CHAPTER ONE : INTRODUCTION

Introduction

ACCEPT ME…….

Please accept me the way I am

I may not always say the things you want me to say

I may not always be the person you want me to be

But I am someone who cares about you

And it is important for me to know that you care about me

But also want to be I am who I am

So Please…..

Accept me the way I am…..

This is true mainly for most of the normal but maladjusted children due to faulty parental rearing. This can be also true for the children with disabilities due to pathological problems such as learning disability, intellectual disability, hearing impaired and so on. For the first time when the parents notice that their child is not normal, it is very difficult for them to accept the child as it is. They have hopes, expectations, and aspirations beyond imagination about their child. Especially if it is a single child the parents are not ready to accept the fact that their child is below average.
And if there are siblings in the family they keep on comparing and consequently ridiculing the performance of the disabled child with the normal child in the family.

Babies do not have to be taught such basic skills as grasping, crawling and walking. When the central nervous system, muscles and bones are mature enough and the environment offers the right opportunities, babies keep surprising the adults around them with their new abilities. The more babies can do, the more they can explore; and the more they can explore, the more they can learn and do. The skills and other development of an individual are believed to be genetically programmed. Motor skills proceed from simple to complex and follow two principles of development i.e. i) from head to toe (cephalo-caudal) ii) from inner to outer (proximo-distal). Most babies follow a particular sequence of developmental tasks as per the given timetable which is called as a series of milestones. The developmental milestones such as neck holding, turning on one side of the body, grasping an object has certain time. Few babies attain these milestones earlier than the given time where as few cross the time also.

It is true that if the time taken to attain a particular skill or development is too delayed it can affect the child’s further development. Earlier the parents notice the delays in the development of the child, more it is beneficial for the child. Most of the time, they think hopefully, that the delay is only because of individual differences. However, most of the parents are not ready to accept the fact that there is something wrong with their child. Hence due to lack of acceptance they keep on doing doctor shopping, this delays the further intervention necessary for the child’s development. When the parents accept the child as a special child, Their mere concern is that there is a need for special education.
In India, lots of development has occurred with respect to the special schools for the special population. Recently, under the scheme of ‘Sarva Shiksha Abhiyan’ the government has also introduced inclusion of all type of children under one roof. It has taken one step ahead towards mainstreaming this special population. But still the need of special school especially for the mentally subnormal children remains as it is, as the need requires to be geared up in special manner. After reading literature the researcher found evidences regarding the importance of home and the normal environment for the mentally subnormal child.

In February of 2008, the American Association on Intellectual and Developmental Disabilities replaced the term mental retardation with intellectual disabilities. Intellectual disability (ID) is defined as “a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills” which originates before the age of 18 (AAIDD, 2008). In the current research considering the medical and political significance, the term Intellectual Disability is continued henceforth.

Intellectual Disability is a term applied to a condition of delayed mental development present at birth or in early childhood as is characterized mainly by limited intelligence combined with difficulty in adaptation. It is an educational, psychological, and social problem. Intellectual Disability is not only an issue that concerns the nation or a people but also an issue that concerns the whole mankind.

It is crucial to establish the education policy, goals, programs and methods that will develop each individual’s ability to its fullest, and specifically for those staying at residential institution. The maximized learning is based on Psychology as it provides the principles of learning.
1.01 CONCEPT OF INTELLECTUAL DISABILITY

The term idiot is based on the Greek word for a “private person” (Kanner, 1964). Until mid 19th century, children and adult who today would be diagnosed as having Intellectual Disability were often lumped together with those suffering from mental disorders of medical conditions. There were typically ignored or feared, or even by the medical profession, because their differences in appearance and ability were so little understood.

Very old concept refers Intellectual Disability to subnormal intellectual functioning manifested during developmental period and is associated with implication in adaptive behavior and incomplete mental development.

According to mental deficiency act of England (1927), “Mental defectiveness means a condition of arrested or incomplete development of mind existing before the age of 18 years, whether arising from inherited cause or induced by disease or injury. (Robinson and Robinson, 1965).

The real criterion for Intellectual Disability is social one, and that a mentally defective individual, whether a child or an adult is one who by reason of incomplete mental development is incapable of independent social adaptation.

One of the most famous early definitions is that of Doll (1941), who listed six basic elements of Intellectual Disability, which was widely used in 1940s and 1950s.

