

One only understands the things
that one tames....If you tame me,...I
shall know the sound of a step that
will be different from all the
others....Then we shall need each
other....

Antoine de Saint-Exupéry, 1943

What is Intellectual Disability?

Introduction

It should be mentioned from the outset that this document is meant to be an overview of the present state of salient knowledge in the field of intellectual disability. Undertaking a comprehensive status report would be a colossal, but nonetheless, desirable task, considering the plethora of literature on the subject. The content of this paper is essentially divided into eight parts: historical background, conceptual frameworks, etiology, normalization and social role valorization, self-determination, and integration into society, school and the workplace.

1. Historical Background

Perceptions of the world around us change from one era to the next. Traditions and customs considered common, desirable or, at the very least, acceptable in one epoch may be deemed totally unacceptable in another because of new knowledge. It is important to bear this in mind when considering an historical survey of intellectual disability.

Durant (1935, quoted in Martin, 2002) states that, in Prehistoric times, there were several tribes who killed children considered to have been born under inauspicious circumstances. He adds that, during famines or when there was fear of famine, most children were strangled, and even eaten by some tribes. Martin (2002) stresses that Neanderthal man was not essentially barbarous or cruel when he committed infanticide, but was only trying to ensure his own survival. In some parts of the world trephination (perforation of the skull) was practised in order to rid individuals with mental health problems or intellectual disabilities of demons.

As for the era of Antiquity, Sheerenberger (1983, quoted in Martin, 2002), reports that one of the first classifications of “differences” was found in Mesopotamia on a cuneiform tablet dated 2800 B.C. It mentions “monsters” by reason of excess size or number (e.g. hydrocephaly or six fingers); smallness in size or appendices (e.g. microcephaly); and doubles (hermaphroditism). In Greece it was common for young children to be hurled from cliffs if they had an apparent defect. The father had the right to decide if he would keep a child. If he rejected it, the child would be thrown on a garbage heap and left to die. Romans were permitted to practise infanticide within eight days of a child’s birth; after that time, unwanted children were taken in charge by the State and institutionalized. It was recommended by law that child monstrosities be exterminated. Persons with an intellectual disability were commonly used as fools at gatherings. In the Middle Ages, the “feeble minded” often became victims of the Inquisition if they displayed behaviours considered to be bizarre, such as epileptic seizures, for example. Thought to be demon possessed, they were burned at the stake.

From a contemporary perspective, the historical evolution of the understanding of intellectual disability may be divided into four major periods. The first period dates from before 1800 when the concept of intellectual disability simply did not exist. People who were “intellectually disabled” were lumped together with abnormal persons, the insane, criminals, thieves and epileptics. This was a very negative time for persons with an intellectual disability as they possessed no real identity and were subject to rejection. The next period, from 1800 to 1870, was much more positive and the first efforts at therapy were made at this time. For example, the years 1789-1790 saw a major differentiation made amongst asylums, hospitals and prisons. In 1801 Itard¹ published his first positive report about the basic learning acquired by his student Victor, a wild child of twelve who had been found in the forests of Aveyron. Then, in 1806 Itard published a second report, in which it appears that Victor’s progress had reached a ceiling. Several years later in 1811, Napoleon had a census taken of “cretins” and ordered that they and their families be “transplanted” into the mountains, the rationale being that the pure mountain air would make them more intelligent. The project failed due to resistance by the villagers who refused to have their “village idiots” removed, since they believed that the latter served as lightning rods, protecting the villages from God’s thunderbolts. In 1837, Édouard Séguin, a

¹ Jean-Marc Gaspard Itard, French Physician (April 24, 1775 – July 5, 1838). He was the first physician to declare that an enriched environment could compensate for developmental delays caused by heredity or previous deprivation. Up to this time, it had been assumed that mentally retarded people were uneducable. As one writer put it, Itard’s work with Victor “did away with the

student of Esquirol and Itard, opened a school for youths with an intellectual disability, although he only had one student registered! After emigrating to the United States, he established the Association of Medical Officers of American Institutions for Idiots and Feeble-Minded Persons in 1876, now known as the American Association on Mental Retardation (AAMR). It was also at this time that Guggenbühl founded Abendberg, the first school for the persons with an intellectual disability. Filled with pity at the sight of a “cretin” praying outside a chapel, he decided to take the man’s education in hand. Guggenbühl rapidly became famous due to the success of his efforts and Abendberg came to be considered as a model. His success, however, led to his frequent absences from the school and living conditions deteriorated to such an extent that the State had no choice but to close it down. The end of this period coincides with the first descriptions of trisomy 21 (called Mongolism at the time and then relabelled as Down syndrome) by Langdon Down. All in all, this period was relatively positive since it was marked by the first attempts at educating persons with an intellectual disability.

However, the limited successes that had been obtained gave rise to a new period from 1870-1940 which was rather negative. Multi-storied institutions were built and these became increasingly overcrowded and grossly understaffed: for instance, in some places there was one doctor for two hundred patients. A study of the case of Martin Kallikak (a fictitious name derived from the words ‘kallos’, meaning ‘good’, and ‘kakos’, meaning ‘evil’) was also presented during this period. This was a genealogical study of two of Martin Kallikak’s descendents. One of the descendents was the fruit of his union with his bourgeois wife, while the other was from an amorous adventure he had had with a feeble-minded peasant girl. The good qualities of the descendents through his wife’s line (lawyers, workers, good parents) contrasted with the inferior qualities of his descendents through the peasant’s line (thieves, crooks, perverts, cretins), and showed, beyond all reasonable doubt, that intellectual disability was hereditary. The period was also marked by famous quotes which influenced the beliefs of the era. For example, Fernald (1912) wrote that, “The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs.” In 1936, Cattell wrote that the national IQ was falling by one point every decade which meant that, in each generation (30 years), there would be a 24% increase in the number of mentally deficient persons. According to his calculations, three hundred years later, half the planet would be mentally deficient. This type of declaration obviously served the purposes of those militating for sterilizing and segregating persons with an

paralyzing sense of hopelessness and inertia that had kept the medical profession and everybody else from trying to do anything constructive for mental defectives”.

