I Learning Disability and Associated Problems that Affect Physical Ability
1 What is Learning Disability?

JEANETTE RENNIE

INTRODUCTION

In the UK the term ‘learning disability’ is used to mean mental retardation or intellectual disability (see Table 1.4 and Chapter 2). It is used throughout this book except where it is important to record terminology of a particular period.

A number of writers have described the history of the concept of mental retardation – for example Morris (1969), Scheerenberger (1987), Trent (1994) and Harris (2006). This chapter examines the way in which history has influenced treatment and management of associated physical disabilities. It does not deal in depth with social and educational developments or specify the work of individual voluntary agencies, nor does it detail all legislation that impinges upon learning disability.

The chapter is divided into sections describing:

• the events and attitudes leading to the establishment of institutions and organisational developments within them
• the concept of community care for people with learning disabilities and its development
• the present legal aspects in the UK and recent changes in health and social care

Tables are used to show international influence on policymaking, UK legislation, development of definitions and terminology and evolution of the definition of ‘normalisation’.

A MIX OF POLITICS, EDUCATION, SOCIAL POLICIES AND MEDICINE

• Have ideologies, theories and practices benefited or deprived people with learning disabilities with regard to facilities that would assist them to lead a fulfilled life?
WHAT IS LEARNING DISABILITY?

- Have neurological and sensory impairments present in people with mild mental retardation (Fryers 1997) been considered worthy of treatment or ignored as a nonspecific associated clumsiness?
- Does the term ‘learning disability’, used in the UK to assist integration into normal society, promote misunderstanding amongst generic healthcare professionals who associate ‘learning’ with ‘education’?
- Does the term ‘learning disability’ hinder research between countries? For example, in the US the term was introduced in 1962 to mean: ‘A disorder in one or more of the basic psychological processes involved in the understanding or in using language, spoken or written, which may manifest itself in an incomplete ability to listen, think, speak, read, write or spell, or to do mathematical calculations . . . ’ It includes ‘perceptual handicaps, dyslexia, developmental aphasia, brain injury, mid brain dysfunction’. It does not include motor handicaps or mental retardation (Education for All Handicapped Children Act. Public Law 94–42, 34 C.F.R. 300.5 [b] [9], in Brown and Aylward 1996).

People with learning disabilities have produced many and varied reactions in those around them. They have also caused philanthropists, educationalists, health professionals and sociologists to consider deeply how their needs may be met. The social and economic climate of the time has influenced thinking, which in turn has informed political decision making, sometimes clashing with isolated progressive thought and sometimes reinforcing it. Many caring and progressive attitudes of previous years, interpreted today as selfish and condescending, were the building blocks for present policies. Key developments and interaction between countries in the developed world are listed in Tables 1.1, 1.2 and 1.3.

Before the development of modern medicine the majority of profoundly learning-disabled children died in infancy. In general, therefore, the literature refers to people who would now be regarded as having mild to moderate learning disability.

Writings such as Arthurian legends and Shakespearean plays refer to people ‘possessed’ or with ‘second sight’ who influenced everyday occurrences or major battles. Such people were either venerated or locked up and maltreated (Morris 1969, Scheerenberger 1987, Trent 1994). In the early fourteenth century in England, differentiation was made between learning disability (people who were born ‘fools’) and mental illness (people who became ‘mad’) on the basis that the former could never become ‘normal’ but the latter might regain their sanity: ‘born fools could not inherit property, the King as parens patriae assumed rights over the fool and his property as if he were an infant’ (O’Connor and Tizard 1956).

Comparison with infants led to a protective and humane attitude towards the more severely learning disabled. It was also possible, however, for anyone to sue for the guardianship and administration of a ‘fool’s estate’ – ‘to beg for
<table>
<thead>
<tr>
<th>Country</th>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td></td>
<td>1806</td>
<td>Pinel published his paper ‘Treatise on Alienism’. ‘Defectives’ had the ability to be trained to their level of intelligence but no further (Trent 1994).</td>
</tr>
<tr>
<td></td>
<td>1846</td>
<td>Seguin published ‘The psychological treatment, hygiene and education of idiots’ a handbook for institutional care (Kanner 1964).</td>
</tr>
<tr>
<td>US</td>
<td>1820–60</td>
<td>The Depression, ideas from Europe and Britain and the Civil War led to end of ‘outdoor relief’ and development of ‘indoor relief’.</td>
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<tr>
<td></td>
<td>1848</td>
<td>Seguin moved to US.</td>
</tr>
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<td></td>
<td>1856</td>
<td>Schools for feebleminded children became residential asylums for training feebleminded adults and idiots. Medically trained superintendents replaced headteachers.</td>
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<td></td>
<td>Late 1800s</td>
<td>Wilbur categorised mental defectives (Table 1.4)</td>
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<tr>
<td></td>
<td>1958</td>
<td>Anthony Dexter conceived a ‘social system concept’ and ‘labelling’</td>
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<tr>
<td></td>
<td>1961</td>
<td>President Kennedy appointed a President’s Panel on mental retardation.</td>
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<td></td>
<td>1969</td>
<td>Concept of normalisation introduced by Bank Mikkelsen and Bengt Nirje (Table 1.5)</td>
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<tr>
<td></td>
<td>1971</td>
<td>International League of Societies for the Mentally Handicapped endorsed philosophy of normalisation</td>
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<td></td>
<td>1973</td>
<td>The Rehabilitation Act</td>
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<td></td>
<td>1987</td>
<td>The Developmental Disabilities Assistance and Bill of Rights Amendments include persons with mental retardation</td>
</tr>
<tr>
<td></td>
<td>1990</td>
<td>Americans with Disabilities Act (ADA) included mental retardation in its category ‘mental or psychological disorder’</td>
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<tr>
<td></td>
<td>2001</td>
<td>The President’s New Freedom Initiative promoted full inclusion of people with disabilities in all aspects of life and work – included mental retardation</td>
</tr>
<tr>
<td></td>
<td>2002</td>
<td>Surgeon General’s Conference on Health Disparities and Mental Retardation</td>
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<tr>
<td>Switzerland</td>
<td>1839</td>
<td>Guggenbuhl established a ‘colony’ on the Abendberg</td>
</tr>
<tr>
<td>Italy</td>
<td>1870s</td>
<td>Lombroso suggested that inherited factors caused criminal tendencies</td>
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<tr>
<td></td>
<td>1978</td>
<td>Law passed to replace all institutions with community care</td>
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<tr>
<td>Denmark</td>
<td>1959</td>
<td>The Government passed an Act concerning Care of the Mentally Retarded and other Exceptionally Retarded Persons (Table 1.5)</td>
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<tr>
<td>Canada</td>
<td>Early 1970s</td>
<td>Responsibility for people with mental handicap transferred from health to social welfare and educational ministries.</td>
</tr>
<tr>
<td>Australia</td>
<td>1970s</td>
<td>Several states acted upon reports recommending mentally handicapped people transfer to the community</td>
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<tr>
<td></td>
<td>1998</td>
<td>The state of Western Australia proposed ‘local area coordination’.</td>
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</tbody>
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Table 1.1. Continued

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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</thead>
<tbody>
<tr>
<td>1971</td>
<td>Declaration on the Rights of Mentally Retarded Persons</td>
</tr>
<tr>
<td>1975</td>
<td>Declaration on the Rights of Disabled People</td>
</tr>
<tr>
<td>2004</td>
<td>Reported that disability was beginning to be treated as a broad human rights issue</td>
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<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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</thead>
<tbody>
<tr>
<td>1980</td>
<td>International Classification of Impairments, Disabilities and Handicaps (Table 1.4)</td>
</tr>
</tbody>
</table>

**WHO**

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1990</td>
<td>Recommended that all institutions close</td>
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</tbody>
</table>

**Sweden**

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<thead>
<tr>
<th>Year</th>
<th>Event</th>
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</thead>
<tbody>
<tr>
<td>1990</td>
<td>European Social Charter (revised) Article 15: the right of persons with disabilities to independence, social integration and participation in the life of the community</td>
</tr>
<tr>
<td>2002</td>
<td>European Year of People with Disabilities</td>
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</tbody>
</table>

(Compiled in part from Morris 1969, Scheerenberger 1987, Trent 1994)

Table 1.2. UK, key reports and legislation

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1713–14</td>
<td>Vagrancy Acts: ‘apprehension of those who might be dangerous’</td>
</tr>
<tr>
<td>1774</td>
<td>Madhouses Act: ‘provision of minimum standards of care and for the control of private madhouses’</td>
</tr>
<tr>
<td>1808</td>
<td>County Asylums Act: public asylums in England replaced private madhouses.</td>
</tr>
<tr>
<td>1908</td>
<td>Report of Royal Commission on Care and Control of the Feebleminded.</td>
</tr>
<tr>
<td>1913</td>
<td>Mental Deficiency Act: people with mental deficiency dealt with as a specific group. Segregation introduced. Mental defectives classified</td>
</tr>
<tr>
<td>1914</td>
<td>Mental Deficiency Act: Local authorities to protect mentally defective patients by providing accommodation.</td>
</tr>
<tr>
<td>1927</td>
<td>Mental Deficiency Act: Creation of separate institutions for the mentally ill and mentally handicapped.</td>
</tr>
<tr>
<td>1946</td>
<td>National Health Service Act: minimum standard of care available for all who needed it.</td>
</tr>
<tr>
<td>1948</td>
<td>The National Health Service Act (as amended) standardised mental subnormality hospitals in accordance with general hospitals.</td>
</tr>
<tr>
<td>1959</td>
<td>Mental Health Act repealed all previous legislation. Emphasis placed on voluntary instead of compulsory admission to hospital. Civil rights of patients recognised, including access to a Health Service Commissioner.</td>
</tr>
<tr>
<td>1961</td>
<td>Minister of Health proposed start of ‘running down’ mental hospitals.</td>
</tr>
<tr>
<td>1971</td>
<td>Better Services for the Mentally Handicapped</td>
</tr>
<tr>
<td>1975</td>
<td>The National Development Group and National Development Team for the Mentally Handicapped established</td>
</tr>
<tr>
<td>1978</td>
<td>Helping Mentally Handicapped People in Hospital</td>
</tr>
<tr>
<td>1978</td>
<td>Warnock Committee Report on special educational needs</td>
</tr>
<tr>
<td>1979</td>
<td>Jay Report. Policy based on principles of normalisation. Special help would be required from their communities and the professional services. Advocacy recommended</td>
</tr>
<tr>
<td>1979</td>
<td>‘A Better Life’ (Scotland). Concept of community care endorsed, gradual progress recommended</td>
</tr>
</tbody>
</table>
Table 1.2. Continued

