# Social Work Education (SWE)

**Paper: Social Work in the Field of Disability (SWFD)**

**Module 13: Intellectual Disability/Developmental Delay**

**Component IA**

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<thead>
<tr>
<th>Role</th>
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<th>Affiliation</th>
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<tbody>
<tr>
<td>Principal Investigator</td>
<td>Dr. Geeta Balakrishnan</td>
<td>Principal, College of Social Work, Nirmala Niketan, Mumbai.</td>
</tr>
<tr>
<td>Paper Coordinator</td>
<td>Dr. P. Saleel Kumar</td>
<td>School of Social Work, Marian College Kuttikkanam, Kuttikkanam (Post), Peermade, Idukki (Dist), Kerala, India 685 531. Mobile: 08300175801 E-Mail: <a href="mailto:saleelkumar1973@gmail.com">saleelkumar1973@gmail.com</a></td>
</tr>
<tr>
<td>Content Writer</td>
<td>Ms. Renjini Jose</td>
<td>School of Social Work, Marian College Kuttikkanam, Kuttikkanam (Post), Peermade, Idukki (Dist), Kerala, India 685 531.</td>
</tr>
<tr>
<td>Content Reviewer</td>
<td>Dr. Cherian P. Kurien</td>
<td>Professor &amp; Director, School of Social Work, Marian College Kuttikkanam, Kuttikkanam (Post), Peermade, Idukki (Dist), Kerala, India 685 531.</td>
</tr>
<tr>
<td>Language Editor</td>
<td>Dr. Ruble Raj</td>
<td>Professor &amp; Principal, Marian College Kuttikkanam, Kuttikkanam (Post), Peermade, Idukki (Dist), Kerala, India 685 531.</td>
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**Component IB**

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SWE/SWFD/13 by Ms. Renjini Jose
1. Introduction

Intellectual disability is one of the commonest disabilities during the developmental period. Braddock and Parish (2002) have defined disability as socially determined interpretation of impairment by others. The term "intellectual disability" is of recent origin. It has replaced the term "mental retardation" to a large extent in many countries. Canada and USA uses the word "developmental delay" to denote life-long disabilities due to diminished mental capacity. The earlier term used was "mental retardation" which is still used infrequently. World Health Organization (W.H.O) has used the words "mental retardation" and "retarded" in the International Classification of Diseases (ICD-10), but are under consideration for change in International Classification of Diseases (ICD-11).

Intellectual disability describes aspects of a person who is either slow to develop, or has not fully developed their speech, language, mental capacity or physical capacity. In this module the definition, the causes of this disability and its management aspects are discussed in detail.

At the end of this module, the learner will:

- Develop adequate knowledge about the meaning and definition of Intellectual Disability.
- Comprehend the causes of Intellectual disability and
- Learn the levels of intellectual disability

2. Meaning and Definition of Intellectual Disability

It is a permanent and irreversible disorder of competence that affects individuals and it requires professional diagnosis, treatment and management. Distinguishing features of this condition are significant intellectual delay and deficits in adaptive behaviours. Such individuals will have severe difficulty adapting to the surroundings. It is also identified by the presence of a significantly reduced ability to understand new or complex information (impaired intelligence) with the reduced ability to cope independently (Impaired social functioning), which started before 18 years of age. Intellectual Disability refers to impairments in both cognitive functioning and adaptive skills whose onset is during the developmental period. It is a developmental, functional and cognitive disability.

International Classification of Diseases (ICD-10) and DSM IVTR continues to use the term "mental retardation" but its use is not encouraged. Some other terms used are "mental handicap" and "learning disability". "Developmental delay" is another such word used. However all these terms are treated as derogatory words in the rights based era.

The American Association of Mental Retardation (AAMR) defines "mental retardation" (2002) as: "Mental retardation is a disability characterised 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".

