PROBLEMS OF LEARNING DISABILITY

Map 92: Prevalence rate of people with a learning disability aged 18 years and over on GP registers by CCG
2013/14

Domain 2: Enhancing quality of life for people with long-term conditions
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

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Context
People with a learning disability have more health problems than other people arising from:
- higher rates of obesity and underweight;
- low rates of physical exercise;
- lack of understanding of when and how to use health services;
- the conditions that cause learning disabilities, e.g. Down syndrome and cerebral palsy;
- poor recognition by healthcare professionals of symptoms presented by people with learning disabilities due to “diagnostic overshadowing” (see “Glossary”, page 268).

People with learning disability are also at risk of receiving poor-quality healthcare. The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD; see “Resources”) found that 37% of the 249 deaths they studied were from causes, and occurred at ages, usually classified as potentially amenable to good medical care. A multidisciplinary panel including family members of people with learning disability considered that 42% of these deaths were premature. A failure to recognise and provide for specific needs arising from learning disability was deemed a major contributor to mortality.

In 2006/07, learning disability registers were introduced under the Quality and Outcomes Framework (QOF):
- to enhance awareness of the health needs of people with learning disability;
- to facilitate annual health checks by GPs;
- to ensure communication of the specific needs of people with learning disability when they were referred to specialist services.

In England, at end March 2014, the overall prevalence of people with learning disability over the age of 18 years on GP registers was 4.8 per 1000 population, less than one-quarter of the proportion of children identified in schools as having moderate or more severe learning disability. School data are based on the results of universal testing in the school curriculum. The prevalence in primary care in England is similar to that for most adult service-use or benefit receipt-curriculum. The prevalence in primary care in England is similar to that for most adult service-use or benefit receipt-based registers of learning disability in other countries with developed economies.

NHS England is committed to improving the health and outcomes of people with learning disability,1 by:
- increasing the take-up of routine health checks – GP health checks, cancer screening, and influenza immunisation;
- ensuring joint working across health and care through the locally led Joint Health and Social Care Self-Assessment Framework (JHSCAF);2
- understanding the causes of premature mortality through a new National Mortality Review Function to improve life-expectancy;
- working with the Care Quality Commission (CQC) to ensure all health services for people with learning disability are monitored and part of the inspection regime.

GP Registers are fundamental to supporting this work.

Magnitude of variation
For CCGs in England, the prevalence rate of people with a learning disability aged 18 years and over on GP registers ranged from 1.9 to 8.6 per 1000 population (4.4-fold variation). When the seven CCGs with the highest rates and the seven CCGs with the lowest rates are excluded, the range is 2.8–7.2 per 1000 population, and the variation is 2.6-fold.

The indicator shows groups of CCGs in which it seems likely that rates of learning disability are genuinely high or low. Low rates seem to occur in localities where there is a high volume of inward economic migration: high property prices make the provision of adult residential care in these areas expensive. High rates are commonly seen in localities where people with learning disability have been resettled in relatively cheaper residential accommodation, and from which economic migrants have moved.

Options for action
Using the results of the JHSCAF, NHS and other commissioners need to assess the health and social care needs of people with learning disability in partnership with the relevant local authority as part of the Joint Strategic Needs Assessment (JSNA) through the local Health and Wellbeing Board.

NHS Commissioners should specify that all service providers need to make “reasonable adjustments” in the organisation and delivery of healthcare so they can fulfil their obligation under the public sector Equality Duty3, in the Equality Act 2010, of advancing “equality of opportunity” in public services. “Reasonable adjustments” include:
- special attention to ensure people with learning disability understand as well as they are able the nature of their health problems;
- additional care, explanation and often time to ensure that examinations and physical interventions can be undertaken safely and without unnecessary distress;
- careful assessment of individuals’ capacity to consent to specific treatments, and appropriate actions under the Mental Capacity Act 20054 when they cannot;
- providing access to advocates to assist with major decisions.

RESOURCES