Addressing the health inequalities found by the Confidential Inquiry into Premature Deaths of People with Learning Disabilities

Lords Debate
Thursday 12th June 2014

The British Medical Association (BMA) is an independent trade union and voluntary professional association which represents doctors and medical students from all branches of medicine all over the UK. With a membership of over 153,000 worldwide, we promote the medical and allied sciences, seek to maintain the honour and interests of the medical profession and promote the achievement of high quality healthcare.

Background
In the UK, there is a significant disparity in morbidity and mortality rates experienced by people with an intellectual disability. It has been shown that this vulnerable group have higher levels of unmet healthcare need and receive less effective treatment than the general population. In the worst cases, people with intellectual disabilities continue to suffer unnecessarily with untreated, or poorly managed, conditions.

The ‘Confidential Inquiry into premature deaths of people with learning disabilities’ (CIPOLD) investigated the deaths of 247 people with an intellectual disability across five primary care trust (PCT) areas in the south west of England between 2010 and 2012. The findings showed that 29 per cent of the deceased experienced difficulty or delay in diagnosis, further investigation or specialist referral for an illness.

In May 2014, the BMA published a report Recognising the importance of physical health in mental health and intellectual disability – achieving parity of outcomes. The report examines ways to reduce the excess morbidity and mortality among these vulnerable groups, and recognises the vital role the medical profession has in delivering the best possible care for them. It stresses the urgent need for action to ensure equal value is placed on mental and physical health. Too often the physical health problems of patients with a mental illness or an intellectual disability are under-addressed, while the mental health of patients with a physical illness is often neglected.

The report identifies a number of areas for action which include:

- The integration of intellectual disability, mental health and physical healthcare should be improved. This should be a priority for all policy makers at a national level, as well as for Directors of Public Health and local commissioning bodies, who must ensure that clear pathways of care, and allocation of responsibility, are established regardless of whether the patient presents with a physical or mental illness.

- Intellectual disability liaison services should be made available in all hospitals.

- A national mortality review of mental health problems should be implemented across the UK for people with intellectual disabilities and those with a mental illness.
• Commissioners should have a good understanding of intellectual disability and encourage the development of services that deliver integrated care.

• Better information must to be available to commissioners on the physical, mental and intellectual disability needs of the population they are serving.

• Undergraduate and postgraduate medical training should shift from teaching mental health separately in a ‘module’ format towards integrating mental health and intellectual disability into the core curriculum. The objective is to improve the diagnosis and management of individuals with a combination of psychological and physical problems.

• Training in intellectual disability that explicitly tackles ‘diagnostic overshadowing’ and unequal treatment should be integrated at undergraduate, postgraduate and continuing professional development levels. All doctors should understand the requirements of the Mental Capacity Act 2005 and the Equality Act 2010.

Prevalence of intellectual disability in the UK
There is a lack of up-to-date data on the prevalence of intellectual disability in the UK. The data which are available suggest that the prevalence of intellectual disability ranges from 3.5 persons per 1,000 to 6 persons in 1,000 across the UK. However these figures represent cases that are known and people that are engaging with services. It is therefore likely to be an underestimate.

The relationship between physical health and intellectual disability
People with intellectual disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. Recent figures published by CIPOLD show that 22 per cent of people with an intellectual disability were under the age of 50 when they died, compared to 10 per cent of the general population. There are further disparities according to gender, with men with intellectual disabilities dying, on average, 13 years sooner than men in the general population and women 20 years earlier.

Life expectancy can vary according to the severity of the intellectual disability. Mortality rates among people with moderate to severe intellectual disabilities are three times greater than in the general population. Mortality is also elevated in some minority ethnic communities and in people with Down’s Syndrome.

The prevalence of epilepsy, mental health problems and respiratory disease are elevated in people with intellectual disabilities. For example one third of people with intellectual disabilities have epilepsy – a rate twenty times higher than that found in the general population. Further, mental health problems are more common among adults and children with intellectual disabilities. The prevalence of psychiatric disorders among children is estimated to be 36 per cent for those with intellectual disabilities, compared to eight per cent of children without intellectual disabilities.

Unmet health needs
It is apparent amongst people with intellectual disabilities that many of their health needs are unmet. The increased rate of early death in this group, particularly from respiratory disease, suggests that people with intellectual disabilities receive less than optimal medical care and that they are in need of better health surveillance and promotion. CIPOLD reported in 2013 that premature deaths among people with intellectual disabilities were found to be mostly linked to delays or problems with treatment, or assessing or investigating the cause of illness.

There are a number of reasons for these disparities in healthcare related to factors including: healthcare provision and organisation; the monitoring and screening of people with an intellectual disability; and commissioning of services. An important factor is discrimination. The issue of unmet health needs amongst people with an intellectual disability is in part attributed to the separation of physical health, mental illness and intellectual disability as separate distinct
spheres of medicine. The organisational structure inhibits the provision of an integrated, coordinated response to the needs of the patient. The lack of care coordination across and between the different disease pathways received by people with intellectual disabilities, particularly when compared to a control group with no intellectual disabilities, was highlighted by CIPOLD.

