

# Unit 4 - Working with people with learning disability

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## Overview

Unit 4 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 in order 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, as well as the concept of a capacity to give consent.
- Highlight the importance of liaison learning disability nurses in mainstream services.



## Introduction

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

The Fatal Accident Inquiry also stated;

*'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.'*

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



## Attitudes and their implications for the delivery of healthcare to people with learning disability

People with learning disabilities (and their carers) frequently comment on the attitudes and behaviours displayed by healthcare 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 nationwide study by the Down's Syndrome Association (1999) reported that one in four people with Down's Syndrome had been discriminated against and thus not received the healthcare that they required. The Association 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 patient had Down's Syndrome. In a further study, which examined the attitudes of adult nurses to people with learning disability, it was found those attitudes were more negative than would be expected from a caring group.

The NHS Executive (1998) has stated that staff should have learning opportunities in order to face their fears or prejudices towards people with learning disabilities, so 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 and emphasise to others that this group are '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.

### *Reflection point 4.1*

*When you have the opportunity, access the web address below for Dunbar's Inquiry and read the suggested sections;*

[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.*

*Reflect upon on his findings. You may wish to discuss them with a colleague.*

The recent White Paper, *The same as you?* (Scottish Executive, 2000), has placed great emphasis on people with learning disabilities, stating that they should:

- Be better understood, included and supported by the communities in which they live:
- Have information about their needs and the services available, so that they can more fully participate in decisions that concern them:
- Be at the centre of decision-making and have more control over their care:
- Have the same opportunities as others to develop as individuals, spend time with family and friends, gain employment and enjoy life, as well as being given the extra support they need to do this: and
- Be 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. Irrespective of whether you work as an Adult, Children's, Mental Health Nurse or indeed a Midwife; you will encounter people with learning disabilities. Nor does it matter where you practice, be it in a hospital, health centre or in the community: you will encounter people with learning disabilities. The days of segregated services for this group of people are gone.

This does not mean, however, 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 your local community learning disability team. The team will be able to point you in the direction of appropriately qualified staff with extensive experience in training others.

Some services are responding to this challenge by using liaison nurses with a specialist back ground in learning disability. A recent article by Foster (2005) has examined the current literature on the effectiveness of the liaison nurse role and has sought evidence to support the development of learning disability liaison roles within acute hospital settings. Whereas this model has been used for some time in psychiatry, it is relatively new to learning disability, therefore much more work is required in this area before we can say with any certainty as to whether this is a helpful development. However, it is difficult to imagine how such appointments can be anything other than an improvement on the current status.

## Holistic assessment of need

Whilst there are many instances of good practice in the delivery of care to people with learning disabilities, there exists a considerable body of evidence to suggest that the 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 disability.

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 a learning disability, 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 by the instance of a man with learning disabilities who was denied food 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 consequences for the people with learning disability 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 a learning disability in the 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. 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 and minimising the demands made on external carers.

### *Reflection point 4.2*

*View the video clip entitled 'Just ordinary people,' which runs for approximately 19 minutes. Firstly, reflect on the messages that this group of people are trying to impart. Secondly, in a small discussion group, explore how healthcare professionals might better assess the needs of this vulnerable group of people.*

Recently in the field of learning disability, a strong emphasis has been placed on improving accessibility for people with learning disabilities, enabling or at least assisting inclusion. One form of exclusion is the inaccessibility of health and social care services.



Figure 4.1: an example of the use of pictures to make text more accessible to people with learning disabilities, *from Promoting Health, Supporting Inclusion* (2002) [Refer to <http://www.scotland.gov.uk/library5/health/phsin-00.asp>].

Improving accessibility is not just a matter of changing the physical environment. It is relatively easy to find ramps for easier wheelchair access for people with physical disabilities. In contrast, consider how bewildering and frightening some health and social care environments can be. There is often a heavy reliance on signs and instructions. There are numerous unwritten social rules about behaviour and role relationships with doctors, nurses and others. Some people with learning disabilities may not understand these modes of interaction, and this can prompt a feeling of isolation and exclusion from healthcare services.

A number of people with learning disabilities face considerable challenges when they communicate with others. This means that you must learn to communicate effectively with a diverse cross section of individuals and groups.

## Communication

Before reading this section, refer back to the section in Unit 1 which addresses how we determine whether someone has a learning disability. Do not assume that because someone is slow to understand you that the person has a learning disability. Seek other indications; such as whether they have a supporter, experience difficulty understanding written forms of communication or have problems in processing a lot of information at once. You may note from their details that they live in some kind of supported living scheme and/or attended a special school. Consider as many factors as possible; not in order to attach a simplistic or dismissive label, but to ensure that you can tailor the health care you provide and that it is of the same standard and quality as that you provide for any other citizen with whom you may come into contact.

