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Library Services to People with Special Needs Section -Glossary of Terms and Definitions

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Introduction

The need for this glossary first became strikingly evident during the development of the section's *Guidelines for libraries serving hospital patients and the elderly and disabled in long-term care facilities.*¹ Within those guidelines, just the single descriptor, 'hospital libraries,' was found to have dramatically different meanings in different parts of the world – in much of Western Europe, for example, 'hospital libraries' almost always meant a library for patients, while in North America, it most often meant a library for health sciences staff. Those different meanings made communication and research in the field, especially research done through the literature, exceedingly difficult. They also had the potential to compromise findings.

The need again became clear during the many discussions the standing committee of the now Library Services to People with Special Needs Section (LSN) had prior to proposing a change from its previous name, Libraries Serving Disadvantaged Persons (LSDP). For example, while the designation 'disadvantaged' seemed to have had a negative connotation in some countries, in others it was either positive or neutral. During those discussions, it also became clear that terms used within some of the special groups for whom the section advocates – for example, within the field of developmental disabilities, the terms handicap or mental retardation - could also be seen as negative, positive or neutral, depending upon the country or even upon personal perceptions within that country.

This, in large part then, is the genesis of the glossary. Hopefully, it provides a guide to usage, both for those working, writing and doing research within LSN as well as those without.

Parameters

Purpose – to define words, terms, phrases and descriptors related to the user groups who are the focus of the Library Services to People with Special Needs section. The glossary also includes definitions related to LSN practice, research and publication.

Need – inconsistencies in the meaning and use of terms country-to-country – often even within countries - makes a glossary such as this highly useful. Hopefully, it will serve as a guide to LSN usage, not only for the section's members, but also for other IFLA sections as well as members of the international community interested in LSN's work.

Scope – the glossary defines terms related to LSN's user groups, that is, those in the community who, for whatever reason, are unable to make use of conventional library resources. Those groups include people in hospitals and prisons; elderly and disabled people in care facilities; the homebound; the deaf; and those who are physically, intellectually or developmentally disabled. For the

most part, the glossary *does not* cover terms related to people with visual limitations, since those are the provence of IFLA's Libraries Serving Persons with Print Disabilities Section (formerly Libraries for the Blind Section).

N.B. – Because the range of Developmental Disorders has grown so, primarily due to better diagnostic tools, a better understanding of the genesis and relationships of disorders, and re-classification of formerly non-included disorders, this glossary could not practically cover every condition. Rather, it has tried to include those that are more commonly seen, e.g., autism spectrum disorders, dyslexia, and cerebral palsy. The user of this glossary is referred to standard medical dictionaries for definitions and characteristics of the rarer disorders not included here.

Limitations - the glossary reflects LSN concepts and usage and, as such, is intended **as a guide**. While, to a large extent, definitions are rooted in internationally developed and / or accepted sources, the glossary is not – and does not aim to be - an authority. Rather, it simply reflects LSN's own working definitions.

Selected Authorities – common authorities used for the glossary include: the United Nations (UN); the World Health Organization (WHO); the World Health Organization, Western Pacific Regional Office (WHO/WPRO); the International Classification of Diseases (ICD-10); the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR); the International Classification of Functioning, Disability and Health (ICF); standard medical dictionaries; and standard English language dictionaries. The *Appendix* includes a selected list of resources.

GLOSSARY

AAIDD – See American Association on Intellectual and Developmental Disorders

Abasia – inability to walk despite normal strength and coordination.

Accessibility – a general term reflecting the degree to which physical facilities, materials, programs and / or services are adapted to accommodate the greatest number of people

Active Aeging/Aging – aging that is a natural process continuing throughout one's lifetime

Acute - sudden, usually of short duration

Acute Care – short-term care that is rendered for an immediately treatable injury, illness, or other health-related condition

ADHD – See Attention Deficit Hyperactivity Disorder

Adapted Literature – books and other reading materials whose form and / or content have been adapted to meet special needs, e.g., large-print books for people with visual restrictions, Easy-to-Read books for cognitively disabled people.

Adaptive Devices – devices designed or modified to meet the needs of people with disabilities

ADI – See Alzheimer's Disease International

Affective Disorder - See Mood Disorder

Aged – the state of being old. A person may be defined as aged based on any one of a number of criteria including chronological age, functional assessment, legislation or cultural considerations. *See also* **Old; Elderly**

Ageing / **Aging** – the lifelong process of growing older at cellular, organ or whole body level. See also **Active Ageing**

Agnosia – inability to recognize sensory impressions, for example, the inability to recognize familiar objects or people

Agoraphobia – fear of open or public spaces

Agraphia – an acquired condition, often resulting from brain damage, in which there is an absent or impaired ability to express thoughts in writing

Akinesia – diminished or absent motor activity; lessening or loss of the power of voluntary movements

Alexia – an acquired condition, often caused by brain damage (for example, brain damage following a stroke), that results in an impaired or absent ability to understand written language (reading)

Alport Syndrome – a genetic syndrome marked by progressive nerve deafness and chronic kidney disease.

Alström Syndrome – A genetic syndrome with progressive vision impairment, sensorineural deafness, and other physiological deficits.

Alternative / Complementary Health Care: health care practices that are outside of conventional medicine; examples include homeopathy and herbal formulas

Alzheimer's Disease – a degenerative brain tissue disease that can result in amnesia (impaired memory), apraxia (motor disorders), agnosia (inability to recognize objects or familiar people), aphasia, (loss of language skills), impaired thinking and judgement, disorientation, marked personality and behavior deterioration, and loss of adaptive abilities.

Alzheimer's Disease is the most common cause of dementia worldwide. It is named after German neuropathologist, Alois Alzheimer (1864-1915).

