

Practical considerations for integral approach of people with intellectual disabilities

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Abstract

People with some disability have worse health prognosis due to biological complications, inadequate access to health services, higher economic expenses, and difficulties in the communication of sensations and perceptions. Therefore, therapeutic strategies and the knowledge generated through scientific research are useful to improve their quality of life. This review addresses the most relevant issues for professionals who are interested in this field, offering the most accepted definition with its implications up to the description of the conditions that should be considered when giving a treatment, conducting research, raising public policies, modifying the health schemes, and availability of supports, among others. For this, the different domains of intellectual capacity, as well as the affected biological systems, are presented to carry out practical actions and generate objective knowledge that enhances the quality of life of people with intellectual disabilities.

Key words: Intellectual disability. Health. Therapeutic. Approach.

Consideraciones prácticas para el abordaje integral de personas con discapacidad intelectual

Resumen

Las personas con discapacidad intelectual tienen un mal pronóstico de salud por las complicaciones biológicas, el acceso limitado a servicios de salud, mayores gastos económicos y dificultades en la comunicación de sensaciones y percepciones. Por ello, las estrategias terapéuticas, así como el conocimiento generado a través de investigaciones científicas, son determinantes para mejorar su calidad. La presente revisión aborda los temas más relevantes para profesionales que se interesan en este campo, ofreciendo la definición más aceptada con sus implicaciones hasta la descripción de las condiciones que deben considerarse al momento de dar un tratamiento, realizar investigaciones, plantear políticas públicas, modificar los esquemas de salud y disponibilidad de apoyos, entre otros. Para ello se presentan los diferentes dominios de la capacidad intelectual, así como los sistemas biológicos afectados, a fin de realizar acciones prácticas y generar conocimiento objetivo que mejore la calidad de las personas con discapacidad intelectual.

Palabras clave: Discapacidad intelectual. Salud. Tratamiento. Abordaje.

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Introduction

Disability is a condition that impacts both individually and collectively, in areas as diverse as health, economy, administration, and politics, due to the implications for both the individual and the family and society that surround it¹. People with disabilities tend to have the worst health scenarios and insufficient access to health-care services, with respect to the general population. They present high rates of health risks including physical inactivity, obesity, smoking, and inadequate emotional support. They also have a high prevalence of chronic conditions such as diabetes, high blood pressure, arthritis, chronic pain, and heart disease. The combination of these conditions makes persons with disabilities vulnerable to a continuous detriment in their functioning and quality of life, making this issue a matter of social interest².

The concept of disability is difficult to define since it has not been used consistently throughout history and can be approached from multiple perspectives, from strictly medical and rehabilitation to other social, educational, work, public health, or even moral. Thus, many concepts can fit in “disability”, such as those problems caused by the loss or abnormality of any body part, or limitations in their function, rehabilitation needs, and difficulties in carrying out usual activities in a specific social and temporal context. Other causes could be included, such as the restrictions on social participation, barriers in mobility or social integration, and problems in the development of social roles for physical or mental causes and in the assumption of responsibilities or in the self-management³.

At present, the most accepted definition of disability is from the American Association of Intellectual and Developmental Disabilities (AAIDD), termed as the expression of limitations in the functioning of the individual in a social context, which represents a substantial disadvantage and often has their origin in a health condition (disorder or disease). It can be stated that disability is a generic term that encompasses deficiencies, limitations in activity, and restrictions on participation. Furthermore, it expresses the negative aspects of the interaction between an individual with health problems and their physical and social environment⁴. In Mexico, according to the NOM-015-SSA3-2012 for comprehensive care for people with disabilities, it is defined as hearing, intellectual, neuromotor, or visual impairment, whether permanent or temporary, which limits the ability to perform one or more daily life activities (Fig. 1). For the present review, the one of interest is the intellectual

disability characterized by limitations in mental functioning and the adaptive behavior of the environment⁵.

