

## **PEOPLE WITH INTELLECTUAL DISABILITIES AND CHALLENGES IN THEIR LIFE.**

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### **Abstract**

From long time the person with intellectual disabilities were ignored. The people with intellectual disabilities have suffered enormous discrimination due to their abnormal intellectual condition. They were subjected face double challenge every day. One challenge relates completely to their own disability and another one to ignorance about their intellectual condition. They have to face social inequalities and are subjected to discriminations. Nowadays a brighter future is currently being developed over populations with intellectual disability. Professional caregivers, teachers, groups of parents and institutions are organizing themselves to promote systematic efforts to change life conditions of the people with intellectual disorder. Awareness and different acts such as “The right of persons with disability act 2016” is now transforming the life of the individuals with intellectual disabilities.

### **Introduction**

People with intellectual disabilities experience inequalities compared with the general population. They are neglected and isolated which leads social stigma. Although their life expectancy is increasing, it remains much lower than the rest of the population. The standardised mortality ratio has been found to be 8.4 for people with severe intellectual disabilities in United States and 4.9 for people with intellectual disabilities of all levels in Australia. People with intellectual disabilities have higher levels of health needs than the normal individual, and these are often unrecognised and unmet. This contributes to ongoing health inequality, chronic ill health, and suicide. The factors like biological, psychological, social, and developmental factors, as well as life experience, contribute to this inequality. People with intellectual disabilities also experience access barriers in using health services. The health needs of people with intellectual disabilities have an impact on primary healthcare services and all secondary healthcare

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specialties. There are different causes and types of intellectual disabilities, for example, epilepsy, gastro-oesophageal reflux disorder, sensory impairments, osteoporosis, schizophrenia, dementia, dysphagia, dental disease, musculoskeletal problems, accidents, and nutritional problems are all much more commonly experienced. Some problems related to behaviours, such as self-injury are specific to intellectual disabilities and may be associated with particular genetic syndromes and it is considered as the commonest causes of death. The current strategies are based on the health needs of the general population and for the people with limbs or other disability. As the pattern of health need and causes of death differ for people with intellectual disabilities, most current policies and public health initiatives will close the health inequality gap.

The people with intellectual disability faces at every aspect of their life. They have no understandings of what is happening, they can't judge about the things happening to them and get subjected to inequality and discrimination. The extent of inequality is greater for people with intellectual disabilities than for other excluded groups. Assumptions are made that reports or guidelines apply to all members of the population, but panels are unlikely to have included expertise on the differing health needs of people with intellectual disabilities. Hence everyone benefits except people with intellectual disabilities. Intellectual disability can happen any time before a child turns 18 years old, even before birth. Intellectual disability is the most common developmental disability. These inequalities and discrimination exist despite of implemented legislation for example, The Mental Health Act, 1987, The Persons with disabilities act 1995, Rights of Persons with Disabilities Act 2016. These laws require services to make reasonable adjustments and accommodations. However, the reality is that legislation does not yet seem to have translated into improved health status for people with intellectual disabilities. We need to change these inequalities. High quality research needs to be supported to develop the evidence base.

### **What is intellectual disability?**

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning such as reasoning, learning, problem solving and in adaptive behaviour, which covers a range of everyday social and practical skills. This disability originates before the age of 18. The term intellectual disability covers the same population of individuals who were

diagnosed previously with mental retardation. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.

While intellectual disability is the preferred term, it takes time for language that is used in legislation, regulation, and even for the names of organizations, to change. There is confusion between the terms developmental disabilities and intellectual disabilities. Developmental Disabilities is a wide term that includes intellectual disability but also includes other disabilities.

### **Causes of Intellectual Disability**

Intellectual disability was formerly known as mental retardation it can be caused by injury, disease, or a problem in the brain. For many children, the cause of their intellectual disability is unknown. Some causes of intellectual disability such as Down syndrome, Fetal Alcohol Syndrome, Fragile X syndrome, birth defects, and infections can happen before birth. Some happen while a baby is being born or soon after birth. Other causes of intellectual disability do not occur until a child is older; these might include severe head injury, infections or stroke. The most common causes of intellectual disabilities are: Genetic conditions. Sometimes an intellectual disability is caused by abnormal genes inherited from parents, errors when genes combine, complications during pregnancy etc. An intellectual disability can result when the baby does not develop inside the mother properly. A woman who drinks alcohol or gets an infection like rubella during pregnancy may also have a baby with an intellectual disability. Problems during birth. If there are complications during labor and birth, such as a baby not getting enough oxygen, he or she may have an intellectual disability. Diseases or toxic exposure. Diseases like whooping cough, the measles, or meningitis can cause intellectual disabilities. They can also be caused by extreme malnutrition, not getting appropriate medical care, or by being exposed to poisons like lead or mercury. Depression is also a cause for intellectual disability, which is now common.

