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

Final report

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# Foreword

The principles of the NHS are familiar to all of us. We expect it to be free at the point of delivery and available to everyone based on need. We expect patients to be at the centre of its care, that they will have positive experiences and be treated with dignity and respect. And we expect clinically effective, high-quality support to manage existing conditions and help us live healthy lives.

People with learning disabilities should expect no less and receive no less a service than anyone else.

In setting out on the CIPOLD review of deaths, we hoped that the lessons from *Death by Indifference* would have been learned and that the recommendations of Sir Jonathan Michael's report would have been implemented. We hoped to find that people with learning disabilities were living long and healthy lives to no lesser extent than those without learning disabilities. Our optimism has been quashed, but we have also been heartened by the many family members, carers and professionals who have been supporting people with learning disabilities creatively, optimally and with the person themselves at the centre of their care. We need to learn and share what is working well and to shine a light on what is possible, as much as identifying what is wrong.

It has been a privilege to have been a part of so many people's lives. People whom we would never meet alive, but who we came to know so well once they had died. We have anonymised their names in this report, but would like to do justice to their experiences, the lessons they have taught us and the reflections they have given us. It feels a tall order. But we hope that, in this report, learning from their lives will make a difference to others living in the present and with lives yet to come. We would like this report to leave a legacy of action, with the imperative to reverse the unacceptable situation in which the NHS is not being provided equitably to everyone based on need.

**The CIPOLD Team**

# Executive summary



## 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 1 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 (IMCA) 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 (CHC) 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.

## 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.

## 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

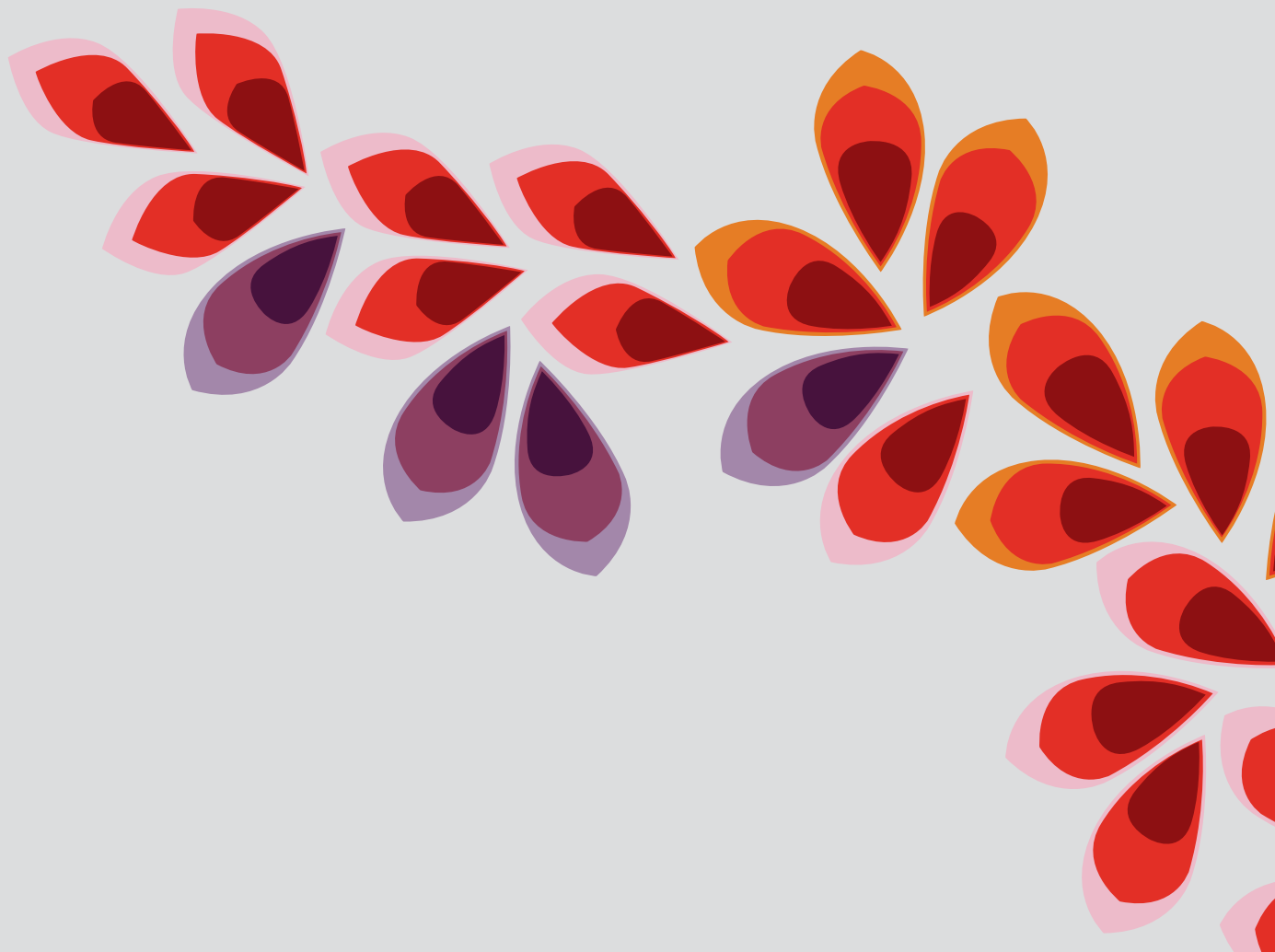
# Chapter 1

## Introduction

This chapter contains information about the background to the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), its aims and operating framework, and the study area within which the reviews took place.

*With Charles<sup>1</sup> nothing would have changed it. As the world was at the time nothing would have changed what happened to Charles. But if coming out of it there's something which we might find from our thoughts is going to help change the system somewhere to help others then fine. ... We want to contribute whatever we can and if there's anything we haven't covered you interrogate us! We want to help.*

**Sister of person with learning disabilities**



## Chapter summary

Longstanding concerns about the care of people with learning disabilities within the NHS were brought to public attention by Mencap in their review of the deaths of six people with learning disabilities. The focus of CIPOLD, as recommended by Sir Jonathan Michael's report *Healthcare for All*, has been to determine the extent of premature deaths in people with learning disabilities. It has been conducted at a time of increasing concerns about the quality of service provision for all patients (see, for example, the Francis Report) and for people with learning disabilities (see, for example, the report of abuse at Winterbourne View, and the findings of The Care Quality Commission review of learning disability services). Indeed, Winterbourne View was located within the CIPOLD study area, although CIPOLD had not reviewed any deaths at the establishment.

The CIPOLD study area included 5 Primary Care Trusts (PCTs) in the South West of England, with a mixture of urban and rural communities and a total population of nearly 1.7 million. The proportion of adults with learning disabilities in the population was approximately 0.48%; this compares with a national average of 0.4% of adults with learning disabilities in England as a whole.

## The background to the Confidential Inquiry

Fifteen years ago Sheila Hollins and her colleagues<sup>2</sup> reported that the risk of people with learning disabilities dying before the age of 50 was 58 times higher than in England and Wales generally. Over the following years, the Disability Rights Commission<sup>3,4</sup> and Mencap<sup>5,6</sup> produced a number of reports highlighting the unequal healthcare that people with learning disabilities often received (see Box 1).

It was Mencap's report *Death by Indifference* in 2007, describing the circumstances of the deaths of Emma, Mark, Martin, Ted, Tom and Warren – 6 people with learning disabilities who died while they were in the care of the NHS – that brought to wide public attention what was considered to be '*institutional discrimination*' by healthcare services towards people with learning disabilities and their families and carers.

The government asked the Parliamentary and Health Service Ombudsman to investigate the deaths of the six people with learning disabilities described in *Death by Indifference*. The Ombudsman conducted detailed investigations into the events that led up to their deaths and published the report *Six Lives: The Provision of Public Services to People with Learning Disabilities* in 2009.<sup>7</sup> This report reinforced the urgent need for systemic change within the NHS for people with learning disabilities and considered that the outcomes were a '*shocking indictment of services which profess to value individuals and to personalise services according to individual need*' (p.17).

An Independent Inquiry was concurrently established by the Department of Health in England, led by Sir Jonathan Michael. The terms of reference required the inquiry to learn lessons from the six cases highlighted in the Mencap report. The inquiry concluded that *'there is evidence of a significant level of avoidable suffering and a high likelihood that there are deaths occurring which could be avoided'*<sup>8</sup> (p.53). It recommended the establishment of the learning disabilities Public Health Observatory, and a time-limited Confidential Inquiry into premature deaths of people with learning disabilities *'to provide evidence for clinical and professional staff on the extent of the problem and guidance on prevention'* (p.44).

### Box 1: Key reports contributing to a call for a Confidential Inquiry into the deaths of people with learning disabilities

*Valuing People*<sup>9</sup> in 2001 committed the government to exploring the feasibility of establishing a Confidential Inquiry into mortality among people with a learning disability.

*Treat Me Right*<sup>10</sup> in 2004 concluded that a Confidential Inquiry into the deaths of people with learning disabilities would not only identify the causes of death, but would also be a powerful lever for improvement in the delivery of health services.

A Disability Rights Commission report<sup>11</sup> in 2006 considered it *'alarming'* that little or nothing had been done to implement the recommendations of Mencap's *Treat Me Right* report by those with the power to do so.

A Disability Rights Commission report<sup>12</sup> in 2007 criticised the lack of strategic change and prioritisation that had taken place following its report the previous year, calling it *'quite literally a matter of life and death'* (p.6).

*Death by Indifference*<sup>13</sup> described the circumstances surrounding the deaths of six people with learning disabilities while they were in the care of the NHS. It suggested that people with learning disabilities, their families and carers were facing *'institutional discrimination'* in healthcare services.

*Healthcare for All* is the report of the Michael Inquiry,<sup>14</sup> which was established to learn lessons from the six cases highlighted in the Mencap report. It reported evidence of *'a significant level of avoidable suffering and a high likelihood that there are deaths occurring which could be avoided'* (p.53). It recommended the establishment of a learning disabilities Public Health Observatory, and a time-limited Confidential Inquiry into premature deaths of people with learning disabilities *'to provide evidence for clinical and professional staff on the extent of the problem and guidance on prevention'* (p.44).



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

The tender for the Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) was awarded to a team at the University of Bristol in spring 2010. The team was tasked with investigating the avoidable or premature deaths of people with learning disabilities through retrospective reviews of deaths. The aim of CIPOLD has been to review the patterns of care that people received in the period leading up to their deaths and to identify errors or omissions likely to have contributed to these deaths, as well as evidence of good practice. Its intention has been to provide improved evidence on best professional practice for health and social care practitioners, NHS organisations, and local authorities.

From the outset, the CIPOLD Team worked closely with the newly established Learning Disabilities Observatory (LDO) to agree a suitable definition of ‘learning disabilities’.<sup>15</sup> When reading this report, you should regard our use of the term ‘learning disabilities’ to be interchangeable with the term ‘intellectual disabilities’.

The CIPOLD study was undertaken at a time of impending change in the commissioning of health and social care services introduced by the Health and Social Care Act 2012.<sup>16</sup> It has also been undertaken at a time of increasing concerns about the quality of service provision. A number of reports have already highlighted concerns about particular patient groups (see Parliamentary and Health Service Ombudsman 2011<sup>17</sup> regarding a report about the care of older people within the NHS), aspects of care (see Care Quality Commission 2011<sup>18</sup> regarding the dignity and nutrition inspection programme) and geographical areas (see Francis 2010<sup>19</sup> regarding the care provided by the Mid-Staffordshire NHS Foundation Trust). More specifically for people with learning disabilities, the abuse that took place at Winterbourne View<sup>20</sup> has prompted a review of learning disability services at 150 NHS, private and social care services, which found that almost 50% of hospitals and care homes inspected did not meet national standards.<sup>21</sup> In order to place the findings pertaining to people with learning disabilities in context, this report into premature deaths of people with learning disabilities includes a comparison of a subset of the people with learning disabilities and a ‘comparator’ group of people who died at similar ages but did not have learning disabilities, whose deaths have been reviewed in the same way. The analysis of data from the comparator groups is important, as it helps to identify aspects of concern specific to people with learning disabilities, and aspects that are also relevant to other people who may die prematurely.

## The CIPOLD study area

The CIPOLD study area included 5 PCT areas in the South West of England with a population of nearly 1.7 million and a mix of urban and rural communities. When considering the Index of Multiple Deprivation, the areas in the CIPOLD study area were, on average, slightly more affluent compared to the country as a whole, although there was considerable variation between local areas. The proportion of the population from non-white British backgrounds was much lower (9%) in the CIPOLD area than in the general population (20%), with just 1 of the PCT areas coming close to the national average. The proportion of the population who died each year (8.8 per 1,000 of the population) in the CIPOLD area was similar to that of the country as a whole (8.9 per 1,000 of the population).

## People with learning disabilities in the study area

Using national data provided by the LDO, and drawn from Quality and Outcomes Framework data for England April 2010–March 2011, the number of adults aged 18 and over with learning disabilities identified by GPs in the CIPOLD study area in 2010–2011 was 6,962, equating to 0.48% of the population aged 18 and over. This compares with a national average of 0.43% of adults in England.

Using census data provided by the LDO and drawn from Department for Education data, the number of children with moderate, severe or profound and multiple learning disabilities in the CIPOLD area in January 2011 was 8,543, equating to 2.5% of the school population. This compares with a national average of 4.0%.

There is potentially an excess of people with learning disabilities who have histories of being in long-stay institutions in the study area. National data suggests that the study area had a greater than average number of long-stay institutions, and when these institutions closed, many of the residents settled nearby.

At the outset of CIPOLD, the best available data (2006–8) suggested that the annual number of deaths of people with learning disabilities in the CIPOLD study area was likely to be around 48 deaths a year. This equates to a crude death rate of 2.9 per 100,000 of the population and suggested that CIPOLD should identify about 100 deaths in the 2-year study period.

## Notes

- 1 All names have been anonymised to protect confidentiality.
- 2 Hollins, S., Attard, M.T., von Fraunhofer, N., McGuigan, S. and Sedgwick, P. (1998) Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental medicine and child neurology*, 40(1): 50–56.
- 3 Disability Rights Commission (2006) *Equal Treatment: Closing the Gap. A Formal Investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. London: HMSO.
- 4 Disability Rights Commission (2007), *Equal Treatment: Closing the Gap – One Year On*. London: HMSO.
- 5 Mencap (2004) *Treat Me Right*. London: Mencap.
- 6 Mencap (2007) *Death by Indifference*. London: Mencap.
- 7 Parliamentary and Health Service Ombudsman (2009) *Six Lives: The Provision of Public Services to People with Learning Disabilities*. London: The Stationery Office.
- 8 Michael, J. (2008) *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Department of Health.
- 9 Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health.
- 10 Mencap (2004) *Treat Me Right*. London: Mencap.
- 11 Disability Rights Commission (2006) *Equal Treatment: Closing the Gap. A Formal Investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. London: HMSO.
- 12 Disability Rights Commission (2007), *Equal Treatment: Closing the Gap – One Year On*. London: HMSO.
- 13 Mencap (2007) *Death by Indifference*. London: Mencap.
- 14 Michael, J. (2008) *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Department of Health.
- 15 See: Emerson E. and Heslop P. (2010) *A working definition of learning disabilities*. Durham: Improving Health and Lives Learning Disabilities Observatory.
- 16 HM Government (2012a) *Health and Social Care Act*. London: The Stationery Office.
- 17 Parliamentary and Health Service Ombudsman (2011) *Care and compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people*. London: The Stationery Office.
- 18 Care Quality Commission (2011) *Dignity and nutrition inspection programme. A national overview*. Newcastle upon Tyne: CQC.
- 19 Francis, R. (2010) *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009*. London: The Stationery Office.
- 20 Department of Health (2012) *Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report*. London: Department of Health.
- 21 Care Quality Commission (2012) *Learning disability services inspection programme: National overview*. Newcastle upon Tyne: CQC.

## Chapter 2

# The methodology of CIPOLD

This chapter describes the way in which the CIPOLD review of deaths were conducted, who was involved in contributing to the reviews, and how the notifications of the people with learning disabilities and the comparator cases without learning disabilities were received.

*The actual interview was the first time I had spoken in depth about my loss to someone that was a professional and I found it very helpful.*

**Mother of person with learning disabilities**



## Chapter summary

The chapter explains the step-by-step process of reviewing the CIPOLD deaths, highlighting the inclusive nature of the approach. The CIPOLD reviews aimed to invite all key individuals and agencies that had been involved in supporting the person who had died to contribute to the review, thus including health, social and family perspectives. Each review included the provision of core data, case note reviews, individual interviews, a panel meeting of all those who had been involved in supporting the person, and external anonymised scrutiny by an Overview Panel. Families were invited to receive bereavement support from a CIPOLD nurse and to contribute their views and thoughts at an individual interview.

This chapter also describes the methods we took to select the comparator groups – a subset of the cohort of people with learning disabilities, and a group of people without learning disabilities. Their deaths were reviewed in order to place the findings into context. The comparator group of people without learning disabilities was weighted on certain factors, in order to produce a balanced comparison.

## The process of conducting CIPOLD

The methodology of CIPOLD is similar to that taken by the national Child Death Review Process.<sup>1</sup> A diagrammatic schema is at Appendix 1. Here, we summarise the key elements of the approach taken.

- 1** A communication network reported the death of a person with learning disabilities. Notifications of deaths came from a wide range of sources. On average, the CIPOLD Team received 1.8 notifications per death. On 2 occasions during the study, additional checks were made with a range of sources for any deaths that might not have been notified to CIPOLD.
- 2** The CIPOLD Team logged the death, verified that the person met the inclusion criteria (that they had learning disabilities, were registered with a GP in the CIPOLD area, and were aged 4 years or older), and requested core standardised information regarding the person who had died from those who had been in contact with them.
- 3** An investigator and nurse were then allocated to the case. The CIPOLD nurse, with agreement from the family, visited the family of the person who had died, to offer bereavement support and advice, and to talk with them about the life and death of the person who had died. This information was shared with the CIPOLD investigator to contribute to the review. The investigator reviewed pertinent case notes and records, interviewed the different professionals involved and undertook a Root Cause Analysis of the death.

- 4 All of the investigation evidence was collated into a standardised format and prepared for a multidisciplinary Local Review Panel meeting. All professionals who had contributed to the review, plus the CIPOLD nurse who had interviewed the family, were invited to the meeting. The focus of this meeting was to identify what lessons could be learned, what evidence of good practice could be shared, and if there were any recommendations that could be made. A summary report of the meeting was distributed to everyone who had contributed to the review process. The CIPOLD nurse relayed a verbal summary of the meeting back to the family.
- 5 Documentation from each case was fully anonymised in preparation for the Overview Panel. The Overview Panel was an external multidisciplinary group, including family carer representatives, which met regularly in order to scrutinise the circumstances leading to the death of each person included in the study.
- 6 Anonymised data was entered into 2 databases (1 for quantitative data and 1 for qualitative data) ready for analysis.

In all cases where the person with learning disabilities who had died was between the ages of 4 and 18, the Child Death Review Team took the lead in investigating and conducting the review of the death, but each case was then reviewed again by the CIPOLD Overview Panel, which was given full access to the reports and outcome of the Child Death Overview Panel review.

## Interviewing those involved

The number of professionals, family members and friends providing information about each death ranged from 2 to 15 per case, with a median of 7 different interviews conducted with key informants per death. For most investigations into the deaths of adults with learning disabilities, the person's main carer was interviewed, along with the person's GP and any hospital or community-based health or social care professionals who had been significantly involved with their care. Wherever possible, paid carers and family members were interviewed.

For investigations into the deaths of children with learning disabilities, information collected by questionnaire or interview would typically be sought by the Child Death Review Team from the child's family, schoolteacher or school nurse, GP and any hospital or community-based health or social care professionals who had been centrally involved with their care.

Every effort was made to contact families and engage with them. Overall, 34% of the families were interviewed and their views contributed to the reviews of these deaths. Family members of the children with learning disabilities were all interviewed by the Child Death Review Team.

The proportion of family interviews that took place was related to the amount of contact the families had had with the person who had died. We interviewed 50% of the families in regular contact with the person who had died, 21% of the families who had had limited contact with the person who had died, and 21% of the families who had had no contact with the person who had died.

We interviewed far fewer (12%) family members of comparator cases – people without learning disabilities whose deaths were reviewed in the same way. The reason for this low response may be due to 2 factors, although we have no way of testing these out. The first is that the families might not have seen the benefits of participating in a study about the deaths of people with learning disabilities. The second may be due to the way in which the families of comparator cases were approached: the National Information Governance Board approval for the CIPOLD study required all families of the comparator cases to be approached via the person's GP, whereas the families of the people with learning disabilities who died were initially approached by the GP, but in Year 2 of the study were approached directly by the CIPOLD Team.

## Notification and length of investigations

The majority (81%) of deaths of people with learning disabilities were reported to CIPOLD within a week – the median time was 2 days. The median time from the notification of the person's death to the completion of the CIPOLD review was 31 weeks.

## Choosing the comparators

The intention of the Confidential Inquiry was to select 60 comparator cases in the second year of the study, so we could compare the circumstances of death of people with and without learning disabilities. The comparator deaths were chosen on a monthly basis from listings of deaths at GP practices where a death of a person with learning disabilities had previously been recorded.

Given the potential disparity in age distribution (the literature suggests that people with learning disabilities die younger) and cause of death (the literature suggests that more of the younger deaths in the general population are related to alcohol, drugs and suicide), we decided to weight the comparator group on certain factors to produce a more balanced comparison. The weighting factors included: (i) month of death, (ii) cause of death, (iii) age, and (iv) gender. It was anticipated that far fewer comparators would have spent their final weeks in residential care homes than those with learning disabilities, but attempts were made to choose some comparators living in residential care settings, so that comparisons could take account of this. The process of investigating the deaths of the comparator group was exactly the same as for the deaths of people with learning disabilities.

## Note

- 1 Sidebotham, P., Blair, P., Evason Coombe, C. et al. (2009) Experience in One English Region Responding to Unexpected Infant Deaths. *Archives of Disease in Childhood*, published online 29 November 2009.

# Chapter 3

## The number of people included in the study

This chapter describes the number of people with learning disabilities in each PCT area whose deaths were reviewed by CIPOLD.

*There is a need to review the long-term impact of policies that exclude people with mild learning disabilities.*

**Overview Panel**





## Chapter summary

The criteria for inclusion in CIPOLD were that the death occurred between 1 June 2010 and 31 May 2012, the person had learning disabilities, was aged 4 or older, and was registered with a GP in 1 of the 5 PCT areas covered by the study.

CIPOLD reviewed the deaths of 247 people with learning disabilities in total. We think that we only missed 1 death in the study period, and this death was eventually included.

The 58 people with learning disabilities chosen for weighting with the comparators were at the younger end of the age spectrum (median age 61 years) compared with the rest of the cohort (median age 67 years). The median age of the comparators was 61 years. Overall, the weighting process was very successful.

## People with learning disabilities

CIPOLD reviewed 247 deaths of people with learning disabilities occurring between 1 June 2010 and 31 May 2012, equating to more than 120 deaths a year. Specifically these deaths were among those aged 4 and older who were registered with a GP in 1 of the 5 PCT areas in South West England.

This was 2½ more people with learning disabilities than we had initially expected. This may in part be due to greater than expected under-reporting from the death certificate data on which our original estimates were based. In part it is also likely to be due to the characteristics of the particular demographics of the study area. Over 40% of the CIPOLD cohort had been resident in long-term institutions and when these institutions closed, many of the residents settled nearby.

Table 3.1 shows the number of deaths of people with learning disabilities reviewed by CIPOLD in each of the PCT areas included in the study. There were 126 deaths in the first year of the study and 121 deaths in the second year.

**Table 3.1: Number of deaths of people with learning disabilities reviewed by CIPOLD in each PCT area from June 2010 to May 2012**

PCT area	Total population	Year 1 deaths	Year 2 deaths	Total deaths	
Bristol	433,100	51	37	88	(36%)
Gloucestershire	589,200	37	41	78	(32%)
North Somerset	209,000	16	19	35	(14%)
South Gloucestershire	262,300	13	18	31	(13%)
Bath and NE Somerset	177,700	9	6	15	(6%)
<b>Total</b>	<b>1,671,300</b>	<b>126</b>	<b>121</b>	<b>247</b>	<b>(100%)</b>

## The comparator group without learning disabilities

We collected data about 58 comparator cases. In choosing the comparators, we wanted to ensure that these deaths had broadly similar characteristics to those of the people with learning disabilities who had died. We therefore selected 1 death in the learning disability cohort for each comparator and 4 characteristics for which we wanted to achieve broad equivalence. The comparators were chosen from the same GP practices from which a person with learning disabilities had died, but as the numbers to choose from were limited, we weighted (balanced) the characteristics to achieve similar distributions in both groups rather than use direct one-to-one matching. The 4 weighting factors included: (i) month of death, (ii) broad categorisation of cause of death, (iii) age at death, and (iv) gender.

Overall, the weighting process was very successful and there were no significant differences between the subset of 58 people with learning disabilities and the 58 comparator cases with regard to month of death, underlying cause of death, age at death and gender.

Along with weighting the comparators on these 4 factors, the comparators were also chosen to maximise the number of deaths that occurred in a residential care setting (care homes, nursing homes and hospices), so that we could look at some of the issues that might be particular to those in residential care. The comparators predominantly lived in their own home (83%), compared with just 7% of those in the subset of people with learning disabilities.