Intellectual disability

During the past 200 years, the concept of intellectual disability has evolved from being imbecility to mental weakness, mental disability, and subnormality. At present, it is identified with the widespread use of the concept of “mental retardation” although it is being replaced by intellectual disability⁶. Over the years, numerous definitions of intellectual disability have been proposed, reviewed, and analyzed, due to it is a condition approached by professionals from diverse disciplines and, therefore, with very different perspectives. Medicine was one of the first professional areas that dealt with intellectual disability; consequently, the earlier definitions accentuated the biological or medical criteria. However, for other disciplines such as education or different therapies, these were not particularly useful. Besides, the culture also affected the way of interpreting disability. These observations led to the need to identify the universal aspects of disability considering the cultural and linguistic differences, integrating them in the development of a definition and classification of disability⁷.

Having a unified and international definition and classification of intellectual disability are useful for sharing and comparing information through epidemiological, sociological, or statistical studies. At present, it is a classification of health and health-related domains to describe changes in body function and structure, what a person with a health condition can do in a standard environment (their level of capacity), as well as what they do in their usual environment (their level of performance). Finally, health is the element that relates to the previous two.

Changes in the terminology used to define intellectual disability have a differential influence on society. The oldest definitions were based primarily on the concept of the degree of inherited intelligence, establishing criteria about how to measure intelligence and how to utilize the results to classify individuals with intellectual disabilities. Nowadays, the definitions try to change the way people think about intellectual disability. For this, it does not emphasize the disabilities of the individual, but the environment and the necessary support for their learning and for the person to improve the level of quality of life. The accepted definition of intellectual disability from the AADID states that “Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability



Figure 1. Definition and classification of disability according to NOM-015-SSA3-2012.

originates before the age of 18⁸. For the application of this definition, some assumptions must be considered:

1. Limitations on current functioning should be taken into account in the context of typical community environments of peers in age and culture.
2. A valid assessment considers cultural and linguistic diversity, as well as differences in communication and sensory, motor, and behavioral factors.
3. Within an individual, limitations often go hand in hand with strengths.
4. An essential purpose of describing the limitations is to develop a profile of the indispensable supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with an intellectual disability generally will improve.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines it in total agreement with the AADID, eliminating the use of the Mental retardation concept, providing the definition of the following domains to be considered for evaluation and above all to determine the levels of severity, and also decreasing reliance on the intelligence quotient (IQ) scores for the categories, as was done in the DSM-IV⁹:

1. Conceptual domain (academic): it includes the competence in memory, language, reading, writing, mathematical reasoning, and the acquisition of practical knowledge, among others.
2. Social domain: it implies the recognition of the thoughts, feelings and experience of others, empathy, interpersonal communication skills for friendship, and social criteria, among others.
3. Practical domain: it includes learning and autonomy in different areas of daily life, such as personal care, responsibility, and organization in school or work tasks, money management, leisure time and recreation, and self-control of their behaviors, among others.

The term intellectual disability, on others such as mental retardation, is better aligned with current professional practices that focus on functional behaviors and

contextual factors, provides a logical basis for the provision of individualized supports based on a social framework. It is less offensive to people with disabilities and is more consistent with international terminology. Some authors, under the influence of DSM-IV, still consider as part of the definition of intellectual disability a value equal to or < 70 referring to the intellectual coefficient, as a criterion for diagnosis, which indicates some limitations in intellectual functioning and adaptive behavior. Although intellectual disability exists independently in certain conditions, there are some that frequently present it, such as Down syndrome, Rett syndrome, X-fragile syndrome, autism spectrum disorder, Prader-Willi syndrome, Angelman, Williams syndrome, and inborn errors of metabolism. However, rather than causes of the condition, these conditions do not have a necessary link with the classification criteria and are present in the minority of people diagnosed¹⁰.

Epidemiology of disability

The United Nations Organization estimated that there are around 600 million people in the world with different types of disabilities, of which 400 million are in low-income countries and approximately 60 million in Latin America and the Caribbean. On the other hand, the World Health Organization and the Pan American Health Organization (WHO/PAHO) estimates that 6-10% of the general population is people with disabilities. However, the disability affects not only the person but also the family and the community, involving approximately 25% of the total population¹¹. Regarding intellectual disability, in particular, it is considered frequent, with an approximate prevalence of 1-4% and a high impact on individual functioning. In Latin America, the prevalence can be 4 times higher due to its association with factors such as malnutrition, obstetric and perinatal complications, prematurity, lead poisoning, and infections of the central nervous system¹².

