

Editorial

Preventing 'deaths by indifference':
identification of reasonable
adjustments is key

Irene Tuffrey-Wijne and Sheila Hollins

**Summary**

People with intellectual disabilities are at risk of premature death due to failings in healthcare provision. To prevent this, it is important for healthcare services to identify and flag not only vulnerable conditions (including intellectual disability, dementia and mental health problems), but

also the specific adjustments needed by individual patients.

Declaration of interest

None.

Irene Tuffrey-Wijne is Senior Research Fellow in Nursing. She leads a programme of research focused on intellectual disabilities, cancer and palliative care, patient communication and health. Sheila Hollins (pictured) is Emeritus Professor of Psychiatry of Disability, providing research support in intellectual disability, patient communication, sexuality and sexual abuse in London, Durham, Rome and Ulm.

People with intellectual disabilities are at risk of healthcare system failings

Adults with intellectual disabilities make up an estimated 2% of the population,¹ and are present in every physical and mental healthcare service. They are not a distinct and separate group, but people who experience the same health problems as the rest of society, albeit problems that might be more difficult to identify and address. A system that provides timely, consistent, individualised and sensitive care and treatment for this group of patients is likely to get it right for all patients, thus providing a benchmark for quality in any service.

It is 7 years since Mencap, a UK charity campaigning for the rights of people with intellectual disabilities, published its pivotal *Death by Indifference* report,² alleging the 'avoidable' deaths of six people due to discriminatory practices within hospitals. A number of studies and inquiries^{3,4} have highlighted widespread poor healthcare provision for patients with intellectual disabilities, leading to compromised patient safety. The recent Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD), which investigated the deaths of 247 people with intellectual disabilities, found that 37% of people with intellectual disabilities had avoidable deaths due to failings in the healthcare system; in comparison, 13% of people in the general population in England and Wales had avoidable deaths that are amenable to good-quality healthcare.⁵ CIPOLD found that people with intellectual disabilities died on average 16 years earlier than people in the general population. This supported Hollins' earlier findings that adults with intellectual disabilities were 58 times more likely to die before the age of 50.⁶

The need for reasonable adjustments

Key to improving patient safety for people with 'protected' characteristics such as disabilities is the delivery of 'reasonably adjusted' health services, in line with legal requirements of all public services in the UK (Equality Act 2010). The 'Improving

Health and Lives' Learning Disability Observatory (IHAL) is collecting evidence about the types of reasonable adjustments currently implemented by healthcare services for people with intellectual disabilities. These include, for example: providing accessible information materials or communication aids; making provision for carers to stay with the patient; amending or extending appointment times; or providing advocacy for people who lack mental capacity.⁷ It is not only people with more severe or profound intellectual disabilities who are at risk of healthcare failings and in need of reasonable adjustments. People with mild intellectual disabilities may be particularly vulnerable owing to difficulties with understanding written materials and instructions, keeping appointments, understanding consent procedures and adhering to treatment regimes.

Difficulties with flagging patients

To ensure that reasonable adjustments are made, services must be able to identify the patients that need them. Recommendations for improving healthcare services for people with intellectual disabilities have therefore emphasised the need for National Health Service (NHS) services to flag this group of patients.³ One of the difficulties is that only a small proportion of adults with intellectual disabilities (estimated 21% in the UK) are known to health and social care services. This means that even if communications with referring general practitioners are good, most people with intellectual disabilities will not have been flagged in the referrals. IHAL argues that NHS services themselves should identify people with intellectual disabilities, and propose that all patients are asked questions to screen for disability, in the same way as they are asked questions about ethnicity.⁸

We recently completed a national patient safety study in England, assessing the barriers to providing safe healthcare for people with intellectual disabilities in acute hospitals.⁹ We found a wide range of barriers to identifying and flagging patients with intellectual disabilities (see Appendix). Given the current lack of national integrated systems for communicating vulnerabilities between primary and secondary care, and thus the reliance on hospital services themselves to identify this patient group, it was of particular note that staff in the study lacked knowledge and skill in identifying the presence of intellectual disability, leading to both underdiagnosis and misdiagnosis of the condition. In addition, and perhaps equally significantly, we found widespread staff reluctance to record the presence of intellectual disability in a routine and systematic way. Staff lacked any real understanding

of the need for this vulnerable group of patients to be identified and a reluctance to 'ask the question', partly because of a fear that this would 'label' them pejoratively.

