HOUSE OF LORDS

In Focus

Premature Deaths Among People with a Learning Disability

Overview

Public Health England estimates that 225,000 children and 901,000 adults in England have learning disabilities.[1] In March 2007, the charity Mencap published a report entitled *Death by Indifference*. This examined the deaths of six people with learning disabilities. Mencap described what it called "institutional discrimination" within the healthcare system leading to "neglect […] and premature death".[2] Following the publication of Mencap's report, the Department of Health established an independent inquiry into access to healthcare for people with learning disabilities, led by Sir Jonathan Michael. One of the recommendations of the inquiry was the establishment of the Department of Health-funded *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* (CIPOLD), published in 2013. The CIPOLD review investigated the deaths of 247 people with learning difficulties over a two year period between 2010 and 2012, and found that:

> 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 percent were under the age of 50 when they died.[3]

On 17 October 2016, the House of Lords will debate what progress the Government has been made in tackling the rate of premature deaths among people with a learning disability.

Recent Developments

CIPOLD made "18 key recommendations". In its response to the recommendations, the Government stated that the Department of Health, NHS England and Public Health England were committed to ensuring "significant improvements in the health and social care received by people with learning disabilities so that they are able to access the same health benefits as the rest of the population".[4]

The response also stated that the Mandate to NHS England:

> […] includes an objective for NHS England to ensure that Clinical Commissioning Groups (CCGs) work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care.[5]

The Coalition Government published a progress update in September 2014. It said that the Government had an ambition to make the UK "among the best nation states in Europe at reducing premature and avoidable deaths". Further actions taken included:

- Extension of "the General Practice register of people with a learning disability […] to be an all age register, so it will include children and young people with a learning disability", to aid in the identification of people with a learning disability.[6]

- The addition of a requirement for providers to undertake an annual audit of reasonable adjustments made for people with learning disabilities was included in the NHS Standard Contract for 2014/15, published on 21 December 2013.[7]

- "Public Health England's Learning Disabilities Observatory working with colleagues in the Department of Health and the Health and Social Care Information Centre to achieve comprehensive monitoring of mortality in people with learning disabilities".[8]

CIPOLD's eighteenth recommendation was the establishment of national mortality review. On 18 June 2015, NHS England, the Healthcare Quality Improvement Partnership (HQIP) and the University of Bristol announced the world's first national review of deaths of people with learning disabilities.[9] Formally known as the Learning Disability Mortality Review Programme (LeDeR), the three year review aims to "get to the bottom of why people with learning disabilities typically die much earlier than average, and to inform a strategy to reduce this inequality".[10]

The Department of Health's 2016–17 mandate to the NHS in England includes the goal to "close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole" by 2020.[11]

Further Information

- Public Health England, 'Improving Health and Lives Learning Disabilities Observatory', accessed 7 October 2016

- Foundation for People with Learning Disabilities, 'The UK Health and Learning Disability Network', accessed 7 October 2016

- House of Commons Library, *Learning Disability—Overview of Policy and Services*, 26 April 2016

[1] Public Health England, 'Frequently Asked Questions—What Are Learning Disabilities?', accessed 7 October 2016.
[2] Mencap, *Death by Indifference*, March 2007, p 18. The individual cases were subsequently examined by the Parliamentary and Health Service Ombudsman in *Six Lives: The Provision of Public Services to People with Learning Disabilities*, March 2009.
[3] *Confidential Inquiry into Premature Deaths of People with Learning Disabilities*, March 2013, p 2.
[4] Department of Health, *Government Response to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities*, July 2013, p 29.
[5] ibid, p 2.
[6] Department of Health, *Premature Deaths of People with Learning Disabilities: Progress Update*, September 2014, p 3.
[7] ibid, p 3.
[8] ibid, p 20.
[9] NHS England, 'NHS Launches World's First National Review of Deaths of People with Learning Disabilities', 18 June 2015.
[10] ibid.
[11] Department of Health, *The Government's Mandate to NHS England for 2016–17*, 17 December 2015, p 17.