intellectual disability. Finally and fortunately, the fourth period, which dates from 1940 to the present day, gave rise to more realistic and optimistic attitudes, due in large part to better knowledge of intellectual disability. The role that heredity played was reduced.. Foeling described oligophrenia phenylpyruvic amentia; Turpin and Lejeune noticed chromosomal irregularities, and observation showed that persons with an intellectual disability could work and have families and it was possible for their children to be less intellectually impaired or not impaired at all.

2. Conceptual Frameworks and Definitions

According to Martin (2002), one of the first attempts at defining intellectual disability goes back to 1534 when Sir Anthony Fitzherbert qualified as a “sot” or an “idiot” anyone who could not count twenty pence or state who his father and mother were. Later, Jean Étienne Dominique Esquirol put forward a more sophisticated definition by qualifying “idiocy” as a state of non-development of the intellectual faculties, observable from a very young age and which nothing could change. Then, in the nineteenth century, Séguin suggested a classification scheme which defined “idiots” as being individuals with moderate or severe intellectual disability and “imbeciles” as those with a mild intellectual disability. In this regard, Garcin (Tassé & Morin, 2003) rightly points out that there are numerous definitions of the state of intellectual disability (which is not an illness – Martin, 2002) and that it is called by various names such as mental retardation, mental handicap, intellectual disability, learning disability, or intellectual disability. Nevertheless, all these definitions have three criteria in common: significant limitations in intellectual functioning associated with significant limitations in adaptive behaviour, all of which appear before adulthood. There are, however, wide conceptual and operational differences with regards to these criteria. To better understand these differences, the four most commonly used definitions of intellectual disability will be examined: those given by the *American Association for Mental Retardation*, the *World Health Organization*, the *American Psychiatric Association*, and the *American Psychological Association*.

A. AAMR (2002)

The *American Association for Mental Retardation* advanced the following new definition of mental retardation, as well as a new ecological conceptual framework, in its 2002 manual:

Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. (Page 8)

The AAMR's new conceptual model is illustrated in Figure 1. Essentially, it maintains an ecological approach based on three key elements that permit an understanding of the relationship between a person's intellectual disability and his level of functioning. The AAMR proposes a multidimensional model consisting of five dimensions: (a) intellectual abilities, (b) adaptive behaviour, (c) participation, interactions and social roles, (d) health, and (e) contexts that influence the individual's functioning. Consequently, the assessment made of an individual's level of functioning determines the type and intensity of the support he receives. In return, the support provided has either a favourable or unfavourable influence on the development of the individual's abilities, which translates into strengths or limitations in each of the five dimensions. It is thus a matter of a reciprocal relationship between the person and his environments.

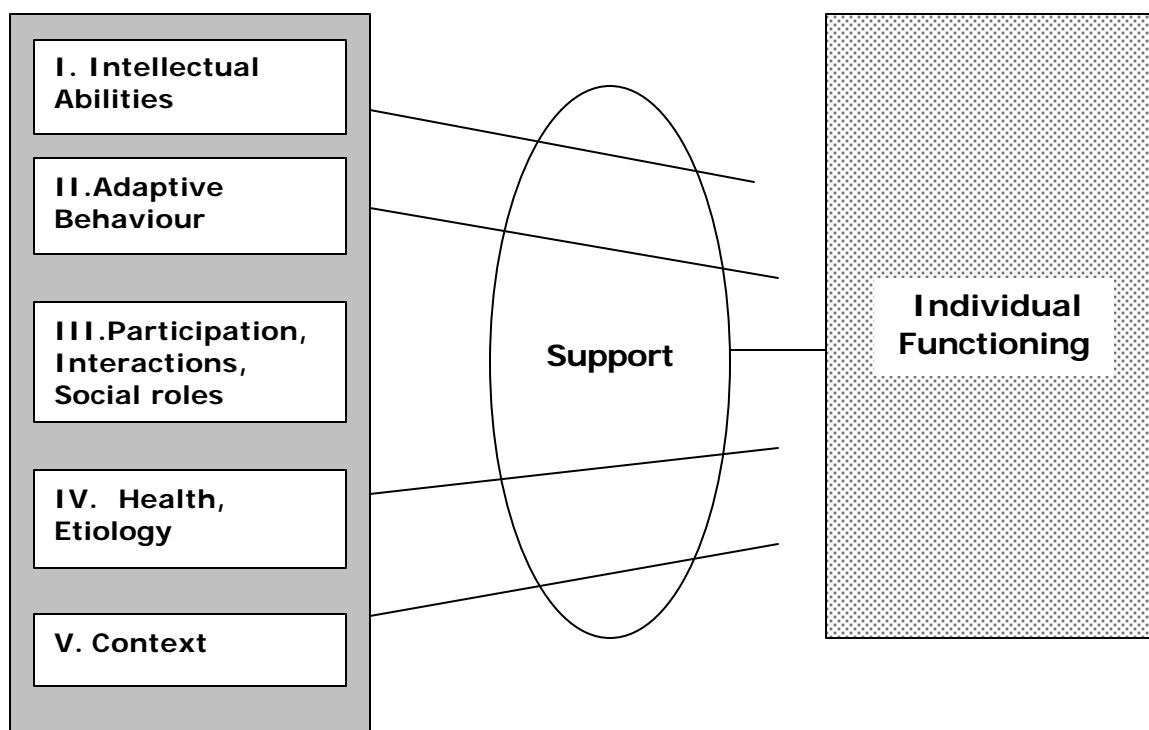


Figure 1. Theoretical model of mental retardation (taken from Luckasson et al., 2002, p. 10)

