

Getting it right
together

NHS Education for
Scotland

Copyright © NHS Education for Scotland 2004

Permission is granted to any individual or institution to use, copy or redistribute these materials whole or in part, so long as it is not sold for profit and provided that the above copyright notice and this permission notice appear in all other copies.

Where any part of these materials is included in another document, due acknowledgement is required.

However, the *Just Ordinary People* video may not be reproduced and cannot be used in any way other than as part of these learning materials.

For any further information regarding this material please contact;



NHS Education for Scotland

2nd Floor
Hanover Buildings
66 Rose Street
Edinburgh
EH2 2NN

Tel: 0131 225 4365
Fax: 0131 220 8650
www.nes.scot.nhs.uk

Contents

Introduction and guidance notes for students	i
Introduction and guidance notes for lecturers and facilitators	iii
Unit 1 - The nature of learning disabilities	1
Outline	1
Introduction	2
How do we decide whether someone has learning disabilities?	4
Social competence	8
Definitions of learning disability	10
Incidence and prevalence of learning disability	13
Introducing the narratives	16
Conclusion	17
References	18
Further reading	20
Resources	21
Unit 2 - Causes and manifestations of learning disabilities	23
Outline	23
Introduction	24
Importance of diagnosis	25
Classification of learning disabilities	26
Genetic causes of learning disabilities	27
Chromosomal abnormalities	29
Environmental factors	35
Conclusion	37
References	38
Further reading	39
Resources	40
Unit 3 - A history of learning disabilities	43
Outline	43
Introduction	44
People with learning disabilities in Ancient Greece and Early Modern Britain	45
Eugenics and the problem of the feeble-minded	48
Life in an institution	52
The introduction of the concept of community care and the principles of normalisation	55
Conclusion	58
References	59
Recommended reading	62
Plates	63
Resources	64

Unit 4 - The importance of inclusion and health care for people with learning disabilities	65
Outline	65
Introduction	66
Healthcare for people with learning disabilities	69
Informed consent	74
References	76
Resources	77
Unit 5 -Working with people with learning disabilities	79
Outline	79
Introduction	80
Attitudes and their implications for the delivery of health care for people with learning disabilities	81
Holistic assessment of need	83
Communication	85
Consent	86
Final thoughts	87
References	88
Resources	89
The narratives	91
Resources	103

These materials are currently undergoing an evaluation. If you would like to give any comments on how you have used the materials, please log onto www.nes.scot.nhs.uk and give your feedback in the Promoting Health Supporting Inclusion section of the Forums.

Introduction and guidance notes for students

This resource - *Getting it right together* on learning disabilities has been written for all pre-registration nursing students in Scotland. It comprises five units of study that will support something in the order of 12 to 15 hours of directed and, or, facilitated learning on a range of issues that relate to learning disabilities. The learning material has a number of intended learning outcomes and these are that you should, at the end of studying this material be able to:

- Recall what learning disabilities means; how it is caused and how it may manifest itself.
- Identify the number of people with learning disabilities and appreciate how this will impact on your practice as a health care professional.
- Appreciate the historical significance of how people with learning disabilities have been (mis)understood in the past and how this impacts on how they are understood in the context of current health service provision.
- Appreciate the concept of inclusion and identify barriers to people with learning disabilities that serve to exclude them from mainstream services.
- Articulate the additional health challenges that some people with learning disabilities present with and appreciate the challenges this will make upon mainstream health services in meeting those health needs.
- Appreciate the importance of working in partnership with people with learning disabilities using advanced communication skills and appreciating the importance of the concept of capacity to give informed consent recognising the impact this may on your practice as a health care professional.

No matter which branch of nursing you intend to pursue you will inevitably encounter people from diverse backgrounds. Some will have mental health problems, some will be elder members of our communities, some will be children, some women, and some men, some from different ethnic minority groups and some will have learning disabilities. We know from a lot of research people with learning disabilities do not fare very well in mainstream health services (See Units 4 and Unit 5). You, as a nurse have a duty and a responsibility to care for all people and treat each person as a valued citizen, and that is why we have developed this learning resource. We believe that it

will offer all of you an opportunity to reflect on how important you are in ensuring the health and well-being of this much devalued group of people.

Your lecturer or facilitator will discuss with you how you might best use this resource to obtain optimum learning. We advise that you engage in some individual study and supplement this with group discussions. Throughout the units you will find a number of essential and optional reader activities. Those that are marked essential should be undertaken by you and you should discuss your findings with your lecturer/facilitator. Those that are optional need only be undertaken if you are interested in learning more deeply about the subject material; it is likely that these will be undertaken by students who may be progressing to the learning disability branch of nursing. However you use this resource we hope that you enjoy the content and find the material interesting. Equally we hope that in some small way it will help prepare you to work with people with learning disabilities and engender in you a sense of valuing their citizenship so as to help them enjoy good health.

Bob Gates, Professor of Learning Disabilities, Thames Valley University -
London, Wellington Street, Slough, Berkshire, SL1 1YG.

October 2003

Introduction and guidance notes lecturers and facilitators

This resource - *Getting it right together* on learning disabilities has been written for all pre-registration nursing students in Scotland. It comprises of five units of study that will support something in the order of 12 to 15 hours of directed and, or, facilitated learning on a range of issues that relate to learning disabilities. There is also a series of narratives that relate to the units and learning activities and an extensive range of resources that you or your students might like to explore. The learning material has a number of intended learning outcomes and these are that each student should, at the end of studying be able to:

- Recall what learning disabilities means, how it is caused and how it may manifest itself.
- Identify the number of people with learning disabilities and appreciate how this will impact on professional health care practice.
- Appreciate the historical significance of how people with learning disabilities have been (mis)understood in the past and how this impacts on how they are understood in the context of current health service provision.
- Appreciate the concept of inclusion and identify barriers to people with learning disabilities that serve to exclude them from mainstream services.
- Articulate the additional health challenges that some people with learning disabilities present with and appreciate the challenges this will make upon mainstream health services in meeting those health needs.
- Appreciate the importance of working in partnership with people with learning disabilities using advanced communication skills and the importance of the concept of capacity to give informed consent while recognising how this may impact on professional healthcare practice.

No matter which branch of nursing your students intend to pursue they will inevitably encounter people from diverse backgrounds. With the final closure of the long-stay learning disability hospitals in Scotland it is inevitable that your students will come into contact with people with learning disabilities. We now have substantial body of research that tells us that people with learning disabilities do not fare very well in the mainstream health services (See Unit 4 and Unit 5). Your students have a duty and a responsibility to care for all people and treat each person as a valued citizen, and you have a duty and responsibility to ensure that they are adequately prepared for the

diversity of practice that they will encounter. That is why we have developed this learning resource. We believe that it will offer your students the opportunity to reflect on how important they are in ensuring the health and well-being of this much devalued group of people.

This resource has been written with you in mind as well as your students and people with learning disabilities. We believe that this resource can be used very flexibly, you may wish to use the material in very directive ways alternatively you may wish to get your students to undertake individual study and supplement this with group discussions. We recommend that for the narratives of Callum's stories that you should form a number of small discussion groups. The narratives should be read by all students. You should allow at least an hour for each discussion group and contain the size of the group to no more than 20 people - this way you can make sure that everyone engages with the discussion and the topics being discussed. Make sure that everyone reads Callum's stories and then consider using some, if not all of the questions listed below. You can ask the group to divide into half and provide flip charts so they can feed back to the larger group. All of their discussions should be facilitated so they relate them to the recommendations of '*Promoting health, supporting inclusion*'; therefore the following questions could be used in discussions and tutorials:

Recommendation 4 - '...NHS Boards should ensure there are Community Learning Disability Nurses based in and working collaboratively as integrated members of primary care teams.'

How could a nurse working in this context have made a difference to Callum and his family?

Recommendation 5 - 'NHS Boards should ensure that all people with learning disabilities - particularly those with complex needs - have regular assessments of their health needs and plans of care developed as part of their Personal Life Plan... '

How would you go about assessing Callum's health needs? How would you communicate with him? Who would you involve in the process? What difference might it make to his health and quality of life?

Recommendation 7 - 'NHS Boards should develop and ensure there is access to a Learning Disability Liaison Nursing service within acute general, paediatric and psychiatric hospitals to support children and adults with learning disabilities and their families and care workers throughout the care journey.'

What would have been the role of such a nurse when Callum was admitted to hospital? What impact might the nurse have had on the quality of his care?

Recommendation 8 - 'NHS Boards should ensure there are specialist health services in place to respond appropriately to people with learning disabilities who have complex health needs.....'

Do you think Callum would benefit from specialist health services? If so what services and how would they relate to mainstream healthcare?

Recommendation 9 - 'All people with learning disability who have complex health care needs, wherever they live, should have a named Children's or Learning Disability Nurse as a member of a specialist team to liaise, co-ordinate and link with all tiers of health care and other care systems....'

What skills and experience would make a nurse suitable for this role?

Recommendation 11 - 'NHS Boards and Local Authorities should ensure that Children's and Learning Disability Nurses are available to plan, co-ordinate care and provide practical 'hands-on' nursing care and support across the full range of settings where children and adults with complex health needs receive care. The need for some may be life long....'

What 'practical hands-on nursing care and support' at home and in community settings could make a difference to people with complex needs and their families?

Callum has uncontrolled epilepsy: what other complex needs might need this level of support from a trained nurse rather than from a social care worker? What special nursing skills and knowledge might be involved?

Recommendations 16-20 - Nurse Education

Clearly the new agenda of inclusion and the pursuance of equity in health care represent a significant challenge not only for health services but also us as educators of future practitioners within health care settings. As an alternative to the questions above concerning Callum you may prefer to choose a more generic group task such as the one that follows.

Imagine yourself as a busy nurse on an acute general medical or surgical ward. A young man with profound and multiple learning disabilities is admitted to the ward. You have not met him before and have had no previous experience of working with people with complex needs and no conventional communication skills. What would your feelings be? What would be the difficulties for you as a nurse? How would you react?

You might like to consider yourself how we can best prepare our students to work with people with learning disabilities. You may care to reflect on the following question. This is an exercise that can be undertaken in parallel with your students.

How do you think schools of nursing can best prepare student nurses, both specialist and non-specialist, for working with people with profound and multiple learning disabilities and their families?

Learning activities

Throughout the units your students will find a number of essential and optional reader activities. Those that are marked essential should be undertaken by them and you should check with them their understanding of the activity also any discussions/findings/learning they have made in small group tutorials.

Those that are optional need only be undertaken by those students who are interested in learning more deeply about the subject material; it is likely that these may well be undertaken by students who are progressing to the learning disability branch of nursing. However you and your students use this resource we hope that they enjoy the content and find the material interesting.

Equally we hope that in some small way it will help you prepare your students to work with people with learning disabilities and engender in them a sense of valuing the citizenship of those people who come from diverse backgrounds.

Bob Gates, Professor of Learning Disabilities, Thames Valley University -
London, Wellington Street, Slough, Berkshire, SL1 1YG.

October 2003

Unit 1 - The nature of learning disabilities

Bob Gates
Professor of Learning Disabilities
Thames Valley University
London

Outline

This Unit will:

- Explore why it is difficult to define learning disability because it means many things to many people.
- Identify that learning disability comprises significant sub-average intellectual functioning that coexists with below average social functioning and that this manifests itself before the age of 18.
- Identify that over time intellectual ability, legislative definitions, and social competence have all been used as indicative for establishing whether someone has learning disabilities.
- Confirm that 3-4 persons per 1,000 of the general population will have severe learning disabilities and 25-30 persons per 1,000 of the general population will have mild learning disabilities.
- Specifically identify the number of people with learning disabilities in Scotland.

Introduction

The first part of this unit explores how we decide whether someone has learning disabilities, and to this extent it will help us to define what learning disability means. This is sometimes difficult because, as will be explained later in this unit, the term *learning disability* means many different things to many different people not only in Scotland but internationally and also between different health care professionals; other disciplines and service agencies. Following this we will explore some of the important issues surrounding the incidence and prevalence of learning disabilities and relate this particularly to Scotland, but it will be seen that this is an issue of universality. The final part of this unit will require you to read a number of narratives and undertake some essential learning activities. For those students interested in this field a number of optional activities will also be provided. The narratives originate from Callum (and his mum), Marie, Shona, Scott, Alan and Purdie; these names have been changed to respect confidentiality. These narratives are included to bring to this unit a sense of authenticity about the lives of people with learning disabilities and the experiences of their families in Scotland.

The review of services for people with learning disabilities, in Scotland - '*The same as you?*' has identified that people with learning disabilities should:

- Be included, better understood and supported by the communities in which they live.
- Have information about their needs and the services available, so that they can take part, more fully, in decisions about them.
- Be at the centre of decision-making and have more control over their care.
- Have 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.
- Be able to use local services wherever possible and special services if they need them. (Scottish Executive, 2000).

In comparison, the new White Paper in England - '*Valuing People*' (DoH, 2001) is based upon the principles of rights, independence, choice and inclusion. Achieving these principles for people with learning disabilities and their families is, in part, dependent upon a knowledgeable and skilled work force.

This first unit articulates a knowledge and value base that promotes people with learning disabilities as equal citizens and lays a foundation for the remainder of the units that follow.

As specialist services for people with learning disabilities in Scotland become scarcer it will become increasingly important that people with learning disabilities do not become a forgotten people, as has been the case in the past (see Unit 3). It is vitally important that those who work with this heterogeneous group of people truly understand the nature of learning disabilities.

How do we decide whether someone has learning disabilities?

This next section considers the following criteria as way of deciding whether someone has learning disabilities;

- intellectual ability
- legislative definitions of learning disability
- social competence.

Intellectual ability

Some would argue that intelligence is an obvious criterion upon which to judge whether someone has a learning disability. An immediate problem with this is being able to decide just what intelligence is. Within this unit we do not have the time or space to explore this issue in any great depth, but it is assumed that intelligence is something to do with the ability to solve problems and that this ability, or the absence of it, can be measured.

One way of measuring intelligence is by using intelligence tests. These tests have been used since the turn of the century; they serve the purpose of enabling a comparison of the intellectual ability of one individual to complete a range of standardised tests, against a large representative sample of the general population. The sample that an individual is compared with will be of similar chronological age. The score that an individual attains, on completion of tests, can then be converted into a percentile, providing information as to how this individual compares with others in the general population. Normally the percentile is converted to an intelligence quotient (IQ) that has been, and still is, used as the principle means for identifying learning disability. The intelligence test seeks to compare the mental age of an individual against their chronological age.

This is achieved by using the following formula:

$$\frac{\text{Mental age}}{\text{Chronological age}} \times 100 = \text{IQ}$$

In the formula, chronological age refers to the actual age of an individual and mental age refers to the developmental stage reached when compared to others of a similar age. If one divides the mental age by the chronological age one will derive a number and if this number is then multiplied by 100 one has arrived at a calculated IQ.

Clearly, given the nature of this formula, if it was continued to be used throughout an individual's life then IQ would progressively diminish, therefore

the formula is only of use until the chronological age of around 18 years. Given that intelligence is present (some would say not) in the population, and is evenly distributed, it is possible to measure how far an individual moves away from what constitutes 'normal'.

The World Health Organisation have organised the degree of disability (retardation) according to how far an individual moves away from the normal distribution of IQ for the general population, as has been discussed previously. Using this system, an individual who consistently scores 2 standard deviations below the 'norm' of an IQ test, that is - a measured IQ of less than 70, would be said to have learning disabilities. Those with an IQ of between 71 and 84 are said to be on the borderline of intellectual functioning whereas those within the range 50-69 are generally identified as having mild learning disabilities (mild mental retardation).

Moderate learning disabilities (moderate mental retardation) is identified when the IQ is in the range of 35-49. Severe learning disabilities (severe mental retardation) is reserved for people whose IQ is in the range of 20-34. Finally the term profound learning disabilities (profound mental retardation) is reserved for people whose complex additional disabilities, for example sensory, physical or behavioural, makes the measurement of IQ difficult.

