Definitions

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function.

Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.
Source: World Health Organization: definitions (1980).

Self-advocate: People with intellectual/developmental disabilities who speak for themselves. Some may require help with communication. Source: The Self-Advocates Council of Community Living Ontario

Habilitation: Programs and environments that help people with developmental disabilities learn and keep skills that help them cope with their disability and their environment. Source: Florida State Handbook for families.

Rehabilitation: Typically called psychosocial rehabilitation. "A range of social, educational, occupational, behavioral, and cognitive interventions for increasing the role performance of persons with serious and persistent mental illness and enhancing their recovery"
Source: Barton, R. (1999). Psychosocial rehabilitation services in community support systems: A review of outcomes and policy recommendations. Psychiatric Services, Vol 5, p. 525 – 539. Available at: http://psychservices.psychiatryonline.org/cgi/content/full/50/4/525

Normalization: This concept originated in Sweden in the 1960's and was defined as "making available to the mentally retarded patterns and conditions of everyday life, which are as close as possible to the patterns of mainstream society."
Source: Baxter, J. A. & Cain, N. (2006). Psychotherapeutic interventions. In N. Cain, G. Holt, Davidson, P. & Bouras, N (eds). Training handbook of mental disorders in individuals with intellectual disability. Kingston, NY: NADD Press.

Accessibility: The Accessibility for Ontarians with Disabilities Act, passed in 2005, provides the mechanism for the development of accessibility standards that are to ensure that all people with disabilities can go to school, shop, work, travel, obtain services without barriers.
Source: Accessibility for Ontarians with Disabilities Act. Available at: http://www.mcss.gov.on.ca/mcss/english/pillars/accessibilityOntario/questions/aodo/act2005.htm

Inclusion: People with disabilities should enjoy the same level of participation in society as anyone else.

Support circle or support network: The people involved in individuals' lives who know them well, assist them to express what they want and value their

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contributions. The network may include family, friends, community members, volunteers and paid supports.

Service partnership: Those local agreements between and among agencies to serve their particular client group.

Service network: A broad regional grouping of large organizations and ministry departments who have a joint responsibility to see that the dually diagnosed are served.

Developmental disabilities

Defining *developmental disabilities* is a complicated task – with many sources attempting to capture all facets in one or just a few sentences. Advocates, people with developmental disabilities and their families have struggled with the stigma related to the term mental retardation. Thus they have sought terms that are less marginalizing – and would hopefully lead more easily to inclusion and social acceptance.

Intellectual disability: a term often used synonymously with developmental disability, however there are differences. Intellectual disability refers specifically to people with cognitive deficits that occur during the developmental period – up to age 18.

Where as "developmental disability" is a broader category that may or may not include intellectual disability e.g. higher functioning Autism Spectrum Disorder, and Fetal Alcohol Spectrum Disorders
Source: The American Association of Intellectual and Developmental Disability. Discussion available at: http://www.aaidd.org/About_AAIDD/MR_name_change.htm

Some examples:
The American Association of Intellectual/Developmental Disabilities
"A particular state of functioning that begins in childhood and is characterized by limitations in both intelligence and adaptive skills."

The Canadian Association for Community Living

This organization has updated the term they use from developmental disability to intellectual disability

" Intellectual disability is a term used to refer to the challenges that some people face in learning and often communication. These challenges are usually present from the time they are born or from an early age. Often the most serious challenges people with intellectual disabilities face are the stereotypes, negative perceptions and discrimination by others in response to unique and different ways of learning and communicating.

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Intellectual disability was at one time called *mental retardation*. People who have an intellectual disability tell us they resent being labeled by this term. “Label jars, not people” we are often told. For this reason, we always refer to people for who they are, as people first. Preferred terms are:

- intellectual disability
- developmental disability

About 2% of the Canadian population has an intellectual disability.

Source: http://www.cacl.ca/about-us/definitions-terminology (2013).

