

# Caring of intellectual disable child improves the quality of life: Front-side perspective

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## ABSTRACT

Intellectual disability (ID), also known as mental retardation, is a generalized neurodevelopmental disorder characterized by significant limitations in both intellectual and adaptive functioning. This disability originates before the age of 18 years. It is defined by an intelligence quotient under 70, in addition to deficits in two or more adaptive behaviors that affect everyday, general living. This not only affects the individual having ID but also the family and society as a group. ID affects about 2–3% of the general population. Quality of life (QOL) of primary caregiver is affected which depends on the severity of the disability of the child, presence of cognitive or behavioral problems, socioeconomic status of the families, lack of education, low social support, etc. There are various factors responsible for causing ID such as genetic and environmental that impairs the brain function in such individuals. There may be the physical, social, and economical burden in raising these children due to their less ability to learn new things. These individuals are less able to grasp abstract, concepts, and learning various things. These intellectual and adaptive behaviors can be improved with the help of various supportive measures and with the help of family’s support and also from doctors, nurses, psychiatrists, and help from other agencies, for example, social workers, psychologists are also must. These individuals should be treated kindly to improve their QOL.

**Keywords:** Intellectual disable child, mental retardation, quality of life

## Introduction

Raising a child in today’s world is a challenge, especially when the child is intellectual disability (ID). Three to seven children/1000 are born with ID.<sup>[1]</sup> In developing countries, 10–15% of people are affected with disabilities,<sup>[2]</sup> from which, 1–3% suffer from ID. ID refers to individuals with an intelligence quotient of <70 with impaired adaptive functions that have been occurred before the age of 18 years.<sup>[3]</sup> ID, once called mental retardation (MR), is characterized by below-average intelligence or mental ability and a lack of skills necessary for day-to-day living. People with ID can and do learn new skills, but they learn them more slowly. There are varying degrees of ID, from mild to profound.<sup>[4]</sup>

These progressive infirmities are characterized by limitations in socioadaptive functioning and intellectual abilities. To improve, these individuals also require special long-term or life-long interdisciplinary

or generic care, treatment, or other services to be individually planned or coordinated.<sup>[5,6]</sup> Children’s disabilities and distresses may burden their family members, especially their parents, who are their long-term caregivers affecting their quality of life (QOL).<sup>[7]</sup> QOL as defined by the World Health Organization is an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns.<sup>[8]</sup>

Managing of children disabilities depends on various factors such as personal characteristics, lifestyle type, remaining abilities, cooperation of family members, and the role of rehabilitation team.<sup>[9]</sup> QOL is not equally affected in parents or caregivers of the intellectually disable children. However, the various studies have shown that parents of children with various developmental disabilities experience heightened stress, overburden, and marginalization in society sense of self-blame, tiredness, or exhaustion commenting that little attention has been given to the health outcomes of caregivers of developmental disabilities. Talley and crews identify caregiving as an issue that must be considered in the context of health (physical and psychological) that varies across the lifespan according to the characteristics and developmental levels of both caregivers and care recipients.<sup>[10]</sup>

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## Epidemiology

ID affects about 1% of the population and of those about 85% have mild ID. Males are more likely than females to be diagnosed with ID.<sup>[11]</sup>

India has a prevalence of 10.5/1000 in ID. Urban population has slightly higher rate (11/1000) than rural (10.8/1000;  $P = 0.044$ ). Age was found to be highly correlated with the prevalence of ID in rural children ( $Q = 98$ ,  $P = 0.019$ ) as well as in children ( $Q = -0.954$ ,  $P = 0.0000$ ) and adults ( $Q = -0.957$ ,  $P = 0.000$ ) in urban population. The possibility of confounding or the existence of covariates for children in urban setting was noted.<sup>[12]</sup>

## Causes of ID

The causes for the ID can be any condition that impairs the development of the brain prenatally, perinatally, or postnatally. The cause of IDs is a difficult process to determine. There may be multiple of reasons responsible for individual's IDs and frequently the cause is unknown. Factually, in about half of all cases of IDs a specific cause can be cited.<sup>[13]</sup> The causes can be divided into three groups: Organic, genetic, and sociocultural. There is a greater probability that a particular cause cannot be determined if the retardation is less severe.

## Classification of ID

The ID can be classified according to the level of their severity as shown in Table 1.<sup>[14]</sup>

The ID can also be classified according to the four levels of support as shown in Table 2.

