



# Fatal error

Service users with learning disabilities face many barriers to joined up care as they move between stakeholders – and the price can be their lives. **Clare Connell** and **Henry Hunt** investigate how to prevent healthcare inequalities and improve life expectancy

Institutional discrimination in the health and social care system causes premature and avoidable deaths in those with learning disabilities in the UK. But, there is an opportunity for independent providers to increase the equality of health and mortality for people with learning disabilities.

Over recent weeks, this fact has been highlighted by the release of a report from the Learning Disabilities Mortality Review (LeDeR) programme. Run by the University of Bristol, this programme aims to support local areas to carry out reviews into the deaths of people with learning disabilities. All deaths of people with learning disabilities over the age of four are reviewed, regardless of the cause or place of death (*figure 1*). If, in these initial reviews, any areas of concern are identified, or it is felt that a more comprehensive review might lead to improved practice in the care of people with learning disabilities, then a comprehensive and multi-agency review will be undertaken.

Beginning in 2015, the plan was to identify and examine the circumstances leading to the deaths of people with learning disabilities, and therefore to aid health and social care professionals and policymakers to reduce the factors contributing to these fatal incidents, and identify what works well to support long and healthy lives.

## Barriers to communication

The review has been limited, in a sense, by the magnitude of its task. During the most recent data period, between 1 July and 30 November 2017, LeDeR was notified of 1,311 deaths. By 30 November, it had only managed to look into 103. Admittedly, there must be a lag between notification and review – for

example a notification on 29 November 2017 will not have had sufficient time to be reviewed. In any case, of the 103 that were reviewed, it was indicated that 13 deaths were in some way adversely affected by institutional failings involving delays in care or treatment, gaps in service provision, organisational dysfunction, or neglect and abuse.

For one person, Nick, the issue was that he had been discharged from hospital with a catheter, but his care staff had never received appropriate training in catheter care; Nick was shortly readmitted to hospital with possible urinary sepsis. The failure here was in communication – there was a breakdown in the liaison between hospital staff and carers, and the assessment of their knowledge and skills in catheter care.

For another, who presented with severe learning disabilities and was also non-verbal, there was no professional coordination in relation to his long-term conditions. This individual was unable to speak up for himself, and so his treatment for weight loss took months, but also the identification and treatment of kidney stones was severely delayed. Not only did this mean the individual had inadequate pain relief, but the antibiotics he received at the end of his life should have been prescribed sooner, and may have more effectively treated the bacterial infection of the kidney, pyelonephritis, that was eventually cited as the cause of death.

Based on the in-depth reviews of deaths for 2016-17, several national recommendations have been made in order to improve the state of care for individuals with learning disabilities. Most recommendations focus upon increased collaboration and effective communication between the different providers of care that feature in the life of a person with learning disabilities.

## The need for a collaborative approach

From commissioners and placement managers in local authorities, to acute care in NHS hospitals, to the day-to-day care from independent providers of care in residential homes and supported living settings, all parties must work in partnership to avoid the simple failures driven by poor communication. Distinct parties engaged in the provision of care may hold vital information that would improve or even save the lives of individuals with learning disabilities, but, through systemic barriers between agencies, data is not passed on – even if everyone involved is engaged wholeheartedly in the delivery of good quality care.

In order to achieve this partnership approach, there has been a push for greater electronic integration (with appropriate security controls) of health and social care records. This will make it easier for stakeholders to pass on data. In some care provider groups, paper records are used almost exclusively; a major barrier to the easy transmission of information. The best providers of care will have readily exportable data, and will encourage health professionals to consult that data frequently and comprehensively.

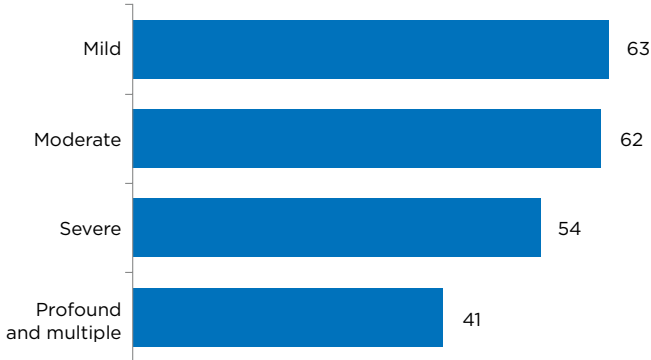
Moreover, a recommendation has been made to ensure an individual with learning disabilities with two or more long-term conditions should have a named healthcare coordinator. Such a coordinator would be a conduit for data from distinct care providers. If, for example, an individual with learning disabilities also presents with mental health issues and a physical disability or issue such as kidney stones, then the health coordinator would be responsible for consolidating and presenting health assessments for, and to, each agency. ►