(1) social incompetence, (2) due to mental sub-normality, (3) which has been developed mentally arrested, (4) which obtains at maturity, (5) is of constitutional origin and (6) is essentially incurable.
According to Tredgold (1947), “Mental Deficiency is a state of incomplete mental development of such a kind and degree that the individual is incapable of adapting himself to the normal environment of his fellows in such a way to maintain existence independently of supervision, control or external support.”

Jervis (1952), “Mental deficiency may be defined from medical point of view, as a condition of arrested or incomplete development induced by disease or injury before adolescence or arising from genetic causes.

According to Heber (1959), “Intellectual Disability refers to sub average general intellectual functioning, which originates during the developmental periods and is associated with impairment in adaptive behavior.”

Grossman (1973), the American Association of Mental Deficiency (AAMD) committee Chairperson proposed, “Intellectual Disability refers to significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the development period.

According to many authorities mental deficiency is fundamentally a social and not simply a medical or psychological problem.

World Health Organization (WHO) recommended the use of the term mental subnormal which in turn is divided into two separate and distinct categories 1) mental retardation and 2) mental deficiency (Biswa, M. 1980).

According to WHO nosology, Intellectual Disability “is reserved for subnormal functioning due to environmental causes in absence of central nervous system pathology and mental deficiency describes subnormal functioning due to pathological
causes”. It is also used often as a legal term which applies to people with I.Q. below 70. If the I.Q. score falls one standard deviation below the mean, the individual is labeled as intellectually disabled.

As American Association on Intellectual Disability (American Association of Mental Retardation) (AAMR, 1983) suggested, “Intellectual Disability refers to significantly sub-average general intellectual functioning resulting in or associated with concurrent impairment in adaptive behavior and manifested during developmental period.

The American Psychiatric Association (APA) (1994) defines Intellectual Disability in DSM-IV as “significantly sub average general intellectual functioning i.e. accompanied by significant limitations in adaptive functioning in certain skill areas such as self care, work, health and safety. To qualify for the diagnosis, these problems must have begun before the age of 18.”

As per ICD-10 (1996) Intellectual Disability is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.

Intellectual Disability can occur with or without any other mental or physical disorder. However, intellectually disabled individuals can experience the full range of mental disorders, and the prevalence of other mental disorders is at least three to four times greater in this population than in the general population. In addition, intellectually disabled individuals are at greater risk of exploitation and physical/sexual abuse. Adaptive behaviour is always impaired, but in protected social environments where
support is available this impairment may not be at all obvious in subjects with mild intellectual disability.

Intelligence is not a unitary characteristic but is assessed on the basis of a large number of different, more or less specific skills. Although the general tendency is for all these skills to develop to a similar level in each individual, there can be large discrepancies, especially in persons who are intellectually disabled. Such people may show severe impairment in on particular area (e.g. language), or may have a particular area of higher skill (e.g. in simple visuo-spatial tasks) against a background of severe intellectual disability. This presents problems when determining the diagnostic category in which a retarded person should be classified. The assessment of intellectual level should be based on whatever information is available, including clinical findings, adaptive behaviour (judged in relation to the individual’s cultural background), and psychometric test performance.

The axis I is used to record codes from Section F7 of the classification. Severity of retardation is recorded with a second digit code (F70 to F79).

It is possible to record problem behaviours by using a decimal place code.

In ICD-10 abnormal behaviour associated with mental retardation can be specified in only three ways as: none or minimal (x.0); significant, requiring attention or treatment (x.1); or ‘other’ (x.8). In this guide 6 additional second decimal codes have been provided to record the type of behaviour when x.1 (significant) is employed. The coding for degree of mental retardation is as follows:

F70 Mild Mental Retardation
F71 Moderate Mental Retardation
F72 Severe Mental Retardation
F73 Profound Mental Retardation
19 Other Mental Retardation

F79 Unspecified Mental Retardation.

As per DSM-IV-TR (2000) the criteria for Intellectual Disability consist of three core features that describe this disorder in both children and adults:

a) Significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test.

b) Concurrent deficits or impairments in present 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.

c) The onset is before age 18 years.

Children with Intellectual Disability vary widely in their degree of disability. Some show cognitive impairments, such as limited vocalization or poor self-regulation, from early infancy, whereas others may go relatively unnoticed through the elementary school years. Because of the wide variation in cognitive functioning and impairment, classification system for Intellectual Disability have always attempted to delineate various degrees of intellectual impairment in some manner. The DSM-IV-TR has continued the tradition by designating retardation as mild, moderate, severe, or profound; these designations are primarily based on IQ scores.