Alzheimer's Disease International - as of this writing, the umbrella organization for Alzheimer associations worldwide

Ambulation – walking (a gross motor skill)

Ambulatory – able to walk or move about, with or without assistance

Ambulatory Care – care provided on an outpatient basis (the patient is not admitted to the hospital)

American Association on Intellectual and Developmental Disorders (AAIDD) – publishes *Mental Retardation: definition, classification and systems of supports,* one of the most commonly used sources worldwide for diagnosing and classifying mental retardation.

Amnesia – impaired memory

Anomia – an acquired condition in which there is an impaired or absent ability to name objects or recognize names

Aphasia – defect or loss of the power of expression by speech, signs or writing, or of the ability to comprehend spoken or written language, due to brain centers disease or injury

Aptitude – a person's potential for learning a specific skill or developing a particular kind of knowledge.

Apraxia – inability to perform purposeful movements in the absence of paralysis or other motor or sensory loss; especially an impaired ability to use objects correctly

Asperger Syndrome (AS) – a pervasive developmental disorder commonly referred to as a "high-functioning" form of autism; an autism spectrum disorder characterized by eccentric and obsessive interests, impaired social interactions, gross-motor clumsiness, and communicative deviance.

People with Asperger Syndrome show average to above-average intelligence and relatively well-preserved linguistic and cognitive development. They occupy the mild end of the autistic spectrum.

Assistive Device - a device or system used to maintain, increase or improve the functional capabilities of people with disabilities

Assisted Living Facility – a facility providing accommodations and care for people who cannot live independently but who do not need nursing care; usually includes domestic assistance, e.g., meals, laundry

Assistive Listening System – a hearing enhancement system consisting of a transmitter and a receiver – generally a hearing aid or a device connected to a hearing aid – designed to eliminate background noise interference. There are several types of communication access systems, e.g., audio loop, AM systems, FM sound systems, and infrared systems.

Astasia – inability to stand due to lack of motor coordination

Asymptomatic – without symptoms; showing no symptoms

Attention Deficit Hyperactivity Disorder (ADHD) - a neurobehavioral disorder occurring in children and adolescents and characterized by impulsivity, short attention span, and, hyperactivity. Sometimes generally referred to as **Minimal Brain Dysfunction**.

Audio Induction Loop - a wire loop (or thin loop pad) attached to an amplifier. It creates a magnetic field that broadcasts sound, in pure, undistorted form, directly to people who are within the loop and have a hearing aid containing a telecoil

Audiology – the study of hearing and hearing disorders, especially in the evaluation, measurement, and rehabilitation of impaired hearing

Auditory – of or relating to hearing or audition

Autism – a central nervous system dysfunction characterized by impaired communication skills and social interaction.

Children with autism - who can have high IQs - can be extremely withdrawn and have an obsessive desire to maintain the status quo. They can be self-absorbed, inaccessible and unable to relate to others, including parents. Autistic children can carry a wide range of manifestations, from those having no speech or social interaction skills, to those where the only symptoms are slight difficulties in social interaction.

It is said that people with autism have been among the world's greatest mathematical and musical geniuses.

Autism was described by Leo Kanner (1894-1981) in 1934.

Autism Spectrum Disorder (ASD) – refers to certain pervasive developmental disorders that include: Asperger syndrome; autism; and pervasive developmental disorder not otherwise specified (PPD-NOS - children having some autistic features but not qualifying for a diagnosis of autism).

ASDs can affect an individual's communication and social skills, and intelligence. As the term 'spectrum' suggests, people with the condition can have mild to severe symptoms. Those at the lower-functioning end of the spectrum may be profoundly unable to break out of their own world and may be diagnosed as having Kanner's Autism (or simply autism); those at the higher-functioning end, e.g., people with Asperger Syndrome, may be able to lead independent lives but may still be awkward in social interactions.

Barrier-Free – for LSN purposes, describes library buildings, facilities, areas, materials, programs, or services that have been adapted for use by the greatest number of people.

Basic Literacy – a basic level of skill in reading and writing

Bed (Hospital) – a bed maintained and staffed for an inpatient; the total number of such beds is used as a measure of hospital size, e.g., a 500 bed hospital, a 200 bed hospital.

Benchmark – a standard or point of reference against which to measure quality or performance

Benchmarking – a process of measuring quality or performance against a standard

Best Practice – commonly: 1) asserts that the particular technique, process, method or activity in question is more effective in delivering a particular outcome than any other; 2) the most efficient and effective means of accomplishing a desired outcome.

Because 'best practice' is a comparative designation that, unless benchmarked, suggests that every like practice has been examined – often not the case - LSN prefers use of the non-comparative 'Successful Practice.'

Binaural – referring to both ears

Binaural Hearing Aids - hearing aids simultaneously worn in both ears

Bipolar Disorder – a disorder characterized by extremes of mood happiness and sadness, and excessive behavior that reflects the particular mood. Previously known as manic-depressive disorder.

Body Functions / **Body Structures** – <u>body functions</u> are the physiological functions of body systems, e.g., circulatory system, gastrointestinal system, whereas <u>body structures</u> are the anatomical parts of the body, e.g., organs, limbs and their components.

Book Collections – See **Book Stock**

Book Stock – the inventory of books held in a library or other reading facility

Braille – a system of representing letters by raised dots, which people with visual limitations read by touch.

CAI – See Computer Assisted Instruction

Captioned – refers to a film, video or TV program where the dialogue is shown in print on the screen. The printed dialogue may be either always visible (open captioned) or visible only with the addition of a decoder (closed captioned), which is a machine that translates the invisible signal into visible print.

Captions – in LSN context, printed text of a program shown on a screen (e.g., video or television screen) or computer monitor that displays what is being said (sound portion). As noted above, captions may be "open," that is always visible when the program is on, or "closed," which may or may not be visible when the program is on.