## Comparing the subset of 58 people with learning disabilities with the rest of the cohort of people with learning disabilities

There were no significant differences between the deaths of the subset of 58 people with learning disabilities and the remaining 189 people with learning disabilities in the cohort regarding the weighting factors of month of death or gender. Reviewing the ICD-10<sup>1</sup> categories for cause of death suggested that the subset of 58 people with learning disabilities more frequently died from cancer and congenital or chromosomal abnormalities and fewer died from disorders related to the nervous system. The subset of 58 people with learning disabilities used for the weighting of comparators was also significantly younger than the rest of the cohort.

## Note

- 1 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

# Chapter 4

## Demographic characteristics of people with learning disabilities

This chapter describes the demographic characteristics of the people with learning disabilities whose deaths were reviewed by CIPOLD. It describes their age at death, gender, marital status, ethnicity, socio-economic markers, the cause and severity of their learning disabilities and whether they were registered with their GP as having learning disabilities.

*And he's not the only person with Down's syndrome at the surgery. It's not like they've never seen a Down's syndrome person, he's not an alien, he hasn't come down from another planet, and he's a perfectly normal person, so they should have been aware. They should have been aware of the fact that he was Down's and therefore there are certain things that are more complicated for them.*

**Mother of person with learning disabilities**



## Chapter summary

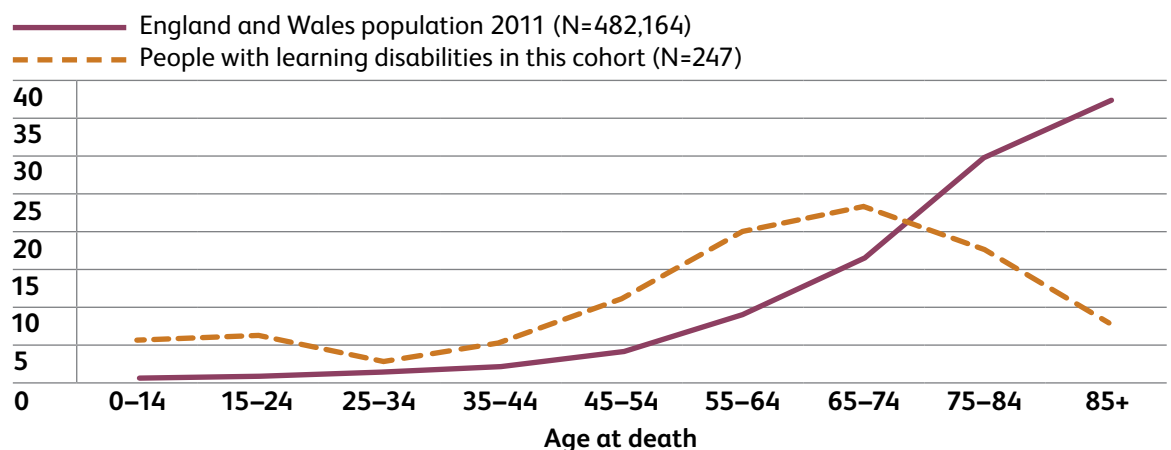
The median age of death for the 247 people with learning disabilities was 65 years for men and 63 years for women. Thus the men with learning disabilities in the CIPOLD study died on average 13 years earlier than in the general population, while the women with learning disabilities died 20 years earlier. Nearly a quarter of people with learning disabilities in the CIPOLD study were under the age of 50 when they died, compared with approximately 9% of the general population.

Over a half of the people with learning disabilities were men. The majority were single. Almost all were of white UK ethnicity, which is a significant under-representation of people of non-white UK ethnicity. The cause of a person's learning disability was unknown for more than half, although identified genetic syndromes accounted for a quarter, of which almost half had Down's syndrome. Of those whose deaths were reviewed, 40% had mild learning disabilities, 31% had moderate learning disabilities, 21% had severe learning disabilities and 8% had profound and multiple learning disabilities. The majority (92%) of adults were identified on a GP register as having learning disabilities.

## Age at death

The median age at death for the 247 people with learning disabilities who died was 64 years, ranging from 4 to 96 years. The age at death distribution of people with learning disabilities is in sharp contrast with age at death for the general population in England and Wales in 2011 (Figure 4.1). Nearly a quarter (22%) of people with learning disabilities in the CIPOLD study were under the age of 50 when they died, compared with approximately 9% of the general population. The median age of death in the general population in 2011 was 78 years for men and 83 years for women, compared with 65 years for men and 63 years for women among those with learning disabilities. Thus the men in the CIPOLD study died on average 13 years earlier than in the general population, while the women died 20 years earlier.

Figure 4.1: Age at the time of death of people with learning disabilities compared with the population of England and Wales



These findings confirm that people with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. This was especially so for people with Down's syndrome: their median age of death (60 years) was significantly lower than that of people with learning disabilities who did not have Down's syndrome, whose median age at death was 66 years.

## Gender

Of the people with learning disabilities whose deaths were reviewed by the CIPOLD study, over half (58%) were men.

## Marital status

Most (93%) of the people with learning disabilities were single. A small proportion were married (4%), or divorced, widowed or separated (3%). Of those who were single, about a quarter had 1 or more significant friendship.

## Ethnicity

Almost all (96%) of the people with learning disabilities were of white UK ethnicity, the remaining 10 people being described as being of Irish, non-UK white, Gypsy and Traveller, Pakistani, African or Caribbean backgrounds. This is a significant under-representation of people from non-white UK ethnicity in CIPOLD, and the findings of this Confidential Inquiry should be interpreted with this in mind.

## Socio-economic deprivation, employment and education

The people with learning disabilities lived in slightly more deprived areas than the population of the area as a whole in 4 of the 5 PCT areas. The majority of people with learning disabilities lived in residential homes, so the data reflects where these homes are sited rather than the socio-economic circumstances of the people living in the homes. Other markers of socio-economic position, such as educational attainment or type of occupation, were not possible to use for the CIPOLD cohort, due to the small number of people in any type of education and knowledge about education in childhood being poor.

## Causes of a person's learning disabilities

The cause of a person's learning disability was unknown for over half (56%) of the 247 adults and children with learning disabilities who died. Identified genetic syndromes accounted for a quarter of the cohort (25%), of which almost half (13% overall) had Down's syndrome. Learning disabilities acquired *in utero* or in the perinatal period (up to 1 week after delivery) accounted for 11% of learning disabilities, and 8% were acquired postnatally in childhood.

## Severity of learning disabilities

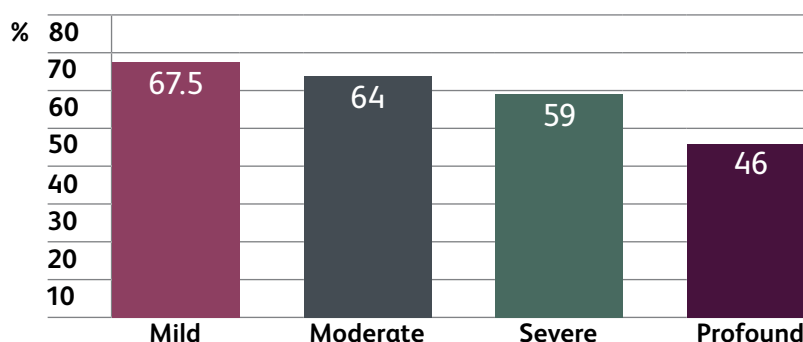
Of the 247 adults and children with learning disabilities, 40% had mild learning disabilities, 31% moderate, 21% severe and 8% had profound and multiple learning disabilities (Table 4.1). Compared with national data, our cohort is over-represented by those with severe or profound and multiple learning disabilities among both adults and children.

Table 4.1: Severity of learning disabilities

Severity	Children %	Adults %	All %
Mild	21	41	40
Moderate	36	31	31
Severe	29	21	21
Profound and multiple	14	7	8
<b>Total</b>	<b>100%</b> <b>(N=14)</b>	<b>100%</b> <b>(N=233)</b>	<b>100%</b> <b>(N=247)</b>

The age at death decreased with increasing severity of learning disabilities (Figure 4.2). Essentially, the more severe a person's learning disabilities, the younger they were likely to die. Even so, the median age at death in those with mild disabilities was still considerably younger (71 years in men and 65 years in women) than in the general population (78 years for men and 83 years for women).

Figure 4.2: Median age of death by severity of learning disabilities



## Identification of people with learning disabilities on GP registers

Almost all (92%) of the adults with learning disabilities were identified as being on a register of people with learning disabilities held by their GP practice. This was the case for 100% of those with profound and multiple learning disabilities, 100% of those with severe learning disabilities, 96% of those with moderate learning disabilities and 83% of those with mild learning disabilities.

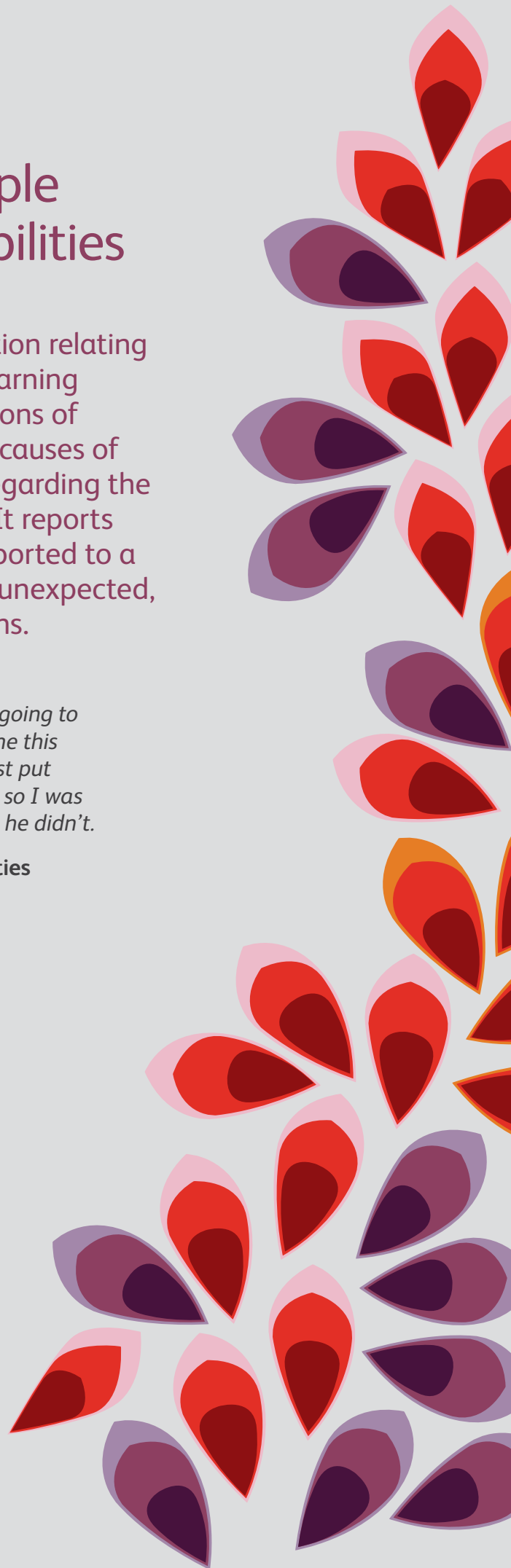
# Chapter 5

## The deaths of people with learning disabilities

This chapter describes information relating to the deaths of people with learning disabilities. It includes descriptions of the underlying and immediate causes of death, temporal information regarding the death and the place of death. It reports on the proportion of deaths reported to a coroner, and the proportion of unexpected, premature and avoidable deaths.

*The doctor was talking as though he was going to pull him out of it because he said next time this happens the best thing for you to do is just put him nice and comfortable and let him go, so I was thinking he was going to pull through but he didn't.*

**Mother of person with learning disabilities**





## Chapter summary

The underlying causes of death for the largest proportions of people with learning disabilities were disorders relating to the heart and circulatory disorders (22%) and cancer (20%). This was a similar pattern to the general population. A greater proportion of people with learning disabilities had their underlying cause of death recorded as a disorder relating to the nervous system or due to congenital and chromosomal abnormalities than did the population of people in England and Wales as a whole.

The immediate cause of death is the final condition that led to death. The most prevalent immediate cause of death in people with learning disabilities was respiratory disorders, followed by heart and circulatory disorders.

Using the CIPOLD definition of unexpected death, 43% of deaths reviewed by CIPOLD were unexpected. Using ICD-10 codes of underlying causes of death that can be assumed to cause an unexpected death, the CIPOLD data was similar to that of England at about 25%.

Using the CIPOLD pathway approach to identifying premature death, 42% of deaths were considered to be premature. The most frequent reasons given for a death to be premature was because of delays or problems with treatment, or because of problems with assessing or investigating the cause of illness.

Of the deaths reviewed by CIPOLD, over a quarter (27.5%) were amenable to better-quality healthcare. Just under half would be considered to be avoidable using the Office for National Statistics (ONS) definition.

## Underlying and immediate cause of death

Cause of death certificates state the immediate, direct cause of death and then go back through the sequence of events or conditions that led to the death until the underlying cause of death, that which initiated the fatal sequence, is reached. Most routine mortality statistics are based on the underlying cause of death. In addition, cause of death certificates will also note 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.

The individual ICD-10 codes for underlying cause of death in our study have been provided by the ONS, which matched the NHS numbers or personal details against its records; for 3 individuals, which the ONS coding for their cause of death was not available.

First we looked at the broad categorisation of underlying cause of death, considering deaths from cancer, heart and circulatory disorders, respiratory disorders and 'other' causes. Table 5.1 shows this broad categorisation for men and women in England and Wales in 2011 and for those with learning disabilities in the CIPOLD study.

Table 5.1: Broad categories of common underlying causes of death for those with learning disabilities and the general population (England and Wales in 2011)

Broad category	Gender	England and Wales 2011			CIPOLD (learning disabilities)		
		N	(%)	Median age	N	(%)	Median age
Cancer (neoplasm)	Male	75,323	(32)	75–79 yrs	31	(22)	60–64 yrs
	Female	67,858	(27)	75–79 yrs	19	(19)	55–59 yrs
Heart and circulatory	Male	69,587	(30)	75–79 yrs	36	(25)	65–69 yrs
	Female	70,119	(28)	85–89 yrs	17	(17)	70–74 yrs
Respiratory disorders	Male	32,033	(14)	80–84 yrs	21	(15)	65–69 yrs
	Female	35,657	(14)	85–89 yrs	17	(17)	70–75 yrs
Other	Male	57,717	(25)	—	54	(38)	—
	Female	76,073	(30.5)	—	49	(48)	—
Total number of deaths	Male	<b>234,660</b>	<b>(100%)</b>	—	<b>142</b>	<b>(100%)</b>	—
	Female	<b>249,707</b>	<b>(100%)</b>	—	<b>102</b>	<b>(100%)</b>	—

Source: Office for National Statistics. Deaths registered in England and Wales in 2011 for age 28 days and over ([www.ons.gov.uk/ons/taxonomy/index.html?nscl=Causes+of+Death](http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Causes+of+Death))

The most common cause of death in England and Wales in 2011 was cancer (30%), slightly more common among men than women and with a median age of death between 75 and 79 years for both gender groups. Deaths from cancer in those with learning disabilities were less prevalent (20%), again slightly more common among men, but occurred at a much younger age than in the general population, especially among women (median age of death: 55–59 years).

The second most common underlying cause of death in England and Wales in 2011 was heart and circulatory disorders (29%), which were almost as common in men and women and notably occurred at a much later age in women (85–89 years). Deaths from heart and circulatory disorders were less prevalent in those with learning disabilities (22%), were notably less prevalent in women (17%) and occurred at a younger age for both gender groups than in the general population.

The third most common underlying cause of death in the general population was respiratory disorders (14%), which were equally common in men and women. Deaths from respiratory disorders were only slightly more prevalent (16%) in people with learning disabilities, and occurred at an earlier age than in the general population but with a similar gender gradient of women dying at a later age.

Of those labelled ‘other’ underlying causes of death in this broad categorisation, mental and behavioural disorders (6%) and diseases of the nervous system (4%) were the most prevalent in the general population, while diseases of the nervous system (15%) and deaths related to congenital and chromosomal disorders (7%) were the most prevalent among those with learning disabilities.

Looking more closely at age of death for those with learning disabilities (Figure 5.1), deaths due to heart and circulatory disorders and respiratory deaths were more common in the older age groups, while deaths caused by cancer were rather more evenly spread across the age range. ‘Other’ underlying causes of death were more typical of the younger age groups, in particular the median ages of people dying from congenital and chromosomal disorders (45 years) and disorders of the nervous system (49.5 years).

Figure 5.1: Broad category of death by age group

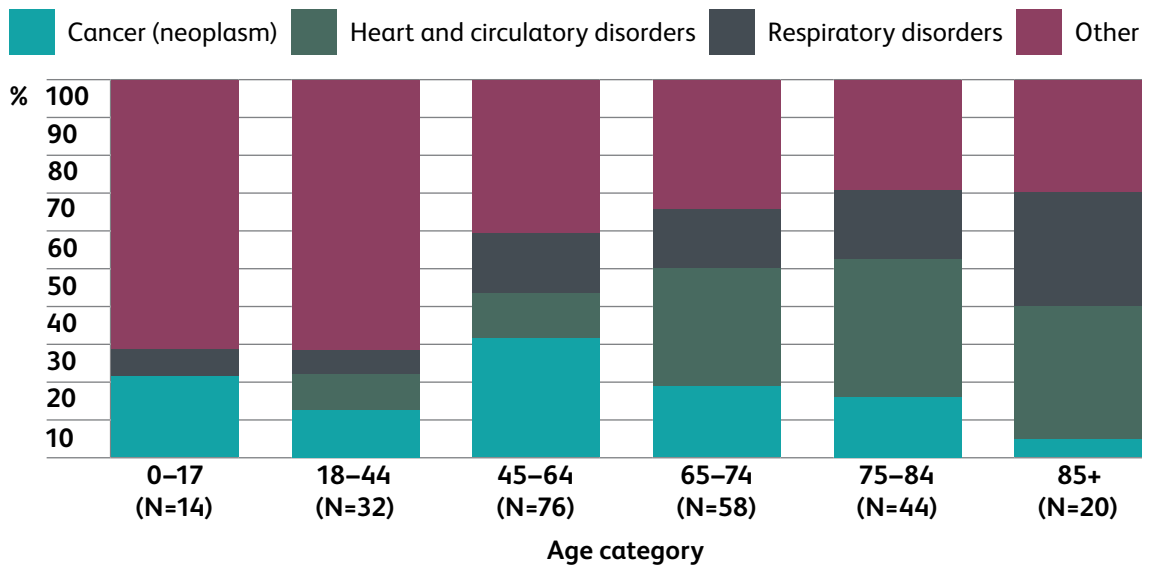


Table 5.2 presents the underlying cause of death in more detail, comparing the prevalence for England and Wales in 2011 and those with learning disabilities in the CIPOLD study. Table 5.2 also provides a breakdown of the immediate cause of death, the final condition that led to death, i.e. the ‘cause’ of death given at 1a on the cause of death certificate.

Table 5.2: The underlying and immediate cause of death (ICD-10 categories)

ICD-10 category of cause of death	Underlying causes			Immediate causes	
	Proportion in England and Wales 2011	LD deaths in the study period		LD deaths in the study period	
		N	%	N	%
Cancer (neoplasm)	30	50	20	35	15
Heart and circulatory disorders <sup>1</sup>	29	53	22	52	21
Respiratory disorders	14	38	16	82	34
Mental and behavioural disorders	6	8	3	3	1
Digestive system	5	9	4	10	4
Nervous system	4	38	16	23	10
External causes	4	10	4	7	3
Abnormal clinical and lab findings <sup>2</sup>	2	3	1	10	4
Genitourinary system	2	4	2	2	1
Endocrine, nutritional & metabolic	1	5	2	1	<0.5
Infections	1	1	<0.5	12 <sup>3</sup>	5
Musculoskeletal system	1	4	2	0	0
Skin and subcutaneous tissue	<0.5	1	<0.5	1	<0.5
Congenital and chromosomal	<0.5	18	7	1	<0.5
Diseases of blood	<0.5	1	<0.5	3	1
Other <sup>4</sup>	<0.5	1	<0.5	0	0
<b>Total</b>	<b>100%</b>	<b>244</b>	<b>100%</b>	<b>242</b>	<b>100%</b>

Notes: 1 Includes cerebrovascular disease

2 Not otherwise specified

3 The majority of infections were pneumonia related

4 Includes i) diseases of the eye and adnexa; ii) diseases of the ear and mastoid process; iii) deaths related to pregnancy, childbirth and the puerperium; iv) conditions originating in the perinatal period; v) injury and poisoning

In terms of the underlying causes of death, a smaller proportion of people with learning disabilities died of cancer or heart or circulatory disorders than in England and Wales as a whole. However, a greater proportion of people with learning disabilities died of disorders relating to the nervous system (most commonly deaths due to cerebral palsy or epilepsy) or from congenital and chromosomal abnormalities (most commonly deaths reported as being due to Down's syndrome or congenital heart malformations) than the proportion of people in England and Wales as a whole.

The most prevalent immediate cause of death (i.e. the final condition that led to death) in people with learning disabilities was due to respiratory disorders (median age 67 years).

Three deaths of people with learning disabilities were categorised by the Overview Panel as being due to *'deliberately inflicted injury, abuse or neglect'*.

## Seasonality and day and time of week of death

The number of deaths for each month was fairly uniform, with the proportion of deaths being between 5% and 10% each month. There was no excess of deaths of people with learning disabilities in the coldest quarter of the year. The day of the week on which the death occurred, and the time of day of death, was also fairly uniform.

## Place of death

CIPOLD data suggests that a slightly smaller proportion of people with learning disabilities died in hospital (46%) than in the general population (54%). More than twice the proportion of people with learning disabilities died in a residential care setting.

## Certification of death

Table 5.3 summarises the certification of deaths in the CIPOLD study compared with national data. We found that learning disabilities was mentioned on the cause of death certificate for less than a quarter (23%) of people. People with profound and multiple learning disabilities were identified as having a condition associated with learning disabilities much more frequently (58%) than those with mild learning disabilities (9%).

Table 5.3: Death certification by severity of learning disabilities

	Severity of learning disabilities					General population %
	Mild	Moderate	Severe	Profound	Total	
	% (N=98)	% (N=77)	% (N=53)	% (N=19)	% (N=247)	
LD mentioned on the death certificate	9	27	30	58	23	40 <sup>1</sup>
Death reported to the coroner	39	36	40	32	38	46 <sup>2</sup>
	Of all deaths reported to the coroner					
	% (N=38)	% (N=28)	% (N=21)	% (N=6)	% (N=93)	
Post-mortem performed	95	100	28	83	90	42 <sup>2</sup>
Inquest carried out	8	25	24	16	17	14 <sup>2</sup>

Notes: 1 Glover, G. and Ayub, M. (2010) *How people with learning disabilities die*. Durham: Improving Health and Lives Learning Disability Observatory

2 Ministry of Justice Coroners Statistics 2011 England and Wales

The proportion of all registered deaths in England and Wales reported to coroners was estimated to be 47% in 2010. This was more than the 38% of deaths reported to the coroner in CIPOLD. In a number of cases, the Overview Panel had concerns that deaths should have been reported to the coroner when they had not been. Some of these deaths had occurred soon after hospital admission in circumstances in which the treating hospital doctor could not be sure of the cause of death, or when the circumstances preceding the hospital admission raised concerns about possible abuse or neglect. No discernible pattern was observed regarding the severity of a person's learning disabilities and whether or not the death was reported to the coroner.

A much larger proportion of the CIPOLD deaths that were reported to the coroner had a post-mortem examination (90%) than did people in the general population (46%) whose deaths were reported to the coroner. There was no discernible pattern observed regarding the severity of learning disabilities and whether or not a post-mortem was performed.

The Overview Panel expressed a number of concerns relating to the length of time it took for some post-mortem reports to be made available and the quality and accuracy of information in reports. In some cases, it was apparent that the medical history given to the pathologist had been very limited and, importantly, potentially contributory factors that might have been considered were thus missed. In other cases, no histology, bacteriology or toxicology screens had been performed in circumstances in which it was quite possible that 1 or more of these investigations might have shed important light on the cause of death.

Of some concern too was the attribution of unexpected deaths to 'sudden unexpected death in epilepsy' (SUDEP) in people with a past history of epilepsy (sometimes without having had a seizure for many years) with very limited further investigations undertaken, such as blood levels for relevant anti-convulsant medication.

The proportion of CIPOLD deaths reported to the coroner and which had an inquest opened was 17%, similar to that of the general population. Derek's death (see below) is an example of where the CIPOLD review considered that a fuller investigation should have been undertaken and an inquest opened.

### Case study – Derek

Derek was in his late 40s and had moderate learning disabilities. He lived alone in supported living accommodation. He had no contact with any family. He was supported by 2 different care agencies, but there was evidence of a lack of coordination and communication between the carers, and a lack of monitoring of the situation. From the care records it was not at all clear that he was getting the 23 hours of carer support each week that was being paid for. Derek had had difficult relationships with neighbours in the past. He was known to be vulnerable, and would let people into his flat even though he did not want them there. In the past he had had money taken from him and had engaged in sexual activities he did not want. A few weeks before his death Derek was noted by one of his carers to have unexplained marks on his body. Derek was found dead in his flat. His death was unexpected. He was sitting on the sofa with his clothes and shoes on, and the door to the flat was ajar. A post-mortem examination gave his cause of death as being an epileptic seizure, although Derek had not had a seizure for more than 15 years and this was inconsistent with the observation of his body when he was found. No toxicology or histology examination was performed, the police were not involved and no inquest was held.