It is widely recognised that some people with a learning disability find reading, remembering and even processing information difficult. Research has also indicated that some people with learning disabilities, when compared with the general population, have difficulty in recognising and interpreting differing facial expressions. There is an excellent series of books that you might find useful when thinking about accessibility known as '*beyond words*,' developed by Professor Sheila Hollins at St George's Hospital London. These can be obtained from the Royal College of Psychiatrists. Further information is provided in the Resources section at the end of this unit.

Also available are a series of documents, leaflets and pamphlets from both the Scottish Executive and the Department of Health in England, which can usually be obtained free of charge. Again, relevant addresses can be found in the Resources section at the end of this unit.

Another important issue for consideration is communicating with the person with learning disabilities themselves. People with a learning disability often complain that doctors (and other healthcare professionals) tend to talk to their carer or helper, rather than talking to them directly. Finding time for people with learning disabilities is extremely important. Most people with learning disabilities 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, whilst always taking care to steer clear of a patronising tone or manner. Avoid using long or complicated explanations and try to communicate in the present tense: telling someone with learning disabilities that something will happen in ten minutes may mean nothing to them.

Try to find out about signs and symbols that can be used to improve communication with people with learning disabilities. Alternatively, endeavour to learn some very basic signs in order to assist your contact with someone with learning disabilities. Consider the scenario of working in a busy medical ward where someone with communication challenges and learning disabilities has been admitted. If you could sign 'hello' and ask how they are without anxiety or hesitation, this would allow you to greatly assist in the improvement of their health and wellbeing. If someone has even greater difficulties in communicating; seek the advice and/or help of that person's advocate, supporter, friends, relatives, carers, or anyone else from their circles of support.

Another excellent source of information on communicating with people with learning disabilities can be found in Rita Ferris-Taylor's chapter 'Communication' (2003).

The Lothian Primary Care Roodlands symbol project, using the Bonnington system, is just one Scottish example of how healthcare services are attempting to use symbols as a way of making their services more accessible to people with communication difficulties. You might wish to read about this project by visiting the web site listed below:

<http://www.modemoperandi.co.uk/symbols/Images/Newsletter%20March%202004.pdf>

The lack of communication with and involvement of people with learning disabilities (and their carers, families etc) directly in their own healthcare is a common area for complaint. This is not unique to the delivery of healthcare, 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 (nurses') 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 pp117-118)

The recent White Paper, *The same as you?*, makes user involvement and working with families central to the delivery of services therefore is of the utmost importance that you ensure your constant attention to this in your daily practice.

## Consent

Unit 3 has already examined the concept of consent. However, because of the tremendous implications that this issue will have for your future practice, it is worth exploring the concept in more detail.

The recent Adults with Incapacity (Scotland) Act (2000) has emphasised that people with learning disabilities must be given the opportunity, where possible, to make decisions about their own lives. Where this is not possible, an appropriate range of individuals may be used to support the individual or advocate their views. Recent studies into consent procedures involving people with learning disabilities suggest that they are frequently not consulted about the care that is to be delivered to them, and that doctors and nurses often fail to provide adequate information, thus preventing informed decision-making on the part of the patient. 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 in consenting (or otherwise) to a programme of treatment.

When nurses are involved in the care of a person with learning disabilities, they must make every attempt to involve the person in decisions about his or her care. This may require the use of alternative forms of communication, such as pictures and symbols, or the simplification of basic concepts. It will 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 also 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.

*Reflection point 4.3*

*Reflect on national guidelines on consent for people with learning disabilities. List the main factors to be considered when assessing someone's ability to give informed consent.*



## Conclusion

It is worth remembering when working with people with learning disabilities that we share a common humanity. The attributes of patience, kindness and persistence are vital. Nurses are very well placed to offer these, to offer support to people with a learning disability and to ensure that the person is as involved as possible in the delivery and management of their care. Nurses are also in a position to minimise the distress that may be incurred when people with learning disabilities are faced with new and potentially frightening situations, particularly in hospitals or clinics. By taking the time to understand and actively communicate, they can ensure that people with a learning disability are included and have access to the same high quality healthcare that the general population receives.



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## Resources

### **The Scottish Executive**

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

For copies of 'The same as you?'  
The Stationery Office Bookshop  
71 Lothian Road  
Edinburgh EH3 9AZ

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

### **Glasgow City Council**

<http://www.ixseed.com/>

This is an example of how useful city council web page link can be. You may wish to make a web search to find useful resource in your area for your own resource section in this learning resource.

### **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.dh.gov.uk/>

The Royal College of Psychiatrists  
17 Belgrave Square  
London SW1X 8PG

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