Caregiver – one who provides support and assistance with various activities to people unable to manage for themselves; includes people with disabilities, long-

term illnesses, or people who are elderly. The caregiver may provide emotional and / or financial support as well as hands-on help with different tasks.

CCTV - closed circuit television, ordinarily made available for people who have hearing limitations.

Central Nervous System – that portion of the nervous system consisting of the spinal cord and brain

Cerebral Palsy – a motor impairment caused by nonprogressive damage to the brain. Associated dysfunctions can include intellectual disability, learning disabilities, hearing loss, visual impairment, sensory deficits and emotional problems

Charter for the Reader – Adopted in 1992 by the International Publishers Association and the International Book Committee, and published by UNESCO, the Charter for the Reader declares that reading "is the key to our cultural and scientific heritage and promotes international understanding." To make reading freely available to everyone, publishers, libraries and other information providers should work in consort with cultural, educational, and social organizations to engage in the promotion of reading. Such an alliance of public and private interests offers the best hope of fulfilling universal reading

Childhood Disintegrative Disorder - a disorder characterized by normal development in the first two years of life, after which all previously acquired skills are forgotten

Chronic - long-lasting, sometimes permanent

Chronic care – ongoing care needed for those with chronic health conditions

Cleft Lip – congenital splitting of the lips; can be associated with speech disorders and conductive hearing loss

Clinic – generally, a facility devoted to the diagnosis, treatment, and / or rehabilitation of outpatients; a hospital unit or a free-standing facility that provides treatment or rehabilitation for non-hospitalized patients

Closed captioned – See Captioned

Cognition – the process of thought or thinking; that operation of the mind by which one becomes aware of objects of thought and perception, including all aspects of thinking, perceiving, and remembering; the process of being aware, knowing, thinking, learning and judging.

Cognitive Disorder – generally, a deficiency in the ability to think, perceive, reason or remember. Dementia, for example, is characterized by cognitive disorders.

Communicative Disorder - disorder in a person's ability to communicate. Communicative disorders are generally categorized as:

a) <u>central</u>, which includes language disorder, learning disability and autism, and b) peripheral, which includes hearing or visual impairment

Community – a group of people, often living in a defined geographical area, who may share a common culture, values and norms, and who are arranged in a social structure according to relationships the community has developed over time.

Computer Assisted Instruction – the use of computer programs to teach people, in LSN's context, especially people with special needs

Computer-Assisted Note Taking – a system whereby a note taker types on a computer keyboard what is being said during a meeting. After a short time, the notes are displayed on a projection screen or a monitor.

Computer-Assisted Real-Time Captioning – a system in which a skilled count reporter uses a shorthand machine and a computer to translate spoken language into written text. The verbatim text may then be immediately read on a video monitor or a projection screen.

Conductive Hearing Loss - See Hearing Loss

Congenital – from birth

Convention of the Rights of Persons with Disabilities – adopted by the UN in 2006, the Convention "reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms." Among its precepts, the Convention recognizes the importance of disabled people's accessibility to physical environments and to information and communication.

Correctional Institution – See **Prison**

CNS – See Central Nervous System

DAISY - See **Digital Accessible Information System**

DAMP - See Deficit in Attention, Motor Control, and Perception

deaf – written with a lower case 'd,' an audiological term meaning severe or profound hearing loss; deaf focuses on the hearing impairment

Deaf – written with an upper case 'D,' focuses on the person and refers to those who consider themselves part of the Deaf culture. <u>Deaf</u> people share a common cultural heritage, a common language, common life experiences and a common sense of identity.

Deaf Awareness Week (DAW) – celebrated the last full week of September, DAW was initiated by the World Federation of the Deaf and is is held annually to commemorate the first World Congress for the Deaf (1951).

Deaf-Blind – profound or total loss of auditory sensitivity perception combined with profound or total loss of visual perception

Deaf Community – has different meanings in different contexts. For LSN purposes, it refers to: 1 – sign language users

- 2 bilingual users of sign language and spoken or written language
- 3 people with hearing disabilities who communicate primarily through spoken language and speech reading
- 4 late-deafness adults
- 5 older adults with age-related hearing loss
- 6 deaf people who use neither sign nor written language
- 7 hard of hearing individuals
- 8 deaf-blind people
- 9 hearing family members
- 10 professions who serve the above

Deaf Culture – generally, a term applied to the social movement that sees deafness, not as a disability, but rather as a different human experience

Deaf Person – a person who is either partially or wholly unable to hear

Deafness – profound degree of hearing loss; the inability to hear. *See also* **Hearing Loss**

Decoder – a machine attached to, or built into, a television that translates the electronic signals of a closed captioned video program into words. The words are then printed on a screen with the rest of the video images.

Deficit in Attention, Motor Control, and Perception (DAMP) – having some or all of the characteristics of attention deficit/hyperactivity disorder (ADHD) *in addition to* motor difficulties *(motor control)* and problems interpreting what is seen and heard *(perception)*.

DAMP is diagnosed on the basis of coexisting ADHD and developmental motor difficulties in children who *do not* have severe learning disability or cerebral palsy.

Dementia - a collective name for brain disorders that disrupt memory, thinking, behavior and emotion. Dementia is characterized by a decline in mental abilities accompanied by changes in personality and behavior.

Dementia can be caused by a range of illnesses, most of which are currently incurable and cause progressive, irreversible brain damage. According to the WHO, dementia includes: 1) "Alzheimer's disease (the most common cause); 2) vascular disease; 3) frontal lobe dementia; and 4) Lewy Body disease. Symptoms of dementia can include memory loss, difficulties with language, judgement and insight, failure to recognize people, disorientation, mood changes, hallucinations, delusions, and the gradual loss of ability to perform all tasks of daily living."