### Unexpected deaths

Unexpected deaths were those defined in CIPOLD as 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*'. Using this definition, the Overview Panel came to the decision that over half (57%) of deaths were expected, and 43% of the deaths were unexpected.

Looking at the data in a different way, the National End of Life Care Intelligence Network (2011) has drawn out the ICD-10 codes of underlying causes of death on death certificates that can be assumed to cause an unexpected death. These include the underlying causes of death such as acute myocardial infarction, pulmonary embolism, pulmonary aneurysm, and cerebrovascular disease. They suggest that 25% of deaths reported in England between 2006 and 2008 had an underlying cause that was unexpected, a similar proportion found in the CIPOLD study (Table 5.4).

Table 5.4: Unexpected deaths

Unexpected deaths		LD deaths		English population 2006–2008
		n/N=247	%	%
<b>Overall</b>		<b>57/247</b>	<b>23</b>	<b>25</b>
By age	0–64	19/125	15	17
	65–84	31/102	30	23
	85+	7/20	35	31
By gender	Male	30/143	21	24
	Female	27/104	26	26

## 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’. This approach allowed consideration of 2 issues. One was whether something had (or had not) happened in the care of the person that may have contributed to the death. The second was that additional life-limiting factors (such as lifestyle or co-morbidities) and demographics (such as gender or socio-economic status) could also be considered. By exploring the ‘pathway’ leading to that death, a transparent rationale could be given as to why the death was thought to be premature or not which did not solely rely on age or cause of death. This provided a close fit with the purpose of the CIPOLD Inquiry, which was to illuminate any extra risks that people with learning disabilities face.

Overall, the Overview Panel agreed that 42% of the deaths were premature. As Table 5.5 shows, significantly more of the premature deaths were at younger ages, although older age in itself did not negate the possibility of premature death; a fifth (20%) of those aged 75 or more were considered premature deaths. Premature deaths did not differ significantly by gender, the severity of a person’s learning disabilities or whether the person lived in a residential care setting.



Table 5.5: Premature deaths

		n/N	%	P-value <sup>1</sup>
<b>Overall</b>		<b>100/238</b>	<b>42</b>	
By age	0–17 years	4/13	31	
	18–44 years	21/33	64	
	45–54 years	14/24	58	
	55–64 years	22/50	44	
	65–74 years	27/57	47	
	75–84 years	10/43	23	
	85+ years	2/18	11	p=0.006
By gender	Male	57/138	41	
	Female	43/100	43	p=0.88
By LD severity	Mild	38/97	39	
	Moderate	32/72	44	
	Severe	22/52	42	
	Profound	8/17	47	p=0.79
By accommodation	Residential	60/150	40	
	Non-residential	40/88	46	p=0.41

Note: 1 Chi-square test

The 2 most frequently given reasons why the deaths were premature were that there had been delays or problems with a person’s treatment (36%) and problems with assessing or investigating the cause of illness (29%). For some people with learning disabilities, up to 4 reasons for premature death were given.

## Avoidable deaths

One way of assessing whether a death is premature or not at a population level is to consider avoidable deaths. The UK ONS developed a set of national indicators of avoidable mortality in 2012. The definition of avoidable deaths is as follows:

- **Amenable mortality:** A death is amenable if, in the light of medical knowledge and technology at the time of death, all or most deaths from that cause (subject to age limits if appropriate) could be avoided through good-quality healthcare.
- **Preventable mortality:** A death is preventable if, in the light of understanding of the determinants of health at the time of death, all or most deaths from that cause (subject to age limits if appropriate) could be avoided by public health interventions in the broadest sense.

- **Avoidable mortality:** Avoidable deaths are all those defined as preventable, amenable, or both, where each death is counted only once. Where a cause of death falls within both the preventable and amenable definition, all deaths from that cause are counted in both categories when they are presented separately.

Just under half of the deaths (48%) in the CIPOLD cohort were avoidable (Table 5.6). Avoidable deaths were less prevalent among those aged 75 or older, and there was a significantly higher prevalence of avoidable deaths in people with learning disabilities not living in a residential care setting.

Table 5.6: Avoidable deaths

		n/N	%	P-value <sup>1</sup>
Overall	Amenable	67/244	28	
	Preventable	29/244	12	
	Amenable and preventable	23/244	9	
	Not avoidable	125/244	51	
By age	0–17 years	7/14	50	
	18–44 years	21/32	66	
	45–54 years	17/27	63	
	55–64 years	28/49	57	
	65–74 years	42/58	72	
	75–84 years	3/44	7	
	85+ years	1/18	6	p<0.001
By accommodation	Residential	62/155	40	
	Non-residential	57/89	64	p<0.001
By LD severity	Mild	44/96	46	
	Moderate	38/77	49	
	Severe	28/53	53	
	Profound	9/18	50	p=0.87
By gender	Male	69/142	49	
	Female	50/102	49	p=0.95

Note: 1 Chi-square test

The NHS Outcomes Framework stipulates mortality from causes considered amenable to healthcare to be an overarching indicator for preventing people from dying prematurely. Over a quarter (27.5%) of the deaths reviewed by CIPOLD were amenable to change with good-quality healthcare.

Table 5.7 compares deaths that are specifically amenable to change with the deaths in the rest of the CIPOLD cohort. The difference in age was quite striking: the median age of the deaths that could be avoided by good-quality healthcare was 54 years old, compared with the median age of death at 68 years of age in the rest of the cohort. The difference in the severity of a person’s learning disabilities was also striking: people with more severe learning disabilities were significantly more likely to have had deaths that could have been avoided by good-quality healthcare interventions. The underlying cause of death was also significantly associated with amenable deaths. Deaths related to the nervous system, congenital and chromosomal abnormalities and the respiratory system were all more likely to be avoided by good-quality healthcare interventions. Of significance too was whether a person was married, had a partner or had a significant friend. Those whose deaths were amenable to good-quality healthcare interventions were less likely to have had such a significant person in their life.

**Table 5.7: Amenable deaths compared to the rest of the cohort**

		Amenable deaths	Rest of cohort	P-value <sup>1</sup>
		% (N=67)	% (N=177)	
<b>By age</b>	0–17 years	7	5	
	18–44 years	28	7	
	45–54 years	16	9	
	55–64 years	21	20	
	65–74 years	27	23	
	75+ years	0	36	p<0.001
<b>By LD severity</b>	Mild	16	48	
	Moderate	37	29	
	Severe	34	17	
	Profound	12	6	p<0.001
<b>Underlying cause of death</b>	Neoplasm	6	26	
	Heart	12	25	
	Respiratory	21	14	
	Nervous system	28	11	
	Congenital/	27	0	
	Other	6	24	p<0.001
<b>Married, partner or significant friend</b>	Yes	12	32	
	No	88	68	p=0.01
<b>By accommodation</b>	Residential	42	35	
	Non-residential	58	65	p=0.29
<b>By gender</b>	Male	54	60	
	Female	46	40	p=0.38

Note: 1 Chi-square test

# Chapter 6

## The health and social care needs of people with learning disabilities

This chapter describes the health and social care needs of the people with learning disabilities whose deaths were reviewed by CIPOLD. It includes information about health behaviours and conditions, health promotion and screening, and accommodation and support needs. It highlights just how vulnerable the people with learning disabilities were in terms of the support that they required to meet their health and care needs.

*When he came here to us, he did that every week, then we would walk him up and down our hall to keep him walking. But they were not allowed to do this apparently at the residential home ... and he lost the ability to walk.*

**Sister of person with learning disabilities**



## Chapter summary

The profiles of the people with learning disabilities who died indicated that many of them were at considerable risk of a range of vulnerabilities. Thus, when reviewing their deaths, we need to be mindful of the disadvantage that these vulnerabilities, individually or in combination, placed them at.

The Body Mass Index (BMI) profile of the people with learning disabilities whose deaths were reviewed was very different from that of the general population, with a significantly greater proportion of the CIPOLD deaths being underweight. Those who were underweight had a lower median age at death than those who were of optimal weight, overweight or obese.

As well as a high prevalence of impairments, people with learning disabilities had multiple medical conditions: the median number of conditions per person was 5; and a fifth of those who died had 7 or more medical conditions. The most frequently reported long-term conditions were epilepsy, cardiovascular disease and hypertension. The median number of medications that were prescribed to each person was 7. National Institute for Health and Clinical Excellence (NICE) Guidelines are mostly based on single conditions, rather than the pattern of multi-morbidity found in the CIPOLD cohort, a factor that can make people with learning disabilities particularly vulnerable.

The majority of people with learning disabilities had received an Annual Health Check in the previous year, but there was no relationship between this and a person having a Health Action Plan. A fifth had a hospital 'passport'-type document, but there was no evidence to suggest that this supported medical staff in coordinating the needs of a person with multiple co-morbidities. More than a third had difficulties in identifying or verbally communicating any pain they had, but in almost all cases there was no evidence of any formally documented pain assessment tool. Access to cancer screening services was variable, but people with learning disabilities appeared to have most problems with accessing the bowel screening programme.

Two-fifths of the adults with learning disabilities included in CIPOLD had lived in a long-term institution in the past; those with the more severe disabilities had been admitted at a younger age and had spent a longer time in an institution. At the time they died, nearly two-thirds lived in a residential care home, either with or without nursing.

The majority of the people with learning disabilities required support in many areas of their life; as well as with accessing healthcare, they required support with their mobility, eating and drinking, continence, decision-making and literacy. However, more than a quarter had not had their support reviewed for over a year, if at all – a particularly important vulnerability factor, as evidenced in the recent review of abuse at Winterbourne View, and because more than 1 in 10 of the people with learning disabilities in the CIPOLD cohort had had previous safeguarding concerns investigated.

## Health behaviours

### Body Mass Index (BMI)

BMI is a commonly used measure to assess the amount of body fat a person has. It is calculated by using height and weight measures. A BMI of 18.5 to 25 indicates optimal weight; a BMI lower than 18.5 suggests that the person is underweight; a score from 25 to <30 suggests that the person is overweight and a score of 30 or more that the person is obese.

BMI cannot be regarded as an accurate measure in children or in people who are frail or ill. We have therefore calculated the BMI for the CIPOLD cohort of adults who had not had significant weight loss in the year prior to their death, and compared this with data from the Health Survey for England.<sup>1</sup>

Table 6.1 shows that there was an excess of people with learning disabilities who were underweight compared with the general population, an eightfold difference in both men and women. The difference between CIPOLD data and the Health Survey for England for those who were obese was significant among the women, but not among the men.

**Table 6.1: BMI status of adults with learning disabilities compared with the general population (removing those with rapid or significant weight loss in year prior to death)**

BMI status	Males		Females	
	People with learning disabilities	General population <sup>1</sup>	People with learning disabilities	General population <sup>1</sup>
	%	%	%	%
Underweight	16	2	18	2
Normal weight	35	32	25	41
Overweight	21	44	26	33
Obese	28	22	31	24
<b>Total</b>	<b>100% (N=82)</b>	<b>100%</b>	<b>100% (N=61)</b>	<b>100%</b>

Source: <sup>1</sup> The Health Survey for England (2009) people aged 16 and over. Data has been weighted for non-response (N=2,055 males and 2,045 females)

There was a significant difference in the age at death of people in the CIPOLD cohort according to their BMI. The median age at death was highest among those with optimal weight (69.5 years), lower for those who were overweight (65 years), lower still for those who were obese (62 years), but lowest of all for those who were underweight (57.5 years).

## Smoking and alcohol use

Compared with the general population, fewer of the people with learning disabilities smoked: only 24% of men and 12% of women were reported to have ever smoked, compared with 51% men and 42% women in the general population. The median age of death of people with learning disabilities who were current or ex-smokers was 63 years, compared with 73 years among those who had never smoked – a significant difference.

Few of the people with learning disabilities had current or previous problems with alcohol or drugs: 6 were reported to have misused alcohol and 2 had misused drugs.

## Impairments of people with learning disabilities

Table 6.2 lists the impairments of people with learning disabilities.

Table 6.2: Impairments of people with learning disabilities

Adverse condition		% (N=247)
<b>Mobility (usual)</b>	Independent	34
	Some support	48
	Total support	18
	<b>Total</b>	<b>100%</b>
<b>Mobility (prior to death)</b>	Independent	13
	Some support	24
	Total support	63
	<b>Total</b>	<b>100%</b>
<b>Sensory problems</b>	Vision	51
	Hearing	29
	Vision and hearing <sup>1</sup>	21
<b>Verbal communication</b>	Good	48
	Limited	30
	None	22
	<b>Total</b>	<b>100%</b>
<b>Psychological problems</b>	Behaviour problems	55
	Emotional problems	54
	Diagnosed with mental health problems <sup>2</sup>	39
	Ever self-harmed	16

Notes: 1 This is not a mutually exclusive category but calculated from the combination of the vision and hearing variables

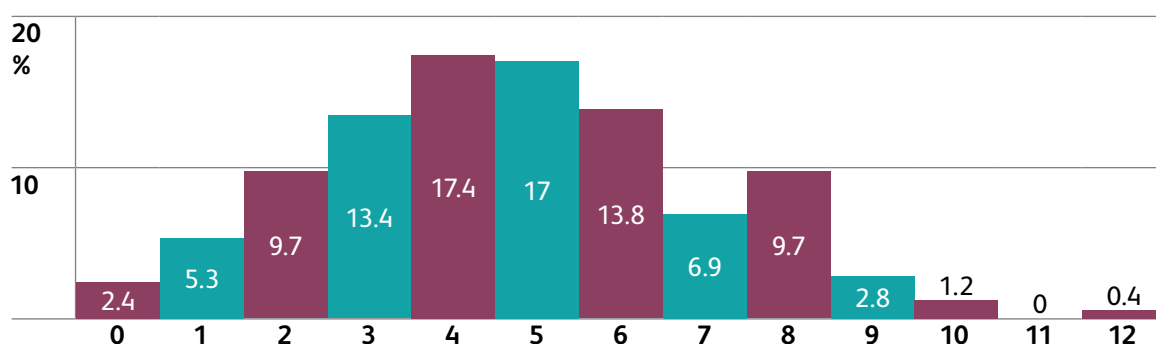
2 This does not automatically include 12/247 (4.9%) diagnosed with Autism unless they were diagnosed with additional mental health problems

As Table 6.2 shows, only a third (34%) had independent mobility and this proportion fell to 13% in the period leading up to death. Half of the cohort had problems with vision and over a quarter had a problem with their hearing; over a fifth (21%) had problems with both vision and hearing. Verbal communication was limited for 30% and a further 22% were described as being unable to communicate verbally. More than half the cohort had behavioural or emotional problems, 39% had been diagnosed with a mental health problem, and 16% had engaged in self-harm.

## Medical conditions of people with learning disabilities

As well as a high prevalence of impairments, people with learning disabilities had multiple medical conditions. Most (98%) had 1 or more long-term health conditions or treatable medical conditions prior to death (Figure 6.1). The median number of conditions per person was 5 and a fifth of those who died (21%) had 7 or more medical conditions.

Figure 6.1: Number of long-term or treatable health conditions per person



### Long-term health conditions

Long-term conditions are those that generally cannot be cured, but can be managed with treatment. Table 6.3 lists the long-term health conditions that the people with learning disabilities were reported to have had.



Table 6.3: Long-term health conditions

Condition	% (N=247)
Epilepsy (ever diagnosed)	43
Cardiovascular disease	39
Hypertension	22
Arthritis or osteoarthritis	14
Dementia	14
Hypothyroidism	14
Osteoporosis	13
Gastrostomy feeding	12
Asthma	10
Cerebral Palsy	10
Diabetes (Type 2)	9
Chronic Obstructive Pulmonary Disease (COPD)	7
Degenerative condition (neuro or muscular)	5
Diabetes (Type 1)	3

The most common long-term condition was epilepsy: 43% of people with learning disabilities had been diagnosed with epilepsy and of these, 72% had experienced a seizure within the last 5 years. Thus, 31% of the whole cohort of people with learning disabilities had experienced a seizure in the previous 5 years. We are aware that a number of people with learning disabilities had received a label of epilepsy and remained on treatment, despite not having had a seizure for very many years. Even so, the prevalence of reported epilepsy in our cohort (43% who had ever been diagnosed with epilepsy, and 31% who had had a seizure in the previous 5 years) is considerably greater than that reported in other studies. In all, 10 people with learning disabilities had a cause of death reported as ‘sudden unexpected death in epilepsy’ (SUDEP). Of those 10 people, 5 were men and 5 were women; 2 had mild, 2 had moderate, 5 had severe learning disabilities and 1 had profound and multiple learning disabilities. Their median age at death was 34 years.

Cardiovascular disease (39%) and hypertension (22%) were also quite common among the CIPOLD cohort.

The prevalence of dementia in the CIPOLD cohort was 14%, and was higher among older adults with learning disabilities than in the general population (16% in the over-65s in the CIPOLD cohort, compared with 6% in the general population). The prevalence of dementia was also high in those under the age of 65 (14%) and especially in those with Down’s syndrome: 22 of the 32 people with Down’s syndrome had dementia (69%), with a median age of 61.5 years at death.

The CIPOLD cohort prevalence of 13.4% with osteoporosis is more than double the prevalence in the general population.

On average, people with learning disabilities had 2 long-term conditions. Only 11% had none and 17% had 4 or more.

### Treatable medical conditions

People with learning disabilities were additionally reported to have had a range of other potentially treatable medical conditions. Table 6.4 lists the most frequently reported treatable conditions prior to death among people with learning disabilities, along with whether people had these conditions at the time of death. The most commonly reported treatable conditions were constipation (37%), pressure sores (34%) and gastro-oesophageal reflux (33%).

Table 6.4: Treatable medical conditions

Condition	Ever had the condition prior to death	Had the condition at death
	% (N=247)	% (N=247)
Constipation	37	—
Pressure sores	34	17
Gastro-oesophageal reflux or regurgitation	33	—
Pneumonia	28	39
Sleeping problems	25	—
Skin problems	23	—
Significant surgery in the past year	20	—
Allergies	12	—
Anaemia	10	—
Deep vein thrombosis/pulmonary embolus	6	6
Cancer	4	21

On average, people with learning disabilities experienced 2 of these treatable conditions at some point in their lives. Just 8.5% of people with learning disabilities had none of these conditions and 25.5% had 4 or more conditions.

## Medications

The vast majority of people with learning disabilities (97%) were on some sort of medication prior to death. The median number of medications was 7, but some people had up to 21 medications prescribed for them. The most commonly prescribed medication was for epilepsy (39%). More than half (51.5%) of those on epilepsy medication were on at least 2 types, and 5% were on between 5 and 7 medications for this condition alone.

There was a significant difference in the prescribing of opioid analgesics<sup>2</sup> according to severity of learning disabilities. Opioid analgesics were more commonly prescribed for people with mild learning disabilities (37%) than for those with moderate (16%), severe (17%) or profound and multiple (21%) learning disabilities.

## Preventative care and health promotion

### Annual health checks

The majority (71%) of people on a register of people with learning disabilities at their GP surgery had received an Annual Health Check in the year prior to their death (Table 6.5). More than 1 in 10 (12%) were reported to have never had an Annual Health Check. Of note is an observation that the quality and recording of Annual Health Checks appeared to be very varied. There was no particular type of approach taken, some did not cover key aspects of care (such as asking about post-menopausal bleeding, or assessing cardiovascular risk factors), and many were so poorly documented that it was difficult to be sure that a full health assessment had been conducted.

**Table 6.5: Recent Health Check among adults identified as being on the GP practice learning disability register**

Time period	%
<1 month	19
1–<3 months	10
3–<6 months	18
6–<12 months	24
12 months or more	17
Never had a Health Check	12
<b>Total</b>	<b>100% (N=196)</b>

## Cardiovascular disease risk assessment

Few people with learning disabilities had had a cardiovascular disease risk assessment (9%). Of the 53 people with learning disabilities whose underlying cause of death was related to the heart and circulatory system, just 15% had had a cardiovascular disease risk assessment recorded.

## Health Action Plans

A Health Action Plan was found for a third (34%) of the cohort on a GP register of people with learning disabilities. Whether a person with learning disabilities had a Health Action Plan or not had little bearing on whether they had had a recent Annual Health Check from their GP.

Where Health Action Plans were in place, they seemed to have been used with some degree of effectiveness to facilitate better personal control, as an aide-memoire to the person themselves about the actions that they should be taking to maintain good health, or to document information about particular aspects of the person's health, such as their wishes for their end-of-life care, or their targets for losing weight. However, there was little evidence that Health Action Plans were used as a mechanism to link people with the range of services and supports that they received, or to share information about them effectively.

## Hospital 'passports' or patient profile documents

A fifth (19%) of the CIPOLD cohort of people with learning disabilities had a hospital 'passport', patient profile document or 'traffic light' document that could accompany them to hospital. A small number of people had copies of their profiles already available on the wards that they most frequently used. There was evidence to suggest that such documents helped nursing staff to understand a person's needs and provide person-centred nursing care. However, there was no evidence to suggest that such documents supported medical staff in coordinating the needs of people with multiple morbidities.

## Recognition and reporting of pain

More than half (56%) of those with learning disabilities were reported as being able to identify and verbally communicate their pain. Reporting their pain was more sophisticated in some than others, but for these people identifying that they were in pain, and verbally communicating this to others, would not generally depend on a carer knowing the person well. More than a third (38%) of people with learning disabilities had difficulties in identifying or verbally communicating any pain they had. For almost all of these people, their family or paid carers were able to describe what indications the person would give that they were in pain. A small number of people (6%) were described as having 'atypical' responses to pain, which made identification of their pain more difficult for carers. Typically they would be described as being able to tolerate what most people would experience as a significant degree of pain.

Significantly, 32% of those who could describe their pain were on opioid analgesics at the time of death, compared with just 12% of those who couldn't – a significant difference, which may indicate that people with more severe learning disabilities were having pain at the end of their lives sub-optimally managed.

Despite potential difficulties in external recognition of the manifestations of pain for almost half of the CIPOLD cohort of people with learning disabilities, just 4 people had a formal pain assessment tool such as the Disability Distress Assessment Tool<sup>3</sup> documented which would provide information about how the person indicated whether they were in pain or not.

### Access to cancer screening services

NHS national cancer screening programmes are designed to assess whether a person is at raised risk of developing cancer, and help to identify – and therefore treat – certain serious conditions early.

The greatest difficulties for people with learning disabilities appeared to be with access to bowel cancer screening. Many did not respond to the invitation to participate, possibly because they did not understand the importance or implications of the screening, and possibly because they found the process difficult to follow. CIPOLD found little support provided to people with learning disabilities to enable them to engage with the bowel screening programme; there was no evidence that people had received accessible information about the screening programme, and it appeared that no reasonable adjustments had been made to support their participation. Where people were supported by carers, there was evidence of some confusion on the part of carers as to what the process should be. For example, some carers believed that stool samples could not be collected from incontinence pads and so did not return a sample for testing; others reported that there was a lack of advice about how to get a sample from a person who could not collect their own and/or who found changes to their routine, or interference with privacy, distressing.

CIPOLD found evidence of some difficulties for women with learning disabilities accessing cervical screening, because of presumptions being made about their sexual histories or current sexual activity. Some women were excluded from the screening even though nothing was known about their past history, and 1 care home appeared to have a 'blanket' policy of not sending women for screening.

Overall, CIPOLD found evidence of many women receiving timely breast screening, although there was some concern about a lack of reasonable adjustments being made for women who could not tolerate the correct positioning at the mammogram.

## The accommodation and support of people with learning disabilities

### History of long-term institutionalisation

Two-fifths (42%) of the adults with learning disabilities who died had lived in a long-term institution in the past. The median age of entry was 11 years and the median length of time they stayed there was 33 years, ranging from 1 to 74 years. The age of entry to an institution decreased with increasing severity of learning disabilities, and the length of time spent in an institution increased with increasing severity of learning disabilities. None lived in a long-term institution at the time of their death.

### Accommodation

Nearly two-thirds (64%) of the people with learning disabilities usually lived in a residential care home, either with or without nursing (Table 6.6). The number of residents in these care homes ranged from 2 to 102. The median number of residents was 11.

Table 6.6: Type of current accommodation

Type	% <sup>2</sup>
Residential home	47
Nursing home	18
Housing provider <sup>1</sup>	13
Parental home	13
Own home	8
Other private residence	2
<b>Total</b>	<b>100% (N=247)</b>

Notes: 1 Supported or sheltered accommodation

2 Total does not equal 100% due to rounding

Those who lived in a residential care home or a residential home with nursing care were significantly older at the time of their death (68 years) compared with those who did not (52 years).

Of those who lived in residential care settings (including all residential homes or nursing homes), the majority (76%) lived in a residence that specialised in supporting people with learning disabilities; the median number of residents in these homes was 9 (Table 6.7). Those who lived in generic residential homes tended to have less severe learning disabilities.

Table 6.7: Type of residential care setting

Type	%
Specialist learning disabilities	62
Some beds devoted to learning disabilities	14
Specialist dementia	6
Specialist other (e.g. sensory impairment)	2
Generic (all impairment groups)	16
<b>Total</b>	<b>100%</b> <b>(N=159)</b>

Almost a quarter (23%) of the people with learning disabilities lived in their parental home, their own home or in another private residence. More than 1 in 10 (13%) lived alone, and these were mostly people with mild learning disabilities.

