Use of the Term “Learning Disabilities” in the United Kingdom: Issues for International Researchers and Practitioners

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This paper presents a background as to use of the term “learning disabilities” that is widely used in the United Kingdom (UK). The paper also briefly explores how this usage may differ from that of other countries. To contextualize its use, a brief history of learning disabilities in the UK is outlined alongside diagnostic criteria, and epidemiological and etiological aspects of learning disabilities. These are relevant both to the UK and for international comparison. Finally, the practice of diagnosing and assessing learning disabilities in children and adolescents is briefly explored, as well as identifying the health and social care professionals who most commonly provide specialist support to people with learning disabilities in a range of educational, social, and healthcare settings in the UK. In particular distinction is made between the terms “learning disabilities” and “learning difficulties” – a source of continuing and common confusion amongst researchers, clinicians, and educators from countries outside of the UK. The paper concludes that non-UK international researchers, clinicians, and educators need to be cognizant of the importance of ensuring that the terminology they use is clearly understood. This is particularly relevant within the context of an ever-growing exchange of international ideas, research, and practice concerning people with learning disabilities.

Keywords: terminology, international differences, learning disabilities, learning difficulty, history, etiology, diagnostic criteria, United Kingdom.

INTRODUCTION

This paper explores use of the term “learning disabilities,” alongside its history, etiology, epidemiology, and diagnosis, all from the perspective of the United Kingdom. Internationally, there is wide-ranging use of terminology to refer to learning disabilities; in some countries terms are used interchangeably, whereas as in other countries terms have specific axiomatic meanings. In this paper, a distinction is made between “learning disabilities” and “learning difficulties.” In the UK, the former refers to global developmental delay, whereas the latter is used to refer to specific difficulties processing certain forms of information. These difficulties include, for example, dyslexia and dyspraxia or attention deficit hyperactivity disorder (ADHD). From the onset of this paper, the term “learning disabilities” is used, which is the prerogative term used in the UK to refer to people who have significant global developmental delay resulting in arrested or incomplete achievement of the “normal” milestones of human development. Internationally, other alternative terms are used, such as “intellectual disability,” “men-
tal retardation,” and “mental handicap.” Some of these terms have international utility whereas others portray negative imagery concerning people with learning disabilities. Within an international context, multiple use of terminology makes it problematic to share a common understanding of the term “learning disabilities.” Therefore, it is important to clarify how it is used in the UK compared with other countries.

**A Brief History of Care Provision in Learning Disabilities in the United Kingdom**

During the 18th and 19th centuries in the UK, similar to other western countries, a prevailing and dominant perception held was that some people with learning disabilities, not only presented a threat to society but were incapable of being productive.

The Industrial Revolution (from circa 1760 onwards) had created new demands for a skilled labor workforce, and it was apparent that people with learning disabilities did not have the social or economic skills required to become part of this workforce. As Race (1995) suggested, the Industrial Revolution brought about, “the measurement of people by their ability to cope with the new technological and commercial processes” (p. 46).

At this time, people with learning disabilities were perceived as unprofitable members of society, due to a lack of skill and intelligence and, subsequently, were viewed as a financial burden. The Poor Law Amendment Act 1834 responded to this by ensuring that they were segregated into workhouses. However, attitudes toward them continued to evolve. For example, there was a common belief that this group, along with a number of other groups, was responsible for the “social ills” of the time. This opinion of threat dominated late-19th and early-20th-century thinking, and was based on a belief that criminality, prostitution, and alcoholism were closely associated, in particular, with people with mild learning disability—a group that, at that time, was referred to as “feeble-minded” (Tredgold, 1909). It was also believed that procreation amongst this group would result in the spread of these social ills, thereby gradually eroding society’s physical, intellectual, and moral core, resulting in its eventual collapse—a view starkly illustrated by the following contemporary comment: “…the danger lies in the fact that these degenerates mate with healthy members of the community and thereby constantly drag fresh blood into the vortex of disease and lower the general vigor of the nation” (Tredgold, 1909, pp. 97-104).