The WHO's 2002 report on the Global Burden of Disease noted that dementia was the 11th leading cause of YLDs (years lived with disability) in the world, accounting for 2% of total global YLDs.

Developmental – pertaining to development *See related* **Developmental Disorder**

Developmental Delay – any significant lag in a child's physical, cognitive, behavioral, emotional or social development in comparison to the norm

Developmental Disorder – a disorder occurring at a stage of a child's physical or psychological development that results in one or more disabilities. Developmental Disorders are often categorized as follows:

- 1 Mental Retardation (Intellectual Disorder)
- 2 Autism Spectrum Disorders
- 3 Sensory-related Disorders
- 4 Metabolic Disorders

Developmental Disorders are often sub-categorized as: Neurodevelopmental Disorder (ND), Pervasive Developmental Disorder (PDD), and Specific Developmental Disorder (SDD).

Developmental Disabilities (DDs): a term used to describe disabilities attributable to mental and/or physical impairments that occur and are manifest prior to adulthood (in some definitions, prior to age eighteen, in others, prior to age twenty-two).

DDs can affect a range of social and cognitive areas including communication, learning, judgement, and interpreting and responding to social cues. Generally, they are present at birth or considered to be intrinsic to the organism (i.e., not acquired through illness or accident, except when the incident occurs early enough to significantly interfere with acquisition of the social and cognitive areas).

DDs are distinguished from mental illnesses in the following ways. First, they are generally stable or progressive, but not generally relapsing or remitting. Second, they primarily affect cognition and perception, and are not necessarily associated with distortions in thinking or with affective disturbances.

It is important to remember that people with developmental disabilities may also have underlying treatable illnesses.

Diagnosis – the identification of a disease, disorder, illness or other health condition

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) – published by the American Psychiatric Association, and currently in its 4th edition, it is a worldwide reference source of diagnostic criteria for mental disorders. The manual is essentially a guide listing categories of mental disorders and the criteria for diagnosing them.

Digital Accessible Information System (DAISY) – an accessible multi-media presentation very useful for people with reading and understanding problems. The technology is developed and maintained as an international standard for digital books by DAISY Consortium – www.daisy.com

DAISY Multimedia can be a talking book or a computerized text as well as a synchronized presentation of text and audio produced according to DAISY Standards. The materials can be distributed on a CD/DVD, memory card, or through the Internet, and they can be read with computers using DAISY playback software, mobile phones and PDA.

Disabled – the UN classifies as disabled people having physical, sensory or mental impairments. It further distinguishes between the terms "disabled" and the related "impaired" and "handicapped," noting that:

- **an impairment** is an abnormality or loss of physiological, psychological or anatomical structure or function. Essentially, impairments are disorders at the **organ level**, for example, blindness, deafness, paralysis;
- a disability, which an impairment causes, is the "restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being." It is a limitation in function at the level of the person, for example, difficulty in seeing, hearing, moving about;
- a handicap is a "disadvantage resulting from a...disability." It exists within the context of socioeconomic roles, placing disabled people at a disadvantage when compared to non-disabled people. Examples of a handicap include being unable to use public transportation, being socially isolated, being confined to bed.

Thus, an *impairment* causes a *disability*, which results in a *handicap* that in turn places people at a *disadvantage*.

Disability – a restriction or lack of ability to perform an activity in the manner or within the range considered usual for a human being. *See* also **Disabled**

In the WHO's *Disability at a Glance: A profile of 28 countries and areas in Asia and the Pacific*, 2004-2005, The Republic of Korea provides a succinct and practical definition: "[A disability is] a condition that impairs or imposes restrictions on a person's ability to function at normal or expected levels of mental or physical activity."

Disadvantaged – lacking advantage or equality

Down Syndrome – a set of mental and physical characteristics related to having an extra copy of Chromosome 21. Characteristics of Down syndrome can include: small flattened skull; decreased muscle tone; short stature; flat facial profile; eye slits; small ears; speckling of the eye's iris; short fingers; cardiac defects; thyroid disorders; conductive hearing loss; and mental retardation.

DSM-IV-TR – See Diagnostic and Statistical Manual of Mental Disorders

Dyslexia – a neurologically-based disorder that interferes with the acquisition and processing of language and is thus characterized by problems in reading, spelling, writing, speaking, and / or listening; an inability to learn to read and write well despite normal intelligence and sufficient effort

Derived from the Greek words *dys* (meaning poor or inadequate) and *lexis* (meaning words or language), dyslexia is a congenital condition thought by some to be a genetically-transmitted organic difference in the language center of the brain. It *is not* caused by mental or sensory defect, emotional disturbance or cultural deprivation.

The European Dyslexia Association (EDA) estimates that 8% of the world's population has a form of dyslexia; 2-4% of that group can be seriously affected by it.

Both the inventor, Thomas Edison, and the artist, Leonardo da Vinci, are said to have had dyslexia

Easy-To-Read Books - can be either existing books adapted for, or books written especially for, people with cognitive or reading limitations

Easy-To-Read Materials - adaptation of text that makes it both easier to read and

comprehend; high-interest / low reading level materials for people with reading or comprehension limitations

EDA - European Dyslexia Association

Elderly – the WHO notes: "Most developed world countries have accepted the chronological age of 65 years as a definition of 'elderly'... While this definition is somewhat arbitrary, it is many times associated with the age at which one can begin to receive pension benefits. At the moment, there is no United Nations

standard numerical criterion, but the UN agreed cutoff is 60+ years to refer to the older population." See related **Old.**

Epidemic – from the Greek *epi* (upon) and *demos* (people), exists when a disease or disorder's rate of occurrence greatly exceeds normally expected rates, either in the numbers affected or the rapidity of occurrence

Epilepsy – a nervous system disturbance resulting from abnormal electrical activity of the brain. Epilepsy is not a specific disease, but rather a group of symptoms related to any number of conditions that can overstimulate brain cell nerves. Epilepsy is generally classified as either idiopathic (genetic, essential) or symptomatic (acquired, organic).