1980 SHAPE (Scottish Health Authorities Priorities for the Eighties)
1981 Education Act for Children with Special Education Needs and Education (Scotland) Act. Education should be fitted to the child’s requirements as far as possible. Statement of needs and needs assessments proposed.
1983 The All Wales Strategy
1983 Mental Health Act
1984 The Mental Health (Scotland) Act
1986 The Disabled Persons Act (Tom Clarke Bill). Right to representation, assessment, information, consultation. Carers right to ask for assessment of disabled persons’ needs and carers’ ability to care taken into account.
1988 Community Care: Agenda for Action (Griffiths Report)
1988 SHARPEN (Scottish Health Authorities Review of Priorities for the Eighties and Nineties)
1989 White Paper Caring for People: Community Care in the next Decade and Beyond.
1995 The Health of the Nation including ‘A strategy for people with learning disabilities and their carers’
1998 ‘Signposts for success’
1998 Health laws for Northern Ireland devolved to Northern Ireland Assembly
1999 Health laws for Scotland devolved to The Scottish Executive
1999 The Health Act to improve coordination of services for everyone
1999 National Assembly for Wales established The Learning Disability Advisory Group
2000 The Same as You? A Review of Services for People with Learning Disabilities encouraged use of generic services with appropriate support
2000 The Adults with Incapacity (Scotland) Act
2001 The Learning Disability Advisory Group reported to the Welsh Assembly ‘Fulfilling the Promise’
2001 Seeking consent: working with people with learning disabilities
2003 Partnership for Care, Scotland’s Health White Paper
2003 The Mental Health (Care and Treatment) (Scotland Act) had relevance to people with a dual diagnosis of learning disability and mental disorder by making new arrangements for detention, care and treatment
2004 Improving Mental Health law: towards a New Mental Health Act
2005 The Mental Capacity Act
2006 White Paper, Our health, Our care, Our say; A New Direction for Community Services
2006 Start of three-year strategic plan for assessing and encouraging improvement in the healthcare of adults with learning disabilities
What is learning disability?

Before the Industrial Revolution, however, local people with learning disabilities were an accepted part of life. This probably contributed to the success of outdoor relief given as direct aid to ‘worthy’ dependants in the US before 1820 (Trent 1994).

Until France produced pioneers such as Itard, Pinel and Seguin in the early nineteenth century, positive treatment or teaching had been deemed impossible. The first steps towards enabling ‘defectives’ to learn and to grow in

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### Table 1.3. Development of terminology

<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Terminology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Late 1890</td>
<td>US</td>
<td>Wilbur’s categories of mental defectives (Table 1.4)</td>
</tr>
<tr>
<td>Late 1890</td>
<td>UK</td>
<td>Feeble minded, imbecile, idiot</td>
</tr>
<tr>
<td>1913</td>
<td>UK</td>
<td>Moral imbecile, feeble minded, imbecile, idiot</td>
</tr>
<tr>
<td>1921</td>
<td>US</td>
<td>Mental Retardation</td>
</tr>
<tr>
<td>1927</td>
<td>UK</td>
<td>England, moral defective replaced moral imbecile</td>
</tr>
<tr>
<td>1959</td>
<td>UK</td>
<td>Legal terminology England and Wales; subnormal, severe subnormal. (Also used ‘mental handicap’ and ‘severe mental handicap’)</td>
</tr>
<tr>
<td>1968</td>
<td>WHO</td>
<td>Mental Retardation: mild, moderate, severe, profound</td>
</tr>
<tr>
<td>1978</td>
<td>UK</td>
<td>Education terminology England and Wales moderate and severe learning difficulties replaced moderate and severe educationally subnormal</td>
</tr>
<tr>
<td>1980</td>
<td>WHO</td>
<td>Mental Retardation – all people with IQ of &lt;70</td>
</tr>
<tr>
<td>1981</td>
<td>UK</td>
<td>Education terminology: one category – learning difficulty</td>
</tr>
<tr>
<td>1983</td>
<td>UK</td>
<td>England and Wales mental impairment, severe mental impairment. Scotland mental handicap, severe mental handicap</td>
</tr>
<tr>
<td>1995</td>
<td>UK</td>
<td>Learning disability accepted terminology. Medically, used in conjunction with more specific definition (Chapter 2 and Table 1.4)</td>
</tr>
<tr>
<td>2000</td>
<td>US</td>
<td>Began to use intellectual disability in documents and referred to a wide range of terms used world wide</td>
</tr>
<tr>
<td>2003</td>
<td>US</td>
<td>Federal Advisory Committee replaced Mental Retardation with Intellectual Disability – the ‘President’s Committee for People with Intellectual Disabilities’</td>
</tr>
<tr>
<td>2003</td>
<td>AAMR</td>
<td>Continued the use of mental retardation, ‘American Association on Mental Retardation’</td>
</tr>
<tr>
<td>2003</td>
<td>Scotland</td>
<td>Learning disability confirmed as legal terminology</td>
</tr>
<tr>
<td>2006</td>
<td>WHO</td>
<td>The 2006 version continued the use of Mental Retardation</td>
</tr>
<tr>
<td>2006</td>
<td>ICD 10</td>
<td></td>
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</tbody>
</table>

a fool’ (see The Chambers Dictionary, 1994 edition). In the sixteenth and seventeenth centuries various tests were devised to verify ‘fools’, both to protect them and to gain their property rights.
self-esteem were Itard’s use of warm baths as sensory stimulation to train ‘defectives’, Pinel’s humanitarian, psychological approach and Seguin’s ‘physiological and moral training’ with 10 ‘idiots’ in Paris (Kanner 1964).

Spa treatment was being used throughout Europe for a variety of medical conditions and the term ‘hydrotherapy’ was an accepted description for specifically medical treatment in England. However, Itard appears to have used baths for training purposes only and not to improve physical abilities in ‘mental defectives’.

**DEVELOPMENT OF INSTITUTIONS**

During the mid-nineteenth century two parallel strands developed:

- an awareness that ‘defectives’ had an ability to learn and that it was society’s duty to provide education and security for them
- the proposal that low intellectual ability was an entirely inherited factor – the ‘degeneration’ theory, which later gave rise to eugenics

In 1839, Guggenbuhl established a colony for the cure of cretinism on the Abendberg in Switzerland. It was closed 20 years later due to failure to discover a ‘cure’. However, the principle of ‘colonies’ and Guggenbuhl’s treatment theories of a sensible diet, massage and physical exercise, spread to other countries in Europe, the UK and the US.

In the UK, philanthropic reformers began to found institutions to replace the asylums where mentally ill and learning-disabled people were kept together, a problem only solved in the early twentieth century. For example Dr and Mrs Brodie (Henderson 1964) founded the Edinburgh Idiot Asylum in 1855. It transferred to Stirlingshire and became The Scottish National Institution for the Education of Imbecile Children and subsequently the Royal Scottish National Institution for Mental Defectives, the first purely for ‘mental defectives’.

In the Republic of Ireland, Stewarts Hospital in Dublin was opened in 1869. This was a private charitable institution administered on a voluntary basis by a committee of management, supported by the state through revenue allocations and capital grants.

The US responded to pressure from local officials, parents and superintendents by ending outdoor relief and following the UK’s government-driven programme of building large centralised hospitals for ‘idiots’ and ‘feeble-minded’ individuals.

Gradually medically trained superintendents and medical terminology became normal practice in the residential institutions and an increasing number of physicians was employed. Dr John Haydon Langdon-Down, who had been Superintendent of the Asylum for Idiots, Earlswood, since 1858,
opened a private home for ‘mental defectives’ in 1868. There, he recognised and described ‘Mongolism’ (Down syndrome). The home developed into a community where residents learned life skills and sports and enjoyed various excursions.

Despite this development, all study and research appears to have been directed towards assessing and categorising ‘idiots’ into different levels by intellectual ability.

**CATEGORISATION**

Galton (in 1869) and McKeen Cattell (in 1890) were amongst the earliest individuals to attempt categorisation and measurements using new tests of IQ (intelligence quotient). The most notable tests, however, were devised by Binet and Simon. (Savage 1970). The tests were revolutionary but assumed that intelligence could be tested in isolation, without reference to an individual’s social and environmental conditions or physical disabilities. They therefore reinforced the theory of hereditary transmission, which inadvertently fostered fear of a further increase in the number of people with learning disability. In the late nineteenth century this fear led to the development of the eugenics movement and custodial care of people with learning disability.

**SEGREGATION**

In 1908, the first edition of Tredgold’s renowned book, *Textbook on Mental Deficiency*, was published. In 1909, in an article in the *Eugenics Review*, he referred to the high inheritance factor in mental deficiency and a relatively high birth rate amongst the poor and the handicapped. It has been suggested that this influenced the addition of a statutory instrument to the Mental Deficiency Act of 1913 in 1927. The 1913 Act had originally been introduced to separate people with learning disabilities from those with mental health problems. The statutory instrument that was added to become part of the 1927 Act introduced the category of ‘moral defective’, which segregated ‘mentally deficient’ people from the general population and from the opposite sex to prevent an increase in ‘mental deficiency . . . as a protection of society as a whole’.