Diagnostic and Statistical Manual of Mental Disorders, 4thEdition [DSM IV (1994)] states that his mental disorder is diagnosed in individuals who, from whatever cause have intelligence below an arbitrary level beginning before adulthood and whose adaptive functioning is impaired in any of a variety of area American Psychiatric Association, 1994).

range is 50-69. Moderate intellectual disability is when a person has an IQ between 35 and 49. It becomes Severe Intellectual disability if IQ is in the range of 20-34. The last category is Profound Intellectual disability and individuals with an IQ less than 20 falls in this category.

The Rights of Persons with Disability Bill 2012, India (PWD Bill) states that ‘Intellectual Disability’ refers to a condition characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills.

**Developmental Delay**

According to the Developmental Disabilities Act (Pub. L. 106-402), the term developmental disability means a severe, chronic disability that is attributable to a mental or physical impairment or a combination of those impairments; occurs before the individual reaches age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: (i) self care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. Before the age of ten, an infant or child with developmental delays may be considered to have an intellectual or developmental disability if his or her disabilities are likely to meet the above criteria without intervention.

There are certain developmental milestones that every child is expected to reach at different stages of growth. The child sits without support by the time he or she is one year old, the child walks well by the time he or she turns two, at three years the child join words into simple sentences etc. Children reach developmental milestones at their own pace. Minor, temporary delays are usually no cause for alarm. An ongoing delay or multiple delays in reaching milestones is called developmental delay. Developmental milestones include language, thinking, and motor skills.

**3. Levels of Intellectual Disability**

Intellectual disability is categorized into mild, moderate, severe and profound levels on the basis of IQ scores. These levels give some guide to the level of support someone might need but the way a person functions in their life also depends on other factors including: personality, coping skills, other disabilities such as physical, social or sensory, and what is demanded of them in different situations.

**3.1. Mild intellectual disability**

A mild intellectual disability is defined as an IQ between 50 and 70. Such a person has the ability to use speech in everyday situations and usually has full independence in self care. Difficulties in identification of this population arise, as those with borderline disability may not be in contact with service providers. In general the behavioural, emotional, and social difficulties of the mildly intellectually disabled and the needs for treatment are more closely similar to those found in people of normal intelligence than to the specific problems of the moderately and severely intellectually disabled.

**3.2. Moderate intellectual disability**

A moderate intellectual disability is defined as an IQ between 35 and 50. People in this category are slow in comprehension, requires supervision of self care, and has retarded motor skills. Individuals in this
category are slow in developing comprehension and use of language, and their eventual achievement in this area is limited. Achievement of self-care and motor skills is also retarded, and some need supervision throughout life. Generally, such people are fully mobile and physically active and the majority show evidence of social development in their ability to establish contact, to communicate with others, and, to engage in simple social activities.

3.3. Severe intellectual disability

A severe intellectual disability is defined as an IQ between 20 and 35. There is a marked impairment of motor skills, clinically significant damage to Central Nervous System.

3.4. Profound intellectual disability

The IQ in this category is estimated to be under 20, which means in practice that affected individuals are severely limited in their ability to understand or comply with requests or instructions. Most such individuals are immobile or severely restricted in mobility, incontinent, and capable at most of only very rudimentary forms of nonverbal communication. They possess little or no ability to care for their own basic needs, and require constant help and supervision.

4. Types of Intellectual Disability

Some of the main types of Intellectual disability are:

a) **ADHD:** Attention Deficit Hyperactivity Disorder (ADHD) is one of the most common childhood disorders and can continue through adolescence and adulthood. Symptoms include difficulty staying focused and paying attention, difficulty controlling behavior, and hyperactivity (overactivity).

b) **Autism:** Autism is defined as a severe behaviour disorder with onset in early childhood that is characterized by extreme withdrawal and self-stimulation. It significantly affects verbal and non-verbal communication and social interaction, usually evident before age 3 years, which adversely affects a child’s educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotypes movement, resistance to environmental change or change in daily routines and usual sensory experiences. It’s also a neurological disorder that leads to deficits in child’s ability to communicate, understand language, play, develop social skills and relate to others.