Similarly to the earlier system of 1992, five important assumptions are included in the application of the 2002 definition of intellectual disability. Firstly, limitations in an individual's present functioning must be considered within the context of typical community environments. It is important, therefore, not to evaluate a person's functioning based on isolated or segregated environments, but on the typical living environment, which includes the home, neighbourhood, school, place of work, etc., in which his peers tend to live, play, work and interact. Secondly, it is important to remember that valid assessment will take both the person's cultural and linguistic diversity into account. This implies that a serious assessment must consider a person's individual characteristics and unique response factors. Such an evaluation will also take culture and ethnic origin into account, including the language spoken in the home, means of nonverbal communication, and any customs that might influence assessment results. Thirdly, it must be borne in mind that within the same individual, limitations co-exist with strengths. Persons with an intellectual disability are complex human beings who have certain gifts as well as limitations and, like everyone else, are better at doing some things than others. For example, it is quite possible for them to have strengths in social or physical capabilities, along with major limitations in other areas of adaptive behaviour. Fourthly, it is important to carefully define an individual's limitations in order to develop a profile for the level of support he needs to improve functioning. Finally, the fifth assumption is that a person with an intellectual disability's functioning will generally improve if he receives appropriate personalized support over a prolonged period. It would appear, therefore, that the old stereotype that persons with an intellectual disability never improve is erroneous. Other than a few exceptions, appropriate support fosters improvement in a person's functioning.

B. International Classification of Functioning, Disability and Health (ICF)

The *World Health Organization's new International Classification of Functioning, Disability and Health (ICF)* (WHO, 2001) presents another conceptual model (Figure 2). Because of its structure, the model provides a conceptual framework for disability which can prove very useful in harmonizing international communication. The classification is an extension of the *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)* (WHO, 1980), which revolutionized the conception of intellectual disability by proposing that it no longer be regarded as a disease or even the simple physical or psychological consequence of disease, but rather as a problem of functioning of the whole person. In this model, functioning is considered as interaction of the person with his environment. The new classification improves on the 1980 model by adding the factor of environmental context and insisting on the fact that functioning is

the result of interactions between a person who is experiencing health problems and environmental factors. It thus provides a universal model which is able to describe and explain the functioning of all persons.

At present, it seems that an increasing number of professional and scientific organizations as well as associations of parents and of persons with an intellectual disability are using this conceptual model, which could greatly facilitate harmonization of the language used by these various players. The classification is complementary to the *International Statistical Classification of Disease and Related Health Problems (CIM-10)*, which defines intellectual disability as being “arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence” (WHO, 1993).