The AAMR (American Association of Mental Retardation), in contrast, has restructured its description of different degrees of intellectual disability.

As a group, children with mild retardation typically develop social and communication skills during the preschool years (age 0-5 years), perhaps with modest
delays in expressive language. They usually have minimal or no sensori-motor impairment, and engage with peers readily. By their late teens, these children can acquire academic skills up to approximately the sixth-grade level. During their adult years, they usually achieve social and vocational skills adequate for minimum self-support but may need supervision, guidance and assistance, especially when under unusual social or economic stress. With appropriate supports, individuals with mild Intellectual Disability can usually live successfully in the community, either independently or in supervised settings.

According to the DSM-IV-TR definition (APA, 2000), persons with mild mental retardation (IQ level of 50-55 to approximately 70) constitute the largest group, estimated to be as many as 85% of persons with the disorder (APA,2000). Children with mild Intellectual Disability often show small delays in development during the preschool years, but typically are not identified until academic or behavior problems emerge in the early elementary years. This category also has an overrepresentation of minority group members.

Persons with moderate mental retardation IQ level of 35-40 to 50-55) constitute about 10% of those with Intellectual Disability. Individuals at this level of impairment are more intellectually and adaptively impaired than those with mild Intellectual Disability, and are usually identified during the preschool years as a result of delays in reaching early developmental milestones. By the time they enter school, they may communicate through a combination of single words and gestures, and slow self-care and motor skills similar to those of an average 2 to 3 years old. Many persons with Down syndrome function at the moderate level of retardation. Some of these
individuals may require only a few supportive services to get along on a daily basis, but others may continue to require some help throughout life.

Most individuals with this level of disability acquire limited communication skills during their early years, and by age 12 may be using practical communication skills. They benefit from vocational training and, with moderate supervision, can attend to their personal care. They can also benefit from training in social and occupational skills but are unlikely to progress beyond the second-grade level in academic subject. Adolescents with moderate Intellectual Disability often have difficulties in recognizing social conventions, such as appropriate dress or humour, which interferes with peer relationships. By adulthood, the majority of persons with moderate Intellectual Disability adapt well to living in the community and able to perform unskilled or semiskilled work under supervision in sheltered workshop or in the general workforce.

Those with **severe mental retardation** (IQ level of 20-25 to 35-40) constitute approximately 3-4% of persons with Intellectual Disability. Most of these individuals suffer one or more organic causes of retardation, such as genetic defects, and are identified at a very young age because of substantial delays in development and visible physical features or anomalies. Milestones such as standing, walking, and toilet training may be markedly delayed, and basic self care skills are usually acquired by about age 9. In addition to intellectual impairment, they may have problems with physical mobility or other health related problems, such as respiratory, heart, or physical complications.

Persons with **profound mental retardation** (IQ level below 20 or 25) constitute approximately 1-2% of those with Intellectual Disability. Such individuals are typically identified as infants because of marked delays in development and biological anomalies such as asymmetrical facial features. During early childhood they show considerable
impairments in sensori-motor functioning; by the age of 4 years, for example their responsiveness is similar to that of a typical 1-year-old. They are able to learn only rudiments of communication skills, and intensive training is required to teach them basic eating, grooming, toileting, and dressing behaviors.

1.02 PSYCHOMETRIC CRITERION FOR INTELLECTUAL DISABILITY

Specifically, significant sub-average intellectual functioning refers to performance on intelligence tests which shows more than two standard deviations from the mean or average performance of the general population. Modern methods of IQ testing continue to follow the formula originated by Alfred Binet many years ago.

Table 1.1

*Categories of Intellectual Capacity*

<table>
<thead>
<tr>
<th>IQ</th>
<th>Standard Deviation</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>100-115</td>
<td>1 SD above the mean</td>
<td>Normal</td>
</tr>
<tr>
<td>85-100</td>
<td>1 SD below the mean</td>
<td>Normal</td>
</tr>
<tr>
<td>70-84</td>
<td>2 SD below the mean</td>
<td>Borderline*</td>
</tr>
<tr>
<td>55-69</td>
<td>3 SD below the mean</td>
<td>Mild Intellectual Disability</td>
</tr>
<tr>
<td>40-54</td>
<td>4 SD below the mean</td>
<td>Moderate Intellectual Disability</td>
</tr>
<tr>
<td>26-39</td>
<td>5 SD below the mean</td>
<td>Severe Intellectual Disability</td>
</tr>
<tr>
<td>9-25</td>
<td>6 SD below the mean</td>
<td>Profound Intellectual Disability</td>
</tr>
</tbody>
</table>

*The AAMD encourages the elimination of this classification.