This led to the inevitable segregation of people with learning disabilities from the rest of society through institutionalization (negative eugenics). Initial attempts at institutional care for people with learning disabilities (in the early 19th century) incorporated an educational philosophy of care reflecting a belief that the “mental defect” was sensitive to modification. However, later models of institutional care became more custodial and less reforming, reflecting a growing belief that feeble-mindedness was resistant to change.

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1 Throughout the 20th and into the 21st century, terms used in the UK to describe people with learning disabilities have continued to evolve. At the beginning the 20th century, the term “feeble-minded” was in common use. Chronologically afterwards, terms used include “mentally defective,” “idiot,” and “imbecile;” “mental and severe mental subnormality;” next, “mental handicap and severe mental handicap;” and finally “learning disabilities.”
The Wood Committee (1929) accelerated the policy of institutionalization and advocated for the formation of self-sufficient “colonies” that would take care of all groups of mental defect, regardless of age or level of disability. The term “colony” was eventually replaced by the term “hospital,” following establishment of the National Health Service Act 1946, under which control of these colonies was transferred from local councils to regional hospital boards.

During the 1950s and 1960s, a number of significant events brought the appropriateness of institutional care for people with learning disabilities into question. These events began to pave the way for the eventual introduction of community care for this group, and undoubtedly influenced the human and civil rights movements culminating in the European Convention on Human Rights (Council of Europe, 1950). In the 1960s, a number of reports on the state of institutional care in the UK identified impoverished and squalid living conditions, lack of privacy for patients, and an emphasis on predominantly physical care along with custodial attitudes among staff. The most famous of these was the Report of the Committee of Enquiry Into Ely Hospital (Howe Report, 1969). In addition, well-known sociological studies were undertaken in the 1950s, which demonstrated that a significant number of people living in such institutions had both the intellectual and social capabilities that would enable them to live adequately in the community (Race, 1995).

These social influences were reflected in a modified social and political agenda. In 1957, recommendations of a Royal Commission on the law relating to mental illness and mental deficiency paved the way for a new Mental Health Act 1959. This ended compulsory certification, which had been the case until then, enabling the discharge of many people with learning disabilities from the long-stay institutions. In 1971, a white paper, Better Services for the Mentally Handicapped (DHSS), was introduced, advocating a 50% reduction in hospital places by 1991 and an increase in the provision of local authority-based residential and day care. It also called for an end to custodial methods of care in hospitals and recommended the retraining of hospital staff. By 1979, The Jay Report had re-emphasized a need for local authority-led care and, important, a service philosophy based on principles of normalization. At this point, a social rather than a medical model of care and support was advocated.

In the UK, the principles of normalization adopted were interpreted by O’Brien and Tyne (1981) as the “five service accomplishments”: community presence, choice, competence, respect, and community participation. These accomplishments, in turn, became developmental goals by which organizations strove in their attempt at achieving community care.

Since the introduction of these service accomplishments, a steady stream of policy and legislative documents have continued to influence the trajectory of service provision for people with learning disabilities. In 1989, for example, a white paper, Caring for People, confirmed the government’s commitment to the development of locally based health and social care services. Following this, the government introduced the National Health Service and Community Care Act 1990 to provide the necessary support structures to enable (where possible) people to remain in their own homes, thereby reducing the demand for long-term care. These structures included an increase in the range of domiciliary, respite and day services, including the promotion of independent care options, and a greater emphasis on supporting infor-
mal care givers. Central to these developments was that future provision of services should be tailored to the needs of individuals, along with the introduction of community care assessments that would be undertaken by social services with assistance of healthcare professionals.

A Brief History of Statutory Terminology

In the UK, reference to learning disabilities, as we know it today, appeared in the 13th century in a document (Pregotiva Regis), which described them as natural fools/idiots or fools, with both groups of people described as persons *non compos mentis* (Neugebauer, 1996). Natural fools referred to those born with learning disabilities, whereas the term “fool” was reserved for those whose learning disabilities resulted from accidents. The term “non compos mentis” was used to describe both groups of people; during this period the Realm took possession of the property rights of such individuals.

