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### RESEARCH ARTICLE

#### PEOPLE WITH INTELLECTUAL DISABILITIES-AN APPROACH TOWARDS MANAGEMENT ISSUES

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#### Abstract

Intellectual disability (ID), formerly known as mental retardation is a disability of intellectual functioning and adaptive behavior that arises during the period of time from conception to the beginning of adulthood. With ID, the individual has significant limitations in both intellectual ability and adaptive behavior, which are manifest before the age of 18. People with intellectual disability have varying degrees of impairment, classified from mild to profound. Every person who has intellectual disability is a unique individual and as such they face many barriers when it comes to school, relationships, and daily living. Supporting individuals in need of Mental Health Care and fostering a relationship with them are ways to embrace diversity in communities.

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#### Introduction:-

Intellectual disability is the most common developmental disability. Intellectual disability (or ID) is a term used when a person has certain limitations in cognitive functioning and skills, including conceptual, social and practical skills, such as language, social and self-care skills.<sup>1</sup> According to AAIDD, 2010, Intellectual Disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18. Previously the definition of ID was only focused on individual's impairment on Cognitive ability. Now it includes impairment in both Cognitive functioning and Functional skills in their everyday life (Adaptive skills). (Chavan &Rozatkar, 2016)<sup>2,3</sup>

Intellectual disability is significantly more common in low-income countries—16.41 in every 1,000 people. About 85% of the affected people have a mild intellectual disability.<sup>4,5</sup> Incidence is challenging to accurately calculate as mild disabilities may be under-recognized until later in childhood. Intellectual disability is reported to peak at the ages of 10 to 14 years and is 1.5 times more prevalent in males than females.<sup>6</sup> Prevalence studies may not identify all people with intellectual disabilities. Many school age children receive a diagnosis of learning disability, developmental delay, behavior disorder, or autism instead of intellectual disability.<sup>7,8</sup> Approximately 1 – 3 percent of the global population has an intellectual disability—as many as 200 million people Non-syndromic or idiopathic ID accounts for 30–50% of cases. About a quarter of cases are caused by a genetic disorder.<sup>9</sup>

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### Psychological Classification of Intellectual Disability

People with intellectual disability have varying degrees of impairment, classified from mild to profound. At one point, IQ was more heavily relied upon when diagnosing an intellectual disability and determining its severity. While the **DSM-5** still recognizes these categories, more emphasis is placed on the skills associated with each level rather than their IQ<sup>10, 11</sup>

- **Mild:** Those with a mild intellectual disability may have an IQ between 50-70. Eighty-five percent of intellectually disabled people are at this level, and they can often live on their own with minimum support from others.
- **Moderate:** The IQ for a moderate intellectual disability can range from 36-49. Those with a moderate intellectual disability make up roughly 10% of cases on this spectrum. These individuals may need more support in day-to-day life and may live in a group home.
- **Severe:** Making up about 3.5% of those with intellectual disabilities, these individuals may fall into the 20-35 IQ range. They typically need daily supervision to keep them healthy and safe and may need help with basic self-care tasks.
- **Profound:** Individuals with a profound intellectual disability may have an IQ under 20 and make up only 1.5% of intellectual disability cases. They may need constant care and supervision to meet their basic needs.

### How Does Intellectual Disability Happen?

In the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth edition text revision (DSM-5-TR), the formal name for this condition is "intellectual developmental disorder." Although for many individuals, the exact cause of their intellectual disability is unknown, many cases of intellectual disability happen because of differences in brain development. Less commonly, they can develop because of brain damage from an illness, injury or other events when a person is younger than 18 years old.<sup>12, 13</sup>

Experts suspect that in many cases, there are multiple causes and contributory factors that can influence the development of intellectual disability before or during birth and during the earliest years of childhood.<sup>14</sup>

A cohort study conducted on the etiological factors of intellectually disabled children in Anhui Province, China. It was found that various perinatal factors (premature birth, asphyxia, ischemic hypoxic encephalopathy, etc.), severe cerebral palsy, and psychosocial factors were the main etiological factors, accounting for 27.42%, 22.29%, and 17.16% respectively.<sup>15</sup>

A research study conducted towards an etiological approach over the past two decades, mental retardation research converges on three general themes: co-occurring mental retardation and psychopathology; families of offspring with mental retardation; and the developmental approach regarding behavioral sequences and profiles.<sup>16</sup>

