

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

## Executive summary

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## Background

Mencap's report *Death by Indifference* described the circumstances surrounding the deaths of six people with learning disabilities who died while they were in the care of the NHS, exposing 'institutional discrimination'. An Independent Inquiry chaired by Sir Jonathan Michael followed, which recommended the establishment of the learning disabilities Public Health Observatory, and a time-limited Confidential Inquiry into premature deaths of people with learning disabilities.

The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) was tasked with investigating the avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths. The aim was to review the patterns of care that people received in the period leading up to their deaths, to identify errors or omissions contributing to these deaths, to illustrate evidence of good practice, and to provide improved evidence on avoiding premature death.

## Methodology

CIPOLD investigated the sequence of events leading to all known deaths of people with disabilities (aged 4 years and older) over a 2-year period in 5 Primary Care Trust (PCT) areas of South-West England; the area had a mixture of urban and rural communities and a population of 1.7m.

In order to identify whether findings were specific to people with learning disabilities, the study included 58 comparator cases of adults without learning disabilities who died in the study area. They were selected so they were comparable to people with learning disabilities included in CIPOLD, weighted for i) month of death, ii) cause of death, iii) age, and iv) gender.

## The CIPOLD cohort

CIPOLD reviewed the deaths of 247 people with learning disabilities over the 2-year period in 2010–2012, approximately 2½ times the number expected. This apparent difference may reflect the under-recognition of people with mild learning disabilities in the community and that two-fifths (42%) had previously lived in local long-stay institutions and then settled nearby. Most (96%) were of white UK ethnicity.

The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died.

Of the 247 people with learning disabilities, 40% had mild, 31% moderate, 21% severe, and 8% had profound and multiple learning disabilities. Of the 233 aged 18 or over, most (92%) were identified as being on a GP register of people with learning disabilities.

## Causes and certification of deaths of people with learning disabilities

As with the general population, the most common underlying causes of death were heart and circulatory disorders (22%) and cancer (20%), although both were less prevalent than in the general population (29% and 30% respectively). The final event leading to death was most frequently a respiratory infection in the people with learning disabilities. That a person had learning disabilities was mentioned on few (23%) cause of death certificates.

Fewer deaths of people with learning disabilities (38%) were reported to the coroner compared with the general population (46%). When deaths were reported to the coroner, people with learning disabilities were more likely to have a post-mortem and were as likely to have an inquest opened. Of note is that the CIPOLD Overview Panel identified some additional deaths that they thought should have been reported to the coroner, and expressed concerns about some coroners' reviews of deaths.

## Unexpected and premature deaths

Using the same definition as is used in the child death review process,<sup>1</sup> 43% of the deaths of people with learning disabilities were unexpected. Using ICD-10<sup>2</sup> data on conditions that are commonly known to be unexpected (e.g. myocardial infarction, pulmonary embolus, cerebrovascular disease), there was no significant difference between people with learning disabilities and the general population.

In the CIPOLD study, a death was considered as premature if, '*without a specific event that formed part of the "pathway" that led to death, it was probable that the person would have continued to live for at least one more year*'. This allowed the Overview Panel to take account of both lifestyle and co-morbidity in assessing the potential significance of events or omissions in the care of the person concerned, regardless of their age. Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs.

## Health and social care needs of people with learning disabilities

When considering the health and social care needs of the people with learning disabilities, it was apparent that they were a very vulnerable group. Significantly more (17%) were underweight than the general population (2%), even after excluding those who had lost weight in their final illness. Two-thirds lacked independent mobility, half had problems with vision, a quarter had problems with hearing, over a fifth (21%) had problems with both vision and hearing, 30% had limited verbal communication, and 22% did not communicate verbally at all.

Almost all (97%) had one or more long-term or treatable health condition, including 43% with epilepsy (31% had had a seizure in the previous 5 years), 39% with cardiovascular disease, 22% with hypertension, 14% with dementia and 13% with osteoporosis.

Of people known to be on GP learning disability registers, 71% had received an annual health check in the year before death, but 12% had never had an annual health check. More than a third were reported as having difficulty in communicating their pain, but a pain assessment tool such as DisDAT<sup>3</sup> had been used with only 4 people. Engagement in the bowel cancer screening programme was problematic.

At the time of their deaths 64% lived in residential care homes, most with 24-hour paid carer support. For 20% of the people with learning disabilities, safeguarding concerns had previously been raised; for a further 8% safeguarding concerns were raised to the CIPOLD review retrospectively – these had not been reported or investigated at any time previously.

## Factors contributing to vulnerability and premature deaths of people with learning disabilities

While the great majority (86%) of the illnesses that led to the deaths of people with learning disabilities were promptly recognised and reported to health professionals, for 29% there was significant difficulty or delay in diagnosis, further investigation or specialist referral, and for 30% there were problems with their treatment. The lack of reasonable adjustments to facilitate healthcare of people with learning disabilities, particularly attendance at clinic appointments and investigations, was a contributory factor in a number of deaths. GP referrals commonly did not mention learning disabilities, and hospital 'flagging' systems to identify people with learning disabilities who needed reasonable adjustments were limited.

