Care adjustments for people with learning disabilities in hospitals

Jim Blair describes how ensuring staff have immediate access to patient information has improved treatment for this client group

Abstract

Health inequalities start early in life for people with learning disabilities. In the UK, they can arise from various barriers that people experience when trying to access care that should be appropriate, timely and effective. Inequalities in health care are likely to result in many NHS organisations breaching their legal responsibilities, as outlined in the Disability Discrimination Acts 1995 and 2005, the Equality Act 2010 and the Mental Capacity Act 2005 (Emerson and Baines 2010). This article seeks to help nurses, healthcare professionals and hospital managers ensure that better services are delivered by encouraging them to explore how reasonable adjustments can improve outcomes for people with learning disabilities.

Keywords

Discrimination, reasonable adjustments, learning disabilities, law

Correspondence
jim.blair@stgeorges.nhs.uk

Date of acceptance
October 3 2011

Peer review
This article has been subject to open review and has been checked using antiplagiarism software

Author guidelines
www.nursingmanagement.co.uk

MAJOR ILLNESSES that result in hospital admission are more common among people with learning disabilities (Disability Rights Commission 2006). Furthermore, a greater number of people with learning disabilities are living longer and so are likely to use healthcare services more frequently as they age. It is increasingly important therefore that care staff can meet their needs appropriately.

Department of Health (DH) (2001) emphasised that people with learning disabilities receive a ‘worse deal’ from health services than the rest of the population. The charity, Mencap, has also highlighted the poor care experienced by people with learning disabilities in acute and primary care (Mencap 2004). It is worrying that such care is still evident in 2011, as a BBC Panorama documentary, transmitted in May, demonstrated, with individuals with learning disabilities being abused in a Bristol private hospital. As a result of the programme, the Care Quality Commission is undertaking a widespread series of unannounced inspections of learning disability care services.

Learning disabled people are admitted to hospital almost twice as frequently as the general population, with Mencap (2004) estimating the annual admission rates at 26 and 14 per cent respectively.

A report Mencap (2007) details the stories of six people with learning disabilities who the charity and their families think died unnecessarily in healthcare settings. The document centres on the care decisions taken and suggests that they were based on assumptions about learning disabilities and quality of life, rather than the life-saving interventions required.

Health service ombudsman Ann Abraham, in a document examining these deaths (Parliamentary and Health Service Ombudsman 2009), noted: ‘The quality of care in the NHS and social services for people with learning disabilities is at best patchy, and at worst an indictment of our society.’ She also highlighted ‘distressing failures in the quality of health and social care’ and found that people with learning disabilities were treated worse than others, leading to ‘prolonged suffering and inappropriate care’.

An independent inquiry (Michael and Independent Inquiry into Access to Healthcare for People with Learning Disabilities 2008) that followed Mencap’s report (2007) stated: ‘Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. They are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same, but rather may need to be adapted to meet special needs.’

There is evidence of a lack of adherence in the NHS to basic human rights such as equality, dignity and respect (Disability Rights Commission 2006, Healthcare Commission 2007, Michael and Independent Inquiry into Access to Healthcare for People with Learning Disabilities 2008, DH 2009).

Additionally, these inquiries and reports highlight a lack of leadership, training and guidance for service
Box 1  Case studies: how hospital passports can improve safety

**Katherine**
Katherine has severe learning disabilities and her passport says she is allergic to eggs.

After reading this, the ward sister telephoned Katherine’s home to clarify whether she experienced anaphylactic reactions or a rash. This was a precautionary measure, rather than a response to anything that had happened.

**Vivek**
Vivek was informed he could not eat or drink for some time because a doctor had read in his passport that he bubbles up liquids and regurgitates food.

This could indicate dysphagia, which can result in a person choking. Dysphagia is more common in people with a learning disability, so it is vital to assess a patient for this, if there are any indications, as there were in Vivek’s case.

Box 2  Core reasonable adjustments at St George’s

The following are standard for people with learning disabilities and their carers in St George’s Hospital, to help reduce patient anxiety, permit experts by lived experience, such as family, to provide emotional and advocacy support, and to enable professionals to treat people in an efficient and timely ways.

- No fixed visiting times for family, carers and friends of people with learning disabilities is general policy so they can be with them for as long as they want.
- Food and drink for family and carers is offered to ensure that they can be with the person they support at any time.
- The first or last appointment of the day should always be offered, so people who find it traumatic to wait do not have to do so.
- Double appointments are helpful because they permit a fuller assessment of people’s needs, which is likely to result in more effective treatment and outcomes.
- A bed and/or chair is provided for a family member or carer.

There are a range of hospital passports in use in the UK, but this article concerns the scheme at St George’s Hospital, London.

