FASD-related Glossary (North America)

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21 September 2013

Abstract thinking – Ability to use concepts and to understand generalizations.

Accommodation – Adjustment made to rules or practices in order to meet the needs of persons with disabilities.

Acquired brain injury – Brain damage caused by events <u>after</u> birth, such as traumatic brain injuries (accidents, assaults, near-drowning or other head injury), or nontraumatic injuries such as stroke, infection, poisoning, or encephalopathy.

Acting out – Inappropriate and impulsive behavior, in response to stress or anger. The behavior is usually anti-social, and can often be an unconscious or sub-conscious effort to get attention.

Adaptive functioning – Ability to interact effectively with others, practice life skills (including appropriate self-care), and respond to opportunities for improvement in life.

ADD / ADHD - see Attention Deficit Disorder / Attention Deficit Hyperactivity Disorder

Advocacy / Advocate – The expression or action showing public support for a cause or another person. An "advocate" is someone who engages in advocacy. "To advocate" is to support, urge, write or speak in favor of an issue or on behalf of someone.

Alcohol addiction – A chronic disease caused by habitual intoxication, leading to dependence or abuse and serious health problems, with extreme withdrawal symptoms when alcohol consumption stops abruptly.

Alcohol-Related Birth Defects – A term proposed for persons with prenatal alcohol exposure who have heart, bone, kidney, vision or hearing defects. These defects are not rare in FASD, but they are not as common as other FAS physical features.

Alcohol-Related Neurodevelopmental Disorder – Disability that affects persons who were prenatally exposed to alcohol and who have behavioral problems and central nervous system damage, but without the significant growth deficiency or facial features of someone with FAS. It was meant to replace the earlier term, Fetal Alcohol Effects.

ARBD - see Alcohol-Related Birth Defects

ARND – see Alcohol-Related Neurodevelopment Disorder

Assessment – Evaluation done by professionals, often using tools such as tests, questionnaires or tasks, in order to determine a medical diagnosis.

Attachment disorder - see Reactive Attachment Disorder

Attention Deficit Disorder / Attention Deficit Hyperactivity Disorder – Disability characterized by an impaired ability to concentrate, control impulses, or be organized. Persons with the ADHD (hyperactive) type may be fidgety, restless, noisy or unable to sit still.

Binge drinking – Excessive consumption of alcoholic beverages within a short period of time (generally, 4-5 drinks or more in about two hours).

Black-and-white thinking – Practice of seeing only the extremes of a situation (e.g., all good or all bad), without recognizing any 'gray area' or middle-ground; inability to understand nuances or accept ambiguity.

Boundaries – Self-defined guidelines, rules or limits on the reasonable, safe or permitted ways that others can behave around an individual. It can refer to interactions at the physical, mental, emotional, or spiritual levels.

CanFASD – Canada FASD Research Network

Cause-and-effect reasoning – Recognition that certain actions, events or conditions (causes) normally result in specific consequences (effects).

CCSA - Canadian Centre on Substance Abuse

CDC – Centers for Disease Control and Prevention (USA)

Central nervous system – Part of the nervous system, consisting of the brain and the spinal cord, which receives information from and controls activity in all parts of the human body.

Cerebral cortex -- see Frontal lobes

Circle of support – see 'Support network / Support system'

CNS – see Central nervous system

Cognitive deficits – Impairment in mental processing, generally found in intellectual disabilities, and in more specific conditions such as learning disabilities or dyslexia, or drug-induced cognitive/memory impairment.

Community programs – *Programs administered at a local level (town, city or county) to aid in the prevention of social problems (homelessness, substance abuse, etc.) or services for affected persons.*

Complex post-traumatic stress disorder -- Condition of experiencing chronic trauma that is repeated or prolonged, often resulting in symptoms in addition to those known for Post-traumatic stress disorder – for instance, changes in sense of self, or inability to adapt to stressful events. It has also been called Disorders of Extreme Stress Not Otherwise Specified (DESNOS).

Concrete thinking – Considering objects or ideas to be discrete, unique items, rather than any representation of a general concept; inability to think in abstraction or to generalize.

Congenital brain defects – Abnormalities in the brain that are present at birth.

Corpus collosum – Wide, flat bundle of nerve fibers in the brain, which connect the left hemisphere with the right hemisphere, necessary for normal mental processing.