The official reports on disability in Mexico come exclusively from the Population and Housing Census, which does not represent a diagnostic measurement but provide data. The 2010 census included an expanded questionnaire that reports to the population that presents some disability, seen this from the focus of limitations in the activity¹³. That is, people with some restriction to attend to personal care, walk and move, listen, talk or communicate, pay attention, see, or with some mental limitation, were counted. Depending on this report, disability reached 5.1% of the total population, that is, around 5,739,270 Mexicans. However, this registry includes many other conditions, which do not allow observing a specific figure of intellectual disability. However, as a public health issue, the underestimation of intellectual disability in Mexico is emphasized. Epidemiological research and not only general census data would confirm the existence of up to 4 million people with intellectual disabilities in Mexico, assuming a prevalence similar to the universal one of 1-4%.

Classification of intellectual disability

Intellectual disability is a heterogeneous condition, so it is essential to evaluate the difficulties and strengths of functioning in each to propose an appropriate therapeutic plan. For this reason, it is important to diagnose it, considering an integral evaluation of the intellectual coefficient and the adaptive level, as well as the evaluation of the functioning of the people who suffer it. For this, it is necessary taking into account not only their health condition (disorder or illness) but also their functions and body structures, their activities and participation in the community, without forgetting their context.

The classification of intellectual disability is a difficult task, which may vary according to the aspect evaluated and the interests of the classification (Table 1). Educators use different terms to designate to the various levels of intellectual disability. For many years, students with intellectual disabilities were classified as educable mentally retarded (EMR) or trainable mentally retarded (TMR), referring to the levels of mild and moderate intellectual disability, respectively. This system did not consider children with severe and profound intellectual disabilities because they were often excluded from public education. Even though at present it is still possible to find the EMR and TMR classifications, most educators consider them inappropriate due to suggest the existence of predetermined limits of intellectual functioning.

Conventionally, IQ scores have been the primary criterion for classifying people with intellectual disabilities as mild, moderate, severe, and profound severity rating.

However, the score of upper and lower limits of each level is set according to the test used, which indicates the lack of accuracy of the intelligence assessments and the importance of the clinical judgment to determine the level of severity. Overtime, the weight of IQ scores has been reduced thanks to the development of other dimensions that show importance in the interaction of people and their environments such as adaptive behaviors and the context of social roles. The classification according to the need for support focuses on the needs of people, with the aim of providing strategies for intervention. The aspects that must be taken into account to classify an individual according to their need for support are the intellectual capacity, adaptive behavior, participation, health, interaction, and social roles. At present, disability, in general, is classified according to the framework given by the International Classification of Functioning, Disability and Health, commonly known as ICF, developed by the WHO to measure the health and disability of the individual. It classifies human functioning considering some components: (1) body functions, referring to the physiological functions of body systems, (2) body structures, anatomical parts of the body such as organs, limbs, and their components, (3) activities and participation, where activity is the execution of a task or action by an individual and participation is involvement in a life situation, and (4) environmental factors that make up the physical, social, and attitudinal environment in which people live and conduct their lives¹⁴.

Problems in health and health care

People with intellectual disabilities form a heterogeneous population, with different functional levels and needs. Most experiment a stressing time when visiting the health service, due to the difficulties in communicating and correctly processing large amounts of information and technical vocabulary from the health personnel. They may have trouble giving temporary referrals, such as when they feel unwell or when was their last medical visit. They also have problems in expressing “correctly” when they go through states of discomfort or pain and could show it in the form of less adapted behaviors such as screaming, aggression, self-aggression, and hyperactivity, among others. Some people have difficulty processing sound, visual, and even tactile stimuli, being a challenge for them to tolerate situations in which the environment presents a large number of stimuli. For these reasons, it is necessary for health professionals to facilitate collaboration during the therapeutic visit, considering the difficulties that may arise and generate negative behavior¹⁶.