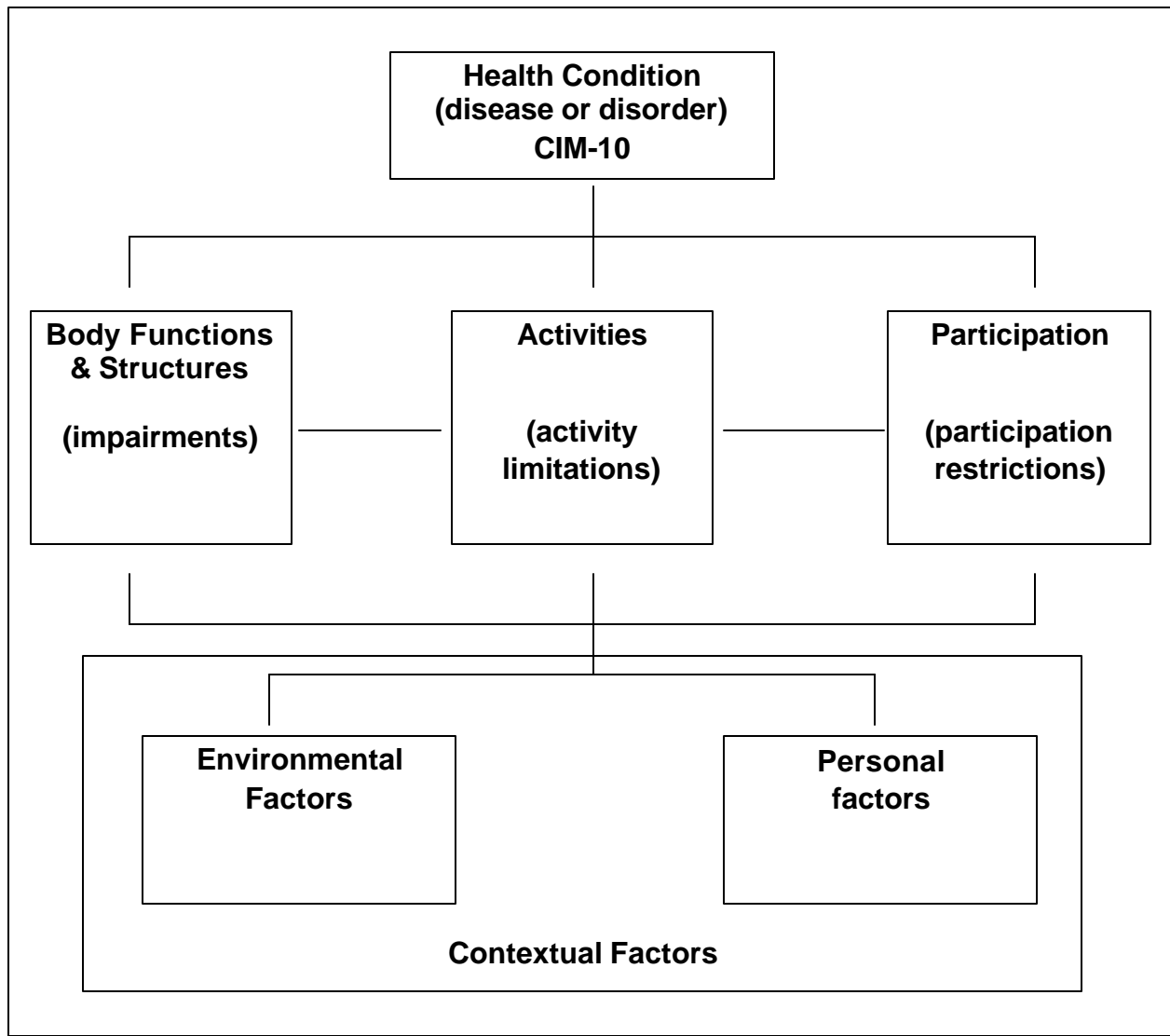


Figure 2. General Framework of the ICF (WHO, 2001)

C. American Psychiatric Association

In the most recent edition of its *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000)*, the *American Psychiatric Association* defines mental retardation as being:

Significantly subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, work, leisure, health, and safety. The onset must occur before age 18 years.

According to the association, there are five degrees of mental retardation: mild (IQ 50-55 to 70), moderate (IQ 35-40 to 50-55), severe (IQ 20-25 to 35-40), profound (IQ below 20-25), and severity unspecified (impossible to measure).

D. American Psychological Association

In its latest manual (Jacobson & Mullick, 1996), the *American Psychological Association* states that mental retardation is characterized by (a) significant limitations in overall intellectual functioning, (b) accompanying significant limitations in adaptive skills, and (c) manifestation before the age of 22.

According to the American Psychological Association, mental retardation also manifests itself in varying degrees of severity: mild (IQ 55 to 70 or two standard deviations below the norm), moderate (IQ 35 to 54 or three standard deviations below the norm), severe (IQ 20 to 35 or four standard deviations below the norm), and profound (IQ below 25 or five standard deviations below the norm). The authors add that mild and moderate mental retardation must be accompanied by significant limitations in at least two areas of adaptive skills, whereas with severe and profound mental retardation there are significant limitations in all areas of adaptive skills.

3. Etiology of Intellectual Disability

Etiology refers to the known causes of intellectual disability. It would appear that there remains a lot to learn in this regard since many authors agree that 40% to 50% of the causes of intellectual disability are unknown (Garcin, 2003; Luckasson et al., 2002; Martin, 2002; L'abbé, Labine, Lemieux & Lespinasse, 2004). Nevertheless, Juhel (1997) points out that considerable progress has been made in medicine, biology, psychology and in sociology over the past few decades. Tassée and Morin (2003) report that the rates of occurrence of intellectual disability mentioned in the literature vary between 1% to 3% of the population. As regards etiological factors, most of the literature suggests there are four categories of factors which can occur before, during or after birth. These are genetic disorders, chromosomal disorders, biological and organic causes, and environmental causes (Tassée & Morin, 2003).

A. Genetic Disorders

Genetic disorders are transmitted to the child through genes at the time of conception. The most frequent disorders are fragile X syndrome, phenylketonuria, tuberous sclerosis or Bourneville's disease, and Lesch-Nyhan syndrome.

Fragile X syndrome is the most common hereditary cause of intellectual disability, as well as being the second most common genetic cause after trisomy 21. It involves a mutation of the FMR1 gene on the X chromosome, causing it not to produce a protein which is important for pre- and post-natal development of the brain. In most cases, persons with this syndrome present characteristics associated with autism, such as hand flapping, poor eye contact, anxiety and sudden mood changes. It is estimated to occur in 1 in 4000 males and 1 in 7000 females. Phenylketonuria (PKU) consists of a disturbance in the metabolization of amino acids leading to an accumulation of the phenylalanine hydroxylase enzyme, which corrodes the myelin in the brain. People with this syndrome often suffer from epilepsy and have neurological problems (Dykens et al., 2000 quoted in Tassé & Morin, 2001), without actually presenting any particular behavioural characteristics. Its occurrence is estimated at 1 in 15,000. They must avoid food containing phenylalanine, such as dairy products, chicken, fish, eggs, fruit and vegetables. In tuberous sclerosis or Bourneville's disease the presence of a tubercule or benign tumour instead of normal tissue results in a disorder in the differentiation and migration of cells. Over 40% of children with this syndrome have an autistic disorder or symptoms of autism, along with hyperactivity. It is estimated to occur in 1 out of every 6800 to 12,000 births. Lastly, Lesch-Nyhan syndrome involves a disability of the HRPT enzyme which allows purines to be synthesized, thus resulting in an excess of uric acid. Most children with this syndrome display self-mutilating behaviours, such as finger and lip biting, and are often aggressive towards others. Prevalence is estimated at 1 in 100,000, with the syndrome only affecting males.

B. Chromosomal Disorders

Chromosomal disorders occur during the arrangement of chromosomes. The most common of these disorders are Down syndrome, Prader-Willi syndrome, and Angelman syndrome.