C-PTSD – see Complex post-traumatic stress disorder

Decompress – To calm oneself following an emotionally intense event or argument. Parents or caregivers should not try to discipline, lecture or reason with an FASD child while either is in the state of anger, frustration, shock or despair. Techniques that are often suggested include: taking a time-out; deep breathing; meditation, Tai Chi or stress-reducing exercise; listening to music; calling a friend to 'vent;' or distracting oneself with a pleasurable activity.

Developmental age – A measure of the child's development in terms of body size, motor skills, behaviors, and cognitive abilities. With FASD, the child or young adult is developmentally 'younger' than his/her chronological age.

Developmental disability – A severe, life-long disability caused by mental and/or physical impairment resulting in significant functional limitations and barriers to independent or typical lifestyle.

Diagnostic and assessment clinic – A clinic that offers testing and analysis leading to diagnosis of a particular disease or disability.

Diagnostic and Statistical Manual of Mental Disorders – The official manual of the American Psychiatric Association, creating a standard language and criteria for the classification of mental disorders.

Disability – A physical or mental condition that limits a person's movements, senses or activities; formerly known as a 'handicap' or 'retardation.'

Disorder – An irregular or abnormal physical or mental condition; the term is most often used by medical professionals, while 'disability' is generally used for social and legal contexts.

DSM – see Diagnostic and Statistical Manual of Mental Disorders

Dysfunctional – Abnormal or unhealthy, usually referring to behaviors or relationships.

Dysmaturity – In the field of FASD, this term relates to the gap or imbalances between different measures of maturity. Those affected by FASD may have normal or above-average IQ, for example, but are unable to meet expectations for social and academic milestones.

Epicanthal folds – Skin of the upper eyelid that covers the inner corner of the eye, normal in people of Asian descent, but also common in children with Down syndrome or Fetal Alcohol Syndrome.

Ethanol – Pure alcohol, also called grain alcohol, it is the fluid that produces intoxication when consumed in alcoholic beverages.

Executive functions – Cognitive processes that control, manage or regulate other mental processes, including planning, working memory, problem solving, inhibition, verbal reasoning, mental flexibility, judgment, task switching, setting goals or priorities, and initiating and monitoring actions.

Exploitation / Vulnerability – Individuals with FASD may choose undesirable friends or engage in risky or illegal activities, due to impaired impulse control, problems with judgment, or difficulty understanding consequences or cause-and-effect; they are more easily led or influenced by peer pressure, and are often exploited by peers who recognize their deficits.

External brain – A responsible person (parent, caregiver, teacher, life coach, sibling or spouse) who can mentor, guide, assist, supervise or monitor the FASD-affected person in order to maximize his/her potential.

FAE – see Fetal Alcohol Effects

FAS – see Fetal Alcohol Syndrome

FASD - see Fetal Alcohol Spectrum Disorders

FASD ID Card – An identification card carried by a person affected by FASD, which can state that FASD is a birth defect that causes brain damage, and that this person will not sign contracts or other agreements, waive Miranda rights, or allow a search without the presence of or consultation with his attorney or other representative.

Fetal Alcohol Effects – One of a spectrum of neurological impairments that affect persons who were prenatally exposed to alcohol, but who lack the facial characteristics of those with Fetal Alcohol Syndrome. This term is little-used now, replaced by 'Alcohol-related neurodevelopmental disorder,' or simply considered under the broader, more inclusive name, 'Fetal alcohol spectrum disorders.'

Fetal alcohol exposure – see Prenatal alcohol exposure

Fetal Alcohol Syndrome – A type of birth defect consisting of mental and physical damage to the fetus, and continuing throughout life, associated with alcohol consumption during pregnancy. Its primary symptoms are specific abnormalities in facial features, below average height and weight, and damage to the Central nervous system. FAS was discovered in 1968, and named in 1973.

Fetal Alcohol Spectrum Disorders – The whole range of disorders, on a spectrum from severe to mild, for the physical damage to the brain and other parts of the body, caused by prenatal exposure to alcohol, and resulting in behavioral and cognitive impairment. This is the current 'umbrella' term used for research, prevention, intervention, and services for those affected by FAS, ARND, etc.

First Nations – The aboriginal (indigenous) peoples of Canada, including over 630 governments or bands.

Food intolerance – Certain foods may irritate the stomach or cannot be digested properly, for some children and adults. In persons with FASD, the resulting gas, cramps or bloating, heartburn, headaches, irritability or nervousness can trigger or exacerbate other FASD symptoms such as hyperactivity or acting out. Changes in diet (e.g., eliminating dairy products, gluten products, etc.) can sometimes have good outcomes.

Frontal lobes – Also known as the Cerebral cortex, this part of the brain controls the Executive functions.