Of note is that a number of people with learning disabilities were described as having inadequate or inappropriate accommodation. This included inadequate physical space, the accommodation not being fully equipped for the person's needs, difficulties for the person in accessing the community, and the home environment not being able to fully meet the needs of the individual.

## The provision of support to people with learning disabilities

All of the children who died (N=14) were living in their parental home and were supported by their parents without additional paid support.

Of the adults with learning disabilities who lived in residential care settings, all were supported by paid carers from an organisation and the vast majority (97%) were supported 24 hours a day (Table 6.8).

For those in non-residential care settings, over half (56%) received support from a paid carer from an organisation or an agency, but over a third (39%) relied on their main support to be provided by their parents or other family members. One in five (20%) of those in non-residential care settings received support on a weekly basis or less frequently than that.

Table 6.8: Main support (adults only)

	Residential care setting % <sup>1</sup>	Non-residential care setting %
<b>Usual provider</b>		
Paid carer from an organisation	100	36
Paid carer from an agency	0	20
Parents	0	19
Other family member(s)	0	20
Informal support from neighbours or friends	0	1
No support	0	3
<b>Total</b>	<b>100% (N=158)</b>	<b>100% (N=75)</b>
<b>Frequency of support</b>		
24 hours a day	97	27
Daily	3	53
Weekly	0	8
Less than weekly or none	0	12
<b>Total</b>	<b>100% (N=158)</b>	<b>100% (N=75)</b>
<b>Most recent review of support arrangements</b>		
<6 months	51	47
6 to <12 months	22	21
12 months or more	27	19
Never had review	1	13
<b>Total</b>	<b>100% (N=143)</b>	<b>100% (N=62)</b>
<b>Family contact</b>		
Family in regular contact	46	69
Family in limited contact	21	13
Family have no contact	22	11
No known family	11	7
<b>Total</b>	<b>100% (N=158)</b>	<b>100% (N=75)</b>

Note: 1 Totals may not equal 100% due to rounding



Half of the adults with learning disabilities (50%) had had their support reviewed within the past 6 months. However, more than a quarter (27%) of those in residential care settings had not had their support reviewed for over a year, if at all. For 1 person living in a residential care setting and 1 in supported accommodation there was no evidence that a review of their support needs had ever been carried out.

Although people in residential care settings may have been receiving their main support from organisational carers, nearly half (46%) were in regular contact with family members and 21% in limited contact. For those living in non-residential care settings, the proportion was higher: 69% were in regular contact and 13% had limited contact with their family.

### The usual support needs of people with learning disabilities

The usual support needs of those with learning disabilities included in CIPOLD are shown in Table 6.9. For most of the activities of daily living shown, a majority of people with learning disabilities required a high level of support.

Table 6.9: The usual support needs of those with learning disabilities

	%
<b>Mobility (N=247)</b>	
Independently mobile	34
Requires some support with mobility	48
Needs total support with moving	18
<b>Total</b>	<b>100%</b>
<b>Contenance (N=247)</b>	
Needs support with continence	63
<b>Personal care (washing/dressing, etc.) (N=247)</b>	
Manages own personal care independently	20
Requires some support	48
Needs total support with personal care	32
<b>Total</b>	<b>100%</b>
<b>Verbal communication (N=247)</b>	
Good verbal communication	48
Limited verbal communication	30
Unable to communicate verbally	22
<b>Total</b>	<b>100%</b>
<b>Eating (for those who can do so orally) (N=220)</b>	
Requires support	52
<b>Drinking (for those who can do so orally) (N=220)</b>	
Requires support	30
<b>Posture (N=247)</b>	
Requires postural support	29
<b>Literacy (adults) (N=226)</b>	
Does not need support with reading and writing	19
Needs some support with reading and writing	34
Needs total support with reading and writing	47
<b>Total</b>	<b>100%</b>

*Table continues on page 54*

	%
<b>Housework (adults) (N=233)</b>	
Manages housework independently	10
Requires some support	52
Needs total support with housework	38
<b>Total</b>	<b>100%</b>
<b>Decision-making (adults) (N=233)</b>	
Generally able to make most decisions for self	22
Likely to need support with complex decision-making	33
Needs some support to make day-to-day decisions	28
Likely to need total support with all decision-making	17
<b>Total</b>	<b>100%</b>

## Safeguarding

More than 1 in 10 (11%) of people with learning disabilities in the CIPOLD cohort had had previous safeguarding concerns investigated. For another 8.5% of people, safeguarding issues had been suspected and reported but were then not taken forward to full investigation. For a similar proportion of people (8.5%), safeguarding concerns were raised to the CIPOLD investigators or nurses by professionals, carers or relatives retrospectively; these had not been reported or investigated at any time previously.

## Notes

- 1 The Health Survey for England is a national survey that collects data about the health of people living in private households in England. The survey focuses on different health issues each year, although a number of core questions remain the same.
- 2 Opioid analgesics are prescribed for moderate to severe pain.
- 3 Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L. and Clarke, C. (2007) Understanding distress in people with severe communication difficulties: Developing and assessing the disability distress assessment tool (DisDAT). *Journal of Intellectual Disability Research* 51, 277–292.

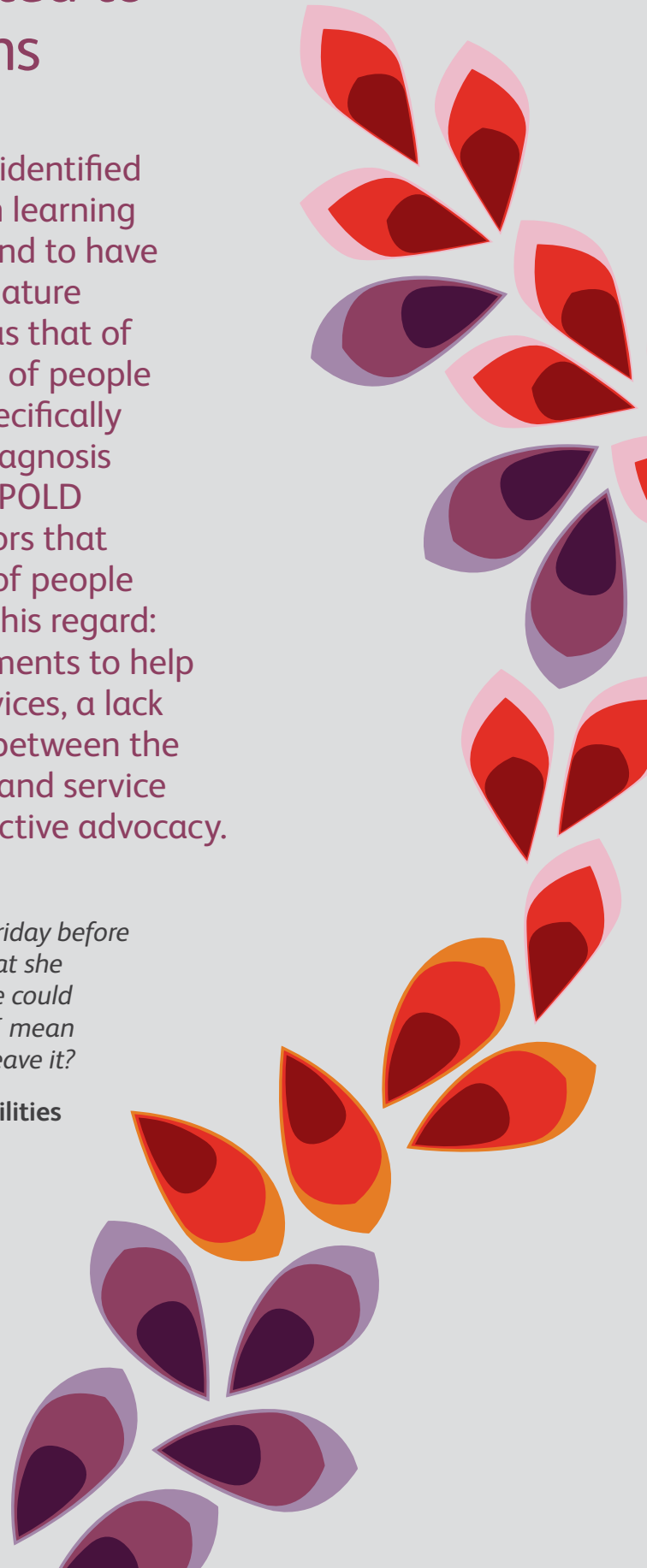
# Chapter 7

## Issues that have directly contributed to premature deaths

This chapter explores issues identified in the deaths of people with learning disabilities that CIPOLD found to have directly contributed to premature deaths. The central issue was that of delays in the care pathways of people with learning disabilities, specifically relating to investigations, diagnosis and treatment. However, CIPOLD identified 3 associated factors that enhanced the vulnerability of people with learning disabilities in this regard: a lack of reasonable adjustments to help people to access health services, a lack of coordination across and between the different disease pathways and service providers, and a lack of effective advocacy.

*I mean the doctor came out on the Friday before she died and said that he thought that she had a water infection. He said that he could either give her antibiotics or leave it. I mean what did he mean by that? I mean, leave it?*

**Sister of person with learning disabilities**



## Chapter summary

The problems in the care pathways of people with learning disabilities most frequently appeared to occur at the point of investigating, diagnosing or treating illness, not in identifying that a person was unwell.

Two in every 5 people whose illness was reported to a doctor experienced problems with having their illness diagnosed. The most frequently reported problem was that the investigations needed to diagnose their illness were not done or posed difficulties. Of note is that in a quarter of cases the concerns of the person with learning disabilities, their family or paid carers were reportedly not taken seriously enough by medical professionals.

Two in every 5 of those whose illness was reported to a doctor experienced problems with the treatment of their condition. The most frequently reported problem was that of the administration or receipt of the treatment itself, such as the person not taking, or not being given, prescribed medication and delays in treatment plans being activated once a diagnosis had been reached.

## Delays in the care pathways of people with learning disabilities who had died

There are many potential barriers to identifying, diagnosing and treating ill-health in people with learning disabilities. Such barriers can occur at any point in the care pathway. While many people received timely and effective care for their illnesses and conditions, CIPOLD found evidence of some 'weak spots' in the chain of the care pathway which either alone, or in combination, have contributed to the premature deaths of people with learning disabilities.

### Identifying that the person may be unwell and responding promptly in seeking medical advice

The majority (86%) of people with learning disabilities who died had been identified, either by themselves, a family member or a paid carer, as being unwell prior to the diagnosis and treatment of their final illness. For some people, this was a non-specific 'being off colour' or a change in behaviour that had been noticed by people most familiar to the person concerned. For others, there were clearer symptoms, such as the person vomiting, refusing to walk or reporting pain.

It did not seem to be a problem in the majority of deaths reviewed by CIPOLD for the individual, their family members or paid carers to respond promptly to the signs that the person was unwell and to seek medical advice in a timely way. Of those who had died and who had been identified as being unwell prior to the diagnosis and treatment of their final illness, most (84%) had sought medical attention in a timely way.

## A correct diagnosis being made

Of the 171 people who had been identified as being unwell and had sought medical attention, 40 had 1 or more problems with their illness being diagnosed. The types of problems that people experienced in having their illness diagnosed are shown in Table 7.1.

These diagnostic problems were not mutually exclusive: of those who were identified as being unwell, who responded promptly in reporting this to a doctor and with whom there were problems in reaching a diagnosis, 58% experienced 1 of the above problems, but 42% had between 2 and 5 of these problems.

**Table 7.1: Problems with diagnosis for those identified as unwell and who responded appropriately to signs of illness**

Type of diagnosis problem	% (N=69)
Problems with the investigations	41
Died with undiagnosed significant illness	33
Concerns of person, family or paid carers not taken seriously enough	25
Problems with referral to specialist	19
Misdiagnosis	7
Other delays in diagnosis	7
Symptoms/events in hindsight should have been investigated but were not	7
Investigations conducted but no diagnosis of illness	4
Other problems <sup>1</sup>	3

Note: 1 Includes: patient refusing further investigations; and wrong scan result sent.

The most frequently reported problem was that the investigations that were needed to diagnose the problem were not done or posed difficulties. Robert provides an example of this.

### Case study – Robert

Robert was found to be unwell by his care home staff and they called the out-of-hours doctor. He was taken to hospital unaccompanied, so the information that he had possibly been aspirating food and fluids was not passed on. Robert had an ECG but no chest X-ray or blood tests and was then returned home. His assessment at that time was deficient, given the lack of a clear history and his significant co-morbidities. Robert continued to have respiratory problems and was seen twice over the weekend by the out-of-hours doctors and prescribed antibiotics. On the Monday morning his own GP was asked to visit. She recognised his deterioration and admitted him to hospital, but his pneumonia was described as 'severe' by this stage with a complete 'white out' of 1 lung. Robert's condition deteriorated and it is possible that an earlier diagnosis of his pneumonia might have prevented his premature death.

The second most frequently reported problem was that the person died before a diagnosis could be made – most commonly of cardiovascular disease or deep vein thrombosis leading to pulmonary embolism.

Of note is that in a quarter of those identified as being unwell and who responded appropriately (25%), the concerns of the person with learning disabilities, their family or paid carers were reportedly not taken seriously enough by medical professionals. The concerns of Henry's family, for example, were not taken seriously when they took him to hospital.

### Case study – Henry

Henry was taken into A&E at about 8am. His sister reported to the CIPOLD nurse that the hospital staff had been convinced that Henry had had a seizure and did not listen to his family when they said that it was something different. His sister recalled suggesting to the hospital staff that Henry had either had a stroke or a brain haemorrhage. His sister said: 'I am no medical expert but I said he's bleeding from his nose and from his mouth and they said that he had probably bitten his tongue while he was fitting. Mum kept saying that she didn't see a fit and it wasn't a seizure bearing in mind that she has been doing this for however many years...I said to the nurse something is not right...he is in pain...and they said no he's not... They took him up for the MRI scan. It all changed then didn't it? They were very nice to us then, let's go in to the side room and all that business... Of course it was a haemorrhage wasn't it? All she could say to us was that she was very sorry. It seems like yesterday because I felt that I had let him down. I hadn't fought his corner hard enough to say it's not what you think it is. You are just looking on the papers, in the textbook... he has collapsed so he has got epilepsy. You are not listening to my Mum and she was his main carer but all they could say was that they were sorry. They were sorry because they had missed it and that it had taken so long and that he had been in pain from 7am until 5pm.

Almost 1 in 5 (19%) of the problems with diagnosis related to difficulties with referrals to specialists, including delays in referring a person for specialist advice, specialists not responding in a timely manner, or specialists undertaking a cursory examination of the person and then referring them back to their GP.

A small number of problems with diagnosing a person's illness were due to misdiagnosis (7%). Misdiagnosis occurred in a range of complaints, but in most cases it was cancer that had been misdiagnosed as another illness. For some people, it appeared that once a provisional diagnosis had been made, it prevented doctors from having an open mind and challenging the provisional diagnosis as symptoms developed.

## Clear care pathways being in place so that people receive evidence-based optimal care for their conditions

In the UK, the National Institute for Health and Clinical Excellence (NICE) develops evidence-based guidelines on the most effective ways to diagnose, treat and prevent disease and ill-health. The CIPOLD reviews have shown that in some cases NICE Guidelines had not been adhered to, particularly those relating to the management of epilepsy (CG20 replaced by CG137 in 2012), falls (CG21), venous thromboembolism prevention (QS3), and nutrition support in adults (CG32).

Exactly why established care pathways were not followed for some people was not easy to determine; it may have been due to misunderstandings, system failures, ignorance or any number of other reasons, including that the person had learning disabilities. Without documented evidence of the rationale for why treatment decisions were or were not made, it is not possible to unpick this, and such documentation was largely lacking. One such example was the care given to Jim.

### Case study – Jim

Jim had had 2 previous strokes. He had 2 further episodes of slurred speech, 1 accompanied by collapse from which he seemed to recover. He scored 3 on the ABCD test<sup>1</sup> but as he had had 2 possible transient ischaemic attacks (TIAs) in a week he should have been considered to be at high risk. However, his GP treated him as if this was his first TIA and faxed a referral to the TIA clinic. NICE Guidelines (CG68) suggest that Jim should have seen a stroke specialist and had a brain scan within 24 hours of his symptoms starting. The following day Jim collapsed at his home and was taken to hospital, where he died from a major stroke.

Of the 171 people with learning disabilities who were identified as being unwell and sought advice in a timely way, 42% were known to have experienced problems with their treatment. Over a quarter (30%) of the whole cohort of people with learning disabilities had 1 or more problems with their illness being treated. The types of problems that people experienced with the treatment of their illness are shown in Table 7.2.



**Table 7.2: Problems with treatment for those identified as unwell and who responded appropriately**

Type of treatment problem	% (N=70)
Problem with giving and receiving treatment	47
Problem with treatment itself	31
No treatment given	31
Other treatment problem <sup>1</sup>	11

Notes: <sup>1</sup> Includes: treatment should have been given earlier; treatment not followed by carers; and 6 for whom the reason for the problem was not specified

Again the treatment problems were not mutually exclusive. Most people had 1 problem with their treatment, although 16 people had 2 problems.

The most frequently reported problem (47%) was that of the administration or receipt of the treatment itself, such as a person not taking or not being given prescribed medication, and delays in treatment plans being activated once a diagnosis had been reached. Almost a third (31%) of those with problems had received no treatment for their condition before they died, although treatment would have been indicated. The same proportion of problems (31%) was related to the treatment itself, such as medication being given at sub-therapeutic doses, complications arising from surgery, or the person being sub-optimally treated. Brian’s treatment exemplifies some of these issues.

### Case study – Brian

Brian lived on his own with 12 hours of support each week. He had diabetes and a severe visual impairment. He was diagnosed with leukaemia and prescribed oral chemotherapy to be given by his carers and injections to be administered by the District Nurses. Brian did not receive his oral chemotherapy for 3 months, due to a lack of understanding on the part of his carers and miscommunication between the hospital and his carers. It appeared that the haematology team had understood there to be more support available for Brian to help him with his drug regimens than there actually was. Although the Overview Panel agreed that Brian’s death was not premature because of the aggressive nature of his leukaemia, they did identify his 3 months of missed treatment as being a potentially modifiable factor in relation to the timing of his death.

The reviews of the deaths of people with learning disabilities found very limited evidence of the type of information that might have been provided to people about their investigations and treatments. Very little, if anything, was documented in case notes about what people understood about their condition, or the proposed investigations or treatments for them. This is important, because if a person's capacity to consent to treatment was being assessed, it would be expected that the person's understanding would be documented. The lack of appropriate provision of accessible information was problematic, and appeared to contribute to the disadvantage experienced by people with learning disabilities and those supporting them. This is an issue that is discussed further below.

### The provision of follow-up or aftercare as needed

For more than half (58%) of the people with learning disabilities, having post-treatment or long-term follow-up of the condition from which they died was not appropriate, because, for example, they might have died during an acute episode of illness. Where follow-up was appropriate, it had been problematic in almost 2 in 5 cases, and there was evidence that this had contributed to the vulnerability of people with learning disabilities and in some cases their death. Jessica's case illustrates the impact of the lack of effective and regular follow-up.

#### Case study – Jessica

Jessica had surgery for congenital heart disease at age 4. She had biannual follow-ups from the paediatric congenital heart disease team throughout her childhood. She was expected to be reviewed again by the adult congenital heart disease team 3 years after moving from paediatric to adult services, but this did not happen. She was later discharged from the clinic as being 'lost to follow-up'. Jessica had little contact with health services, and did not receive Annual Health Checks from her GP. She subsequently died from complications of her heart disease, and the Panel reviewing the circumstances of her death identified the lack of follow-up for her heart disease as being a contributory factor in her premature death.

### **Case study – George**

When the care pathways of people with learning disabilities had been effective

George had severe learning disabilities and co-morbidities. He had experienced a number of chest infections and was referred for a videofluoroscopy to assess his swallowing. This showed that he was aspirating some of his food and drink, and that this was the likely cause of his repeated chest infections. He had a dysphagia risk assessment. George did not have the capacity to make a decision for himself about the risks involved in feeding him orally, so a full Best Interest meeting was held, which included his sister, where it was agreed that a gastrostomy would be the safest way of feeding George and preventing further aspiration. While waiting for the gastrostomy, George had a trial with a nasogastric tube for feeding, but this was unsuccessful. George had a gastrostomy inserted but he was unable to tolerate it and he pulled it out a few days later. Another Best Interest meeting was held and it was agreed that because George could not tolerate nasogastric or gastrostomy feeding, the risk of aspiration would be managed by a puréed diet and thickened drinks. The GP contacted specialist services, including the lung centre, to seek advice on how best to support George's complex health needs and his inability to tolerate feeding tube interventions. The lung centre and microbiologist developed a plan that enabled George to receive oral antibiotics on rotation and this was put in place. George was cared for at home and treated with oral antibiotics. Further meetings were held to agree advanced care planning for George in the final year of his life and he was followed up regularly by his GP.

### **Issues related to the delays in the care pathways of people with learning disabilities who had died**

The CIPOLD study has identified problems in the care pathways of people with learning disabilities that have directly contributed to their deaths. The problems most frequently appeared to occur at the point of investigating, diagnosing or treating illness, not in identifying that a person was unwell. There were 3 associated factors that enhanced the vulnerability of people with learning disabilities in this regard: a lack of reasonable adjustments being made for them, a lack of coordination of their care, and a lack of effective advocacy.

## A lack of reasonable adjustments to help people to access healthcare services

*His Hospital Passport document was done by the staff so this went with him when he moved from place to place and whenever he went into hospital it went with him and 9 times out of 10 the nurses always said, 'What a wonderful document to have.' And I would say, 'Well, doesn't everybody?' 'No. It's fantastic.'*

Sister of person with learning disabilities

Sir Jonathan Michael, in 2008, stressed that:

*What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment. I have learned that 'equal' does not mean 'the same' and that 'reasonable adjustments' that are needed to make services equally accessible to people with learning disabilities are not particularly difficult to make.<sup>2</sup>*

(Foreword)

In general, the CIPOLD reviews found little evidence that reasonable adjustments were being made for people with learning disabilities on a day-to-day basis. More specifically, and in relation to premature deaths, CIPOLD found many occasions when reasonable adjustments that should have been made were not, thereby disadvantaging people with learning disabilities at crucial stages of the care pathway. The lack of reasonable adjustments to help people access non-emergency secondary care, particularly attendance at clinic appointments and for clinical investigations, was especially problematic and a contributory factor in association with a number of deaths. At root of many of the problems that people with learning disabilities had in accessing hospital non-emergency care was that GP referrals sometimes did not mention that the person had learning disabilities, and that hospitals did not routinely 'flag' people with learning disabilities who might need reasonable adjustments made for them. Even when such 'flags' were available, administrative systems were often not flexible enough to take this into consideration.

Without any reasonable adjustments being made for them, people with learning disabilities struggled to find out about their own health condition and negotiate their way through hospital systems. Problems with booking appointments included the inaccessibility of the 'Choose and Book' system for people with learning disabilities and their inability to negotiate it either electronically or by phone. Appointment letters were problematic too, as they were usually sent in a standard format that was not easy to read for those with limited literacy skills. On occasions, people were routinely sent written instructions for planned investigations. If the instructions were not followed correctly, the investigations were unsuccessful and needed to be repeated.

Despite the obvious cost of this to the NHS, there often did not appear to be any reasonable adjustments made to this process for people with learning disabilities who had limited understanding and literacy skills. Their timely access to such procedures was therefore seriously disadvantaged, as Alan's story typifies.

### Case study – Alan

Alan lived alone with daily support. He was 'fast track' referred for a colonoscopy by his GP when he had lost a significant amount of weight and was found to be anaemic. He was expected to have the investigation within 2 weeks. Three months later his GP was concerned that Alan had not had the procedure. On investigation by the GP it transpired that 2 appointments had been arranged but that Alan had sent the hospital transport away on each occasion, because he had diarrhoea and he had not understood that the special drinks he had taken in readiness for the procedure would give him diarrhoea. The lack of reasonable adjustments for him resulted in a 14-week delay between referral and diagnosis.

Where reasonable adjustments had been made, they appeared to have made a significant difference to the individuals concerned, but in general, there appeared to be a lack of systematic embedding of this. There was little evidence, for example, of any measures taken to ensure the longer-term continuation of any identified reasonable adjustments.

### Case studies

#### When reasonable adjustments had been made

- Margaret's GP noted that Margaret was calmer when accompanied by her main carer and proposed that she rearrange Margaret's Annual Health Check for when this member of staff was on duty.
- Once Linda's vulnerability had been established, one-to-one support from a carer known to her was arranged and funded during her hospital stay.
- The Community Learning Disability Team (CLDT) nurse visited Mary at the nursing home prior to her planned admission to hospital. The nurse ensured that she understood how Mary liked to be supported and what her needs were. She initiated the preparation of a 'traffic light' document for the ward staff, detailing the important information they needed to know about Mary, provided Mary with easy read information about going into hospital, and visited Mary on the ward to support her with treatments.
- William was diagnosed with coeliac disease. The CLDT dietician visited the shop where William and his family bought their food and took pictures of the types of food that William could eat, in order to explain his diet to him.