One of the effects of segregation was to retain children and adults who had a combination of physical disabilities and learning disability in hospitals specialising in learning disability. Staff were not equipped to treat their physical disabilities and were, on the whole, unable to recognise the impact that such disabilities made upon communication, mobility and daily living skills and subsequently to frustration and resulting in aggressive behaviour.

Photographs from large UK and US hospitals, however, showed that active exercise was provided for physically able people with learning disabilities, in
Institutions grew in size and numbers and segregation continued but gradually attitudes towards aims of treatment within the institutions changed. For example, Dr Chislet the first medical superintendent of Lennox Castle Hospital, Glasgow, wrote in 1936 that treatment should consist of ‘Custodial care for those who require such for life, i.e. the lower grades of defectives, and an endeavour by treatment and training to render certain defectives fit to take their place in the general community.’

Suggestions and Instructions regarding the developing ‘colonies’ included the ‘. . . necessity of a rural setting away from danger . . . adequate classification according to sex, age, ability, medical condition and behavioural problems’ (Loudon 1992).

However, isolated institutions were liable to have difficulty attracting specialist staff to deal with medical conditions and behavioural problems. They therefore tended to become self-contained units largely ignored by the rest of the nursing and medical professions, and society as a whole.

The 1948 National Health Service Act (as amended) required

- appointment of appropriately qualified senior doctors
- local authorities to remove ‘persons in need of care and attention to suitable premises’
- local authorities to provide temporary accommodation where necessary

This produced rapid expansion of both the number of hospitals for people with learning disability and the patients that they could accommodate.

**NEW THOUGHTS ABOUT INSTITUTIONS**

The Mental Deficiency Act 1913 had introduced a category of ‘moral imbeciles’. People with borderline learning disabilities, angry and frustrated teenagers and sexually promiscuous adults who lacked perception of the consequences of their actions and so appeared to be potential criminals were frequently hospitalised for life. Although this was preferable to life imprisonment in a standard gaol it still grossly restricted their freedom.

During the 1950s, publicity about such hospitalisation led to the Royal Commission on the Law relating to Mental Illness and Mental Deficiency (1957) and the Mental Health Act 1959. This Act introduced informal admission to learning disability hospitals and changed terminology. It created a greater awareness of ‘mental handicap’ and mental illness, although 50 years later confusion still arises between the two in the mind of the general public.

At this time there was a worldwide search for a more appropriate definition and method of care. The medical model was increasingly considered
inappropriate for people with learning disabilities who had no single physical disease that could be cured by medical intervention. Lewis Anthony Dexter proposed a ‘social systems concept’ in 1958. He viewed the ‘cost and trouble’ caused by ‘mental defectives’ in society as a result of both ‘society’s expectations of the mentally defective and the mental defectives’ learned role as to what was expected of them’ (in Scheerenberger 1987).

It was gradually acknowledged that only the most severely ‘subnormal’ people required skilled nursing care and few needed the support of custodial care. However, appropriate nursing care for the most severely ‘subnormal’ who also had severe physical disabilities was considered to be palliative and protecting, not stimulating, and did not enable patients to achieve their maximum potential.

Access to a range of treatments for children with physical disabilities and normal intelligence was being developing by people like Karl and Bertha Bobath in England in the 1930s (Bobath and Bobath 1975). In Hungary in the 1940s Andreas Peto was developing conductive education (Hari and Akos 1988). Infants with physical disabilities and learning disability were usually excluded on grounds of lack of understanding and short life expectancy. In the UK treatment was made available through special schools such as Trefoil, founded in 1939, Westerlea, founded in 1948 and Craig-y-Park, Drummonds and Thomas de la Rue all founded in 1955. Many paediatric services began to provide preschool treatment either at hospital outpatient departments or on a domiciliary basis.

**INTRODUCTION OF THE CONCEPT OF ‘COMMUNITY CARE’**

Community care was first mentioned in a statutory report of midwives in 1955 but the Danish government’s Parliamentary Act acted as the major catalyst for change (see box).

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**Danish government passes the Act of ‘Normalisation’, 5 June 1959**

The Act profoundly affected the lives of people with learning disabilities throughout the world by:

- permitting children to go to normal schools
- permitting adults to leave their parents’ home and be trained, taught and employed

At the time the Danish government was accused of abdicating responsibility for the mentally retarded.
In the US, four alternative methods of care were proposed in the 1960s (Scheerenberger 1987):

- the least restrictive alternative allowed equal protection under law including the right to deny and accept treatment, and requiring informed consent by individuals or their guardians
- the developmental model: mentally retarded children and adults were capable of growth, learning and development
- mainstreaming recommended integration of mentally retarded children into mainstream schools but offered no additional assistance
- normalisation

At about the same time Wolfensberger introduced the concept of ‘citizen’s advocacy’, by which volunteers were able to represent the views of individual institutionalised residents.

In 1961 the President’s Panel, set up by President Kennedy to produce recommendations for mental retardation, included ideas for research, preventive health measures and production of a new legal as well as social concept of ‘the retarded’. However, the concept of normalisation was not introduced to the US by Nirje until 1969. It was followed in 1970 by an Act that gave Federal authorisation to ‘assist States to ensure that people with disabilities were enabled to receive the necessary care treatment and other services to live their lives to the maximum’ (Scheerenberger 1987).

Although community care is known to have been mentioned as early as 1955 and was first recommended for people with learning disability in the UK in 1961, partly as a cost-cutting exercise (Scrivens 1986) the number of residents in large institutions peaked at approximately 52,000 in the early 1970s (Brown 1992). A number of factors lay behind this statistic including:

- the statutory obligation of the National Health Service (NHS) to meet the care needs of the whole population
- the NHS was supported by central funding, which removed dependence on local rates or charitable donations
- prevailing medical and social opinion was that the most appropriate form of care was sheltered living, offered by hospital services
- people with learning disability were living longer

This was the period in which therapists began to expand their work in hospitals for people with learning disability. For example, occupational therapy started at Gogarburn Hospital, Edinburgh, in 1964, physiotherapy began in 1966, and speech therapy was seconded from the Scottish Council for Spastics (now Capability Scotland) in 1966. Recreation was recognised as an important part of rehabilitation (Luckey and Shapiro 1974) and remedial gymnasts began to organise sporting activities (see Chapter 15). Physiotherapy, occupational therapy, speech therapy and psychology were available for children and young
adults in Oslo Observasjonshjem og Poliklinikk for Andssvake, Norway, in the 
1950s, physiotherapy and occupational therapy started at St Michael’s House 
in Dublin in 1955 and physiotherapy started in Denmark and Bermuda in the 
early 1960s. In the former Eastern region of Nigeria, people with learning dis-
abilities were treated in small general hospitals and specialist parts of large 
general hospitals in the 1970s and day centres and special education centres 
began to be established.

The first attempts were made to quantify the number of therapists working 
in this field in the UK in 1970. The numbers at the time were:

England
- occupational therapists 77 (others, for example technicians and assistants 212)
- physiotherapists 37 (others, for example assistants 4)
- speech therapists 18
- chiropodists 20
- other therapists 285 (in 1971)
- psychologists 54 (DHSS 1987)

Scotland
- occupational therapists 0.22 per 100 patients
- physiotherapists 0.17 per 100 patients
- speech therapists 0.06 per 100 patients
- chiropodists 0.06 per 100 patients
- other therapists 0.27 per 100 patients
- psychologists 0.07 per 100 patients (Scottish Home and Health Department 
  1970)

In many hospitals residents were encouraged and supported to live their 
lives as fully as possible but this failed to achieve full individual development. 
In other hospitals, residents lived in restricted and repressive conditions. A 
series of scandals resulted in the publication of Better Services for the Mentally 
Handicapped (Department of Health and Social Security 1971).

Internationally, in 1971 the United Nations published the Declaration on 
the Rights of Mentally Retarded Persons. It prescribed that they should have 
‘to the maximum degree of feasibility the same rights as other human beings’ 
and a right to a qualified guardian.

Central government support for community care in the UK began with 
publication of Better Services for the Mentally Handicapped (DHSS 1971).

- multiprofessional teams encouraged, to support and enable people with 
  ‘mental handicap’ to live more normal lives in the community
- links encouraged between health authorities and local authorities
- community integration strongly recommended
Wolfensberger’s reworded principle of normalisation and his introduction of the term ‘social integration’ encouraged worldwide progress towards care in the community (Loudon 1992).

**Social integration**

Living as an integrated member of the local community; participating in local activities.

However, multidisciplinary and interagency work has always been impeded by variations in terminology both nationally and internationally (Table 1.4 and see Chapter 2). An attempt to reduce frequency of change in terminology was made by the American Association on Mental Retardation in 1973. When it revised its definitions, it also defined aims for future development and standardisation of a common base for classification of terminology.

**ACCELERATION OF COMMUNITY CARE**

Acceleration towards community care was further assisted by the United Nations Declaration of the Rights of Disabled People in 1975. It included, among its 13 statements, the assertion that disabled persons have the inherent right to respect for human dignity. Whatever the origin, nature and seriousness of their handicaps and disabilities, they have the same fundamental rights of their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and as full as possible (in Mittler 1979).