The hospital passport

The hospital passport was adapted from one created by the then Gloucestershire NHS Primary Care Trust and introduced at St George's Hospital in 2008.

People with learning disabilities and health practitioners from Merton’s and Wandsworth’s community learning disability teams, in partnership with staff in the hospital, developed the passport to improve the health outcomes and experiences of people with learning disabilities and their families while accessing St George’s Hospital.

The passport provides a picture of the ‘whole person’ by including information that is not exclusively about illness and health. It is completed by the person with learning disabilities and his or her family, carers and supporters.

Passports are distributed via community learning disability teams, day services, GP practices and hospital settings.

Patients with learning disabilities attending hospital bring their passports with them when they come, although the documents can still be useful if they are brought later, after admission. The passport is owned by the individuals concerned and many people bring with them various versions that they have created themselves.

Hospital passports ensure that people with learning disabilities are more involved in their care, and that this care is provided in a more personalised and dignified manner.

Passports have led to direct changes in the way that care is delivered because of the information they contain. They also ensure that better histories are available to those involved in care provision so that patients have to provide less information over and over again. Passports also enhance the safety of patients (Box 1).

The following case study illustrates how the information recorded in passports enables staff to make small, personalised adjustments based on the information they contain.

When Mary, a 45-year-old woman with Down’s syndrome, was admitted to hospital, staff found out from her passport that she had a fear of the dark. Mary was provided with a bedside nightlight to ensure that she was never in the dark. Staff also found out that she likes Elvis Presley, so they talked to her about the singer before undertaking any procedures such as blood-pressure monitoring.

Services can become more flexible and responsive to individual needs because of the information
recorded in hospital passports. Healthcare professionals reading and acting on the information become better educated in how to treat and care for the people in question, so they are less likely to have misguided assumptions about the patient’s quality of life.

The hospital passport used at St George’s has been adopted by various services in the UK, as well as in Australia, Canada, the US and in translation in several European countries, including Norway.

In 2009, St George’s hospital passport won a Foundation of Nursing Studies award for innovation and it has been adapted for people with dementia who use local care services.

For care and treatment to be equitable, adjustments need to be made so that the healthcare experiences and outcomes of people with learning disabilities in hospital are improved. The passport is one reasonable adjustment that health services can adopt. Other core reasonable adjustments that people with learning disabilities and their carers can expect to receive at St George’s are shown in Box 2.

Reasonable adjustments can include providing support for people, to ensure that they are safe from harming themselves and that they receive the treatments they require. An example of this at St George’s involved Trevor, a man who had capacity to consent to have dialysis, but who pulled out the tubes after 30 minutes because he was unable to judge how long the procedure had taken and wanted to leave.

The reasonable adjustment in this case was to provide a healthcare assistant to be with him throughout the four-hour treatment to talk with him and encourage him to complete dialysis. Over time, he stopped needing to have someone with him and now has dialysis by himself.

Healthcare staff can also make environments as suited to patients with learning disabilities as possible. An example of this was making Natasha’s side room as much like her usual bedroom as possible, incorporating elements such as bright pink bed clothing and music that she enjoyed.

Ensuring discharges are safe is also important. This can be done by involving patients and carers
throughout the hospital stay and in discharge discussions, and making sure they are clear about what is planned for their care after discharge.

Using signing, photos and fewer words often helps people with learning disabilities to understand what is happening and the options that they face. This is particularly useful when assessing people’s mental capacity in line with the demands of the Mental Capacity Act 2005.

Protecting beds in advance of admission increases the likelihood of effective care and treatment being delivered in a timely, safe and compassionate manner. Doing so ensures that important information about patients can be shared with clinical staff before admission so that care is better planned and patients and carers are less anxious.

Learning disability issues should be included and explored at all levels as part of an organisation’s induction and mandatory training. At St George’s Hospital, training is carried out alongside specific bespoke educational sessions for different clinical areas and focuses on issues that have arisen in these settings. As a result, staff are educated in the requirements, health and wellbeing of people with learning disabilities. The St George’s Healthcare NHS Trust intranet has different materials to assist staff in acquiring knowledge about people with learning disabilities.

Improving clinical practice

For healthcare professionals to improve their practice, it is important that people with learning disabilities and their families, carers and supporters are acknowledged as experts in the patients’ care needs.

Box 3 provides a brief guide for healthcare professionals on how they can improve care for people with learning disabilities.

The use of hospital passports and other reasonable adjustments have improved care by ensuring that it is appropriate and timely, thereby reducing inequalities and meeting legal obligations.

A service that is deemed to be providing good care and treatment is one where the stated aims of support, care and treatment are accomplished to a high standard. Moreover, the service should ensure that people for whom it provides care are treated with respect, dignity and compassion. It is important therefore to ensure that all services improve their care for people with learning disabilities.

References