Genetic factors – Family medical history, or the genes passed through one's family, are influential in the likelihood of developing alcohol addiction, variations in how the birthmother metabolizes alcohol, and in the extent to which a fetus is affected by the alcohol exposure. Researchers are also studying whether or not parents who have FASD themselves are more likely to have children affected by FASD.

Hippocampus – Major component of the brain, part of the cerebral cortex. When the hippocampus is damaged by fetal alcohol exposure, it results in deficits in memory functions and spatial navigation.

Hyperactivity – Overly active and disruptive, often with impulsivity.

IEP – see Individualized Education Plan

Impulsivity – Inability or resistance to controlling one's impulses; engaging in actions without rationale or consideration of consequences; often such actions are prohibited or may be harmful to self or others. (See also 'Self-regulation.')

Individualized Education Plan – A process and a product developed for a student who has learning disabilities, to set goals, determine strategies, plan and execute, monitor and evaluate a program aimed at maximizing his/her success in school. (USA)

Intellectual disability – Having significantly impaired cognitive functioning combined with some deficits in adaptive functioning. Until recently, it was formerly called 'Mental retardation.'

Intelligence Quotient – A standard test score that measures intelligence, usually with 100 as the average. Historically, the IQ score had to be 70 or less to receive a diagnosis of FAS. However, it is common to have FASD with a low IQ or an average IQ, or sometimes even an above-average IQ.

Intentional behavior – A deliberate, willful act based on a conscious decision. Persons with FASD can sometimes be thought to be uncooperative, lazy, inattentive, defiant or careless. But many times it is not that they $\underline{won't}$ understand or perform a task, but rather, that they $\underline{can't}$ understand the instructions or perform the task in the same way that a neurotypical person can.

Interdependence –Mutual dependence between persons, groups or things. Since FASD is a lifelong disability, persons who are affected need support and services, and cannot be expected to achieve true independence. (See also 'External brain' and 'Support network.')

International FASD Awareness Day – Observed each year on Sept. 9, the FASD Awareness Day was first celebrated on 09/09/99, having chosen the number 9 to remind the public of the nine months that a pregnant woman should refrain from alcohol. In many countries around the world, there are government proclamations and press releases, seminars or rallies, and other events to promote FASD prevention, interventions, and services.

Intervention – Services provided by treatment centers or by individuals to help persons with FASD to improve their behaviors, social skills, focus, attention, self-regulation, math skills, working memory and safety skills. Young adults with FASD are often taught to make lists to stay organized and remember things, do role-playing for practicing life skills, and to advocate for themselves (ask for more explanations and assistance). There is no cure for FASD, but these strategies can help improve quality of life.

Invisible disability – A disability that is not immediately apparent. Also called 'hidden disability,' it can create obstacles for the individual at school, work, or in society, because the reality of the disability can be difficult for others to recognize or acknowledge.

IQ - see Intelligence quotient

Learning assistance – Term used in Canada, for school programs to address special needs of children with cognitive or physical disorders, especially learning disabilities. Students may attend remedial classes, receive individual tutoring, or try alternative learning methods, among other strategies. In USA it is called 'Special education.'

Life skills – Competencies needed in order to succeed as an adult, and lead a purposeful, productive life. Skills include finding and keeping employment; making a budget, shopping, and paying bills; handling relationships; housekeeping; meal planning, diet and cooking; scheduling and keeping appointments; meeting transportation needs; time management; and so forth.

Lifebook – A personal journal-scrapbook, often created with the child's help, to make a story of his/her life in pictures and words. This is useful for foster and adoptive children to maintain a sense of connection with their families, friends, helpers, to preserve memories, and to aid in the formation of identity.

Lutke, Jan – A well-known FASD expert in Canada, she has many publications about FASD, has served on several government advisory boards/councils, and lectured widely to professionals as well as parents or caregivers, for over 20 years.

Magical thinking – Condition in which the psychology patient believes (wrongly, and without scientific evidence) that certain acts, thoughts or conditions will cause or have caused a particular result. An example might be, "My mom left me because I am ugly." Or, an unrealistic expectation or fantasy.

Meltdown – An emotional breakdown, during which the affected person rages or has a temper tantrum. Behaviors might include yelling, crying, swearing, hitting, and/or destroying property.

Mental retardation – Former term (in English-language countries) for 'Intellectual disability.'

Misdiagnosis – A medical error in which there is an inaccurate or incomplete diagnosis of a disease, injury, syndrome, behavior, or other ailment.