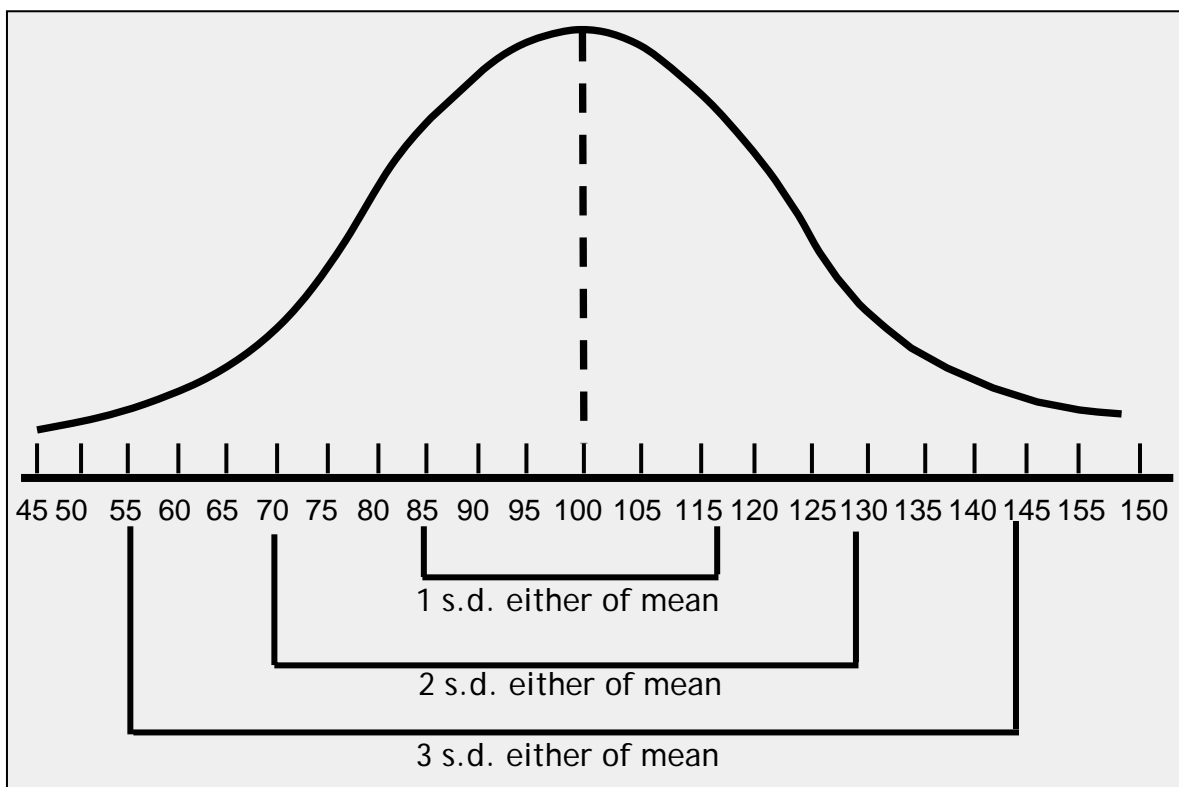


Figure1.1 The normal distribution curve of intelligence

Intelligence tests were used extensively during the 1960s and 1970s; however, recognition by psychologists and others, of the many limitations of their use has made them less popular today. These limitations include cultural bias, poor predictive ability, and a lack of relevance for the identification of learning disability. Despite the range of criticisms constructed against the use of intelligence tests, if used appropriately and by properly trained technicians then they do provide a relatively objective measure of the intellectual ability of an individual. In addition, if such a measure is used in conjunction with other criterion, such as social competence, this may be helpful in identifying whether an individual has learning disabilities.

Legislative definitions of learning disability

It is the case that legislators, both within the UK and in other countries, have for centuries attempted to use the law to define learning disability and people conflating learning disabilities with mental illness may in part explain this. By this it is meant that the *clumping* together of two states of being has resulted in people with learning disabilities being the subject of much unnecessary legislation. This brief exploration only considers legislation this century, and in particular focuses upon mental health legislation. For a summary of the historical passage of legislation as it has affected people with learning disabilities see Unit 3.

The Mental Deficiency Act of 1913 said:

'Mental defectiveness means a condition of arrested or incomplete development of mind existing before the age of eighteen years, whether arising from inherent causes or induced by disease or injury'.

This Act followed the Radnor Commission of 1908, and introduced the compulsory certification of *defectives*. In a sense, this Act reflected the strong eugenics movement of the time; not surprisingly the Act required that 'defectives' be identified and then segregated from the rest of society. By 1959 terminology, and perhaps attitudes, had changed and the Mental Health Act of (1959) introduced the terms listed in Box 1.1.

Subnormality - a state of arrested or incomplete development of mind, not amounting to severe subnormality, which includes subnormality of intelligence, and is of such a nature or degree which requires, or is susceptible to, medical treatment or other special care or training of the patient.

Severe subnormality - a state of arrested or incomplete development of mind which includes subnormality of intelligence and is of such a nature or degree that the patient is incapable of living an independent life or guarding himself/herself against serious exploitation, or will be so incapable when of an age to do so.

Psychopathic disorder - a persistent disorder or disability of mind, whether or not including subnormality of intelligence, which results in abnormally aggressive or seriously irresponsible conduct, on the part of the patient and requires, or is susceptible to, medical treatment.

Box 1.1 Classifications of the 1959 Mental Health Act

This Act required local authorities to make day service and residential provisions for people with a *mental subnormality* and placed a new emphasis on the re-integration of this group of people into being part of the communities to which they belonged. However, this Act must be seen in context, and it should be remembered that it followed the implementation of the NHS Act (1948). The consequential medicalization of 'mental subnormality' following the NHS Act is clearly reflected in the Mental Health Act of 1959, and therefore its definitions reflected this. Note the strong emphasis, in the definitions, that was placed on treatment. In addition, the Act made extensive reference to the Responsible Medical Officer. It is at this point in the history of mental health legislation that the influence of medicine in defining the nature of learning disability exerted its greatest impact. As a result of continued social reform and pressure from lobby groups, mental health legislation was again reformed in 1983; the old Act of 1959 was replaced with the 1983/4 Mental Health (Scotland) Act; once again old terminology was changed and replaced with the terms shown in Box 1.2.

Severe mental impairment - a state of arrested or incomplete development of mind, which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct of the person concerned.

Mental impairment - a state of arrested or incomplete development of mind (not amounting to severe mental impairment) which includes significant impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.

Box 1.2 Classifications of the 1984 Mental Health (Scotland) Act

It can be seen that the nature of these definitions excluded the large majority of people with learning disability; that is, unless learning disability (mental or severe mental impairment) coexisted with aggressive or seriously irresponsible behaviour, then they were not subject to this new piece of legislation. This Act represented a major shift in the perception of people with a learning disability in mental health legislation; for law separated the first time learning disability and mental illness.

Social competence

The final criterion, in this chapter, that is used for identifying learning disability is that of social competence. Mittler (1979) has suggested that most countries have used criteria based on social competence that include the ability of an individual to adapt to the changing demands made by the society in which that individual lives. Of course this sounds relatively straightforward; that is, one simply identifies people who are socially incompetent, and who do not respond well to changing societal demands. Burton (1996) has said,

'Social competence concerns such areas as understanding and following social rules, adjusting social behaviour to the situation, social problem-solving, and understanding others. These are the areas where people typically fail independent living.' (Burton, 1996 p40)

On the basis of an individual performing significantly below what might be considered as *normal*, one presumably may say that they might have a learning disability. However, there are a number of problematic issues to consider in relation to the criterion of social competence. First, social incompetence is to be found in a wide cross-section of people; and not just those with a learning disability. Consider, for example, people with chronic mental health problems as well as non-conformists to societal norms.

Alternatively, there may be problems of communication, hearing and vision that could also be the cause of social incompetence, and may not necessarily involve a learning disability. Second, there is an issue here of expectation and the notion of a self-fulfilling prophecy. Assume, momentarily, that an individual is identified as having a learning disability, on the basis of measured social incompetence. Is it the case that this individual genuinely has learning disabilities, or is the social incompetence merely an artefact of the hospital setting in which this individual spent their formative years? Such a finding is not beyond the realms of credibility. It is only relatively recently in Scotland that the large learning disability hospitals have been closing. It is the case that thousands of people with a learning disability were segregated from society, and led very devalued life styles.

Opportunities for the development of social competence were few and far between even when opportunities arose; generally these were perverted attempts to create some kind of social reality within an institutional setting. There have been numerous studies undertaken on the effects of people who are deprived of normal environments. Dennis (1973) had found that institutionalised children were delayed in basic competencies such as sitting, standing and walking, and reported that they had no opportunity to practise these skills. It was also noted that with the additional lack of stimulation there was also significant delay in language acquisition, social skill development and emotional expression:

..... as babies they lay on their backs in their cribs throughout the first year and often for much of the second year.....Many objects available to most children did not exist.....There were no building blocks, no sandboxes, no scooters, no tricycles, no climbing apparatus, no swings. There were no pets or other animals of any sort.....they had had no opportunities to learn what these objects were. They never saw persons who lived in the outside world, except for rather rare visitors. (Dennis, 1973 pp22-23)

In short, the expectations of people in these environments were low, and therefore it is not unreasonable to assume that their ability to develop social competence in such environments was reduced. Despite the criticisms made in this section, the use of social competence as means for the identification of a learning disability remains a globally used criterion.

Definitions of learning disability

Generally speaking in the UK the term learning disability is used, and this is accepted to mean:

'A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with, a reduced ability to cope independently (impaired social functioning) and which started before adulthood, with a lasting effect on development.' (DOH, 2001 p14)

Specifically in Scotland the term learning disability is used to describe:

'... those with a significant, lifelong condition that started before adulthood, that affects their development and which means they need help to understand information, learn skills and cope independently.' (Scottish Executive, 2000)

In the USA the American Association on Mental Retardation defined what we would call learning disability as:

'Mental retardation refers to substantial limitations in present functioning. It is characterised by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work. Mental retardation manifests itself before age 18.' (AAMR, 1997 p.5)

A general discussion on terminology

It should be pointed out that the term 'learning disability' is relatively new; Emerson et al (2001) have suggested that its origins lie in a speech to Mencap by Stephen Dorrell, Minister for Health in England in 1991.

Its general usage in the UK is reserved for describing a group of people with significant developmental delay that results in arrested or incomplete achievement of the 'normal' milestones of human development. These milestones relate to intellectual, emotional, spiritual and social aspects of development. Significant delays in a number of these areas may lead to a person being described, defined or categorised as having learning disabilities. Despite wide usage of this term in the UK it should be remembered that it is not one that is used internationally (refer to the AAMR definition of learning disability [mental retardation]), nor is it a term that has been used for very long in the UK. Until recently the term 'mental handicap' was much more frequently used but was replaced, because it was felt that it portrayed negative imagery concerning people with disability. Interestingly a study by Nursey et al (1990) has demonstrated that parents and doctors had preferences in the words that they chose to use when referring to people with

learning disability. The study was conducted using a questionnaire and established that both parents and doctors preferred the term 'mental handicap' or 'learning difficulties'. However, the doctors were more inclined to accept the words dull, backward and developmentally delayed. In the USA (see above) the term 'mental retardation' is widely used for the classification of learning disability. This system is based upon the ICD-10 Classification of Mental and Behavioural Disorders, World Health Organisation 10th revision (1993). This uses the term 'mental retardation' to refer to:

'a condition of arrested or incomplete development of the mind, which is especially characterised by impairment skills manifested during the developmental period which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.'

Interestingly the USA has recently been engaged in considerable debate about the use of the term mental retardation;

'As all of us have experienced, the term mental retardation has expanded from a diagnostic label embedded in both legislative and social norms to a pejorative, stigmatising term that is increasingly offensive to a large group of individuals.' (Schalock, 2001 p4)

Notwithstanding this, the American Association on Mental Retardation, 'noted that after two years of exploration for an alternative term they had not found one that meant the same thing, and on this basis they recommended that the term should not be replaced.' (Schalock, 2001 4)

You are asked to pay attention to terminology, as it is likely that America and other countries will adopt the term 'Intellectual Disability' in the future - remember people are sensitive to the labels or terms applied to them and some of these can be very hurtful.

It is becoming increasingly common for professional carers not to use the diagnostic labels and categories of description outlined earlier (Emerson et al, 2001). This is because they represent static measures that tell us nothing of the needs of each individual person; these needs will vary considerably between people, even if their measured IQ is an exact match with another.

In the field of learning disabilities, one of the problems in deciding which term to use is the possibility that the term may become used as a label that conjures up negative imagery. The use of labels for people with a learning disability has in the past served as a way of segregating this group from society at large.

Essential

Reader Activity 1.1

Spend ten minutes listing as many labels or terms that you have heard being used to refer to people with learning disabilities. Next compare your list with those in Box 1:3. These are all labels that I have heard people use when they refer to those with learning disabilities - do you think such labels assist in devaluing this group of people?

Imbecile	Nutter
Cretin	Moron
Spastic	Benny
Subnormal	Retard

Box 1.3 Terms used to describe people with a learning disability

Incidence and prevalence of learning disability

Calculating the incidence of learning disability is extremely problematic. This is because there is no way of detecting the vast majority of infants who have a learning disability at birth. It is only the obvious manifestations of learning disability that can be detected at birth; for example Down's syndrome. In this example, the physical characteristics of Down's syndrome enable an early diagnosis and the ability to calculate incidence of this disorder. Where there is no obvious physical manifestation, one must wait for delay on a child's development in order to ascertain whether they have a learning disability. Therefore it is more common in learning disability to talk about the prevalence. Prevalence is concerned with an estimation of the number of people with a condition, disorder or disease as a proportion to the general population.

If one uses IQ as an indicator of learning disability then one is able to calculate that 2-3% of the population has an IQ below 70. This represents a large segment of society - given that a large number of people with such an estimated IQ never come into contact with any caring agency. It is more common to refer to the 'administrative prevalence'. Administrative prevalence refers to the number of people that are provided with some form of service from caring agencies. Historically, there has been a general consensus that the overall prevalence of moderate and severe learning disabilities was approximately 3-4 people per 1000 of the general population (see, for example Open University, 1987; DoH, 1992; Scottish Executive, 2001).

Such prevalence would appear to be universally common. For example, as long ago as 1985 Craft had suggested that international studies have identified a relatively constant prevalence for severe and moderate learning disability as 3.7 per 1000 population. The prevalence of mild learning disabilities is actually quite common; it has been estimated to be in the region of 20 persons per 1000 of the general population. In the UK it has been further calculated that of the 3-4 persons per 1000 population with a learning disability, approximately 30% will present with severe or profound learning

disabilities. Within this group it is not uncommon to find multiple disability that includes physical and, or, sensory impairments or disability as well as behavioural difficulties. It is this group of people that require life-long support in order for them to achieve and maintain a valued life style.

Drawing on more recent and extensive epidemiological data Emerson et al (2001), have reinforced the above estimations of prevalence rates for severe learning disabilities. They state it to be somewhere in the region of 3-4 persons per 1,000 of the general population. The prevalence rates for that section of the learning-disabled population referred to, as mild learning disabilities are much more diverse. It is estimated that this figure might lie between 25-30 people per 1,000 of the general population. Based on these estimates it can be assumed that there are some 230,000-350,000 persons with severe learning disabilities, and possibly 580,000-1,750,000 persons with mild learning disabilities. It is also known that there is a slight variation in ratio of males to females in both mild and severe learning disabilities; with males having slightly higher elevated prevalence rates. In Scotland there are an estimated 120,000 people with learning disabilities, however only 30,000 of these will have regular contact with local authorities or the National Health Service. Enable (2003) have suggested that 20 people out of every 1,000 have a mild or moderate learning disability and that 3-4 in every 1,000 have a profound or multiple disability. They also state that the number of people with learning disabilities has increased by 1.2 % a year over the last 35 years and that since 1965 the number of people with severe learning disabilities has increased by 50%.

