

## Practitioner's blog

# Reading the signs

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There has been much emphasis in recent years on improving communication in healthcare settings, particularly for those for whom English is not their mother tongue, or who come from one of the many minority cultures in the UK. Obtaining informed consent to treatment and assessing mental capacity are fraught with difficulty if the patient is frightened and cannot absorb or understand what is being said. Guidelines that encourage and recommend the use of interpreting services are therefore to be welcomed and held up as best practice, as skilled interpreting not only reduces anxiety but also decreases the risks inherent in obtaining an accurate medical history and informed consent from a patient. However, interpreting is not always the solution to issues of communication, as there are other groups of people who are often overlooked or not always understood. These are individuals with learning disabilities (LDs) or intellectual disabilities (IDs), a hidden community who can be extremely vulnerable in healthcare settings.

The move away from institutional care during the past few decades has meant that people with LDs are living in the community, where they often have to rely on friends or carers to help them to access health services. Sometimes, however, such help is unavailable and they have to cope alone. In such instances it is essential that healthcare professionals act as advocates to ensure equality of access and appropriate care. They need to understand the special needs of those with LDs, and to be aware that they are no more a homogenous group than the rest of us, and will vary in their ability to comprehend and communicate their needs. Degrees of disability vary. Although the presence of a mild learning disability is not usually perceived as a health problem on its own, the physiological, psychological and social implications of cognitive impairment may compound the vulnerability of people with LDs in accessing healthcare (Wallace and Beange, 2008).

Evidence from practice and indeed the literature suggests that people with LDs have more health problems and higher morbidity and thus a greater need for

healthcare than the rest of the population (Cassidy *et al*, 2002; MENCAP, 2004). As a result, they are more likely to have significant healthcare needs that go unrecognised and untreated due to poor communication, discrimination or indifference (Cumella and Martin, 2000; Healthcare Commission, 2007; MENCAP, 2007). They face barriers in accessing secondary healthcare, and their life expectancy is lower than that of the rest of the population (Kerr, 2004).

The vulnerability of this group becomes very apparent in the fast-moving emergency setting, where rapid communication is the norm and is often critical to optimum outcomes for the patient. The emergency department can be a very frightening place for those of us who can communicate effectively, but for those with LDs it can be a terrifying experience that may adversely affect their normal communication patterns. This was the case for a woman who was recently brought to one London emergency department by ambulance following an episode of prolonged fitting. She was 40 years old and had an LD, but this was not known at the time. Her arrival caused disruption as she was very combative in the department, both with the ambulance personnel and with the emergency staff.

She presented as incoherent, uncoordinated and very unstable on her feet. Despite this physical vulnerability, she refused to sit on the trolley or on a chair, and backed herself into a corner of the resuscitation room. She initially appeared to be mute, but then it was noticed that she became increasingly agitated on overhearing staff discussing her condition. All efforts, however well intentioned, to calm and reassure her were met with greater resistance on her part. She appeared very afraid and anxious, and the initial impression was that this woman had a severe neurological or psychiatric condition.

One of the nurses who had some experience of caring for patients with LDs noticed what was happening and offered to help. She asked the other staff to move away in order to give the woman some space. She managed to communicate with her using sign language, and found out that all she wanted and needed to do was to

walk. The nurse spent the next hour or so walking round and round the department with the woman, supporting her and calmly reassuring her, but at the same time managing to assess her and find out more about her.

The more the woman walked, the more her mobility improved, and she then began to talk. It transpired that what had happened was not unusual for her. After having a fit she would usually experience transient loss of speech and have difficulty mobilising. This transient hemiplegia or monoplegia after an epileptic seizure is known as Todd's paresis. Once the woman had regained her equilibrium she was quite happy to sit down and be formally assessed. Epilepsy affects about 1% of the general population. It is significantly more prevalent in people with LDs (one-third of this population have the condition; National Society for Epilepsy, 2009). The prevalence rises with increasing severity of disability, with nearly 50% of individuals with severe LDs having epilepsy (Royal College of Nursing, 2006).

People with LDs often have more than one type of seizure and more complex seizure patterns. They are at risk of further cognitive impairment due to prolonged seizures, and there is a risk that secondary injuries might go unrecognised because of these individuals' inability to communicate, and also due to lack of understanding by healthcare staff. Although severe and profound LDs will be recognised, staff who are unfamiliar with the communicative patterns of people with LDs across the spectrum of functioning may not recognise new or additional health disorders, instead attributing the behavioural disturbances to the LD (Bradley and Lofchy, 2005). Although most professionals in emergency settings are well intentioned and will try to understand the patient with an LD, this may not be enough, and consequently their lack of knowledge often leads them towards overdependence on carers (Sowney and Barr, 2005).

In this incident it was fortuitous that there was a professional present with the knowledge, skills and understanding necessary to intervene to ensure that this woman was comforted and reassured, and that account was taken of her very specific needs. However, the outcome could quite easily have been less than favourable if her disability had not been recognised at the outset. This case highlights the way in which seemingly developed healthcare systems still fall short in responding to the diversity of individuals in terms of understanding LDs and ensuring that professionals are suitably equipped to respond appropriately. It also demonstrates how our healthcare structures and processes are not yet flexible enough to accommodate diversity in all its forms. This woman needed time, understanding and a period of one-to-one attention. It is likely that if a carer had been present they would

have had to assume that role, as nurses often have competing demands for care and little extra time to spend with patients on a one-to-one basis. Fortunately, on this occasion the nurse recognised this woman's urgent need and responded in the most intuitive and compassionate way, accepting her difference and adapting the departmental protocol to meet her needs effectively, rather than expecting her to conform to the conventional hospital processes.

More importantly, she gave the woman time, which served to maintain this patient's autonomy and dignity. Above all she set an excellent example by upholding a professionalism and a belief that endorsing the concept of diversity in health and care really means accepting that individuals function in different ways and have different needs. Patients with intellectual disabilities need carers who are creative and flexible in their approach but who are, above all, compassionate and prepared to adapt the rules to meet the needs of those whose voices are not always heard.

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