Another important development in our current understanding of the term “learning disabilities” are the historical concepts of “idiocy” and “lunacy.” From the 13th century, the concepts of “idiocy” and “lunacy” became part of English law for the purposes of administration of justice (Rushton, 1996). This was a significant development because this terminology was then used for medical practice and social welfare, much as it still is today. Idiocy was considered to be permanent and untreatable, whereas lunacy was considered to be temporary and reversible. Diagnosis of both idiocy and lunacy was a legal process based on whether an individual had numeracy and language skills for social functioning. These legal developments meant that idiots and lunatics could have their social rights withdrawn and could be detained. The Madhouses Acts 1774, 1828, and 1832 created a Commission of the Royal College of Physicians for England and Wales that had powers for licensing asylums for lunatics. The Lunacy Act 1845 and the County Asylums Act 1845 both granted licenses to “asylums” so as to be able to detain lunatics, idiots, and “people of unsound mind.”

In the UK, among other countries, use of the term “feeble-minded” began in the late 19th century. This term was used to describe disorders or deficiencies of the mind, and its use encompassed educational as well as social deficiencies. According to Jackson (1998), feeble-mindedness was a spectrum ranging from idiocy to imbecility through to feeble-mindedness. Use of the term “imbecility” originates from the Latin referring to “feebleness” or “weaknesses.” Its use in the context of learning disabilities began in the 19th century, and was used to refer to people with intellectual functioning above that of an idiot. The Royal Commission on the Care and Control of the Feeble-Minded (1904-1908) defined the feeble-minded as:

Persons who may be capable of earning a living under favorable circumstances, but are incapable from mental defect, existing from birth or from an early age: (a) of competing on equal terms with their normal fellows, or (b) of managing themselves and their affairs with ordinary prudence (Bartley, 2000, p. 121).

At the turn of the 20th century, the Mental Deficiency Act 1913 was the first law in the UK to legally identify people with “mental deficiency” in order of vulnerability, idiots, imbeciles, feeble-minded persons, and moral imbeciles. Later, the Mental Health Act 1959 introduced the terms “sub-normality and severe mental
“sub-normality” to replace “mental deficiency,” and abolished the term “moral imbecile,” which was introduced in the Mental Deficiency Act 1913. Later still, the Mental Health Act 1983 introduced and defined “mental impairment” and “severe mental impairment,” whereas the terms “learning disability” and “severe learning disability” were introduced in the Mental Health Act 2007.

**Current Use of the Term “Learning Disabilities” in the United Kingdom**

In health and social care practice in the UK, the most contemporaneous term in general use is that of “learning disabilities,” and this accepted to mean:

A significantly reduced ability to understand new or complex information (impaired intelligence), to learn new skills with reduced ability to cope independently (impaired social functioning) which started before adulthood with lasting effect on development. (Department of Health, 2001, p. 14)

This definition is similar to the World Health Organization’s (WHO, 2016) definition, which states that:

Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

The term “learning disabilities” is relatively new in the UK, having been introduced by Stephen Dorrell, then Minister for Health, in 1991 in a speech to Men-cap (a national UK charity for people with learning disabilities). In the UK, learning disabilities, as discussed in this paper, encompasses scientific (intellectual disability), legal (mental impairment), and social (learning disability) perspectives. The research/scientific community’s definition is based on international norms, and is based on psychometric testing. From a legal perspective, learning disability remains as defined by the Mental Health Act 1983. From a social perspective, the definition of learning disability is based on social functioning assessment by local authorities for the purpose of social care provision, and this varies across the UK. This variation in how learning disability is understood can be a source of significant confusion, in particular, in terms of the relationship between “learning disabilities” and “learning difficulties.”

In UK the term “learning difficulty” is used extensively to describe children through to adulthood who have “specific learning difficulties,” such as alexia, dyslexia, dyspraxia, and dyscalculia (Campbell, 2013). Children and adults who have “learning difficulties” may, or may not, have “learning disabilities.” In the context of special educational needs, it is common to find the terms “moderate learning difficulty,” “severe learning difficulty,” and “profound and multiple learning difficulties” being used; these correspond to “mild learning disabilities,” “moderate learning disabilities,” and “severe and profound learning disabilities,” as already discussed in this paper.