## A lack of coordination of care across and between the different disease pathways and service providers

*They had I don't know how many people seven or something ... but for her she's used to seeing the same people and any person who's unwell to see different faces ... and they didn't know her and as far as I ... I don't know what sort of handover they got from the home but on turning her somebody would place a hand across her back where she had spinal metastases and I said 'Don't touch her there.' You know, where is the handover? Where is the detailed information saying Maria likes this, Maria doesn't like that, don't handle her this way ... I found that quite poor.*

Sister of person with learning disabilities

A striking finding of CIPOLD was the multiplicity and complexity of clinical conditions that people with learning disabilities had. The key problem was the lack of coordination of care across and between the different disease pathways and service providers. This was largely because of the way in which secondary services are organised for adults, which limits the opportunity for a holistic focus on a person's health and for effective coordination of the various specialists involved. CIPOLD frequently reviewed the deaths of people with learning disabilities whose multiple needs were being served by different specialists, sometimes in different hospitals, with no designated or responsible coordinator for their care. This resulted in each hospital admission being micro-managed as a distinct entity, but without any consideration of the whole picture and the overall pattern of the person's illnesses, so contributing to their vulnerability, deteriorating health and sometimes their death. The review of the circumstances leading to David's death illustrated these problems.

### Case study – David

David had multiple morbidities and faced considerable difficulties as a result of receiving care from different hospitals and different departments within each of those hospitals. Referrals were made internally and externally with no apparent systematic tracking, coordination or follow-up of responses or actions, and the transfer of information or access to David's medical notes between departments and hospitals was problematic. It was felt that there was confusion about who was taking responsibility for David's overall care within secondary services, and this impacted on his speed of access to appropriate care and to pre-existing conditions never being satisfactorily resolved. His social care provider appeared to be neither equipped nor resourced to chase up appointments or monitor his progress through so many different systems, and there was no one else to do this on his behalf.

In addition to the systemic problems with the way in which services are organised, there appeared to be, in some cases, a concerning lack of awareness of the roles and responsibilities of different professionals and agencies and how they might offer support to people with learning disabilities. Most common was the apparent lack of understanding on the part of some hospital staff about the differences between residential care homes, residential care homes with nursing, and supported living schemes. This resulted in assumptions being made about the type and availability of support that a person might receive upon discharge from hospital that did not accord with the reality of their lives. There was also evidence of GPs not being aware of the possibilities for Community Learning Disability Team (CLDT) involvement, or of the potential for hospital-based Learning Disability Liaison Nurses (LDLNs) to facilitate and support hospital attendances and admissions. It appeared, in some cases, that professionals were working in 'silos' and not drawing on the range of expertise available to them that might, in part, help smooth the path for people with learning disabilities through the complexities of the health system.

### **Case study – Susan**

#### **When care coordination had worked well**

Susan had profound and multiple learning disabilities and lived in a care home near her family, who were closely involved with supporting her. Susan had a number of co-morbidities and had frequent admissions to 2 hospitals. There was fragmentation of her care, a lack of coordination and information sharing, and her parents submitted formal complaints about her care on 2 occasions. After a particularly problematic 2 years, a new Care Coordinator took over. A Best Interest meeting was convened by the Care Coordinator, which hospital and community health and social care staff and Susan's parents all attended. The meeting focused on ways to improve Susan's care, shorten any hospital admissions, identify the reasonable adjustments that Susan required to be able to access health services effectively, and to plan for Susan's future care and end-of-life needs. Clear decisions were made at the meeting, and Susan's family and the professionals involved in her care agreed a way forward. The Care Coordinator worked with the newly appointed LDLNs at the hospital to arrange the additional funding that Susan required to meet her needs when she was an inpatient, and to alert staff of an impending admission, so that any delays in Susan's care could be avoided. Susan's agreed care plan worked well during a subsequent hospital admission.

#### **A lack of effective advocacy for an individual with multiple conditions and vulnerabilities so that they remained central to the provision of their healthcare**

Given the issues already identified about the delays in the care pathways of people with learning disabilities who had died, the lack of reasonable adjustments to help people to access healthcare services, and the lack of coordination of care across and between the different disease pathways and service providers, it was little surprise that the need for advocacy was highlighted as a serious issue for so many people.

Indeed, the poor adherence to the Mental Capacity Act and to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) guidelines (see Chapter 8), made the provision of effective advocacy life-saving for some people. In many cases, family and paid carers tried to fulfil this role, representing what they perceived to be the person's views and promoting their interests.

*There was an amazing phone call she (GP) and I had after I'd been told by the hospital that Michael had kidney stones ... and she said '... that's all normal isn't it?' And I said 'No'. I said 'He's got kidney stones.' And she said 'Really? It says on the discharge summary that there aren't any kidney stones.' And I said 'No, a nurse stood at the end of Michael's bed and announced that he'd got kidney stones.' So on her computer she could link into the results from the hospital and she said 'You're absolutely right.'*

Sister of person with learning disabilities

However, paid carers reported feeling intimidated at times by medical professionals, feeling as though they could not get their voice heard, and as though they had little expertise, confidence or authority to take on this role. Family carers too, reported at times that they struggled to get their voices heard when they tried to advocate for their family member. Once the person with learning disabilities reached the age of 18, family members felt they had even less credibility as an effective advocate. Lionel's story illustrates the disadvantages that he faced in not having a strong and effective advocate who knew him well.

### Case study – Lionel

Lionel had a diagnosis of vascular dementia. It was recorded in the GP notes that Lionel's nephew had 'Power of Attorney' and that neither Lionel's nephew nor a niece ever visited Lionel and they did not know him well. Lionel was placed in 3 different care homes over the period of 2 months, and there was no evidence to suggest that Lionel was consulted or had any involvement in the decision to move into the different care homes. There was no one who followed Lionel through his changes of residence, held his personal history, understood his preferences and could act as his advocate. His final care home, at which he lived for a year before his death, became subject to ongoing safeguarding concerns by the Local Authority and the police, and at this stage Lionel was supported by an Independent Mental Capacity Advocate (IMCA). Lionel was admitted to hospital with concerns that he was bleeding internally. It was documented in the GP's notes that it was decided by the hospital's doctors, with the agreement of Lionel's nephew, that he was not fit for surgery and was to receive end-of-life care only. The IMCA contacted the hospital ward to inform them of her involvement with Lionel, but was not contacted or consulted with regard to the decision not to treat him, because hospital staff had spoken with Lionel's nephew. From this point, Lionel only received palliative care and he subsequently died.



The CIPOLD reviews did identify some cases where the provision of advocacy had worked well for the individual for a specific issue, as Stanley's case below illustrates. The provision of effective advocacy had almost always come from professional advocates with statutory responsibilities and the authority to be able to access information, question professionals and challenge views where necessary. However, the lack of ongoing advocacy generally placed the person at continued risk. In Stanley's case for example, once the Independent Mental Capacity Advocate (IMCA) had completed the work with him regarding his feeding, there was a continued apparent lack of coordination of his care in relation to his multiple co-morbidities, postural management, follow-up regarding his gastrostomy tube and end-of-life care planning.

### Case study – Stanley

#### When advocacy support regarding a single issue had worked well

Stanley had a number of health conditions, and had progressive frailty and significant weight loss. Eating had become an ordeal and it was exhausting him. An IMCA was appointed to be involved in the decision-making process regarding an investigatory procedure to investigate his weight loss, and the insertion of a gastrostomy tube through which he could be fed. The IMCA convened a series of Best Interest meetings, communicated and liaised with Stanley's primary and secondary care agencies and ensured that all the relevant information was being considered in clinical decisions. It was agreed that it would be in Stanley's best interests to insert a gastrostomy tube for feeding him, although one consultant felt that the procedure would be futile and would not consider authorising it. The IMCA was confident to challenge this, and Stanley was referred to another consultant who was, despite the risks that it involved, fully supportive of the procedure. Following the procedure the IMCA convened a further Best Interest meeting, when it became apparent that the gastrostomy would need replacing. Following a second procedure, the gastrostomy significantly contributed to Stanley having a further 12 months of better-quality life.

### Notes

- 1 The ABCD test is used to predict the risk of stroke and to identify high-risk individuals who require emergency investigation and treatment.
- 2 Michael, J. (2008) *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Department of Health.

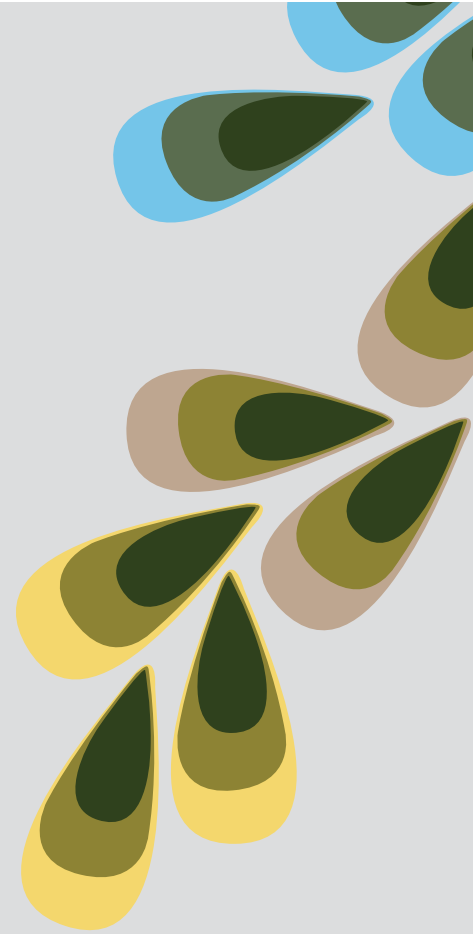
## Chapter 8

# Issues identified in the deaths of people with learning disabilities that made the person particularly vulnerable to premature death

This chapter considers issues identified in the deaths of people with learning disabilities that while not being a direct cause of premature death for most people, considerably increased their vulnerability to the likelihood of premature death. Key issues identified were problems with adherence to the Mental Capacity Act and DNACPR guidelines, poor record-keeping and a lack of proactive care.

*When she came out of hospital, the home staff, actually the head of home, said to us 'I think there's a Do Not Resuscitate note on Joanne's file and it shouldn't be there unless you particularly want it there.'*

**Parents of a person with learning disabilities**



## Chapter summary

CIPOLD identified considerable concerns about adherence to the Mental Capacity Act and the differences in the understanding and implementation of each of its principles. Key problems concerned poor recording of any assessment of capacity and Best Interest decisions, delays in convening Best Interest meetings, and confusion about the process of decision-making, what 'serious medical treatment' involves and when an IMCA should be appointed.

Concerns about the use of DNACPR Guidelines related to incomplete documentation that failed to record the rationale for the order not to attempt resuscitation and occasions when the decision not to resuscitate a person appeared to have been made prematurely.

Concerns about the quality of record-keeping were in relation to decisions about particular treatments, and the completeness of records in relation to nutrition monitoring (particularly of diet and fluid intake and of a person's weight), bowel movements, and of seizures.

The final issue that made people particularly vulnerable to premature death was the relative inattention given to predicting potential problems, in particular addressing the knowledge that a person was fearful of contact with medical professionals, and predicting and planning for a person's future health and care needs.

## Adherence to the Mental Capacity Act

The Mental Capacity Act, which came into force in 2007, sets out 5 key principles applying to decisions and actions taken under the Act. The *Six Lives Progress Report*<sup>1</sup> cited that failures by healthcare staff to comply with the Mental Capacity Act and its Code of Practice were among the most worrying evidence received. The CIPOLD review of deaths has also identified considerable concerns about adherence to the Mental Capacity Act, and the differences in the understanding and implementation of each of its principles on the part of some health and social care professionals.

A key concern has been a lack of assessment (or documentation to this effect) to establish that a person might not have the capacity to make a particular decision at a particular time. In some cases, the decision that a person lacked capacity appeared to have been made on the basis of their appearance or presentation, or because they had been assessed as having or lacking capacity to make a (sometimes different) decision in the past.

Where a person does not have the capacity to make a decision for themselves, the Mental Capacity Act stipulates that it should be made in their 'Best Interests'. This process, however, has been identified as an area of concern in a number of cases reviewed by CIPOLD. Problems identified in the CIPOLD investigations have included delays in convening Best Interest meetings, confusion as to who should be taking the lead in Best Interest decision-making, poor recording of Best Interest decisions, and misunderstandings about the process to follow in case of disagreement about Best Interest decision-making. While there has also been some evidence of good practice in this respect, the frequency with which this has occurred is far outweighed by the cases where there have been concerns.

### Case study – Mildred

The Mental Capacity Act did not inform the process of deciding if Mildred should have surgery or not. Mildred had mild–moderate learning disabilities and was able to convey her likes and dislikes. She had only sporadic and infrequent contact with her siblings. Mildred was diagnosed with gallstones, including one obstructing her common bile duct which was causing pain, vomiting and jaundice. She was not considered to be a good anaesthetic risk for an investigative and therapeutic procedure that would require an anaesthetic, and was discharged home from hospital while her GP sought further support for her. Mildred's condition deteriorated. There was another attempt to have her admitted to hospital but notes record that the decision not to admit Mildred was influenced by the fact that the local A&E department was full and that if she were admitted, she may be waiting on a trolley for many hours. Following discussion with the staff at her care home, the GP made the decision to keep Mildred at home. At no time was Mildred's capacity assessed, nor was there a formally considered and documented Best Interest process involving the multidisciplinary team, her family or an IMCA, or other people who knew her well. Mildred died the next day and her underlying cause of death was reported as being the inflammation of her gall bladder.

The Mental Capacity Act specifies that an IMCA should be appointed when 'serious medical treatment' is considered for a person lacking capacity to make a decision about this themselves, and who does not have anyone other than a paid worker available to consult in deciding what would be in the person's best interests. CIPOLD uncovered considerable confusion as to exactly what serious medical treatment involves and whether, for example, invasive investigations should be classed as 'treatment' or whether procedures not requiring a general anaesthetic should be regarded as 'serious'.

In addition to concerns about the process of decision-making in relation to the Mental Capacity Act, we also have concerns about the outcome of Best Interest decisions that have been made and the timeliness of their implementation. On occasions, the decisions made and documented, appear to have been overruled by other considerations, including those of the cost of a service, administrative delays and bed pressures in hospital, without any apparent review as to the impact of this on the individual.

### **Case study – Brenda**

#### **The value of the Mental Capacity Act**

When Brenda was admitted to hospital her medical notes on admission described her as ‘mute, aphasic and having learning difficulties’. A plan was made to stop any treatment for her and to transfer her back to the nursing home for ‘TLC’ (tender, loving care).

The nursing home manager disagreed with this treatment plan and Brenda’s GP also disagreed with the decision not to treat her. The nursing home manager reported to the CIPOLD review that she had to insist on the Mental Capacity Act being followed and a Best Interest meeting being held, and had explained to the doctors that ‘just asking the relatives would have been illegal’.

A Best Interest meeting was held that afternoon, attended by the hospital doctors involved, the nursing home manager, hospital LDN, and 4 members of Brenda’s family. Active treatment was resumed as a result of the decisions made, and Brenda had improved greatly within 48 hours. Brenda was discharged 2–3 weeks later and lived for more than another year before dying peacefully at home.

## **Adherence to guidelines about decisions whether or not to resuscitate an individual**

The second issue identified in the CIPOLD review of deaths of people with learning disabilities that made people particularly vulnerable to premature death was that of DNACPR orders. Over half (57%) of the CIPOLD cohort had a DNACPR order at the time of their death.

CIPOLD uncovered considerable evidence of poor adherence to national guidelines about decisions not to attempt cardiopulmonary resuscitation. This was frequently the case for people with learning disabilities, but there were also some issues with DNACPR orders for the comparator cases of people without learning disabilities whose deaths were reviewed. On the whole, most concerns related to incomplete documentation that failed to record the rationale for the order not to attempt CPR. In some circumstances, such was the quality of the documentation that the assumption that the order was made because the person had learning disabilities could not be ruled out. In addition, there were a number of cases where the decision not to resuscitate a person appeared to have been made prematurely in a non-emergency situation, before a full assessment of the person and/or before gaining the views of those who knew them best.

A further issue regarding adherence to Resuscitation Council Guidelines was confusion about the implications of DNACPR orders. The Resuscitation Council Guidelines (2009) are clear that DNACPR decisions only apply to attempted cardiopulmonary resuscitation, and should not imply that any other aspect of treatment will or will not be provided. However, CIPOLD has found that this is not always interpreted as such by family and paid carers, who were, at times, concerned that orders not to attempt CPR implied the withdrawal of regular medication or feeding, or a general reluctance to actively treat emerging problems.

### **Case study – Annie**

**When a decision not to attempt CPR had been challenged because the correct process had not been followed**

Annie had no contact with any family members and lived in a care home. During her final illness, Annie's GP discussed Annie's deterioration with 3 members of the care home staff and they agreed that Annie was not for cardiopulmonary resuscitation should her heart stop. The GP updated Annie's Care Plan Summary. Three weeks later a social worker visited to assess Annie. The care home manager told them that the GP had felt it best not to offer further active treatment or to attempt resuscitation. The social worker advised the care home manager that as Annie did not have the capacity to be involved in the decision herself, the manager should contact an IMCA and arrange a Best Interest meeting. The IMCA visited the care home and held a preliminary meeting with Annie's key worker and the manager and attempted to carry out a Mental Capacity assessment with Annie but she was too weak to engage. Later the same day, a Best Interest meeting was held at the care home with the manager, assistant manager, Annie's GP, the District Nurse and the IMCA. The decision whether or not to undertake cardiopulmonary resuscitation on Annie was fully discussed and confirmed the decision not to attempt cardiopulmonary resuscitation, but to actively treat her infection with antibiotics.

### **Record-keeping and access to records**

The third issue that made people particularly vulnerable to premature death was poor record-keeping. There were many concerns reported by the CIPOLD investigators about the quality of record-keeping across a range of health and social care professionals and care settings. We have already mentioned poor record-keeping in relation to reporting assessments of capacity, Best Interest decisions and DNACPR orders. We have also noted concerns about record-keeping in relation to decisions about particular treatments. Without fully documented decisions and the rationale for these decisions it was difficult to ascertain if optimal care for the individual concerned was being provided. The review into Gary's death illustrates this.

## Case study – Gary

Gary was diagnosed with infective colitis. A decision was made not to operate, and not to perform CPR should his heart stop. His notes contained no information about this decision-making process, nor the rationale for the decisions that were made, leaving the professionals concerned open to allegations of neglect.

Other concerns about record-keeping included the incompleteness of social care records in relation to nutrition monitoring (particularly of diet and fluid intake and of a person's weight), bowel movements, and of seizures. Each of these was found to be a contributory factor in a person's death. If accurate records were not kept, the severity of a person's condition, or the worsening of their condition was not recognised in a timely way.

## A lack of proactive care

The final issue identified in the CIPOLD review of deaths that made people particularly vulnerable to premature death was the relative inattention given to predicting potential problems, and then having to respond to those problems in a crisis. The main areas highlighted were: firstly, addressing the knowledge that a person is fearful of contact with medical professionals, and secondly, predicting and planning for the future health and care needs of people who were likely to have changing support needs as their condition progresses, or their circumstances change.

### Addressing the knowledge that a person is fearful of contact with medical professionals

Almost a sixth (16%) of people with learning disabilities whose deaths were reviewed by CIPOLD were described as having had a significant fear of contact with medical professionals such that it might affect healthcare interventions. This was also the case for a small proportion (9%) of the comparator cases without learning disabilities. Such fears were contributing factors in a number of the deaths both of people with learning disabilities and of comparator cases. Despite the intensity of some people's fears, there was little evidence of measures being taken to address such fears proactively, or of them being addressed in a Health Action Plan for people with learning disabilities. Typically a health crisis occurred and then measures were taken to try to manage the person's fears with varying degrees of success, as Samantha's story illustrates.

## Case study – Samantha

Samantha had a number of existing health conditions which required regular review but this had proved impossible to conduct. When her physical health significantly deteriorated she would not tolerate any physical examination and there were considerable delays in making decisions on her behalf under the Mental Capacity Act. Six months after the initial deterioration of her health a community nurse offered advice to Samantha's carers about familiarising Samantha to physical examination and loaned her carers a blood pressure cuff to introduce to Samantha. Eleven months after the initial presentation that something might be physically wrong with Samantha and before a planned scan had taken place she died suddenly and apparently unexpectedly. Her cause of death was related to the existing health condition for which she had not received regular review.

Forward planning where it is known to be likely that the person would have changing support needs as their condition progresses, or their circumstances change

A number of people with learning disabilities whose deaths were reviewed by CIPOLD developed progressive long-term conditions. The most common of these was dementia (14% of the cohort). Dementia is a significant and common health condition in people with Down's syndrome, often with a more rapid and consistent progression than in other people. Dementia care pathways should identify issues that are likely to arise, such as potential swallowing difficulties, incontinence and reduced mobility, and allow them to be addressed proactively. However, a considerable amount of planning appeared to be responsive to problems that arose, rather than being anticipatory of problems arising in the future. This made people more vulnerable, for example, making them more susceptible to aspiration pneumonia which was a significant cause of death.

Particular areas in which the lack of forward planning was particularly evident were regarding postural care, planning for discharge from hospital, planning for the transition from children's to adults services, and with regards to long-term conditions or the attendance of people with learning disabilities at chronic disease management courses.



## Case study – Barbara

### Examples of when forward planning had been effective

Barbara had experienced several moves of home in the past. When she was diagnosed with dementia her views about where she would like to live were sought. She was offered a placement where the staff were fully aware that her health and abilities would diminish, and where the environment could meet her changing needs. Barbara was very clear about her end-of-life wishes and her views had been sought well enough in advance by her GP while she was still able to articulate them.

## Note

- 1 Department of Health (2010) *Six Lives Progress Report*. London: Department of Health.

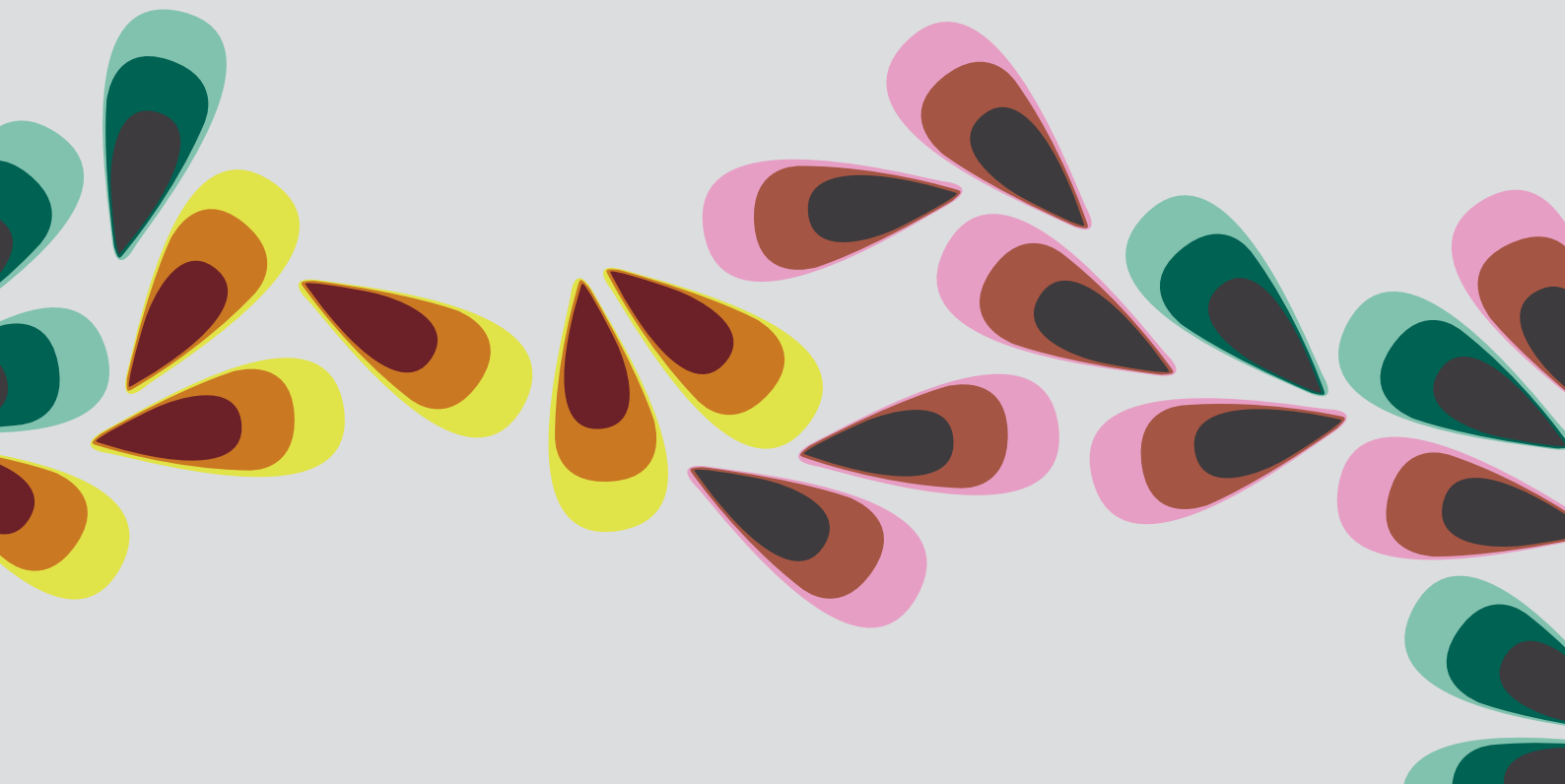
# Chapter 9

## Issues identified in the deaths of people with learning disabilities that made the person vulnerable to a poor-quality death

This chapter considers issues identified in the deaths of people with learning disabilities that while not being a direct cause of premature death, made them vulnerable to having a poor-quality death. Key issues here were problems with end-of-life care and access to Continuing Healthcare funding.

