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Re: Meeting the needs of patients with learning disabilities

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EDITORIALS

Meeting the needs of patients with learning disabilities

A recent inquiry highlights failings in the delivery of care to this vulnerable group

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In March 2013, the Confidential Inquiry into Premature Deaths of People with Learning Disabilities reviewed the deaths of 247 people with learning disabilities over a two year period, as well as 58 comparator cases of adults without learning disabilities.¹ It found that men with learning disabilities died on average 13 years earlier than men in the general population, and that this figure was 20 years for women. Overall, 22% of people with learning disabilities were under the age of 50 when they died, compared with 9% of the general population. Premature deaths in the comparator group were largely due to lifestyle factors, whereas those for people with learning disabilities were mostly due to delays or problems with investigating, diagnosing, and treating illnesses and with receiving appropriate care.

These results are alarming but not surprising. There is a remarkable degree of coherence and agreement with the findings and recommendations arising from previous work. These include inquiries,²⁻³ research studies,⁴⁻⁵ surveys and reports published by charities and interdisciplinary advisory groups (such as the group that created the charity Mencap's "Getting it Right" charter),⁶⁻⁸ and statements and guidance by professional bodies.⁹⁻¹⁰

A recent study investigated the factors affecting the implementation of measures to improve the safety of people with learning disabilities in NHS hospitals.¹¹ Its emerging findings (currently undergoing editorial review) support those of the confidential inquiry: safety risks for hospital patients with learning disabilities are related to omissions of care and treatment. The Disability Discrimination Act 2005 requires that services make reasonable adjustments to enable disabled people to benefit fully, but the study found that a lack of such adjustments contributed to the poor care that disabled people received. Patients with learning disabilities were largely invisible within the healthcare system, and healthcare workers were often ignorant about their particular vulnerabilities.

Unfortunately, it seems that mainstream health professionals seldom raise concern about failures in the treatment of people with learning disabilities. Concern about causes of death in patients with learning disabilities has developed slowly since the turn of the century. In 1998, a study of death certification

highlighted the premature mortality and unusual patterns of death in people with learning disabilities.⁴ Although policy makers began to consider the possibility of funding a confidential inquiry in 2001,¹² it took another 10 years to identify funding and to secure policy backing. By contrast, other confidential inquiries have been in place for years—for example, child death review, maternal deaths and perinatal mortality,¹³ suicide and homicide by people with mental illness,¹⁴ patient outcome and death.¹⁵

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities was established only three years ago. Its main recommendation is for the establishment of a national learning disability mortality review body. There are strong economic and humanitarian reasons for such a review body. The system of intellectual disability mortality reviews that was established in 15 states in the United States has been shown to be effective. This system ensures that the deaths of people with learning disabilities are reviewed and that questions about individual circumstances and systemic concerns are pursued.¹⁶ Lessons learnt from trends in mortality data have led to changes in practice.

Achieving change invariably requires informed advocacy and the ability to argue the economic benefits of changes in practice or legal enforcement. The post-legislative scrutiny of the Mental Capacity Act 2005 by a parliamentary select committee may help.

Specialists who advocate and care for patients with learning disabilities fear that the new commissioning arrangements in the NHS in England will leave people with learning disabilities at increased risk of premature death despite the outcomes framework specifically seeking to reduce such deaths. By bringing together health and social care planning, health and wellbeing boards could create integrated care pathways, improve information sharing, and encourage clinical commissioning groups to improve the care purchased. However, experience shows that strong informed advocacy for this group of patients is needed to maintain a focus on their needs, so the design and provision of services will probably vary greatly. Furthermore, specialist learning disability staff—who traditionally work in

separately funded segregated community services—are often unfamiliar with mainstream service organisational policies, procedures, culture, and practice. It has been suggested that acute trusts should employ learning disability liaison nurses to facilitate continuity of care to institutions.

The confidential inquiry's call for an ongoing national learning disability mortality review should be strongly supported. NHS England should also require clinical commissioning boards to take heed of the consistent recommendations of how to improve the healthcare of people with learning disabilities. People should be clearly identified within the healthcare system, they should be afforded specialist advocacy, their families should be included as expert care partners, and their care should be adjusted to take account of their particular vulnerabilities.

The recent Francis inquiry called for a culture change in the NHS that would see the needs of patients come first. Patients with learning disabilities—perhaps more than any other patient group—need special focus, knowledge, and skill to ensure that their healthcare needs are met. All of this requires clinical leadership and a strong commitment at policy level.

Competing interests: We have read and understood the BMJ Group policy on declaration of interests and declare the following interests: SH has hosted four seminars funded by the BMA at the House of Lords on topics related to healthcare for vulnerable groups; her son has an intellectual disability and uses services; she chairs Beyond Words, a charitable organisation that publishes picture books on topics relevant to the editorial; and ITW has co-authored some titles. ITW was principal investigator of the NIHR HS&DR funded project 10/1007/22 (see reference 11).

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expressed here are those of the authors and do not necessarily reflect those of the HS&DR programme, NIHR, NHS, or the UK Department of Health

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