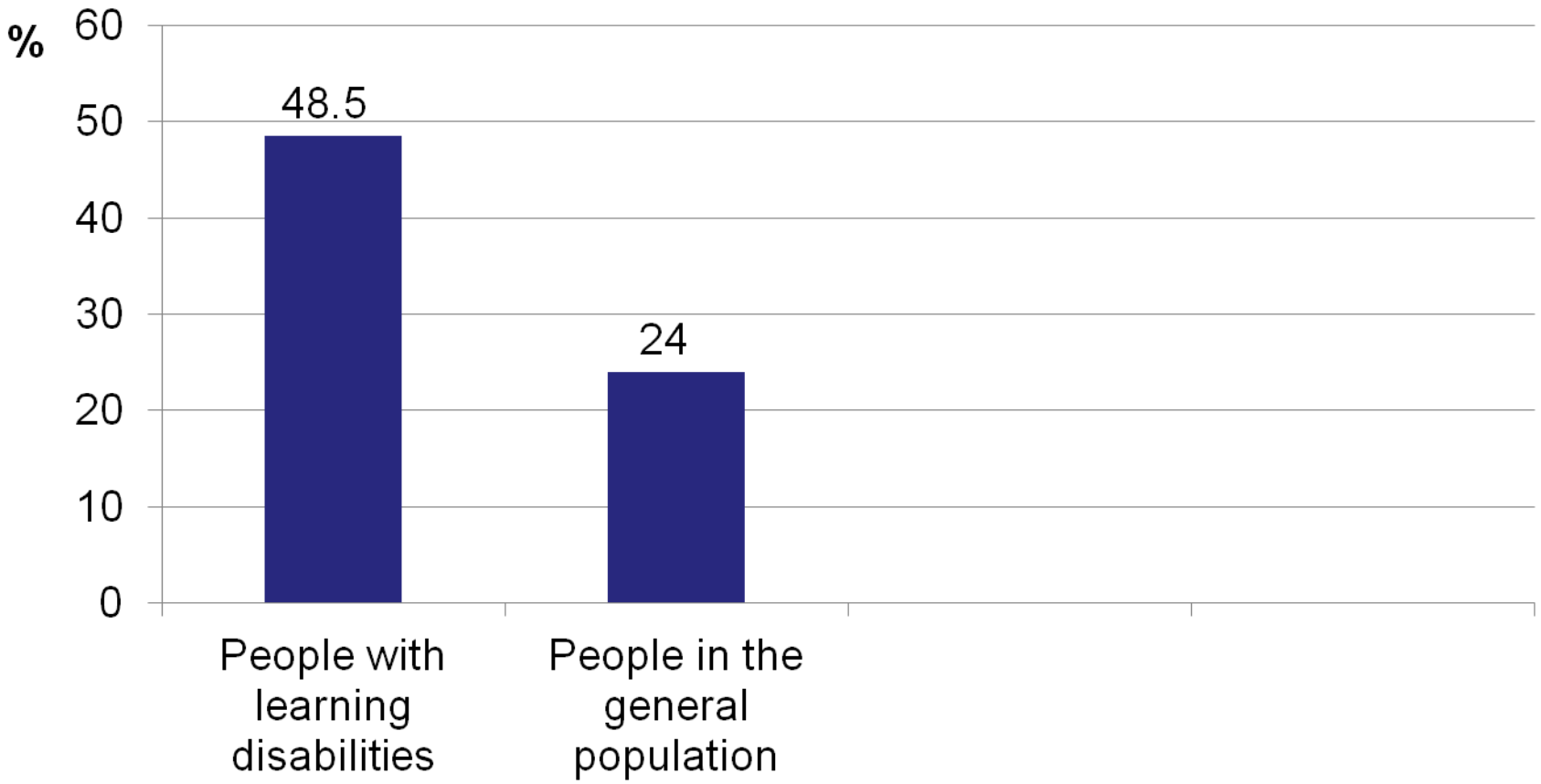


- The most common underlying reasons for people with learning disabilities dying were:
- heart and circulatory disorders (22%)
- cancer (20%).

Unexpected deaths

- Using ICD-10 codes of underlying causes of death that can be assumed to cause an unexpected death
- 25% nationally
- 23% in CIPOLD deaths

Total avoidable deaths



For every one person in the general population

who dies from an avoidable cause of death

two people with learning disabilities will do so.

Avoidable deaths

Preventable mortality

All or most deaths from that cause could be avoided by public health interventions in the broadest sense.

Amenable mortality:

All or most deaths from that cause could be avoided through good quality healthcare.

12% **9%** **27.5%**

For every one person in the general population

who dies from a cause of death that could be prevented by good quality care

three people with learning disabilities will do so.

Deaths amenable to good quality healthcare

Significance of:

- age
- severity of learning disabilities
- underlying cause of death
- if had a significant partner/friend.