Etiology – the cause of a disease or disorder. Etiologies are usually characterized as belonging to one of the following groups: genetic; infection; trauma; tumor; and toxin (poison).

Fetal Alcohol Spectrum – symptoms characterized by mental and / or physical abnormalities of an infant that are linked to maternal intake of alcohol during pregnancy

Fine-Motor Skills – skill in coordinating the small muscles of the body, especially of the hand

Fragile-X Syndrome – said to be the most common inherited form of mental retardation, the syndrome is caused by a defect in a specific part of the Fragile X Mental Retardation-1 gene that causes the body to produce low or no amounts of a specific protein. Without that protein, the brain cannot develop normally.

Functional Birth Defects - See Developmental Disorders

Functional Hearing Loss – a hearing loss that is not caused by any organic condition, i.e., the hearing system is working properly

Functional Illiteracy – refers to the inability of individuals to use reading, writing and computational skills effectively in everyday life situations. For LSN purposes, functional illiteracy includes, not only those with limited or no formal or informal education, but also: those limited by a developmental disorder; people immigrated to another country but lacking basic fluency in that country's language; and people with diminished cognitively ability due to an organic (e.g., dementia) or accidental (e.g., head trauma) cause.

Functional Literacy – definitions vary, but generally means the ability to read, write and calculate figures well enough to carry out activities considered needed to function in society

Genetic – of, or related to, or produced by, genes; also, inherited

Gray or Grey Literature – research reports not found in traditional peer-reviewed publications, e.g., government agency monographs, symposium proceedings, unpublished reports.

Gross-Motor Skills – posture and locomotion skills. Early gross-motor skills include rolling over, sitting, crawling, walking and running. The skills, which are built upon, improved and better controlled throughout early childhood, come from large muscle groups and whole body movement.

Group Home – a living facility for people who might or might not have similar special needs

Guidelines – guides to practice that are suggestive rather than mandatory

Habilitation – literally, to make fit or able. Habilitation aims to help people with congenital disease or injury, or disease or injury acquired early in life, to <u>develop</u> the best possible functional ability. It differs from rehabilitation, which aims to help functionally impaired people <u>regain</u> functional ability that was lost or reduced by injury or disease.

Handicap – an individual's disadvantage resulting from an impairment or disability. *See also under* **Disabled**

Health – according to the WHO, a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity

Health Care – normally occurs in three levels:

P<u>rimary care</u>: basic or general health care provided at the point at which a person first seeks assistance from the medical care system, e.g., one's own physician;

Secondary care: specialized care following referral from a primary care agent;

<u>Tertiary care</u>: provision of highly specialized services either in an outpatient or hospital setting

Health Literacy – possession of the cognitive and social skills that determine an individual's motivation and ability to gain access to, understand, and use information in ways that help promote and maintain good health

Healthy Ageing / Aging – an approach that recognizes that growing older is a part of living; recognizes the interdependence of generations; recognizes that everyone has a responsibility to be fair in their demands of other generations; eliminates age as a reason to be excluded from fully participating in community life; encourages communities to value and listen to older people and to cater for

the diverse preferences, motivations, characteristics and circumstances of older people

Hearing Aid – any number of devices, including those worn or implanted, that amplify sound coming to the wearer / user's ear

Hearing Impairment – generic term used to indicate any degree of hearing loss

Hearing Loss – partial or complete loss of hearing.

Hearing loss is usually categorized as: 1) conductive (something, such as a blockage, interferes with sound passing through the outer or middle ear); 2) sensorineural (occurs when hair cells in the inner ear cannot detect incoming vibrations or when impulses are not transmitted to the brain); 3) mixed (conductive and sensorineural hearing loss co-exist in an individual)

Homebound / **Housebound** – confined to home, either temporarily or permanently

Hospital – a licensed institution providing short- or long-term care for any number of health-related problems or conditions; can also mean a specialized facility, for example, a rehabilitation center.

<u>General hospital</u> – provides a range of services for patients of various age groups and with varying disease conditions;

Specialized hospital – a hospital admitting primarily patients with a specific disease or affection of one system, or patients in a specific age group or patients having illnesses of a long-term nature

<u>Teaching hospital</u> – a hospital that provides education for medical students and post-graduate medical doctors

Hospital Library – concepts of this non-specific term vary *greatly*. For purposes of its work, LSN considers a hospital library to be any organized collection of library materials, programs and / or services that exist in a hospital for a particular user group.

Huntington Disease – an adult onset neurodegenerative disease that affects the central nervous system and progresses to dementia

IBC - See International Book Committee

ICD - See International Statistical Classification of Diseases and Related Health Problems

ICF – See International Classification of Functioning, Disability and Health

ICT – See Information and Communication Technology

Idiopathic – of unknown origin; many developmental disorders are idiopathic

Illiteracy – lack of ability to read and / or write

Impairment – loss or abnormality of psychological, physiological, or anatomical structure or function See *also under* **Disabled**

Incarcerated People - includes people who are in prisons, jails, remand or detention centers, forensic hospitals, or other types of institutions administered by prison authorities. In its broader sense, the descriptor 'incarcerated people' refers to people who are institutionalized, for example, those in prisons, hospitals, and care facilities

Inclusion – being part of a whole

Information and Communication Technology (**ICT**) – an umbrella term covering technologies used for the manipulation and communication of information

Inmate – generally one of several residents of a dwelling, especially someone confined to a prison, hospital, or mental institution: for LSPSN purposes, a person serving a sentence in a jail or prison.