People with learning disabilities had a considerable burden of ill-health at the time of their death. Key issues that appeared to be problematic were the lack of coordination of care across and between the different disease pathways and service providers, and the episodic nature of care provision.

In addition, professionals in both health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act 2005, in particular regarding assessments of capacity, the processes of making ‘best interest’ decisions and when an Independent Mental Capacity Advocate should be appointed. Many instances were identified of inappropriate or poorly documented DNACPR<sup>4</sup> orders.

Record keeping was commonly deficient – particularly in relation to fluid intake, nutrition, weight and seizures, and little attention was given to predicting potential problems, e.g. when a person was fearful of contact with medical professionals.

A lack of recognition of the approaching end of life commonly led to problems in coordinating end-of-life care and providing support to the person and their family. Difficulties in obtaining Continuing Healthcare funding were also reported.

## The comparator cases: similarities and differences

The ages and broad causes of death were similar between the subset of 58 adults with learning disabilities and the 58 comparators without learning disabilities. The proportion of premature and unexpected deaths was no different between the two groups, but more of the comparators died of conditions that were potentially preventable by public health measures (e.g. reducing smoking) and more of the people with learning disabilities died from causes that were potentially amenable to change by good-quality healthcare.

Similar proportions in the two groups presented promptly for healthcare, but significantly more people with learning disabilities experienced difficulties in the diagnosis and treatment of their illness than did the comparator group. All aspects of care provision, planning, coordination and documentation were significantly less good for people with learning disabilities than for the comparators.

Dependence on others for mobility and feeding was significantly more prevalent among those with learning disabilities, while lifestyle factors (e.g. smoking and alcohol) were significantly more prevalent among the comparators. Families of people with learning disabilities more commonly felt that professionals did not listen to them.

## Conclusions and recommendations

The quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways. Despite numerous previous investigations and reports, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities. The CIPOLD study has shown the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of ‘reasonable adjustments’ to avoid their serious disadvantage.

The people with learning disabilities included in CIPOLD had a range of impairments and multiple health conditions, and there was considerable evidence of fragmented care. Communications within and between agencies must be improved, and we recommend a named health professional to coordinate the care of those with multiple health conditions, aided by the routine use of patient- or carer-held health records and the continuing involvement of specialist healthcare staff, who are required not to work on a short-term or one-off assessment basis.

Proactive use of annual health checks to develop and implement health action plans, planning for the future and adapting care as needs change rather than in a crisis, and the identification of effective advocates to help people with learning disabilities to access healthcare services are all effective, low-cost measures to address this issue.

Professionals must recognise their responsibilities to provide the same level of care to people with learning disabilities as to others, and not to make rapid assumptions about quality of life or the appropriateness of medical or social care interventions. The weakest link in the chain related to problems with the diagnosis and treatment of people with learning disabilities. People having problems using recognised care pathways must be referred to specialist expertise.

Adherence to the Mental Capacity Act was generally poor. Health and social care providers must ensure that all professionals understand and act in accordance with the Act, and we recommend further work at national and local levels to support conformity to its requirements. We also recommend that guidelines for DNACPR orders be revised to separately address emergency and non-emergency situations.

Finally, we recommend the routine collection and review of data that provides intelligence about the mortality of people with learning disabilities and the establishment of a National Learning Disability Mortality Review Body to take forward the reviews of deaths of people with learning disabilities, in order to learn from experience and continue to provide a driver to reduce inequalities in care for this vulnerable population.

## Notes

- 1 A death which was not anticipated as a significant possibility 24 hours before the death or where there was a similarly unexpected collapse leading to or predicating the events which led to death
- 2 The International Classification of Diseases and Related Health Problems codes diseases, signs and symptoms, abnormal physical findings and causes of injury. ICD-10 is the 10th revision of this classification system
- 3 Disability Distress Assessment Tool (DisDAT)
- 4 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
- 5 National Institute for Health and Clinical Excellence

## The key recommendations from the CIPOLD review of deaths

- 1 Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.
- 2 Reasonable Adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.
- 3 NICE<sup>5</sup> Guidelines to take into account multi-morbidity.
- 4 A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
- 5 Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.
- 6 Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.
- 7 People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.
- 8 Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services.
- 9 Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
- 10 Mental Capacity Act advice to be easily available 24 hours a day.
- 11 The definition of Serious Medical Treatment and what this means in practice to be clarified.
- 12 Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.
- 13 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines to be more clearly defined and standardised across England.
- 14 Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change.
- 15 All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.
- 16 Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.
- 17 Systems to be put in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments.
- 18 A National Learning Disability Mortality Review Body to be established.

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A full copy of the report, an easy read version, and an easy read short 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.

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This is the Executive Summary of the CIPOLD report into premature deaths of people with learning disabilities.

The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) took place from 2010 to 2013 and reviewed the deaths of 247 people with learning disabilities within 5 Primary Care Trusts in the South-West of England. It also reviewed the deaths of 58 people without learning disabilities, to place the findings in context.

The study reveals that the quality and effectiveness of health and social care given to people with learning disabilities was deficient in a number of ways. Key recommendations are made which, were they individually and collectively implemented, would lessen the risk of premature death in people with learning disabilities.