

# Unit 4 - The importance of inclusion and health care for people with learning disabilities

Andy Wilson  
Lecturer  
Thames Valley University  
London

## Outline

This unit will:

- Examine the concept of inclusion for people with learning disabilities.
- Identify barriers that serve to exclude people with learning disabilities from parts of mainstream society.
- Consider pre-requisite skills, knowledge and opportunities needed to function independently.
- Identify actions which may promote inclusion.
- Identify additional health needs for some people with learning disabilities.
- Look at access to health services within the social inclusion agenda.

## Introduction

All people have fundamental rights and this also includes those with learning disabilities. In response to this the Scottish Executive (2000) has identified social inclusion as a core issue to consider when looking at improving opportunities for people with learning disabilities. This derives from the recognition that people with disabilities have the same human rights as everyone.

When introducing the strategy for services which support people with learning disabilities in England, the Department of Health (2001) has described inclusion as:

*'Being part of the mainstream is something most of us take for granted. We go to work, look after our families, visit our GP, use transport, go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.'* (p24)

Expectations of equality and inclusion are enshrined in law. The Human Rights Act 2000 has declared fundamental rights of individuals purely as a consequence of citizenship (Scottish Executive, 2002). This is of particular interest relating to experiences of people with learning disabilities who have been marginalised in decision making about their own lives. The Disability Discrimination Act (1995) has;

*'placed an onus on providers of goods and services to make reasonable adjustments for disabled people.* (Ferris-Taylor, 2003, p257)

This clearly impacts upon societal mechanisms which serve to exclude (or include) people with learning disabilities. Later in this unit you will consider specific examples relating to a particular social structure which will play a major part of your intended career; the health services.

<i>Essential</i>	<i>Reader Activity 4.1</i>
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*Think of something that you need help to do (such as buying a house or learning a skill).*

*Reflect on the following:*

- *What help do you need and who do you get that help from?*
- *How do you feel when you are getting the help?*
- *How do you view the people who are helping you?*

*Now from the narratives identify three ways that some of the contributors have gained help to achieve something. Within a small group compare the ways of helping that you have identified and reflect on being dependant on somebody or something else to achieve a goal.*

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It may be difficult to fully appreciate the effects of exclusion from our relative point of comfort where non-participation is usually out of choice. However, an inclusive approach recognises that formal and informal elements of the wider society need to change or adapt to enable excluded people to use opportunities and services (Jenkins et al, 2003).

*Essential*

*Reader Activity 4.2*

*Think of an activity that you enjoy or value highly and consider the following questions.*

- *How did you find out about this activity?*
- *How were you introduced to the activity?*
- *How do you get there?*
- *How much does it cost?*

*Within a small group compare your activity answer to the questions above with others and identify possible barriers which may prevent a person with learning disabilities from doing the same.*

## Healthcare for people with learning disabilities

People with learning disabilities tend to have greater health needs than the rest of the population yet seem to fare worse in the health services they receive. (Department of Health, 2001 p59) Some examples of these greater health needs are:

### Mental illness

It is now widely accepted that the prevalence rates for mental ill health amongst people with learning disabilities are greater than that of the general population. Disorders include; schizophrenia, anxiety and depression. Children with learning disabilities are more likely to experience anxiety disorders. Finally, challenging behaviours, aggression, destruction, self-injury are all more prevalent in this group of people when compared with the general population.

### Epilepsy

Prevalence rates of epilepsy amongst people with learning disabilities have been variously reported and the British Institute for Learning Disabilities and the British Epilepsy Association have estimated that are some 200,000 people with learning disabilities severely affected by this disorder. (BEA/BILD 2001)

### Physical and sensory disabilities

It is the case that people with learning disabilities are much more likely to have a visual impairment than that of the general population. Many more will also have a hearing impairment and people with Down's syndrome are particularly at risk. It is known that people with learning disabilities are frequently not assessed for visual or hearing difficulties because staff often think that the difficulties are a result of their learning disability and this sometimes results in them not receiving aids for hearing and, or, sight.

