

Guest editorial

The last great civil rights issue? Attitudes towards and treatment of people with a learning disability

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Introduction

The last 30 years have seen major progress in the way people with a learning disability are viewed and treated in the UK. The definition of *learning disability* in the UK encompasses people with a broad range of disability, and includes the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), or a reduced ability to cope independently (impaired social functioning), which started before adulthood and has a lasting effect on development. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher-level autistic spectrum condition who may be of average or even above average intelligence, such as some people with Asperger's syndrome (Department of Health, 2001). Learning disability is a UK term that equates to *intellectual impairment*, *mental handicap* and *mental retardation*, terms that are used elsewhere.

The introduction of the Community Care Act in 1990 enabled people with a learning disability to move out of long-stay institutions and live in local communities. The intention behind the Act was to enable these individuals to maintain contact with their relatives, engage in normal everyday activities and, if they were able to do so, to play an active part in society. Unfortunately, society was not prepared for their arrival. The need for suitable care settings for around 9000 people forced the statutory bodies to enter into partnerships with organisations in both the not-for-profit sector (charities) and private businesses. Neither of these sectors was equipped to provide care for this new client group in terms of either suitable accommodation or a workforce with the appropriate skills.

There is no doubt that, since that time, significant improvements have taken place. The White Paper, *Valuing People*, brought a radical agenda for change in the care of people with a learning disability (Department of Health, 2001). *Valuing People* outlined four key principles. People with learning disabilities have the same legal and civil rights as everyone else in society which means, for example, that they have the right to education, to vote and to start a family. They have the right to make choices, to make decisions about their own lives and to live independently with appropriate support. They also have the right to social inclusion, to live in society and access facilities and resources according to their wishes and needs (Department of Health, 2001).

These principles are still considered to be the gold standard for the care of people with learning disabilities, but unfortunately many still struggle to live in community settings. They are still regarded and treated by many as children and thus as incapable of taking any responsibility for themselves. They are widely excluded from the democratic process even though they have the right to vote. In 2010, only about 15% of people with learning disabilities voted in that year's general election, despite a long-lasting campaign by learning disability organisations to support and facilitate their right to do so. Prejudice against them remains high; eight out of ten have experienced some form of hate crime, often on a regular basis (Mencap, 2011). The level of abuse ranges from name calling to financial exploitation, physical attack and even murder. A subcategory of hate crime has developed and been termed 'mate crime.' In such cases the person with a learning disability is targeted and then 'befriended' by a group or an individual for the purposes of financial

or other forms of exploitation, which may in turn lead to physical abuse and, in extreme cases, murder. It is estimated that 'mate crime' accounts for 30% of reported hate crimes committed against those with learning disabilities in England and Wales (Mencap, 2011).

Some of the reasons for this situation are historical. In the 19th century, industrialisation and the migration of people from the countryside to the cities reduced the capacity of families to care for relatives with disabilities. Institutions offered a safe and convenient solution to the problem of what to do about those with learning disabilities. However, institutions also served to separate ordinary people from those with learning disabilities, or indeed from anyone who seemed different to themselves. Once they were removed from everyday society, people with learning disabilities became 'other', 'different', 'dangerous', 'sub-human' or a source of amusement; they were described as being *mentally subnormal*. The general attitude was that they were of no real use to society and it might be better for everyone if they did not exist. Such prejudice took generations to develop, and it is now taking generations to correct.

In recent years, a number of high-profile reports have revealed the extent to which these old attitudes persist. Examples include the BBC's *Panorama* programme about Winterbourne View, a private care home, in which hidden cameras filmed staff physically and verbally abusing residents (BBC, 31 May 2011). Investigation revealed a lack of staff training about understanding challenging behaviour from a functional perspective, and a lack of positive behavioural support interventions, which had led to the overuse of physical restraint. A lack of leadership and accountability was also identified, and unqualified members of staff were found to be participating in abusive practices. Appropriate safeguarding procedures were not followed, and patterns of abuse went unnoticed by regulatory bodies such as the Care Quality Commission (Department of Health, 2012). People were, quite rightly, shocked by what they saw, and there was considerable media coverage of both the programme and the subsequent actions taken. Custodial sentences have been given to a number of staff from Winterbourne View, and a recent BBC news report indicated that Castlebeck, the private care company that ran Winterbourne View, has gone into administration (BBC News, 2013b). However, as with so many other examples, attention waned, and events at Winterbourne View were dismissed as an isolated incident involving individuals in a particular setting, rather than as evidence of a systemic failure to look after vulnerable people.

