Caring for people who have intellectual disabilities

Jim Blair explains how practitioners should assess capacity in people with learning disabilities and ensure that they receive an equitable standard of care.

Abstract

This article explores some of the challenges people with intellectual disabilities must overcome when they attend emergency departments. It also discusses some of the issues that arise for staff involved in assessment and care of people with intellectual disabilities, including their legal responsibilities to provide care for such people that is similar in standard to that provided for the rest of the population.

Keywords

Intellectual disability, capacity, reasonable adjustments

A REPORT entitled Death by Indifference, by learning disability charity Mencap (2007) tells the stories of six people with intellectual disabilities said to have died unnecessarily in healthcare settings. The report examines the care decisions that were made and concludes they were based on assumptions about intellectual disabilities and quality of life, rather than on the life-saving treatments required. Since then, Mencap (2012) has published another report on avoidable deaths in healthcare settings of 74 people with intellectual disabilities.

In 2011, there were about 1.2 million people with intellectual disabilities, including 180,000 boys and 106,000 girls aged under 17, in England. Of the 905,000 adults, about 530,000 of whom were men and 375,000 women, 185,000 (20 per cent) were known to learning disability services (Emerson et al 2012). Fifty per cent of people with intellectual disabilities who present at emergency departments (EDs) are subsequently admitted to hospital, a proportion considerably higher than the 31 per cent of people without such disabilities who are admitted after presentation (Emerson et al 2012).

As the parliamentary and health ombudsman (2009) says: “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.”

Clearly, reasonable adjustments should be made so that people with intellectual disabilities have equitable access to health care to achieve similar health outcomes to the rest of the population.

This article addresses some of the issues that arise when people with intellectual disabilities present at EDs and draws on examples from the author’s practice to offer guidance on improving care. It also examines the need to make reasonable adjustments, discusses how to assess mental capacity, and gives general advice on how to improve ED environments, assessments and care. The article focuses mainly on adults, but many of the issues and solutions can be applied to children.

Intellectual disability

Definition

Intellectual, or learning, disabilities are common, lifelong conditions, rather than a disease or illness. They can be distinguished from learning difficulties, such as dyslexia.

Intellectual disability is defined by the World Health Organization (2010) as ‘a condition of arrested or incomplete development of mind, which is characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence and to cognitive, language, motor and social abilities’.

The British Psychological Society (2000) defines intellectual disability as a significant impairment of intelligence and of adaptive functioning that occurs before adulthood.

In the UK, people are deemed to have an intellectual disability if their IQ is lower than 70.
Box 1  Common health problems in people with intellectual disabilities

- **Cancer** Gastrointestinal cancers, including those of the oesophagus, stomach and gall bladder, are about twice as prevalent in people with intellectual disabilities, while prevalences of lung, prostate, breast and cervical cancer are much lower than in the general population. Lymphoblastic leukaemia is particularly prevalent in people with Down's syndrome.

- **Coronary heart disease** This is the second highest cause of death in people with intellectual disabilities.

- **Dental problems and oral hygiene** People with intellectual disabilities are more likely to have tooth decay, loose teeth, untreated oral disease and gum disease than the average member of the general population.

- **Diabetes** The higher prevalence of diabetes than in the general population may be linked to a greater incidence of obesity, less activity and poorer diet.

- **Epilepsy** About one in three people with an intellectual disability has epilepsy, depending on severity of disability, compared with one in 100 of the general population.

- **Gastrointestinal problems** Experienced by about 70 per cent of people with intellectual disabilities (Bohmer et al 1999, Galli-Carminati et al 2006), gastrointestinal disorders are far more prevalent in this patient group than in the population as a whole.

- **Mental ill health** Anxiety disorders, depression and schizophrenia are among the more common mental health problems experienced by people with intellectual disabilities. Schizophrenia, for example, is three times more common in people with intellectual disabilities than in the general population (Hardy et al 2011).

- **Obesity** This is far more common in people with intellectual disabilities, especially women with mild disabilities, than in the general population.

- **Respiratory disease** This is the most common cause of death among people with intellectual disabilities.

