Improving hospital care for patients with intellectual disabilities

Adults with intellectual disabilities, who make up an estimated 2% of the population (Emerson and Hatton, 2008), have the same health problems as everyone else but their problems are harder to identify, investigate and treat. Intellectual disability is not a disease but rather a state of being which has many different causes, most of which cannot be ameliorated. Experienced doctors and other health professionals will adjust their communication, allow extra time and be willing to adapt the way they work to give this particular group of patients the best chance. This includes supporting decision making by adapting their communication style (Hollins et al, 1998a), working effectively with family and paid carers, and using best interest meetings when needed as required by the Mental Capacity Act 2005.

Specialists in intellectual disability should not normally replace primary and secondary care services, but be available to facilitate and advise. Every health professional needs to be able to work with patients with intellectual disabilities as they will present in every physical and mental health service; from surgery to gynaecology, ophthalmology to the diabetic clinic, psychological therapy to eating disorders and so on. *Valuing People Now* (Department of Health, 2009) was explicit that where possible people with intellectual disability should access mainstream (evidence-based) treatments, and only when this is not possible should specialist services be provided. The onus is on mainstream services to make reasonable adjustments to their treatments and to know when and how to refer to specialist services as required by the Equality Act 2010 (Hatton et al, 2010).

Discrimination

Seven years ago, Mencap, the UK charity that campaigns for the rights of people with intellectual disabilities and has a long lasting concern about health, published its shocking *Death by Indifference* report (Mencap, 2007), describing alleged avoidable deaths of six people which they attributed to discriminatory practices within hospitals. The government of the day established an independent inquiry to take evidence about Mencap's allegations of institutional discrimination, and the inquiry report made ten wide-ranging recommendations (Michael, 2008).

A subsequent study explored how far four of these recommendations had been implemented in six acute NHS hospitals, and how effective they were in improving people's safety (Tuffrey-Wijne et al, 2013). The study found that safety risks for hospital patients with intellectual disabilities were largely related to omissions of care and treatment, as well as to failures to make reasonable adjustments to interventions or to involve carers appropriately. The lack of shared care protocols and an inability to flag patients with intellectual disabilities meant that their special needs were not recognized by services.

Many reports and inquiries have pointed to poor health-care provision for patients with intellectual disabilities, leading to compromised patient safety. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD), which investigated the deaths of 247 people with intellectual disabilities in England and Wales, reported that people with intellectual disabilities died on average 16 years earlier than people in the general population. The inqury also reported that 37% of people with intellectual disabilities had avoidable deaths having received fewer investigations and less treatment than patients in a comparator group. Only 13% of people in the general population died prematurely of similar conditions (Heslop et al, 2014).

All of these findings support Hollins et al's (1998b) earlier research that adults with intellectual disabilities were 58 times more likely to die before the age of 50 years.

Poorer health outcomes for those with intellectual disabilities

It has now been shown decisively that people with intellectual disability have poorer health outcomes than the general population, for reasons unconnected with the causes of their cognitive impairment. Poor training and awareness for health-care staff exacerbate the barriers to adequate health-care provision.

The General Medical Council has developed a unique section of their website (www.gmc-uk.org/learningdisabilities/) to help raise awareness and address some of these inequalities. As the responsible body for undergraduate education, the General Medical Council stipulates that all medical students must acquire the skills and attitudes needed to provide equal care for people with intellectual disabilities and autism. The Mental Capacity Act post legislative scrutiny committee reported that NHS staff were inadequately informed and skilled in the application of this empowering Act, and that people with intellectual disabilities were among those most disadvantaged by its poor implementation (House of Lords, 2014).

The NHS Outcomes Framework 2014/15 commits to reducing the excess mortality rate for people with learning disabilities under the age of 60 years, recognizing that so many premature deaths are avoidable (Department of Health, 2013). The Outcomes Framework has greater aspirations for other groups of patients for whom the excess mortality rate for those aged under 75 years is considered achievable.

The British Medical Association has recently added its voice to the growing call for parity of access and of outcomes for people with intellectual disabilities of all ages with respect to their physical health (Board of Science, 2014). The British Medical Association report highlighted the excess morbidity and mortality in people with intellectual disabilities, and supported the establishment of a National

Mortality Review body. This has now been announced by NHS England and should be in place by March 2015. The expectation is that the data gathered about premature avoidable deaths will lead to interventions that reduce premature mortality in the future, as has been achieved in parts of the USA.

Conclusions

Radical measures are needed to give all people with intellectual disabilities the best chance of good health, and it seems that after generations of failures, the tide may be turning, with educational, structural and research initiatives all coming together. **BJHM**

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KEY POINTS

- The NHS is still failing patients with intellectual disabilities in all departments, all specialties and all services.
- The Equality Act requires public services to make reasonable adjustments so that disabled people can access services and get the best possible outcomes.
- All senior clinicians should have mandatory advanced training on the Mental Capacity Act, to acquire skills in the assessment of decision-making capacity, and on good practice in holding best interest meetings.

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