Down syndrome, also known as trisomy 21, occurs when there is an extra chromosome in the 21st pair. It is generally characterized by the development of a short flat nose and slanted eyes. People with Down syndrome usually have pleasant personalities and tend to smile and be in good humour most of the time. Prevalence is estimated to be 1 out of every 650 births. Prader-Willi

syndrome is a complex disorder of the paternal chromosome 15, characterized by obesity along with small hands, feet and genitalia. People with this syndrome often exhibit obsessive-compulsive behaviours, have fits of rage and scratch themselves. Its prevalence is estimated at 1 in 15,000. Angelman syndrome is a complex disorder of the maternal chromosome 15 and is characterized by a long face, prominent jaw, flattening of the occipital region, deep-set eyes and microcephaly. The syndrome is also called the “Happy Puppet Syndrome” because of the jerky movements associated with it. Its prevalence is estimated at 1 in 12,000 to 25,000.

C. Biological-Organic Causes

Biological/organic causes can occur before, during or after birth. The primary pre-natal causes of intellectual disability are measles or rubella in the mother, ingested toxins (mercury-contaminated fish) or certain medications. Perinatal (during birth) causes include exposure to toxins or infections (e.g. genital herpes), excessive pressure on the head or asphyxiation. Post-natal causes include cranial trauma, meningitis or exposure of the child to lead.

D. Environmental Causes

Environmental causes are those factors that can be controlled, such as dietary deficiencies in the mother during pregnancy, consumption of drugs or alcohol, lack of physical and sensory stimulation and absence of health care.

4. Normalization and Social Role Valorization

The past forty years have been influenced by the concept of normalization, which appeared first in Denmark (Bank-Mikkelsen), then in Sweden (Nirje, 1969) and, finally, in North America (Wolfensberger, 1972). According to this approach, it is important to promote living conditions that are as normalized as possible for the individual. Emphasis must be placed on the person’s abilities while removing the obstacles that society puts in his way. This principle revolutionized attitudes at the time (Juhel, 1997).

The principle of normalization greatly influenced intervention policies and practices in intellectual disability (Flynn & Lemay, 1999). Normalization was first described by Bank-Mikkelsen as being the acceptance of persons with an intellectual disability with their limitations, and access for these people to the same living conditions as other citizens (Perrin in Dionne et al., 2002). Later, Bengt Nirje refined the principle by stating that persons with an intellectual

disability could only truly exercise their rights in the human and cultural context of their community. The principle of normalization therefore involves offering persons with an intellectual disability the same (or as similar as possible) living conditions as those enjoyed by other citizens. Dionne et al. (2002) stress the importance of reciprocity in the normalization process recommended in Sweden. This means that persons with an intellectual disability must adapt to society and vice versa.

Dissatisfied with the popular general interpretation of this principle and the pejorative meaning that the term acquired, Wolfensberger (1991) propounded the principle of social role valorization (SRV). SRV consists of applying what science says on the subject of the development, establishment, strengthening and maintenance or defence of valorized social roles for persons with an intellectual disability (Dionne et al., 2002). Based on this principle, Dionne et al. (2002) recommend that special attention be paid to intervention practices, with the following seven corollaries:

- Continuously seek to identify the potentially negative effects that services can have on the people to whom they are provided. For example, the term “sheltered workshop” may have a negative connotation which goes against the principle of SRV by emphasizing the difficulties people may experience.
- Be sensitive to the role that expectations play in what people become. Our behaviour towards others is largely conditioned by our own perceptions; by using infantile language with a person with an intellectual disability we exert a negative influence on his perception of himself.
- Seek to reduce the prejudicial effects of stigmas through means that are validating. It is important to reduce, as far as possible, the negative effects of stigmas (e.g. by wearing appropriate clothing) on the perception of others.
- Foster the development and exercise of skills. It is important to allow the person to acquire skills and to provide him with opportunities to use these skills.
- Be sensitive to the important role imitation plays. Imitation is a very important process in learning and has a strong influence on social development: a child who is integrated into the school in his neighbourhood will have access to social models that are appropriate for his age and culture.

- Seek to improve the social image of devalued persons. It is a well-known fact that the social image we have of a person, or group of persons, has a direct influence on our attitudes and behaviour towards them.
- Encourage integration and social participation. The maximum development of a person's potential necessarily involves access to living conditions that allow him to have a variety of experiences, make choices, take decisions and have access to validated social roles.

5. Self-Determination

Historically, self-determination refers to a nation's right to govern itself, a principle in international justice. In terms of a personal construct, self-determination refers to a person's ability to govern his own life (Lachapelle & Wehmeyer, 2003). It is defined as "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1996; p. 24).

Behaviour is self-determined only if it reflects the following four essential characteristics: (1) the individual acts autonomously; (2) the behaviour is self-regulated; (3) the person acts in a psychologically empowered manner; and (4) the person acts in a self-realizing manner. These four essential characteristics describe the function of the behaviour which make it self-determining or not. A person's actions, therefore, must reflect each one of these four functional characteristics to a certain degree. Age, the availability or absence of opportunity, abilities and events are also factors that may influence the degree to which each one of these essential characteristics is present. Consequently, relative self-determination expressed by an individual is the result of three determining factors: (1) individual abilities related to learning situations and personal development; (2) opportunities provided by the environment and life experiences; and (3) the types of support offered (Figure 3). Nevertheless, the essential characteristics must be present, with each one being necessary (but not sufficient) for behaviour to be self-determined.