The intelligence quotient (IQ) is the ratio of Mental Age to Chronological Age multiplied by 100.
IQ = MA / CA x 100

Continued and multiple testing of the general population has produced the mean of 100 points with a standard deviation of 15 points. Thus Table 1.1 represents the categories of measured intellectual capacity. (Bencho, 1984).

The current classification manual stresses that significantly sub-average is defined as an IQ of 70 or below. Webster's New World Dictionary defines intelligence as "the ability to learn or understand from experience; the ability to acquire and retain knowledge." Successful learning depends upon the ability to pay attention, perceive, remember, think, recognize relationships, form generalizations, and comprehend abstractions. Koch and Dobson (1976) utilized Thorndike's (1905) thoughts that intelligence has three basic aspects: (1) abstract or verbal intelligence involving the use of words and symbols; (2) practical intelligence involving the application of knowledge as that necessary in self-care and employment skills; and (3) social intelligence involving the ability to interact with others. To Thorndike, one's intelligence is reflected in one's behavior and ability to express thoughts and needs. Adequate mental ability is considered insufficient if one's personal behavior is not appropriate.

1.03 CAUSES OF INTELLECTUAL DISABILITY

There are many causes of Intellectual Disability. The AAMD has classified these into 10 general categories. Categories and examples within them are:

1. Infections and intoxications, pre or post-natal, which result in brain damage. Examples include rubella, syphilis, and toxemia of pregnancy, hyperbilirubinemia, lead poisoning, or fetal alcohol syndrome.
2. Trauma or brain injury before, during, or after birth. Hypoxia is included in this category.

3. Disorders of metabolism or nutrition such as hypoglycemia, phenylketonuria, and thyroid dysfunction.

4. Conditions where there is gross brain disease; examples are neurofibromatosis, leukodystrophy, or degeneration of cerebral tissue.

5. Brain malformations such as anencephaly, cranio-facial anomalies, meningomyelocele, and hydrocephalus.

6. Chromosomal anomalies, the most common being Down Syndrome, Turner Syndrome, and Klinefelter Syndrome.

7. Other conditions originating in the prenatal period, which include immaturity, delayed foetal growth, high or low birth weight, and maternal nutritional disorders.

8. Specific psychiatric disorders.

9. Disorders resulting from environmental influences. A child who has suffered maternal deprivation and extreme environmental restrictions, or who has a psychosocial disadvantage, falls within this category.

10. Other conditions; this category is reserved for persons with sensory handicaps or for persons who have intellectual disability without a known cause.

In United States there is agreement, at least from the educational and medical viewpoint, that all disorders must be evident and diagnosed by the child's 18th birthday for a person to be classified as being intellectually disabled. Another point of view comes from Great Britain, where Eldridge (1979) states that mental impairment
(retardation) can be acquired through a head injury in both children and adults. To him, if a person has had normal intelligence prior to the accident and that person can no longer function physically or socially as previously, this constitutes a mental handicap. He further simplifies the aetiology of mental impairment into two categories: (1) primary genetic disorders or those present at birth; and (2) acquired conditions or those factors affecting a foetus, child, or adult that can produce mental handicap. Whatever the cause, these individuals have limited ability to learn and gain social skills. They may further be hindered by various physical handicaps. In working with adult intellectually disabled persons, it must be remembered that they have had their affliction for many years and their deviations have been noted, evaluated, and perhaps rejected by society. Their present behavior may well be a reflection of what their general life experiences have been.