- **Sensory impairments** An estimated 40 per cent of people with intellectual disabilities have difficulties seeing and a similar proportion has problems hearing.

- **Swallowing and eating problems** Difficulties in swallowing are more prevalent among those with intellectual disabilities than in the general population and are highest among those with profound intellectual disabilities.

Such people tend to have difficulties with self-care, adaptive behaviours and self-organisational skills, but their likes and dislikes, opinions and life histories can be as varied as those of any group of people, and their rights are the same or similar to everyone else's.

Some intellectual disabilities, such as Down's syndrome, can be identified at birth, but many people have no identifiable 'syndrome' with, for example, specific facial features.

Severe or profound intellectual disabilities are more likely to be noticed before mild-to-moderate disabilities, but most forms of intellectual disability are diagnosed in early childhood when the children concerned fail to reach developmental milestones.

Common problems: People with intellectual disabilities often have difficulties reading, writing, interpreting and processing new information to a level generally expected of people at their age. They may also have problems recalling information such as where they live or their date of birth, telling the time, maintaining self-care and accomplishing activities that require daily life skills.

Clinicians in EDs should therefore consider the following four questions during assessments:

- Does the person have significant communication difficulties?
- Does he or she have a social worker, care manager or key worker?
- Does he or she attend a special school, a mainstream school with special support or a day centre?
- Is the person known to intellectual disability services (Hardy et al 2011)?

If there is any doubt about the answers to any of these questions, emergency staff should seek more information and advice from the local hospital learning disability nurse, community learning disability team or social work services.

Emergency departments are usually noisy and fast-paced settings, and can be frightening to people who are ill and vulnerable. People with intellectual disabilities who present at EDs often become anxious and distressed, and some display behaviours such as self-biting, scratching, head banging, screaming and shouting, that other people can find distressing.

It should not be assumed that these behaviours are linked to an intellectual disability, however. They could be linked to a presenting complaint or anxiety, and underlying health problems or other potentially treatable causes should be considered.

The assumption that such people's behaviour is due solely to their disabilities, known as diagnostic
overshadowing (Gates and Barr 2009), is particularly pertinent when new behaviours emerge or existing behaviours escalate. People with intellectual disabilities have a higher-than-usual risk of a range of diseases and conditions, and it is essential that physiological or pathological reasons for variations in behaviour are considered.

Common health problems among people with intellectual disabilities are shown in Box 1.

**Mental capacity** When people are ill, their level of cognitive functioning can be reduced. It does not follow, however, that people with intellectual disabilities who become ill lack mental capacity.

It should be remembered that a person’s capacity is not necessarily indicated by his or her appearance. For example, people with intellectual disabilities who seem to lack speech or have hearing difficulties may actually be scared, and clinicians must not assume that they cannot make decisions and thereby exclude them from discussions about their care.

Under the Mental Capacity Act 2005, everyone has the right to make such decisions unless it becomes evident on assessment that, due to impaired functioning of the mind or brain, he or she lacks capacity.

Assessing capacity to consent to treatment is always time, decision and topic dependent, however. Each decision requires a separate capacity assessment, which means that people can have capacity in some, but not all, aspects of their care and treatment. For example, they may have capacity to consent to teeth extraction but not to a heart operation.

The patient’s capacity was clearly in question so a four-point capacity test was carried out. This test involves checking whether patients can:

- Understand information relevant to a decision about their care.
- Retain the information long enough to make the decision.
- Use or weigh up the information.
- Communicate their decisions.

The patient could do none of these things. Because he is over 18 years old, his mother could not make decisions on his care on his behalf. As a result, it was decided that, although he wanted to become better, he lacked capacity to understand the need for a blood sample to be taken. The patient was given a small amount of sedative medication to reduce his anxiety and this enabled the doctor to take his blood.

**Reasonable adjustments** Under the Disability Discrimination Act 2005 and the Equality Act 2010, health and social service staff are required to make reasonable adjustments to ensure that people, including those with intellectual disabilities, can access appropriate and timely care. Failure to make adjustments is regarded as a form of discrimination.