Behavioural autonomy: The use of the term "self-determination" in the proposed theoretical structure originates from two primary sources: the literature of developmental psychology, where autonomy is synonymous with individuation, and from the literature on intervention, where functional or behavioural autonomy is used synonymously with independence. Sands and Wehmeyer (1996) define behavioural (functional) autonomy as the ability to indicate one's preferences, make choices and act accordingly. From this perspective, self-determined behaviour

is autonomous behaviour, to the extent that a person acts in accordance with his interests, preferences and aptitudes and in an independent manner without undue external influence.

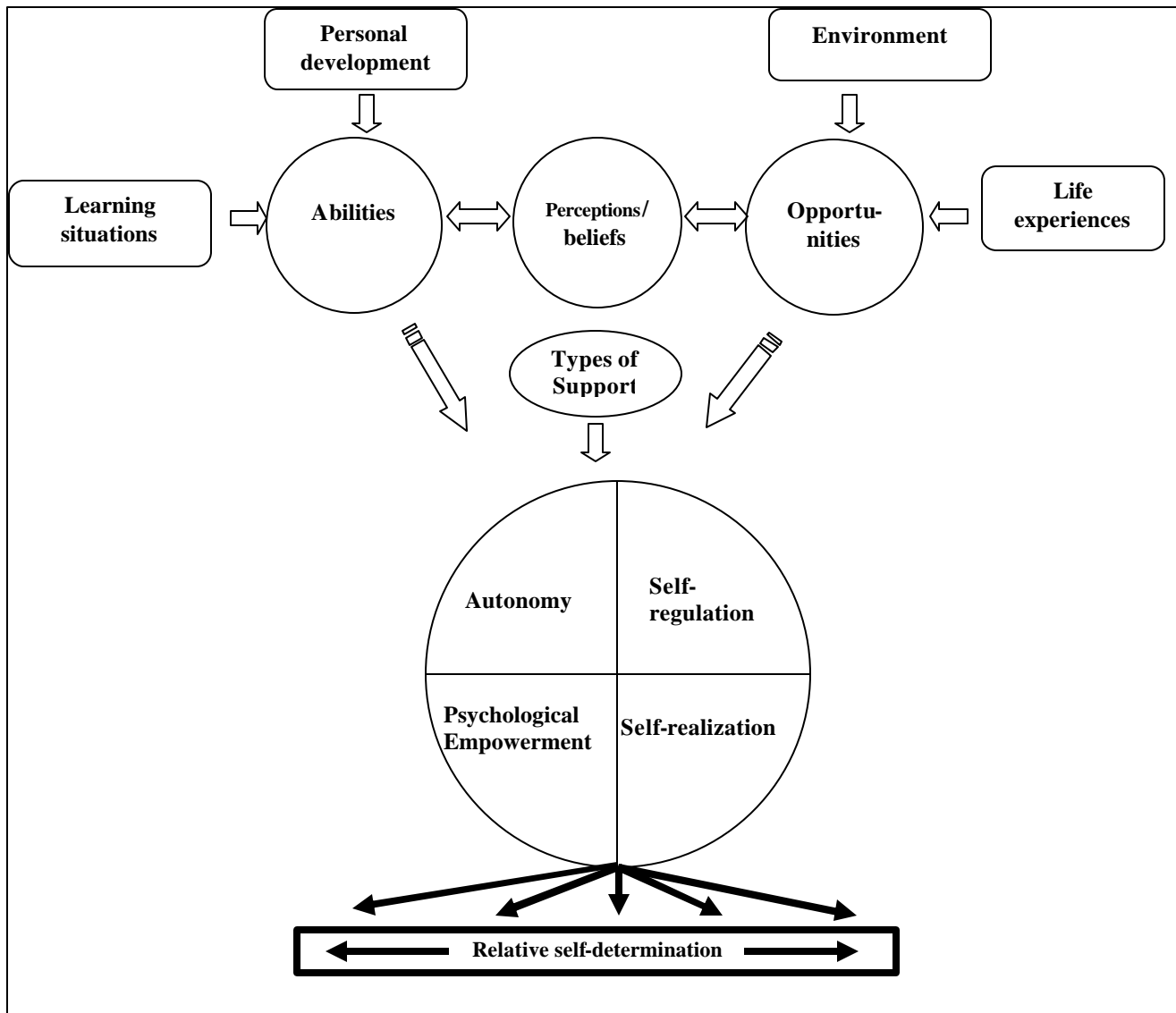


Figure 3. Process of self-determination (Wehmeyer, 1998, p. 55)

Self-regulation: According to Whitman (1990), self-regulation consists of “a complex system of responses which enables individuals to examine their environments and their repertoires of responses for coping with those environments to make decisions about how to act, to act, to evaluate the desirability of the outcomes of the action, and to revise their plans as necessary” (p. 373). Self-regulation involves recourse to self-management strategies (self-instruction, self-

evaluation, self-reinforcement), the ability to set goals, problem solving, decision making and observation (Agran, 1997).

Psychological Empowerment: The concept of psychological empowerment comes from the field of psychology and refers to the multiple dimensions of perception and control: personal effectiveness, locus of control and motivation. It is through the process of learning and using problem solving skills, along with the development of a perception of control over their lives, that people develop the perception of psychological empowerment. This perception allows them to achieve goals such as social inclusion and participation in the community (Zimmerman and Rappaport, 1988; Zimmerman, 1990).

Self-realization: The term self-realization originated with gestalt psychology and refers to the intrinsic goals of a person's life. More comprehensively, the term is related to an individual's tendency to fashion or influence the course of his life from a global perspective (Angyal, 1941, p. 355). Basically speaking, self-determined people know their strengths and act accordingly. They demonstrate a realistic knowledge of themselves (strengths and weaknesses), which is sufficiently accurate for them to act in ways which capitalize on this knowledge. Self-awareness and self-knowledge are acquired by experience, based on the interpretation of one's environment, judgements made by significant people and the validation and ownership of one's own behaviour.