1.04 PREVALENCE OF INTELLECTUAL DISABILITY

Although the actual number of intellectually disabled individuals in the population is not known, consensus is that the prevalence is 1 percent. This means that about 1,000 people in a city of 100,000 are intellectually disabled. The percent prevalence estimate has been corroborated in studies conducted by Mercer (1973), who actually conducted a census of a city of 100,000 people. Mercer (1973) noted that a one-dimensional definition of intellectual disability (e.g. IQ scores only) might yield a prevalence rate approaching 3 percent. The use of multidimensional definitions that include both IQ and adaptive behavior yields a prevalence rate of roughly 1 percent. According to AAMD (1973) about 2 per cent of the total population, that is four million out of 200 million are intellectually disabled in USA.
Different prevalence rates for disability are available in India. According to the **Census 2001**, in India there are 2.19 thousand people with disabilities who constitute 2.13 % of the total population (Census 2001). Out of the 21,906,769 people with disabilities, 12,605,635 are males and 9,301,134 females and this includes persons with visual, hearing, speech, locomotor and mental disabilities (Census 2001). In contrast, the **National Sample Survey Organization** (NSSO) estimated that the number of persons with disabilities in India is 1.8% (49-90 million) of the Indian population (NSSO 2002), that 75% of persons with disabilities live in rural areas, 49% of the disabled population is literate and only 34% are employed (NSSO 2002). But both Census 2001 and NSSO-2002 indicated that the mental disability is 10% of the total population.

Traditionally, the ratio of EMR to TMR to SMR is estimated to be 12:3:1 (or 75:20:5 in terms of percentages). This means that of a hundred identified intellectually disabled children in the population, 75 can be expected to be in the educable range, 20 would be in the trainable range, and 5 would be in the severely/profoundly range. This ratio was fairly well confirmed by Mercer (1973) in her study of the community of 100,000 people.

Rehabilitation council of India, 1996 estimated that there could be 8.94 million children with loco-motor disability, 3.24 million children with hearing impairment, 1.96 million with speech defects, and 9.00 million children with intellectual Disability in the age group of 5-14 years in India.

**1.05 MEASUREMENT OF INTELLECTUAL DISABILITY**

The AAMD strongly encourages that both intelligence and adaptive behavior be evaluated before the diagnosis of intellectual disability is made. Tests are available
which determine the degree of adaptability. These tests assess self-help, self-direction, communication, socialization, and loco-motor skills. Deficits of adaptive behavior are classified as being mild, moderate, severe, or profound depending upon the client's ability in relation to chronological age. The most widely used tests for this purpose are the Vineland Social Maturity Test (VSMS) and the AAMD Adaptive Behavior Scale. Other tests are available to measure more specific functions and abilities, such as language, fine motor skills, or visual perceptive ability. All tests provide valuable information to plan educational programs for intellectually disabled persons, but caution should be taken in using the results. Tests can sometimes be used to label or stereotype a person, much to his or her disadvantage. Intellectually disabled persons are persons first, and retardation is only one characteristic of their uniqueness. Too much emphasis can be placed on their deficits, resulting in less concern or attention being given to their abilities and potential.

The general intellectual functioning is now defined by an intelligence quotient (IQ or equivalent) based on assessment with one or more of the standardized, individually administered intelligence tests, such as the Wechsler Intelligence Scale for Children-III (WISC-III), the Stanford-Binet-IV, and the Kaufman Assessment Battery for Children. These tests assess different verbal and visual-spatial skills in the child, such as knowledge of the world, similarities, and differences, and mathematical concepts, which together are presumed to constitute the general construct known as intelligence (Mash and Wolfe, 2002).

1.06 HISTORICAL PERSPECTIVE
In ancient times, all mental intellectually disabled were believed to be possessed by demons who could only be driven out by magic or prayers. Today it is no longer regarded as the curse of an evil spirit or as disgrace, but rather as one of nature’s error.

There is extremely little written information about intellectually disabled persons prior to the nineteenth century, with only spare references available. Many of the descriptions are, in fact not verbal; they are pictorial, e.g., the “fools” of King Phillip IV of Spain as painted by Velasquez. While there could be many reasons, the major one seems to be that the topic was not much of interest either to writers or to those concerned with the health of societies.

The earliest written reference to intellectual disability appears to have been the Papyrus of Thebes (1552 B.C.) which discussed the treatment of persons whose exceptionality was intellectual. That some treatment was attempted is suggested by the various remains in Europe, South America, and Central America of skulls with crude surgery, generally intended to allow spirits to escape from the body. As there was no distinction between mental illness and intellectual disability at that time, some of the victims were probably intellectually disabled persons. (Repp,1983).