c) **Asperger’s Syndrome (AS):** The term Asperger’s Syndrome is defined as a developmental disorder that is characterized by difficulty with social interactions and difficulty in dealing with other people. The disorder of the Asperger’s Syndrome is now recognized as a relatively common intellectual disability. The impact of AS on children and their families is profound. It is also identified as an intellectual disorder and is assumed to be a mild case of autism.

d) **Learning Disabilities:** The label learning disability refers to a category of children and does not describe the specific deficit or dysfunction of the child or the specific academic or achievement problem of the child. The label assists persons in identifying and classifying children who need special help. It specifically means a disorder in one or more of the basic psychological process involved in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia.
e) **Down syndrome**: It is a condition in which a person is born with an extra copy of chromosome 21. People with Down syndrome can have physical problems, as well as intellectual disabilities. Every person born with Down syndrome is different. It is the commonest cause of severe mental disability with an incidence of 1 in 650 live births in virtually all countries.

f) **Tuberose Sclerosis**: Tuberous sclerosis is a rare genetic disease that causes benign tumors to grow in the brain and other organs. Those who have the mild form of the condition may live perfectly normal lives and the diagnosis may only come to light when the diagnosis of the severe form comes to light in one of their children. In the severe form many organ systems may be affected and this is characterised by developmental delay, epileptic seizures and severe behaviour disorders.

g) **Fragile X syndrome**: This condition is the most common cause of inherited mental handicap with an estimated prevalence of 1 in every 1000 males and 1 case of generally milder mental handicap in every 200 females. In males it is characterized by moderate to severe mental handicap, long thin faces with prominent jaws, large protuberant ears, macroorchidism and autistic features. The responsible gene, FMR-1 includes a repeated CGG triplet sequence that constitutes the Fragile X mutation. All mothers of children with Fragile X are carriers and have a small increase in CGG repeats while everyone with a full mutation (a large increase in CGG repeats is intellectual disability).

5. **Prevalence of Intellectual Disability**

Intellectual disability is thought to affect about 1% of the world population. Of those affected, 85% have mild intellectual disability. In India, Census 2001 has revealed that over 21 million people in India as suffering from one or the other kind of disability. This is equivalent to 2.1% of the population. Out of this, 10.3% falls under this type of disability. It was also found during the NSSO survey in 2002 that the prevalence of this disability is higher in females than in males. There are 4.34 lakh males in rural India affected with Intellectual disability, while it is 6.995 lakh for females in rural area. In urban sector the numbers are slightly lower and is 1.824 lakhs in urban males and 2.951 lakh in urban females (NSSO Survey, 2002)

5. **Causes of Intellectual Disability**

The reason or cause is not always known. However over half are caused by factors before birth (prenatal), others by factors around the birth period (perinatal) and some later (postnatal).

5.1. **Prenatal**: These are disabilities that are acquired before birth. These may be due to diseases that have harmed the mother during pregnancy or genetic incompatibilities between the parents. Chromosomal problems, genetic disorders, syndromes like Williams Syndrome, Prader-Willi Syndrome etc, infections of the mother during pregnancy, use of drugs, alcohol, toxins etc during pregnancy can also lead to intellectual disability in the child.

5.2. **Perinatal factors**: These are disabilities that are acquired during birth. This could be due to prolonged lack of oxygen due to the obstruction of the respiratory tract, damage caused to the brain during birth or due to reasons of accidental misuse of forceps or due to premature birth, trauma during birth, biochemical abnormalities such as low sugar levels, Children with low birth weight are at increased risk of having these complications after birth.
5.3. **Postnatal factors**: These disabilities are gained after birth. They can be due to accidents, infections, head injuries, poisons, near-drowning, extreme malnutrition, exposure to toxic substances such as lead, and severe neglect or abuse can also lead to intellectual disability.