6. Social Integration and Support

As far as social integration of persons with an intellectual disability goes, it appears that in many cases it is social obstacles – e.g. lack of transport or adapted housing – that creates limitations for these people. As a result, some people with severe disabilities are able to participate fully in social life while others, who may be a lot less handicapped, are unable to do so due to these social obstacles.

Social and environmental obstacles are numerous, significant and prove particularly difficult to overcome. Amongst other things, it may be a question of the difficulty someone has in understanding the meaning of a traffic or other signs. It may also be a question of difficulty in managing one's money. In certain countries where bank notes are all the same shape, size and colour, their proper use requires a certain amount of care and judgement, as well as an ability to distinguish numbers, and this can be problematic for people with cognitive difficulties. In other

countries bank notes, for example the euro, come in different colours and sizes, making them much easier to use. There may be other problems associated with residence or apartment living. The simple fact of being able to use a video player, television set, microwave oven or alarm clock implies that one is able to count, tell time and read an instruction manual. It is, therefore, almost unthinkable for a person to be able to live independently without possessing a minimum of technological knowledge. These environmental obstacles which confront persons with an intellectual disability in their progress towards social integration could be removed.

Adherence to a philosophy of social integration for persons with an intellectual disability requires that diversified support be provided so they can participate more fully in society. Moxness & Dulube (quoted in Tassé & Morin, 2003) present six types of support: (a) assistive education follow-up, (b) support for integration, (c) respite, (d) residential resources, (e) support for health professionals, and (f) support in crisis situations.

Assistive education follow-up refers to the support offered by caregivers working to develop daily life skills in the person at home, at school, in a leisure activity setting, in a practicum or at work. Support for integration consists of facilitating social integration for persons with an intellectual disability by offering them accompaniment services in the community on an individual or group level, depending on their needs. The implementation of integration also involves recourse to administrative action, the establishment of programs and intervention plans, as well as the reciprocal collaboration of other members of the community. Another type of support service is respite for family members. There are various types of residential resources available depending on the level of support offered. The last two types of support concern caregivers more specifically. In the context of access to the community and to health services that are available to the general population, it is important to support health professionals (doctors, nurses, technicians, specialists, etc.) by offering them specific sensitization, information/training and intervention activities (Government of Quebec, 2001). Finally, service centres also offer support in crisis situations, for example by offering temporary beds for persons in emergency situations.

The means of support may vary depending on the needs of the individual and his family and are modified according to the person's age. For example, services for early childhood (0 to 5 years) may consist of access to babysitting services, early intervention, coordination of the individual service plan (ISP), respite and accompaniment for parents. For children aged 6 to 12, there are

other needs such as integration into kindergarten and primary school along with needs related to learning social skills. In adolescence (13 to 18 years), major support needs emerge, such as how to make friends, access to leisure activities and the acquisition of the skills necessary for daily living. During this period of life, assistive education services are particularly important. As adults, these people especially need to develop the necessary skills for life in a residence or apartment, integration into the job market, access to adapted transport, or the use of public transport. Finally, services should also be available to the elderly who are losing their independence. Their special needs involve maintaining acquired daily living skills, maintaining or regaining health, keeping busy and accompaniment to funerals, which become more frequent.

In spite of the diversity in services, integration tends to always remain more physical than social. Integration is not only the result of increasing competencies in the individual, it is also conditional on the support and openness of the community. Developing and experimenting with methods of community intervention is a project that is both engaging and promising and **requires close collaboration amongst all players**. Successful social inclusion of persons with an intellectual disability in order for them to experience true social participation is a project which involves society as a whole.

7. School Integration and Support

There are two co-existing visions of school integration: mainstreaming which consists primarily of specialized classes in regular schools, and inclusion which involves integrating students into regular classes in regular schools. Martin (2002) stresses that integration into regular classes requires a great deal of perseverance on the part of those parents who make this choice for their child. To back this up, he reports statistics which are rather disquieting. Whereas 83% of children with a mild intellectual disorder and 71% of children with a moderate intellectual disorder are integrated into regular classes at the kindergarten level, the percentages are significantly lower in the first year of primary school with 35% and 25% respectively of children being integrated. This indicates that most students who were integrated into regular kindergarten are then sent to special classes in regular schools or even to special schools.

Should school integration be by mainstreaming or by inclusion? Opinions are divided on this point and, depending on one's viewpoint, each option appears to have its advantages and drawbacks. Defenders of mainstreaming believe that specialized teaching is better suited to the

specific needs of children with an intellectual disability since there is access to different types of specialists such as psycho-educators, speech therapists and psychologists who are able to provide specialized services. The smaller number of students per class and the professionally trained teachers are two other arguments used by proponents of this approach. Proponents of inclusion decry the fact that segregating children with an intellectual disability in no way contributes to their school integration since, most of the time, children are integrated into schools outside the area in which they live and so are unable to make friends with other children in their neighbourhoods (Martin., 2002). Furthermore, by mainstreaming, the community encourages negative prejudice and prevents its members from having the opportunity to rub shoulders with persons with an intellectual disability. In response to the claim that children integrated into special classes learn more, numerous cases of integration into regular classes have shown that there is little or no difference in terms of learning and that children who are integrated into regular classes acquire more social skills since they have the opportunity to observe and imitate their peers. Finally, the argument concerning specialists and teacher training raises the following question: *As a society, should we be dealing with persons with an intellectual disability on the basis of available services or should we be dealing with our services on the basis of the people in our community who have differences?*

Obviously, viewpoints differ based on attitudes, beliefs, values, knowledge and living environments. Studies have shown that an attitude of less-than-enthusiastic openness on the part of administrators, teachers, parents and regular students to the idea of integrating students with an intellectual disability into regular classes can change once integration has been shown to be successful. It is also helpful to remember that the values behind integration are *equality of persons, respect for persons, the right to the satisfaction of fundamental needs, and equality of opportunity* (Doré, Wagner & Brunet, 1996).