Inpatient – a person admitted to a hospital or other health care facility for at least one overnight stay

Intellect – the power of the mind by which one knows or understands, as distinguished from that by which one feels; the faculty of thinking

Intellectual Disability (ID) – meaning and usage vary *greatly*. However, the WHO defines intellectual disability as an: "...arrested or incomplete development of the mind that can occur with or without any other physical or mental disorders, and is characterized by impairment of skills and overall intelligence in areas such as cognition, language, and motor and social abilities."

Further: "Many terms and definitions are used to refer to intellectual disabilities... Nevertheless, all these definitions have three criteria in common: significant limitations in intellectual functioning, significant limitations in adaptive behaviour, and manifestation of these symptoms before adulthood."²

Intellectual disability is in some parts of the world alternately expressed as cognitive disability, learning disability, mental retardation, mental handicap, mental disability.

Intelligence Quotient (IQ) – a score derived from a standardized test that attempts to measure intelligence.

Intelligent Quotient Test - a test that measures mental ability.

International Book Committee – an NGO advisory committee with consultative status to UNESCO. Among other groups, the committee represents publishers, authors, booksellers and librarians in making recommendations to national and international agencies regarding printed materials and the flow of information. A number of organizations, e.g., the International Booksellers Federation and the International Copyright Society, participate in IBC's work.

International Classification of Functioning, Disability and Health (ICF) — published by the WHO, a classification of health and health-related domains that describe body functions and structures, activities, and participation. Thus, classification is done from three perspectives - body, individual, and social. The WHO notes: "ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction."

ICF is the WHO's framework for measuring health and disability at both individual and population levels.

International Publishers' Association (IPA) – an international federation established in 1896 that represents all aspects of book and journal publishing. Its mission is: "...to promote and protect publishing and to raise awareness for publishing as a force for economic, cultural and political development." The IPA also aims to combat global illiteracy through its support of World Book Day and by providing books to those in need.

International Statistical Classification of Diseases and Related Health Problems (ICD-10) – published by the WHO, a list of diagnoses and identifying codes used by health care providers; the coding and terminology provide a uniform language that permits consistent communication on health claim forms. The ICD-10 is used worldwide for morbidity and mortality statistics, health care reimbursement, and decision support in medicine

Interpreter – for LSN purposes, a person skilled at translating spoken communication into either sign language or clear oral signals

Sign Language Interpreters – people skilled at translating spoken language into sign language and translating sign language into spoken word

Oral Interpreters – people who can silently mouth a speaker's words. The interpreters use no sign language but instead make substitutions for words that are difficult to speechread.

IPA – See International Publishers Association

Jail – See Prison

Kurtzweiler Reading Machine – a text-to-voice reading machine with speech output.

As one example, the Kurzweil 3000 reading machine scans a printed document, displays the page just as it appears in the original document (e.g., book, magazine), with the color graphics and pictures intact, then reads the document out loud while highlighting the image of the print as it is being read.

Language Disorder – a developmental disorder characterized by disabilities of reception, integration, recall, and /or production of language; may be spoken, written, or both

Late-Deafened Adult – one who loses hearing after acquiring speech. Also known as **Post-Lingual** deafness.

Learning Disorder – generally refers to disorders that affect a range of academic and functional skills, for example, the ability to speak, listen, read, write, spell and organize information. A learning disorder *does not* indicate low intelligence; in fact, people so affected often have above-average intelligence. The difficulty comes in the brain's ability to process information it receives. For that reason, people with learning disorders often need alternate means of learning.

Length of Stay – duration of a person's hospital stay

Lewy Body Disease – A common causes of progressive dementia, Lewy Body disease happens when abnormal structures, called Lewy bodies, build up in certain areas of the brain. The disease causes a range of symptoms, both physical and mental, that can include: loss of memory and confusion; diminished alertness and attention; muscle stiffness; and movement and posture disorders. Alzheimer's and Parkinson's diseases also can cause similar symptoms, so Lewy Body Disease if often difficult to diagnose.

Lingual – of or pertaining to the tongue; pertaining to languages

Long-Term Care – a range of health care, personal care and / or social services provided to individuals who, due to frailty or disability, cannot live independently.

Long-Term Care Facility – any institution, including hospitals, homes, care facilities, and group residencies, providing on-going physical, psychological, custodial or other care.

Manic Depressive Disorder – See **Bipolar Disorder**

MBD - See Minimal Brain Dysfunction

Medically Indigent – those who cannot afford needed health care due to insufficient income and / or lack of adequate health insurance

Mental – of, or pertaining to, the mind

Mental Health – meaning varies greatly; generally, the absence of psychiatric disorders or traits (includes those influenced by biological, environmental, emotional, or cultural factors)

Mental Retardation – See Intellectual Disability

Mental Retardation: Definitions, Classification and Systems of Supports – published by the AAIDD, it is, along with ICD-10, ICF and DSM-IV-TR (acronyms defined in this glossary), one of the four most commonly used sources worldwide for diagnosing and classifying mental retardation

Minimal Brain Dysfunction (MBD) – covers a group of symptoms that can include: short attention span; distractibility; impulsive behavior; hyperactivity; changeability; motor incoordination; visual-perceptual motor disturbance; and language disorder. MBD embraces attention deficit hyperactivity disorder (ADHD), learning disabilities, developmental language disorder, and clumsy child syndrome.

Minimal Language User – one who has limited knowledge of formal spoken, signed, or written language

Mobility – the ability to move with appropriate range and flexibility

Mood Disorder - disorder in which a person's mood is abnormally elevated or depressed. Mood disorders may be functional (without any physical basis) or organic (caused by damage to the brain).

Motor Disorder – a movement disorder that involves delay or limitation in performing gross-motor (posture and locomotion) or fine-motor (eye-hand) skills

Motor Function – functioning of the voluntary muscles of the body and the nerves supplying them

Multiple Sclerosis – a neurological disease characterized by weakness, muscular incoordination, speech and visual disturbances. The course is usually prolonged, with remissions and relapses over a period of many years.