Table 1. Categories used for the classification of intellectual disability

Categories of classification	Description
By etiology	Prenatal causes: <ul style="list-style-type: none"> – Chromosomal alterations – Inborn errors of metabolism – Alterations of brain development Perinatal causes: <ul style="list-style-type: none"> – Intrauterine disorders – Neonatal disorders Postnatal causes: <ul style="list-style-type: none"> – Cranial trauma – Infections – Degenerative disorders – Seizure disorders – Toxic-metabolic disorders – Malnutrition – Lack of social environment
By intellectual capacity	Interpretation according to the IQ score obtained in the Wechsler tests: <ul style="list-style-type: none"> > 130: very superior 120-129: superior 110-119: high average 90-109: average 80-89: low average 70-79: borderline < 69: extremely low
According to the need for educational support	<ul style="list-style-type: none"> – Borderline intellectual disability: they show a delay in learning or some concrete learning difficulties. Many children from a disadvantaged socio-cultural environment could be included – Mild intellectual disability: it is the majority group, not clearly deficient. They have greater difficulty with subjects such as reading, writing, and mathematics. Minimal delay in areas in perceptual and motor areas but can develop social and communication skills – Moderate intellectual disability: most show a significant developmental delay during preschool age. When they grow up, the differences in intellectual, social, and general motor development that separates these children from those without disabilities often increase. They present an acceptable motor development and can acquire basic pre-technological skills to perform some work – Severe intellectual disability: in this category, people generally need protection or help, since their level of autonomy, both social and personal, is very poor. They usually present a significant psychomotor impairment. They can learn some communication system, but their oral language will always be very poor and their comprehension very limited. Autonomy in displacement, cleanliness, feeding, and other personal care activities is hardly achieved – Profound intellectual disability: they present a serious deterioration in the sensory-motor and communication aspects. Personal autonomy is seriously affected to the degree of not being able to take care of their physical needs, partially or totally lacking independent mobility, or requiring specialized care 24 h a day
For support needs	<ul style="list-style-type: none"> – Intermittent: support in “the occasions that are necessary,” characterized by its episodic short-term nature (for example, supports necessary in lifetime transitions such as loss of work or acute medical crises) – Limited: characterized by consistency overtime, time constraint, but not of an intermittent nature, requires fewer support members and less costs than more intense levels of support (e.g., support for transport) – Extended: characterized by performing in some environments (school, work, and home) and has no time limit (long-term support and life in the home) – Total: high intensity characterized by its permanence and nature of life support, usually requires more support members

IQ: intelligence quotient.

(Adapted from Muñoz-Quesada, et al., 2017)¹⁵.

People with intellectual disabilities have a different profile of health need and higher rates of mortality and morbidity, as well as an increase in the use of health services. Higher rates of prevalence and risk have been found for important diseases such as epilepsy, diabetes, chronic constipation, human immunodeficiency virus, sexually transmitted diseases, gastrointestinal reflux, dementia, gastrointestinal cancer, thyroid disease, osteoporosis, allergies, cerebral palsy,

different genetic syndromes, and genitourinary system diseases, among others¹⁷. The mental health problems and challenging behaviors that these people show, make them one of the most medicated groups in society¹⁸.

People with intellectual disabilities have, for various reasons, more risk of presenting medical pathologies compared to people without disabilities (Table 2). This fact is related to different factors such as styles and

Table 2. Principal health problems in people with intellectual disabilities and general recommendations