### Complex health needs in people with severe and profound disabilities

People with learning disabilities are much more likely to be either underweight or obese when compared with the general population. It is thought that only a small percentage of people with learning disabilities eat a balanced diet, with an insufficient intake of fruit and vegetables and a lack of knowledge and choice about healthy eating. A significant number of people with learning disabilities engage in levels of physical activity below the minimum recommended by the Department of Health, also when compared with the general population. Obviously those with severe and profound learning disabilities are particularly at risk if they have physical disabilities and, or impairments as well.

### Chronic dental disease from poor oral health

It has been estimated that a high percentage of adults with learning disabilities and particularly those with Down's syndrome have unhealthy teeth and gums. It is known that adults with learning disabilities who live with their families are more likely to have untreated tooth decay along with poorer oral hygiene. People with learning disabilities tend to receive their dental care from community dental services although the frequency of attendance is not as regular as that of the general population.

Those students with an interest in this are directed to an excellent paper that has been constructed by Greig (2003), in this he collates a significant volume of research that demonstrates the health challenges that face many people with learning disabilities.

*Essential*

*Reader Activity 4.3*

*Imagine someone who can not communicate in any conventional sense. How do you think this might impact on their life if the examples above were not detected or treated?*

Once a day (Department of Health, 1999) describes some of the difficulties that some people with learning disabilities might face in gaining access to health services. Some of them are listed below with suggestions for you to consider on your next placement in a busy hospital ward or a Health Centre:

- Poor physical access to buildings.
- How easy is it for someone with limited mobility to get to their destination?
- How complicated is the journey for someone who uses a wheelchair?
- Fear of doctors.

Think back to the health service of 25 years ago or ask someone what it was like (this may be the abiding memory of someone with learning disabilities), or refer to Unit 3.

- How were health professionals dressed?
- What signified status/rank?
- How was the clinical environment arranged?
- How might a person with a learning disability view all of this?

How different is it now?

- Long waits to see health professionals.
- Do health professionals work to time limits for consultations?
- How long does it take to find out information relating to, say, a chest pain and how long does it take to find out the same information using symbols?
- What could you say to someone with learning disabilities to persuade them that today's Health Service is more user friendly for them? How could you show them this in tangible terms?

Unfortunately there is still considerable ignorance of the possible needs of people with learning disabilities. Think back to your last placement in a District General Hospital and ask yourselves the following questions.

- How was information made available for people who may not be able to read?
- How could they be sure that people are able to give informed consent?
- Did basic information records include how a patient communicates?

- How could they show somebody that a MRI scan was harmless?
- Did clinical staff know how to contact the local Community Learning Disabilities Team (CLDT)?
- Could clinical staff describe the services offered by a CLDT?

*Essential*

*Reader Activity 4.4*

*Think of the stages involved in seeing your GP.*

- *What are the skills required? (Such as being able to use a telephone.)*
- *What understanding may be helpful? (Such as possible signs and symptoms of illness.)*
- *Identify three situations from the narratives where contributors have had negative experiences with health services.*

*Within a small group compare your answers.*



The Scottish Executive (2002) has given a commitment on behalf of nurses and midwives to provide an inclusive and co-ordinated approach in providing nursing care. This recognises the need to consider people with learning disabilities throughout the health services and across all relevant agencies.

## Informed consent

The principle of seeking informed consent is central to healthcare ideologies and that is why we are looking at informed consent in this Unit and also in Unit 5. It holds the individual central to decision-making whilst demanding fairness and impartiality from those who might exercise influence (Eldridge, 2003). A dilemma many professionals face when considering consent and people with learning disabilities is how to preserve the rights of the individual, demonstrate the individual's capacity to understand choices and their implications and to arrive at an outcome which is legally and ethically sound (Hart, 2001). A legislative framework does exist under the Adults with Incapacity (Scotland) Act (2000). This provides;

*'flexible options for dealing with situations where someone might need help with decision-making.'* (Enable, 2002).