In 16th century (1534) Fitzherbernt made one of the first attempt to define Intellectual Disability as “idiot from his birth is such a person who cannot account or number 20 pence, not he can tell who was his father or mother nor how old he or she is etc., so it may appear that has no understanding of reason that shall be for his profit nor what for his loss.

Swinburne (1591) proposed an additional criteria of capacity, among other tests measuring a yard of cloth and naming the days of week.
During 17th century Willis recognized that there were different levels of intellectual disability. Some are unable to learn letters but can handle mechanical arts, others who fail at this can easily comprehend agriculture, still other are unfit except to eat and sleep.

Pablo, J. (1620) a Madrid Physician, revolutionarized Spanish educational procedures by attempting to educate the intellectually disabled. He was driven away from Spain because of the prejudice and stigma against intellectually disabled persons.

Itard (1775-1838), a physician who was working in an institution in Paris for the deaf, and who had adopted the “sensationalist” theory that learning is acquired through the senses and that all persons could learn given the proper sense training. The boy was brought to the French Academy of Science, Itard was challenged, and the first scientific attempt at educating a intellectually disabled person was about to begin. Itard became the first man to bring science to the aid of intellectually disabled.

Jean Esquirol (1772-1840), a French pioneer in mental health who organized the first educational program in psychiatry, who was the first to describe two grades of intellectual disability (idiocy and imbecility), and who determined that idiocy was not a disease but rather a condition originating before the complete development of the intellect. Esquirol’s view approached the modern definition, except that the term “idiocy”, which in the 19th century meant intellectual disability, has how become a derogatory term. He classified idiots and imbeciles as separate entities, taking speech or lack of it as the criterion.

Seguin (1812-1880) carried forward Itard’s work. Seguin worked with several senses, unlike Itard who concentrated first only on hearing and considered touch,
hearing, and sight as the most important. His work, while certainly indigenous, to his era, is remarkably current in his anticipation of gradually increasing the difficulty of tasks (now called shaping) and of gradually making discriminations less obvious (now called fading). Seguin clearly understood B.F. Skinner’s century-later concept of contingencies, the relation of environment events to responding, and demonstrated this understanding through the use of antecedent stimuli such as the form board. The form board was developed by Seguin along-with the use antecedent procedures such as fading, and the use of Programmed consequences of responding. Although choosing a consequence infrequently used in today’s applied programs, Seguin demonstrated the use of Programmed consequences of responding. For example, the use of response-produced events by applying fear training (now called avoidance conditioning) in which idiots were taught to avoid punishment by performing tasks sequenced carefully for increasing difficulty.

The importance of Seguin’s influence for the century, however, went beyond his theory of instruction. In 1837 or 1838, the first successful public residential institution for intellectually disabled persons was established. In 1842, a portion of the Bicêtre was set aside for instructing idiots, and Seguin was appointed as its director. He called his teaching “the psychological method- the whole training of the whole child.”

With the influence of Seguin and Howe, schools continued to propagate so that by 1898 there were 24 state schools operated by 19 states and one school operated by the City of New York.

In 1901, category of “feeblemindedness was included in census. It was recognized and declared by householders or workhouse masters to be feebleminded.
About 1930, parents of intellectually disabled began to help each other. Parent’s organization spread rapidly from state to state.

In England Andreq Reed’s efforts in 1940 at training mentally deficient resulted in foundation of first asylum for idiots.

According to Education Act of 1944 the term subnormal came into common use in Britain. The term was introduced as “Educationally subnormal children”.

In 1950, National Association for intellectually disabled children was established in U.S.A. They also organized preschool classes, recreational programs, sheltered workshops, occupational training center and programs of parent’s guidance and public education.

1.07 DEVELOPMENT OF AWARENESS AND CARE OF THE INTELLECTUALLY DISABLED IN INDIA

Numerous authorities in the field of intellectual disability have offered their definitions. The definitions most widely used in India are ones given by DSM-III and American Association on Mental Deficiency (AAMD). These are also accepted by W.H.O. According to W.H.O. intellectual disability is also defined as “significantly sub-average general intellectual functioning, resulting in, or associated with deficits or impairments in adaptive behavior.”

Intellectual disability poses a major social problem because it requires special training facilities and procedures while in some instances institutionalization is advisable.
The first pioneering work in this field was started in the city of Mumbai and now it has expanded greatly in Maharashtra state. Other states have also taken steps to tackle the problem of the intellectually disabled.