Progress could be seen by developments in both private and charitably run facilities and the long-stay hospitals. For example, in the Republic of Ireland, St Michael’s House, Dublin, was extending its services to support learning-disabled children in integrated education, to provide appropriate further education through developmental day centres, to give support and training for clients in open employment and to provide residential services for very small groups in ordinary homes. Also in Dublin, Stewarts Hospital began to develop clinical services with family support and respite for children and adults, courses for sports and leisure, an introduction to parenting and budgeting skills and advice on nutrition. Its residential numbers decreased and its services became more available both on the campus and to clients in the community.
### Table 1.4. Development of definitions

<table>
<thead>
<tr>
<th>Period</th>
<th>Region</th>
<th>Definition</th>
</tr>
</thead>
</table>
| Late 1800 US | Wilbur’s categories | Simulative idiots: could be prepared for ordinary duties and enjoyments of humanity  
Higher grade idiots: would attend common schools to be qualified for civil usefulness and social happiness  
Lower grade idiots: could become decent in their habits, educated in simple occupations, capable of self support under judicious management in their own families, or in public industrial institutions for adult idiots.  
Incurables: aim to achieve some education. (In Trent 1994). |
| 1913 UK Mental Deficiency Act | Idiots – people unable to guard themselves from physical danger  
Mental Imbeciles – people incapable of managing themselves or their affairs  
Feeble-minded persons – people who require care, supervision or control for their own protection or the protection of others.  
Children who cannot benefit from ordinary schools  
Moral imbeciles – people with a mental defect coupled with strong vicious or criminal propensities on which punishment has no or little deterrent effect |
| 1921 US (AAMR) | American Association on Mental Retardation (AAMR) published first edition of *Manual on terminology and classification in mental retardation* |
| 1973 US (AAMR) | ‘Mental Retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period’ |
| 1980 WHO ICD 10 | International Classification of Diseases  
Mental retardation  
Mild: IQ: 50–70 individuals who can acquire practical skills and functional reading and arithmetic abilities with special education, and who can be guided towards social conformity  
Moderate: IQ: 35–49 individuals who can learn simple communication, elementary health and safety habits, and simple manual skills, but do not progress in functional reading or arithmetic  
Severe: IQ: 20–34 – individuals who can benefit from systematic habit training  
Profound: IQ < 20 – individuals who may respond to skill training in the use of legs, hands, and jaws |
| 1980 WHO | *International Classification of Impairments, Disabilities and Handicaps*  
Impairment: musculo skeletal abnormality, and organ misfunction.  
Disability: the resultant functional ability  
Handicap: the disadvantage arising from impairment or disability.  
Intellectual Impairments include: intelligence, memory and thought but excluded language and learning  
Impairments of intelligence include: ‘disturbances of the rate and degree of development of cognitive functions, such as perception, attention, memory, and thinking, and their deterioration as a result of pathological processes’ |
<p>| 1983 US (AAMR) | Definition of Mental Retardation updated (In Scheerenberger 1987) |</p>
<table>
<thead>
<tr>
<th>Year</th>
<th>Country/Region</th>
<th>Definition/Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1983</td>
<td>UK (England and Wales)</td>
<td>‘Mental impairment’: ‘a state of arrested or incomplete development of mind which includes a significant impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned’ (Mental Health Act 1983)</td>
</tr>
<tr>
<td>1983</td>
<td>UK (Scotland)</td>
<td>Mental handicap replaced mental deficiency but had the same general meaning. (Mental Health (Scotland) Act 1983).</td>
</tr>
<tr>
<td>1992</td>
<td>WHO ICD 10</td>
<td>ICD 10 Mental retardation accepted terminology but definition updated</td>
</tr>
<tr>
<td>1992</td>
<td>US (AAMR)</td>
<td>Mental retardation: accepted terminology. In 1992 AAMR began to develop a more functional approach by changing its 1973 definition to require ‘significant delay in two or more of ten areas of adaptive functioning’, which include ‘daily living skills, self care and communication’</td>
</tr>
<tr>
<td>1995</td>
<td>UK</td>
<td>‘Learning disability’ accepted terminology. Generally used to mean mental retardation: impaired intelligence and impaired social functioning . . . a reduced ability to understand new or complex information and learn new skills and a reduced ability to cope independently. Learning disability is a condition that starts before adulthood and has a lasting effect on development (DOH 1995). Medically used in conjunction with ICD10, AAMR or DSM-IV</td>
</tr>
<tr>
<td>1995</td>
<td>UK</td>
<td>‘Learning disability’ accepted terminology. Generally used to mean mental retardation: impaired intelligence and impaired social functioning . . . a reduced ability to understand new or complex information and learn new skills and a reduced ability to cope independently. Learning disability is a condition that starts before adulthood and has a lasting effect on development (DOH 1995). Medically used in conjunction with ICD10, AAMR or DSM-IV</td>
</tr>
<tr>
<td>2001</td>
<td>UK</td>
<td>In Valuing People’ (DOH 2001a) Learning Disability includes the presence of: • A significantly reduced ability to understand new or complex information learn new skills (impaired intelligence), with; • A reduced ability to cope independently (impaired social functioning); • Which started before adulthood, with a lasting effect on development. It encompasses people with a broad range of disabilities. Many people with learning disabilities also have physical and/or sensory impairments. The definition includes adults with autism and learning disability. It does not include people with ‘learning difficulty’, which is more broadly defined in education legislation. Medically used in conjunction with ICD10, AAMR or DSM-IV-TR</td>
</tr>
<tr>
<td>2002</td>
<td>US AAMR</td>
<td>Revised definition ‘... a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before the age of 18.’ (See current classification in Chapter 2.)</td>
</tr>
<tr>
<td>2006</td>
<td>WHO ICD 10</td>
<td>Mental retardation accepted terminology but definition updated to include ‘Intellectual abilities and social adaptations may change over time, and, however poor, may improve as a result of training and rehabilitation’ (see current classification in Chapters 2 and 3)</td>
</tr>
</tbody>
</table>
In the UK the National Development Group and Development Team for the Mentally Handicapped was established to facilitate progress from hospitals to the community. A series of consultation documents have continued to be issued and Parliamentary Bills passed. These are listed in Table 1.2.

Community care was also stimulated by:

- increasing awareness amongst families
- the growth of voluntary organisations
- realignment of funding from central government
- increased involvement of social services departments
- the Warnock Report (Department of Education and Science 1978) on special educational needs
- the introduction of a named ‘key worker’ to work with and coordinate activities for one or more adults with learning disabilities
- pressure groups, leading to campaigns on related issues for adults

**DEVELOPMENT OF HEALTH SERVICES**

**WORKING PRACTICE**

The unexpected opportunities given to many people with learning disabilities meant that healthcare staff had to learn how to work closely with people whose background was socially, not medically, orientated. It was essential to find workspace. It was also essential to ensure that social services and voluntary agency staff understood that appropriate equipment supplied by therapists was necessary to enhance quality of life and was not re-enforcement of a disability.

In 1977 the numbers of therapists working with learning disabled people in England had risen to

- occupational therapists 113 (helpers 484)
- physiotherapists 103 (helpers 62)
- speech therapists 32
- chiropodists 23
- other therapists 269 (decrease)
- psychologists 140 (Department of Health and Social Security 1987)

**VIEWS OF PEOPLE WITH LEARNING DISABILITIES**

While reformers were working hard to integrate people with learning disabilities into normal society they themselves were not necessarily acquiescent of the principle. At a National (American) Conference on Normalisation and Contemporary Practice in Mental retardation in 1980 representatives of the People First International, an organisation of disabled persons, stated that ‘consumers need a group identity. They need a culture, a history and their own
heroes. They need each other so that they’re able to develop what the rest of society has . . . Groups give a special meaning and identity.’

They saw themselves as any other minority group in the US and normalisation as a way in which they would become isolated within the ‘normal’ community (Scheerenberger 1987). Table 1.5 shows how Wolfsenberger, one of the main proponents of normalisation (Wolfensberger and Thomas 1983), attempted to answer their concerns by gradually redefining the concept of normalisation.

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1959</td>
<td>Danish Act of Parliament: ‘Whatever facilities are open to all other citizens must, in principle, also be available to the mentally retarded.’</td>
</tr>
<tr>
<td>1969</td>
<td>Bank-Mikkelsen and Bengt Nirje ‘making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.’</td>
</tr>
<tr>
<td>1972</td>
<td>Wolfensberger. ‘Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normal as possible.’</td>
</tr>
<tr>
<td>1983</td>
<td>Wolfensberger redefined normalisation as Social Role Valorisation (SRV): ‘The enablement, establishment, enhancement, maintenance, and/or defence of valued social roles for people – particularly for those at value risk – by using, as much as possible, culturally valued means.’</td>
</tr>
<tr>
<td>1987</td>
<td>Kristiansen and Ness additional accomplishments for quality of life: expression of individuality and experience of continuity in one’s own life.</td>
</tr>
<tr>
<td>1992</td>
<td>Wolfensberger differentiated between valuing a person for themselves and ensuring that that person filled a valued role.</td>
</tr>
</tbody>
</table>

**Table 1.5. Normalisation and beyond**

PROVISION OF SERVICES IN THE COMMUNITY

Between 1967 and 1982, the number of residents in large institutions in the UK fell by over 40%. In 1983 the All Wales Strategy was published. This emphasised development of community services underpinned by the principles of normalisation and has been referred to in many studies.

The DHSS (1987) reported that it was recognised that:

- Most people with learning disability lived at home.
- Of the few children not living at home most were older and had profound learning disability.
- Multidisciplinary ‘community mental handicap teams’ were developing.
- Good community services could improve the quality of life of individuals and their families and could help to ensure that residential care was only for those with greatest need.
WHAT IS LEARNING DISABILITY?

- There were concerns regarding the level of help and priority given to people with learning disabilities by generic services.
- There were also concerns regarding respective roles of health and local authority services in service provision.
- Response to concerns had been made by
  - increased requests for specialist staff to support generic staff in the community and work directly with people with learning disability and their families
  - some social services departments employing healthcare staff
  - some learning disability nurses undertaking domiciliary work from a hospital base.

These trends and the first report by the Development Team for the Mentally Handicapped were endorsed by White Papers for England and Scotland in 1988. They also recognised that education of the general public, families of people with learning disability and health service providers would be required and that hospital residents would need to be re-educated. Appropriate community facilities and resources would have to be in place before any changes occurred.