It is helpful, therefore, for EDs to put a number of ‘core’ reasonable adjustments, such as hospital passports and management plans, in place so that they can be activated quickly when needed.

St George’s NHS Healthcare Trust, London, uses hospital passports that have been adapted in partnership with people with intellectual disabilities and their carers from those used by Gloucestershire NHS Primary Care Trust.

The passports, shown in Figure 1, page 20, can be acquired from GPs, members of community learning disability teams, or day service or hospital staff, and are completed by individuals or their carers.

Passports such as these can hold a range of information, including, for example, whether the person concerned regurgitates food or has food allergies, that provide a benchmark for ongoing assessments, and helps eradicate diagnostic overshadowing.
Assessing and providing care for people with intellectual disabilities can take four times longer than the average for the general population (Houghton 2001), partly because up to 50 per cent of people with intellectual disabilities experience significant difficulties with communication. Nevertheless extra time for the assessment and care of such people is not always given (Gates and Barr 2009).

At St George’s, extra time is given in the ED and the hospital in general to ensure that people with intellectual disabilities receive equitable and timely treatment that is appropriate to their needs. This involves slowing down the triage process and providing information gradually to allow patients time to absorb what is happening and become engaged in their care. Where possible, learning disability nurses should be involved in patient assessments to ensure that their expertise and learning is shared with emergency care staff. Taking more time over triage also allows nurses to assess people’s capacity effectively, prevent diagnostic overshadowing and draw up clear care pathways until discharge (Bradley 2002). Because many people with intellectual disabilities find EDs distressing, it also helps to ensure they have quieter
Case study 2: reasonable adjustments

A young woman with severe intellectual disabilities and no verbal language presents with two carers to the emergency department (ED). Her carers say that she had chest pains and some breathing problems but she refuses to be examined by ED staff and becomes distressed by the ED environment.

Staff take the patient and her carers to a quieter part of the ED, where a consultant doctor and consultant nurse examine her, while her carers reassure her that she is safe. This process is carried out periodically and so the time between first and last examination is about three times longer than it would have been for a person without intellectual disabilities.

As a result, the patient is found to have constipation and mild breathing difficulties, and she and her carers are advised to follow up her treatment with her GP. The patient’s carers report later that they were pleased with the level of care she had received.

areas for assessments. Some example of reasonable adjustments that enhanced the care of one patient at St George’s Hospital are shown in case study 2.

To enhance ED journeys for people with intellectual disabilities, it is important that clinicians regard patient engagement as a core component of assessment. Where possible, they should find a quiet place, where there are likely to be few interruptions, for the assessment and try to establish if there is an emergency care support or management plan in place. These plans may include hospital passports, letters or guidance on how each person with intellectual disabilities behaves when in hospital or when faced with stressful situations. Such people may struggle to recall what has happened to them accurately and nurses may need to talk with their carers, who can usually provide crucial information and know how to support the patients concerned.

It is often important to know whether patients are attending an ED for the first time. If they have attended before, nurses should ask them or their carers about the previous occasions, what worked well and what did not. Nurses can relieve patients’ stress by finding out if they have favourite items or if they engage in self-soothing techniques such as rocking, standing or walking about. When nurses communicate with people with intellectual disabilities they should try to speak more slowly and use fewer words than they would with other patients. They should also avoid medical terminology, repeat explanations and check patients’ understanding by asking them to repeat what has been said.

People with significant intellectual disabilities can be asked to indicate their symptoms by pointing at pictures, signs or symbols in, for example, hospital communication books, such as those published by the Clear Communication People (2012). These forms of communication can be difficult to use, particularly if patients are experiencing acute episodes of illness and are anxious about being in an ED.

Conclusion

Emergency department staff are legally obliged to provide people with intellectual disabilities levels of care similar to those they provide other patients. To do so, they must understand what constitutes an intellectual disability and make reasonable adjustments to the services they provide. Staff must also be able to assess patients’ capacity to consent and engage effectively with patients who have intellectual disabilities to ensure these patients have equitable access to care.

References