Mainstream healthcare settings such as hospitals in the UK have also provided evidence of a different kind of failure, namely neglect. Mencap is a UK charity that

works in partnership with people with a learning disability and provides services, including telephone helplines and Internet websites, to support people in living life as they choose. The charity also has a campaign team dedicated to lobbying for the changes that people with learning disabilities want. Mencap's report on hospital care was based on six case studies which exemplified the neglect of patients with learning disabilities, neglect which extended to unnecessary, avoidable death (Mencap, 2007). Inherent in this neglect were the negative attitudes of hospital staff who did not understand individuals' needs (Dinsmore, 2011). Emerson *et al* (2011, p. 19) further suggest that 'organisational barriers still exist for people with learning disabilities in terms of accessing mainstream healthcare', highlighting a 'continued failure to make "reasonable adjustments" in light of the literacy and communication difficulties experienced by people with learning disabilities.' Serious ongoing concerns were again highlighted by Mencap (2012). A total of 74 people with learning disabilities have died in hospitals during the last 10 years. These deaths were attributed to the practices of doctors who appeared to show no regard for the Equality Act (2010) or the Mental Capacity Act (2005), nurses who failed to provide even basic care, and the overall lack of value placed on the lives of those with a learning disability (Mencap, 2012).

A recent call from politicians and patient safety lobby groups (BBC News, 2013a) for the UK Government to hold accountable the most senior management teams within health organisations where neglect in care is found is at last being acknowledged and raised as an issue. It is no longer acceptable that only the individual clinicians and/or care workers are prosecuted, as is currently the case. The Care Quality Commission was found to be seriously lacking in terms of investigation of reported abuses. In general we are seeing this pattern continue, where many reports suggest courses of action with very little evidence following to show that action has taken place.

What is needed is a radical reform of practice and service delivery.

Practice

- People with learning disabilities should be seen as people first, rather than as their illness or disability.
- Health and social care staff should maintain a person-centred approach in communication, care planning and delivery based on the key principles of *Valuing People Now* (Department of Health, 2009).
- The Equality Act (2010) requires adjustments for people with learning disabilities, to ensure that no one is disadvantaged in terms of care compared with non-disabled individuals; this includes provision of physical care, resources and equipment,

accessible information and, when in need of this, extra auxiliary aid.

- Accessible information and communication are vital to enable effective communication between care providers and the individual with a learning disability; they can take the form of visual information using images, and keeping language simple and jargon free (Heart of England NHS Foundation Trust, undated; The Clear Communication People Ltd, undated).
- There should be equal access to general healthcare, and adjustments to care where and when needed in line with the recommendations of *Healthcare for All* (Michael, 2008), an inquiry into access to healthcare for people with learning disabilities which highlighted ignorance and discrimination as important barriers to obtaining help.
- Medical, nursing and allied health professional education/training should incorporate the needs of patients with learning disabilities (Michael, 2008).
- Inclusion of family members, in order to obtain a fuller understanding of the individual, is extremely important. Carers will know the person well and can provide valuable information about his or her communication needs.

Service delivery

- Staff training that goes beyond physical intervention/restraint and reactive techniques and which incorporates person-centred, non-punitive, evidence-based functional analysis of behaviour leads to understanding of behaviour in terms of what that behaviour is conveying.
- Strong leadership and positive role models are vital if significant changes in care standards are to be made.
- There is a need for organisational commitment both to positive behaviour and the right attitude of healthcare staff towards patients with learning disabilities, and to understanding the need for reasonable adjustments and ensuring that these are put in place (Equality Act 2010).

Until society values people with learning disabilities as human beings with full civil and human rights, the potential for abuse will remain.

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