Native Sign Language User – one whose first language is sign language

ND – See Neurodevelopmental Disorder

Neurodevelopmental Disorder (ND) – a disorder of the growth and development of the brain or central nervous system that can affect emotion, learning ability and memory. Neurodevelopmental disorders include: attention

deficit hyperactivity disorder (ADHD); autism spectrum disorders; genetic disorders such as fragile-X syndrome; Down syndrome and Rett syndrome; epilepsy; fetal alcohol syndrome; learning disorders; and neurological and psychiatric disorders. Neurodevelopmental disorders are grouped under the general umbrella of **Developmental Disorder**.

NGO – See Non-governmental Organization

Non-governmental Organization (NGO) – not-for-profit voluntary groups organized on a local, national, or international level to address issues in support of the public good. WHO notes: "NGOs perform a variety of services and humanitarian functions, bring citizen's concerns to governments, monitor policy and program implementation..."

Nursing Home – facility for the care of people who do not require hospitalization but who cannot for whatever reason be cared for at home; sometimes known as **Residential Care Facility.**

Old – The WHO notes that, generally: people aged 60-74 years are considered "young old," those aged 75 to 84 years are" old," and those aged 85 years + are the "oldest old." *See also* **Elderly**

Open captioned – See Captioned

Oralist – a person who is deaf and who communicates primarily through speech and speech reading

Organic Brain Syndrome (OBS) – a general term referring to diseases (not usually psychiatric disorders) that cause decreased mental function. Associated disorders can include: stroke; brain injury caused by head trauma; degenerative disorders such as Huntington's and Parkinson's Diseases; and Alzheimer's Disease and other forms of dementia.

Symptoms of OBS often vary with the disease, but common manifestations are: confusion; impairment of memory, judgment and intellectual function; and agitation.

Organic Impairment – resulting from a physical rather than nonphysical (emotional, social) cause

Outpatient – a person who is treated at a hospital or other health care facility but who is not admitted for stay

Outpatient Care – care provided to a patient outside of hospitalization

Palliative Care – specialized care for terminally ill people that aims to achieve the best quality of life for them and their families. Palliative care aims neither to hasten nor to postpone death.

Pandemic – an epidemic of global magnitude

Paralexia – reading disturbance in which letters, syllables, or words are substituted or transposed

Patient – a person in contact with the health system who is seeking attention for a health condition *See also* **Inpatient**; **Outpatient**

Patients' Library – a library organized specifically for the use of patients. Materials, programs and services may focus on health information, and / or recreation, general education, and leisure time.

PDD – See Pervasive Developmental Disorder

Penal Institution - See Prison

Penitentiary – See **Prison**

Perception – awareness of an object or event through the sense organs

Pervasive Developmental Disorder (PDD) - disorder characterized by delays in the

development of <u>communication</u> and <u>socialization</u> skills. Symptoms may include: problems with using and understanding language; difficulty relating to people, objects, and events; unusual play with toys and other objects; difficulty with changes in routine or familiar surroundings; and repetitive body movements or behavior patterns.

The most commonly diagnosed PDDs are: autism; Asperger syndrome; Rett syndrome; childhood disintegrative disorders; and Pervasive Developmental Disorder Not Otherwise Specified

Pervasive Development Disorder – Not Otherwise Specified (PPD-NOS) - also called "atypical autism," PPD-NOS includes people who have some of the criteria for autistic disorders or Asperger syndrome, but not all. They usually have fewer and milder symptoms that might cause only social and communication problems.

Pictograms – text or concept defined through pictures

Post-lingual – hearing impairment occurring after an individual has acquired speech and language, usually after age four. See also Late Deafened Adult

Pre-lingual – hearing impairment that is congenital or acquired before an individual has developed speech and language, commonly at or before age four.

Prelinguistic Vocalization – the guttural sounds, cooing and babbling that an infant uses before words. Absence of these can suggest a developmental disorder.

Primary Care – See Health Care

Prison - an institution or facility where people are held in custody or detention. Also referred to as penitentiary, penal institution, jail or correctional institution.

Prognosis – expected outcome (e.g., of a disease, disorder or other health condition)

Public Health – the science and art of promoting health, preventing disease, and prolonging life through the organized efforts of society

Public Library Manifesto – its third revision adopted by UNESCO in 1994, the Manifesto proclaims the "belief in the public library as a living force for education, culture, and information, and as an essential agent for the fostering of peace and spiritual welfare through the minds of men and women."

"The services of the public library are provided on the basis of equality of access for all... Specific services and materials must be provided for those users for cannot, for whatever reason, use the regular services and materials, for example, linguistic minorities, people with disabilities, and people in hospital or prison."

Reading Disability – limitation or absence of an individual's ability to read

Regional Office for the Western Pacific – See WHO/Western Pacific Regional Office

Rehabilitation – treatment to restore function and / or to maximize remaining function so as to bring about the highest possible level of independence - physiologically, psychologically, socially and economically

Rehabilitation Hospital – a hospital specializing in providing restorative services to rehabilitate ill and / or disabled individuals to a maximum level of functioning

Residential Care Facility – *See* **Nursing Home**

Respite Care – alternative care arrangements provided to chronically ill, disabled or frail individuals either in the home, or at a care center, or by temporary placement in a nursing home in order to provide occasional or systematic relief to their caregivers.

Rett Syndrome – a degenerative syndrome occurring in females who develop normally in very early life and then, between ages six to eighteen months, experience rapid regression in motor, cognitive, and social skills that subsequently stabilizes at a level that leaves them with an intellectual disorders. Affected individuals exhibit autistic features and hand stereotypes, such as hand wringing, clapping, tapping, and washing.

