

Learning Disability Nurse Survival Guide

**Common questions and answers for
learning disability nursing**

Note

Healthcare practice and knowledge are constantly changing and developing as new research and treatments, changes in procedures, drugs and equipment become available.

The editors and publishers have, as far as is possible, taken care to confirm that the information complies with the latest standards of practice and legislation.

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learning disability nursing**

edited by

Dave Dalby and Chris Knifton



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Introduction

Learning disability nursing has been defined as

...a person-centred profession with the primary aim of supporting the wellbeing and social inclusion of people with learning disabilities through improving or maintaining physical and mental health.

(Department of Health 2007:7)

Typically, learning disability nurses may find themselves working in a range of different settings to provide this type of support. The Department of Health (2007) indeed notes that whilst most learning disability nurses are now employed in community settings

...significant numbers do still work providing inpatient care, for example, in the assessment and treatment services, forensic services and working in mental health services where there are people with learning disabilities and mental health needs.

(Department of Health 2007: 16)

What, however, remains constant, is the focus on the people with learning disabilities and their families and carers. Nurses new to this area of practice can expect an exciting albeit challenging working environment. This book has been developed for newly qualified learning disability nurses, those returning to practice, and registered nurses from other fields of practice new to working with people with a learning disability. It is intended for everyday use, and as such, it is suggested a copy be left in your workplace, where it can be easily accessed. At the end of each chapter there is a blank page for you to add useful workplace information. Add notes on these pages, and make this book your own resource, to guide you through your introductory years to nursing people with learning disabilities.

Dave Dalby and Chris Knifton
De Montfort University Leicester 2012

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Common syndromes and disorders in learning disability

Catherine Hart and Chris Knifton

- What is a learning disability?
- What terminology should I use?
- Do all forms of learning disability have a known cause/condition?
- What are some of the known common conditions associated with a learning disability?
- What are the known health risks in common conditions associated with a learning disability?
- What are autistic spectrum disorders, Asperger's and autism?

What is a learning disability?

Catherine Hart

Learning disabilities affect a person's ability to learn, communicate and carry out everyday tasks. The Department of Health (2001) has defined learning disability as:

- A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence); along with
- A reduced ability to cope independently (impaired social functioning), and
- An onset of disability which started before adulthood, with a lasting effect on development.

Many services across the UK use both medical and psychologically-based criteria to define learning disabilities. Such definitions exist in classification systems such as ICD-10 (the International Classification of Mental and Behavioral Disorders; World Health Organisation 1992) and DSM-IV (Diagnostic Statistical Manual; American Psychiatric Association 1994). These definitions are mainly used when determining if a person is eligible to use specialist learning disability services. Recent thinking, however, has seen a shift towards access being based on need and not ability, although this has been slow.

Some people who experience other conditions, such as chronic psychosis or acquired brain injury in adulthood, may also meet the first two criteria of the clinical definitions of a learning disability, but they would not be considered to have a learning disability and may therefore not be eligible to use specialist learning disability services.

When working with people who have learning disabilities, you may come across references to the degree of disability – mild, moderate, severe or profound. These originate from a medical perspective. Policy makers are now encouraging services to focus on individual needs rather than previous groupings of people with learning disabilities. These terms are still however commonly used in practice, and are illustrated in *Table 1.1*.

Table 1.1. Definitions of learning disability categorisation		
<i>Standard Score Range</i>	<i>WAIS-IV* Descriptive Classification</i>	
130+	Very superior	
120–129	Superior	
110–119	High average	
90–109	Average	
80–89	Low average	
70–79	Borderline	
≤ 69	Extremely low	Over three quarters of people with learning disabilities have a mild disability. The majority live independently; many have their own families, are in employment and have no need for extra support from services, except in times of crisis People in this category need a higher level of support. Many will need some support with everyday tasks and may have difficulty in communicating their needs. They are likely to be living with their parents, with day-to-day support, or in supported living schemes. They are also likely to use a number of support services such as day, outreach and supported living schemes
50–69	<i>Mild</i>	
35–50	<i>Moderate</i>	

20–35	Severe	<p>People with severe and profound learning disability may have significantly increased health needs, such as higher rates of epilepsy, sensory impairments and physical disabilities. They are likely to have more complex needs and greater difficulty in communicating their needs. Sometimes individuals engage in behaviour that others consider challenging, in an effort to communicate their need or as an expression of their frustration. Self-injury is particularly common in people with profound learning disability. In severe cases this can lead to additional disability, poor health and a significantly decreased quality of life</p>
<20	Profound	
<p>WAIS-R: Wechsler Adult Intelligence Scale – Revised. Adapted from Hardy et al. 2006</p>		

What terminology should I use?