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2 In the UK, there remains debate, and sometimes quite fierce derision, amongst academics, health and social care professionals, as well as the self-advocacy movement as to the most appropriate terminology to use. It remains the case that that “naming is not a simple act” (Luckasson, 2003), and that opinion in the UK is likely to remain divided for the foreseeable future.
By way of contrast, in the United States, for example, “learning disability” is used to describe a number of cognitive disorders that affect the information acquisition, organization, retention, and verbal or nonverbal understanding of such information, such as dyslexia, dyspraxia, and dyscalculia; this use of the term is quite distinct from “learning disabilities” as used in the UK. The use of this term in the United States, to an extent, is similar to the term “learning difficulty” used in the UK. The spectrum of learning disability in this context can affect spoken and written language, reading, and numerical comprehension. In addition, learning disability can have a negative impact on an individual’s organizational skills, social perception, and social interaction. In the United States, academic underachievement is considered to be a key factor in diagnosing learning disability.

Elsewhere in the world, alternative terms are used, such as “intellectual disabilities,” “mental retardation,” and “mental handicap;” for example, in Ireland, the term “intellectual disability” is used, and this is defined as:

Intellectual disability involves a greater than average difficulty in learning. A person is considered to have an intellectual disability when the following factors are present: general intellectual functioning is significantly below average; significant deficits exist in adaptive skills and the condition is present from childhood (eighteen years or less). (Inclusion Ireland, 2013)

In the United States, the American Association of Intellectual and Developmental Disability revised its definition of what was previously known as “mental retardation” to “intellectual disability” as well, which was drawn up in the United States in 2002.

Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. (American Association of Intellectual and Developmental Disability, 2010, pp. 3)

**Diagnostic Criteria for Learning Disabilities**

In the UK, along with much of the international learning disability community, a range of diagnostic manuals are applied. In all of these manuals, three core diagnostic criteria are used, and in the UK this includes:

- significant impairment of intellectual functioning (IQ < 70);
- significant impairment of adaptive/social functioning; and
- the age of onset is set for during the formative years, and must be before adulthood.

**Epidemiology of Learning Disabilities**

Calculating the incidence of learning disability is problematic because there is no way of detecting the vast majority of infants who have learning disabilities at birth. To arrive at an estimate, cumulative incidence is used; this has been calculated at the age of 8, as 4.9, and for severe learning disabilities as 4.3 per 100 live births (Emerson, Hatton, Felce, & Murphy, 2001).
Nonetheless, it is estimated that 2-3% of the population of the UK are likely to have learning disabilities, but it is also estimated that a large proportion of this population will never come into contact with caring agencies; therefore, it is more common to refer to “administrative prevalence;” that is, the number of people provided with some form of service from caring agencies.

Historically, there has been a general consensus that the overall administrative prevalence of severe learning disabilities is approximately 3-4 persons per 1,000 of the general population (DH, 2001). Whereas the Department of Health has suggested that mild learning disabilities is more common – around 20 per 1,000 of the general population. In the UK it has been further calculated that, of the 3-4 persons per 1,000 of population with a learning disability, approximately 30% will present with severe or profound learning disabilities. Within this group it is not uncommon to find multiple disabilities, including physical and/or sensory impairments or disability as well as behavioral difficulties.

Drawing on extensive epidemiological data, Emerson et al. (2001) confirmed the estimation of prevalence for severe learning disabilities, claiming it was somewhere around 3-4 persons per 1,000 of the general population. The prevalence rate for the population referred to as having mild learning disabilities is much more imprecise. It is estimated that it might lie between 25 and 30 people per 1,000 of the general population. Based on these estimates, it can be assumed that there are some 230,000-350,000 persons with severe learning disabilities and possibly 580,000-1,750,000 persons with mild learning disabilities in the UK.

More recently, Emerson et al. (2010) revised these estimates and calculated that in the UK, 1,198,000 people have learning disabilities. This includes:

- 298,000 children (188,000 boys, 110,000 girls) age 0-17;
- 900,000 adults aged 18+ (526,000 men and 374,000 women), of whom 191,000 (21%) are known to learning disabilities services.

There appears to be a slight imbalance in the ratio of males to females in people with both mild and severe learning disabilities, with slightly higher prevalence rates for men. Also, there is some evidence of slightly higher prevalence rates amongst some ethnic groups, including South Asian Groups in the UK (Emerson et al., 2001).