<i>Optional</i>	<i>Reader Activity 1.2</i>
-----------------	----------------------------

Why do you think that the number of people with learning disabilities continues to grow, and why has the number of people with severe learning disabilities increased so dramatically and what implications might this have for future services?

This clearly represents a significant section of Scottish society and your local communities. Like other citizens they are entitled to access the resource of skilled professionals, who are able to meet their health and social care needs, when they are required. It will be noted that the incidence of learning disabilities has only been briefly outlined in this section. Research in this area is uncommon and with the exception of a few manifestations of learning disabilities, for example Down's syndrome (see Unit 3), understanding incidence is fraught with difficulties of explanation because of an inability to identify learning disabilities at birth or even at a relatively young age. Earlier in this unit it was said that people use different criteria in identifying learning disabilities. This different use of terminology has implications for calculating incidence and, or, prevalence. It should be acknowledged that there is some controversy associated with calculation of incidence and prevalence. Some would argue that is unimportant and that the epidemiological study of learning disability creates labelling, and that this perpetuates inappropriate models of care that are developed outside mainstream services available for all of us. One problem, amongst many others, with this line of argument is that without careful epidemiological studies in this area, it is inherently difficult to know how best to target resources for those who may need them. It has long been complained that people with a learning disability are not afforded the same rights as other citizens. Careful measurement of incidence and prevalence provides one way of ensuring that people with special needs are provided with specialist resources when they are required.

Introducing the narratives

The narratives used in this learning resource are intended to illustrate some aspects of five people's lives. These will explore various issues pertaining to these people who happen to have learning disabilities and recounts their experiences with health care professionals. Each of the units will direct you to at least one of the narratives and will ask you to undertake at least one essential reader activity.

<i>Essential</i>	<i>Reader Activity 1.3</i>
------------------	----------------------------

You are asked to read all of the narratives of Marie, Shona, Scott, Alan and Purdie. Consider each of these and then form some small discussion groups and discuss the following questions. You may find it helpful to have someone to facilitate your discussion. You should allow at least one hour to read the narratives and for the discussion.

- *Why do you think the doctor thought Marie was faking her epilepsy?*
- *Why does Shona say that people are frightened of people with learning disabilities? Are you frightened of people with learning disabilities if so why?*
- *What kind of information would you have given Scott?*
- *What would you do if you saw someone being rough with an individual as Alan reports?*
- *What do you think of Purdie's encounter with health care professionals?*

Conclusion

In this unit we have attempted to portray the complexities of learning disabilities. Many textbooks refer to 'people with learning disabilities' rather unproblematically as a homogenous group. This is simplistic and unhelpful; both for people with learning disabilities, their families and professional carers. Consider the narratives of Marie, Shona, Scott, Alan and Purdie, all might be said to have learning disabilities, but equally all are very different unique beings with their own very personal needs and aspirations. Also compare their narratives with that of the account provided about Callum from his mum. His very special needs make him very different from that of Marie, Shona, Scott, Alan and Purdie. Not with standing this people with learning disabilities, regardless of the impact of their learning disabilities, share a common humanity with the general population. Most people desire love, a sense of connection with others, to be safe, to learn, to lead a meaningful life, to be free from ridicule and harm, to be healthy and free from poverty, and people with learning disabilities, in this respect are no different. It is in the spirit of this common humanity that the rest of this text is presented. It is hoped that it will assist, in some small part, carers to bring about the inclusion of people with learning disabilities into their communities. It is for you as nurses to respect this and ensure that you offer nursing care to all people regardless of their difference and in this case we are referring to people with learning disabilities but nonetheless people who are the same as you!

References

American Association on Mental Retardation (1997) Mental retardation: definition, classification, and systems of support. 9th edn. AAMR: Washington.

Bogdan, R. and Taylor, S. (1994) The social meaning of mental retardation. London. Teachers College Press.

Burton, M. (1996) Intellectual disability: developing a definition. Journal of Learning Disabilities for Nursing, Health and Social Care. 1(1) p40.

Craft, M. (1985) 'Classification, criteria, epidemiology and causation'. In Craft, M.; Bicknell, J. and Hollins, S. (eds) Mental handicap: a multidisciplinary approach. London: Baillière Tindal.

Dennis, W. (1974) Children of the crèche. New York: Appleton Century-Crofts.

Department of Health (2001) Valuing people: a new strategy for learning disability for the 21st century. Cm. 5086. Stationery Office: London.

DoH (1992) Social care for adults with learning disabilities. (Mental Handicap (LAC (92)15). London. HMSO.

Begab, M. and Richardson, S. (eds) The mentally retarded and society: A social science perspective. Baltimore: University Park Press.

Emerson, E.; Hatton, C.; Felce, D. and Murphy, G. (2001) Learning disabilities: the fundamental facts. The Foundation for People with Learning Disabilities. London.

Gazaway, R. (1969) The longest mile. Garden City, New York: Doubleday.

Mental Deficiency Act 1913. London: HMSO.

Mental Health Act 1959. London: HMSO.

Mental Health Act 1983. London: HMSO.

Ministry of Health (MoH) (1946) The National Health Service Act. London: HMSO.

Mittler, P. (1979) People not patients: problems and policies in mental handicap. London: Methuen.

Nurse, N.; Rhode, J. and Farmer, R. (1990) 'Words used to refer to people with mental handicaps.' Mental Handicap. 18(1) pp30-32.

Schhallock, R. (2001) Consortium on language presents phase one report. American Association on Mental Retardation. News and Notes. May-June 2001, pp1-4.

Scottish Executive (2000) The same as you: a review of services for people with leaning disabilities. Edinburgh. The Stationery Office.

The Open University (1987) Mental handicap: patterns for living. Milton Keynes: Open University Press.

World Health Organization (1993) Describing developmental disability. Guidelines for a multiaxial scheme for mental retardation (learning disability), 10th revision, Geneva: WHO.

Further reading

American Association on Mental Retardation (1997) Mental retardation, definition, classification, and systems of support. 9th edn. AAMR: Washington.

Marwick, A. and Parrish, A. (2003) Learning disabilities: themes and perspectives. London: Butterworth Heinemann.

Race, D. (2002) Learning disabilities: a social approach. London: Routledge.

Thompson, J. and Pickering, S. (2002) Meeting the health needs of people who have learning disability. London: Baillière Tindall.

Thompson, T. and Mathias, P. (1998) Standards and learning disability. 2nd edn. London: Baillière Tindall.

Resources

Scottish Executive

<http://www.scotland.gov.uk> - links to Scotland's policy's and documents for people with learning disabilities.

Centre on Human Policy

<http://soeweb.syr.edu/thechp/> - John O'Brien home site lots on supported living/advocacy - useful mainly American links.

Department of Health - Learning Disabilities

<http://www.doh.gov.uk/learningdisabilities/> - links to England's policy's and documents for people with learning disabilities.

Enable

<http://www.enable.org.uk/ld/factsfigures.html> - the Enable web site is a useful address for all kinds of information but here you can check out facts and figures for Scotland.

National Electronic Library for Learning Disability

<http://www.nelh.nhs.uk/nelld> - National electronic library - excellent for the learning disability branch-useful reviews for example, supported employment.

British Institute for Learning Disabilities

<http://www.bild.org.uk> - source of good practice guidance; information and resource centre.

The Foundation for People with Learning Disabilities

<http://www.learningdisabilities.org.uk> - works to improve the lives of people with learning disabilities through presenting views, research, and influencing policy.

Joseph Rowntree Foundation

<http://www.jrf.org.uk> - includes research, publications and social policy relating to learning disability.

King's Fund

<http://www.kingsfund.org.uk> - health promotion resource for the London area, research, publications and library.

Unit 2 - Causes and manifestations of learning disabilities

Dr Stellios Ioannides
Programme Leader for Learning Disabilities
Thames Valley University
London

Outline

This unit will:

- Outline a range of causative factors that may result in learning disabilities.
- Distinguish between pre, peri and postal natal factors.
- Identify a range of number of known conditions in learning disabilities.
- Identify some of the health challenges that people with learning disabilities may experience as a consequence of particular clinical manifestations of learning disabilities.
- Specifically outline genetic and chromosomal abnormalities and their manifestation.

Introduction

The isolation and subsequent identification of the many causes of learning disabilities has in the past, been a complex and relatively slow process. However, with recent advances in genetic technology and increasing awareness of the effects of social deprivation, new knowledge and understanding are continually being developed. Learning disabilities cannot be considered a single condition; rather it is a compendium of various degrees of impairment of intellectual and social functioning. The range of causative factors in learning disabilities is variable and diverse and the origin of many conditions is still unknown. Some of the main causes and manifestations of learning disabilities found within society will be explored in this unit. It is envisaged that if you wish to further your knowledge and understanding in this area you will use the recommended reading at the end of the unit. In this unit you will necessarily encounter a range of technical terms that you may be unfamiliar with we have left the responsibility with you to ensure that you research all new terms and understand their meaning.

Importance of diagnosis

Knowing and understanding the cause of an individual's learning disabilities is important for several reasons. Gates (2000) has emphasised that the identification of the cause of a learning disability and the provision of an early diagnosis are crucial in limiting the feelings of self-blame that may be experienced by some parents of children with learning disabilities. He has also suggested that informed parents are less likely to reject the child and more likely to adapt appropriately to the care demands posed by having a child with learning disabilities. Other reasons for the identification of the causes of learning disabilities and early diagnosis include the need to:

- Understand the possible manifestations of the identified condition over a defined period of time.
- Identify the range of therapeutic approaches that may be used to ameliorate the effects of the condition including the mobilisation of specific resources.
- Establish in some cases, the degree of risk to other family members of the condition re-occurring in siblings and offspring.

Classification of learning disabilities

Learning disabilities may be classified in a number of different ways. One way is by the origin of the cause of the learning disability. This may fall into two main categories; genetic or environmental. Genetic conditions may originate prior to conception or during the very early stages of the development of the foetus. Environmental causes on the other hand, include those external factors that may affect the development of a foetus and child either in the pre-conceptual, prenatal, perinatal or postnatal periods. The stage of development at which the damage to the child is incurred is a second method by which learning disabilities may be classified. Where the cause of the learning disability is unknown, such conditions are usually described as *idiopathic*.

The following sections will enable the reader to understand some of the clinical features associated with specific conditions or syndromes found within learning disabilities. When reading each section, the student may like to reflect upon the type of health care that maybe required in responding to the needs of affected individuals and their families.

Genetic causes of learning disabilities

Many of our physical features (phenotype) originate from our genetic make up (genotypes). The information required for the development of these characteristics exists in the form of genes that are passed from parents to offspring during the process of cell division. Genes can be found on structures called chromosomes that are present within the nucleus of every human cell and consist of the genetic material DNA (Deoxyribose Nucleic Acid). A generalised cell structure is shown in Figure 2.1 and the genetic material we are talking about here will be found located in the nucleus at the heart of the cell. This nucleus, and every other cell nucleus, contains 23 pairs of chromosomes, of which 22 are referred to as autosomes and 1 which is referred to as the sex chromosomes (XX in females and XY in males). This is shown as the normal (male) karyotype in Figure 2.2. During the process of cell division (meiosis), the chromosomes from each parent combine and then divide. During this process, changes in both the structure of the chromosomes and their respective genes can occur and this may give rise to genetic abnormalities that are the cause of some learning disabilities.

It is believed that between 30-40% of moderate to severe learning disabilities are caused by changes in the genetic makeup of an individual (Knight et al, 1999) and developments in genetic technology arising from The Human Genome Project suggest that the percentage may be higher. A relatively recent study by Knight et al (1999) has shown that a number of previously undiagnosed conditions in learning disabilities could be attributed to subtle chromosomal rearrangements.

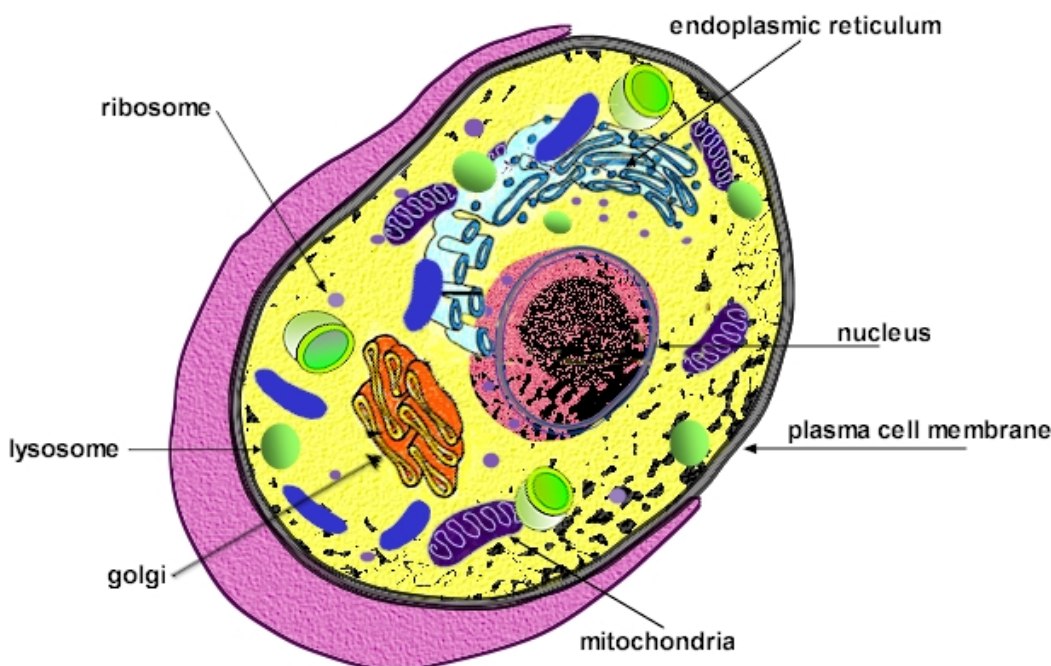


Figure 2.1 Structure of human cell

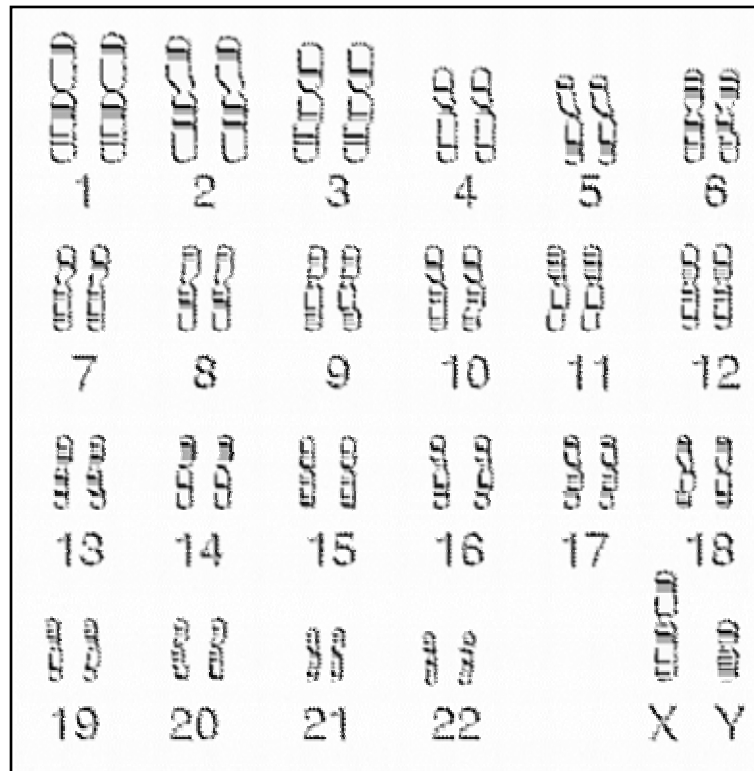


Figure 2.2 The human karyotype

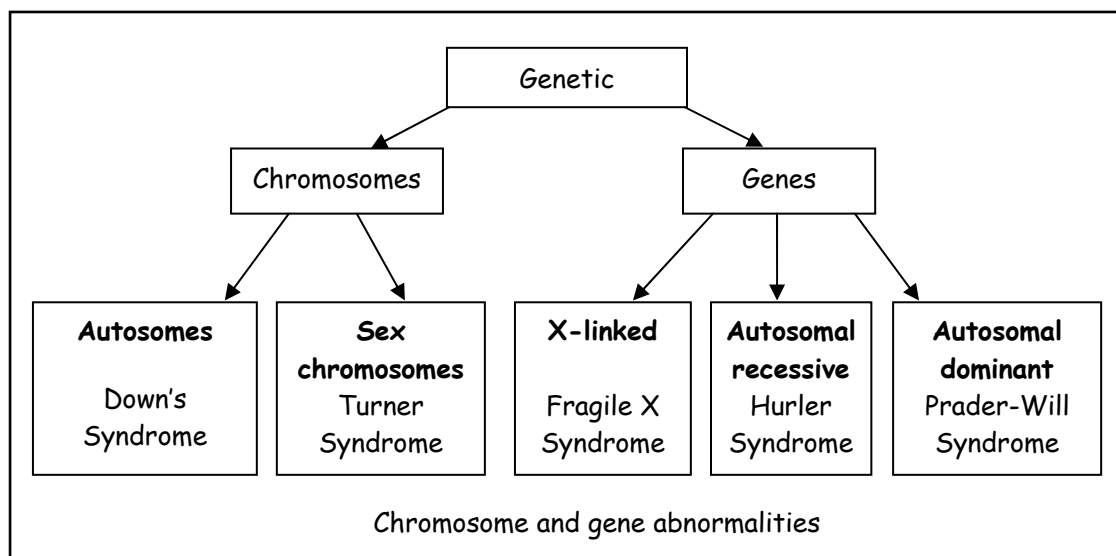


Figure 2.3 A simple classification system of the genetic causes of learning disabilities

Figure 2.3 presents a simple classification system of the genetic causes of learning disabilities. It can be seen that an example is given for each group and some further examples of each are provide in the next section of this unit.

