Learning disability: barriers to effective communication

Communication is the act or process of using words, sounds, or behaviours to express ideas, thoughts feelings, or exchange information (Merriam – Webster, 2014).

People with learning disabilities die younger than other people (Heslop et al, 2013). The Independent Inquiry into Access to Healthcare for People with Learning Disabilities (Michael, 2008) followed the Mencap report Death by Indifference (2007). The report concluded that there are inherent risks in the care system that result in high levels of health needs not being met. The inquiry found that people with learning disabilities appear to receive less effective care and that there are many shortcomings in the way treatment is delivered, with avoidable suffering caused by untreated ill health.

Effective communication is essential in ensuring high quality health care (Balandin & Hemsley, 2008) and is an essential skill for nurses (Nursing Midwifery Council (NMC), 2007). Because communication difficulties are characteristic of people with learning disabilities, the nurse needs strategies that can be used to promote communication and understanding by removing barriers, and developing their skills and knowledge.

Why ?

Effective communication is a recurring and pervasive theme in government policies, reports and best practice guidelines (Turner, 2014). Good practice guidance on working with parents with a Learning Disability (Department of Health, 2007), the survey of the human rights of adults with learning disabilities, *A life like any other? (* Joint Committee on Human Rights, 2008) and *valuing people now* (Department of Health, 2009). In particular, *A Life*

Any Other? highlights the ways in which barriers to communication can all too easily result in the human rights of people with learning disabilities being breached, unmet communication needs can restrict access to public services. For example, research commissioned by Mencap showed that, of 215 GPs interviewed, 75% had received no training to help them treat people with a learning disability (Taylor Nelson Sofres, 2004, cited in Mencap, 2004).

Children with LD

Regnard et al. (2007) found more than twenty changes in behaviour in children with learning disability when they encountered distress, and it is likely those who have no verbal language are likely to be more receptive to non-verbal communication (Tuffrey –Wijne & McEnhill, 2008). It is therefore vitally important for professionals working directly with children to engage with them however possible.

Adults with LD

Difficulties with communication have been consistently reported as a barrier in supporting adults with learning disabilities at the end of life .

HEALTH NEEDS

A high People with learning disabilities are likely to need assistance in communication. It has estimated that there are 1. 5 million people in the United Kingdom (UK) with learning disabilities and between 50% and 90% suffer from sensory loss (Eric et al, 2012). Most people with learning disabilities have greater health needs than those with no disabilities. They are also likely to die at a younger age (Mencap, 2007). A number of reports

in recent years have shown that there are failings in accessing services and in providing appropriate treatment for people with learning disabilities(Equal Treatment: Closing the Gap(2006); Death by Indifference (2007)). A life like no other (2007), a report into services for people with a learning disability in England, found that adults with a learning disability are particularly vulnerable to breaches of their human rights in healthcare services.

There is considerable evidence that people with learning disabilities are not receiving the same level of health care as other people. In the UK, there have been many documented examples of secondary health services causing te preventable death of people with learning disabilities, with contributory factors reported to include poor communication, a failure of heath service staff to recognise pain, delays in diagnosis and treatment, a lack of basic care, and the use of Do Not Resuscitate orders (Heslop et al., 2013; Mencap, 2012a). A UK based Confidential Inquiry into premature deaths of people with learning disabilities (Heslop et al., 2013) estimated that 37% of deaths were potentially avoidable.

When people with learning disabilities use health services, staff may have difficulty in meeting their needs because they are unable to communicate effectively with them. A number of reports (Department of Health, 2008; Mencap, 2012; Royal College of Nursing, 2010) highlighted the communication complexity between patient and the staff which have resulted in some cases of deaths and poor quality hospital care.

HISTORY

A report from Mencap (2007), entitles *Death by Indifference,* highlights the poor treatment received by six people with learning disabilities admitted to acute adult and mental health service. This poor treatment ultimately led to these peoples' deaths. The report goes as far to say that institutional discrimination exists within the National Health Service (NHS) towards people who have a learning disability with them getting worse health care than non-disables people. One of the major concerns raised by Mencap was the notion of diagnostic overshadowing. This is neglecting to recognise signs and symptoms of ill health assuming them to be characteristic of a person's learning disability.

Death by indifference

In 2004, Mencap published *Treat me Right,* a report which highlighted the inequities of NHS healthcare provision to people with learning disabilities. This also highlighted that that healthcare professional should not depend on carers or family to communicate with service users with learning disabilities and hospitals must perform their legal duty of care. Healthcare providers are accountable to make sure that these service users have their needs met and this include an easy-read information in place. In 2006, the Disability Right Commission further emphasised concerns that people with learning disabilities were not afforded equitable access to healthcare services and treatment and as a consequence suffered more ill health and were more likely to die. In 2007, Mencap published *Death by Indifference,* a report which told the shocking stories of six people with learning disabilities who suffered potentially avoidable deaths while in various NHS healthcare service by improving communication. A subsequent independent inquiry (Micheal,

2008) and port by the Local Government Ombudsmen and Parliamentary and Health Service Ombudsmen (2009) both confirmed that people with learning disabilities were consistently being placed at risk within primary and secondary healthcare services due to lack of and staff –patient communication

http://www. ombudsman. org. uk/__data/assets/pdf_file/0013/1408/six-lives-part1-overview. pdf

Death by Indifference (Mencap, 2007) attributed the unacceptable standards if care largely to an ignorance or apathy by nurses and other health professionals to understand and listen to their clients with learning disabilities. It is important that the individual is continually consulted about their care regardless of the extent of their learning disability.