### **How intellectual disability can be identified?**

The intellectual disability cannot be identified generally, it can only be determined through proper diagnosis by a psychiatrist. Intellectual disability is identified by problems in both intellectual and adaptive functioning. Adaptive functioning is assessed through standardized measures with the individual and interviews with others, such as family members, teachers and caregivers.

Moderate or severe categories. The symptoms of intellectual disability begin during childhood or adolescence. Delays in language or motor skills may be seen by age two. However, mild levels of intellectual disability may not be identified until school age when a child may have difficulty with academics. Intellectual functioning is assessed with an exam by a doctor and through standardized testing and procedures. 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. However, the IQ score must be interpreted in the context of the person's difficulties in general mental abilities.

### **Prevention**

There are various therapies such as Developmental social-pragmatic model, applied behaviour analysis, behavior therapy, sensory processing act. Certain causes of intellectual disability are preventable. The most common of these is fatal alcohol syndrome. Pregnant women shouldn't drink alcohol. Getting proper prenatal care, taking a prenatal vitamin, and getting vaccinated against certain infectious diseases can also lower the risk that your child will be born with intellectual disabilities. In families with a history of genetic disorders, genetic testing may be recommended before conception. Certain tests, such as ultrasound and amniocentesis, can also be performed during pregnancy to look for problems associated with intellectual disability. Although these tests may identify problems before birth, they cannot correct them. Care and love is the only medicine which can give some relief to the people with intellectual disabilities.

Significant advances in research have helped in prevention of many cases of intellectual disabilities. Early Intervention programme with high risk infants and toddlers have shown positive effects on intellectual functioning. Early comprehensive prenatal care and preventive measures prior to and during pregnancy increase a woman's chances of preventing intellectual disabilities in the new born. Dietary supplementation with folic acid, taken before and during pregnancy, reduces the risk of neural tube defects.

### **Obstacles and barriers**

Intellectual disabled persons are exposed to personal limitations in the economic, physiological and social spheres. The intellectual disabled individuals are subjected to ostracism. Considering

him/her mentally ill they are easy targets for ridicule, discrimination, and mockery. As such, it is imperative to assist them with ways of dealing with these unpleasant encounters. The psychological effects of physical and mental disability can leave a lasting impression on the life of person with intellectual disorder. The people with intellectual disabilities are vulnerable to social injustices and attacks. This is attributed to the fact that physically and mentally challenged individuals can be easily manipulated due to their inability to resist. This situation is common to young children, who are prone to sexual abuse. At first, intellectual were misunderstood. Initially, they were considered spiritual acts of payback. As time went on, the medical causes became known. Once this occurred, the prejudice against people with ID shifted. Public perception shifted from fear and outright rejection. These hostile attitudes were replaced with compassionate rejection, or patronizing over-protection. The people with ID are viewed as objects of pity. Rather than outright abominations, they were considered ill and in need of treatment. Sometimes people with these disabilities are considered unresponsive to help. As such, they are considered a burden to society. Alternatively, they are considered ill and in need of treatment. They are subjected to segregation from mainstream society. When people are not challenged to develop their strengths and abilities. Without recognizing and tapping into these strengths, they cannot reach their full potential. In our country, people shows less concern toward person with intellectual disability and in such situation, family is a very important asset in the management of intellectual disability. But discriminations completely destroys the confidence of the challenged individual. If the importance of family for this purpose is discouraged, persons living with intellectual disability and intellectual impairments may get abandoned and isolation will lead to roam them the streets.

