Premature deaths of people with intellectual disabilities

People with learning disabilities die, on average, at a much younger age than people without learning disabilities and a significant number of these deaths could be avoided by making improvements to care and health services. So finds CIPOLD (2013), the Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK, which was launched in the wake of Mencap’s disturbing report *Death by Indifference* (2007). The study aimed to review patterns of care in the period before death and identify omissions and/or errors in provision that may have been contributing factors in these deaths.

Examining the deaths of 247 people with learning disabilities, the Inquiry found that nearly a quarter of these individuals were younger than 50 when they died. The median age at death for men with learning disabilities was 13 years younger than that of men in the general population of England and Wales (65 compared to 78). The median age of women with learning disabilities at death was no less than 20 years younger than their counterparts in the general population (63 compared to 83). People with severe and multiple learning disabilities tend to die younger than those with milder disabilities, however the median age at death for the latter was still substantially lower than that of the general population.

Although some premature mortality is to be expected due to common co-morbidities among people with learning disabilities (such as nervous system disorders or congenital and chromosomal abnormalities), the report concluded that higher death rates cannot be sufficiently explained by the greater prevalence of chronic medical conditions. It found that, of its cohort of individuals with learning disabilities, 37% had died “from causes amenable to change by good quality health care”. This was compared to 13% of the general population whose deaths were classified in the same way by the Office for National Statistics.

What does this mean? It means, according to the study, that there is a high likelihood that disparities in the quality of health care provided for non-disabled and disabled people are a contributory factor in premature deaths in the latter population. To substantiate this, the detailed circumstances leading up to the deaths of a subset of 58 people with learning disabilities were analysed against a control group of the same number of people without learning disabilities, comparable in terms of age, sex, time of death and broad cause of death. The analysis showed that “All aspects of care provision, planning, coordination and documentation were significantly less good for people with learning disabilities than for the comparators.”

More specifically, a significantly greater proportion of individuals in the learning disabilities group had inadequate or inappropriate housing for their needs. Although there was no significant difference between the two groups in terms of timely requests for healthcare, significantly more people with learning disabilities experienced delays or difficulties in the diagnosis and treatment of their illness. It was more common for families and carers of people with learning disabilities to feel that they were not listened to. A greater proportion
of people with learning disabilities experienced problems with advanced health care planning and problems in the recognition of needs and adjustment of care according to changes in those needs. Finally, the study identified poor adherence to the Mental Capacity Act as a contributory factor in premature deaths, in relation to assessment of a person’s capacity to make decisions and the appointment of Independent Mental Capacity Advocates.

As with nearly all studies of this nature, there are methodological issues which mean its results must be treated with caution. Most importantly, the findings are “observations of associations that might not be causally linked to each death reviewed”. However, there are “consistent patterns” which in themselves make a compelling case that this vulnerable population continues to be placed at a serious disadvantage by systemic problems in health care services, as it remains unequal in access to and enjoyment of other “public goods”. The Inquiry certainly presents strong evidence to support its many recommendations for “meaningful changes in practice”, particularly the urgent need for greater communication and information sharing between family carers, professionals and health and care organisations.

References

CIPOLD full report: http://www.bris.ac.uk/cipold/fullfinalreport.pdf

CIPOLD findings, The Lancet: http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)62026-7/fulltext