74 deaths and counting (2012)????

The report by Mencap, 2012 relayed details of more potentially avoidable deaths of people with learning disabilities within NHS services.

Reasonable adjustments

The failure of public services to make reasonable adjustments regarding communication not only makes it extremely difficult for people with learning disabilities to access services, but it may also breach the Equality Act (2010) and Article 8 pf the European Convention on Human Rights (Micheal, 2008, p24). Poor communication with people who have learning disabilities has consequences that range from the relatively insignificant. For example a service user is given coffee when they would prefer tea.

NON VERBAL COMMUNICATION

Non-verbal communication is as important as verbal in interactions that influence dignity. For example, in a study of older people's transitions (include older people with learning disabilities) between care service, Ellins et al. (2012) noted the following:

' one of the most striking findings was that even the smallest gestures by providers to connect with somebody as a human being, such as a smile or a hug could make

MAKATON

The Makaton language programme is commonly used by people with learning disabilities. Many people with learning disabilities use speech, there are also a range of altranative methods of communication which can be used in conjunction with speech. Sign systems are used widely among people with learning disabilities, either alone or in conjunction with speech. One of the common systems is Makaton(Williams, 2009). However, Hannon (2003) found that no one at the hospital had heard of it. One of the people with a learning disability involved in the study said any of the health care professionals did not understand him.

EASY READ

Some people can benefit from written information being into an easy-read format. This involves the use of simple sentences and language and the use of photos or pictures to support the meaning of the written words. When producing written information for patients, it may be worth considering

accessibility for patients who may be non-verbal or have a learning disability. An easy –to –read, information resource with picture and images and dew words can support people with learning disabilities to have a greater understanding of information and support their decision making.

Talking Mats is ‘ a visual framework that uses picture symbols to help people with a communication difficulty communicate more effectively’ (Murphy and Cameron 2005, p. 3). Using pictures to represent topics and options and a visual scale with people with little or no speech and people who have difficulty in understanding speech can assist them to express their wishes about what will occur in their own life. Service providers, including case managers, can use this tool to help the person with disability consider and discuss a variety of options. The pictures are placed on a mat so that the person with disability can look at the options and choices available and then move them using the visual scale to indicate how they feel about each option. The visual scale might include symbols for liking something, for being unsure and for definitely not liking or wanting something. More complex visual scales can be created, depending on the person’s needs and abilities.

Many people with a variety of disabilities use Talking Mats successfully. Nevertheless, there are some people for whom this system is not suitable. Murphy and Cameron (2005) suggested that to use Talking Mats successfully, the person using the mat must be able to recognise picture symbols and must be able to understand at least two keywords at a time. The person must also have a reliable way of confirming his or her views so that the case manager or service provider can be sure that the placement of pictures on the mat does in fact reflect the person’s views

PERSON-CENTRED APPROCH

Patient- or person- centred approaches to health are increasingly seen as more effi cient as they promote good communication between the clinician and patient but research to support this is lacking (Lewin et al., 2009). The Mental Capacity Act (2005) is based on person- centred principles and gives legal backing to previous guidelines for good practice (Mencap, 2010). It gives responsibility to all healthcare professionals to follow person- centred guidance in addressing issues of choice and consent in healthcare with the learning disabled. The key principles of this include the person being at the centre of any planning and discussion. This does not mean decisions are simply taken in their best interests but ways are sought to actively involve them in decision- making using accessible communication systems when necessary.

McCaffery et al. (2010) argues that although there have been major advances in way to increase patient involvement in health decisions, with the benefits of greater involvement and shared decision-making now widely accepted, there has been little attention given to the development of tools and strategies to support participation of adults with lower literacy, who are members of a group with poor health knowledge, limited involvement in health decisions and poor health outcomes. McCaffery et al. (2010) proposed a framework to consider the different stages of shred health decision making and the tasks and skills required to achieve each stage.

The 6cs

In 2012, the Department of Health carried out a widespread consultation exercise on values for nurses, which were published in ‘ Compassion in Practice: Nursing, Midwifery and Care staff: Our Vision and Strategy’. The vision is based around six values: care, compassion, competence, communication, courage and commitment. The vision aims to embed these values (the 6Cs) in all nursing, midwifery and caregiving settings throughout the NHS and social care to improve care for patients.

Conclusion

In conclusion, the author highlighted the importance and the barriers of communication when working with people with a learning disability, and the some communication methods that a learning disability nurses can use to work effectively with this client group. Good communication is the basis of effective care provision, and the value of developing a relationship and getting to know the individual demonstrates how this enables effective communication to take place. Health care professionals need to develop competencies in identifying individual communication needs, and developing creative ideas for how to overcome these, using a range of tools to aid communication. Person-centred approaches provide a framework to do this on an individual basis, enable and support people to make choices.