When an adolescent enters secondary school, he is faced with an environment that is less accessible and into which it is much more difficult to become integrated. Secondary schools are physically and structurally less hospitable than primary schools. Groups are more numerous, the established framework more rigid and constraining, and the teaching a lot less individualized. Only 9% of young people with a mild intellectual disability and 4% with a moderate disability are integrated into regular classrooms in Quebec. As for access to post-secondary education, various models are presently being tried out (Martin, 2002).

In order for school integration of youths with an intellectual disability to succeed, schools have put in place various policies and measures. These tools should clearly present the school's philosophy on integration, the means of administrative and budgetary support, the human and material resources available, the number of students per class, and the means of transportation. The regular study program must be modified to allow for the integration of students with an intellectual disability. In order to do this, it is possible to use new pedagogical approaches which take into account different levels of learning, different learning styles such as cooperative learning and learning through activity, as well as different teaching styles, such as multi-programming, mastery learning, peer teaching and tutoring. Use of these new intervention practices requires planning and ensuring that teachers, students, parents, professionals, school principals, support staff, caregiver groups, etc. are properly trained. In line with this objective, present introductory teacher training programs are including an increasing number of activities that take into account the integration of youths with an intellectual disability. Supervision and follow-up require team work, which means that almost all students with an intellectual disability now have access to an education intervention plan – or even a transition plan – which allows them to set long-term goals concerning, for example, work integration and transition into adulthood. Successful school integration cannot, of course, be achieved without a close and very real collaboration amongst the school, parents and other players in the community.

8. Work Integration and Support

Persons with an intellectual disability are extremely under-represented in the job market. However, various efforts are being made to remedy this situation and give them as many chances as possible for access to socio-professional activities. Since 1980 there has been an evolution in socio-professional integration services for adults with an intellectual disability, with a movement from occupational segregated sites towards more regular work sites. For example, socio-professional integration can be carried out through a partnership between a specialized caregiver and a company where non-disabled people work. It can also be a matter of subsidized employment or an individual or group unpaid practicum (work stations). The main advantage of a regular work site over a specialized site is the chance for integration with non-disabled workers and the chance to experience activities that are culturally validating. From the sheltered work environment to employment in the regular job market, it is possible to identify four types of support for the actualization of the worker role. In the sheltered work environment, persons with an intellectual disability participate in production activities for goods and services in an

environment that is fully adapted and populated by persons with an intellectual disability. The individual practicum allows a person with a disability to participate in a regular work environment thanks to a series of measures which allow him to develop work skills. These support measures mainly involve individual follow-up by a person outside the work place, as well as accommodation in the work place itself.

Persons with an intellectual disability can also access the regular job market as a group. With work stations, groups of individuals carry out a variety of tasks or distinct functions in a regular working environment. Another method is the creation of competitive productive entities on the production market, made up largely of persons with a disability. These entities often have the status of cooperatives or social economy enterprises. Lastly, an individual may hold down a regular competitive individual job while receiving support that is more or less intensive in the form of follow-up by a professional, a community member, a work colleague or a supervisor. A certain amount of accommodation may be made in terms of working conditions.

9. Conclusion

The purpose of this paper has been to give an overview of present knowledge and practice in the field of intellectual disability. It is essentially meant to be a working document and we hope to see it evolve over the next few years, enriched by other contributions.

In conclusion, we should mention the **BSVD** approach used by Robert Schalock. The letter **B** invites us to be part of the great group of **Builders** in the pursuit of a better future for the people we meet in our daily lives.

The second letter, **S**, stands for **Synergy**. By virtue of our functions, we are all builders who are making significant contributions to development in our fields. However, in spite of sharing the ideology of a multi-disciplinary approach where each one contributes his expertise, we still have a long way to go in terms of being able to affirm that we really work synergetically and efficiently and are thus able to take advantage of each person's strengths.

But what must we build synergetically? We could agree today on what appear to be the best intervention practices and implement them in our respective environments. But would this guarantee success? For whom? Why? How? Building with synergy should be done in terms of a

common **Vision (V)**. More often than not, we act in the place of others rather than acting with them. Our vision of the future in intellectual disability is greatly influenced by the desire to promote the emergence of self-determination for these people by modifying their practical know-how, so that they can gain increasing control over their own lives. It is our job to agree on a common vision on which we can build with synergy. The Conference in which we will be participating is a decisive moment in our quest for achieving this vision.

Finally, Professor Schalock invites us to hang on to the right to **Dream (D)**. He reminds us that a dream which is not based on a vision is most often ephemeral, whereas a dream which results from a common vision generally works as a profound motivator, constantly guiding behaviour. Are not the principles of normalization, social role valorization, social, school and work integration and inclusion the result of dreams which led great people such as Bank-Mikkelsen, Nirje, Wolfensberger and others to invite us to share a vision of the world where persons with a disability are no longer excluded?

It is our job to build together a society where social participation, quality of life and self-determination are no longer only ideologies or theoretical models, but rather ways in which we can do things differently, a society where we *accompany* persons with an intellectual disability on the road to real social inclusion.

Yves Lachapelle

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