Catherine Hart and Chris Knifton

Some people with learning disabilities prefer the term ‘learning difficulties’. This is the wording used by People First, an international advocacy organisation. However, this term also often refers to individuals who have a specific problem with learning, such as dyslexia. Particularly with children, a learning difficulty might arise as a result of medical problems, emotional problems, and/or language impairments. The term ‘learning disabilities’ however, indicates an overall impairment of intellect and function. In the past, terms such as ‘mental handicap’, ‘mental subnormality’, ‘mental deficiency’ and ‘mental retardation’ have also been used. These terms are to be avoided in contemporary practice. It is however worth noting that differing terminology may be used in other countries – America, for example, may still use the term mental retardation, and Ireland may use intellectual disability.

Do all forms of learning disability have a known cause/condition?

Chris Knifton

No. It is suggested that in between 40 and 80% of cases the cause cannot be determined (Wymbrandt and Ludman 2000).

What are some of the known common conditions associated with a learning disability?

Chris Knifton

These are varied and include a range of genetic abnormalities (e.g. Down's syndrome, Edwards' syndrome, Patau syndrome, Cri-du-chat syndrome, Turner syndrome, Apert syndrome, tuberous sclerosis, galactosaemia, Sanfilippo syndrome, Tay-Sachs disease, phenylketonuria, fragile X syndrome, Coffin-Lowry syndrome, Prader-Willi syndrome, Hurler syndrome, Hunter syndrome, Cornelia de Lange syndrome, hydrocephalus); prenatal factors (e.g. rubella acquired, cytomegalovirus acquired), and maternal health (e.g. foetal alcohol syndrome, kernicterus). Other causes include hypoxia, infections, environmental risks, and trauma. Examples of conditions often associated with a learning disability are listed in *Table 1.2*, with the date of discovery/reporting of the condition.

What are the known health risks in common conditions associated with a learning disability?

Chris Knifton

Down's syndrome

This condition was first described by Dr Langdon Down in 1866. It is caused by an extra chromosome on autosome 21, commonly referred to as trisomy 21, and is the commonest chromosomal abnormality. There is an increased incidence as maternal age rises. Turner (2001) notes that, despite the risk of death due to respiratory infection reducing over the years, mortality rates still remain high. The biggest cause of death however is congenital heart disease.

Additional specific healthcare points you need to be aware of include:

- Alzheimer's disease, a form of dementia, is common as the person ages. This also brings the added risk of epilepsy in people with Down's syndrome.
- Atlanto-axial instability – strength in the neck joints/cervical spine are compromised. MacLachlan et al (1993) reported that 13% of adults with Down's syndrome were at risk, with additional risks of degenerative arthritis being common (Howells 1989).
- Cataracts (Pueschel 1987).
- Congenital heart defects – the biggest single cause of death (Turner 2001, McGrother and Marshall 1990).

Table 1.2. Conditions commonly associated with a learning disability				
Date	Author/s	Condition	Also known as	Cause
1853	Little	Cerebral palsy		Various Note: not all cases have a learning disability
1866	Langdon Down	Down's syndrome	Mongolism – term not to be used but may appear in old medical notes/ journals Trisomy 21	Extra chromosome at pair 21
1880		Tuberous sclerosis	Epilolia	Autosomal dominant gene
1881/ 1886	Tay and later Sachs	Tay-Sachs disease		Abnormal storage of fats (lipids) in tissue
1908	Reuss	Galactosaemia		Carbohydrate (galactose) disorder
1934	Fölling	Phenylketonuria	PKU	Raised levels of phenylalanine
1941	Gregg	Rubella syndrome		Infection with rubella virus while <i>in utero</i>
1942	Klinefelter et al	Klinefelter's syndrome		Extra X chromosome in males
1943	Kanner	Autism		Unknown
1960	Edwards et al	Edwards' Syndrome	Trisomy 18	Extra chromosome at pair 18
1960	Patau et al	Patau's syndrome	Trisomy 13	Extra chromosome at pair 13
1961	Sandberg et al	XYY syndrome		Extra Y chromosome
1963	Lejeune et al	Cri-du-chat Syndrome		Deletion of short arm of chromosome 5