Chromosomal abnormalities

This section will provide specific examples of conditions in learning disabilities that result from changes in either the structure or number of autosomes and sex chromosomes. Where changes in the structure of the chromosome may occur, this may include the deletion, duplication, translocation non-disjunction or inversion of genetic material.

1. Manifestations of autosomal abnormalities

Down's Syndrome (Trisomy 21) - this syndrome was first described by John Langdon Down in 1866 and results from the non-disjunction of chromosome 21 pair during cell division resulting in an individual having three rather than two chromosome 21. Incidence rate of this syndrome is between 1 in 650 and 1 in 700 (Mueller & Young, 1998) but becomes higher with an increase in maternal age. Typical characteristics of individuals include: short stature, small ears, ear and eye defects, heart defects and an increased susceptibility to infections. In rare cases, some individuals with Down's Syndrome may have a mixture of cells that contain either trisomy 21 or the normal number of chromosome 21 and this condition is known as *mosaicism*.

Cri-de-Cat - a relatively rare condition with an incidence rate of about 1 in 37,000 live births. It was first described in 1963 by Lejeune et al and given the name because affected infants are found to have high pitched cries like those of a cat. Typical characteristics include microcephaly, low set ears, wide spaced eyes and moderate-severe learning disabilities.

2. Manifestation of sex-chromosome abnormalities

Klinefelter Syndrome (XXY) - this syndrome was first described by Klinefelter and associates in 1942 and only affects males. It results from the non-disjunction of the XY chromosomes during cell division resulting in an individual having an extra X chromosome. Incidence rate of this syndrome is between 1 in 500 and 1 in 1000 births. Typical characteristics include a large forehead, ears and jaw, and following the onset of puberty hypogonadism (enlarged testicles) and gynecomastia (enlarged breasts). Psychosocial problems are also common. The degree of learning disability is said to be moderate, with a few cases of individuals with profound learning disabilities.

Turner Syndrome (XO) - this syndrome only affects females and results from the loss of one of the normal two XX chromosomes. Incidence rate is estimated to be 1 in 2,500 births. Typical characteristics include short stature, web like neck, non-functioning ovaries, and in some cases, learning disabilities although the normal range of intelligence is generally associated with this syndrome.

Essential

Reader Activity 2.1

Case illustration

Michael is a man with Down's syndrome who lives at home with his elderly parents. He breathes through his mouth and has a congenital heart disease. He tends to get respiratory infections fairly commonly and often he has eye infections.

Using your acquired knowledge of Down's syndrome write a short paper on the kind of support would you give to Michael and the sorts of advice you might provide for his elderly parents? Also describe any preventive measures that you would recommend in relation to Michael's common infections.

Optional

Reader Activity 2.2

Find out the address and contact information on a range of local organisations that offer support for parents of children with genetic conditions. This exercise is useful in raising your awareness of the types of organisations that are available to parents also it will increase your knowledge of another aspect of learning disabilities.

3. Manifestations of gene abnormalities

This section will provide specific examples of conditions in learning disabilities that result from changes in the structure of the genetic material making up a gene. These changes may include the deletion, duplication, addition, inversion and substitution of the parts of the DNA. Gene abnormalities are generally categorised by the mode of transmission of the defective gene, you may wish to refer back to the simple classification system in Figure 2.3. These forms of transmission can be described as autosomal dominant, autosomal recessive or X-linked and these are all described below. Some conditions may result from the interaction of various genes (polygenic) although these have not been described in this unit.

Autosomal dominant conditions

In the case of autosomal dominant conditions, transmission is reliant upon only one parent carrier of the defective gene and there is a 50% chance of it occurring in the offspring. (see Figure 2.4)

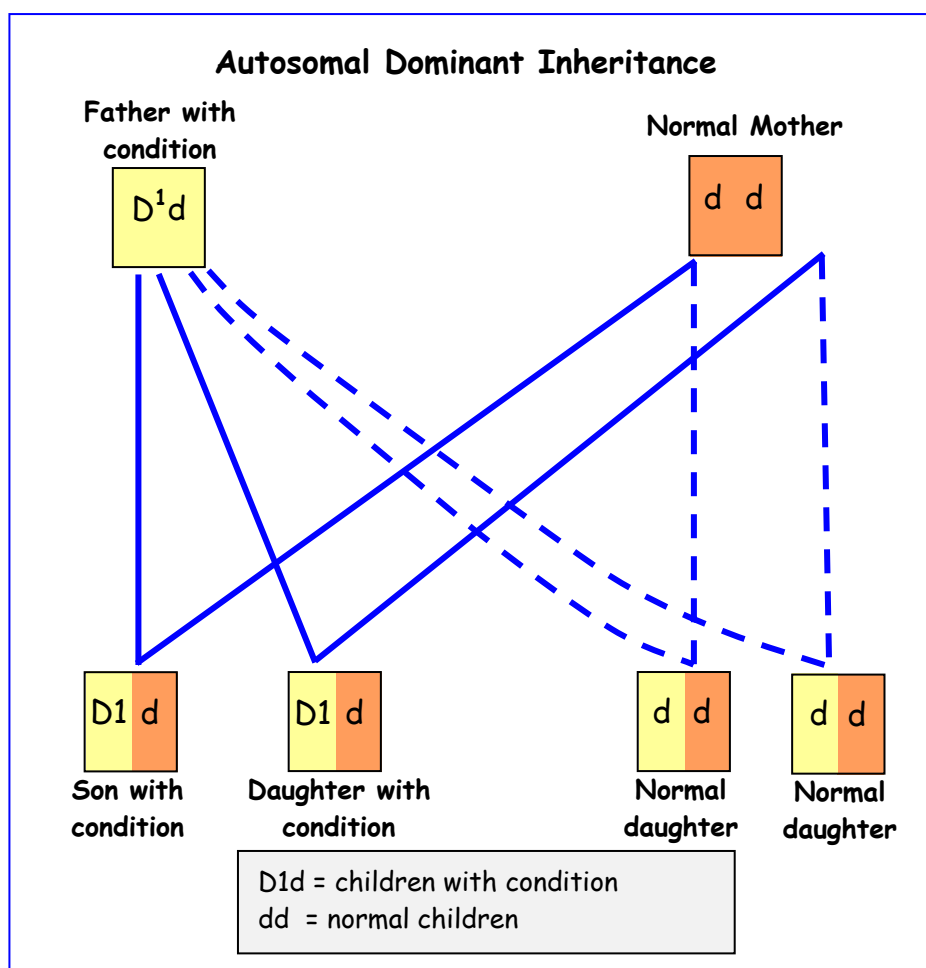


Figure 2.4 Dominant inheritance

The next section provides you with some examples of disorders that are inherited through this process.

Prader-Willi syndrome - this syndrome results from deletion of part of the genetic material on the long arm of chromosome 15 and usually originates from the father. Incidence rate is approximately 1 in 15,000 and affects males and females alike. Characteristics of this condition include small hands and feet, hypogenitalism (underdeveloped testes) and cryptorchidism (undescended testes) in males. One of the most notable characteristics, however, is hyperphagia (excessive over eating). Without proper help and support, people with this syndrome commonly experience gross obesity and the related conditions of heart disease and diabetes which may result in premature death.

Tuberous sclerosis (epiloia) - this condition was first described in 1880 and is estimated to affect between 1 in 30,000 to 40,000 births. It is characterised by growths on the brain and major organs. A butterfly shaped rash (adenoma sebaceum) will be present on the face. Epilepsy is common in people with this condition. Whilst normal intelligence may be present, 60% of affected people have some degree of learning disability.

Autosomal recessive condition

In the case of autosomal recessive conditions, transmission is reliant on both parents being carriers of the defective gene and in this case, there is a 25% chance of the condition manifesting in the offspring. (see Figure 2.5)

The next section provides you with some examples of disorders that are inherited through this process.

Phenylketonuria - this condition was described by Fölling in 1934. It is a disorder that affects protein metabolism resulting in raised blood levels of phenylalanine. If not maintained at a normal level through diet control, these levels may become toxic and result in brain damage. This condition is believed to affect approximately 1 in 12 000 live births. It is commonly diagnosed using the Guthrie's test (heel prick test) which is a blood test carried out 6 to 14 days after birth. If left untreated, typical characteristics include lack of pigmentation in the eyes, skin and hair, hyperactivity, autistic features and epilepsy. Degree of learning disability is severe in individuals where condition is not treated.

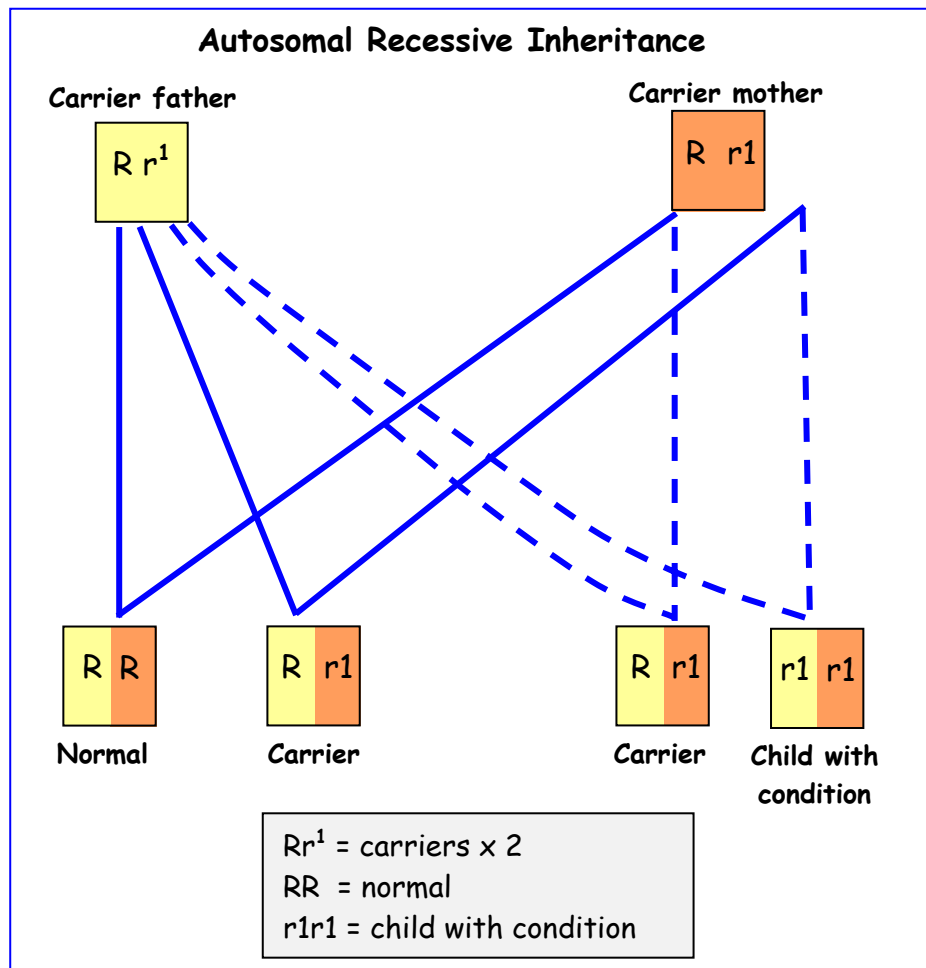


Figure 2.5 Recessive inheritance

Hurler syndrome - Hurler syndrome is one of a number of mucopolysaccharide disorders and has an estimated prevalence rate of 1 in 150,000 births. It is characterised by the abnormal storage of mucopolysaccharides in connective tissue that ensures that affected individuals are short in stature and have thick coarse facial features and a low nasal bridges. Hirsutism is a common characteristic as is the more lethal presence of heart defects. Affected individuals may also have sight and hearing impairments. Death normally occurs in adolescence.

X-linked recessive conditions

Fragile X Syndrome - a syndrome that occurs more commonly in males than females with a prevalence rate of 1 in 4000 and 1 in 8000 respectively. It is believed to be the most common cause of learning disabilities next to Down's syndrome. This condition arises from the breaking off of the bottom tip of the X chromosome making the site fragile. Common characteristics include oversized head, long face, prominent ears, large jaw, language difficulties and varying degrees of learning disability. Behavioural problems are also characteristic.

Essential

Reader Activity 2.3

Genetic counselling is a service offered to people who may be at risk from a disorder that may be hereditary in nature. During the consultation process the patient is informed about the characteristics of the condition and its likely progression. Advice may be given with regard to the probability of its reoccurrence in future generations providing vital information to families.

Find out about the current genetic tests that may be used to diagnose the presence of genetic conditions. To do this you may use the web or try your local library or resource centre at the University. Given that the Nursing and Midwifery Council are to introduce minimum competencies concerning genetics in the near future it seems sensible to address this issue now.

