

# Unit 5 - Working with people with learning disabilities

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## Outline

This unit will:

- Introduce you to the importance of working in partnership with people with learning disabilities, their families, carers and, or, supporters.
- Outline the importance of assessment and the need to involve others to determine likes and dislikes.
- Emphasise the centrality and importance of good communication strategies when working with people with learning disabilities.
- Explore the importance of understanding consent issues along with the concept of a capacity to give consent.

## Introduction

In 2000 a man with learning disabilities and mental health problems died in a Dundee hospital following spinal injuries that went undiagnosed after a fall in hospital. In the Fatal Accident Inquiry that followed the Sheriff Ian Dunbar made 21 recommendations that included the need for doctors and nurses to pay attention to close family members and record notes of what they say (Dunbar, 2003).

He also said;

“people with learning disabilities or a mental illness should be treated in the same way as other people, not in side rooms... this lessens the chance of the person being out of sight, out of mind” (Dunbar, 2003).

The chief executive of Enable said that a lack of proper training and communication had led to discrimination in treatment of this individual. As we have already said in Unit 1 you as a nurse will come into contact with all kinds of people including those with learning disabilities. This unit will explore with you aspects of working with people with learning disabilities and outline how you may better understand their needs and work effectively and sensitively with them.

## Attitudes and their implications for the delivery of health care for people with learning disabilities

People with learning disabilities and their carers frequently comment about the attitudes and behaviours of health care professionals (Band, 1998; DOH, 2001). In many instances positive attitudes and behaviours are reported, however, negative attitudes and subsequent discriminatory practices are also a feature of care for this group of people. A nation wide study by the Downs Syndrome Association (1999) reported that one in four people with Down's Syndrome had been discriminated against and had not received the health care that they required. They reported incidents where inappropriate and derogatory language had been used by doctors and nurses to refer to children with Down's Syndrome; these included the use of the term 'Mongol'. Some children had been denied access to aids such as glasses and hearing aids that would lead to an improved quality of life whilst other incidents revealed that medical professionals had refused to treat treatable medical conditions on the basis that the person had Down's Syndrome. In a further study that examined the attitudes of adult nurses to people with learning disabilities, it was found those attitudes were more negative than would be expected from a caring population.

The NHS Executive (1998) has stated that staff require learning opportunities to face their fears or prejudices towards people with learning disabilities in order that they may learn to treat them with respect and as equals. It is therefore essential that nurses seek to inform themselves of the needs of people with learning disabilities that emphasise this group as people first. Every opportunity must be taken to meet and join with people with learning disabilities as equals in a range of situations in order that possible stereotypes of this group are challenged.

Essential	Reader Activity Reader 5.1
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Access the web address below for Dunbar's Inquiry and read the sections identified below;

[http://www.scotcourts.gov.uk/opinions/cb12\\_02.html](http://www.scotcourts.gov.uk/opinions/cb12_02.html)

Communication with relatives

Communication between Doctors and Nurses, and then

Discuss your thoughts on his findings in a group you should allow approximately 45 minutes for this exercise.

The recent White Paper - The same as you (Scottish Executive, 2000) has placed great emphasis on:

- being included, better understood and supported by the communities in which they live;
- having information about their needs and the services available, so that they can take part, more fully, in decisions about them;
- being at the centre of decision making and have more control over their care;
- having the same opportunities as others to get a job, develop as individuals, spend time with family and friends, enjoy life and get the extra support they need to do this; and
- being able to use local services wherever possible and special services if they need them. (Scottish Executive, 2000)

This drive towards including people with learning disabilities in mainstream services will present you with significant challenges in your practice it really does not matter whether you are training to become an Adult, Children's, Mental Health Nurse or indeed a Midwife - you will encounter people with learning disabilities. Nor does it matter where you intend to practice whether this in a Hospital, Health Centre, Community - you will encounter people with learning disabilities. The days of segregated services for this group of people are gone.

This does not mean that we no longer need to train professionally qualified nurses in this specialist area. Much of their training is devoted to exploring strategies to help people access ordinary services. If you want further training and, or, education in this area you are strongly advised to make contact with the learning disability lecturers at your institution, they will be able to point you in the direction of appropriately qualified staff who already spend a lot of their time training others.

## Holistic assessment of need

Whilst there are many instances of good practice with regard to the delivery of care to people with learning disabilities, there exists a plethora of evidence to suggest that needs of people with learning disabilities and their carers are not being adequately met in acute care settings. A failure to complete a full and comprehensive assessment of needs may lead to the delivery of not only poor quality but wholly inappropriate care practices that fail to meet the individual needs of a person with learning disabilities. In a study by Fox and Wilson (1999) parents of people with learning disabilities recently admitted to general hospitals recalled the inappropriate use of sedation to control the behaviour of the person with learning disabilities, whilst another recalled the use of a child's play pen in a bid to contain the adult dependent. Lack of communication skills were also noted and exemplified through a man with learning disabilities not being given a meal for three days because he was unable to read or sign the menu card. The authors concluded from this project that had it not been for the presence of carers, the potential consequences for the people with learning disabilities could have been more serious.

Whilst it is acknowledged that there will be times when the presence of a carer is required to support an individual with learning disabilities in a hospital setting, this should not be regarded as being standard practice. As a nurse you need to ensure that a comprehensive assessment is carried out on the needs of the individual with learning disabilities and where possible, a pre-admission visit should be arranged. This would ensure that the nursing team was fully aware of the medical, social, and psychological needs of the person thereby enhancing the delivery of person centred care whilst minimising the demands made on external carers.

Essential	Reader Activity 5.2
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View the video clip entitled 'Just ordinary people', it runs for approximately 19 minutes. Spend some time, firstly to reflect on the messages that this group of people are trying to impart, and then in a small discussion group explore how health care professionals might better assess the needs of this vulnerable group of people.