Theories Regarding Etiology of Learning Disabilities

Etiology of learning disabilities falls into two broad categories, genetic and environmental. Genetic aberrations may originate prior to conception, or during the very early stages of the developing fetus. The latter is defined by the stage of development at which damage to the child occurred. Environmental causes, on the other hand, include those external factors that may affect the developing fetus, and or a child either in the pre-conceptual, pre-, peri-, or post-natal periods. Where cause of learning disability is unknown, generally such manifestation is described as idiopathic. To illustrate this etiology examples are provided for each of these categories.

Genetic Causes

It is believed that in 30-40% of people their moderate to severe learning disabilities are caused by changes in their genetic makeup of (Knight, Regan, & Nicod, 1999). Developments in genetic technology arising from the Human Genome Project
have suggested that the percentage may be even higher. A study by Knight et al. (1999) has shown that a number of previously undiagnosed conditions in learning disabilities could be attributed to subtle chromosomal rearrangements.

**Chromosomal abnormalities.** Changes in the structure of autosomes or sex chromosomes may occur, and when this happens, it may include deletion, duplication, translocation, nondisjunction, or inversion of the chromosome in which genetic material is located. Figure 1 provides examples of autosomal and sex chromosomal abnormalities.

*Figure 1. Manifestations of autosomal and sex chromosomal abnormalities.*

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<tr>
<th>Manifestations of Autosomal Abnormalities</th>
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<tr>
<td><strong>Down Syndrome (Trisomy 21)</strong> – first described by John Langdon Down in 1866 – results from the nondisjunction of chromosome 21 pair during cell division, resulting in an individual having three rather than two chromosome 21. Incidence rate is between 1 in 650 and 1 in 700 (Mueller &amp; Young, 1998), becoming higher with an increase in maternal age. Typical characteristics include short stature, small ears, ear and eye defects, heart defects, and an increased susceptibility to infections, particularly, upper-respiratory tract and eye infections. In rare cases, some individuals have a mixture of cells that contain either trisomy 21 or the normal number of chromosome 21; this is known as mosaicism.</td>
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<td><strong>Cri-du-Chat</strong> – a relatively rare condition with an incidence rate of approximately 1 in 37,000 live births. Described in 1963 by Lejeune et al., and given this name because affected infants have high-pitched cries like those of a cat shortly after birth. Characteristics include microcephaly, low-set ears, and wide-spaced eyes. The condition is usually associated with moderate to severe learning disabilities. Infants may present with feeding problems because of difficulty swallowing and sucking, and low birth weight, and they may develop challenging behaviour (Gilbert, 2000; Wiedemann, Kunze, &amp; Dibbern, 1992).</td>
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<th>Manifestation of Sex-Chromosome Abnormalities</th>
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<td><strong>Klinefelter Syndrome (XXY)</strong> – first described by Klinefelter and his associates in 1942, this syndrome only affects males. It results from the nondisjunction of the XY chromosomes during cell division, resulting in affected individuals having an extra X chromosome. The incidence rate is between 1 in 500, and 1 in 1,000 births. Typical characteristics include a large forehead, ears and jaw, and following the onset of puberty, hypogonadism (small testicles) and gynecomastia (enlarged breasts); psychosocial problems are said to be common. The degree of learning disability is moderate, with a few cases of individuals presenting with profound learning disability (Gilbert, 2000; Wiedemann et al., 1992).</td>
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<td><strong>Turner Syndrome (XO)</strong> – this syndrome only affects females, and results from the loss of one of the two XX chromosomes. Incidence rate is estimated to be 1 in 2,500 births. Typical characteristics include short stature, weblike neck, nonfunctioning ovaries, and, in some cases, learning disabilities; a normal range of intelligence is more generally associated with this syndrome (Gilbert, 2000; Wiedemann et al., 1992).</td>
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**Figure 2. Autosomal dominant, recessive, and X-linked recessive conditions.**