Flagging the need, not the label

Linked to the reluctance to flag the patient's vulnerability was a lack of staff understanding of the kind of adjustments people with intellectual disabilities might need to make healthcare more accessible to them. This is complicated by the fact that the specific adjustments needed by a particular patient with intellectual disabilities may be highly individual. It seems, therefore, that flagging the vulnerability itself may not be sufficient, as it does not necessarily lead to the next crucial step: the provision of adequately adjusted services. Perhaps it is time to look not only at how we identify and flag all vulnerable patients (including for example, patients with dementia, mental health problems, sensory and physical impairments), but also how we identify the service adjustments they need. Instead of flagging the condition which is considered to cause their vulnerability, we propose that identifying the need for a specific service adjustment would go some way to avoid the labelling dilemma as well as some of the difficulties of correctly identifying and flagging the condition, while effectively individualising the service response. Examples of flagging the need for health service adjustments might include: 'needs a carer/advocate present', 'needs extra time for procedures', 'needs minimal changes of staff/wards' or 'needs to be sent appointment letters/procedure explanations in easy-read or pictorial format'.

Identifying the need for specific service adjustment would require organisations to take an individual, patient-centred approach. There may be particular adjustments that are needed by a significant number of people with intellectual disabilities. It would be helpful, therefore, to investigate more fully not only what kind of reasonable adjustments are routinely provided by healthcare services, but also what kind of adjustments are most needed by different vulnerable patient groups, together with their resource implications. However, there are also likely to be some highly individualised adjustments that cannot be easily addressed through a checklist approach. Examples from our study included a patient who needed to be nursed on a mattress on the floor to ensure his safety, a patient who would only accept oral medication if given with mustard, and a patient who was so frightened of hospitals that his pre-treatment sedative medication had to be administered in the car park (with his consent and his family's support).⁹

Growing numbers of NHS hospitals have implemented patient-held documentation such as 'hospital passports', which record some of the patient's particular needs (including communication needs), but our study found that this document was not reliably carried by patients or referred to by staff. Rather, we believe that NHS services should begin to look into ways in which the specific requirements of individual patients can be assessed and documented within their own patient records. It is clear from the evidence obtained by CIPOLD, IHAL and our study that a lack of reasonable adjustments leads to compromised patient safety. Given the importance of this in the light of preventing patient harm and avoidable deaths, we suggest that the systematic recording of patient-specific reasonable adjustments should be subject to inspection by the Care Quality Commission in England and Wales and reporting to the healthcare organisation's board.

Finally, we propose that a senior clinical manager, most obviously the ward manager in an in-patient service, should be responsible for identifying any reasonable adjustments required by all patients at the time of referral or admission, and making and monitoring adequate arrangements to deliver these. Given

that a significant minority of patients will require an individualised service on every shift, this is a vital role which too should be subject to inspection and reporting.

Irene Tuffrey-Wijne, PhD, Kingston University and Faculty of Health, Social Care and Education, St George's University of London; Sheila Hollins, FRCPsych, FRCPCH, FRCP, St George's University of London, UK

Correspondence: Professor the Baroness Hollins, 4.09, 1 Millbank, London SW1A 0PW, UK. Email: hollinss@parliament.uk

First received 22 Nov 2013, final revision 12 Mar 2014, accepted 1 May 2014

Appendix

Barriers to identifying people with intellectual disabilities in acute hospital services⁹

Cross-organisational

- Most people with intellectual disabilities are unknown to any service
- Lack of integrated patient record systems with other health services

Organisational

- Lack of effective flagging systems
- Lack of senior management support
- Ambiguity with regard to who could/should record information about intellectual disability

Staff: individuals and teams

- Lack of staff knowledge about intellectual disability
- Lack of staff understanding of the need for identification
- Lack of staff willingness to identify/flag

Patients and carers

- Mild/moderate intellectual disabilities may be hard to identify
- Patient communication/cognitive difficulties may make identification difficult
- Patients may not want to be identified
- Lack of advocacy

References

- 1 Emerson E, Hatton C. *People with Learning Disabilities in England*. Public Health England, 2008
- 2 Mencap. *Death by Indifference*. Mencap, 2007.
- 3 Michael J. *Healthcare for All*. Aldridge Press, 2008.
- 4 Emerson E, Baines S, Allerton L, Welch V. *Health Inequalities and People with Learning Disabilities in the UK: 2012*. Public Health England, 2012.
- 5 Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet* 2014; **383**: 889-95.
- 6 Hollins S, Attard M, von Fraunhofer N, McGuigan S, Sedgwick P. Mortality in people with learning disability: risks, causes, and death certification findings in London. *Dev Med Child Neurol* 1998; **40**: 50-6.
- 7 Hatton C, Roberts H, Bain S. *Reasonable Adjustments for People with Learning Disabilities in England: A National Survey of NHS Trusts*. Public Health England, 2010.
- 8 Glover G, Emerson E. *Have you got a Learning Disability?* Public Health England, 2011.
- 9 Tuffrey-Wijne I, Giatras N, Goulding L, Abraham E, Ferwick L, Edwards C, et al. *Identifying the Factors Affecting the Implementation of Strategies to Promote a Safer Environment for Patients with Learning Disabilities in NHS Hospitals: A Mixed-Methods Study*. National Institute for Health Research, 2013.