*Caring for People* (Department of Health 1989) placed responsibility for assessing and providing for people’s needs with local authorities. They could provide services themselves or contract or buy in from other agencies. Voluntary organisations and families would assume some responsibilities previously provided by Social Services. Residential care was recommended for people with special medical or nursing needs.

By 1993 a joint meeting of a Forum on Learning Disabilities and the Centre for Physiotherapy Research reported that physiotherapists in England and Wales were starting to join multidisciplinary teams. Five hundred and thirty-three were identified and the survey showed that, of the 427 who responded, approximately one-third were working in a hospital, one-third from a community base and the remainder from day centres or a variety of settings. They tended to be experienced senior clinicians who had additional areas of specialisation. (Partridge 1994).

CONSULTATION

Problems of interpreting views of people with learning disability about their future needs continued to be discussed. The necessity for accurate and acceptable terminology, which did not reflect professional or ideological bias, was highlighted in meetings organised by the British Institute of Mental Handicap and the Department of Health (Harris 1991). Cullen (1991) reflected the dichotomy that can arise and the problems of oversimplification. He suggested that ‘Normalisation and social role valorisation had suffered at the
hands of those who yearn for a simple approach to life’. Mesibov (1990) indicated a similar attitude when he stated that:

Some of the commonly held tenets of normalisation are vague and unattainable; inappropriate practices are often carried out in the name of normalisation, for example, discouraging contact between people with disabilities; many advocates of normalisation have been overzealous and this overzealousness has resulted in distrust and antagonism.

Such confusion raised concerns amongst healthcare professionals regarding community facilities for the management and treatment of physical disabilities of residents leaving long-stay hospitals.

These concerns were confirmed by data based on 108 community care plans in 1993/4 throughout England (Turner et al. 1995). Proposed community facilities had not been established and resources were still needed for long-stay hospitals, for example:

- Widespread plans for development of day care provision including: employment, training, respite care, education, leisure and advocacy.
- Only three plans anticipated completion of resettlement by 1993.
- On average there were 3.6 long-stay residents per 10 000 population.
- The independent sector had increased provision in at least half of the areas. The provision of nursing homes and hostels together equalled the total of group homes and ordinary houses.

In Scotland, where hospital reprovisioning was progressing more slowly, the report on *The Future of Mental Handicap Hospital Services in Scotland* (Loudon 1992) appeared to provide answers to many of the concerns. These included:

- Facilities with high standards should be available before hospitals closed.
- Individuals and their families should be involved in a pre-transfer assessment of needs.
- Guidelines should be issued for residential care to meet the special clinical needs of people with mental handicap and serious behaviour problems and/or major psychiatric illness and/or multiple handicap.
- All Health Boards should be expected to ensure access to a full range of services.
- The Social Work Department, The Education Department and employers should be expected to provide opportunities for recreation, education and high quality work.

In 1995, the UK Government publicly adopted the term ‘learning disabilities’ in *The Health of the Nation* (England and Wales). A booklet specifically for people with learning disabilities accompanied this strategy for people with learning disabilities (Department of Health 1995). It defined ‘learning disability’ (Table 1.4) and listed related problems including obesity and poor
cardiovascular fitness, together with behavioural, psychiatric, orthopaedic and mobility problems. This term was not used in legislation until years later, for example in the Mental Health (Care and Treatment) (Scotland Act) 2003.

Restructuring of the NHS in the late 1990s led to concerns about allocation of health service resources for people with learning disabilities. However, it also alerted relevant committees to their needs. *Signposts for Success* (Lindsey, 1998) stated that community learning disability health services should:

- offer a wide range of co-ordinated support and advice for people with learning disabilities, their families and carers
- provide therapeutic services
- offer training for people with learning disabilities, their families, carers and staff of other organisations
- work closely with other agencies
- help the development of good practice in relation to health promotion and healthcare
- facilitate access to general health services

In practice these aims were partially met but coordination of services continued to be the greatest stumbling block:

- the development of multiprofessional teams improved management of physical disabilities in people with learning disabilities (see Chapter 5)
- well planned joint working provided new opportunities for effective treatment and management
- care in the community provided opportunities for training parents and carers individually in handling older people with profound disabilities
- use of community facilities enabled adults with learning disabilities to carry their treatment and management into everyday life

However:

- closure of specifically designed physiotherapy treatment areas and hydrotherapy pools limited the range of treatment offered to adults with profound physical and learning disabilities
- parents and carers of people with profound multiple disabilities had difficulties working with health and social services to find day, respite and future long-term care
- general health services did not always have sufficiently long appointment times to accommodate people with learning disabilities
- the move from day centres to individual packages of care involved time-consuming arrangements for therapy sessions, increased travelling time for therapists and reduced client contact time
- attempts to include people with learning disabilities only in ‘normal’ community activities tended to deprive them of the opportunity to participate in therapy-led peer group work.
The Health Act 1999 sought to improve coordination of services for everyone in the UK. It gave rise to the ‘Partnership in Action’ agenda, which encouraged improvement of services through flexible interagency work, a practice of seamless working that had long been attempted on an *ad hoc* basis for the benefit of people with learning disabilities. This Act proposed to support local flexible working practices by allowing agencies working together on specific packages of service to pool their budgets. In some areas of the UK it was suggested that delivery of services for people with learning disabilities might be progressed along the lines of Western Australia’s Local Area Coordination. In this model local area coordinators hold a budget from which direct payments can be made to clients and their families to select and pay for their own services (Disability Services Commission – Western Australia 1998).

**UNITED KINGDOM DEVOLUTION**

**UK Devolution**

- Laws relating to Health in England continue to be framed by the Department of Health at Westminster.
- In 1998 the Health Department for Northern Ireland was devolved to the Northern Ireland Assembly but from 2002 the Secretary of State and his Ministers have been responsible for Northern Ireland Departments.
- In 1999 the Health Department of the Scottish Office became fully devolved to the Scottish Executive.
- In 1999 Laws relating to Health in Wales remained with the Department of Health at Westminster but more responsibility for their framing and interpreting passed to the National Assembly for Wales and the Welsh Assembly government.

1999/2001

**Wales 1999**

One of the first actions of the National Assembly for Wales in 1999 was to establish the Learning Disability Advisory Group and commission it to prepare a draft service framework for people with learning disabilities. The group listened to people with learning disabilities, their supporters, and representative groups. Their proposals, *Fulfilling the Promise*, were presented to the Assembly in June 2001.

**The United Kingdom 2000/2001**

The ideals that developed into the principles of normalisation and inclusion of people with learning disability in everyday activities developed into locally
accepted codes of practice and relevant legislative provision with enabling powers but few were translated into laws specifically for the benefit of people with learning disability. However, people with learning disabilities were included as of right in the comprehensive proposals set out in the NHS Plan 2000 (Department of Health 2000), Partnership for Care – Scotland’s Health White Paper (Scottish Executive 2003) and the Community Care and Health (Scotland) Act 2002. More specifically their comments became the basis for proposals in the two reviews of services The Same as You? A Review of Services for People with Learning Disabilities (Scottish Executive 2000) and Valuing People – A New Strategy for Learning Disability for the Twenty-first Century (Department of Health 2001d).

Both White Papers reported the achievement of many of the aims of the Better Services for the Mentally Handicapped (Department of Health and Social Security 1971).

The most fundamental change in these reports was their emphasis on the decision making that people with learning disabilities could and should engage in to contribute to their own life style. While encouraging inclusion the reports also acknowledged that full participation frequently required extra help and facilities. This was highly relevant to therapists and nurses who needed to ensure that appointments were kept, treatment routines maintained and that medication was taken regularly.

Scotland 2000

The Same As You? (Scottish Executive 2000) included recommendations from the Scottish Consortium for Learning Disabilities, 13 organisations concerned with the care and support of people with learning disabilities, including service users. It based its decisions on seven key principles. People with learning disabilities:

- should be valued and encouraged to contribute to their community
- are individual people
- should be asked about the services they need and involved in making choices
- should be helped and supported to do everything that they are capable of doing
- should be helped to use standard local services wherever possible
- should benefit from specialist social, health and educational services
- should have services that take account of their age, abilities and other needs

It progressed the idea proposed in the 1999 Health Act from local flexible working practices to joint commissioning, in partnership between statutory services and voluntary organisations, and recommended:
• closure of the remaining long-stay hospitals by 2005
• development of health service models in the community to support and assess people with the most complex and challenging needs
• healthcare provision within mainstream services
• further development of advocacy services
• support for people with learning disabilities within their local community and development of local links through Local Area Coordination
• enabling individual flexible support via direct payments

The practical difficulties reported anecdotally following earlier hospital closures and greater inclusion in mainstream facilities were echoed in this review. It acknowledged problems encountered by young adults accessing therapy services after leaving school and inconsistency of physiotherapy, occupational and speech therapy services across the country. Lack of facilities, staff shortages and increased referrals for people with complex needs were cited as the cause. The Health Service employed the most therapists and they were usually linked to community learning disability teams. Schools and social services also employed therapists. Occupational therapists continued to develop joint working practices. Many areas established joint equipment stores.

**England and Wales**

*Valuing People A New Strategy for Learning Disability for the Twenty-first Century* (Department of Health 2001d) included consultations with children and adults with learning disabilities their parents, carers and relevant staff.

The strategy refined the 1995 definition of ‘learning disability’ and estimated the prevalence and future numbers in England (see Chapter 2). Its principles of rights, independence, choice and inclusion were grounded in previous rights legislation and had also evolved from the idea of local flexible working practices proposed in the 1999 Health Act.

Recommendations included:

• Increased funding, within which were
  – the Learning Disability Development Fund resources, only to be used as pooled funds under the Health Act
  – an Implementation Support Fund which would exist for three years following the fund’s introduction
  – increased financial support for carers

• Eleven broad objectives:
  – maximising opportunities for disabled children living in the community
  – transition into adult life ensuring continuity of care, support and equal opportunity
WHAT IS LEARNING DISABILITY?