Environmental factors

Environmental factors have an important influence on the physical and intellectual development of individuals. Where the environment contains positive factors for growth such as food, warmth, love, safety and sensory stimulation, normal development should ensue. However, in some cases, certain environmental conditions may hinder the growth and development of an individual and this could result in a learning disability. Environmental factors that may exert influence on development might occur in the pre-conception, prenatal, perinatal and postnatal stages and include infections; trauma, drugs and social deprivation. (see Figure 2.6)

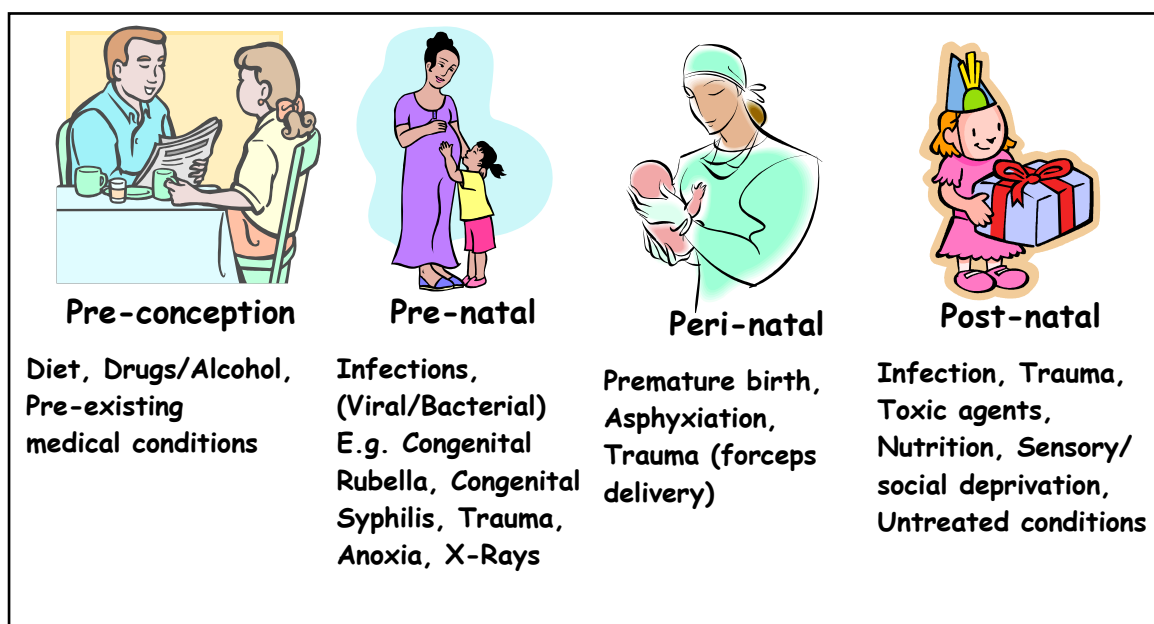


Figure 2.6 Environmental causes of learning disability

Environmental causes of learning disabilities includes trauma during the pre-natal, perinatal and postnatal phases and includes accidental and non-accidental injury. At the prenatal stage, this also includes the delivery of the child using forceps or suction. Restriction of the oxygen supply to the foetus during the prenatal and perinatal phases can result in brain damage. In the latter stage, asphyxiation may occur if the umbilical cord becomes wrapped around the baby's neck. The consumption of drugs including alcohol also accounts for the stunted growth and lack of brain development observed in some children. Toxic agents, lead poisoning, chemical pollutants and hard metals such as mercury, manganese and strontium poisoning are also known causes of brain damage. In the postnatal phase of development, poor nutrition and a lack of sensory and social stimulation can impair development and result in learning disabilities. Other causes of learning disabilities include acquired infection that can result in brain damage at prenatal, perinatal and postnatal stages of development and includes rubella (German measles, mumps and chickenpox). In the past syphilis was a common cause of learning disabilities but is now less common. Viral infections may give rise to

encephalitis or inflammation of the brain and the subsequent degree of learning disabilities can be severe. Dehydration, which will occur very rapidly, leads to brain haemorrhage, which can cause brain damage.

Congenital Rubella - this condition was first described by Gregg in 1941 and is characterized by a number of severe defects which include cataracts, deafness, congenital heart defects and learning disabilities. Damage occurs when the rubella virus passes across the placenta and attacks the developing nervous tissue in the unborn foetus. In recent years, the prevalence of congenital rubella has declined with the introduction of rigorous immunization programmes.

Conclusion

This unit has examined the varying causes and manifestations of conditions in learning disabilities. It has been demonstrated that changes in the genetic makeup of individuals can result in the manifestation of specific syndromes, whilst environmental factors can also cause brain damage in the prenatal perinatal and postnatal periods. Diagnosing the cause of learning disabilities is important for families in allowing them to adapt to their child. It is also important for health services, as it provides specific information about actual and potential needs of individuals that allows the mobilisation of appropriate resources. Caution however, must be exercised as providing a diagnostic label may reduce individuality. As it will be demonstrated in Units 4 and 5, health professionals must ensure that they always see and value the person and their individual characteristics before any diagnosis.

References

Gates, B. (2000) 'Knowing: the importance of diagnosing learning disability.' Journal of Learning Disabilities, 4(1) pp5-6.

Knight, S.J.L.; Regan, R.; Nicod, A. (1999) Subtle chromosomal rearrangements in children with unexplained mental retardation. Lancet, 345(9191) pp1676-1681.

Mueller, R.F. and Young, I.D. (1998) Emery's elements of medical genetics. 10th edn Edinburgh: Churchill Livingstone.

Further reading

Barr, O. (1999) 'Genetic counselling: a consideration of the potential and key obstacles to assisting parent adapt to a child with learning disabilities.' British Journal of Learning Disabilities 27:pp30-36.

Health Departments of the United Kingdom (1998) Advisory committee on genetic testing: report on genetic testing for late onset disorders. London: Department of Health.

Hogenboom, M. (2001) Living with genetic syndromes associated with intellectual disability. London: Jessica Kingsley.

Watson, D. (2003) Causes and manifestations of learning disabilities. In: Gates, B. (ed) Learning disabilities: toward inclusion. Edinburgh: Churchill Livingstone.

Resources

ASSERT (Angelman Syndrome Support Education and Research Trust)

P O Box 505
Sittingbourne
Kent ME10 NE
Tel: 01980 625616

The National Autistic Society

393 City Road
London EC1V 1NE
Tel: 020 7833 2299

Cornelia de Lange Foundation

Tall Trees 106 Lodge Lane
Grays
Essex RM 16 2UL
Tel: 01375 376439

Cri-du-chat Syndrome Support Group

Penny Lane
Barwell
Leicestershire LE9 8HJ
Tel: 01455 841680

Down's Syndrome Scotland

Head Office
158-160 Balgreen Road
Edinburgh EH11 3AU
Tel: 0131 3134225
Email: info@dsscotland.org.uk

SOFT UK (Edward's Syndrome)

48 Froggarts Road
Walmley
Sutton Coldfield
West Midlands B76 8TQ
Tel: 0121 351 3122

Foetal Alcohol Syndrome Trust

15 Wasdale Road
Aintree
Liverpool L9 8AS
Tel: 0151 284 2900

FORESIGHT The association for the promotion of preconceptual care

28 The Paddock, Godalming

Surrey GU7 1XD

Web: www.foresight-preconception.org-uk

Fragile X Society

53 Winchelsea Lan

Hastings

East Sussex TN35 4LG

Tel: 01424 813147

Klinefelter's Syndrome Association

56 Little Yeldham Road

Little Yeldham

Nr Halstead

Essex C09 4QT

Tel: 01787 237460

The Research Trust into Metabolic Diseases in Children

(RTMDC)

Golden Gates Lodge

Weston Road

Crewe

Cheshire CW1 1XN

Tel: 01270 250221

Society for Mucopolysaccharide Diseases

46 Woodside Road

Amersham

Bucks HP6 6AJ

Tel: 01494 434156

Neurofibromatosis Association

82 London Road

Kingston-on-Thames

Surrey KT2 6PV

Tel: 020 8547 1636

National Society for Phenylketonuria (UK) Ltd

7 Lingley Lane

Wardley

Gateshead Ne10 8BR

Tel: 01845 603 9136 (helpline)

Prader-Willi Syndrome Association (UK)

2 Wheatsheaf Close
Horsell
Woking
Surrey GU21 4BP
Tel: 01483 724784

Royal National Institute for the Blind

Resource Centre, 9 Viewfield Place
Stirling FK8 1NL
Peter McConnachie
Tele: 01786451752
Email: Ekennedy@rnib.org.uk

The Scottish Society for Autistic Children

Head Office, Hilton House
Alloa Business Park
Whins Road
Alloa FK10 3SA
Scotland
Tel: 01259 720044
Fax: 01259 720051
Email: ssac@autism-in-scotland.org.uk
Web: www.autism-in-scotland.org.uk/

Tay-Sachs and Allied Diseases Association

Golden Gates Lodge
Weston Road
Crewe
Cheshire CW1 1XN
Tel: 01270 250221

Tuberous Sclerosis Association of Great Britain

Little Barnsley Farm
Catshill
Bromsgrove
Worcestershire B61 0NQ
Tel: 01527 871898

The Turner Syndrome Society

C/o The Child Growth Foundation
2 Mayfield Avenue
London W4 1PW
Tel: 020 8994 7625/020 8995 025

Unit 3 - A history of learning disabilities

Helen Atherton
Lecturer (Learning Disabilities)
University of Hull

Outline

This unit will:

- Briefly trace a history of learning disabilities from ancient through to recent times. This will be linked to the changing configuration of service provision for this group of people.
- Explore the range of attitudes and beliefs that societies often hold toward people with learning disabilities.
- Consider the range of factors that have underpinned the changing social position of people with learning disabilities in respective societies and will include a consideration of political, social and economic influences.
- Explore the influence of social policy documents and legislation on both the type and quality of service provision for people with learning disabilities.

Introduction

Demonstrating knowledge and understanding of the role of people with learning disabilities in history is vital to your understanding of their position in contemporary society. In the past people with learning disabilities have been perceived as objects of fascination and fear, resulting in them being both worshipped and, or, vilified. This unit will explore with you some of the ways in which society has labelled people with learning disabilities, and how these labels have subsequently affected the type and quality of care afforded to them. The effects of labelling are particularly important for you as providers of health care to this group. This is because it is known that stereotypical attitudes and beliefs generated about this group from history may result in the provision of poor health quality care. (Fitzsimmons and Barr, 1997)

People with learning disabilities in Ancient Greece and Early Modern Britain

Historically, those with learning disabilities have been labelled differently by respective generations depending on the attitudes and beliefs about the place of this group of people in society at any one time. Such labels have included subhuman organism, menace, unspeakable object of dread, object of pity, holy innocent, diseased organism, object of ridicule and eternal child (Wolfensberger, 1972). Early writings from Ancient Greece would suggest that people with learning disabilities were among a number of social groups considered to have a deleterious influence on developing societies and therefore needed to be eradicated as the following statement suggests:-

"...then this is the kind of medical and judicial provision for which you legislate in your state. It will provide treatment for those citizens whose physical and psychological constitution is good; as for others, it will leave the unhealthy to die, and those whose psychological constitution is incurably corrupt it will put to death."

(Plato, 427 - 347 BC in Lee, 1987)

Similarly in medieval times, the existence of people with learning disabilities in society was linked to people's beliefs about the relative influence of supernatural forces upon respective communities. In the absence of medical knowledge about the cause of disabilities, people's understanding of abnormal pathology was often based upon myth and legend, resulting in people with learning disabilities being both persecuted and fostered. Stratford (1996), for example, has made reference to the reliefs, sculptures and artefacts of the Olmec tribe who lived around the Gulf of Mexico from 1500 BC-AD 300. These depict people with Down's Syndrome as god-human hybrids resulting from sexual intercourse between senior members of the tribe and a jaguar, the sacred totem of the tribe. This led Stratford to conclude that people with Down's Syndrome were probably worshipped by the tribe and given preferential treatment. In support of this Miles (1996) has referred to a shrine in Gurjat, Pakistan where people with microcephaly lived. They were known as 'chuas' and their maintenance as a community was at one time essential as they were deemed to hold religious significance for the country. Eberly (1988) has discussed the influence of disabilities on the portrayal of mythical characters such as those found in Scottish folklore. She concluded that both fairies and hybrids (offspring resulting from sexual relations with non-humans such as supernatural forces or beasts) were more likely than not, based upon the characteristics of individuals with some form of congenital disability.

Examples of this included the *silkie* (seal people) found in the Orkney Isles who had webbed fingers and toes or the *Aberdeenshire Brownies* who had no separate fingers and thumb. Treatment of such creatures was varied. In the case of the Changeling found in Celtic folklore they were deemed to bring either luck to a community or be a bad omen. In the case of the latter, treatment of the Changeling included being placed on a red-hot shovel, pressed into red hot ashes, laid on a red-hot grid, being fed with leather or red-hot iron or being made to drink poison (Haffter, 1968).



Figure 3.1 Illustration of a silkie
Reproduced by kind permission of Sigurd Towrie

Despite the beliefs about the nature of people with learning disabilities in earlier times, they were generally still supported within their own communities. State assistance for their maintenance was not to become a feature of their care until early modern Britain where *De Prerogativa Regis* (1325) gave legal rights to either families or elected guardians to protect the lands of both people with learning disabilities ('idiots' or 'natural fools') and people with mental health problems ('lunatics') ensuring that they remained profitable (Kirman, 1975). Distinction between those individuals with mental health problems and those with learning disabilities was based on a series of tests that included being able to tell one's age, name one's parents and be able to name the days of the week. *De Prerogativa Regis* could be regarded as the first attempt at state managed community care for people with learning disabilities.

During the 17th century, state care for this group was revised and control was transferred to local parishes. Under the Elizabethan Poor Act (1601) people with learning disabilities were among a number of 'unattached' groups that were deemed to be a threat to the stability of the establishment. State response to this problem was their incarceration in poor houses and these may now considered to be early examples of institutional care for this group.

Essential

Reader Activity 3.1

A range of beliefs have existed about the nature of people with learning disabilities.

- 1) List your personal attitudes and beliefs about people with learning disabilities.*
- 2) List the ways in which attitudes and beliefs about people with learning disabilities are initially conceived and then possibly shaped.*

Having made these lists spend some time discussing your responses.

Eugenics and the problem of the feeble-minded

The perceived threat of people with learning disabilities on the establishment continued into the 18th and 19th centuries with revised vigour. The need for skilled labour arising from the new demands created by the Industrial Revolution (from about 1760 onwards) ensured greater prominence of the deficiencies in the social and economic skills of people with learning disabilities. As Race (1995) has suggested the Industrial Revolution brought about *"the measurement of people by their ability to cope with the new technological and commercial processes."* People with learning disabilities were not considered to be profitable members of society due to a lack of skill and intelligence and were therefore considered to be a financial burden. The Poor Law Amendment Act 1834 responded to this situation by ensuring that such groups were segregated in workhouses. However, the subsequent threat posed by people with learning disabilities was to extend beyond their limited usefulness for communities to reflect a belief that this group was one of a number responsible for the dissemination of social ills within the population. This was to result in a new series of strategies being employed to control this group of people.

During the late 19th and early 20th centuries, it was believed that the social ills of criminality, prostitution and alcoholism were closely associated with people with mild learning disabilities (Tredgold, 1909). This group were at that time known as the *'feeble-minded'*. It was believed that procreation amongst this group would ensure the spread of these social ills that would gradually erode society's physical, intellectual and moral core, resulting in its eventual collapse. This view is reflected in the following statement:-

" the danger lies in the fact that these degenerates mate with healthy members of the community and thereby constantly drag fresh blood into the vortex of disease and lower the general vigour of the nation." (Tredgold, 1909)

This fear was given all the more credence because people believed that the feeble-minded were among a number of groups deemed to reproduce at a more prolific rate than the rest of the population causing an eventual imbalance between the supply and demand of food (Malthus, 1798). In addition to this, it was believed that the condition of feeble-mindedness was a hereditary characteristic, like eye colour, passing between generations and resistant to any endeavours that sought its 'improvement' through education and training. Patterns of transmission were often demonstrated in pedigree charts such as the one displayed below that depicts the infamous Kallikak family.