*'I think one of the biggest problems is that the other care people such as the hospice nurse and the district nurse didn't understand what that home was about. It was a supported living home and it wasn't a residential home for people who were sick ... it was her home and the carers there were not equipped to deal with a person with illness who was dying.'*

**Sister of person with learning disabilities**



## Chapter summary

It was apparent from the review of deaths of people with learning disabilities that there were some difficulties with identifying when the end of life was approaching and then placing them on an end-of-life pathway. There were also problems with coordinating care at the end of life. With a lack of planning and coordination often came poor-quality care in the final days of a person's life. The second issue that made people with learning disabilities vulnerable to having a poor-quality death was that of problems gaining access to CHC funding. Although CHC funding can be applied for at any time, and not just as a person approaches death, CIPOLD found evidence of confusion about CHC funding, and problems with the timeliness of its receipt.

## End-of-life care

The End of Life Strategy<sup>1</sup> recommends the use of an end-of-life care pathway for people approaching the end of their life. However, it was apparent there were some difficulties with identifying when the end of life was approaching for people with learning disabilities and then placing them on an end-of-life pathway.

There was some evidence of end-of-life care planning for two-fifths (43%) of people with learning disabilities. Most commonly, the end-of-life plan was in the form of a 'When I die' booklet which documented a person's preferences for what would happen near the time of their death and subsequent to this. For some children, a 'Child and Family Wishes Advance Care Plan' had been used. Where such end-of-life plans had been made, there was evidence that they had contributed to effective care of the individual and that professionals had gone to considerable lengths to ensure that the plan was followed.

### Case study – Mary

#### Example of where advanced care planning had worked well

Mary's GP initiated a Best Interest decision-making process to fully consider her needs and treatment options for end-of-life care as Mary herself did not have the capacity to do so. The Best Interest meeting was led by the GP and involved an IMCA, members of the Community Learning Disabilities Team and the care staff. The meeting was fully recorded and evidenced, with the range of options being considered in full. At the end of the meeting everyone involved with supporting Mary was clear about what they were doing and why. The care staff said that they were more confident and this improved the quality of their contacts with other professionals. The process improved efficiency as agencies contacted each other appropriately in the context of a clear plan rather than because they didn't know what to do. It also increased professionals' trust in each other. Mary received care and support from people who were working together to meet her needs in a timely way within a clear end-of-life plan during the final months of her life.

Once a care plan has been agreed, the services which the person needs must be effectively coordinated. There may be multiple services or agencies involved in supporting a person at the end of their life, and lines of communication need to be good. When services are well coordinated, it can enhance the quality of a person's death. There did, however, appear to be some problems with this and a number of people had end-of-life care that was unplanned, uncoordinated and contributed to them being at risk of not having a 'good death' as was the case with Arthur.

### Case study – Arthur

Arthur had bowel cancer and following a hospital admission was not able to return to his residential care home because it was not able to meet his increased nursing needs. He was discharged from hospital to a nursing home, but once at the nursing home communication between his GP, the nursing home staff and the palliative care team seemed fragmented with a lack of continuity. Palliative care staff reported finding it difficult to gauge what was going on as they would receive different messages from different people, there was some confusion about the prescribing and administering of medications and the management plan proposed by the palliative care nurse was not followed. The CIPOLD Panel reviewing Arthur's death had concerns about the quality of his death.

Although Arthur had received specialist palliative care, few of the other people with learning disabilities had. One in 5 (20%) had received support from a specialist palliative care team, 1 in 10 (10%) had received support from a hospice, and 6 had died in a hospice.

Identifying that a person is dying can be difficult, but it is important that signs of this are recognised and that people and their relatives and carers receive a high standard of care in the last days and hours of their lives. The Liverpool Care Pathway for the Dying Patient (LCP) provides guidance on different aspects of care, and although CIPOLD found evidence of the LCP being used effectively with some people in that it provided a framework to guide their care, for others the last days of their life appeared to have been less organised and problems with anticipatory prescribing, or support for the family were encountered.

## Case study – Michelle

### Examples of where end-of-life care had worked well

Michelle's parents spoke very highly of the care that the hospice provided to Michelle and the support that they received. They recalled that Michelle had liked her room and that the staff had offered their daughter a wide variety of foods and drinks and ensured she felt comfortable and safe. It was evident from the hospice's medical notes that they were continually adjusting Michelle's medication to relieve her pain and to manage her levels of anxiety. For the last few days of her life it was noted that Michelle was very settled and comfortable and that she died very peacefully with both her parents at her bedside.

## Continuing Healthcare (CHC) funding

The second issue that made people with learning disabilities vulnerable to having a poor-quality death was that of problems obtaining access to CHC funding. CHC funding provides for health-related support outside hospital, arranged and funded by the NHS, for people with ongoing healthcare needs. Those nearing the end of their life are also likely to be eligible if they have a condition that is rapidly getting worse and may be terminal.

Assessments for CHC funding had been made for 32 people with learning disabilities. In general, CIPOLD found evidence of confusion about CHC funding, and at least 8 people should probably have been assessed for CHC funding as they neared the end of their life but were not. In some of these cases it appeared that no application had been made because of a lack of knowledge; in some cases it appeared to have been due to confusion about who should take the lead in making the application. Of concern too, were those cases where CHC funding had been applied for, but had not been approved before a person died, and one case where funding had been approved but not granted before the person died. Anthony's experiences highlight how problematic the delay in the receipt of a CHC funding decision could be.

## Case study – Anthony

Anthony was diagnosed with an untreatable brain tumour and extensive secondaries. While Anthony was in hospital, CHC funding was applied for to fund the extra nursing support that he would need at his supported living home, but it had not been approved before Anthony was discharged from hospital. Anthony was mainly nursed in bed at home, he was incontinent, and required feeding and all nursing care. Many of the staff worked long hours, often without additional pay, to ensure that Anthony was cared for appropriately. On the day that Anthony died, some 6 weeks after returning home, CHC funding for extra staff was approved.

## Note

- 1 Department of Health (2008) *End of Life Care Strategy. Promoting high quality care for all adults at the end of life*. London: Department of Health.

# Chapter 10

## Quality of care issues

This chapter pulls together the quality of care issues already identified in relation to people with learning disabilities, and explores additional issues with regard to the knowledge of the person as an individual and providing nutritional support. It also reviews the input of specialist staff and the identified training needs of staff.

*We're not saying it's to do with neglect, they might have found he just wouldn't eat anything but if somebody doesn't eat for days and days, you do something don't you, surely you do?*

**Sister of person with learning disabilities**



## Chapter summary

Many aspects relating to quality of care have already been identified in earlier chapters. These include:

- issues with care pathways
- problems with recognising needs and adjusting care as needs change
- problems with coordination of care and adherence to legislation and guidelines
- a lack of reasonable adjustments to help people to access healthcare
- a lack of effective advocacy for people with learning disabilities so that they remain central to the provision of their healthcare
- poor record-keeping and information sharing
- a lack of proactive care.

Just over a quarter of the deaths of people with learning disabilities were amenable to good-quality healthcare interventions and may therefore have been avoidable.

In addition to this, the CIPOLD reviews have identified concerns about 2 further issues: the knowledge of the individual person, and nutritional support.

Specialist learning disability services, in particular provided by CLDTs and hospital-based LDLNs, had effectively supported the care of people with learning disabilities, but some concerns were raised in relation to service criteria and accessibility.

## Introduction

The CIPOLD reviews of the deaths of people with learning disabilities took into consideration the quality of health and social care provision. Many aspects relating to quality of care have already been identified in earlier chapters. This chapter briefly summarises those already identified as being of concern, and considers additional quality of care issues that appeared to make people with learning disabilities vulnerable to, or protected from, premature death.

## Quality of care issues already identified

Many aspects relating to quality of care have already been identified in earlier chapters. These include:

- Issues with care pathways, particularly with the diagnosis and treatment of illness.
- Problems with recognising needs and adjusting care as needs change.
- Problems with the coordination of care.
- Problems with adherence to legislation and guidelines, particularly in relation to the Mental Capacity Act and DNACPR Guidelines.
- A lack of reasonable adjustments to help people to access healthcare, particularly in relation to accessing non-emergency secondary care.

- Poor record-keeping, in particular in relation to the rationale for decisions being made, and the incompleteness of records about diet and fluid intake, weight, bowel movement and seizures.
- Little proactive care, such as cardiovascular risk assessments, Health Action Plans, hospital passport-type documents, formal pain assessment tools.
- More than a quarter had not had their support reviewed for over a year, if at all.
- Poor-quality end-of-life planning.

In addition to this considerable range of quality of care issues in relation to people with learning disabilities who died, the CIPOLD reviews have identified the quality of care in relation to 2 further issues as being of concern. These relate to the knowledge of the person as an individual and providing nutritional support.

## Knowledge of the individual

An important aspect of responding appropriately and effectively to the continuing health needs of individuals is having a clear understanding of them as a person, their life histories and their medical histories. It was particularly striking when reviewing the deaths of people with learning disabilities just how important this is, and how often it was lacking.

For many people, the role of their families appeared to be crucial in this. Their families held their personal and medical histories and were central in sharing these when appropriate. However, over a quarter (27%) of people with learning disabilities had no known family members or no contact with any family members. For some people, nothing was known about their early lives; it was not uncommon for care home staff to report that they had no information about the person's life experiences, or previous medical history until the person had moved into their current residential setting. The implications of this were particularly serious for some people, as Howard's story highlights.

### Case study – Howard

None of the members of the Local Review Panel meeting that reviewed Howard's death had previously been aware of his history of Hodgkin's lymphoma. They agreed that it was concerning that such a significant medical history appeared to have been lost over time and that this had important implications should he have presented with symptoms indicating a possible reoccurrence.



## Quality of care issues related to nutritional support

We make reference in Chapter 6 to the greater than expected proportion of people with learning disabilities who were at either end of the spectrum of scores on the BMI scale and who were underweight or obese rather than of optimal weight. Inadequate knowledge about nutrition by care staff was reported to have led to a lack of awareness and recognition of malnutrition in some deaths reviewed by CIPOLD.

An issue of crucial importance in identifying malnutrition is that of weighing people, and the CIPOLD review of deaths identified an apparent lack of facilities for weighing a person in the community. The majority of care providers relied on the use of stand-on or sit-down scales for weighing a person, but people who were unable to use these weighing scales were frequently disadvantaged by having no easy method of monitoring their weight. Not all care establishments had access to specialised scales to weigh people with complex needs and the resultant ad hoc methods used appeared to lead to spurious results at times. While some people were taken to other organisations or weight clinics in order to weigh them, others were not weighed at all, leaving them vulnerable to unrecognised deteriorating health.

A second quality of care issue in relation to nutritional support was poor evidence that care pathways for people considered to require gastrostomy feeding were in place. More than 1 in 10 (12%) of the people with learning disabilities whose deaths were reviewed had a gastrostomy tube inserted, but there were often significant omissions that compromised their health and wellbeing. Of most concern was the timing of the insertion of a gastrostomy, in particular the long wait from a decision that a gastrostomy was needed, to the actual procedure being undertaken. This placed people at high risk of reduced nutritional intake, with serious consequences in particularly vulnerable individuals with low body weight and little resistance to infection. Further, there appears to have been little monitoring of the condition of individuals while waiting for the procedure, allowing deterioration to go undetected.

## Case study – Sarah

### When eating and drinking had been well managed

Sarah had input from the speech and language therapist to help her with communication and her feeding regimen and swallowing. Drinking became more difficult in the last 2–3 years. She was reassessed, prescribed thickeners for her drinks and supplied with a special cup to drink from.

Sarah had eating and drinking guidelines drawn up by the dietician, speech and language therapist and Sarah's family. A film was made to demonstrate the guidelines, which was transferred onto DVD for training those who may be required to feed Sarah. A poster was also made to highlight the guidelines. In addition, Sarah had an 'All about me' document to share important information about her care with her carers.

Sarah continued to receive regular support from the dietician and her weight was monitored. She had a target weight of between 6 and 7 stone which she maintained fairly well. Her weight started to fall during her last year and it was taking longer and longer to feed her so the dietician advised dietary supplements to increase her calorie intake – these were then prescribed by her GP. The dietician also discussed with Sarah's mother the possibility of a gastrostomy and what this might entail for Sarah.

## The skills of staff

It was not within the remit of CIPOLD to review the skills of staff per se. People with learning disabilities were supported by a range of professionals, some of whom were highly skilled and experienced in working with people with learning disabilities, and others who were less so.

### Community Learning Disability Teams

Two-thirds of people with learning disabilities whose deaths were reviewed by CIPOLD had been supported at some time by a member of the CLDT.

There was clear evidence of CLDTs supporting people's healthcare in the community in a number of different ways:

- Supporting people to access health services.
- Providing expert advice, support and training to health and social care providers.
- Providing individual assessment, care coordination and therapeutic interventions for people with learning disabilities.
- Offering advice and support for the provision of reasonable adjustments for people with learning disabilities, including the provision of easy read information.

For the most part, access to CLDTs had been unproblematic, although there was evidence that some professionals, including GPs, were unaware of the existence of such a service and how it could be of support to their patients with learning disabilities. Where significant issues had occurred with access to the service, they had mostly been in relation to the eligibility criteria set by teams, and eligibility being determined not on the basis of risk and need, but on a one-off IQ score or other assessment of the severity of a person's learning disabilities. This had led to some people falling into a gap between being able to be independent on the one hand, and fitting the criteria for learning disability services on the other, even though they may have been more vulnerable than a person with more severe learning disabilities who was assessed as being eligible to use the service.

In some cases, the CLDT did not have the capacity to respond to a request for support in a timely and effective way. In these cases the CIPOLD investigators found little evidence of clear alternative pathways into non-specialist support, or of alerting commissioners to the situation, although it is accepted that the latter may not always have been apparent to the investigators reviewing individual deaths. Perhaps reflective of the pressures on the CLDT service, CIPOLD also came across circumstances when people had been discharged from CLDT caseloads, despite having progressive degenerative conditions that were likely to lead to increased support needs in the future. The pressure to discharge patients worked against continuity of care and against the possibility of reshaping emerging situations, before they became a crisis, which could only be identified by ongoing involvement.

### Hospital-based Learning Disability Liaison Nurses (LDLNs)

Hospital-based LDLNs were employed at 3 of the 5 acute Trusts in the area covered by CIPOLD. The nurses provide a dedicated resource to facilitate equal access to healthcare for people with learning disabilities. There was clear evidence of them doing this in a wide variety of ways including:

- Facilitating hospital visits prior to admission.
- Identifying a person's needs to the ward staff and what reasonable adjustments were required in their receipt of healthcare.
- Providing advice to ward staff about a range of issues including mental capacity and consent.
- Providing formal and on-the-job training to ward staff about learning disability issues.
- Taking a strategic role in audit, systems review, learning disability action plans and the implementation of national recommendations.

The CIPOLD review of deaths recognised the crucial role that LDLNs took in facilitating access to healthcare for people with learning disabilities. To a large extent, this was also the case with the learning disability lead nurses in the other 2 acute hospitals, but the pressures on them of their other roles and responsibilities appeared to create tensions that limited the effectiveness of their role when compared to that of the dedicated learning disabilities liaison nurse role.

Where there were concerns documented about LDLNs or their equivalents, it was always in the context of their availability or the referral pathways for their input. LDLNs (and their equivalents) were generally only available on weekdays and in daytime hours. Referral of patients to them was usually by phone or via the IT system, with messages being picked up during office hours. However, there were a number of cases documented where it was felt that the referral pathways for input from the LDLNs (or their equivalents) had been significantly delayed beyond this, or the referral had not been made at all, resulting in people with learning disabilities being admitted to the hospital without the opportunity for timely, specialist support from the liaison nurse.

## **Non-specialist health and social care providers**

CIPOLD reviewed the deaths of many people who were supported by skilled and committed carers. It also reviewed deaths where there were some concerns about apparent gaps in the knowledge and skills level of non-specialist health and social care providers in a range of settings. In a number of cases this was assessed as having made the person more vulnerable to a premature death. The perceived gaps in the skills and knowledge of health or social care workers reported to CIPOLD were about learning disability awareness itself, but also about the particular condition(s) of the person or treatment(s) required by the person.

A commonly reported need was for learning disability awareness training for hospital staff and staff in generic residential care homes (with or without nursing) or providing support to people in supported living settings. As well as general learning disability awareness training, there were particular concerns about the need for and availability of training in the management and use of a gastrostomy for feeding, and the administration of midazolam as a 'rescue' medication in epilepsy. Training for staff with regards to these issues was sometimes felt to be difficult to access. There were also problems identified when insufficient numbers of staff had been trained in the techniques, or the use of Bank or Agency staff meant that there was not always a trained person on duty able to administer midazolam should it be required.

The other most commonly identified training needs for health and social care staff related to:

- The Mental Capacity Act.
- Decisions not to attempt CPR.
- Applying for CHC funding.
- End-of-life care and the use of end-of-life care pathways.
- First aid.
- Communication skills.
- What commonly used medications were for.
- Dementia.
- Risk assessments.
- The prevention and management of pressure sores.
- The prevention and management of falls.
- The prevention and management of venous thromboembolism.

### **Case study – Kathleen**

#### **Where non-specialist care workers had excelled**

Kathleen had inoperable cancer and was dying. The staff at her residential care home made every effort to allow Kathleen to live out her life in what had become her home. They were prepared to acquire equipment and take on new skills to allow this to happen. The palliative care consultant provided a teaching session for the care home staff to explain about the process of dying of cancer, pain control, syringe drivers, and other aspects of terminal care. Kathleen was successfully cared for at home by the care home staff with support from the Macmillan service and her GP, with good symptom control.

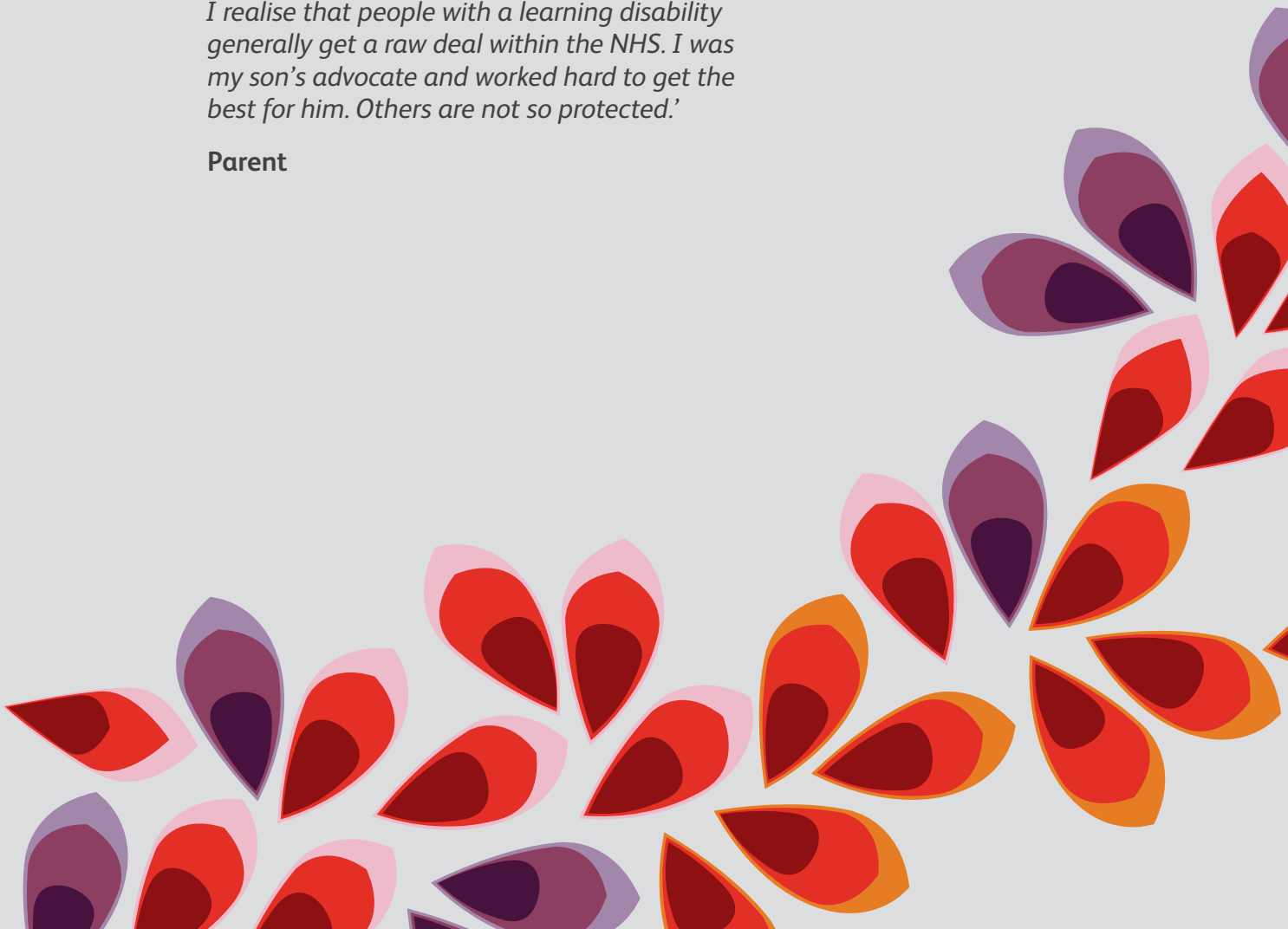
# Chapter 11

## Comparator cases

To find out whether the characteristics and factors associated with deaths of people with learning disabilities were unique to this particular group or shared with those who died at the same age but did not have learning disabilities, we compared the deaths of a subset of people with learning disabilities and those from the general population. In this chapter we compare the premature nature of the deaths, care pathways, contributory factors and the health-related problems associated with these 2 groups.

*'I'm hoping that the research will help others – I realise that people with a learning disability generally get a raw deal within the NHS. I was my son's advocate and worked hard to get the best for him. Others are not so protected.'*

**Parent**



## Chapter summary

Using the pathway approach to defining premature deaths, the proportion of deaths identified by the Overview Panel as being premature was not significantly different between the subset of people with learning disabilities and the comparator group of people without learning disabilities. The reasons why a death might be considered to be premature were, however, different between the 2 groups. The numbers are too small to demonstrate any statistically significant differences although it was notable that reasons associated with lifestyle choice were more common in the comparator group and reasons associated with the coordination of care and information sharing, and delays or problems with diagnosis and treatment were more common for those with learning disabilities.

The proportion of unexpected deaths using ONS ICD-10 codes was not significantly different between the 2 groups. Nor was the proportion of deaths considered to be avoidable by the ONS. However there were significant differences when considering whether the deaths were amenable or preventable. Typically more of the comparator deaths were preventable (i.e. could be avoided by public health interventions) while more of the deaths of people with learning disabilities were amenable to change (i.e. could be avoided with good-quality healthcare). Of significance was that people with learning disabilities were more likely than the comparator group to have problems with having their illness diagnosed.

We looked in more detail at the contributory factors associated with premature deaths of people with and without learning disabilities within the framework of 4 domains. In the individual domain, dependence on others for mobility and feeding was significantly more prevalent among those with learning disabilities, while problems of lifestyle choices (such as smoking and alcohol consumption) were significantly more prevalent among the comparators. In the family and environment domain, people with learning disabilities were significantly more likely to have had inadequate or inappropriate accommodation for their needs, and family or paid carers who did not feel listened to. In the care provision domain, 4 contributory factors were significantly more prevalent among those with learning disabilities than among the comparators: problems with care planning, problems with information sharing, problems with recognising and adjusting for changing needs, and problems with record-keeping and accessing and sharing records. In the service provision domain, problems with the Mental Capacity Act being followed and delays in the diagnosis and treatment of healthcare problems were significantly more prevalent in those with learning disabilities than in the comparators.

There was a significant difference between the subset of people with learning disabilities and the comparator group of people without learning disabilities in terms of lifestyle factors. People with learning disabilities were less likely to smoke or drink alcohol, were as likely to be obese, but were more likely to be significantly underweight.

There was a significant difference in the number of medical conditions between the subset of people with learning disabilities and the comparators. Long-term health conditions significantly more prevalent among the subset of people with learning disabilities were epilepsy, hypothyroidism, cerebral palsy and Type 2 diabetes. People with learning disabilities also had a significantly higher prevalence of constipation and gastro-oesophageal reflux. Comparator cases had a significantly higher prevalence of ever having had pressure sores in the past.

There was little difference in the number of medications being given to people with or without learning disabilities, but there was a difference in the type of medications. Significantly more of those with learning disabilities were given medication for constipation, epilepsy and hypnotics (medication that causes sedation), while significantly more of the comparators were being prescribed opioid analgesia at the time of their deaths.

## The comparison

As described in Chapters 2 and 3 we chose a subset of 58 people with learning disabilities from the total cohort and 58 people without learning disabilities from the same GP practices, who died at the same age, from broadly the same cause of death and at the same time of year. Few of the deaths reviewed for this comparison were from minority ethnic groups; 98% of those with learning disabilities and 95% of the comparator cases were of white British ethnic background. Given the paucity of work experience, reduced educational opportunities and the predominance of residential care in those with learning disabilities, it was not possible to use traditional markers of socio-economic status to match the 2 groups. This is essentially a comparison of people who died young with an average age of around 60 years in both groups.