Mood swings – Rapid (and sometimes extreme) fluctuations in emotional state, usually alternating between feelings of happiness and well-being and feelings of anger, irritability or depression.

Motor deficits – Developmental delays in gross motor skills (controlling body movements), such as running or jumping. For children with FASD, such deficits can also include poor hand-eye coordination, weak grasp, unstable posture, delayed reaction time, etc.

Native Americans – The aboriginal (indigenous) peoples of USA, including over 560 governments from 40 major tribes. Also known as 'American Indians.'

Neurobehavioral disorders – A large group of behavioral disorders caused by <u>brain diseases</u> (such as stroke, dementia, MS), transient or permanent <u>brain impairment</u> (metabolic or toxic damage, including from alcohol), and/or brain injuries (trauma, hypoxia, etc.)

Neuropsychology – Study of the structure and function of the brain and their relation to psychological processes and behaviors.

Neurotypical – A label for persons who are \underline{not} affected by FASD. The term was originally created by the autistic community for people who are not on the autism spectrum.

NIAAA - National Institute on Alcohol Abuse and Alcoholism (USA)

NIH – National Institutes of Health (USA)

NOFAS - National Organization on Fetal Alcohol Syndrome (USA)

NT – see Neurotypical

Occupational therapy – Use of treatments designed to develop, maintain or recover daily life and work skills, for persons with a physical, mental or developmental condition. For those affected by FASD, occupational therapists can often identify sensory processing issues, and suggest strategies to eliminate or reduce the stimuli or environments that trigger the offending sensation.

ODD – see Oppositional defiant disorder

Oppositional defiant disorder – A condition of pervasive anger and hostility, disobedience, and defiance towards authority figures that goes well beyond what is normal for children and adolescents.

OT – see Occupational therapy

Overstimulation – Excessive or lengthy activities, bright lights, loud noises and even uncomfortable clothing can overwhelm children with FASD, causing them to 'act out,' become irritable, or have a meltdown. Adults with FASD can also feel emotional discomfort or disorientation, and may 'shut down' when visual, auditory, tactile or other stimuli are too numerous or difficult to process in the moment.

Partial effects of FAS -- Also written as 'pFAS,' this is another term for Fetal Alcohol Effects.

PDB – Persons with Disability Benefits (Canada)

Perseveration – Act of repeating a word, statement or gesture several times, or an inability to switch tasks or ideas, usually a symptom of brain injury or disorder. This occurs often in ADHD and autism, as well as in FASD.

PHA - Public Health Agency of Canada

Philtrum – The vertical groove in the middle of the upper lip and below the nose. For babies and children affected by FAS, the philtrum is smooth, rather than grooved.

Physical symptoms of FAS – Primary facial features of FAS include small eyes, a smooth philtrum, and thin upper lip. Other physical symptoms can include low weight, short height, small head circumference, overlapping fingers, ear abnormalities, short nose, joint disability, organ defects, and other anomalies.

Prefrontal cortex – The forward part of the frontal lobes of the brain; controls complex cognition, personality expression, decision making, and regulation of social behavior.

Prenatal alcohol exposure – The leading known cause of intellectual disabilities. When a pregnant woman drinks, the alcohol crosses the placental barrier and can stunt fetal growth, damage neurons and brain structures, cause other physical damage, and result in psychological or behavioral problems. (Also stated as 'Prenatal exposure to alcohol.')

Present (verb) -- To become manifest; to bring to one's attention; to display; to exhibit. An example might be, 'FASD presents as highly similar to ADHD.'

Processing speed – Time it takes to receive and process (understand) information that is read, heard or seen. Persons with FASD have slower information processing speed than neurotypical people.

Public awareness – Attitudes, opinions and understanding by the general public on a particular subject.

PWB – 'Persons with a disability,' or, 'People with disabilities'

RAD - see Reactive Attachment Disorder

Reactive Attachment Disorder – A condition in which babies or young children do not form healthy bonds with parents or caregivers, usually due to abuse, neglect or abandonment. Often occurring in foster or adopted children, it can permanently change the child's growing brain, resulting in many behavior problems and hurting his/her ability to form future relationships.

Residential treatment center – A live-in rehabilitation center, for treating substance abuse, mental illness or behavioral problems. Some centers now specialize in or offer treatments for FASD.

Respite – A method for relieving parent or caregiver stress, in which volunteers or paid substitute workers take care of persons with FASD temporarily, while the parent or caregiver takes a break. In the foster care system within Canada, the practice is called 'relief.'