### Common Sign & Symptoms

Intellectual disability (ID) becomes apparent during childhood and involves deficits in mental abilities, social skills, and core activities of daily living (ADLs) when compared to same-aged peers.<sup>17</sup> There often are no physical signs of mild forms of ID, although there may be characteristic physical traits when it is associated with a genetic disorder (e.g., Down syndrome). Some of the early signs can include<sup>18</sup>

1. Delays in reaching, or failure to achieve milestones in motor skills development (sitting, crawling, walking)
2. Slowness learning to talk, or continued difficulties with speech and language skills after starting to talk
3. Difficulty with self-help and self-care skills (e.g., getting dressed, washing, and feeding themselves)
4. Poor planning or problem-solving abilities
5. Behavioral and social problems<sup>19</sup>
6. Failure to grow intellectually, or continued infant childlike behavior
7. Problems keeping up in school
8. Failure to adapt or adjust to new situations
9. Difficulty understanding and following social rules<sup>17</sup>

## **Models of Intellectual Disability**

### **Medical Model of Disability**

The medical model of disability is presented as viewing disability as a problem of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care provided in the form of individual treatment by professionals.<sup>20,21</sup>

### **Social Model of Disability**

In this model, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. From this perspective, equal access for someone with an impairment/disability is a human rights issue of major concern.<sup>20,21</sup>

### **Moral Model of Disability**

The moral model of disability refers to the attitude that people are morally responsible for their own disability. For example, the disability may be seen as a result of bad actions of parents if congenital, or as a result of practicing witchcraft if not.<sup>20</sup>

### **Economic Model of Disability**

The economic model of disability defines disability by a person's inability to participate in work.

It also assesses the degree to which impairment affects an individual's productivity and the economic consequences for the individual, employer and the state.<sup>20</sup>

### **Empowering Model of Disability**

The empowering model of disability allows for the person with a disability and his/her family to decide the course of their treatment and what services they wish to benefit from. In other words, this model "empowers" the individual to pursue his/her own goals.<sup>20</sup>

## **Problems faced in the Workplace**

Every person who has intellectual disability is a unique individual and as such they are going to face many barriers when it comes to school, relationships, and daily living. Some common difficulties include<sup>22,23</sup>

1. Unemployment is a major issue that many adults with Autism spectrum Disorder and similar intellectual challenges face. Intellectual challenges make it difficult for such individuals to succeed in a traditional workplace environment.
2. Most people associate work with productivity and various social situations. For individuals with intellectual challenges, this can be especially overwhelming or stressful.
3. Assistive technology like visual or electronic aids can help people with keep track of tasks. Some organizations also provide resources to help their residents maintain employment.
4. Requires special teaching and training to be able to learn
5. Needs support to solve everyday problems
6. Inability to establish interpersonal relationships
7. Difficulties functioning on a daily basis
8. Not being able to live on their own
9. Suicidal thoughts and behaviors

## **How to Diagnose an Intellectual Disability**

Intellectual disability is identified by problems in both intellectual and adaptive functioning.

- **Intellectual functioning** is measured with individually administered and psychometrically valid, comprehensive, culturally appropriate, psychometrically sound tests of intelligence. While a specific full-scale IQ test score is no longer required for diagnosis, standardized testing is used as part of diagnosing the condition. A full-scale IQ score of around 70 to 75 indicates a significant limitation in intellectual functioning.<sup>24</sup>
- **Three areas of adaptive functioning are considered:**<sup>25,26</sup>
  1. **Conceptual** – language, reading, writing, math, reasoning, knowledge, memory.
  2. **Social** – empathy, social judgment, communication skills, the ability to follow rules and the ability to make and keep friendships.
  3. **Practical** – independence in areas such as personal care, job responsibilities, managing money, recreation, and organizing school and work tasks.

Some research shows that about 20-35% of people who have an intellectual disability are also likely to develop other mental health conditions like anxiety or depression. In determining your child's diagnosis, several tests might be ordered by your healthcare provider and the team of specialists taking care of your child. These tests include<sup>27</sup>

1. Neurological tests such as an electroencephalogram (EEG) or magnetic resonance imaging (MRI) to determine if there are any abnormalities in the brain
2. Genetic tests to help identify if there is an inherited disorder like Fragile X syndrome that could cause intellectual disability
3. General medical tests depending on the symptoms your child is exhibiting
4. Special education tests
5. Developmental screening tests to determine your child's level of intellectual and social functioning
6. Prenatal screening to determine if there are any developmental challenges while a parent is still pregnant
7. A hearing evaluation in case a hearing problem is responsible for the impaired intellectual functioning and not an intellectual disability.