### **Legal Framework**

**UN Declaration:** UN declaration focuses on rights of intellectual disabled individuals. It urges all national and international communities to abide by the norms of UN declaration for the rights of intellectual disabled persons and its norms act as framework and reference for the protection of the rights of the mentally challenged individuals. These rights consider intellectual disabled person has the maximum degree of feasibility and the same rights as other human beings. These individuals has a right to proper medical care, physical therapy, education, training, rehabilitation and guidance which will enable him to further develop their ability, and reach maximum

potential in life. The intellectual disabled person has a right of economic security and of a decent standard of living. He/she has a right to perform productive work or to participate in any other meaningful occupation to the possible extent of their capabilities. He and his family members should be motivated and encouraged emphasising that these individuals are same as normal individual and they have full right to live with their families and they should live with them or their foster parents. The family with which he lives should receive assistance and support to look after the suffering individual. If an institutional or medical care becomes necessary then it must be provided. The intellectual disabled person has a right to a qualified guardian when this is required in order to protect his personal well-being or interests. These personal has a right to get protection from exploitation, abuse and a degrading treatment. If prosecuted for any offence; he shall have right to the due process of law, with full recognition being given to his degree of mental responsibility. This act also specifies that if any circumstance arise when there is requirement for the denial of these rights to the disabled person then it should be done in a meaningful way or procedures used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse.

### **The right of persons with disability act 2016**

The RPWD Act 2016 contains 17 chapters with 102 sections. All these chapters are important to Psychiatrists while chapters 1,5,10 and 11 hold special importance, as the provisions in these chapters are closely associated with the ethics of physical and mental health professionals. The definitions of specified disabilities given at the end of the Gazette Notification as a ‘Schedule’ are an extension of definitions given in chapter 1, section 2. Different mental illness like intellectual disabilities, specific learning disabilities and autism spectrum disorders are clubbed together creating confusion for the certifying doctors and implementing Government department. This Act contains a new disability known as ‘Chronic Neurological Disorder’. The term ‘Person with Disability’ denotes long-term impairment. Still the word chronic is added for more clarity during certification. It would have been nice to prefix the term ‘chronic/ long standing/ prolonged’ before Mental Illness as a disability. This act mentions that person with intellectual disabilities have right to be admitted, treated and cared in a psychiatric hospital or psychiatric nursing home established or maintained by the Government. They cannot be denied from their right to get treated. Even mentally ill prisoners and minors have a right of treatment in

psychiatric hospitals or psychiatric nursing homes of the Government. Any minors under the age of 16 years, persons addicted to alcohol or other drugs, which lead to behavioural changes, are entitled to admission, treatment and care in separate psychiatric hospitals or nursing homes established or maintained by the Government. The central and State government are vested with authority to establish regulations under the Act and issue licenses for establishing and maintaining psychiatric hospitals and nursing homes. Treatment at Government hospitals and nursing homes mentioned above can be obtained either as in-patient or on an outpatient basis. This act provide authority to the police to take neglected or intellectually disabled person in to their custody and inform their relative or they can also produce them before magistrate for issue of reception orders. The section 7(2) under this act protects PWD from acts of abuse, violence and exploitation. The act has included intellectual disability as one of the condition of disability but there is requirement to address, special needs of Persons with Intellectual disability and their families. The nature of illness emphasis special requirement and care for these individuals. Lack of insight and their illness leads them in a position where they cannot understand their illness and disability. In such circumstances, their families are great asset in providing them care and support. Family members need to be involved to the greatest extent in the mental healthcare and family support should be encouraged as it provides moral, emotional, and physical support to them.

### **Conclusion & Suggestion**

The constitution of India assures for the equality, safety and respect to citizen. It assures that that all citizen are equal and will not be discriminated on any ground. Under the frame of the constitution, various laws and acts has been drafted and some of them were implemented. Despite of the effort and measures, there is hardly any change in the living condition and standard of the person living with intellectual disabilities. The pain and trauma of these people is far behind imagination. It is not hidden that these people abused and are subjected to violence by others. In our country, their family members and close relatives only generally look them after. However, how many of them really care and support the person with ID? Either they are locked in a room or they are left out on the street for wandering. They are never considered as the part of our social life. They are always left out from rest of the gathering. They feel isolated and left out. It would have been better if the specific aspects concerning the persons living with mental