SAMHSA – Substance Abuse and Mental Health Services Administration (USA)

Secondary disorders / Secondary disabilities – Persons with FASD may have predispositions to mental health problems and drug addiction, possibly from genetic influences. But the idea that someone with a diagnosis of FASD can simultaneously have secondary disorders has become controversial. Many symptoms of FASD overlap with symptoms of ADD/ADHD, autism, ODD, PTSD, Sensory processing disorder, Bipolar disorder, and/or depression. Persons affected by FASD may have been misdiagnosed as having one or more of those disorders. However, now it is believed that the wide range and variability of FASD symptoms, with its underlying brain damage, can be the single cause of the symptoms presented.

Self-regulation – Ability to control one's behavior to conform to standards, ideals or expectations of society or one's own values or goals. (See also 'Impulsivity.')

Sensory processing –The way in which the brain receives messages from the senses and turns them into appropriate motor and behavioral responses. Some persons affected by FASD have impaired sensory processing abilities. (See also 'Occupational therapy' and 'Overstimulation.')

Shut down – The condition of being unable or unwilling to communicate with others, often as a reaction to stressful events, feelings of social isolation, and/or the belief that no one can or will understand you. It can be a sign of depression, hopelessness or helplessness.

Special education – Term used in USA, for school programs to address special needs of children with cognitive or physical disorders, especially learning disabilities. Students may attend remedial classes, receive individual tutoring, or try alternative learning methods, among other strategies. In Canada it is called 'Learning assistance.' (See also 'Individualized Education Plan.')

Spectrum disorder – In reference to mental disorders, it is a range of linked conditions with a single cause; it is not a unified disorder but rather, a syndrome consisting of different subgroups that may range in severity from 'severe' to 'mild' forms of the disorder.

SSI – Supplemental Security Income Benefits (USA)

Stigma – Birthmothers of children with FASD may feel stigmatized, or 'marked,' by the blame others might apply to them for having caused their child's disability; however, in most cases the mother was ill with an alcohol addiction, did not know where or how to find help, or was uninformed or misinformed about the dangers of alcohol consumption during pregnancy. Persons who have FASD can also feel stigmatized, shame or embarrassment for being labeled with the disability.

Stranger danger – Guideline or practice of cautioning children not to talk to, go with, or accept gifts from strangers (since bad people don't always look bad). FASD children often are uninhibited, even too friendly, around strangers.

Streissguth, Ann – Leading researcher and professor at Univ. of Washington School of Medicine, Dept. of Psychiatry and Behavioral Sciences, who has written and lectured extensively on FASD and worked with FASD patients, their families and communities for more than 30 years.

Subsidized transportation – Reduced prices for public transportation (buses, subways, commuter trains, or specific-use vans), offered to qualified persons.

Support network / Support system – A team or a group of advocates, helpers and agencies who can significantly aid persons with disabilities. (See also 'Interdependence' and 'External brain.')

Supported housing – Housing and services that are designed to help marginalized or at-risk persons to live as safely and independently as possible. Such programs may be supported by governments, or religious or charitable organizations, to address homelessness, poverty, and the special needs of persons with disabilities. Also called 'Supportive housing.'

Tax on alcohol – A type of 'sin tax,' which is a tax specifically imposed on goods or services that are considered to have negative or damaging consequences to society -- for instance, alcohol and tobacco. In 2002 the state of Alaska (USA) increased its taxes on alcoholic beverages, planning to spend the generated extra funds on programs to prevent or treat alcoholism and on FASD diagnosis and services.

TBI – see Traumatic brain injury

Teratogens – Substances or environmental factors that cause birth defects. These include alcohol, drugs and medications; environmental chemicals; radiation; infections; and metabolic imbalances.

Teratology – The study of abnormalities in physiological development, such as birth defects.

Treatment – The use of drugs, exercises, therapies, and/or services to cure an illness or alleviate the symptoms of an incurable condition.

Traumatic brain injury -- Brain damage caused by accidents (such as falls or traffic accidents), military or criminal assaults, near-drowning, or other head injuries.

Trigger – A topic, word or phrase, action or event that makes someone angry, anxious, irritated, or upset, or reminds him/her of a traumatic experience. Commonly this results in the affected person reacting with inappropriate or undesirable behaviors.

Working memory – Linked to learning and attention, working memory is a system wherein the mind holds various types of information which are expected to be needed for upcoming verbal and nonverbal tasks, and for further information processing. It is usually impaired in persons with FASD, and often declines in all persons during old age. The concept is roughly the same as 'Short-term memory.'