CIPOLD recommended that NICE guidelines should include information on how to manage people with more than one condition or illness, and that a named healthcare coordinator should be allocated to people with complex or multiple health needs, or two or more long-term conditions. The Government responded to CIPOLD agreeing that NICE clinical guidelines should take multi-morbidity into account where appropriate and that there was a need for a named healthcare coordinator.

The BMA believes that the integration of intellectual disability, mental health and physical healthcare should be improved. This should be a priority for all policy makers at a national level, as well as for Directors of Public Health and local commissioning bodies, who must ensure that clear pathways of care, and allocation of responsibility, are established regardless of whether the patient presents with a physical or mental illness.

Establishing a national mortality review
Improving the identification, treatment and recovery of patients with co-occurring intellectual disability, mental health problems and chronic illnesses is a key challenge facing the NHS. All too often, patients from these groups are failing to receive the types of interventions that have the potential to reduce the burden of co-morbid disorders and are suffering unnecessarily. There is a clear need to move from inaction to action on these issues.

Achieving parity of outcomes requires a commitment at the highest level. An important starting point for this is the establishment of a national mortality review process intended to promote a culture of safety through seeking to understand systems issues that are working well and those that need improvement. The case has already been made by CIPOLD for a permanent National Learning Disability Mortality Review Body. The DH agreed that better information is needed to for accurate assessment of the causes of death of people with learning disabilities but that the costs and benefits of establishing a National Learning Disability Mortality Review Body needed to be assessed.

The BMA believes that a national mortality review system should be implemented across the UK in relation to people with intellectual disabilities.

Commissioning
One of the barriers to providing joined-up care is the way in which services tend to be commissioned separately, to the extent that co-morbidities fail to be recognised in either process. The planning and commissioning of services for people with intellectual disabilities, mental health problems, and chronic physical conditions must take greater account of the diverse healthcare needs of these groups. To facilitate this, commissioners need to have the knowledge and skills to understand how best to provide services for people with mental health problems and with an intellectual disability.

Knowledge of intellectual disability must be accompanied by greater access to accurate information on the physical, mental and intellectual disability needs of the population that a commissioning body or Local Authority is serving. This includes data on the prevalence of mental health problems, intellectual disability and chronic illness, so that commissioned services have sufficient capacity to treat the local population. The development of intellectual disability liaison services may hold the potential to improve the care of patients with an intellectual disability by providing access to trained professionals competent in identifying and addressing their healthcare needs.
At a local level, individual surgeries and hospitals need to make sure that they collect appropriate information about their patients’ needs. For a patient with an intellectual disability, it is difficult for services to prepare properly or make any necessary ‘reasonable adjustments’ if patients’ communication and other special needs are unknown. The BMA recognises that there are some changes on the horizon with one of the ‘actions’ from the Winterbourne View report being that DH will develop a new learning disability minimum data, collected through the Information Centre from 2014/15.30

The BMA believes that commissioners should have a good understanding of intellectual disability and encourage the development of services that deliver integrated care.

Intellectual disability liaison services should be made available in all hospitals.

We also call for better information to be available to commissioners on the physical, mental and intellectual disability needs of the population they are serving.

Education and training of the medical workforce
Achieving parity of outcomes between mental health, intellectual disability, and physical health is complicated by gaps in training and workforce planning, apparent during medical school, the Foundation Programme (FP), and speciality training. A better understanding of mental health and intellectual disability, achieved through training at all stages of a doctor’s medical career, holds the potential to raise doctors’ aspirations for these groups while at the same time improving access to, and the quality of, care for mental health and intellectual disability patients.

Training provided to medical students and to postgraduate clinical trainees on intellectual disabilities is inconsistent and sporadic. While it is a recognised theme in the undergraduate medical curriculum, the way in which it is taught and incorporated into medical courses varies widely across UK medical schools31 although there are examples of good practice.32

Training in intellectual disability, which explicitly tackles ‘diagnostic overshadowing’ and unequal treatment, should be integrated at undergraduate, postgraduate, and continuing professional development (CPD) levels. We are pleased that the RCGP Curriculum 2010 already contains a dedicated section on the care of people with an intellectual disability and, the GMC has produced teaching materials around these issues.33 Other specialities should begin to incorporate an understanding of the relationship between intellectual disability, and mental health problems, in their training, examinations and assessments.

Undergraduate and postgraduate medical training should shift from teaching mental health separately in a ‘module’ format towards integrating mental health and intellectual disability into the core curriculum. The objective is to improve the diagnosis and management of individuals with a combination of psychological and physical problems.

Training in intellectual disability that explicitly tackles ‘diagnostic overshadowing’ and unequal treatment should be integrated at undergraduate, postgraduate and continuing professional development levels. All doctors should understand the requirements of the Mental Capacity Act 2005 and the Equality Act 2010.
References