Services and Supports to Promote the Social Inclusion of Persons With Developmental Disabilities Act (2008), Ontario. Effective July 1, 2011

Significant limitations in cognitive functioning and adaptive functioning and those limitations

(a) originated before age 18 years;
(b) are likely to be life-long in nature; and
(c) affect areas of major life activity, e.g. personal care, language skills, learning abilities, capacity to live independently

Diagnostic and Statistical Manual of Mental Disorders – DSM-5

Intellectual Disability **(ICD-10 -Intellectual Developmental Disorder)**

“… a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains. The following three criteria must be met.

A. Deficits in intellectual functions such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.
B. Deficits in adaptive functioning that result in failure to meet developmental and social-cultural standards for personal and social responsibility. Without ongoing support the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation and independent living, across multiple environments, such as home, school, work, and community.
C. Onset of intellectual and adaptive deficits during he developmental period.”

Levels of severity are described in a table according to mild, moderate, severe and profound across 3 domains: conceptual, social and practical functioning. It is noted that adaptive functioning determines the level of supports required” as opposed to the previous DSM-IV emphasis on IQ scores

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Source: The Diagnostic and Statistical Manual, Fifth Edition, American Psychiatric Association, 2013 p. 33- 36.

Autism Spectrum Disorder

"A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive.

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing gof interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or devidits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for ecample, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends, to absence of interest in peers

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g. simple motor stereotypies, lining up of toys or flipping objects, echolalia, idiosyncratic phrases)
2. Insistence on sameness, inflexible adherence to routine or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusal objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life.

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnosis of autism disorder and intellectual disability, social communication should be below that expected for general developmental level."

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Levels of severity are described in a table according to the following:

- Level 3 – requiring very substantial support
- Level 2 – requiring substantial support
- Level 1 – requiring support

And across 2 domains: social communication impairments and restricted, repetitive patterns of behaviour.

These severity specifiers must be used to describe the current symptomatology. So you might see a diagnosis of Autism Spectrum Disorder, Level 2.

Source: The Diagnostic and Statistical Manual, Fifth Edition, American Psychiatric Association, 2013 p. 50 - 52.

Dual Diagnosis

Dual Diagnosis is not a formal diagnosis that is found in the DSM. This is because using the DSM one can have more than 1 diagnosis – e.g. Intellectual Disability, Autism and Anxiety Disorder. It has become used more as an description to describe a complex set of diagnosis/disorders. It can overlap with substance use disorders, however the practice is to use Dual Diagnosis referring to intellectual disability, plus mental health or behavioural issue; and Concurrent disorder as substance use and mental health issue.

"Individuals who have a diagnosed emotional/psychiatric disturbance as well as a diagnosed developmental disability."

Source: Interministerial Initiative on Dual Diagnosis (1990)

"Individuals with a developmental disability and mental health needs"
Source: Interministerial Dual Diagnosis Guidelines, 1997 and 2008

Causes of developmental disabilities

Prenatal - Genetic / Chromosomal abnormalities or syndromes, maternal age, low IQ of parents

Perinatal - Asphyxia, substance use in pregnancy, poor prenatal care

Postnatal - Malnutrition, mercury or lead poisoning, non-stimulating environment, childhood diseases, head trauma, seizure disorder

Environmental Factors - poor medical attention, under stimulation, disadvantaged environment

Unknown – In many cases, it is simply not known what caused the developmental disability.

Sample of Genetic Syndromes

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Down Syndrome	The most common genetic cause of moderate developmental disability – resulting from an extra chromosome 21. Characterized by particular physical features such short fingers, short stature and facial features, along with physical health concerns including increased risk for congenital heart disease and gastrointestinal conditions.

Source: Lovering, J., & Percy, M. (2007) Down Sydrome. In I. Brown & M. Percy, A comprehensive guide to intellectual and developmental disabilities. Baltimore, MD: Paul H. Brookes Publishing Co.

Phenylketonuria (PKU)	The performance of certain enzymes is inhibited and can be corrected with special diet – however, if the diet is not begun very soon after birth, mental retardation can result.
Fragile X Syndrome	Twice as common in boys, it involves an array of developmental problems: learning and intellectual disabilities, attention problems, anxiety and identifying facial features. Girls may not show deficits whereas 80% have developmental disabilities.
Prader-Willi Syndrome	Characterized by cognitive impairment, low muscle tone and an ongoing sense of hunger that can lead to morbid obesity.
Cerebral Palsy (spastic)	There are four types of cerebral palsy (spastic, athetoid, ataxic and mixed). People with spastic cerebral palsy also commonly have learning and developmental disabilities.