- Gastrointestinal disorders – including duodenal stenosis, oesophageal atresia and Hirschsprung's disease (Levy 1992).
- Hepatitis B infections.
- Lack of the enzyme lysozyme (a natural antiseptic), which can lead to blepharitis and conjunctivitis.
- Leukaemia – there is a higher incidence of death from this than usually found in the general population (Turner 2001, Fong and Brodeur 1987).
- Poorly developed nose bridge, small mouth with a high palate and large tongue leading to mouth breathing and increasing risk of respiratory tract infection.
- Thyroid disorders.

Edwards' syndrome

This condition was first described by Edwards and colleagues in 1960. It is caused by an extra chromosome on pair 18, commonly referred to as trisomy 18. There are signs of hypertelorism, small low-set ears, and a short neck. Growth deficiency is common, and overlapping fingers are evident. Learning disability is often severe. Usually congenital abnormalities of the heart, abdominal organs, nervous system, kidneys and ears are apparent.

Turner syndrome

Turner syndrome was first described in 1938. Also known as X0 syndrome, it is caused by a lack of an X chromosome in females. Secondary sexual characteristics are under-developed. Notably, not all people with this condition have a learning disability. Nurses need to be aware of the risk of osteoporosis in Turner syndrome during later life.

Klinefelter's syndrome

This syndrome was first described in 1942. Also known as XXY syndrome, it is caused by an additional X chromosome in males. There are usually under-developed secondary sexual characteristics and longer lower limbs. Additional X chromosomes can occur (although these conditions are not referred to as Klinefelter's syndrome), and the greater the number of X chromosomes, the more severe the learning disability. Nurses need to be aware of the risks of gynaecomastia, leg ulcers, osteoporosis and breast carcinoma in this condition. Not all people with this condition have a learning disability.

Prader-Willi syndrome

This was first described in 1956. It is usually associated with chromosome 15 deletions. Features include growth deficiency, reduced muscle tone, small hands and feet, and an often insatiable appetite. Latterly this may lead to behavioural difficulties when appetite desires are not met. There is also an association with self-injurious behaviour. Nurses need to be aware of the insatiable appetite and both the mental and physical effects this has on the person, including risks of depression, obesity and diabetes mellitus.

Fragile X syndrome

This is the most common cause of inherited learning disability. It can occur in people of either sex. However, it is important to note that not all will develop a learning disability. Mortality for congenital heart abnormalities is higher in this group of people than in the general population (Turner 2001). Other health-related problems may include vision or hearing losses, and skeletal and connective tissue problems (Davids et al 1990).

Lesch-Nyhan syndrome

This condition was first described in 1964 by Lesch and Nyhan, and is caused by an X-linked recessive gene leading to deficiency of an enzyme responsible for purine metabolism. This leads to an accumulation of uric acid in the blood causing severe learning disability. An important healthcare implication is the increased risk of self-mutilation.

What are autistic spectrum disorders, Asperger's and autism?

Catherine Hart

The autism spectrum of disorders is a continuum of psychological conditions characterised by widespread abnormalities of social interactions and communication, as well as restricted interests and repetitive behaviour. Autism is a lifelong, pervasive developmental disorder. Approximately 25% of people with autism have learning disabilities (Chakrabarti and Fombonne 2001). The majority of people with autism who do not have accompanying learning disabilities are described as having either 'high functioning autism' or Asperger's syndrome.

Autism is referred to as a ‘spectrum condition’ because it varies considerably in how it affects each person. However, there are three core features of autism, known as the ‘triad of impairments’:

- *Impairment of communication*: this affects both verbal and non-verbal communication. Some people may present with echolalia, repeating what they have heard. Difficulty in understanding certain types of words, such as abstract concepts and negatives, is common.
- *Impairment of social interaction*: this can range from someone who seeks out social interaction, but lacks the social skills to develop and maintain relationships, to someone who is withdrawn and apparently indifferent or actively avoids other people.
- *Impairment of imagination*: people with autism do not develop the same imaginative skills as other people; they tend to think in a very concrete way, for example, thinking in terms of actual objects, and have difficulty with abstract concepts, such as emotions.

People with autism are vulnerable to developing mental health problems, notably depression and anxiety disorders, and are particularly vulnerable around times of transition and change.

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