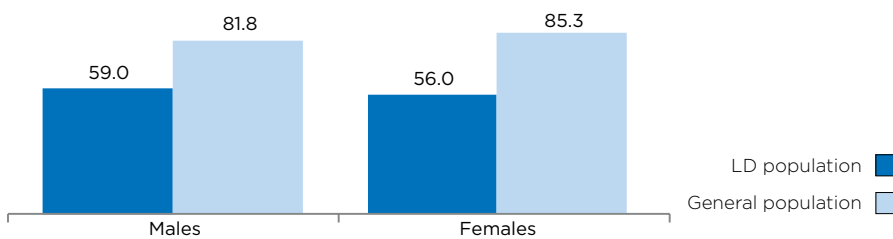
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FIGURE 1: AGE AT DEATH

Median age at death by severity of learning disabilities, years n=958



Median age at death of males and females with learning disabilities (LD) versus the general population of England and Wales, years



- Of the 958 people (range 4-97 years) whose death was notified to the LeDeR programme and an age was provided, the median age of death was 58 years
- For males notified to the LeDeR programme, the median age of death was 59 years (range 4-92 years), and for females it was 56 years (range 4-97 years)
- The difference in age at death between people with learning disabilities (whose deaths were notified to the LeDeR) and the general population of England and Wales is 22.8 years for males and 29.3 years for females
- The median age at death decreased with increasing severity of a person's learning disabilities; however, the median ages at death for people with mild learning disabilities was still considerably less than that of people in the general population

► **Illnesses of particular concern**

The LeDeR allowed for the identification of particular illnesses prevalent in those with learning disabilities, and when looking at the data collected, pneumonia and sepsis are the clear frontrunners in the causes of death (figure 2). A full 41% cite pneumonia as the cause of death, with 11% caused by sepsis. In comparison, when looking at the general population of England and Wales, the leading causes of death are dementia, heart and vascular diseases, and cancers. Sepsis is responsible for 8% of deaths and pneumonia is the cause of death in just 5% of cases. Both sepsis and pneumonia are diseases amenable to good care and treatable by fairly standard antibiotics if caught quickly. Their prevalence is an indicator of the improvements that can be made in the quality of care delivered to those with learning disabilities, and a specific recommendation is that there should be a national focus on pneumonia and sepsis, in order to raise awareness of prevention, identification and early treatment.

The recommendations made by LeDeR are driven by the data to hand; sepsis and pneumonia clearly need addressing, and many of the in-depth reviews are good at identifying a fundamental issue – reconciling the numerous agencies engaged in the delivery of care. But,

also acknowledged is the lack of awareness of how people with learning disabilities might require treatment differently to the general public. This may be the key difference in why there is an ongoing inequality in the health of people with learning disabilities.

Training is required across a whole spectrum of roles, from paramedics, to those in A&E, to staff in acute wards and GP surgeries. Essentially, all those who, in their day-to-day roles, may encounter people with learning disabilities and have a profound effect on their lives through delivery of care.

A shortfall is often the ability of an individual with learning disabilities to communicate their needs. Those generally unfamiliar with learning disabilities may not understand, for example, that behaviour can be a means of communication. That might be a deliberate attempt at communication, or an unconscious change in behaviour or mood as symptomatic of an underlying medical condition. For someone unfamiliar with learning disabilities, or someone unfamiliar with that particular individual with learning disabilities, this communication may go unnoticed, causing delays to the delivery of appropriate care, reducing health and increasing mortality.