A study conducted on Identification of the underlying cause of intellectual disability (ID) is important as it improves genetic counseling, management, adaptation; yet its etiologic heterogeneity is challenging and often leads to an expensive work-up. To improve this diagnostic trajectory, the multidisciplinary Complex Diagnostic Clinic (CDC) was established for ID patients. The diagnostic yield of the CDC was higher than expected with confirmed and working diagnoses in 11 (46%) and 9 (38%) children respectively.<sup>28</sup>

## Management

### Models of Intellectual Disability Nursing: The 6Ps<sup>29</sup>

1. Intellectual disability nursing is perceived to be the **purist** form of nursing, supporting people with disabilities and their families from the cradle to the grave (Gates, Ferns & Welch, 2015)
2. It involves nurses working in **partnership** with people with intellectual disabilities and their significant others to ensure that their significant others to ensure that their needs are met.
3. **Planning** focuses on person centered approaches, working in partnership with other professionals, identifying individual strengths and the most appropriate strategies to achieve the best possible outcomes.
4. It could be argued that to be **professional** in this area of work we need **passion**, we certainly need knowledge and, we can often be extraordinary.
5. This model will look at our **purpose** as intellectual disability nurses and some of the nursing models used across the world.

### Community Participation and Support for People with Intellectual Disability

1. Community participation is a central theme in policies seeking to create a better life for people with intellectual disabilities. In Australia, the landmark 1986 Australian Disability Services Act aimed to support people with disability to live "as valued and participating members of the community."<sup>30,31</sup>
2. Supporting individuals in need of Mental Health Care and fostering a relationship with them are ways to embrace diversity in communities. It is also providing access to basic support such as equity education, employment, healthcare, habilitation services, adaptive aids, peer support across the individual's lifespan.<sup>32</sup>

### AAIDD recommends four levels of support that the individual requires functioning in the natural settings of home and community<sup>33</sup>

1. 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).
2. 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.
3. 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).
4. 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.

**Robert's 7 Point Plan<sup>34</sup>**

Robert Strike is a leading advocate for people with intellectual disability in NSW, and has years of experience in the community sector working to improve the lives of members of the community.

1. Look beyond the disability label - you will be surprised. Labels are for jars not people!
2. Talk to us, NOT at us or through others.
3. Hearing is not enough. Listen to us and respect what we say.
4. Do things with us, NOT for us.
5. Explain things slowly and get straight to the point.
6. Talk to us face to face.
7. Be honest with us...we have antennas for bullshit!!

**Tips for Parents and Caregivers<sup>35</sup>**

1. Ask for help; learn about your child's disability.
2. Connect with other parents of children with disabilities.
3. Be patient; learning may come slower for your child.
4. Encourage independence and responsibility.
5. Educate yourself on the educational services your child deserves.
6. Learn the laws that are written to help your child live their best life.
7. Look for opportunities in your community for social, recreational and sports activities (such as Best Buddies or Special Olympics).