Affected system	Principal problems	Recommendation for health area staff
Respiratory diseases	Pneumonia aspirative	Attention in textures and food consistency in people with severe and profound intellectual disabilities
Cardiovascular diseases	Aortic insufficiency Mitral insufficiency	Prevention of risk factors such as obesity, sedentary lifestyle, high blood pressure, and dyslipidemias
Digestive diseases	Constipation	Promotion of mobility and right hydration with a complete and high-fiber diet
Infectious diseases	Pneumonia Endocarditis Urinary tract infection	Correct washing of hands Consider immune deficits
Genitourinary diseases	Testicular neoplasia in men with severe intellectual disability	General examination of genitalia periodically
Obstetric and gynecological diseases	Dysmenorrhea, menorrhagia, and amenorrhea	Pay special attention to hygiene problems associated with menstruation
Neurological diseases	Epilepsia	Need to use more than one drug for the control of the crisis considering side effects (constipation, gingival hypertrophy, and excessive sedation) and drug interactions with other treatments
Sensory problems	Vision and hearing problems	Revision of auditory ducts
Endocrine diseases	Diabetes <i>mellitus</i> Hypothyroidism	Modify lifestyles such as avoiding inappropriate diets, to prevent obesity and consider the influence of certain psychotropic drugs such as some atypical antipsychotics Have control over the treatment of lithium salts
Oncological diseases	Gastrointestinal neoplasia (esophagus, stomach, and bile ducts)	Avoid high-fat diets and decrease other risk factors such as gastroesophageal reflux and constipation with correct eating habits
Bucodental diseases	Loss of teeth Gingival pathology Malocclusion problems	Correct dental hygiene Dental treatments with fluoride regularly

living conditions (obesity, restricted diets, smoking, and sedentary lifestyle) that predispose them to suffer specific pathologies. Due to abnormalities in brain structure and functioning, people with intellectual disabilities suffer epilepsy more frequently. Finally, certain genetic disorders involve anomalies in the functioning of some organs or systems, either congenitally or over the years.

Respiratory diseases

They represent one of the leading causes of death in people with intellectual disabilities, although many of them can be prevented with primary care. One of the primary respiratory pathologies is pneumonia, very prevalent in the segment of people with severe intellectual disability and those with associated physical problems. In all these cases are frequent feeding problems mainly dysphagia, which leads to a risk of aspiration pneumonia, secondary to choking.

Cardiovascular diseases

Most people with intellectual disabilities suffer from congenital heart diseases (coarctation of the aorta, ventricular, or atrial septal defects) that can be diagnosed at birth or remain asymptomatic until adulthood. Many of these congenital diseases are usually associated with genetic syndromes, the most common being Down syndrome, Turner syndrome or Williams syndrome, and Di George syndrome. However, they can also present non-congenital heart diseases attributable to the presence of other risk factors such as obesity, high blood pressure, and a sedentary lifestyle, prevalent in people with intellectual disabilities.

Digestive diseases

Gastroesophageal reflux affects approximately half of the population with intellectual disability, mainly the

severe type, frail X syndrome, and those who suffer severe scoliosis. Although gastroesophageal reflux is easily treated, the main problem is the difficulty of diagnosis due to the difficulties for explaining the symptoms. Gastroesophageal reflux should be suspected in those who have negative attitudes about food intake, discomfort after eating, self-injurious behavior, cough at bedtime, tooth erosion, iron deficiency anemia, or weight loss. Constipation is also a very prevalent pathology in people with intellectual disabilities (especially for those with severe disabilities), attributable to immobility, hydration deficits, a restricted or low-fiber diet, and anticonvulsant medications¹⁶.

Overweight and obesity

One of the foremost public health concerns of the 21st century is the obesity. 70% of obese adolescents remain obese adults with physiological, psychological, and social consequences¹⁹. Obesity is associated with a higher incidence of health problems in people with intellectual disabilities, including decreased social, physical, and quality functioning of life, difficulty in establishing relationships and stigma and discrimination between young people with and without disabilities²⁰. Obesity in people with intellectual disabilities is one of the many characteristics used to measure inequality in health compared to the general population. It is likely that obesity contributes to increasing disparities, that is, high rates of mortality and undetected health need¹⁹. In addition to this, people with intellectual disabilities who are obese have an increased risk of diabetes, a situation that it can be exacerbated by the consumption of certain psychotropic drugs, especially some atypical antipsychotics.

