Study finds people with learning disabilities are more likely to have a premature death compared with general population

March 20 2013

A three-year study into the extent of premature death in people with learning disabilities has found that those with learning disabilities are more likely to have a premature death compared with individuals in the general population. The findings, published in a Department of Health report, have made a series of recommendations aimed at improving the quality of healthcare that people with learning disabilities receive.

The confidential inquiry into the premature deaths of people with learning disabilities (CIPOLD) study, led by academics at the University of Bristol and funded by the Department of Health, aimed to investigate the extent of premature death in people with learning disabilities and to offer guidance on prevention.

Researchers from the University's Norah Fry Research Centre and School of Social and Community Medicine, together with colleagues from NHS Bristol and the Royal College of General Practitioners, reviewed the sequence of events leading to all known deaths of 233 adults with learning disabilities, 14 children with learning disabilities and 58 comparator cases (adults without learning disabilities who died in the study area during the same period of time). All deaths occurred over a two-year period in any of five Primary Care Trust (PCT) areas of South West England.

The findings showed that people with learning disabilities are more

likely to have a premature death than those in the general population. Researchers found that men with learning disabilities died, on average, 13 years sooner than men in the general population. Women with learning disabilities died, on average, 20 years sooner than women in the general population. Overall, 22 per cent of the people with learning disabilities were under the age of 50 when they died, compared with just nine per cent of people in the general population.

A review of comparator cases, which had been broadly matched to people with learning disabilities by age, cause of death category, gender, month of death, and geographical area, found that they were more likely than people with learning disabilities to die prematurely of conditions connected with their lifestyle. These conditions included diseases related to smoking, alcohol and an unhealthy diet, all of which could be prevented by improved public health measures.

The people with learning disabilities were significantly more likely than the comparators to die prematurely because there had been delays or problems with investigating, diagnosing and treating their illnesses. They were also more likely to have problems in having their needs identified and appropriate care being provided in relation to their changing needs. Their families or carers had more problems in getting their views heard and listened to.

The review found evidence that the quality and effectiveness of health and social care given to people with learning disabilities is deficient in a number of ways, and that premature deaths could be avoided by improving the quality of the healthcare that they receive.

Dr Pauline Heslop, the study's lead author at the University of Bristol Norah Fry Research Centre, said: "This report highlights the unacceptable situation in which people with learning disabilities are dying, on average, more than 16 years sooner than anyone else. The

cause of their premature death is not, like many in the general population , due to lifestyle-related illnesses. The cause of their premature deaths appears to be because the NHS is not being provided equitably to everyone based on need. People with learning disabilities are struggling to have their illnesses investigated, diagnosed and treated to the same extent as other people. These are shocking findings and must serve as a wake-up call to all of us that action is urgently required.

"We have, over the past few years, been rightly horrified by the abuse of people with learning disabilities at Winterbourne View hospital and of vulnerable patients at Mid-Staffordshire. The findings of the confidential inquiry into the deaths of people with learning disabilities should be of no less a concern."

The report makes a number of key recommendations. These include:

- The 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.
- A named health professional to co-ordinate the care of those with multiple health conditions, aided by the routine use of portable patient or carer-held health records and the continuing involvement of specialist healthcare staff, who can work with the individual on a long-term basis.
- The identification of effective advocates to help people with learning disabilities access healthcare services.
- Proactive planning for the future and anticipating needs, rather than responding in a crisis.
- Better adherence to the protection of the Mental Capacity Act. There is a need for greater awareness of professional responsibility and further work at national and local levels to

support conformity to its requirements.
- Guidelines for orders not to attempt cardiopulmonary resuscitation on a person to be revised and clarified.
- The routine collection of data that provides information about the age and cause of death of people with learning disabilities at national level.
- The establishment of a National Learning Disability Mortality Review Body to take forward the reviews of deaths of people with learning disabilities.

Findings from the Department of Health-funded Improving Health and Lives Learning Disabilities programme will be presented at a two-day conference on the 20 and 21 March 2013. The 20 March will be devoted to the findings of the confidential inquiry into deaths of people with learning disabilities. Norman Lamb, the Minister of State for Care and Support, will be attending the conference on 21 March.

Provided by University of Bristol