Source: Owen, F. & MacFarland, J. (2002). The nature of developmental disabilities. In D. Griffiths, C. Starvraki & J. Summers (Editors). Dual diagnosis: An introduction to the mental health needs of persons with developmental disabilities. Sudbury, ON: Habilitative Mental Health Resource Network

Rett's Disorder	Early normal development followed by a loss of hand skills, reduction in growth of head size, and loss of social engagement and language skills at 6-24 months of age. Only affects females.

Source: Perry, A., Dunlap, G., & Black, A. (2007) Autism and related disabilities. In I. Brown & M. Percy, A comprehensive guide to intellectual and developmental disabilities. Baltimore, MD: Paul H. Brookes Publishing Co.

Tourette's Disorder	Motor and vocal tics, occurring in bouts many times a day. The words, sounds and movements interrupt social, occupational and relational functioning. Usually not accompanied by an intellectual disability.

Source: The Diagnostic and Statistical Manual – IV.

Cri du Chat	A rare disorder involving a characteristic high pitched cry and eventually a high pitched voice accompanied by multiple physical and intellectual impairments.

Source: Australian Cri du Chat Support Group. Available at: http://www.criduchat.asn.au/criduchat/what.htm#Cri%20du%20Chat%20Syndrome

Fetal Alcohol Spectrum Disorders	The result of maternal consumption of alcohol. First described in 1973, it involves multiple intellectual and growth deficits with characteristic facial features. Some will have no outward expression of deficit but will suffer lifelong brain dysfunctions affecting social and vocational development. FASD is not a diagnostic category.

Source: Chudley, A. Conry, J. Cook, J. Loock, C. Rosales, T. & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Canadian Medical Association Journal (supplement). Vol 172, p. 1 – 21.

Mental health and mental illness

"Mental health (or well being) is an ideal we all strive for. It is a balance of mental, emotional, physical and spiritual health. Caring relationships, a place to call home, a supportive community, and work and leisure all contribute to mental health. However, no one's life is perfect, so mental health is also about learning the coping skills to deal with life's ups and downs the best we can.

Mental illness is a serious disturbance in thoughts, feelings and perceptions that is severe enough to affect day-to-day functioning. Some names for mental illnesses are:

- schizophrenia - seeing, smelling or hearing things that aren't there or holding firm beliefs that make no sense to anyone else but you – symptoms that are often called psychosis, noting that psychosis can be associated with other disorders such as depression or in relation to drug abuse,
- depression - intense feelings of sadness and worthlessness – so bad that you have lost interest in life,
- bi-polar disorder - cycles of feeling intensely happy and invincible followed by depression,
- anxiety disorders - panic attacks, phobias, obsessions or post traumatic stress disorder,
- eating disorders – anorexia (not eating), bulimia (eating too much and then vomiting), or binge eating disorder (eating too much and not purging – often leading to obesity), and
- borderline personality disorder - severe difficulty with relationships, placing yourself in danger, making decisions that turn out to be very bad for you – most often as a result of a history of child abuse, abandonment or neglect."

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Recovery

"Recovery defines consumers, not as passive objects of treatment, but as active participants – along with their families and caregivers - in creating and maintaining their own mental health. Recovery focuses on wellness rather than illness. Recovery is not a cure. There is no timeline. It is living life to the fullest despite challenges.

Consumers say that recovery is much more than just dealing with the symptoms of mental illness. People have other life experiences that have affected their mental health. Recovery acknowledges and validates all these experiences and opens the door to a broader base of coping mechanisms than simply diagnosis, medication or therapy."

Source: Working together towards recovery: Consumers, families, caregivers and providers. A publication of the Canadian Collaborative Mental Health Initiative. Available at: http://www.ccmhi.ca/en/consumers.html p. 5 - 6 and p. 39.

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