Infectious diseases

Infectious diseases in people with intellectual disabilities are more prevalent mainly due to behaviors that may be frequent such as incorrect hand washing or taking things to the mouth, as well as some residential environments and immune deficits characteristic of certain hereditary diseases. Communication difficulties impact whether the diagnosis of infections is delayed or not diagnosed, worsening the prognosis, and increasing the risk of mortality. Examples of frequently underdiagnosed infections in people with intellectual disabilities are pneumonia and endocarditis. In hospital and residential contexts, it is advisable to pay attention to the prevention of infectious pathology through hygienic norms and vaccination, as well as the establishment of

protocols for rapid action against possible contagious outbreaks.

Genitourinary diseases

A higher incidence of prostate and urinary tract cancer has been reported in men with intellectual disability compared to those who do not possess this condition. Furthermore, higher rates of testicular neoplasms have been observed in men with severe intellectual disability, probably due to the more significant presence of genetic alterations in germ cells. For women with intellectual disability problems of dysmenorrhea, menorrhagia, and amenorrhea should be considered, as well as pay particular attention to the hygiene problems associated with menstruation. When it comes to behavior problems in menstruating women, it should always be kept in mind that in the premenstrual stage or during the days of menstruation, discomfort or pain can be associated with self-aggressive or heteroaggressive behaviors (mainly in people with communication difficulties or severe intellectual disabilities). The incidence of cervical cancer in women with intellectual disabilities is very low (mostly in institutionalized settings). However, given that women with intellectual disabilities are increasingly likely to be active on a sexual level, the relevance of screening for cervical cancer in those considered necessary according to their sexual habits should be considered¹⁶.

Neurological diseases

Epilepsy is a neurological condition, particularly common in people with intellectual disabilities. For this population, prevalence rates range between 20 and 30%, increasing with the severity of the intellectual disability²¹. Studies suggest that approximately one in five people with intellectual disabilities will have epilepsy except for people with Down syndrome in whom the rate is lower with about one in 10 people in adulthood²².

Sensory problems

The hearing and vision problems in people with intellectual disabilities are often underdiagnosed, mainly due to the difficulties to realize and express them and the problems of making a careful assessment. These deficits will mean for people with intellectual disabilities a decrease in communication skills and a significant worsening in their quality of life. Ear problems are poorly diagnosed and poorly treated. It must be remembered that a frequent cause of hearing loss is impaction of earplugs in the ear canals¹⁶.

Oral problems

The dental treatment is contraindicated in conditions of little cooperation of the patient or parents because it is difficult to obtain a positive result; besides, iatrogenesis in the event of caries and gingival inflammation is likely. Therefore, oral hygiene is the crucial factor that determines whether or not to perform the treatment because the minimal manual ability, accompanied by poor muscle activity, can be very harmful to the patient. Other common obstacles are typical behavior, excessive limb movement, low level of cooperation, and altered nausea reflex. All these affect negatively, from the taking of X-rays and impressions for appliances to the treatment itself. Reports on the oral health of people with intellectual disabilities have identified problems such as poor oral hygiene, untreated caries, and a high prevalence of periodontal disease. In addition to worse overall health, people with intellectual disabilities experience more difficulties in obtaining dental care than people in the general population, with a significant proportion of teeth extracted and a higher prevalence of traumatic dental injuries. A good promotion of oral health can reduce the burden of diseases such as dental caries, gingivitis, and periodontal disease that is among the highest secondary conditions in people with intellectual disabilities that cause limitations in their daily activities. The oral health of these people in many cases depends on a large extent on the knowledge, attitudes, and practices of their family members or care providers. Motor impairments are a limiting factor for access to treatments²³.

Conclusions

The approach to intellectual disability, whether to define a therapeutic strategy or design a research protocol, is a multifaceted process. This complexity can be observed in the moment of determining operationally the intellectual disability, as well as the variability of concomitant conditions that can affect the outcome of an intervention. The health area staff should consider the possible involvement of numerous systems; the therapist, the diversity of behavior; and the researcher, the potential variables that may influence their object of study. However, with adequate strategies and designs, the health professionals involved in the approach of people with intellectual disabilities will be able to generate knowledge, in such a way that substantial improvements in the quality of life of this group will be achieved shortly.

Conflicts of interest

The authors declare that in this study, there are no relevant conflicts of interest.

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