## Premature, unexpected and avoidable deaths

### Premature deaths

Using the 'pathway' approach to defining premature deaths (see Chapter 5), the proportion of deaths identified by the Overview Panel as being premature was 52% in the subset of people with learning disabilities, higher than the 43% of the comparators without learning disabilities, but not significantly so. Premature deaths occurred across all broad underlying cause of death categories with no statistically significant differences between the subset of people with learning disabilities and the comparators.



The reasons why the death was felt to be premature were more likely to be associated with delays or problems with diagnosis and treatment, problems with the coordination of care, and problems with information sharing in the subset of people with learning disabilities. Problems regarding one’s lifestyle were more common in the comparator group of people without learning disabilities.

### Unexpected deaths

The proportion of unexpected deaths using ONS ICD-10 codes (see Chapter 5) was 22% among the subset of people with learning disabilities and 21% among the comparators, a non-significant difference.

### Avoidable deaths

As described in Chapter 5, avoidable deaths have been defined by the UK ONS as those deaths that are amenable to change (i.e. could be avoided with good-quality healthcare) or preventable (i.e. could be avoided by public health intervention), or both. Of the subset of people with learning disabilities, 69% died from underlying causes of death that would be considered to be avoidable by the ONS compared with 65% among the comparators, a non-significant difference.

There were significant differences when considering whether the deaths were amenable or preventable (Table 11.1). Typically more of the comparator deaths were preventable (i.e. could be avoided by public health interventions). Those deaths amenable to change by good-quality healthcare were significantly more common among the people with learning disabilities (38%) than the comparators (9%).

**Table 11.1: Comparison of avoidable deaths**

	Chosen LD cases		Comparators		P-value
	n/N	%	n/N	%	
Amenable	22/58	38	5/57	9	—
Preventable	10/58	17	14/57	25	—
Amenable and preventable	8/58	14	18/57	32	—
Not avoidable	18/58	31	20/57	35	0.002

## Care pathways: Identifying, responding, diagnosing and treating the final illness

We have already seen in Chapter 7 that there appeared to be ‘weak spots’ in the chain of the care pathway which either alone, or in combination, had contributed to the premature deaths of people with learning disabilities. Of particular concern were difficulties in diagnosing and treating illness in people with learning disabilities, rather than identifying that people were unwell in the first place. In order to identify if this was a problem only with people with learning disabilities, we have compared the experiences of the subset of people with learning disabilities with the comparator group of people without learning disabilities in this regard (Table 11.2).

Of the 58 selected people with learning disabilities, 93% were identified as being unwell and for 80% the individual, their family members or paid carers responded promptly to the signs that the person was unwell and sought medical advice in a timely way. Among the comparator group of people without learning disabilities, 79% were identified as being unwell and 79.5% responded promptly and sought medical advice.

Of those identified as being unwell and responding promptly to seek medical advice, 55% of the subset of people with learning disabilities had problems in having their illness diagnosed, significantly more than the comparator group of people without learning disabilities (31%). More of those with learning disabilities had problems with the treatment of their illness (42%) than the comparator group of people without learning disabilities (29%) although this difference was not significant.

Table 11.2 Problems with recognising and responding to final illness

	Chosen LD cases		Comparators		P-value
	n/N	%	n/N	%	
Identified as being unwell	54/58	93	45/57	79	0.03
Responded appropriately when identified	40/50	80	35/44	79.5	0.96
<b>Of those who were identified as being unwell and responded appropriately</b>					
Problems with diagnosis	22/40	55	11/35	31	0.04
Problems with treatment	16/38	42	10/35	29	0.23

## Contributory factors to deaths

The CIPOLD review of deaths examined factors that may have contributed to the vulnerability, ill-health or death of the person concerned, or that provided a complete and sufficient explanation for the person's death. Many of these factors have already been identified in this report. We looked in more detail at the contributory factors associated with deaths of people with and without learning disabilities within the framework of 4 domains – individual, family and the environment, care provision and service provision. Table 11.3 presents the significant findings from this analysis.

In the individual domain, we explored the following factors:

- A person's attitudes to, interactions with and acceptance of care from health and social care services.
- Lifestyle choices (smoking, alcohol, use of non-prescribed drugs, recorded unhealthy diet, etc.).
- Dependence on others for mobility and feeding.
- Swallowing problems.
- Being underweight.
- Being obese.

Lifestyle choices known to be related to poorer health (such as smoking, alcohol, use of non-prescribed drugs and having a poor diet) were significantly more prevalent among the comparator group of people without learning disabilities. Dependence on others for mobility and feeding was significantly more prevalent among the subset of people with learning disabilities. All of the other factors were not found to be statistically significant between the 2 groups.

In the family and environment domain, we explored the following factors:

- Problems regarding family/carers seeking or accepting care.
- Family/paid carers not feeling listened to.
- Health problems in close family member.
- Inadequate or inappropriate accommodation for the person's needs.

The subset of people with learning disabilities was significantly more likely to have had inadequate or inappropriate accommodation for their needs than those in the comparator group. They were also significantly more likely to have had family or paid carers who did not feel listened to than those in the comparator group. None of the other factors were significantly different between the groups.

In the care provision domain, we explored the following factors:

- 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.

Each of these contributory factors was significantly different between the subset of people with learning disabilities and the comparator cases. A significantly greater proportion of people with learning disabilities had problems with care planning, with having their needs recognised and their care changed according to their changing needs, with the coordination of their care and information sharing, and with record-keeping and accessing records.

In the service provision domain, we explored the following factors:

- Problems with DNACPR orders.
- Problems with the Mental Capacity Act being followed.
- Delays in the diagnosis and treatment of healthcare problems.
- Problems with end-of-life care.

The subset of people with learning disabilities was significantly more likely to have had problems with the Mental Capacity Act being followed than the comparator group. The subset of people with learning disabilities was also significantly more likely to have had delays in the diagnosis and treatment of their final illness than those without learning disabilities. Both groups had problems with DNACPR orders and end-of-life care.

Table 11.3: Comparison of significant contributory factors

Contributory factors	Subset of LD deaths	Comparator deaths	P-value <sup>1</sup>
	% (N=58)	% (N=58)	
<b>Significant contributory factors affecting more people with learning disabilities</b>			
<b>Individual factors</b>			
Dependence on others for mobility and feeding	26	10	0.03
<b>Family or environmental factors</b>			
Inadequate or inappropriate accommodation for the person's needs	33	5	<0.001
<b>Factors regarding the provision of care</b>			
Family/paid carers not feeling listened to	14	0	0.006 <sup>2</sup>
Problems in advanced health and care planning	41	10	<0.001
Problems with recognising needs and adjusting care as needs change	41	19	0.009
Problems with coordination of care and information sharing	45	26	0.03
Problems with record keeping and accessing records	35	17	0.03
<b>Factors regarding service provision</b>			
Problems with adherence to the Mental Capacity Act	36	9	<0.001
Delays in the diagnosis and treatment of healthcare problems	67	47	0.02
<b>Significant contributory factors affecting more people without learning disabilities (comparator cases)</b>			
<b>Individual factors</b>			
Lifestyle choices (smoking, alcohol, use of non-prescribed drugs, recorded unhealthy diet, etc.)	21	41	0.02

Notes: 1 Using Chi-square test

2 Expected cell less than 5, so using Fisher's exact test

## Comparison of health-related information, medical conditions and medications

### Smoking and alcohol use

A fifth (21%) of the subset of people with learning disabilities smoked at the time of their death or had smoked in the past, compared with 50% of the 58 comparators without learning disabilities; this difference was statistically significant.

Few of the subset of people with learning disabilities had current or previous problems with alcohol that had been reported, a significant difference between the subset of people with learning disabilities and the comparator group.

### Body mass Index (BMI)

BMI was recorded for 51 of the 58 deaths in the subset of people with learning disabilities and 50 of the 58 comparators without learning disabilities. Using optimal BMI as a reference group there was no significant difference between the 2 groups in terms of obesity or people being overweight, but significantly more of those with learning disabilities were underweight. Removing those who had rapidly lost weight prior to death yielded too few numbers to make such a comparison as above, although the proportion underweight was not dissimilar to that described above.

### All medical conditions

In Chapter 6 we showed that on average the 247 people with learning disabilities had 5 medical conditions each that were either long-term or treatable conditions prior to the final illness. The median number of conditions in the subset of people with learning disabilities was 4, compared with a median number of 3 conditions in the comparator group: a significant difference.

### Long-term health conditions

Four long-term conditions were significantly more prevalent among the deaths of the subset of people with learning disabilities. These were epilepsy, hypothyroidism, cerebral palsy and Type 2 diabetes. More of the comparators without learning disabilities (28%) had no long-term health conditions compared with the subgroup of people with learning disabilities (12%); and fewer of the comparators (41%) had 2 conditions or more compared with the subgroup of people with learning disabilities (66%): a significant difference. The median number of long-term health conditions was 2 for people with learning disabilities, compared with 1 condition for the comparators without learning disabilities: again, a significant difference.

## Treatable medical conditions

Those with learning disabilities had a significantly higher prevalence of constipation and gastro-oesophageal reflux. A quarter (24%) of people in the subset of people with learning disabilities had pneumonia at the time of death, a higher proportion than among the comparators (12%) but not significantly different.

The comparators had a significantly higher prevalence of having pressure sores in the past (52%) compared with those with learning disabilities (7%), but there was no significant difference in the proportion that had pressure sores at the time of their death.

The median number of treatable health conditions per person was the same in both groups at 2 conditions. More of the people with learning disabilities (24%) had 4 or more treatable conditions than comparators (14%) although this was not statistically significant.

## Medications

There was no significant difference in whether a person was taking prescribed medication or not, or of the number of medications taken between the 2 groups. Significantly more of those with learning disabilities were prescribed medication for constipation, epilepsy and hypnotics (medication that causes sedation) while significantly more of the comparators were prescribed opioid analgesia at the time of their death.

# Chapter 12

## The impact of CIPOLD

This chapter describes the impact of CIPOLD on those who have been involved in any reviews of deaths.

*I found it most helpful to be able to discuss this ... death. Although we had obviously discussed this as a significant event in the practice, I felt that this was somewhat incomplete ... Without this inquiry I would not have been able to express these ideas and concerns, which I feel could lead to an improvement in care, and hopefully avoidance of some preventable deaths in the future.*

### **GP**

*Working on the Confidential Inquiry has enabled me to reflect on how we commission packages of care. Hearing the families and friends' viewpoints has been the biggest learning curve and will influence the way I monitor quality in my role.*

### **CIPOLD Nurse**





## Chapter summary

It quickly became apparent that the process of conducting CIPOLD was making an impact on the way in which professionals thought about issues relating to people with learning disabilities and was leading to changes in practice. This has been described as a ripple effect of the work. Feedback about the impact of being involved with CIPOLD was collected in a number of ways, and highlighted the impact of CIPOLD on professionals' own practice, their awareness of others' roles, their adherence to existing legislation and guidelines, the planning and delivery of end-of-life care, documentation and information sharing, staff confidence and the training of staff. CIPOLD also helped professionals and others to appreciate the importance of knowing and acknowledging the histories of people, and of the role that systems can play in disempowering people.

The chapter concludes with a summary of the role of CIPOLD in following up concerns about individual patients.

## Introduction

Feedback about the impact of being involved with CIPOLD was collected in a number of ways. A feedback questionnaire was sent to those involved in individual case investigations; family members were asked to complete a review questionnaire following their interview with the CIPOLD nurse; some of the Local Review Panel meetings documented changes that had taken place subsequent to the beginning of the investigation; Overview Panel members were asked to reflect on the impact of CIPOLD on their own practice; feedback sessions with hospital safeguarding leads or care home managers recorded any actions taken; individual feedback was collected from each of the nurses; and the investigators were sent a feedback questionnaire to complete and return at the end of their work with CIPOLD.

It quickly became apparent that the process of conducting CIPOLD was having an impact in a number of ways and the ripple effect of CIPOLD was leading to changes in practice.

## The impact of being involved with CIPOLD

The comments from those who had participated in CIPOLD, in whatever capacity, predominantly demonstrated an appreciation of the opportunity to reflect on their practice. In particular, respondents spoke about the importance of seeing a person holistically, of thinking about the issues and relating them to their own practice:<sup>1</sup>

- *'The experience has influenced my practice and I have found myself challenging medical decisions, requesting more professionals' meetings to discuss case management and an insistence that GPs and clinicians working outside the learning disabilities field take a more person centred and holistic approach (i.e. not treat one condition in isolation of others).'* (Speech and language therapist).
- *'I think that my awareness around a range of issues has been heightened, and my response to day-to-day work affected by this. I'm very keen to make others aware of the issues so we can affect change locally wherever possible.'* (Commissioner).

One of the aims of CIPOLD was to identify and share good practice in the treatment of people with learning disabilities within health and care services. We felt that it was important that the reviews captured what had worked well, as well as where improvements could be made. Many professionals seemed to have appreciated this:

- *'I found this rewarding and it helped me feel reassured about my level of care after an unexpected death.'*

CIPOLD has aimed to ensure that the experiences and views of families and paid carers are taken seriously. Many families reported they had appreciated the opportunity to contribute to the CIPOLD review and that although upsetting, it had also been a positive experience. One brother talking about his sister's death commented:

- *'Talking to (the nurse) helped me come to terms with the circumstances surrounding my sister's death.'*

Another parent, talking about their son said:

- *'Our nurse was very sympathetic to our recent loss and it was really good to talk about our son openly and with feeling. The tears were good tears.'*

## The impact of CIPOLD on raising awareness about other members of the multidisciplinary team

The feedback given to CIPOLD suggested that one of the most valuable aspects of the investigation process and Local Panel Review meetings has been to alert professionals to specific services, and to facilitate their knowledge of the roles and responsibilities of other members of health and care teams. The aim of the Local Review Panel meetings was to bring together the range of people and services involved in supporting the individual who had died and it appears that for many attendees this was a unique opportunity to learn more about the range of input of other members of health and care teams. In particular, staff in care homes with and without nursing seemed to have enhanced their knowledge of the availability of CLDTs and hospital-based LDLNs, but other health professionals too gained an awareness of the existence of the more specialist posts.

- *'I was unaware that there is a hospital-based learning disabilities nurse who can support people with learning disabilities during hospital admission.'*

Many of the people whose deaths were reviewed by CIPOLD had complex needs which necessitated multi-agency input. Given the range of people who may be, or could potentially be involved with supporting an individual, respondents commonly reflected on their own role in relation to that of others, and of the importance of good communication and of having a named coordinator when many agencies are involved. The feedback given to CIPOLD suggests that being involved with CIPOLD had raised their awareness of this.

- *'The care of people with the most complex health needs can seem poorly coordinated. There needs to be a stronger emphasis on "health needs" in providing care and maybe for CLDTs to be more proactive in this. Maybe a need for an identified case manager to coordinate/oversee care in relation to health needs.'*

Feedback to CIPOLD indicated that having a greater awareness of the roles of other professionals has already led to some changes in the practice of individuals and local teams:

- *'We will ensure earlier involvement of the IMCA.'*

## The impact of CIPOLD on adherence to existing legislation and guidance

### Mental Capacity Act

There is a range of existing legislation and guidelines that is relevant to the delivery of care and the CIPOLD process has generated many pertinent learning points in this area. It is clear from a review of the impact of CIPOLD that the greatest impact has been in relation to the understanding and use of the Mental Capacity Act. This was an issue for discussion in a great number of case reviews; professionals seem to have gained a great deal of learning about their responsibilities and it appears that this has already led to changes in their practice. This was apparent at all stages of the decision-making process, from assessing a person's capacity to make a decision, through conducting Best Interest decision-making processes, to the recording of the decision.

- It was reported by a member of the Local Review Panel meeting that he has noticed that CIPOLD is having a significant effect on the multi-professional ward meetings that he is attending. CIPOLD is challenging previously held personal and historical decisions and assumptions regarding treatment, DNACPR decisions and the quality of life that people with learning disabilities have. It was reported that doctors were becoming much more aware that they have to have more robust and transparent reasons for making decisions, and that these decisions are now being questioned and noted by investigators from CIPOLD.

### Decisions not to attempt cardiopulmonary resuscitation

Of particular concern in the CIPOLD review of deaths was adherence to guidelines about DNACPR decisions. It seemed this had also been taken on board by a number of health and care professionals and some actions had ensued:

- The Hospice has introduced a new DNACPR form which enables clear reasons to be recorded (e.g. for not involving the person or their representative, and the reason for the decision).

### Safeguarding

There was also reference in a significant number of Local Review Panel meetings to discussions about safeguarding issues and risk assessment processes. For some of these cases the concerns were followed up formally by CIPOLD. It appeared that some learning about the safeguarding of all vulnerable people had taken place and that actions had been taken in this respect:

- There was no learning disability risk assessment (on the specialist unit at one local hospital) which is an expectation for all patients with learning disabilities. This has now become policy within the particular unit.

## Making 'reasonable adjustments'

All public sector services now have a legal duty to provide reasonable adjustments for people with learning disabilities in order to ensure equal access to services. These may include additional support to make a service accessible, such as the provision of easy read information. These could also relate to alterations to policies or procedures in order that the service is as effective for people with learning disabilities. The summary reports of Local Panel Review meetings identified some specific situations where reasonable adjustments could have been made, and these were taken forward into actions in a number of cases:

- Communication plans for people with learning disabilities are to be incorporated in the ward nursing care plans.
- Easy read discharge information has been introduced to A&E so that people with learning disabilities attending A&E have clear information to take with them when they leave the department.

## The impact of CIPOLD on systems, particularly tracking patients through hospital systems

As already mentioned, CIPOLD identified the considerable difficulties people with learning disabilities and their families and carers had with negotiating hospital systems. This was especially an issue for people with learning disabilities who did not have anyone acting as an effective advocate for them. In order to address such problems, some of the hospitals have identified changes that they are making including:

- LDLNs now following up all patients with learning disabilities who do not attend appointments, and feeding back this information to community teams.

## The impact of CIPOLD on the planning and delivery of end-of-life care

Over half of the deaths reviewed by CIPOLD were agreed to be expected, but concerns were often raised about a lack of end-of-life planning. There was evidence from the reports of the CIPOLD Local Panel Review meetings that reflecting on the way in which the end-of-life care was managed was both helpful and educational:

- This was the first time the care home had experienced a life-changing health event and death within the resident group and they felt that they had learned from this. Staff felt that the experience of Henry's death could inform their planning for other service users.

There was acknowledgement that end-of-life planning needs to be timely and many practitioners reflected that they would review the process and documentation of end-of-life planning:

- *'In future, end-of-life discussions will be built into the annual review for all of the residents at the home.'*

## The impact of CIPOLD on documentation and information sharing

The CIPOLD process has reinforced to many practitioners the importance of accurate documentation in notes, and it was clear from responses given back to CIPOLD that taking part in reviews had heightened their awareness and tightened up on practice:

- *'It made me reflect on the records that we keep and how important it is to keep accurate records so that you can answer any queries that come up at times like this.'*

Another frequent problem identified by CIPOLD was that information was not always appropriately shared between the different agencies involved. Involvement with CIPOLD had highlighted the problems arising from this, and had led to a number of practitioners reporting that they were now taking action in this respect:

- GP is to add a 'Special Notes' section in the Out-of-hours IT system documentation specifically about the provision of support for people with learning disabilities.
- Hospital documentation now asks for a 'named person' at a care home with whom the hospital would liaise. The policy is now to share information with the 'named person' and next of kin with consent or as agreed.

## The impact of CIPOLD on staff confidence

Many people with learning disabilities are reliant on somebody else to advocate for them in relation to the care they get or at least to support them in this. Both CIPOLD and other studies have suggested it can be difficult for family or paid carers to challenge or question medical professionals, and that medical professionals sometimes do not listen to the people who know the person with learning disabilities best.<sup>2,3</sup> Being involved with CIPOLD did seem to have an impact on the degree of confidence that carers had to question other professionals:

- *'It has opened my eyes to a certain extent with regard to not just accepting what I'm told by medical professionals, and to probe further to ensure that I understand as early as possible what the key issues are to ensure that I can provide the best possible advocacy support to clients.'*

## The impact of CIPOLD on the training of staff

There has already been reference to training needs around issues raised by CIPOLD such as an understanding of, and adherence to, the Mental Capacity Act and end-of-life planning. However there were other cases where training needs were identified in the CIPOLD reviews and have started to be addressed:

- *'The matron for haematology/oncology has organised a study session for the department specifically looking at the needs of patients with learning disabilities undergoing chemotherapy or radiotherapy and accessing additional resources that will be helpful for supporting them, such as with consent.'*

## The impact of CIPOLD on acknowledging the histories of people

It was clear that especially when people had spent much of their lives in long-stay institutions there was a lack of life history which could impact on their future care and support. It was positive to see evidence that attendees at the CIPOLD Local Review Panel meetings had recognised this and made plans to tackle the problem:

- *'It made me more aware of the importance of gaining accurate past histories of a client.'*

## The role of CIPOLD in following up concerns about individual patients

For 9 people with learning disabilities whose deaths were reviewed, CIPOLD instigated further measures because of concerns that the reviews had raised. These involved meeting with the service provider to identify the death, verifying that the factual information pertaining to the review was correct, and highlighting the concerns that CIPOLD had. In each of these cases, CIPOLD requested further action to be taken. Outcomes of some of these discussions were Accident, Incident and Near Miss reviews and Serious Untoward Incident reviews. Actions are still outstanding for 3 of these cases, which are being passed over to the Clinical Commissioning leads from the end of March 2013 when CIPOLD's work will end.

### Notes

- 1 Direct quotes are given in italics, and excerpts from documentation are presented in normal typeface.
- 2 Mencap (2007) *Death by Indifference*. London: Mencap.
- 3 Parliamentary and Health Service Ombudsman (2009) *Six Lives: The Provision of Public Services to People with Learning Disabilities*. London: The Stationery Office.

# Chapter 13

## Conclusions and recommendations

In this chapter we draw together the conclusions of the CIPOLD review of deaths and identify 18 key recommendations which, were they individually and collectively implemented, would lessen the risk of premature death in people with learning disabilities.

*No, it won't bring her back, no. I just think that if this helps somebody else with learning difficulties being looked after better, and more communication between staff and homes and family, then it would be worth it.*

**Parent of person with learning disabilities**





## Chapter summary

The key recommendations from the CIPOLD review of deaths are:

- 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 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.

## Introduction

The CIPOLD review of deaths have resulted in a wealth of rich information being collected. Trying to distil this information into a set of key recommendations has been a challenge, and we have been aware of the imperative to do justice for people with learning disabilities whose deaths could have been avoided at the time they occurred, to the testament of families who have so generously shared their experiences with us, and to the reflections of professionals contributing to CIPOLD who have for the most part found it a positive and a useful experience. There are many suggestions for improved practice, and examples demonstrating how the provision of support or care could be better that we could have included here. By and large, these would be repeating what we already know, and what previous reviews such as that of Winterbourne View, and the Francis Report have concluded. Here, we have chosen to identify 18 key recommendations that we think, were they individually and collectively implemented, would lessen the risk of premature death in people with learning disabilities.

## Identifying people with learning disabilities and their need for reasonable adjustments

Our first recommendation echoes Recommendation 2 of *'Healthcare for All'*<sup>1</sup> and stresses the necessity to identify people with learning disabilities within health and care services in order to prevent their premature deaths. That a person had learning disabilities was not proactively identified and their needs for reasonable adjustments were overlooked, particularly when they were referred for non-emergency secondary care.

### Recommendation 1: Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems

There is an imperative for the clear and consistent identification of people with learning disabilities, for the provision of key data to be able to determine and monitor the extent of health inequalities at a national level. This is an action for the Department of Health, the NHS Commissioning Board and the Health and Social Care Information Centre to take forward.

Additionally, in all local healthcare record systems, identification of people with learning disabilities is required with information at an individual level about the reasonable adjustments that a person needs to effectively access the delivery of care. Merely identifying that a person has learning disabilities is not sufficient – this information needs to be supplemented by a statement of the reasonable adjustments required. Effective information sharing protocols need to be in place to support the collaborative use of this information between primary, secondary and community health services, including in all GP referral letters. The identification of people with learning disabilities within healthcare systems and a record of the reasonable adjustments that they require must be sufficient so that the reasonable adjustments required for them can be audited, and their care can be tracked across organisational boundaries. This is an action for Clinical Commissioning Groups (CCG), the NHS Commissioning Board (NCB), and the National Commissioning Board Local Area Teams (LATs) to take forward.

### **Recommendation 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.**

We recommend that any reasonable adjustments identified are audited annually and published locally as evidence to help inform Equality Delivery System (EDS) outcomes. Audit methods may include CQUINs<sup>2</sup> or qualitative feedback using Learning Disability quality monitors or Experts by Experience. All commissioners should ensure that reasonable adjustment audit measures are built into all health provider contracts. Examples of best practice should be used to support good-quality care. We recommend that poor compliance with this action should be considered by equality leads, using the Equality Act legal framework.

### **The particular pattern of ill-health of people with learning disabilities**

The profiles of the people with learning disabilities who died indicated that many of them were at considerable risk of a range of vulnerabilities, singly or in combination. They were significantly more likely than the comparator cases to have multiple conditions, and had a high prevalence of impairments, long-term conditions and treatable conditions. NICE Guidelines are mostly based on single conditions, rather than the pattern of multi-morbidity found in the CIPOLD cohort, a factor that makes people with learning disabilities particularly vulnerable.

### **Recommendation 3: NICE Guidelines to take into account multi-morbidity**

People with learning disabilities more often than not have more than one health condition or disease. NICE Guidelines should take into account the pattern of multi-morbidity found in people with learning disabilities, develop guidelines that take into account the most common co-morbidities for any single condition, and offer advice about the management of patients with more than one condition.