Some of the lack of awareness stems from

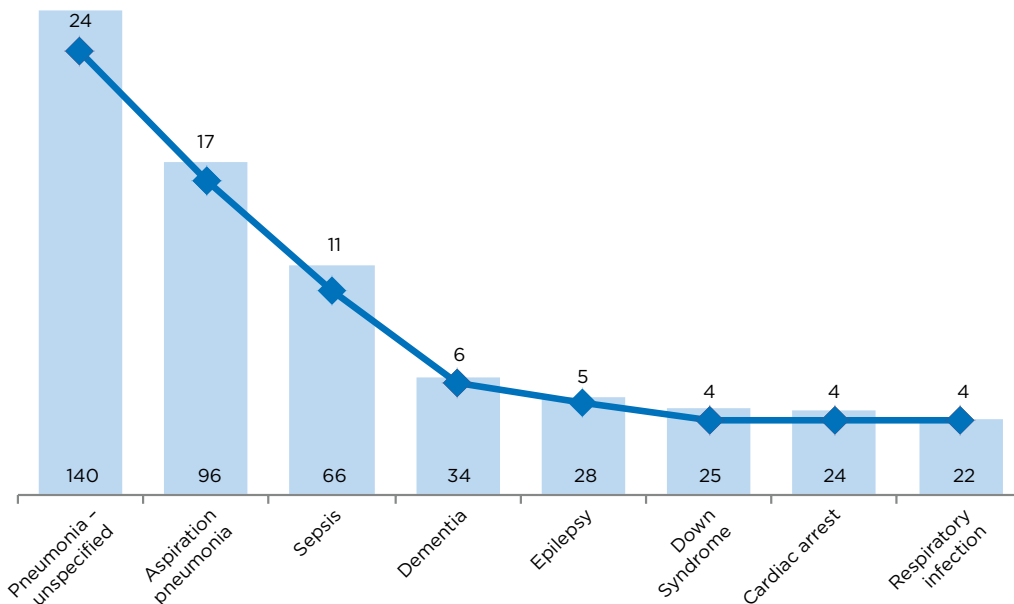
staff not being able to readily access a record of an individual's specific needs. For example, one comprehensive review of a death in the LeDeR report notes that a person with learning disabilities had anxieties about accessing services with stairs. Their healthcare suffered because attendance at healthcare appointments was not consistent. But, there was no communication either of the individual's specific needs from their primary care provider, or, from the other direction, to say that they had been missing appointments. The individual was unable to advocate for themselves, but it seems clear that reasonable adjustments could have been made if there had been more effort made to understand specific needs, as well as an effort on the part of the usual provider of care to pass on information, whether that is a home care team, a supported living service or even a social care worker from the local authority.

For independent providers of care for people with learning disabilities, there could be mitigation of those risks by more readily engaging with the providers of external healthcare. They might take it upon themselves to be the coordinator of care recommended by the LeDeR report. They would be taking on a remit to ensure that a person with learning disabilities is understood fully by all the



FIGURE 2: CAUSES OF DEATH

Most common conditions identified as causes of death anywhere on Part 1 of the Medical Certificate of Cause of Deaths (MCCD) by number (n) and proportion (%) of each condition n=576



- Analysis of any conditions cited in Part 1 of the MCCD\* suggests causes of death broadly similar to underlying causes of death
- However, the fact that sepsis is mentioned on 11% (n=66) of MCCDs is of note, particularly given NHS England's national sepsis action plan
- People aged 25-34 were more likely to have aspiration pneumonia listed in Part 1 of their MCCD than were other age groups (37% vs 24%)
- Other than dementia occurring in older age groups, there were no other differences in conditions listed by age group
- There were no significant differences between males and females in the conditions mentioned in Part 1 of the MCCD

\*Contained within Part 1 of the MCCD is the immediate cause of death, tracking the sequence of causes back to any underlying cause or causes. The WHO defined the underlying cause of death as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced a fatal injury

professionals in the wider healthcare system they come into contact with, as well as be responsible for making sure that the relevant medical records and information are in the hands of those who might need them.

A very proactive provider may well work to build up the knowledge base of the institutions it regularly deals with. One example of good practice in a hospital identified by the LeDeR report was a folder containing advice and support about caring for people with learning disabilities left at the nursing station on the ward. In the same hospital, two staff were recorded as being 'learning disability, autism, and hidden disability champions'. It's likely that the increased awareness of the staff in this hospital means that, when individuals with learning disabilities do access the service, they are received with greater empathy and more

appropriate care. Perhaps if an independent provider has installed a care coordinator, who is supporting an individual with learning disabilities in an acute setting, they could also attempt to improve the general awareness of the ward itself by providing material and prompting discussion around the delivery of care for people with learning disabilities more generally.

#### Preventative measures

Some of the best ways to improve health are preventative rather than reactive; independent providers obviously have a duty of care to people with learning disabilities using their services. That might be in residential homes, where responsibility is broad and explicit, but also in less structured settings like supported living. Residential providers and property developers can choose to construct buildings

on one level as a means of reducing falls down stairs, for example. Supported living services do not have a requirement to maintain the fire safety of the appliances of their tenants, but they could still make sure it's something they look out for when delivering care – something that many do as standard. Fires are one area where people with learning disabilities are more vulnerable than others; independent providers should mitigate risk in their services in a number of small ways. Fire retardant clothing might be recommended for residents for example, and flammable oil-based gels and creams might be avoided. Small efforts to avoid hospital admission could also do well in reducing the health inequalities caused by accessing an NHS that is not fundamentally geared toward the delivery of care to people with learning disabilities. ■

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