## Clinical Symptoms

### Speech

Individual with ID usually may have delayed speech and difficulties in speaking and expressing themselves. The degree of severity varies with

**Table 1: Classification of intellectual disability**

Grade	Intelligence quotient
Mild	50–70
Moderate	35–50
Severe	20–35
Profound	<20

**Table 2: Classification based on needed support**

Support level	Description with examples
Intermittent	Supports are provided on an "as-needed basis." These supports may be episodic, that is, the person does not always need assistance, or short-term, occurring during lifespan transitions (e.g., job loss or acute medical crisis). Intermittent supports may be of high or low intensity
Limited	Supports are characterized by consistency; the time required may be limited, but the need is not intermittent. Fewer staff may be required, and costs may be lower than those associated with more intensive levels of support (examples include time-limited employment training and supports during transition from school to adulthood)
Extensive	Supports are characterized by regular involvement (e.g., daily) in at least some environments, such as work or home; supports are not time limited (e.g., long-term job and home living support will be necessary)
Pervasive	Supports must be constant and of high intensity. They have to be provided across multiple environments and may be life sustaining in nature. Pervasive supports typically involve more staff and are more intrusive than extensive or time-limited supports

Source: Adapted from mental retardation: Definition, classification, and systems of supports, 10<sup>th</sup> ed.. (Washington, DC: American Association on Mental Retardation, 2002). p. 152

the level of impairment of ID, the milder the ID, the less pervasive the language difficulty.<sup>[15]</sup>

## Learning and memory

Individual with ID has difficulties in learning and memory. However, these strategies can be taught and improved.<sup>[16,17]</sup> These cognitive complications related to the severity of ID.

## Movement and behavior

There is a lack of coordination, meaningless, and stereotyped movement in individuals with ID. The severity of the ID is related to the extent of physical differences for the individual.<sup>[18,19]</sup>

## Health problems associated with ID

Individual with ID is at higher risk of having health problems such as epilepsy, cerebral palsy, anxiety disorders, and autistic disorder.<sup>[20]</sup>

## Perception

The reaction and perception of environmental stimuli is slow in individual with ID. They have difficulties distinguishing small differences in the shape, size, and color.

## Diagnosis

The parent's concern and observation about their child should be listened carefully that will help in their developmental screening tests. Medical, genetic, and environmental risk factors should be recognized. The diagnosis can be done through the use of standardized tests of intelligence and adaptive behavior. The three basic criteria should be met for a diagnosis of ID (or MR) according to both the DSM and ICD:

- Significantly sub-average intellectual functioning (IQ of 70 or below), the IQ test could be done through the Bayley Scales of Infant Development (III) and Wechsler scales
- Concurrent deficits or impairments in adaptive functioning in at least two of the following areas: Communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. These parameters could be assessed through Vineland Adaptive Behavior Scale (ABS), Woodcock-Johnson Scales of Independent Behavior – Revised, the American Association on Intellectual and Developmental Disability (ABS-

2nd edition), and the Adaptive Behavior Assessment System (2nd edition)

- Onset is before age 18 years.<sup>[21,22]</sup>

### Prevention

The preventive measure which could be done to avoid ID:

- Public's awareness should be increased regarding the adverse effects of alcohol and other drugs of abuse on the fetus
- Promoting early prenatal care and preventive measures taken before and during pregnancy prevents ID
- Encouraging the use of child safety seats and bicycle helmets reduce traumatic injury
- Avoidable injuries in the home; using appropriate seat restraints when driving and wearing a safety helmet
- Removing lead from the environment reduces brain damage in children. Preventing poisonings by teaching parents about locking up medications and potential poisons
- To reduce the risk of ID caused by encephalitis, meningitis, and congenital infection immunization programs should be implemented.

### Treatment and Management of the ID

Although ID is not treatable, it can be managed through various interventions. The early detection and early intervention can help in minimizing the symptoms and disability through reducing risk so that the individuals feel safe at home or school, teaching life skills, improve life quality, and support families and carers. Usually through screening, if the cause is detected, etiological treatment should be administered.<sup>[23,24]</sup>

As there is wide range of problems such as aggression, self injury, non-compliance, idiosyncratic habits, and socially inappropriate behavior associated with Intellectually disable individuals which interfere their daily life reducing their QOL and survival. These can be minimized and managed through medical help, support from the family, and, in more severe cases, institutionalization.<sup>[25]</sup>

The medication should optimally be used for behavioral management after a comprehensive assessment. Medication is often used<sup>[26]</sup> in the treatment of people with ID. Involvement of the family is very essential. Individual with ID generally has more medical problems and is more sensitive to the side effects of drugs. Therefore, it is prudent to start with a very low dose and gradually increase it according to response and side effects. The use of medications in this group is largely based on clinical experience rather than trial data. The antipsychotics, antidepressants, mood stabilizers, and other psychotropic medications can be used for the individuals with ID with precautions.<sup>[27]</sup>

### Education

Individuals with ID are less efficient in learning in general, but they must attend school. This will improve not only their academic skills but also self-discipline, social, and practical skills for community living.<sup>[28]</sup>

### Conclusion

Individual with ID needs encouragement and support to overcome the probable hurdles which affect their day-to-day life. ID is characterized by significant impairment in cognitive and adaptive behavior which needs family support to improve and various techniques and management programs. This review gives general details regarding the ID and measures to improve them.

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