6. **Causes of Developmental Delay**

Developmental delay may be caused by a variety of factors, including heredity, problems with pregnancy, and premature birth. The cause is not always known. Some conditions, like Down syndrome are genetic in origin. Infection or other problems during pregnancy and childbirth, as well as premature birth, can cause developmental delay. Developmental delay can also be a symptom of other underlying medical conditions, including: autism spectrum disorders, cerebral palsy, fetal alcohol spectrum disorders, Landau-Kleffner syndrome, myopathies, including muscular dystrophies.

7. **Management**

In the earlier days it was the practice that people with intellectual disability were isolated, excluded from society and were kept in separate institutions meant for them. This concept is undergoing a major shift today. There are changes in attitudes, management and treatment of the intellectually disabled, changes which began universally about fifteen to twenty years ago. The practice of sending the people with intellectual disability to the institutions has given way for the practice of Community Based Rehabilitation (CBR). The support of family, community and allied services like health, educational services are required for the service of CBR model.

A social worker plays an important role in educating the family about the positive aspects on the intellectually disabled in living an ordinary life in the community and in supporting them to make this happen. To support people in living an ordinary life means considering all aspects of life, including employment and friendship. This requires both practical and emotional input involving, as Gilbert (1985, p.74) noted, a personal counselling role and the imaginative use of casework skills.

The child with developmental delay has the same needs as any other child. All children benefit from a warm, secure and nurturing environment. They need to feel accepted with their individual patterns of strengths and weaknesses. This is important for the development of self-esteem, which builds confidence for learning new skills. Children with delay learn in a similar way to all children but usually take longer to develop new skills.

There is a need for intense focus and drive towards creating awareness of legislation among families of persons with intellectual disability. Various print and non-print modes are to be used for this purpose so that even illiterate persons will benefit from the information provided.

Children with developmental delay can benefit from a wide variety of experiences within their family and local community. The social worker provides counselling and support for families who have children with special needs. Information about early intervention programs and entitlements and help in finding the most appropriate services, is also given. The social worker can also provide information for parents who wish to meet others with similar experiences.

Programmes on prevention, early detection and early intervention for babies at risk and/or children with developmental delays are carried out by the health department in each state. In addition, a number of voluntary organizations are functioning in the country providing services to infants and children and their families. Institutes such as National Institute of Mentally Handicapped (NIMH) have exclusive early intervention units and also extension programmes to reach out to the families. A number of training programmes are conducted for professionals throughout the country by NGOs also. NIMH conducts post
graduate diploma programme in early intervention and a diploma programme for early childhood special education, approved by the Rehabilitation Council of India (RCI). Empowering family members and working with them in partnership seems to be the trend and focus in the country.

Integrated education of disabled children (IEDC) is implemented by the Department of education, Ministry of Human Resource Development (MHRD), and aims to educate children with disabilities in mainstream schools. The special schools provide education to children with intellectual disability with the focus on functional skills and independent living skills. Functional assessment and programming is followed and there is no centralized curriculum and certifying board of education for children with mental retardation, as seen for other sensory and motor disabilities. Therefore, it provides flexibility to the teacher in planning, but on the flip side, there are no standards on which the programme can be evaluated.

The social worker can also function as a link and educator in creating awareness about the various resources available in India today for the children with intellectual disability. There is also the important aspect of counseling services to the family which the social worker can provide.

7. Summary

In this module, overview about understanding intellectually disability is briefly described covering the whole panorama form the definition of intellectual disability and developmental delay, its meaning, the various levels of intellectual disability, prevalence, causes of intellectual disability and developmental delay and finally its management.

This electronic text is supported with electronic tutorial that consists of multimedia through use of innovative techniques and this intends to give the learner a quick and easy understanding about the lesson delivered through this module. Besides glossary of terms, web resources and bibliography relating to this e-content is provided. Self simulation for assessment and evaluation is also provided to support the effective utility of this content by the learner. This helps the learner to quickly evaluate the understanding developed by the learner regarding the contents discussed in the module. The learner is encouraged to expand on this for achieving comprehensive knowledge base on this content.