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<th>Autosomal Dominant Conditions</th>
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<td><strong>Prader-Willi Syndrome</strong> – this condition results from deletion of part of the genetic material on the long arm of chromosome 15, and usually originates from the father. Incidence rate is approximately 1 in 15,000, and affects both males and females. Characteristics include small hands and feet, hypogenitalism (underdeveloped testes), and cryptorchidism (undescended testes) in males. One of the most notable characteristics is hyperphagia (excessive overeating). Without professional help and support, people with this syndrome commonly experience gross obesity and related conditions of heart disease and diabetes, which may result in premature death (Gilbert, 2000; Wiedemann et al., 1992).</td>
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<td><strong>Tuberous Sclerosis (Epiloia)</strong> – first described in 1880 and estimated to affect between 1 in 30,000 to 40,000 births, this condition is characterized by growths on the brain and major organs. A butterfly-shaped rash (adenoma sebaceum) will be present on the face, and epilepsy is common in people with this condition. Whereas normal intelligence may be present, 60% of affected people have some degree of learning disability (Gilbert, 2000; Wiedemann et al., 1992).</td>
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<th>Autosomal Recessive Condition</th>
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<td><strong>Phenylketonuria</strong> – first described by Fölling in 1934 this disorder affects protein metabolism, resulting in raised levels of phenylalanine in the blood. If protein levels are not maintained at a normal level through diet control, they may become toxic, causing brain damage. This condition is thought to affect 1 in 12,000 live births, and is commonly diagnosed using the Newborn blood spot test, which is carried out 6 to 14 days after birth. If left untreated, typical characteristics include lack of pigmentation in the eyes, skin and hair, hyperactivity, autistic features, epilepsy, and severe learning disabilities (Gilbert, 2000; Wiedemann et al., 1992).</td>
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<td><strong>Hurler Syndrome</strong> – one of the mucopolysaccharide disorders, which has an estimated prevalence rate of 1 in 150,000 births. Characterized by the abnormal storage of mucopolysaccharides in connective tissue, affected individuals are short in stature and have thick, coarse facial features and a low nasal bridge. Hirsutism (male-pattern hair growth on a woman’s face, chest, and back) is a common characteristic, as is the presence of heart abnormalities. Affected individuals may also have sight and hearing impairments; death normally occurs during adolescence (Gilbert, 2000; Wiedemann et al., 1992).</td>
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<th>X-Linked Recessive Conditions</th>
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<td><strong>Fragile X Syndrome</strong> – a condition occurring more commonly in males than females, with a prevalence rate of 1 in 4,000 and 1 in 8,000, respectively. It is believed to be the most common cause of learning disabilities, next to Down’s syndrome. The condition arises from the bottom tip of the X chromosome breaking off, making the site fragile; hence its name. Common characteristics include an oversized head, long face, prominent ears, large jaw, language difficulties, and varying degrees of learning disabilities along with behavioural challenges.</td>
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**Genetic abnormalities.** Specific conditions of learning disabilities may also result from changes in the structure of genetic material. These changes include deletion, duplication, addition, inversion, and substitution of the parts of the DNA. Genetic abnormalities are generally categorized by the mode of transmission of the defective gene. These forms of transmission can be described as autosomal dominant, autosomal recessive, or X-linked. Some conditions may also result from an interaction of various genes (polygenic), although these are not described in this paper. In the main, genetic abnormalities are caused by either autosomal dominant or autosomal recessive conditions. In the case of autosomal dominant conditions, transmission is reliant upon only one parent being a carrier of the defective gene, and there is a 50% chance of it occurring in the offspring. In the case of autosomal recessive conditions, on the other hand, transmission is reliant on both parents being carriers of the defective gene and in this case, there is a 25% chance of the condition manifesting in the offspring. Figure 2 provides examples of autosomal dominant, recessive and X-linked recessive conditions.

**Environmental Factors**

Environmental factors are also known to have an important influence on physical and intellectual development, and some known environmental factors may hinder growth and development, which may result in learning disabilities. These can occur at pre-conceptual, pre-natal, peri-natal, and post-natal periods of development, and typically include infections, trauma, substance abuse, and social deprivation.

Environmental causes of learning disabilities include trauma during the pre-natal, peri-natal, and post-natal phases as well as accidental and non-accidental injury during growth. At the pre-natal stage, this might also include obstetric problems during delivery, forceps or suction. Restriction of oxygen supply to the fetus during pre-natal and peri-natal phases can also result in brain damage. In the latter stage, asphyxiation may occur if the umbilical cord becomes wrapped around baby’s neck for a prolonged period of time.