To illustrate some of the potential issues it may be helpful to consider the following questions either as an exercise or in your next practice placement:

- How do you define a treatment?
- What different methods can be used to explain a treatment?
- How can you tell that someone has understood your explanation?
- How can you tell that someone understands different treatment options and their various implications?
- How do you know that someone is capable of making decisions?
- In what ways can someone indicate a choice/consent?
- What happens if someone makes a decision that you disagree with?
- What if you think that someone is not able to give consent for a particular treatment but you think it is in their interests to have it?
- How can you demonstrate that you have considered all of the previous questions?

*Essential*

*Reader Activity 4.5*

*Watch the video "Just Ordinary People". (Available on CD-Rom)*

*Based on the comments made in the video draw up a charter of expectations for people with learning disabilities who will use health services. How might you present this charter to make it understood by as many people as possible?*

## References

- British Epilepsy Association (2001) Epilepsy and learning difficulties. [www.epilepsy.org.uk/info/](http://www.epilepsy.org.uk/info/)
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- Scottish Executive (2000) The same as you? A review of services for people with learning disabilities. Edinburgh: Scottish Executive.
- Scottish Executive (2002) Promoting health, supporting inclusion. Edinburgh: Stationery Office.

## Resources

Harris, J. and Simpson, N. (1998) Your good health. Kidderminster: BILD.

A set of 12 illustrated booklets to inform people with a learning disability about health issues and explain how to get help for a variety of health issues. Written by health professionals working with groups of people with learning disabilities, these accessible materials will increase awareness and help people with a learning disability get appropriate healthcare.

Health Education Authority (1995) Health related resources for people with learning disabilities. London: Health Education Authority.

This is an excellent resource that covers a wide range of health care publications, games, exercises. The content includes amongst others; advocacy, arts and leisure, bereavement, communication, consultation, hygiene, nutrition, safety, play and sexuality.

Hogg, J.; Northfield, J. and Turnbull, J. (2001) Cancer and people with learning disabilities: the evidence from published studies and experiences from cancer services. Kidderminster: BILD.

This resource examines ways in which cancer services and programmes of treatment can be made more accessible for people with learning disabilities.

Prasher, V. and Smith, B. (2002) Down Syndrome and health care. BILD: Kidderminster.

This book provides practical information for staff, families and other carers on the important health issues for adults with Down syndrome.

Todd, K.; Turk, V. and Christmas, M. (2003) Resource pack for carers of adults with down syndrome and dementia. Kidderminster: BILD.

This is a new resource designed to help family carers, staff and other professionals supporting people with Down syndrome with practical day-to-day issues.

McIntosh, P. and O'Neil, J. (1999) Food, fitness, fun! Brighton: Pavillion.

This activity-based training pack enables health and social care professionals to offer service users a varied and interesting approach to weight management and nutrition. There are eight flexible sessions which can be used in a variety of formats. This will be of particular interest to; direct care staff, primary healthcare staff working with groups or individuals, day centres, care homes, schools and community learning disability teams.

Caldwell, P. (1998) You don't know what it`s like. Brighton: Pavillion.

This package illustrates methods of communication and helps readers and staff to set aside their own sense of what 'reality' is. This enables them to enter the worlds of others who are struggling to interpret and respond to sets of sensory perceptions different to those we experience in our 'normal' world. The key approach in this book is to work creatively, based on an understanding of what a person is experiencing and what it is their behaviour is trying to tell us. This will be of particular interest to; carers who support people with autistic spectrum disorder and behavioural challenges.

Cooper, E. (2000) Becoming a woman. Brighton: Pavillion.

This is a teaching pack to help young women with learning disabilities learn about the management of menstruation.

Dodd, K. and Gathard, J. (1999) Feeling poorly: developing skills to communicate pain and symptoms of illness. Brighton: Pavillion.

This is a teaching pack to help young women with learning disabilities learn about the management of menstruation.

Noonan Walsh, P. and Heller, T. (2002) Health of women with intellectual disabilities. London: Blackwell Publishing.

This text presents a concise yet comprehensive evidence base concerning issues of health amongst women with learning disabilities. Using case studies this text considers the social, economic and political contexts of health promotion. Coverage includes sexuality, prevention of abuse and mental health. This book examines health across the lifespan.

British Institute for Learning Disabilities

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

Use this web site for excellent resource links concerning health care and inclusion.