- enabling people to increase control over their own lives; improved advocacy and person-centred planning
- supporting carers
- good health; to enable access to individually planned health services with additional support where necessary
- housing; enabling choice and control of where and how people live
- fulfilling lives; enabling full and purposeful lives amongst friends and local community
- moving into employment; giving opportunity for valued and, where possible, paid, work
- quality provision of high quality, evidence-based and continuously improving services from all agencies

The first nine points were to be enabled by:

- workforce training and planning; improvement of training and qualifications of all social and healthcare staff
- partnership working; promotion of holistic services through effective working between all relevant local commissioning and service-delivery agencies
- a new role of ‘health facilitator’
- ‘individual health action plans’ as part of person-centred planning

In general, locally accepted codes of practice evolved and an increasing number of service providers began delivering services as individually designed packages. Their success continued to be dependent upon

- good communication between the adult with learning disability and his or her support workers (see Chapter 6)
- continuity of support workers
- willingness of all the support workers of each adult with learning disabilities to participate in that adult’s selected activities, especially those that involved a regular and long-term commitment including therapy and general fitness activities (Chapters 15 and 17)

MOVING INTO PUBLIC AWARENESS

The concept of increased independence combined with appropriate assistance to use standard local services, wherever possible, meant that the needs of learning disabled people began to be included within general legislation. Concurrently, the balance between that concept and the requirement of specialist social, health and educational services and access to individually planned health services led to increased consultations with service users and providers. Learning disability reports, published locally, nationally and internationally, became the basis for local guidelines.
UNITED STATES

In the US, the President’s New Freedom Initiative in 2001 aimed to promote full inclusion of people with disabilities in all aspects of life as proposed in the Americans with Disabilities Act 1990 (ADA). ADA had developed from the Rehabilitation Act 1973 and stated that approximately 43,000,000 Americans had one or more physical or mental disabilities. Mental retardation was included within the category of ‘mental or psychological disorder’. It was recognised that a high level of discrimination occurred throughout all aspects of life against which there was no legal recourse.

Two points highlighted on The White House Web site, ‘Empowering through the New Freedom Initiative’ (www.whitehouse.gov/infocus/newfreedom), were:

- ‘...People with severe disabilities considered ‘homebound’ under the Medicare home health requirements... should be able to leave home occasionally without losing “Medicare cover”.’
- Congress was asked to fund a budget for the New Freedom Initiative, including grants for transport to improve job opportunities and a pilot programme for innovative transport initiatives.

For people with learning disabilities this was progressed by the Surgeon General’s Conference on Health Disparities and Mental Retardation. The conference report (US Department of Health and Human Services 2002) indicated that impediments to equality of healthcare included:

- poor communication directly with people with mental retardation and between support systems
- problems progressing through age-related healthcare systems (transition)
- difficulties finding out about, travelling to, and paying for healthcare
- finding insurance coverage for a range of needs
- inadequate training for generic healthcare professionals in treating people with mental retardation

UNITED NATIONS

In 2002, preliminary findings of the study to protect and monitor human rights for people with disabilities emphasised the need to strengthen present legislation while drafting a new, more specific convention for people with ‘physical, sensory, mental or intellectual disabilities’. They also stated that

... approximately 10 per cent of the world’s population have a disability of one form or another. Over two thirds of them live in developing countries. Only 2 per cent of disabled children in the developing world receive any education or rehabilitation. The link between disability and poverty and social exclusion is direct and strong throughout the world. (United Nations 2002)
EUROPE

The European Assembly argued that respect for the human rights, fundamental freedoms and dignity of people with disabilities was a collective responsibility of society as a whole and of each individual member. It anticipated the European Year of People with Disabilities in 2003 as potentially guaranteeing such people access to equal political, social, economic and cultural rights as laid down in The European Convention on Human Rights.

A conference on disability in Romania in 2003 was proposed by the Regional Director for South East Europe of the British Council. Laws for disability access had been passed in Romania in 1999 but, in a country undergoing extreme political change, high unemployment and low pay, their enforcement was minimal. People with physical or learning disabilities continued to be excluded.

THE UK

Despite good intentions and considerable work at all levels of government, the general public were slow to accept participation of people with learning disabilities in mainstream activities.

Wales

In response to the Learning Disability Advisory Group’s consultation report *Fulfilling the Promises* to the Welsh Assembly (2001), the Joseph Rowntree Foundation (2002) included in its observations:

- continuing problems with public attitudes and discrimination against people with learning disabilities in general
- additional needs of those from black and minority ethnic families
- problems of transfer from child to adult healthcare provision

They welcomed the importance laid on transition planning but referred to the findings of Heslop et al. (2001), which indicated a need for a variety of future options including types of further education and living accommodation for children leaving school.

Scotland

The National Review of the Contribution of all Nurses and Midwives to the Care and Support of People with Learning Disabilities’ (Scottish Executive 2002) indicated a need for children and adults living in the community to be supported by nurses from all specialities working together. It recommended complete assessments to clarify their health needs and ability to access appropriate healthcare provision.
England

New lines of communication were established by the Department of Health in a clarification note as an appendix to ‘Care trust application, consultation, assessment and establishment processes’ (Department of Health 2002). (Figure 1.1).

Local councils were encouraged to refer to the 1999 Health Act flexibilities which allowed for interagency work to ensure the use of the social model and direct access to necessary services. Care trusts should be promoted only in certain circumstances, primarily when in conjunction with other parts of health and social services (Department of Health 2002a). The person-centred approach and support to use mainstream services had to be applied in all proposals.

Concurrently it was acknowledged that a small number of people with highly complex needs have requirements that fall within the category of ‘specialised services’. These national services, resulting from the ‘The New NHS’ (Department of Health 1997), were established in England for groups with low patient numbers where resources are scarce and specialist staff and high-quality research programmes a necessity. They attract different commissioning agents from other NHS services (Department of Health 2002b).

Complex physical disabilities were not mentioned as a qualifying factor for this type of short-term inpatient assessment, treatment and follow-up although any level of physical disability may well be a contributing factor.

| Specialised learning disability services – definition no. 21 of December 2002 (Department of Health 2002b) |
| People with learning disabilities |
| • who have severe challenging needs and present major risks to themselves and/or others |
| • and severe mental health problems who cannot be addressed by general psychiatric services |
| • and autistic spectrum disorder with severe challenging and/or mental health needs. |

![Figure 1.1. Links between government and service users with learning disabilities in England in 2002.](image-url)
PROGRESS TOWARDS PUTTING WORDS INTO ACTION, 2003–6

2003

It became apparent that adults and children with all types of disabilities were becoming increasingly included in the thoughts and planning of legislatures around the world. It was also clear that large areas of great concern remained.

Middle and Eastern Europe

The Romanian conference took place in 2003. It gathered doctors, therapists, lawyers, teachers and policy makers from Non-Governmental Organisations (NGOs) of Armenia, Azerbaijan, Bulgaria, Croatia, Hungary, Iran, Lithuania, Macedonia, Moldova, Netherlands, Romania, Slovenia, and Uzbekistan both as speakers and delegates. Plenary speakers included lecturers, lawyers, politicians and therapists from Canada, Germany, Romania and the UK. The conference papers, Linking Globally: Acting Locally (Wood-Lamont 2004) demonstrated the struggle to implement disability laws without adequate resources, even when there was a sound local knowledge base.

The UK

Progress was made towards implementing the recommendations from Valuing People and The Same as You? by interviewing people with learning disabilities about their quality of life. Distribution of their time, services accessible to them and their own aims for the future were used as indicators.

England

The Department of Health commissioned a major survey of people with learning difficulties. The Government continued to report progress to the Westminster Parliament through its Annual Report based on Valuing People.

2004

United Nations

By 2004 the High Commissioner for human rights at the UN could report that states were beginning to treat disability as a broad human rights issue. However, information, specifically about people with learning disabilities in the most highly populated parts of the world, such as southeast Asia or Africa, was extremely difficult to find. In countries where wars, the AIDS crisis and natural disasters are reported regularly in general news, information
tended to occur in conjunction with the crises. For example, the Reuters Web site (www.alertnet.org) on 17 November 2004 reported that 18% of the Darfurian refugees had mental handicaps. Finance and planning are unlikely to be directed towards apparently less acute problems. Cultural differences were also recognised as playing a large part in hiding and discriminating against people with learning disability. Reports of a few nongovernmental organisations schools and communities for children specifically with learning disabilities in Africa and southeast Asia are available, notably on the Web site of Camphill International Communities (www.camphill.net/index.htm).

THE UK

England and Wales

Delivery of practical and continuous improvements in rights, independence, choice and inclusion was the aim of the Department of Health and the Disability Rights Commission, Framework for Partnership Action on Disability 2004/5 and the Government’s Special Educational Needs Strategy (Department for Education and Skills 2004). The latter included working through Regional Special Educational Needs partnerships, nonprofit agencies and research teams to provide additional learning support and improved transition policies.

Scotland

The Additional Support for Learning (Scotland) Act 2004 similarly made provision for extra support for children who required it to benefit from mainstream education. Multiprofessional Coordinated Support Plans were introduced. Scottish Ministers were allowed to set standards and regulations for special schools. Transition planning was established for all children and young people with recorded needs.

MONITORING PROGRESS IN 2004

England and Wales

Local authority provision was measured against some of the Department of Health’s objectives in Valuing People (Department of Health 2001). However, the strategy was not a ‘National Service Framework’ monitored by the NHS because these objectives had not been set as ‘national targets’. Complementary monitoring and targets were introduced in Wales. The new Healthcare Inspectorate Wales became responsible for local inspection and investigation of NHS bodies.

Delivery of learning disabilities services was included in the monitoring and auditing of all health service delivery by the Healthcare Commission,
established in 2004 under the Health and Social Care (Community Health and Standards) Act 2003.