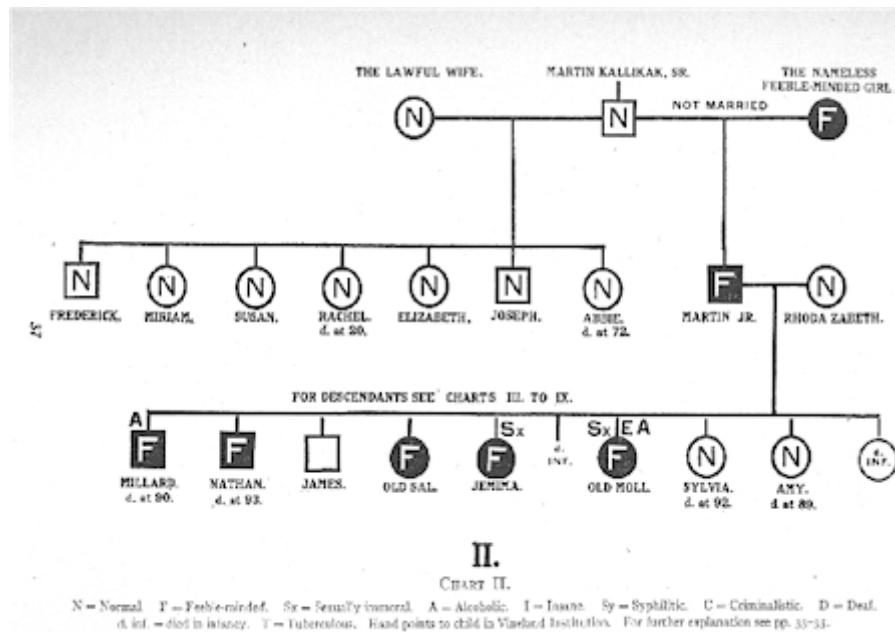


Figure 3.2 The Kallikak Family (Goddard, 1913)

State control of these individuals was again deemed necessary for the survival of society and eugenics was the chosen method of control.

The term eugenics was first coined by Francis Galton in 1883 and was defined as being;

"science of improving inborn human qualities through selective breeding"

(Galton, 1883)

Francis Galton disputed the theory of natural selection provided by his cousin Charles Darwin suggesting that nature could not be relied upon to select the most appropriate characteristics for the survival of the human race. Maintenance of society relied upon the use of artificial methods. He advocated two forms of eugenics; one was to promote procreation in the intellectual classes, a process termed *positive eugenics*, whilst the other was inhibition of procreation amongst classes that were considered to be socially deviant, a process termed *negative eugenics*. Negative eugenics was operationalised in Great Britain in the form of institutionalisation. This was the method advocated by the 1909 Royal Commission set up to investigate the 'problem' of the feeble-minded. In other countries, other methods were employed. This included mass genocide in Germany (Burleigh, 1994) and compulsory sterilisation in the Nordic countries (Tannsjo, 1998). North America at this time also opted for a selective immigration policy.

In 1913 the Mental Deficiency Act was introduced in Great Britain to legalise the detention of individuals with varying degrees of mental defect. It identified four categories of mental defect that provided the necessary diagnostic criteria for the certification of this group. These four categories have been presented in Box 3.1.

Idiots - persons so deeply affected in mind from birth or from an early age as to be unable to guard themselves against common dangers.

Imbeciles - persons who whilst not being as defective as 'idiots' were still incapable of managing their own affairs.

Feeble-minded persons - persons who whilst not being as defective as imbeciles still required care, supervision and control for their own protection or for the protection of others.

Moral defectives - persons who from an early age display some permanent mental defect coupled with vicious or criminal propensities on which punishment has had little or no effect.

Box 3.1 Diagnostic labels of the Mental Deficiency Act 1913

The First World (1914-1918) delayed the implementation of the Mental Deficiency Act, however, the findings of the Wood Committee (1929) resulted in an acceleration of policy with the recommendation that 100,000 individuals suffering from mental deficiency be immediately institutionalised.

Essential

Reader Activity 3.2

Eugenics is a flawed theory conceived of over one century ago but can you think of any contemporary medical or social interventions that are aimed at controlling the type and quality of individuals or groups present within the population?

Life in an institution

Initial attempts at institutional care for people with learning disabilities (early 19th century) included an educational philosophy of care that reflected the belief that mental defect was sensitive to modification. However, later models of institutional care became more custodial and less reforming reflecting the new belief that feeble-mindedness was resistant to change. The emphasis was now on the protection of the wider society.

"You weren't allowed out of the hospital. You had to write up and ask could you leave the grounds. You had to ask the medical or write to the doctor and ask them. You couldn't just go across the road and look at the shops, it wasn't allowed unless you wrote up and asked. I didn't go out because I got so used to not going out. You'd get lost if you're not used to it"

Mabel Cooper - *Forgotten Lives* (1997)

The Wood Committee (1929) had advocated the formation of self-sufficient 'colonies' that would cater for all groups of mental defect, regardless of age or level of disability. The term 'colony' was to be eventually replaced with the term 'hospital' with the implementation of the NHS Act 1946 under which control of colonies was transferred from local councils though to Regional Hospital Boards.

Lennox Castle is one example of a long stay hospital for people with learning disabilities in Scotland. Opened in 1936 it was initially called '*Lennox Castle Certified Institution for Mental Defectives*' and had places for six hundred males and six hundred females. It was the largest institution in Scotland. It initially consisted of twenty dormitory blocks with sixty beds in each dormitory. Facilities for male and female patients including dining rooms were segregated. There were also segregated workshops for patients that included a laundry for the females. Many hospitals at this time relied on the labour of inmates for the maintenance of the hospital (Wood Report, 1929). Orme (2002) recalls his experiences of working as a health care assistant in a 'mental handicap' hospital near Edinburgh in the early 1970s. He remembers having to care for 40 patients on one ward, with 3 staff, one bath and two showers. Patients were also expected to share clothes except on a Saturday which was visiting day. He also remembers the use of punishment to ensure conformity to the hospital regime and this was a common feature of institutional care. (Goffman, 1961)



Figure 3.3 Lennox Castle Hospital, Lennoxtown, near Glasgow
Crown Copyright: RCAHMS

"Typical punishments took the form of withholding privileges such as cigarettes, or confining patients to the ward. For serious misdemeanours, individuals could be made to stay in bed all day. This was called 'pyjama punishment.' " (Orme, 2002)

Admission to a hospital such as Lennox Castle could be at the request of the family, or by a number of people in the form of a petition, and was sanctioned on the basis of the signatories of two doctors, one of whom was officially approved for the purpose. Diagnosis and subsequent certification was undertaken using a number of 'tests' to prove the inability of an individual to live in society. These tests included being able to differentiate between a fly and a butterfly or a stone and an egg; to state the similarities between an apple and an orange; to suggest how many feathers there were on a chicken or how many miles it was to America (National Council for Civil Liberties, 1951; Potts and Fido, 1991). It would appear that little attempt was made to assess a person's individual capabilities so it could be concluded from this that institutionalisation was an inescapable outcome for many people.

<i>Essential</i>	<i>Reader Activity 3.3</i>
------------------	----------------------------

Refer to the narratives and look for Alan's stories. You can see he spent many years in a long stay hospital. He moved to accommodation with support and is now in temporary accommodation with a voluntary organisation while he waits to return to his refurbished accommodation.

He recalls;

"When I was younger I saw two nurses, a male and female threatening other patients by shouting and bullying them. I reported this, yet nothing was done about it. I saw an incident where a guy couldn't get out of bed and the nurses were being very rough with him. They were threatening him saying they would hurt him if he didn't get out of bed."

Using this case study and the recommended reading material at the end of this chapter try and formulate a picture of the lives of people with learning disabilities in long stay institutions. This may tell you something of why some people with learning disabilities are frightened of hospitals and the people who work in them.

The introduction of the concept of community care and the principles of normalisation.

During the 1950s and 1960s a number of significant events brought the appropriateness of institutional care for people with learning disabilities into question. These events began to pave the way for the eventual introduction of community care for this group and included the increasing influence of the human and civil rights movements that culminated in the European Convention on Human Rights (1950). Attention was also being paid to the damaging effects of institutionalisation on the development of the individual. In the 1960s, a number of reports into the state of institutional care in Great Britain identified impoverished and squalid living conditions, lack of privacy for patients, an emphasis on predominantly physical care and custodial attitudes among staff. The most famous of these was the '*Report of the Committee of Enquiry into Ely Hospital*' (Howe Report, 1969). In addition to this, these reports followed a number of sociological studies undertaken in the 1950s that demonstrated that a significant number of people living in institutions had both the intellectual and social capabilities to live adequately in the community. (Race, 1995)

The above changing social influences were to be consequently reflected in a modified social and political agenda. In 1957, the recommendations of the Royal Commission on the Law relating to Mental Illness and Mental Deficiency were to pave the way for the new Mental Health Act 1959 that ended compulsory certification enabling the discharge of many people with learning disabilities from long stay institutions. In 1971 the White Paper '*Better Services for the Mentally Handicapped*' was introduced in Great Britain that advocated a 50% reduction in hospital places by 1991 and an increase in the provision of local authority based residential and day care. It also called for an end to custodial methods of care in hospitals and recommended the re-training of hospital staff. In 1979 The Jay Report re-emphasised the need for local authority led care, and importantly, a service philosophy based on the principles of normalisation.

The concept of normalisation was initially defined as;

'utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible'

(Wolfensberger, 1972)

In the 1980s it was redefined as '*social role valorisation*' to include reference to strategies used in the creation, support and defence of valued social roles for people at risk of devaluation (Wolfensberger, 1998). In Great Britain, the principles of normalisation adopted were those interpreted by O'Brien and Tyne (1981) as the five service accomplishments. These have become the

developmental goals to which organisations then and organisations now strive towards and have been summarised in Box 3.2.

Community Presence - ensuring that service users are present in the community by supporting their actual presence in the same neighbourhoods, schools, workplaces, shops, recreation facilities and churches as ordinary citizens

Choice - ensuring that service users are supported in making choices about their lives by encouraging people to understand their situation, the options they face and to act in their own interest both in small everyday matters and in such important issues as who to live with and what type of work to do.

Competence - developing the competence of service users by developing skills and attributes that are functional and meaningful in natural community environments and relationships, i.e. skills and attributes which significantly decrease a person's dependency or develop personal characteristics that other people value.

Respect - enhancing the respect afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, and forms of dress and use of language promote perception of people with disabilities as developing citizens.

Community participation - ensuring that service users participate in the life of the community by supporting people's natural relationships with their families, neighbours and co-workers and, when necessary, widening each individual's network of personal relationships to include an increasing number of people.

Box 3.2 O'Brien and Tyne's Five Service Accomplishments (1981)

Since the introduction of the O'Brien and Tyne's Five Service Accomplishments into Great Britain, there has been a steady stream of policy and legislative documents that have influenced service provision for people with learning disabilities. In 1989 the White Paper '*Caring for People*' confirmed the government's commitment to the development of locally based health and social care services. Following on from this, the government introduced *The NHS and Community Care Act 1990* to provide the necessary support structures to enable, where possible, people to remain in their own homes thereby reducing the demand for long term care. These structures included an increase in the range of domiciliary, respite and day services including the promotion of independent care options and a greater emphasis on supporting informal carers. Central to these developments was the provision of a service that would be tailored to the needs of individuals and

the introduction of community care assessments that would be undertaken by social services with the assistance of health care professionals.

It is the case that the rate of deinstitutionalisation for people with learning disabilities residing in long stay hospitals in Scotland has been a much slower process than observed in other parts of Great Britain. This has been attributed to a diversity of reasons. These include: the initial absence of a national closure programme; funding disputes including resource transfer; poor inter-agency collaboration; opposition from parent and professional groups; and the debate over the future service configuration for those people with learning disabilities and additional complex needs such as challenging behaviour (Stalker and Hunter, 1999). In 2000, however, the first Scottish White Paper on learning disabilities was published. *'The Same as You'* (Scottish Executive, 2000) detailed a comprehensive review of services for people with learning disabilities in Scotland and included a series of recommendations for future development. In addition to changes in day care provision and the opportunity for people with learning disabilities to have more control over their lives through the introduction of personal life plans and direct payments, it also outlined plans for the closure of Scotland's remaining long stay institutions by 2005. Whilst criticism continues to be lodged at the speed to which this process has been undertaken (Mitchell, 2001), it is clear that the range of services available to people with learning disabilities in Scotland continues to grow and reflect the diversity of needs associated with this group (Atherton, 2000). In addition to this recent legislation implemented has sought to consolidate the human and civil rights of this group of people. The Adults with Incapacity (Scotland) Act (2000) is a piece of legislation yet to be replicated in other parts of Great Britain and is therefore unique to Scotland. It seeks to protect the decision-making rights of people with learning disabilities and ensures the appropriate support to those without the necessary capabilities.

Conclusion

It is the case that attitudes and beliefs about people with learning disabilities have been the subject of change throughout history and have consequently affected the configuration and delivery of services to this group. Traditional models of institutional care have eventually been replaced by models of community care and social inclusion, reflecting a greater appreciation of the human and civil rights of people with learning disabilities. Whilst the rate of change in Scotland has been relatively slow as compared to other parts of Great Britain, it could be argued that this has enabled a more accurate assessment and response to the needs of people with learning disabilities. In addition to this, recent policy and legislation reflects a clear commitment to a more person centred approach to care than previously observed in this country. Since the major recipients of changes in services are people with learning disabilities themselves, the final word is taken from a former patient of Lennox Castle Hospital. Ernest Bell spent 36 years in long term care and now has his own home.

"My life is better now....I like the fact that I have my own space if I want.....But one of the nicest things would be that there is a bit of love and a lot of laughter in my home"

(Bell, 2002)

<i>Essential</i>	<i>Reader Activity 3.4</i>
------------------	----------------------------

The history of people with learning disabilities is punctuated with a number of key developments that have provided the basis for current service provision.

Draw a timeline that depicts the key milestones in the history of learning disabilities.

References

- Adults with Incapacity Act (2000). Edinburgh: Scottish Executive.
- Atherton, H.L. (2000) Our friends in the north. Nursing Times, 96(38) pp30-31.
- Atkinson, D.; Jackson, M. and Walmsley, J. (1997) Forgotten lives. BILD: Kidderminster.
- Bell, E. (2002) cited in Scottish Executive New chapter for Lennox residents available at:
<http://www.scottishexecutive.gov.uk/pages/news/2002/04/Enw004.aspx> - retrieved 2/09/03.
- Burleigh, M. (1994) Death and deliverance: euthanasia in Germany 1900-1945. Cambridge: Cambridge University Press.
- DHSS (1971) Better services for the mentally handicapped. Cm. 4683. London: HMSO.
- DOH (1989a) Caring for people: community care in the next decade and beyond. Cm.849. London: HMSO.
- Disability Discrimination Act (1995) London: HMSO.
- Eberly, S.S. (1988) Fairies and the folklore of disability: changelings, hybrids and the solitary fairy. Folklore, 99(1) pp58-77.
- Elizabethan Poor Law Act (1601) HMSO: London.
- Council of Europe (1950) European convention on human rights. Rome: Council of Europe.
- Fitzsimmons, J and Barr, O (1997) A review of the reported attitudes of health and social care professionals towards people with learning disabilities: implications for education and further research. Journal of Learning Disabilities For Nursing, Health and Social Care, 1(2) pp57-64.
- Galton, F. (1883) Inquiries into human faculty and its development. London: Macmillan.
- Goddard, H.H. (1931) The Kallikak Family. New York: The Macmillan Company.
- Goffman, E. (1961) Asylums: essays on the social situation of mental patients and other inmates. Harmondsworth: Penguin.

Haffter, C. (1967) The changeling: history and psychodynamics of attitudes to handicapped children in european folklore. Journal of the History of the Behavioural Sciences, 4, pp56-61.

Howe Report (1969) Report of the Committee of Enquiry into allegations of ill treatment of patients and other irregularities at the Ely hospital, Cardiff. Cm 3975 London: HMSO.

Human Rights Act (1998) London: HMSO.

Jay Committee (1979) Report of the Committee of Enquiry into mental handicap nursing and care. Cm. 7468 London: HMSO.

Kirman, B. (1975) 'Historical and legal aspects' in Kirman, B. and Bicknell, J. (eds) Mental handicap. UK: Churchill Livingstone.

Lee, D. (1987) Plato: the Republic. (2nd edn. rvsd) London: Penguin.