Premature deaths

CIPOLD deaths were considered to be premature

'*if, without a specific event that formed part of the 'pathway' that led to death, it was probable (i.e. more likely than not) that the person would have continued to live for at least one more year.'*

Premature deaths

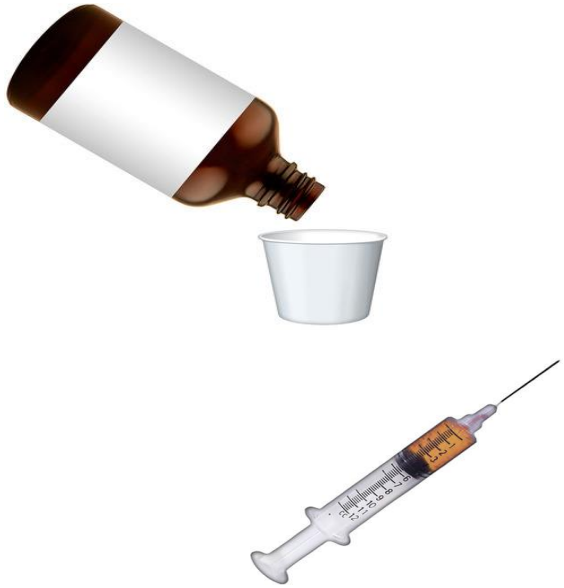
42% of deaths considered to be premature

Most common reasons for premature deaths (1)

- Problems with assessing or investigating the cause of illness.

This affected 2 in every 5 people.

Most common reasons for premature deaths (2)



Problems with the treatment of their condition.

This affected 2 in every 5 people.

Issues related to the delays in the care pathways

- A lack of reasonable adjustments to help people to access healthcare services.
- A lack of coordination of care across and between different disease pathways and service providers.
- A lack of effective advocacy for people with multiple conditions and vulnerabilities.

The comparator study.

Why use comparators?

- Are problems with services the same for everyone?
- What is different for people with learning disabilities?

The comparator study.

Comparators

were people who did not have learning disabilities:

who died at similar ages,

of similar conditions,

in the same local areas

as people with learning disabilities included in the CIPOLD study.

The comparator study.

We selected the comparators from people who had died in the same GP practice as people with learning disabilities, and broadly matched them for:

age,

cause of death,

month of death,

and sex

with people with learning disabilities who had died.

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The comparator study.

We identified:

58 comparators who had died,

weighted to broadly match

58 people with learning disabilities who had died

The comparator study.

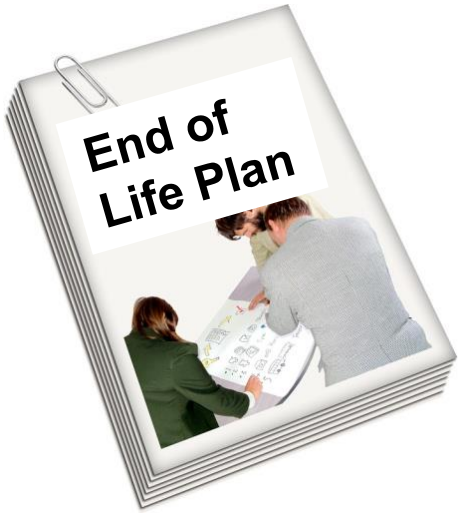
Particular problems identified for people with learning disabilities (all more common than for comparators):

- Problems with advanced health and care planning
- Problems with coordination of care and information sharing
- Problems with recognising needs and adjusting care as needs changed
- Problems with record keeping and accessing records
- Delays in the diagnosis and treatment of healthcare problems

The comparator study.

Problems commonly experienced by both groups:

- Problems with DNACPR orders



- Problems with end of life care

The comparator study.

Summary.

There were significant differences in factors contributing to the deaths of people with learning disabilities compared to people of the same ages, who died in the same communities at the same time.

Many of these factors related to the quality of health and social care provided to the people with learning disabilities.

So what is happening now?

Latest progress update from Department of Health published in September 2014

'we now need to step up the pace….much more needs to be done'

(Norman Lamb, Minister for Care and Support)

Progress being made nationally 1

- GP registers of people with learning disabilities are now expanded to be all age registers.
- A requirement for providers to undertake an annual audit of reasonable adjustments has been included in the NHS Standard Contract for 2014/15.
- The Department of Health is reviewing if further work needs to be done on information sharing protocols between health and social care.
- Four new questions are now being trialled at CQC inspections of acute hospitals, specifically about care of people with learning disabilities.

Progress being made nationally 2

- NICE is working on three guidelines which relate to improving the care and support of people with learning disabilities.
- Annual health checks for people with learning disabilities have been extended to age 14-17 year olds. Health Action Plans are now an expectation.
- Public Health England had developed easy-read materials for breast cancer, bowel cancer and cervical screening programmes.
- Changes have gone into the national flu immunisation plan to be more specific about targeting people with learning disabilities for immunisation.

Progress being made nationally 3

- CIPOLD conclusions were echoed in the findings of the House of Lords Select Committee's post-legislative scrutiny report on the Mental Capacity Act (March 2014). The Government's response (in June 2014), set out a programme of action to tackle low levels of awareness among professionals and drive progress in implementation.
- Work is under way with NHS England, the Health and Social Care Information Centre and Public Health England to provide standardised mortality data for people with learning disabilities.
- A new learning disabilities mortality review function will be introduced.

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Time for questions