**References:-**

1. American Association of Intellectual and Developmental Disabilities; National Center on Birth Defects and Developmental Disabilities; the United Nations Development Program; and the Centers for Disease Control and Prevention
2. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
3. [http://www.wbnsou.ac.in/online\\_services/SLM/MED/B8\\_ID.pdf](http://www.wbnsou.ac.in/online_services/SLM/MED/B8_ID.pdf)
4. [https://www.idrs.org.au/pdf/IDRS\\_%20Introduction\\_intellectual%20disability\\_17Feb09.pdf](https://www.idrs.org.au/pdf/IDRS_%20Introduction_intellectual%20disability_17Feb09.pdf)
5. <https://www.specialolympics.org/about/intellectual-disabilities/what-is-intellectual-disability>
6. Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Res Dev Disabil.* 2011 Mar-Apr;32(2):419-36. [PubMed]
7. Larson, S.L. et al. Prevalence of mental retardation and/or developmental disabilities: Analysis of the 1994/1995 NHIS-D. MR/DD Data Brief. Minneapolis, MN: Institute on Community Integration, University of Minnesota. 2002
8. American Association on Intellectual & Developmental Disabilities. Intellectual Disability: Definition, Classification, and Systems of Supports, 11th Edition. Washington, DC: American Association on Intellectual & Developmental Disabilities. 2011
9. Daily DK, Ardinger HH, Holmes GE. "Identification and evaluation of mental retardation". *American Family Physician.* 2000;61 (4): 1059-67, 1070. PMID 10706158. Archived from the original on 2010-12-04.
10. Types of Intellectual Disabilities retrieved from <https://www.msmanuals.com/en-in/home/children-s-health-issues/learning-and-developmental-disorders/intellectual-disability>
11. Types of Intellectual Disabilities retrieved from <https://www.goodtherapy.org/learn-about-therapy/issues/intellectual-disabilities>
12. American Association on Intellectual and Developmental Disabilities. Multiple pages reviewed.
13. Eunice Kennedy Shriver National Institute of Child Health and Human Development. About Intellectual and Developmental Disabilities (IDDs) (<https://www.nichd.nih.gov/health/topics/idds/condition/info>). Accessed 5/25/25.
14. Kim J, Keary CJ, Palumbo ML, Politte LC, McDougale CJ, Nowinski L. Intellectual Developmental Disorders. In: Silbersweig DA, Safar LT, Daffner KR, eds. *Neuropsychiatry and Behavioural Neurology: Principles and Practice.* McGraw Hill; 2021
15. Li S, Tong G. An etiological study of intellectually disabled Children under 14 years old in Anhui Province, China. *Am J Transl Res.* 2021; 13(4):2670-2677
16. Dykens M Elisabeth, Hodapp M R. Research in Mental Retardation: Toward an etiologic Approach. *The Journal of Child Psychology and Psychiatry and Allied Disciplines.* 2001; 42(1): pp. 49 - 71 DOI: <https://doi.org/10.1017/S0021963001006540>
17. Kaneshiro, Neil K, "Intellectual disability", MedlinePlus, U.S. National Library of Medicine, archived from the original on October 28, 2016, retrieved October 27, 2016

18. American Psychiatric Association. "Highlights of Changes from DSM-IV to DSM-5". Diagnostic and Statistical Manual of Mental Disorders (Fifth ed.). Arlington, VA: American Psychiatric Publishing. 2013; p. 809. doi:10.1176/appi.books.9780890425596. hdl:2027.42/138395. ISBN 978-0-89042-555-8.
19. Queensland Government, "Intellectual disability", qld.gov.au, archived from the original on October 28, 2016, retrieved October 27, 2016
20. Disabled World. Models of Disability: Types and Definitions. Disabled World. Retrieved December 3, 2023 from [www.disabled-world.com/definitions/disability-models.php](http://www.disabled-world.com/definitions/disability-models.php)
21. <https://www.afi.ie/about-us/the-models-of-disability/>
22. <https://www.diversifiedsupportiveservices.org/challenges-that-adults-with-intellectual-disabilities-face-in-the-workplace>
23. <https://www.millcreekofmagee.com/disorders/intellectual-disability/signs-causes-symptoms/>
24. The majority of people, 68%, have IQ scores between 85 and 115.
25. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. Arlington, VA APA Publishing. 2013.
26. <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>
27. <https://www.verywellmind.com/intellectual-disability-definition-symptoms-traits-causes-treatment-5220629>
28. van Karnebeek C, Murphy T, Giannasi W, Thomas M, Connolly M, Stockler-Ipsiroglu S. Diagnostic value of a multidisciplinary clinic for intellectual disability. *Can J Neurol Sci.* 2014 May;41(3):333-45. [PubMed]
29. Gates, B., Fearn, D. and Welch, J. Learning Disability Nursing at a Glance. Chichester: Wiley Blackwell. 2015
30. Camero, N., Anderson S. Identification conceptualizations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: A scoping review. 2017; <https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12390>
31. Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. Self-esteem, stigma and community participation amongst people with learning difficulties living in the community. *Journal of Community & Applied Social Psychology*, 2002;12(6): 430–443.
32. <https://www.diversifiedsupportiveservices.org/challenges-that-adults-with-intellectual-disabilities-face-in-the-workplace>
33. Shree A, Shukla PC. Intellectual Disability: Definition, classification, causes and characteristics. *Learning Community-An International Journal of Educational and Social Development.* 2016; 7(1):9 DOI:10.5958/2231-458X.2016.00002.6
34. [https://www.idrs.org.au/pdf/IDRS\\_%20Introduction\\_intellectual%20disability\\_17Feb09.pdf](https://www.idrs.org.au/pdf/IDRS_%20Introduction_intellectual%20disability_17Feb09.pdf)
35. <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>.