Malthus, T.R. (1798) An essay on the principle of population. Edited by Flew, A. (1970) Harmondsworth: Penguin.

Mental Deficiency Act (1913) London: HMSO.

Mental Health Act (1959) London: HMSO.

Miles, M. (1996) Pakistan's microcephalic "chuas" of Shah Daulah: cursed, clamped or cherished? History of Psychiatry. 7(4) pp571-590.

Mitchell, D. (2001) Scotland puts learning disabilities centre stage. Society Guardian available at:
<http://society.guardian.co.uk/socialcare/story/0,7890,465057,00.html> - retrieved 12/09/03.

National Council for Civil Liberties (1951) 50,000 outside the law: an examination of the treatment of those certified as mentally defective. London: National Council for Civil Liberties.

National Health Service and Community Care Act (1990) London: HMSO.

O'Brien, J. and Tyne, A. (1981) The principle of normalisation: a foundation for effective services. London: CMH.

Orme, E. (2002) A portrait of the nurse as a young man. Nursing Times, 98(16) pp30-31.

Poor Law Amendment Act (1834) London: HMSO.

Potts, M. and Fido, R. (1991) A fit person to be removed. UK: Northcote House.

Race, D. (1995) Historical development of service provision. In Malin, N. (ed) Services for people with learning disabilities. London: Routledge.

Royal Commission (1957) Report of the Royal Commission on the law relating to mental illness and mental deficiency, 1954-57. Cm. 169 London: HMSO.

Scottish Executive (2000) The same as you? A review of services for people with learning disabilities. Edinburgh: The Stationary Office.

Stalker, K. and Hunter, S. (1999) To close or not to close? The future of learning disability hospitals in Scotland. Critical Social Policy, 19(2)pp177-194.

Stratford, B. (1996) In the beginning. In: Stratford, B. and Gunn, P. (eds) New approaches to Down Syndrome. London: Cassell.

Tannsjö, T. (1998) Compulsory sterilisation in Sweden' Bioethics, 12(3) pp236-249.

Tredgold, A.F. (1909) The feeble-minded - a social danger. Eugenics Review, 1, pp97-104.

Tredgold, A.F. (1952) A textbook on mental deficiency. London: Baillière, Tindall and Cox.

Wolfensberger, W. (1972) The principle of normalisation in human management services. Toronto: National Institute of Mental Retardation.

Wolfensberger, W. (1998) A brief introduction to social role valorisation: a high order concept for addressing the plight of societally devalued people, and for structuring human services. 3rd ed. Syracuse, New York: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).

Wood Report (1929) Report of the Mental Deficiency Committee. London: HMSO.

Recommended reading

Atkinson, D. and Williams, F. (eds) (1990) Know me as I am. London: Hodder and Stoughton.

Atkinson, D.; McCarthy, M.; Walmsley, J.; Cooper, M.; Rolph, S.; Aspis, S.; Barette, P.; Coventry, M.; Ferris, G. (2000) Good times, bad times: women with learning disabilities telling their stories. Kidderminster: BILD.

Barron, D. (1996) A price to be born. Harrogate: Mencap Northern Division.

Brigham, L.; Atkinson, D.; Jackson, M.; Rolph, S.; Walmsley, J. (2000) Crossing boundaries. Kidderminster: BILD.

Deacon, J. (1974) Tongue tied. UK: National Society for Mentally Handicapped Children.

Plates

Illustration of silkie, available at
<http://www.orkneyjar.com/folklore/selkiefolk/index.html> - retrieved
02/9/03.

Pedigree of the Kallikak family (Goddard, 1931).

Photograph of Lennox Castle reproduced with kind permission from The Royal
Commission on the Ancient and Historical Monuments of Scotland.

Resources

Resources on the history of idiocy

<http://www.personal.dundee.ac.uk/~mksimpso/>

Image archive on the American eugenics movement

<http://www.eugenicsarchive.org/eugenics>

Learning disability history

<http://www.open.ac.uk/shsw/Research/Idsite/index.html>

A history of mental disability 1000AD-2000AD: from idiocy to intellectual disability

<http://caslater.freesevers.com/disability1.htm>

Disability History Museum

www.disabilitymuseum.org

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.

Essential	Reader Activity 4.1
------------------	----------------------------

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.

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).

<i>Essential</i>	<i>Reader Activity 4.2</i>
------------------	----------------------------

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.

<i>Essential</i>	<i>Reader Activity 4.3</i>
------------------	----------------------------

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?

<i>Essential</i>	<i>Reader Activity 4.4</i>
------------------	----------------------------

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/

Department of Health (1999) Once a day. London: NHS Executive.

Department of Health (2001) Valuing people: a new strategy for learning disability for the 21st century. London: The Stationery Office.

Disability Discrimination Act (1995) London: HMSO.

Eldridge, P. (2003) Ethics and research involving people with learning disabilities. In: Markwick, A. and Parrish, A. Learning disabilities: themes and perspectives. Edinburgh: Elsevier Science pp65-80.

Enable (7 Oct 2002) Adults with Incapacity Act (2000). Available at,
<http://www.enable.org.uk/ld/awi/>

Ferris-Taylor, R. (2003) Communication. In: Gates, B. Learning disabilities: towards inclusion. Edinburgh: Churchill Livingstone. pp255-287.

Hart, S (2001) Spotlight on consent. Learning Disability Practice. 4. (4) pp14-17.

Jenkins, R.; Mansell, I. and Northway, R. (2003) Specialist learning disability services in the UK. In: Gates, B. Learning disabilities: towards inclusion. Edinburgh: Churchill Livingstone. pp349-367.

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 in

Unit 5 - Working with people with learning disabilities

Helen Atherton and Bob Gates

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 a 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.

<i>Essential</i>	<i>Reader Activity 5.1</i>
------------------	----------------------------

Access the web address below for Dunbar's Inquiry and read the sections identified below;

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.

<i>Essential</i>	<i>Reader Activity 5.2</i>
------------------	----------------------------

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.

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.

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

- Adults with Incapacity (Scotland) Act (2000) London: HMSO.
- Alaszewski, A.; Gates, B.; Ayer, S.; Manthorpe, G. and Motherby, E. (2001) Education for diversity and change: ENB research Highlights. London: The English National Board for Nursing, Midwifery and Health Visiting.
- Band, R. (1998) The NHS - health for all. London: Mencap.
- DOH (1998) Signposts for success in commissioning and providing health services for people with learning disabilities. London: NHS Executive.
- DOH (1999) Once a day. London: NHS Executive.
- DOH (2001) Reference guide to consent for examination or treatment. London: DOH.
- Dunbar, I. (2003) Inquiry under the fatal accidents and sudden death inquiry (Scotland) Act 1976 into the death of James Mauchland. Sheriffdom of Tayside, Central and Fife at Dundee, Scotland.
- Ferris-Taylor, R. (2003) Communication in Gates, B. (ed) Learning disabilities: toward inclusion. Edinburgh: Churchill Livingstone.
- Fitzsimmons, J. and Barr, O. (1997) A review of the reported attitudes of health and social care professionals towards people with learning disabilities: implications for education and further research. Journal of Learning Disabilities for Nursing, Health and Social Care, 1(2) pp57-64.
- Fox, D. and Wilson, D. (1999) Parents' experiences of general hospital admission for adults with learning disabilities. Journal of Clinical Nursing, 8, pp610-614.
- Rutter, S. and Seyman, S. (1999) "He'll never join the army" - a report on a Down's Syndrome Association survey into attitudes to people with Down's syndrome amongst medical professionals. London: Down's Syndrome Association.
- Scottish Executive (2000) The same as you? A review of services for people with learning disabilities. Edinburgh: The Stationery Office.
- Slevin, E. and Sines, D. (1996) Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact, and graduate-non-graduate status, a comparative study. Journal of Advanced Nursing, 24, pp1116-1126.

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?'

The Stationery Office Bookshop

71 Lothian Road

Edinburgh

EH3 9AZ

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

The narratives

Marie

I'm in supported housing now and I'm getting the right treatment. Recently I was asked by my GP to participate in the training of nurses to highlight the problems that people with disabilities can encounter. I am looking forward to this as it should prove beneficial to all concerned.

Story 1

When I was 10 years old, I was taking 30 tablets a day for epilepsy. I was told that I would not live to see my 16th birthday. I am now approaching my 41st birthday and my medication is down to 12 tablets a day. I have not suffered an epileptic seizure for six years. When I was told of my life expectancy, I was living in a children's home and I was told by Doctors in my general hospital.

When I was on 30 tablets that was before all the modern medication came into force. Purdie can tell you what seizures I was having. She would know - the two of us went to the same centre.

Story 2

The only problem I have encountered with the NHS is when my epilepsy was questioned by a student Doctor. I felt the Doctor thought I was faking my condition. However, a senior Doctor put the student straight and reassured me and told me not to worry. I felt if the student had checked my medical history, this need not have happened.

I was having an EEG at the time and she didn't even ask my medical history. My file was as thick as the Guinness Book of Records! She discharged me but I only got as far as Casualty and then I had a fit. The consultant gave her a row!

That should never have happened at all - it's terrible. That time when I was taken back into casualty, it happened in front of an ambulance. Casualty phoned the Neurology Department and the consultant came in and saw me and ended up getting the police involved and she was sacked on the spot.

Shona

I am a woman in my late thirties who works for a self-advocacy organisation.

Story 3

My first story is about Practice Nurses giving out wrong information and getting people really confused.

I use sharp pins for testing my blood sugar level. I said one time when I was at the hospital, what do I do with these? They said, if you take them to the doctors, they will get rid of them for you. But the Practice Nurse said, "I will do it this time but not again".

So the hospital was saying one thing and the Practice Nurse something else. I was really confused. I live in a flat and I don't just want to put the sharps in the bin where children might find them.

I phoned the Practice Nurse and the hospital. All you need is a thing to take away the sharp edges of the pin. They don't make it easy!

Story 4

Nurses are scared of us - why?

I spent two months in hospital 5 years ago and I felt very lonely because I picked up a bug in hospital probably. I was treated no different.

Why don't nurses see me as a person not as someone with a condition?

There are some things I want to say.

I think there is a lack of information.

It is not good if people have to wait a long time for an appointment.

What happens if you are an emergency? Are you left to attend this appointment on your own?

Scott

Story 5

My name is Scott. I live by myself in a ground floor flat. I work a number of days a week in a garden job. My community nurse comes to visit me from time to time.

When I was 10 years old I had an eardrum operation on Christmas Eve. I was ten and a half weeks in hospital. I had thick bandages around my ears and nurses came and looked. When I asked questions they just walked away. It made me feel like I wasn't being treated like others. There was some 2nd year and some 3rd year nurses. It was better when there were Sisters. Sisters told you a lot more and took a lot more time to talk to you.

They made me feel like I wasn't there when they kept ignoring me. I wanted to know as much as possible. This was the longest time I'd ever been in hospital. On Christmas Day the nurses wore tinsel and made it feel more Christmassy.

I can still remember the way I felt.

Story 6

After mother passed away I collapsed on the way to the shops and my ulcers burst. Next thing I remember after my operation I was in a lift. I don't like lifts! I told them but there was nothing they could do. A nurse was waiting at the other end. The lift broke down. The nurse shouted at me for being so long. I wasn't sure what was happening. I was not expected. I felt that even if nurse was tired she shouldn't have shouted. The next thing I remember I was in bed. I told them about what I remembered about coming round. Nurse didn't give me a lot of information. They don't seem to give you enough information - they seem to give you less if your have a learning disability. Maybe they think you won't understand. They tell the person in the bed next to you, but they don't tell you.

It doesn't make you feel great when they are taking blood 3 or 4 times a day. I wanted to know why they were doing it. I was in hospital for five and a half weeks. They didn't give me any food. They didn't tell me why not. I was hungry.

Only twice I had a visitor. One was from the Church. There were one or two nice nurses. If they noticed you didn't have a visitor they would spend half an hour with you chatting. It was nice and it passed some time. I was feeling a bit depressed after mother had died. I couldn't go into her room without hearing her voice. I was grieving without knowing it. The nurses didn't talk

about it. I don't think they knew what to say. I wrote how I felt on my computer.

The information I was given wasn't what I wanted. They wouldn't tell me why they were taking blood. They refused to tell me. I felt they could have told me. I had a sore arm after some weeks. I had injections for the pain after the operation - every 4 hours. The stitches burst and I was asked if I'd lifted anything heavy. I had to go back into hospital for 6 days. There were some good experiences. The nurses who spent some time with you chatting and giving information - there wasn't many of them! The Doctor gave me a tour of the hospital.

Nurses should give people more information. They should show you what the ward is like. You should be shown what the Nurses and Doctors are like 2/3 weeks before going. You should be told what will happen. Their attitudes need to change. They should give everyone with a learning disability the same information as others. They should treat them the same as everyone else. They should take more time with people. They should tell people when medication changes. Doctors and Nurses have different ways of changing medication and telling you about this.

I don't always know how they feel.

Alan

Alan spent many years in a long-stay hospital. He moved to accommodation with support and is now in temporary accommodation with a voluntary organisation while he waits to return to his refurbished accommodation.

Story 7

When I was younger I saw two nurses, a male and female, threatening other patients by shouting and bullying them. I reported this, yet nothing was done about it.

I saw an incident where a guy couldn't get out of bed and the nurses were being very rough with him. They were threatening him saying they would hurt him if he didn't get out of bed.

Story 8

I went to see my GP by myself. I tried to explain how I was feeling and he told me to get out, he just would not listen to me. I was really upset about this.

Story 9

When my Dad died I felt really alone with no one understanding my feelings. I felt I needed more support from my family and others.

My mother was also sick at the time and I was worried I would lose her as well. I never told the staff at the hospital how I felt because apart from a couple of them I never felt like they gave me any help, understanding or support.

Purdie

I share a flat. I train doctors and nurses about health issues for people with learning disabilities. I think it is important to say about the good things that are happening.

Story 10

I made an appointment myself at the minor ailments clinic. I knew this was the place I would be seen by a Doctor and Nurse who would look into my problem, which was not serious. I already knew about the clinic. It lets my GP see more serious problems. The medical ailments clinic is a way of making the health service better.

Although I was not going to see my usual Doctor, who I think is good; I knew that the Doctor I would see would have read my notes. My GP is very good about putting down my information in the notes.

When I went to the minor ailments clinic I was first seen by a nurse. The clinic sees two people at the same time and the Doctor was in a different room when I saw the Nurse. I gave the Nurse information about my sore leg. I am lucky as I am able to say how many times I injured my leg. When I was 18 and also 21 I slipped on black ice. I fell again coming out of a shop when I was 32 and again two years ago.

When the Doctor came in he was able to talk to me and read the notes the Nurse had taken. I said there was something else wrong apart from my leg. The Doctor told me that the clinic only dealt with one thing. He examined my leg and told me I had damaged my cartilage and it may mean surgery. I said I had a karate competition and he said I better not compete this time.

I was surprised when the Doctor told me the problem was my cartilage. I was stunned when I heard what the Doctor said. "Oh no, not more surgery." I have had a lot of hospital appointments because I also have a condition called neurofibromatosis.

The Nurse had the right attitude. She greeted me in a friendly way. "How are you? I haven't seen you for a while".

At the clinic I found out what was wrong with my leg. However, I was not able to talk about my other problem. I was told that if my leg problem continued, the clinic would make an appointment for me to see an orthopaedic doctor. I don't think the Doctor or Nurse picked up my worries about more surgery.

I made the appointment myself. I only take a support worker when I go to the geneticist. The tenants where I live are not treated any different from anyone else. We are treated with the same respect as everyone else.

Callum's stories

These stories are to be used in group discussions facilitated by a lecturer- please wait for instructions as to how to use them.

My son is now 39 years old. He is a gentle giant, very caring, with a wonderful personality. People like him. He is like every other young man - he takes a great deal of joy in winding his mum up - in fact in winding anybody up! He enjoys using adapted bikes, wheelchair ice-skating, motorbike rallies, bowling, music, pubs ... just one of the guys.