Screen Reader – a software application that identifies and interprets what is displayed on a screen and then re-presents it through text-to-speech, sound icons, or a Braille output device. Screen readers are potentially helpful for people with visual limitations, people who are illiterate, or people with learning disabilities.

SDD – See Specific Developmental Disorder

Secondary Care – See Health Care

Seizure – uncontrolled electrical activity in the brain that may produce a physical convulsion, minor physical signs, thought disturbances, or a combination of symptoms

Senile – of, pertaining to, or characteristic of, old age; especially referring to a decline of mental faculties

Sensorineural – of, relating to, or involving the sensory nerves, especially as they affect hearing

Sensorineural Hearing Loss – *See* **Hearing Loss**.

Sensory – relating to sensation; relating to the perception of a stimulus and the connection made by incoming sense organ nerve impulses to nerve centers

Sensory Impairment - disorder of a sensory organ, for example, of an eye or eyes (vision), an ear (hearing)

Sign Language – a manual system of communication by which concepts and language are represented visually through hand movements, body movements, and gestures and facial expressions rather than words.

Sign Language Interpretation – the translation of oral information into sign language and vice versa

Sign Systems – includes any number of manual communication systems used within the Deaf community. Sign systems can be national, international or other (e.g., local).

Special Needs – for LSN purposes, relates to the needs of people who, for whatever reason, cannot make use of conventional libraries and / or library materials and services

Sspecific Developmental Disorder (SDD) – specific learning disabilities and developmental disorders that affect coordination. The ICD-10 lists four categories of SSDs: speech and language; scholastic skills; motor function; and mixed SSDs. The DSM-IV-TR categorizes SSDs as: communication disorders; learning disorders; and motor skills disorders.

SDDs are grouped under the umbrella of **Developmental Disorder**

Speech Synthesis – artificial production of human speech, often done, for example, by a computer system

Speech Synthesizer – a computer system used to artificially produce human speech

Spinal Cord Injury (SCI) – trauma or other damage to the spinal cord resulting in loss or impaired function in mobility or feeling.

Standard Rules of the United Nations- entitled *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, these are a series of recommendations adopted by the United Nations by which States (Governments) can ensure that people with disabilities have equal access to physical environments, information and communication.

Standards – a set of rules or recommendations that are mandatory

Successful Practice – a practice that, in an efficient and effective way, produces an optimum desired outcome.

Tactile – of, pertaining to, or affecting, the sense of touch; perceptible to the touch

Talking Books - books recorded in any medium for listening

TDD – telecommunication device for hard of hearing and deaf people

Telemedicine / **Telehealth** – the use of communication technology to provide assistance in the diagnosis, treatment, care and management of health conditions, usually in remote areas

teleTypewriter (TTY) – a device with an electronic text display and a keyboard that allows persons with hearing or speech disabilities to have a visual, two-way

telephone conversation. Similar telecommunication devices can have different names in different countries.

Terminal Illness – an illness for which there is no known or expected cure

Tertiary Care – See Health Care

Text-To-Speech System (TTS) – a system that converts normal language text into speech; ideally, it can allow people with visual impairments or reading disabilities to listen to written works on a computer

TTY – See teleTyperwriter

TTS - See Text-To-Speech System

UNESCAP (a.k.a. ESCAP) - See United Nations Economic and Social Commission for Asia and the Pacific

UNESCO – *See* United Nation's Education, Scientific and Cultural Organization

United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP; ESCAP) - the regional arm of the United Nations Secretariat for the Asian and Pacific region.

UNESCAP was established in 1947 as the UN Economic Commission for Asia and the Far East for the purpose of encouraging economic cooperation among its member states. (Its current name became effective in 1974.) It is one of five regional commissions under the administrative direction of UN headquarters and has fifty-three member States and nine Associate members. It reports to the UN Economic and Social Council (ECOSOC).

Beyond Asian and Pacific countries, UNESCAP's member states also includes France, the Netherlands, the United Kingdom, the United States, and others. Its regional focus is managing globalization through programs in environmentally sustainable development, trade, and human rights.

United Nations Educational, Scientific and Cultural Organization (UNESCO) – a specialized United Nations agency that promotes international cooperation among its Members States in the areas of education, science, culture and communication.

Universal Design - a system whereby programs, services, tools, and facilities are designed to be usable by the widest possible range of users, taking into account a variety of abilities and disabilities. At its optimum, Universal Design is

a broad-spectrum solution that strives to help everyone, not just people with disabilities.

Universal Design emerged from the concepts "barrier-free," "accessible design," and "assistive technology." Examples of universally designed environments include automatic doors, buildings with ramps, and curb cuts.

Visual Warning Signal – a flashing or revolving light that draws the attention of deaf people to audible signals such as fire alarms or public announcements

WHO/Western Pacific Regional Office (a.k.a. Regional Office of the Western Pacific) - located in the Philippines, WPRO represents WHO in health matters in the Asia Pacific region. Its purpose is "to lead the regional response to public health issues on all fronts – medical, technical, socio-economic, cultural, legal and political."

World Federation of the Deaf – an international non-governmental organization composed of national associations for the deaf. The Federation represents approximately 70 million Deaf people worldwide and, in collaboration with the United Nations, works to enhance their social, economic and cultural lives.

WHO/WPRO - See WHO/Western Pacific Regional Office

APPENDIX

Notes

1. IFLA Professional Report # 61

2 Atlas: Global Resources for Persons with Intellectual Disabilities: 2007.

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N.B. To avoid providing Web sites that could become inactive – site addresses can change frequently - the URLs for the references below have been truncated to the organization's main Web page, which is generally a more stable address. A search on that page will point to the desired site; alternately, an Internet search engine should point to the same location.

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