Consumption of drugs, including alcohol (substance abuse), accounts for stunted growth and lack of brain development observed in some children. Toxic agents, lead poisoning, chemical pollutants, and hard metals, such as mercury, manganese, and strontium poisoning, are all recognized causes of brain damage. In the post-natal phase of development, poor nutrition and a lack of sensory and social stimulation (secondary amentia) can impair development and result in learning disabilities.

**Infection.** Other causes of learning disabilities include acquired infection that can result in brain damage at the pre-natal, peri-natal, and the post-natal stages of development, and encompass rubella (German measles), mumps, and chickenpox. In the past, syphilis was a common cause of learning disability, but this is now rare in Western countries. Viral infections may give rise to encephalitis (inflammation of the brain), and the subsequent degree of learning disability can be severe; dehydration occurs rapidly, leading to brain hemorrhage and subsequent brain damage.

Finally, congenital rubella, first described by Gregg in 1941, is characterized by a number of abnormalities, including cataracts, deafness, congenital heart defects, and learning disabilities. Brian damage occurs when the rubella virus passes across
the placenta barrier and attacks the developing nervous tissue in the unborn fetus. In recent years, the prevalence of congenital rubella has declined with the introduction of rigorous immunization programs.

**The Social Model of Disability**

It is important to acknowledge the contribution of the social model of disability toward a contemporary understanding of learning disabilities. Originating in the 1960s, its use emerged in the United Kingdom in the 1980s. The social model of disability represents a reaction to the otherwise dominant medical model of disability, which is argued to be located by functionality – the body being understood as a mechanistic object that can be fixed so as to conform to arbitrary normal values. The social model of disability, on the other hand, advocates that it is systemic barriers, negative attitudes, and exclusion by society that form the contributory factors that disable people. So whereas an individual’s physical, sensory, intellectual, or psychological composition might cause physical limitations or impairment, they of themselves should not lead to disability. Rather, it is society itself that fails to accommodating and include them regardless of their individuality. This is why even in the UK there is multiplicity of terminology with, for example, “learning difficulties” being the terminology of choice by the self-advocacy movement rather than “learning disabilities” – a factor further complicating international understanding of learning disabilities in the UK.

**Common Practice of Diagnosing and Assessing Learning Disabilities in Children, Adolescents, and Adults in the UK**

In the UK, most parents are not aware before birth that their child may have learning disabilities. In most instances, only a small number of parents receive given advance information as a result of some form of screening investigations, such as blood tests, ultrasound scans, or diagnostic investigations such as amniocentesis, chorionic villous sampling or other tests. These are generally undertaken because the parents are perceived as being at high risk; for example, increased maternal age is highly correlated with a diagnosis of Down’s syndrome in any offspring; Age 20 – 1:1,450; Age 29 – 1: 1050; Age 39 – 1:110; Age 49 –1:25 (Morris, Wald, Mutton, & Alberman, 2003). Newer tests are being developed such as CytoScan Dx Assay, which may help identify causation of developmental delay or intellectual disability, and it is believed that this test is superior to Karyotyping and chromosomal testing.

However, unless a definite physical abnormality or characteristic signs (as in children with Down’s syndrome) are present at birth or a traumatic delivery has taken place, learning disabilities is seldom suspected or diagnosed at birth. When a diagnosis does occur, it can vary from the confirmation of the presence of a specific condition (for example, Edward’s syndrome) to a much broader diagnosis of global developmental delay, with no particular condition being identified. Learning disabilities is generally identified during childhood, but sometimes it is not finally diagnosed until early adolescence.