**Scotland**

Quality indicators for learning disability that were first published by the Scottish Health Advisory service (SHAS) in 2000 were revised with the introduction of NHS Quality Improvement Scotland (NHS QIS 2004). These included:

- ‘Set clinical and non-clinical standards of care to help improve performance and set targets for continuous service improvement . . .’
- ‘Review and monitor the performance of NHS Scotland to determine how well NHS services are performing against the targets that we have set.’

**Northern Ireland**

Northern Ireland announced proposals to introduce a review body, HPSS Regulation and Improvement Authority (HPSSRIA), in April 2005 (Office of Public Sector Information 2003b).

**PROGRESSING INCLUSION IN 2004: NEW PROPOSALS MEAN MORE DISCUSSIONS AND CONSULTATIONS**

**England**

*Valuing People: Moving Forward Together*, the government’s annual report on learning disability (Department of Health 2004b) included:

- acknowledgement of concerns of people from black and ethnic minority backgrounds
- implementation of the request to write reports in an accessible way
- gradual increase of people receiving support via direct payment
- acknowledgement that the time scale for closing all long-stay hospitals by 2004 had not been met

**Scotland**

Implicit inclusion of people with learning disabilities was apparent in the National Health Service reform (Scotland) Act 2004. They would benefit from community health partnerships, which had developed from local healthcare cooperatives and four further aims were particularly pertinent to them and their therapy services:

- ensure patients, carers and the full range of healthcare professionals are involved
establish a substantive partnership with local authority services
have greater responsibility in the deployment of Health Board resources
focus on integrating primary and specialist health services at local level

Despite this potential for improvement in healthcare and the Scottish parliamentary policy of social justice and tackling inequalities, the Health Needs Assessment Report for People with Learning Disabilities in Scotland (NHS Scotland 2004) warned that public health policies and practices would widen the health gap for people with learning disabilities. Amongst the assessment’s findings were:

increased incidence of the most severe learning disabilities in each age cohort
increased life expectancy but one that was lower than the rest of Scotland
higher level of unmet health needs than the rest of Scotland
more complex health needs than the rest of Scotland
there was a barrier to having health needs met

Amongst five proposed areas of action were:

specific interventions including a health screening programme for people with learning disabilities
enhancing primary care and specialist community based services for all ages
education for staff and carers including improved induction in NHS Scotland and both pregraduation and postregistration/postgraduation initiatives
greater leadership and accountability to include health improvement strategy development

2005

The UN

The Commission on Human Rights produced a draft resolution that urged governments to:

ensure the full and equal enjoyment by persons with disabilities of all human rights and fundamental freedoms
prevent and prohibit all forms of discrimination against persons with disabilities
integrate a gender perspective in all efforts to protect the full and equal enjoyment of all human rights by persons with disabilities
ensure equal opportunities for full participation of persons with disabilities in all spheres of life
Concern was expressed especially at multiple discriminations. Great concern was shown over the consequences of armed conflict on people with disabilities.

It is clear in all UN papers since 2002 that people with disabilities have been acknowledged increasingly in the area of human rights. The Commission on Human Rights specifically encouraged more rapid progress of the draft convention on the needs of people with ‘physical, sensory, mental or intellectual disabilities’.

FOUR KEY REPORTS FOR ENGLAND AND WALES

England

The *Survey of Adults with Learning Difficulties in England 2003/4* (Emerson et al. 2005) was commissioned in 2002 by the Department of Health. This survey used the term ‘learning difficulties’ at the request of the participants. Participants were interviewed alone or with a support worker or carer. Results from 2,898 participants aged between 16 and 91 years indicated discrepancies between those factors for which legislation can be effective and the more subtle refinements needed for the smooth running of everyday life. For example, the participants were living amongst the general public in urban areas: 38% in supported living schemes, residential care or long-stay NHS accommodation and 62% with parents or family. However, as this was not always in their own home town or the area of their previous long-stay hospital, the results showed that companionship with their peer group had decreased:

- 69% reported some contact with friends ‘at least once a year’
- 31% reported no contact with friends
- 5% reported that they had no friends and did not see their family
- people living in private households or under a supported living scheme were more likely to live in poor and deprived areas with all the attendant social consequences

Although

- 54% had an independent advocate
- 63% indicated that they were happy with the support they received
- 86% said their health was good or very good
- 99% were registered with a general practitioner

the general impression was still one of discrimination and lack of independence. Only 19% received direct payments and 64% of people in supported accommodation had no choice of where or with whom they lived. Having a job was highly desirable and well promoted in all the literature but of those of ‘working age’ only 17% of participants had paid work. Despite that, 47%
of all participants reported to be very happy and only 9–11% reportedly felt ‘sad’, excluded or helpless.

**England and Wales**

The report *Improving the Life Chances of Disabled People* (Cabinet Office et al. 2005) set out to ensure that ‘By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.’ It focused on four areas:

- independent living
- early years and family support
- transition to adulthood
- employment

The report *Valuing People the Story So Far* (Greig 2005) – as in the previous report – showed that progress was being made where the relevant service providers and the local community understood the full implications of *Valuing People*. People’s lives had improved through, for example, well organised person-centred planning, improved coordination of services and response to requests and suggestions from people with learning disabilities and the increased number of people living independently through the Supporting People programme for independent living. Direct payments improved lifestyle. The continuing need to improve transition from childhood to adult services and the additional problems facing people from minority ethnic backgrounds were highlighted. The report listed priorities that it hoped would be achieved during the period 2005–2010.

The *Draft Three-year Strategic Plan for Assessing and Encouraging Improvement in the Health and Healthcare of Adults with Learning Disabilities 2006–2009* (Commission for Healthcare Audit and Inspection 2005) included input from the Commission for Social Care Inspection, the Department of Health’s Valuing People Support Team and the Health Inspectorate for Wales. It was preceded by an extensive consultation and was circulated for further consultation until January 2006. Despite consultation results and recommendations in reports such as *Signposts for Success* (Lindsey 1998) it was still possible for the Healthcare Commission to state in background information to this audit that ‘Those with learning disabilities are amongst the most deprived and excluded populations in the UK. Many are unable to have their voice heard in order to exert influence and exert pressure on services to change, which renders them largely invisible and vulnerable.’

To continue the progress towards rectifying this the Healthcare Commission planned to:

- audit all inpatient care being provided for learning disability service users across the NHS and independent sector, including commissioning arrangements
WHAT IS LEARNING DISABILITY?

- investigate the remaining long-stay hospitals for people with learning disabilities – national guidance had recommended that these be closed (Emerson et al. 2005)
- review the care of people with learning disabilities placed outside their local areas, away from family and friends
- increase the accessibility of the Commission’s services to enable people with a learning disability to raise complaints and concerns about their care
- establish champions, at their regional offices, responsible for monitoring services for people with disabilities

They proposed joint working with the Commission for Social Care Inspection where appropriate.

One Health Service proposal that appeared to have a positive repercussion for learning disability in England and Wales was the National Service Framework (NSF) for Long-term Conditions (Department of Health 2005). The 11 NSF quality requirements for these conditions were remarkably similar to the recommendations set out in *Valuing People* and the government had set no national targets to be achieved. It was possible that people with learning disabilities and associated neurological conditions (Chapter 2) might become included in this NSF.

2006

**The US**

Publication of *Intellectual Disability. Understanding Its Development, Causes, Classification, Evaluation and Treatment* (Harris 2006) gave great prominence to the term ‘intellectual disability’ as a replacement for ‘mental retardation’. The term’s progress towards gradual adoption was similar to that of the term ‘learning disability’ in the UK. People formerly known as being ‘mentally retarded’ preferred to be known as having an ‘intellectual disability’. In 2003 the Federal Advisory Committee for Mental Retardation became the President’s Committee for People with Intellectual Disabilities. The American Association on Mental Retardation (AAMR) decided to continue using its current title in the meantime, despite recommendations to the contrary by its Board of Governors the previous year.

**The UK**

Increasing use of mainstream health services and improved coordination between service providers allowed people with learning disabilities to participate as members of the general public in a further consultation paper in England and Wales. This formed the basis for the White Paper *Our Health, Our Care, Our Say: A New Direction for Community Services* (Department of Health 2006). The aims – to transfer more services from general hospitals into
local communities – would benefit people with learning disabilities who tend to find both travelling and hospital appointments difficult. For this to work successfully time and resources would be needed to implement reports such as the 2006–2009 strategic plan, (Greig 2005):

- people with learning disabilities would need to be assisted to use the services
- general practitioners would need to be aware of them on their case lists
- Health Service staff and the general public would need to understand that, despite, in many instances, poor social skills, the following statement was still valid: ‘People with learning disabilities are individuals. They should be valued for their differences, respected as citizens’ (NHS Scotland 2004).

Despite the emphasis on using mainstream services all the reports indicated that people with learning disabilities also needed access to specialist health services. The number of health professionals working in learning disability services, therefore, needed to be maintained or increased. Many universities managed to include an element of learning disability in already overcrowded medical and allied professional degree courses and placement rotas. Those universities ensured a continuing knowledge of the subject. When this was not the case, learning disability services had difficulty recruiting new staff. In some areas staff recruitment improved when rotational links were made with other hospital departments. Increases in the number of peer reviewed papers in journals such as *Physical Therapy: The Journal of American Physical Therapy Association* (Bruckner et al. 2002), features in professional magazines such as *Physiotherapy Frontline* (Hodges 2005) and contributions from the ACPPLD to reports such as *Working Differently* (Department of Health and the Allied Health Professions Federation 2005) served to raise awareness of the service needs.