illness, such as the matter of their protection from abuse, violence and exploitation, and guardianship limited or otherwise, was covered by suitable and comprehensive provisions in the acts mentioned above, leaving only general provisions to be covered by this Act. The act such as The Persons with disabilities act 1995, Rights of Persons with Disabilities Act 2016 though caters for the protection, treatment, safety and rehabilitation of the person with mental disability, but it lacks clarity. As some section of the law recognizes the impairment of mental state and understanding the severe mental illness, and provide benefit to the persons with intellectual disabilities under its sections forgiving them from the criminal responsibility and sometime to the overlook them like disqualification clauses in holding various public offices including holding the offices of membership of advisory boards. The individual with intellectual disabilities should be given equal respect same as normal individual. They deserve to be treated as human; they have full right to enjoy their liberty, and freedom. They are part of our social. The acts should draft strict punishment for the crime against them. The district administration should cater for the welfare of these personnel. There is requirement to educate normal people about intellectual disability. More NGOs to be promoted. Family members must cope with the stress of witnessing their loved one's daily struggles with self-care, social interactions, and education. They have to face their own troubling emotional reactions. Grief, resentment, disappointment, and frustration are commonly experienced. **Community supports should support by having** has a variety of programs and services that benefit people with intellectual disabilities.

### References

- Mc Grother C, Thorp C, Taub N, Machado O. Prevalence, disability and need in adults with severe learning disability. *Tiz Learn Dis Rev* 2001;6: 4-13.
- McGuigan SM, Hollins S, Attard M. Age-specific standardized mortality rates in people with learning disability. *J Intellect Disabil Res* 1995;39: 527-31. [PubMed] [Google Scholar]
- Patja K. Life expectancy of people with intellectual disability: a 35-year follow-up study. *J Intellect Disabil Res* 2000;44: 590-9. [PubMed] [Google Scholar]
- Decouflé P, Autry A. Increased mortality in children and adolescents with developmental disabilities. *Paed Perinat Epidem* 2002;16: 375-82. [PubMed] [Google Scholar]

- Durvasula S, Beange H, Baker W. Mortality of people with intellectual disability in northern Sydney. *J Intellect Develop Disabil* 2002;27: 255-64. [Google Scholar]
- Wilson D, Haire A. Health care screening for people with mental handicap living in the community. *BMJ* 1990;301: 1379-81. [PMC free article] [PubMed] [Google Scholar]
- Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: A population study. *Am J Ment Retard* 1995;99: 595-604. [PubMed] [Google Scholar]
- Kapell D, Nightingale B, Rodriguez A, Lee JH, Zigman WB, Schupf N. Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Ment Retard* 1998;36: 269-79. [PubMed] [Google Scholar]
- Cooper S-A, Bailey NM. Psychiatric disorders amongst adults with learning disabilities: Prevalence and relationship to ability level. *Ir J Psych Med* 2001;18: 45-53. [PubMed] [Google Scholar]
- Whitfield ML, Russell O. Assessing general practitioners' care of adult patients with learning disabilities: case control study. *Qual Health Care* 1996;5: 31-5. [PMC free article] [PubMed] [Google Scholar]
- Lennox NG, Kerr MP. Primary health care and people with an intellectual disability: the evidence base *J Intellect Disabil Res* 1997;41: 365-72. [PubMed] [Google Scholar]
- NHS Health Scotland. Health needs assessment report. People with learning disabilities in Scotland. Glasgow: NHS Health Scotland, 2004.
- Aldrich R, Kemp L, Williams JS, Harris E, Simpson S, Wilson A, et al. Using socioeconomic evidence in clinical practice guidelines. *BMJ* 2003;327: 1283-5. [PMC free article] [PubMed] [Google Scholar]
- Aspray, T.J., Francis, R.M., Thompson, A., Quillam, S.J., Rawlings, D.J. & Tyrer, S.P. (1998). Comparison of ultrasound measurements at the heel between adults with mental retardation and control subjects. *Bone*, 22, 665-668.
- Bailey, N.M. & Copper, S.A. (1997). The current provision of specialist health services to people with learning disabilities in England and Wales. *Journal of Intellectual Disability Research*, 41, 52-59.
- Barr, O., Gilgunn, J., Kane, T. & Moore, G. (1999). Health screening for people with learning disabilities by a community learning disability service in Northern Ireland. *Journal of Advanced Nursing*, 29, 1482-1491.

- Bell, A. & Bhate, M. (1992). Prevalence of overweight and obesity in Down's syndrome and other mentally handicapped adults living in the community. *Journal of Intellectual Disability Research*, 36, 359-364.
- Bond, L., Kerr, M., Dunstan, F. & Thapar, A. (1997). Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes. *Journal of Intellectual Disability Research*, 41, 391-400.
- Branford, D. (1994). A study of the prescribing for people with learning disabilities living in the community and in National health Service care. *Journal of Intellectual Disability Research*, 38, 577-586.