He has profound learning disabilities and does not speak, although he can communicate in other ways if you know him. He also has severe epilepsy, and a long history of drop attacks and absences. When Callum was first diagnosed, he could take between 80 - 100 drop attacks each day, falling to the floor heavily each time. Until he took epilepsy when he was 18, he had good mobility. Since then his drop attacks and the medication given to treat them have created major mobility problems.

Story 1: Callum's epilepsy

Callum has a history of brittle bones, due to the use of Phenytoin to control his seizures, which has this side-effect. It also causes swollen gums. Despite his history of falling during drop attacks, nobody thought to tell us about these side-effects until he had been on the drug for two years. Over those two years, the number of broken bones he had was unbelievable.

We were given this information by a young junior doctor after he had been admitted to hospital with a broken ankle. By then he had already had a fracture in the arch of the foot, one in his collarbone, another of the elbow and five fractures in his ankles. He had also broken his thumb in two separate places, which was so bad it had to be pinned. On another occasion, he fell twice in a toilet, hitting his face on a grab rail and breaking his nose.

Although Callum seems to accept pain as part of his life can you imagine what all those fractures felt like?

At the next neurology appointment, we talked to the doctor about this, who then agreed to take him off Phenytoin.

Nevertheless, his bones remained brittle after he stopped taking Phenytoin and he was still taking drop attacks. During one of these, he had seven fractures in his lower leg in total, five at the front and two at the side.

He was taken to Accident and Emergency in the small hours of the night and was moved to A & E at another hospital because there was no radiologist available in the first to take the photographs. We were virtually accused of causing the damage ourselves. Callum was not offered any pain relief until

the following morning at 7 a.m. This was finally given so that he would "comply" with having a plaster put on. Only at 8.30 am, was he finally admitted to a ward and given a bed.

When we visited later in the day, Callum was sitting in a chair beside his bed with his leg on a footstool. He was grey. We asked if he had been given any pain relief. The answer was "No - he didn't ask."

This was after we had told all staff in detail about Callum's lack of communication.

I complained about this verbally and in writing but have never had any answer. In my letter I suggested that there should be a member of staff in the health team with at least *some* knowledge of learning disabilities. This was twenty years ago.

Since then he has also broken the metatarsals in his toes four times.

On another occasion, I overheard a nurse saying, "I don't mind them when they're small, but I can't stand them when they are adults. They scare me." Callum was listening.

Over the years because of a poor dental service and the side effects of all the medication he has had to take, Callum has now lost all his teeth. This has changed his smile but not his sense of humour. Apart from the Phenytoin, which affected his gums, many of the other medications including lactulose, fibrogel, ampicillin and other antibiotic syrups, have sugar in them.

After his first seizure at 18 he chipped the corner of a front tooth, and because of poor understanding between the dentist and Callum, he had to have a general anaesthetic. Callum had a hospital admission to have the tooth repaired and arrived back from surgery minus his smile - having had four front teeth taken out. I was devastated. I was so upset that when I went back to my car, I couldn't reverse the car. A man had to offer to do it for me.

Before Callum went to theatre, two junior doctors, an anaesthetist and a senior doctor had tried three times to persuade me to sign a form to consent to Callum having all his teeth out. I refused. One doctor said: "I don't know why you are worried - he'll never be marriage fodder." I was also told I was "a very bad mother to put my son's life in danger, because didn't I realise that he could die if he had to have a GA for more dental treatment." That was really intimidation.

Story 2: Deterioration in Callum's health

Four years ago Callum moved out of the family home and into his own house, shared with three other men. They receive twenty-four hour support. This move has not been without its own problems. There have been difficulties with the GP practice. Over the last year his healthcare needs were not properly monitored. Callum was depressed and after seeing his GP and a psychiatrist there was a possibility he was clinically depressed. He also kept having recurrent urinary infections.

In August the GP made a major prescribing error, which led to a massive overdose of a highly toxic drug. The drug Topirimate was supposed to be increased by 25 mg *weekly*, but this increase was written up as *daily*. Over a period of 7 days they took him up to 200 mg daily. This was on top of his other 4 anti-convulsant drugs. Apparently you are not supposed to have more than 3 at any one time, because of drug interactions. Callum was in a highly drugged state, his head down, like a huge heavy weight. He couldn't focus, drifting in and out of sleep, never conscious for any length of time. He seemed like a junkie might look. Because he was so drugged, he wasn't mobile - as he had been before with assistance.

The error was picked up by his neurologist after a week, but the dosage could only be reduced gradually because of the risk of much worse seizures if taken down too quickly,

There was a possibility that the overdose could damage his liver and kidneys, but it didn't. However, from the August he was going downhill, culminating in November being admitted to an acute hospital. He was still on a big dose of Topirimate. His symptoms were high temperature, not eating or drinking, drifting in and out of consciousness. Meningitis wasn't being ruled out. The consultant diagnosed a chronic infection, very high up the urinary tract.

Because Callum was mostly unconscious, the staff only saw a young man who in their eyes was very disabled, not a person with a great personality and a very enjoyable lifestyle. We had to point out to them the individual he was.

He was admitted on Friday. On the Saturday, I queried his medication. I knew they had made another mistake in his medication. He was getting what was on his chart, but had been written up for half his correct dose. They didn't discover that until the following Thursday, despite my telling them of my concern.

The ward had no hoist or sling. Visiting family and carers had to wash Callum and change his clothing.

The infection did clear up but that Thursday evening, the consultant took us to one side and informed us that he couldn't see Callum getting any better, and what did we want to do? I asked if Callum were in a vegetative state and he replied 'No', but he didn't think he would get any better than he was. He

again repeated the question, "What do you want me to do?" He didn't explain what this question meant, even when I asked him to.

The following morning we arrived at the hospital to be told that Callum was being transferred to another hospital. Nobody explained why. The consultant took us aside and explained the reason why he asked his question. He said that when one of his patients reaches the end of their life, their relatives normally just want them to 'be made comfortable'. I wondered if I would have been treated the same.

Later that morning Callum was transferred to a big teaching hospital. The first day was just a maze of doctors and nurses, coming and going and asking the same questions. I was exhausted and it was all very traumatic. Over the weekend, Callum was fighting for his life. On the Monday afternoon, a houseman took me to a side ward and explained there was no hope for Callum - he was going to die. He asked me what did I want done if it got to the stage where he would need to be resuscitated. He also said that he didn't think that Callum 'qualified' for an intensive care bed. Any treatment would only be given on the ward. I said to him that Callum was far too young to die and we wanted the same quality of support for him that we would expect to receive ourselves.

In the early hours of the following morning, the phone rang. The registrar rang to inform us that Callum was being moved to a side ward. We went straight away and arrived at the hospital to be met by the registrar - a very cold young woman. She proceeded to tell us that Callum's quality of life was not worth fighting for. When we argued the point, she produced her senior - a neurologist. He agreed with her and added, "After all Callum has uncontrollable epilepsy." I phoned for extra support from family and friends with influence. We argued with the doctor who then brought in the consultant from ITU. Again Callum's quality of life was questioned and the value of giving him life-support. The registrar said that if we wanted him to have life-support, there was no way he would get it in that hospital. Only when our friends arrived to back us up, was the decision made to support our son. One-to-one specialist nursing support was provided, with the option of ITU if needed.

Gradually we got the staff on the ward to realise that our son was a real person. He then got excellent support. But why did we have to go through hell to get this for him?

Although there were still problems for him, the support was there and he began to improve. Attitudes changed and the staff were delighted when he responded to treatment.

Callum is back in his own home. He is still not 100%, but progressing daily and enjoying his life again. His mobility however has been badly affected by his treatment over the past year and he still cannot stand unsupported. We don't know whether he will walk independently again. We hope he will.

Issues for consideration with Callum's stories

When your lecturer divides you into groups you may like to consider the following issues in relation to the recommendations of '*Promoting health, supporting inclusion*':

The person

- Respect the person - see the individual, not the disability.
- Imagine how he or she might feel: what would it have been like for Callum during his hospital admissions?
- Communication - communicate at the individual's level.
- Pain - just because it doesn't show and the person can't tell you, doesn't mean it is not there.
- Respect the person's dignity.
- Equality of care and right to treatment regardless of disability.

The family

- Recognise the expertise of the family - and listen to them
- Think about the acute stress on families when a relative with learning disabilities is ill.
- Think about the practical load on family carers. Can you help with that?
- The family not only has the anxiety about their son or daughter's illness, but at this particularly difficult time, has the extra responsibility for teaching staff about his/her needs and acting as advocate. What does this mean for the family? How can you help?

Resources

Website links

Scotland

Key Housing

www.keyhousing.org/html/about.asp

Key was set up in 1977 by a small group of parents concerned about the lack of good quality supported accommodation, and committed to developing alternatives to institutional care for people with learning disabilities.

Turning Point: Scotland

<http://www.turningpointscotland.com>

Turning Point: Scotland manages several services for adults with learning disabilities. All services are tailored around individuals. TPS learning disability services include day support services, social enterprise projects and supported accommodation

Camphill Scotland

www.camphillscotland.org.uk

Camphill's principal role is to work with people who have special needs. This work is not a 'job' in the usual sense of the word, but a way of life.

Enable: Scotland

www.enable.org.uk

ENABLE is the largest membership organisation in Scotland for people with learning disabilities and family carers. It was formed in 1954 by a small group of parents because many families with a child with learning disabilities felt alone and isolated. They wanted better services for their sons and daughters and better support for parents.

Capability Scotland

www.capability-scotland.org.uk

This is Scotland's largest disability organisation, providing a broad range of services to adults and children with disabilities.

Down's Syndrome Scotland

www.dsscotland.org.uk

Down's Syndrome Scotland, formerly the Scottish Down's Syndrome Association, is a membership organisation which works to improve the quality of life for everyone with Down's syndrome in Scotland. Its membership includes individuals who have Down's syndrome, parents, and professionals.

Scottish Executive (learning disabilities)

www.scotland.gov.uk/ldsr

This is the Scottish Executive web section for the National Review of Services for People with a Learning Disability. There is a heavy emphasis on delivering person-centred services; our aim is to develop a framework for better social and health care services for people with learning disabilities. This review was the first in-depth analysis of services for people with learning disabilities in Scotland for over 20 years. Statutory agencies, service users, their carers and people who deliver the services were all involved in the review.

Scottish Consortium for Learning Disability

www.sclld.org.uk

SCLD is made up of 13 partner organisations that have joined together with funding from the Scottish Executive to become the Scottish Consortium for Learning Disability.

Sense Scotland

<http://www.sensescotland.org.uk/>

Sense Scotland is a leader in the field of communication and innovative support services for people who are marginalised because of challenging behaviour, health care issues and the complexity of their support needs.

Momentum Scotland

<http://www.momentumscotland.org>

Momentum works in partnership throughout Scotland to enable and empower disabled and excluded people to identify and achieve their goals. They support people to remain active citizens within their own communities, through the provision of mainstream employment and personal support services.

Other UK addresses

British Institute for Learning Disabilities

www.bild.org.uk

BILD is the British Institute of Learning Disabilities, a not for profit organisation with charitable status, which exists to improve the quality of life of all people with a learning disability. BILD provides information, publications and training and consultancy services for organisations and individuals.

The Foundation for People with Learning Disabilities

www.learningdisabilities.org.uk

This boasts to be the biggest and most comprehensive website on learning disabilities in the UK.

Special Olympics UK

http://www.specialolympicsgb.org/table_1.htm

The only world-wide sports movement for people with a learning disability.

Contact a Family

www.cafamily.org.uk

Contact a Family is the only UK charity providing support and advice to parents whatever the medical condition of their child.

Scottish Society for Autism

www.autism-in-Scotland.org.uk

A provider of services for people with autistic spectrum disorder in Scotland. They deliver a range of expertise in care, support and education for people with autism, their families and carers.

National Electronic Library for Learning Disability

www.nelh.nhs.uk/learningdisabilities/

There are a number of pages on this website that are worth reading if you are new to field of learning disabilities.

Mencap

www.mencap.org.uk

Mencap is one of the UK's best known learning disability charity working with people with a learning disability and their families and carers its sister organisation in Scotland is known as Enable.

Joseph Rowntree Foundation

www.jrf.org.uk

The Joseph Rowntree Foundation is one of the largest independent social policy research and development charities in the UK. It supports a wide programme of research and development projects in housing, social care and social policy.

Values into Action

www.viauk.org/

A group that campaigns for the rights of people with learning disabilities.

Norah Fry Research Centre

<http://www.bris.ac.uk/Depts/NorahFry>

The Centre was established in 1988 as part of the University of Bristol's department of Mental Health. Its principal interests are the evaluation and development of services for people with learning difficulties.

Rescare

<http://www.rescare.com/web/index.asp>

Rescare delivers services to persons with disabilities, youth with special needs and adults with barriers to employment. The phrase *Building Lives, Reaching Potential* is their vision of the wide variety of things they do for the people they help.

Leonard Cheshire

<http://www.leonard-cheshire.org>

Leonard Cheshire is a leading provider of services for disabled people in the UK and operates in over 57 countries across the world.

Home Farm Trust

www.hft.org.uk/

HFT is a national charity for people with learning disabilities. It provides a range of services including supported living, registered care homes, advocacy, supported employment, short-term breaks (respite) and day services. It also provides a support service for carers of people with learning disabilities.

The Tizard Centre

www.ukc.ac.uk/tizard/

This centre seeks to provide teaching through short courses at the University of Kent and elsewhere. They have an extensive programme of research and consultancy, nationally and internationally.

International

Ireland

The National Association for the Mentally Handicapped of Ireland

<http://www.iol.ie/frontline/NAMHI.HTM>

The National Association for the Mentally Handicapped of Ireland, Fitzwilliam Place, Dublin 2, Ireland. Tel: 01-6766035, Fax: 01-6760517. This is a national voluntary association working to improve the welfare of Irish people with mental handicap.

Canada

Developmental Disabilities Centre

<http://www.quasar.ualberta.ca/ddc/INDEX.html>

The JP Das Developmental Disabilities Centre was established in the Fall of 1967 with a grant given to the University of Alberta by the Canadian Association for Mental Retardation; it was then named the Centre for the Study of Mental Retardation. Since 1987, it has been called the Developmental Disabilities Centre. Its current activities include: research, student training, publication, and selected clinical services for children and adults with mental retardation and other disorders that affect learning and originate in the childhood.

Australia

Australian Society for the Study of Intellectual Disability

<http://www.rmit.edu.au/departments/ps/assid/>

This association seeks to enhance the skills, knowledge and commitment of its members to facilitate a supportive network in order to enhance the quality of life of people with intellectual or developmental disability. It also seeks to enhance the skills, knowledge and commitment of its members and to facilitate a supportive network in order to enhance the quality of life of people with intellectual or developmental disability.

America

AAMR

<http://www.aamr.org/>

AAMR promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities.

General

Inclusion International

<http://daniel.waldschmidt.free.fr/euie.htm>

Inclusion International - Formerly the International League of Societies for Persons with Mental Handicap (ILSMH). Inclusion International works for the world's 50 million people with a mental handicap, their families and those who share their lives. It was founded in 1960 by representatives of societies of parents of people with a mental handicap, friends and professionals working in the field and now represents 173 member organisations in 109 countries on all five continents. Inclusion International's aim is to defend the rights and interests of people with a mental handicap.

International Association for the Scientific Study of Intellectual Disabilities

<http://www.iasid.org/>

The International Association for the Scientific Study of Intellectual Disabilities is an international and interdisciplinary scientific organization that promotes worldwide research and exchange of information on intellectual disabilities.

L'Arche UK

www.larche.org.uk

L'Arche is an international federation of communities for people with learning disabilities and assistants. We have eight communities in England, Scotland and Wales. They provide real homes in ordinary houses to well over 100 people with learning disabilities and a similar number of assistants.