### ETHICS AND THE UK LAW

All professionals are ethically bound by their code of conduct, which includes confidentiality in verbal, written and photographic records (Chartered Society of Physiotherapy 2002; Nursing and Midwifery Council (NMC) 2004; British College of Occupational Therapists 2005). Aspects of these codes are revised regularly, for example Core Standards of Physiotherapy Practice (Chartered Society of Physiotherapy 2005) and Communicating Quality 3 (Royal College of Speech and Language Therapists 2006). All Allied Health Professionals must be registered with the Health Professionals Council and undertake continuing professional development (CPD). The professional respect for all with whom they come in contact is reinforced by the Disability Discrimination Act 1995, 2005, Human Rights Act 1998, Race Relations Act 1998 and Race Relations (Amendment) Act 2000.
It is the responsibility of all staff to be aware of any changes in relevant legislation, for example the results of the Safeguarding Vulnerable Groups Bill and the Adult Support and Protection (Scotland) Bill, being discussed in the respective parliaments in 2006.

DELEGATING TASKS TO ASSISTANTS AND SUPPORT WORKERS

A professional who delegates tasks to a support worker, for example an assistant or technician, has a professional obligation and duty of care to ensure that that member of staff is individually trained (Parry and Vass 1997; Saunders 1997a, and Chartered Society of Physiotherapy (2002b). Carers or support workers should only be requested to undertake specific areas of client treatment or management and should be trained for that task. A written record should be kept of what has been taught and the carer or support worker should not be expected to instruct other care staff. Guidelines for delegation of tasks are published by the relevant professional bodies (Chartered Society of Physiotherapy 2002; NMC 2004; College of Occupational Therapists 2003). The Chartered Society of Physiotherapy and British College of Occupational Therapists published *A National framework for Support Worker Education and Development* in 2005.

MANUAL HANDLING

This should be undertaken in accordance with Manual Handling Operations Regulations 2004 and statutory training for the relevant Health and Social Work Service(s). It should be guided by publications such as Handling Home Care (Health and Safety Executive 2002) and the Chartered Society of Physiotherapy (2002b) guidelines. A risk assessment should be undertaken and written up for individual clients who require any assistance in moving. This should be area specific and take account of the differing skills of carers. The care plan should allow for changes in the client’s ability.

RECOGNISING ABUSE

Nurses and physiotherapists, who of necessity see clients unclothed, and speech and language therapists who are in close communication with clients, should be aware of the signs of child and elder abuse and the procedures to take in cases of concern. In respect of Human Rights legislation, if vulnerable people are able to make their own decisions a professional or carer may only recommend services that could be helpful and, if required, assist the individual to access them. Guidelines have been established in many local areas, for example *Protecting Vulnerable Adults: Ensuring Rights and Preventing Abuse* produced in collaboration by the local authorities of East, Mid and West Lothian, Edinburgh and Scottish Borders Councils; NHS Lothian; NHS Borders and Lothian
and Borders Police (East, Mid and West Lothian et al., 2003). This arose from the Miss X abuse case in the home of a male carer in the Scottish borders (NHS Scotland 2004).

All professionals should be aware that people with learning disability have a legal right to assistance from an advocate who is not involved with them in a professional capacity and can speak independently on their behalf (Disabled Persons Act 1986), which is reinforced in Valuing People (Department of Health 2001d).

All staff working in multiprofessional teams will be indirectly involved with legal aspects such as the holding power, compulsory admission, informal admission, in for example nurse’s holding power (Mental Health Act 1983), Adults with Incapacity (Scotland) Act 2000, The Mental Health (Care and Treatment) (Scotland) Act 2003, The Mental Capacity Act (2005), Chronically Sick and Disabled Persons Act 1970, Care Standards Act 2000 and Handling Home Care (Health and Safety Executive) 2002 – see also Department of Health 2004.

Treatment and management of physical disabilities in people with learning disability are most commonly affected by consent to treatment and restraint.

**CONSENT TO TREATMENT**

The NHS Plan (Department of Health 2000) and Partnership for Care, Scotland’s Health White Paper 2003 both committed the National Health Service to improving consent to treatment by actively involving all patients in decision making. In 2002 Northern Ireland produced a consultation document relating to consent. The results were published as a guide for people with learning disabilities (Department of Health, Social Services and Public Safety 2003).

Before commencing treatment with a new client with learning disability it is always wise to consult with medical and nursing staff who have a greater knowledge of the client’s ability to give consent and when possible with parents or support workers. Consent to medical treatment by adults with learning disability is only valid if they understand the significance of the consent – that is, if they have capacity. The NHS Plan 2000 gave rise to the Health Service circular Good Practice in Consent (Department of Health 2001a) and associated documents including Seeking Consent: Working with People with Learning Disabilities (Department of Health 2001c), which stated that the requirements for people to have the capacity to take a particular decision are that they are able to

- Comprehend and retain information material to the decision, especially as to the consequences of having or not having the intervention in question and
- Use and weigh this information in the decision-making process
England and Wales

In England and Wales the health professional undertaking an assessment must also assess for capacity and record the result. National consent forms were introduced as a basis for local documentation in 2002. Relevant law was described in Reference Guide to Consent for Examination and Treatment (Department of Health 2001b).

Scotland

In Scotland incapacity was defined specifically for and within the Adults with Incapacity (Scotland) Act 2000. It specified that capacity was to be assessed for each particular occasion. If incapacity was suspected the adult’s medical practitioner was required to assess for capacity and if necessary sign an incapacity certificate.

### Adults with Incapacity (Scotland) Act 2000

Assessment should establish whether adults

- are capable of making and communicating their choice
- understand the nature of what is being asked and why
- have memory abilities that allow the retention of information
- are aware of any alternatives
- have knowledge of the risks and benefits involved
- are aware that such information is of personal relevance to them
- are aware of their right to refuse and how to refuse as well as the consequences of refusal
- have ever expressed their wishes relevant to the issue when greater capacity existed
- are expressing views consistent with their previously preferred moral, cultural, family and experiential background

Both sets of criteria indicated a change from being an ‘outcome-based’ or ‘status-based assessment to being ‘functionally’ based. Understanding, knowledge, skills and abilities were to be related to the specific decision needed at a specific time

- No individual in the UK can give consent on behalf of an adult with learning disability except a welfare guardian in Scotland where financial guardians with powers over property and financial affairs may also be appointed, and for research, when next of kin can be proxy. When an adult lacks capacity the health professional responsible for that person’s care is legally respon-
sible for deciding whether a proposed treatment is in the person’s best interest. In Scotland this is specifically the medical practitioner who has issued the certificate of incapacity. All the literature recommends that such decisions be taken in conjunction with family and professionals who are most closely involved with the adult.

- Treatment may be given without consent if it is life saving or if it is reversible and immediately necessary to prevent serious deterioration, alleviate serious suffering or prevent the patient from being dangerous to himself or others (Mental Health Act 1983, Mental Health (Scotland) Act 1984). This was retained in subsequent Acts.

The Adults with Incapacity (Scotland) Act (2000), ‘Seeking consent: working with people with learning disabilities’ (2001) and The Mental Capacity Act 2005 clearly indicated that people should not be denied treatment because of their mental incapacity.

RESTRAINT

‘There is an underlying presumption in the law that it is wrong to interfere with the actions of another adult without lawful excuse’ (McKay 1998).

The question repeatedly arises as to whether seating harnesses and other positioning equipment used by people with physical and learning disabilities constitute restraint.

There is no specific piece of legislation setting out what is lawful in a care setting and what is not. It would be wise therefore to examine the case for each piece of equipment against the criterion of whether it breaches any statutory provision or any principle of criminal or civil law.

Breaches of criminal law include:

- assault
- cruel and unnatural treatment
- unjust imprisonment

Breaches of civil law include:

- assault
- unlawful detention/wrongful apprehension/wrongful imprisonment
- force and fear

This may be tested by considering the following questions:

- Is the individual’s physical condition liable to deteriorate if the equipment is not used?
- Is the individual’s general health improved by use of the equipment?
- Does the equipment help to relieve pain?
• Does the equipment enable greater mobility?
• Does the equipment enable greater communication?
• Does the equipment improve overall quality of life?

Seating harnesses are not designed to prevent overactive people or people who wander from moving out of a chair.

CONCLUSION

Ideologies, theories and practices have both enhanced and reduced the lives of people with learning disabilities who also have physical disabilities. For example, fear and the desire to protect them led to segregation. This deprived many people of progressive treatments and of recognition of neurological impairments and sensory disabilities in people with mild mental retardation. Normalisation and the term ‘learning disability’ used in the UK and ‘intellectual disability’ in the USA and elsewhere have assisted development of self-respect and opportunities for many people. Supported flats and small group homes, which the principle has generated, enable people with such disabilities to live amongst the general public in urban areas but they need careful management to allow opportunity for everyday exercise and freedom of movement. Proponents of inclusion need to recognise the value of therapy-led group work with the clients’ own peer group as well as inclusion in local activities with the general population.

Inconsistent terminology still leads to misunderstanding amongst health, educational and social service professionals who are not directly involved in this area and between colleagues internationally. Small groups introducing unique definitions for purposes of apparent clarification can compound this.

Work to enable people with learning disabilities to lead an increasingly full and active life is being progressed by politicians, educationalists, social services and healthcare professionals today. It is presently undertaken through person-centred planning and inclusion, multiprofessional and interagency work and self-advocacy. Management and treatment of physical disability sustained in conjunction with learning disabilities between birth and 16–21 years (Accardo and Capute 1998) or acquired later in life is treated in accordance with the standards laid down by the individual professional bodies. Aims of treatment are achieved while working in a variety of socially accepted settings and while encouraging all people with learning disabilities to enjoy a healthy lifestyle. Treatment and management of their physical disabilities will continue to develop in conjunction with the increased life expectancy of people who have
learning disabilities (Fryers 1997; Herge and Campbell 1998; Department of Health 2001d).

In Scotland, Professor Kerr’s consultation report *A National Framework for Service Change in the NHS in Scotland* led to reconfiguration of administrative bodies, and delivery of services in partnership with other support and care providers.

**REFERENCES**

United Kingdom Acts of Parliament are listed in Appendix C.


REFERENCES


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REFERENCES