Children with severe or profound learning disabilities with complex needs are much more likely to be noticed as having learning disabilities at a younger age than those with mild to moderate learning disabilities. Learning disabilities is most
frequently diagnosed in early childhood, usually when a child fails to reach “normal” but critical developmental milestones. During this period, parents may have expressed concerns over the nature of their child’s progress and suspected a problem. When this happens, standard practice is to monitor the child’s progress on a regular basis; that is, more frequently than the usual screening checks, with records being kept. It is considered good practice to respond sensitively to parents, acknowledging their unique insights. Active family involvement can be damaged in the short term, and possibly for many years, when a diagnosis of learning disabilities is finally confirmed, especially if repeated concerns have been raised by parents only to be dismissed or ignored. That is why it is important to identify both the nature and the extent of learning disabilities and either exclude or include other more specific developmental disorders that are sometimes present; for example, autistic spectrum conditions, attention deficit hyperactivity disorder, or dyspraxia. Finally, identifying possible causes of learning disability and the provision of an early diagnosis are important to …

- limit potential feelings of self-blame that may be experienced by some parents,
- reduce possible challenges in the adaptation of parents to their child and, hopefully, avoid rejection.

Other reasons for identifying the presence of learning disability and forming a diagnosis include a need to …

- understand the possible manifestation and trajectory of an identified condition over time,
- identify a range of therapeutic approaches that may be used to ameliorate the effects of the condition, this will include mobilizing and accessing resources (Gates, 2000),
- establish, in some cases, the degree of risk to other family members of the condition reoccurring in their siblings and offspring through genetic counseling.

**COMMON INVOLVEMENT OF HEALTH AND SOCIAL CARE PROFESSIONALS IN MEETING THE NEEDS OF PEOPLE WITH LEARNING DISABILITIES**

Over the last 20 years, in the UK health and social care policy has focused on moving specialist services for people with learning disabilities to “mainstream” services; that is, an inclusive community-oriented agenda. So, whereas in the past many specialist and quite often separate services and specialist staff existed for this group of people, increasingly they are now located in the same services and use the same personnel as does the general population. Nonetheless a range of specialist educational, health, and social care staff remains that includes:

**Education**
- Special education teachers
- Educational psychologists
Health

• Speech and language therapists
• Physiotherapists
• Occupational therapists
• Consultant psychiatrists in learning disabilities
• Social workers
• Specialist learning disability nurses
• Consultant clinical psychologists
• Child and Adolescent Mental Health Services (CAMHS)

Notwithstanding these specialist staff, parents and people with learning disabilities also use and rely on a wide range of nonspecialist, generic, health, and social care professionals, including:

• General practitioners (GPs)
• Dentists
• Chiropodists
• Optometrists

This reliance on, and use of, generic health services and personnel can be explained by the disproportionate health burden that this group of people experience in comparison with the general population (Van Schrojenstein Lantman-de Valk & Walsh, 2008).

Conclusions

This paper has sought to present a background as to the specific use of the term “learning disabilities” in the UK and how this may differ from terminology used internationally. This discussion was grounded in a brief history of learning disabilities in the UK. The paper also outlined diagnostic criteria, along with epidemiological and etiological aspects of learning disabilities, all relevant to the UK but of use for international comparisons. It is hoped that the paper will assist researchers, clinicians, and educators from outside the UK in understanding terminology used in the UK and some of the inherent tensions that may be partly remedied by adopting appropriate terminology. The practice of diagnosing and assessing learning disabilities in children and adolescents was also explored, along with identifying the health and social care professionals who provide specialist support to people with learning disability in a range of educational, social, and health care settings. Within a continuing context of a lack of consensus on terminology, both within and between countries, used for this group of people, it is suggested that the international community of researchers, clinicians, and educators outside of the UK recognize the importance of ensuring adoption of the culturally normative use of terminology. This is important, not least, because of the ever-growing desire, necessity, and indeed pressure for international exchange of research and practice initiatives relevant to this group of people.
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Anyone involved in the workings of a school in a community setting will find the chapters in this book to be useful in strengthening the existing relationships among schools, families, and community members and building powerful new ones. The authors cover a variety of important topics related to forging networks that support positive student development and school success.

Co-editors Young and Michael have invited experienced educators to share their success stories in case studies that illustrate school-family-community partnerships that work together to solve the challenges of contemporary education in this country. Their creative approaches represent best practice in thinking about how to maximize scarce resources, how to engage families in our increasingly diverse society, how to leverage the strengths of community agencies and businesses, and how to involve students in leadership initiatives to better their schools.

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