## The fragmentation of the healthcare provided to people with learning disabilities

The CIPOLD review of deaths found considerable evidence of fragmented care, with a 'systems' approach to the care of the individual, rather than addressing their holistic needs. Given the current way in which secondary care in the NHS is structured, robust measures are needed to counteract this disadvantage for people with learning disabilities and others with multiple co-morbidities.

### Recommendation 4: A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions

People with learning disabilities require the involvement of healthcare workers who are trained in managing complexity and multi-morbidity. This is particularly important in secondary care where increasing sub-specialisation may result in multiple clinical teams' involvement with no overall leadership. We recommend commissioners ensure that the coordination of care role is enshrined and monitored in contracts across health and social care, with named lead professionals to coordinate care across and beyond episodic reviews. There is much, we believe, that could be gained from adopting best practice from the *Team Around the Child* model of service delivery, which supports joined-up working, information sharing, early intervention, joined-up assessments, a lead professional to coordinate care and keeping the individual and their family at the centre of the process.

For people with complex and multiple health issues we recommend a single consultant to fulfil the lead professional role, who has ongoing (rather than episodic) responsibility for the care and coordination of the health needs of an individual, with clear referral pathways from the consultant to multidisciplinary specialist input as required, following the model commonly used in Old Age Medicine.

For people with learning disabilities with 2 or more long-term conditions, and for those living unsupported (or minimally supported) in the community with one or more long-term conditions, a named healthcare coordinator is required. The role of the healthcare coordinator should be to support proactive action to meet the healthcare needs of the individual, to smooth the person's pathways through healthcare systems, and to support the individual with developing Health Action Plans and pain assessment tools, with the self-management of their long-term conditions, with accessing health screening, and ensuring that reasonable adjustments are provided. We recommend co-locating CLDT nurses into GP surgeries (or groups of surgeries) in order for them to fulfil this role.

### Recommendation 5: Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.

Any person with 2 or more long-term conditions should have a patient-held health record (possibly held securely online and/or on a memory stick). For people with learning disabilities this should include a single integrated long-term condition care plan, their Health Action Plan, a personal profile or hospital passport-type document, a summary of the reasonable adjustments that the person would require in order to access healthcare services, a list of their current medication and a summary of health interventions and issues. A standardised record, similar to the child health 'red book', with a standard recognisable cover and content, but with the capacity for some local variation, should be available and updated at all medical consultations. We recommend commissioners should require patient-held records for all people with learning disabilities in receipt of commissioned services. Responsibility for ensuring these are 'active' documents should rest with the person's key worker, or their healthcare coordinator. For those in non-commissioned services, patient-held health records should be reviewed at their Annual Health Check, or with their healthcare coordinator as appropriate.

### Recommendation 6: Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans

There needs to be significant input at a national level to make the Directed Enhanced Service (DES) for learning disabilities in General Practice permanent and standardised. This is an action for the Department of Health.

Given the variability found in the content, quality and recording of Annual Health Checks in the CIPOLD reviews, we recommend that minimum requirements for Annual Health Checks are introduced, with the updated Cardiff Health Check as the standard template for Annual Health Checks in people with learning disabilities for national use. The health check should include an examination by an experienced doctor who has completed their training. In addition the doctor should provide the person with learning disabilities with a short, written accessible Health Action Plan which clearly identifies the health issues, the person who is responsible for addressing these issues and a specific timeframe in which they will be achieved. This should be a standard national document. The care provider (when there is one), or the person's named healthcare coordinator should be responsible for ensuring that the health plan is translated into action. When there is no significant provider and no healthcare coordinator, and there are health needs, a referral should be made to the CLDT to ensure that the health plan is actioned. This recommendation for amending the DES is an action for the Department of Health and the NCB.

## Deaths amenable to healthcare interventions

We examined premature deaths by examining the ICD-10 codes for the underlying causes of death that are considered to be avoidable using ONS definitions.

In particular, we looked at deaths amenable to healthcare interventions in the whole cohort of people with learning disabilities. The differences across the cohort were striking. People significantly more likely to die of causes that could have been avoided by good-quality healthcare interventions were younger, had more severe learning disabilities, had underlying causes of death related to the nervous system, congenital and chromosomal abnormalities and the respiratory system, and were unsupported by a significant person in their life who could advocate for them.

Comparing the subset of people with learning disabilities with the comparator group of people without learning disabilities, we found almost two-fifths (37.9%) of people with learning disabilities died from causes amenable to good-quality healthcare, but this was the case for just 8.8% of the comparator cases without learning disabilities.

The weakest link in the chain of the care pathway for people with learning disabilities was problems in having their illness diagnosed. The most frequently reported problem was that the investigations needed to diagnose their illness were not done or posed difficulties. Missed or delayed appointments, incomplete preparations for investigations that then need to be repeated, and the need for inpatient care while investigations are undertaken because of a lack of appropriate support in the community or reasonable adjustments being made, is both costly for the NHS and potentially life-threatening for the individuals concerned. The CIPOLD reviews have evidenced examples of where the thoughtful and committed use of reasonable adjustments to support people to access investigations and diagnostic tests on a par with people without learning disabilities has been effective and instrumental in them having their health needs met, while also reducing wasted appointments. This recommendation is for the Department of Health, the NCB and the Academy of Medical Colleges to consider how to improve diagnosis in a timely manner.

**Recommendation 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**

Given the problems that people with learning disabilities experience with having their illness diagnosed we recommend that investigations be undertaken early in the care pathways of people with learning disabilities. This is a recommendation for all healthcare providers.

The starting point should be that all patients have the right to follow the same care pathway as any other patient, unless a decision is made (following the Mental Capacity Act and Best Interest decision-making processes if necessary) to deviate from that pathway. The legal requirement for reasonable adjustments to be made to ensure that people with learning disabilities have access to the same investigations and treatments as the general population must be enforced; only when reasonable adjustments are not sufficient should alternatives to clinical guidelines or recognised care pathways be considered. Here, given the difficulties that people had with using the bowel screening programme, we also make particular reference to ensuring the accessibility of cancer screening programmes for people with learning disabilities.

Reasonable adjustments in many cases could include the provision of specialist advice and support from a hospital-based LDLN or the CLDT. The CIPOLD review of deaths have been impressed by the input of specialist nurses working with people with learning disabilities to support their health interventions. There is a lot more that specialist nurses could do in this respect, given optimal resources, and we recommend that CCGs and healthcare providers support much closer working between CLDT nurses and GPs, hospital-based learning disability nurses be distributed across all hospitals, and that a named learning disability lead be available 24 hours a day in all secondary care providers.

### **Recommendation 8: Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services**

People with learning disabilities who are experiencing barriers in accessing healthcare should be referred to specialist learning disability services to help facilitate access.

We recommend commissioners, and other agencies, review their eligibility criteria for access to specialist learning disability services. These must all be based on vulnerability and need, not on an assumed level of a person's learning disabilities.

Potential barriers a person might have in accessing healthcare services because of their own fear of healthcare interventions must be addressed proactively. People with learning disabilities reluctant to engage with medical professionals should have early desensitisation work done with them in anticipation of need. This should be documented in their Health Action Plan and reflected in service contracts. Where specialist expertise is required, the CLDT should be involved in working with the individual, their family and carers and creating a bridge to primary and secondary health services to facilitate familiarisation and desensitisation.

## Recommendation 9: Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems

While there was little difference in the prevalence of respiratory disease being the underlying cause of death between people with learning disabilities and the general population, over a third of people with learning disabilities died with respiratory disease (usually pneumonia) reported as the immediate cause of their death. For them it was respiratory disease that was the final illness from which they died. We therefore make some recommendations in this regard.

First, we recommend that people with learning disabilities are recognised as a high-risk group within the national immunisation programme for the receipt of seasonal flu and pneumonia immunisations, irrespective of whether or not they live in a residential care setting.

Second, CCGs must ensure they are commissioning sufficient, and sufficiently expert, preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural care support, aggressive treatment of gastro-oesophageal reflux, the ready availability of speech and language therapists or other suitably qualified nurses able to undertake swallowing assessments, the development of clear clinical pathways for gastrostomy insertion, and the frequent review of patients waiting for a gastrostomy procedure to protect them from risk of aspirating.

## Adherence to legislation and guidelines

### Mental Capacity Act

The CIPOLD reviews of the deaths of people with learning disabilities identified concerns about adherence to the Mental Capacity Act, and the differences in the understanding and implementation of each of its principles. There was evidence of disagreement as to what professionals understood by ‘serious medical treatment’, and thus a lack of consistency about appointing IMCAs to support those without family members to represent their views. The Mental Capacity Act has now had more than 5 years to be embedded into practice, and there are a range of resources available to professionals to support its implementation, but clearly more needs to be done in this regard. We are therefore making a number of recommendations to strengthen the protection of people with learning disabilities under the Mental Capacity Act and to clarify the responsibilities of professionals.



## Recommendation 10: Mental Capacity Act advice to be easily available 24 hours a day

It is the responsibility of each professional to ensure that they are adhering to the Mental Capacity Act. However, in light of the significant concerns evidenced in the CIPOLD reviews that this is not happening, we recommend a 24-hour Mental Capacity Act phone line staffed by expert advisors in all matters relating to the Mental Capacity Act.

We also recommend Mental Capacity Act Advisors be employed locally, at a senior level in every secondary healthcare institution and cluster of GP surgeries. The role of the post-holder would be to supplement individual knowledge and responsibility, and drive forward:

- The delivery of robust, high-quality training for all direct care staff at induction, baseline and routine follow-up intervals.
- The provision of advice about assessments of capacity.
- Best Interest decisions being taken according to statutory requirements and ensure that the quality of documentation of decision-making is of a high standard.
- Regular audits of adherence to the Mental Capacity Act.
- The sharing of learning and good practice across the organisation(s).
- The NCB and CCGs must ensure that they have adequate oversight of the appropriate Mental Capacity Act safeguarding arrangements and together with regulators must enforce adherence to the Act.

## Recommendation 11: The definition of Serious Medical Treatment and what this means in practice to be clarified

The Code of Practice accompanying the Mental Capacity Act only advises on medical treatments, not invasive investigations, and more specific recommendations and guidance on both treatment and investigation would be welcome. In particular, we recommend that the Department of Health should issue a clear definition of what constitutes 'serious medical treatment', and provide relevant, illustrative, practice-based examples and case studies that more subtly illuminate best practice. We suggest the definition of 'serious medical treatment' should be clarified to include:

- Decisions taken when any illness is newly diagnosed
- Health screening
- Any decisions not to treat or investigate symptoms
- Decisions about ceilings of treatment
- Non-emergency DNACPR decisions
- Any major decision that may be life-changing.

## Recommendation 12: Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care

Mental Capacity Act Training should be mandatory core training, and minimum training standards are needed. It should be linked in to, and a part of, safeguarding training. Given the differing interpretations of aspects of the Mental Capacity Act that the CIPOLD investigations have uncovered, we recommend the development, by the Department of Health, of an approved e-learning package with worked examples and case studies, supported by individual applied training in the practice environment. Mandatory training updates are required on an annual or biannual basis, possibly to be determined by a screening assessment. Training activities regarding the Mental Capacity Act must be monitored by the NCB and CCGs as part of their contracts with service providers.

## Do Not Attempt Cardiopulmonary Resuscitation Guidelines

CIPOLD uncovered considerable evidence of poor adherence to DNACPR Guidelines when reviewing the deaths of people with learning disabilities. There were concerns about incomplete documentation that failed to record the rationale for the order not to attempt resuscitation, blanket policies in care homes regarding DNACPR status, and occasions when the decision not to resuscitate a person appeared to have been made prematurely. We also identified instances when the decision not to implement CPR led to a failure to provide basic health or nursing care, including nutrition and fluid intake. We are aware that the current DNACPR Guidelines are being reviewed, and would like to make the following recommendation for the British Medical Association and the Resuscitation Council (UK) about DNACPR orders.

## Recommendation 13: Do Not Attempt Cardiopulmonary Resuscitation Guidelines (DNACPR) to be more clearly defined and standardised across England

We recommend the revised guidelines for DNACPR should separately address emergency and non-emergency situations and that different decision-making processes and recording templates are needed in this respect.

All decisions in non-emergency cases should involve those who know the person best and allow time to be taken in coming to the decision in the best interests of the person concerned. If the DNACPR decision is made in relation to quality of life, there should be evidence provided that a range of views has been gathered regarding the quality of the person's life beforehand, and what might be expected if CPR was to be performed. Those involved in making the decision, and the rationale for the decision should be clearly documented and open to scrutiny and regular review.

DNACPR orders in emergency situations should always be made in consultation with others whenever feasible and backed with appropriate documentation. If the decision is that CPR would be futile, the rationale for this should be clearly stated. They should be reviewed with any change in condition, and transferred to the non-emergency process for DNACPR as soon as possible and revised documentation completed.

We recommend that the current localised DNACPR arrangements in England need standardisation (as is currently the situation in Scotland) and that firm guidance is required about the need to inform the patient and their family and carers.

We also recommend that regulators need to strengthen their scrutiny of this area, to ensure that all DNACPR decisions are made on an individual basis, that there is evidence of the decision being made following Mental Capacity Act guidelines in non-emergency situations and any advanced directives to refuse treatment must be documented as being specific to a situation and/or occasion.

## The imperative to forward plan

An issue that made people particularly vulnerable to premature death was the relative inattention given to predicting potential problems, recognising changing needs and adjusting the provision of care as needs changed. We have already mentioned the need to proactively address the knowledge that a person was fearful of contact with medical professionals, but in other areas too there was an evident need for good assessment and planning undertaken by a person who understands and can anticipate specific trajectories associated with specific health conditions or the aging process and who could work with the individual concerned to help them have some understanding and control of their potential changing needs. Given that the trajectory of most long-term conditions is well known, we recommend that services need to be more proactive about predicting and coping with changing needs, including when a person is diagnosed with a long-term condition.

### Recommendation 14: Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and be flexible and responsive to change

We have already made mention of the high proportion of people with learning disabilities with long-term conditions. We recommend the long-term conditions work-stream at the NHS Commissioning Board takes account of the often complex needs of people with learning disabilities in managing their long-term conditions. The diagnosis of a long-term health problem should trigger a proactive plan which includes identification of risks and ways of managing these, a crisis plan and clear guidance about when hospital admissions are appropriate. For unsupported people with learning disabilities the diagnosis of a long-term or terminal condition must trigger a referral to the CLDT for ongoing support, and consideration of the identification of a health coordinator for that person. In the case of dementia or other terminal conditions, proactive plans should include timely end-of-life planning while the individual has the capacity to be meaningfully involved in this. People with learning disabilities who have long-term conditions should have reasonable adjustments made for them to access Expert Patient Programmes, or should have experienced individual staff members who can support them in this way, so that they can be helped to develop coping strategies and be centrally involved in decision-making and managing their condition.

For all people with learning disabilities, service agreements must specify that care and support planning reviews should incorporate proactive planning to look at the long-term needs of the individual, rather than merely reviewing a placement at the current point in time.

Commissioners must additionally pay particular attention to the changing needs of those in supported living environments; supported living providers need to be able to move into extended care and the policy of supported living must facilitate sufficient support for people living with multiple co-morbidities, increased care needs and requiring support to die at home.

## End-of-life care

It was apparent from the reviews of deaths of people with learning disabilities that there were some problems with end-of-life care. People with learning disabilities were less likely than the comparator group of people without learning disabilities to have access to specialist palliative care services and received less opioid analgesia in their final illness. Their deaths were sometimes described as not being planned for, uncoordinated and poorly managed. We are aware of a number of recent initiatives to improve end-of-life care for people with learning disabilities, in particular the recent work of Help the Hospices in widening access to palliative care for people with learning disabilities, of the Palliative Care for People with Learning Disabilities Network chaired by Irene Tuffrey-Wijne at St George's, University of London, and of the National End of Life Care Programme (2011). We are confident their work will contribute to a better experience for people with learning disabilities, and we recommend the broader dissemination of their work and best practice examples. Here, we would like to suggest a targeted recommendation regarding end-of-life care that has arisen specifically from the CIPOLD reviews.

### Recommendation 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

We recommend that all decisions that a person is to receive palliative care only should be supported by the framework of the Mental Capacity Act and a Best Interest process followed if the person does not have the capacity to contribute their own views. This would prevent people being put on a palliative care pathway without sufficient investigations into the cause of the person's illness, or because of assumptions about their quality of life. The National End of Life Care Programme and the Department of Health need to take a lead on this.

We recommend palliative care teams should consider the needs and circumstances of people with learning disabilities as being potentially complex; in addition to their learning disabilities people are likely to have significant co-morbidities, physical and sensory impairments, mental health support needs, difficulties in identifying pain, and communication difficulties. The criteria for the palliative care team's involvement must be based on the grounds of a person's vulnerability and the likely complexity of their needs, not the severity of their learning disabilities – a commissioning issue.

It is clear that palliative care teams need to be sufficiently confident and skilled to meet the needs of people with learning disabilities, and Palliative Care Leads play an important role in this. Where necessary they should work in partnership with specialist learning disability teams to better meet the needs of people with learning disabilities who require palliative care. We recommend the use of practice facilitators, learning disability 'champions' and networks where palliative care teams working with people with learning disabilities can share their experiences.

## Reviewing deaths of people with learning disabilities in the future

Given the inequity in access to good-quality healthcare documented in this time-limited Confidential Inquiry into the deaths of people with learning disabilities, it has become apparent there is a need for ongoing surveillance and review of the deaths of people with learning disabilities. The CIPOLD study has now set a benchmark against which future progress can be measured, and has identified areas where targeted action is required.

We now propose a number of recommendations in this regard.

### Recommendation 16: Improved systems in place nationally for the collection of standardised mortality data about people with learning disabilities

We recommend to the Department of Health and the NHS Information Centre the routine collection of data that provides intelligence about the reasons why people with learning disabilities die. There is a need to link data about cause of deaths with appropriate registers of adults and children with learning disabilities, so that we can monitor, at a national level, a reduction of premature deaths and the pattern of underlying and immediate causes of death of people with learning disabilities.

Given the extent of the disparities between people with learning disabilities and those without learning disabilities regarding deaths amenable to good-quality healthcare, we recommend that the Department of Health sets clear targets for the reduction of amenable mortality, monitors this on an annual basis and provides a public reporting mechanism. This recommendation is an action for the Department of Health, the Nation Health Information Centre, Public Health England and the LDO.

### Recommendation 17: Systems in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments

Reducing differences in life expectancy, along with increasing healthy life expectancy in the most vulnerable groups in society, such as people with learning disabilities, are key objectives of the Public Health Outcomes Framework. Good intelligence is central to understanding how health inequalities impact on the health of these groups. From April 2013 as the responsibility for planning and delivery of services moves to local authorities, Joint Strategic Needs Assessments will need to ensure that a wide range of information exists and is available about the most marginalised groups. In considering the particular health needs of people with learning disabilities, methods to collect this data should include mortality registers that include numbers, ages, cause, and place of death. This information can be used to help inform local Health and Wellbeing board priorities as well as appropriate needs-based commissioning.

### Recommendation 18: A National Learning Disability Mortality Review Body to be established.

We recommend the Department of Health establishes a National Learning Disability Mortality Review Body. The National Learning Disability Mortality Review Body would:

- Provide support to local agencies conducting reviews of deaths of people with learning disabilities. We strongly recommend that professionals should be mandated to participate in the death review process as is the case with reviews of child deaths.
- Oversee the establishment and running of a national Overview Panel.
- Scrutinise locally conducted reviews of deaths of people with learning disabilities.
- Identify 'red flag' deaths (those for which the causal circumstances of death have a high probability of potentially modifiable factors) and a random selection of deaths which must be reviewed.
- Provide a clear mechanism for supporting the reviews of deaths of people with learning disabilities about which concerns have been expressed.
- Work with the Death Certification Programme to ensure that the new processes for death certification incorporate necessary intelligence about people with learning disabilities.
- Produce an annual English Learning Disabilities Mortality Report to monitor and document mortality information, and provide an evidence-base for effective interventions through which to reduce the health inequalities experienced by people with learning disabilities.

These recommendations are aimed at improving the health and wellbeing of people with learning disabilities, and their life expectancy. They should be taken in the context of the recent findings of the Care Quality Commission's learning disability services inspection programme and the Department of Health's report regarding Winterbourne View hospital. We suggest the CIPOLD recommendations should be incorporated into the programme of action by the Department of Health to transform services so that people with learning disabilities are cared for in line with best practice and have accessible health services.

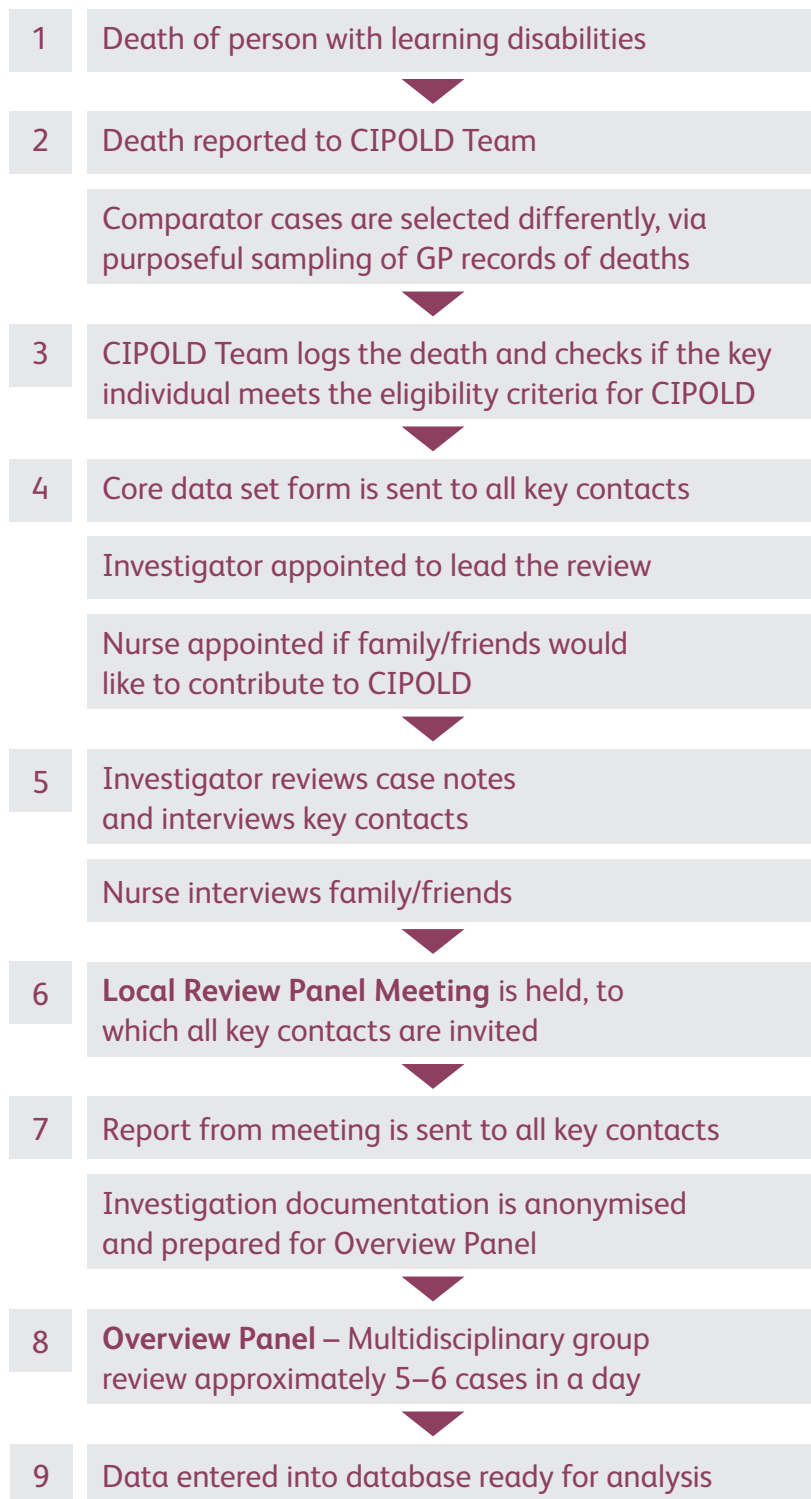
Although the time-limited Confidential Inquiry, which we are now reporting, was one of the recommendations of the Michael Report (2008), not all of the other 9 recommendations have been fully implemented. We therefore propose that the 18 recommendations from the CIPOLD review should be closely monitored, and a public annual report issued by the Department of Health on progress towards the recommendations of the whole learning disability work-stream at the Department of Health, including the CIPOLD recommendations. In addition, we suggest using the findings from CIPOLD to provide information and support for people with learning disabilities, their families, carers, healthcare professionals and commissioners in relation to the recommendations listed. We are all too aware that very often valuable material gets locked in a report and, if not aligned with the recommendations is in danger of getting lost. The issues here are too serious and the findings too imperative to not use them in ways that will support continued action by a range of different groups and agencies.

## Notes

- 1 Michael, J. (2008) *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Department of Health.
- 2 Commissioning for Quality and Innovation

# Appendix 1

## The step-by-step process for CIPOLD reviews





# Acknowledgements

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### Disclaimer

The views and opinions expressed in this report are those of the authors and do not necessarily reflect those of the Department of Health.

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

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An executive summary, 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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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.



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