Recently in the field of learning disabilities a strong emphasis has been placed on making things accessible for people with learning disabilities - thus enabling inclusion, or at least assisting it. One of things that may exclude people is the inaccessibility of health and social care services.

Making things accessible is not just about the physical environment. It is relatively easy to find ramps for easier wheel chair access for people with physical disabilities. However, consider how bewildering some health and social care environments are and this can be frightening. Often there is a heavy reliance on signs and instructions also you will find numerous unwritten rules about how to behave and your role relationship with doctors, nurses and others. Some people with learning disabilities may not understand these and this can contribute to them feeling that services are not made very accessible for them.

This means that you must learn to communicate effectively with people, and some people with learning disabilities face considerable challenges when they communicate with others.

## Communication

Some people with learning disabilities find reading, remembering, and even processing information difficult. We also know from research that some people with learning disabilities, when compared with the general population, have difficulty in recognising different facial expressions and deciphering what they mean. An excellent series of books that you might find useful to refer to when thinking about accessibility are those known as 'beyond words' that have been developed by Professor Sheila Hollins at St George's Hospital London - these can be obtained from the Royal College of Psychiatrists and their address is included in the resource section at the end of this unit.

Also obtainable are a series of documents, leaflets and pamphlets from the Scottish Executive and the Department of Health in London - these can usually be obtained free of charge. Addresses are included in the resource section at the end of this unit. Another important issue for you to consider is communicating with the person with learning disabilities themselves. People with learning disabilities often complain that when they see Doctors and other health care professions they have a tendency to talk to their carer or helper rather than talking to the person themselves. During your Common Foundation Programme why not try and find out about signs and symbols that can be used with people with learning disabilities, even better why not try and learn some very basic signs to help communicate with someone with learning disabilities. Imagine you are working on a busy medical ward and someone with communication challenges and learning disabilities is admitted to your ward and you could sign hello, how are you and don't be afraid - imagine the power you can exercise for someone's health and well being!

Also remember if someone has even greater difficulties in communicating then seek the advice and, or, help from that person's advocate, supporter, friends, relatives, carers, indeed any one from their circles of support. An excellent source of information concerning communication and people with learning disabilities can be found in a chapter written by Rita Ferris-Taylor (2003). Communicating and involving people with learning disabilities and their carers in their health care is often complained about. This is not unique to the delivery of health care as it has also been found in nurse education (Alaszewski et al, 2001).

While the course documentation indicated that users and carers were involved in the development and delivery of the curriculum. Course lecturers indicated that their involvement was more restricted and they were not systematically involved in the development of the educational curriculum or the delivery of courses (Alaszewski et al 2001, 117-118).

Given the centrality of user involvement and working with families in the recent White Paper - The same as you - it is of the utmost importance that you ensure that you pay regular attention to this in your day to day practice.

Essential

Reader Activity 5.3

Spend a few moments reading story 5 from Scott. Join a discussion group and spend some discussing why these nurses were ignoring him.

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## Consent

In Unit 4 you have already considered issues of consent this is explored again in this unit because of the tremendous implications that this issue will have for your future practice when working with this group of people. The recent Adults with Incapacity (Scotland) Act (2000) has emphasised that people with learning disabilities must be given the opportunity, where possible, to take decisions about their own lives. Where this is not possible, an appropriate range of individuals maybe used to support the individual or represent their views as advocates. Recent studies in the consent procedures involving people with learning disabilities would suggest that they are often not consulted about the care that is to be provided to them and that doctors and nurses fail to provide adequate information to them thereby failing to enable informed decision-making. Hart (1999) has found that health professionals failed to communicate effectively with a person with learning disabilities and that this seriously undermined their basic human rights to exercise choice over whether not to consent to a programme of treatment.

When nurses are involved in the care of people with learning disabilities every attempt must be made to involve them in decisions about their care. This may require the use of alternative forms of communication such as pictures and symbols, or the simplification of basic concepts. It will be sometimes be the case that the person with learning disabilities is unable to consent and therefore the nurse must ensure that the best interests of the person are at the forefront of any decision-making. The nurse must ensure that national guidelines relating to consent are followed and that when other individuals, for example parents and, or, carers or a guardian, have to become involved that they are clearly representing that person's best interests.

Essential

Reader Activity 5.4

Using national guidelines on consent for people with learning disabilities list the main factors that should be taken into consideration when assessing someone's ability to give informed consent.

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## Final thoughts

Finding time for people with learning disabilities is also very important. Most people with learning disabilities, by the very nature of their condition, have difficulty absorbing information, especially that involving abstract concepts. When working with people with learning disabilities learn to be as straightforward and concrete as you can, but at all costs avoid being patronising. Avoid using long and complicated explanations for things, and try and deal with things in the present-telling someone with learning disabilities that something will happen in ten minutes may mean absolutely nothing to them. Finally, remember when working with people with learning disabilities that we all share a common humanity; the attributes of patience, kindness and persistence are vital. Ensure that the person is as fully involved as possible in the delivery of their care. This may serve to minimise the distress that may be incurred when faced with new and potentially frightening situations.

## References

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## Resources

British Institute for Learning Disabilities

<http://www.bild.org.uk/links/>

This is an excellent web page that enables you to access a range of other relevant web sites relevant to learning disabilities.

Department of Health

<http://www.doh.gov.uk>

The Royal College of Psychiatrists

17 Belgrave Square

London

SW1X 8PG

<http://www.rcpsych.ac.uk/>

The Scottish Executive

<http://www.scotland.gov.uk/>

For copies of 'The same as you?'

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71 Lothian Road

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EH3 9AZ

(There is a video tape available that describes the key features of the above report)