All India Association of Intellectual Disability was founded in 1965 at Chandigarh. In 1966, the first All India Conference on Intellectual Disability was organized by voluntary societies and was inaugurated by the former Prime Minister Mrs. Gandhi in New Delhi. The federation for the welfare of intellectually disabled was formed at this conference. The initiative taken by the Federation and association also stimulated the postal and telegraph department to highlight social problem of the intellectually disabled by issuing a commemorative postage stamp on the 8th December, 1974. This day is observed as the National Day of Mentally Retarded every year.

1.08 HISTORY OF RESIDENTIAL PLACEMENT FOR THE INTELLECTUALY DISABLED

The early history of residential placement for the intellectual disability, which begins in the mid-19th century, is enlightened by today’s standards and much more humane than the subsequent developments in the early to mid-20th century. The first residential school specifically designed for the treatment of the intellectually disabled was founded in Switzerland circa in 1840 by Johann Jacob Guggenühl (Scheerenberger, 1975). Guggenühl was enthusiastic about the potential of education for intellectually disabled persons and established his facility on this premise, stressing intensive training for this population. After initial acclaim for this program, it was closed because of the inability to maintain humane living condition. At about the same time, Edouard Seguin, who was also hopeful regarding the educability of intellectually disabled persons, designed a program of community residential care because of his belief that there was
no need to isolate these people for the protection of the rest of society or for educational purposes. Despite these enlightened views, many factors, not the least of which was the apparent limited success of these early programs, led to a more pessimistic attitude regarding the educability of the intellectually disabled. This produced a focus on simple vocational programs and housing in progressively larger residences because of limited financial support for new facilities (Scheerenberger, 1983).

The first residential institution for the intellectually disabled was established in July 1848 in Barre, Massachusetts. There was a notion that when child is placed in residential institution, their intellectual condition is hopeless. This idea may result from the facts that

1. In the early days these institutions were referred to as “places for training idiotic children” and
2. The more extreme cases (those from unfortunate homes and environment) are sent to these institutions.

Undoubtedly many of the children placed in institutions for intellectually disabled are incapable of being trained for adequate social and economic adjustments and large percentage of others will need constant supervision and guidance throughout the life. There is increasing emphasis on the different roles of residential institutions concerning the Program in residential schools for the educable intellectually disabled, Martens has written “the plan of school activities can be best compared with the program of special classes for intellectually disabled children in day schools. A residential school has a distinct advantage over the day schools in that it has the whole child, whole day and the whole year.”
The primary objective in the education of pupils in residential schools should be good health. Physical defects and various conditions contributing to poor physical and mental health should be given first consideration. Educational efforts towards the development of sensory and motor abilities and good sensory motor coordination should receive good deal of attention, for it has been shown that intellectually disabled boys and girls are able to do this type of work better than more abstract and verbal type. Although there may not be much transfer in manual abilities, such skills do provide a partial basis for further growth, for socialization and for the growth of mental and emotional attitudes.

Around the turn of the century, the nature of treatment for the intellectually disabled changed drastically, largely through the work of Henry Goddard, who suggested that genetics played a major role in determining human behavior. The implication of his work was that the negative behaviors of the intellectually disabled were inevitable and, because of their genetic origin, likely not changeable. This view was taken to its limit by the eugenics movement, which sought, with a great deal more success than most people today would have hoped, to control intellectual disability by isolating this population in large residential facilities located in rural areas, restricting marriage, and sterilizing intellectually disabled individuals. Treatment in these large facilities took the form of protective paternalism, which merely involved “watching over” the residents (Scheerenberger, 1983).

This attitude toward isolated residential treatment began to change in the early part of this century for several reasons ((Scheerenberger, 1983): (1) it became economically unfeasible to house all intellectually disabled persons; (2) the doctrines regarding heredity and behavior came under severe attack; (3) it became obvious that society did
not really need “protection” from this group of citizens; and (4) some intellectually disabled people were shown to be able to meet the demands of living in open society. Institutions once again began to undertake advanced training efforts, and significant community programs began to develop. These efforts stagnated, however because of the effects of the Depression and lack of an advocacy group to speak to the needs of intellectually disabled persons.

After World War II, more emphasis began to be placed on human treatment as parents and professionals began to clamour for institutional reform (Scheerenberger, 1983). Community support for this population began to grow slowly, evidenced by the increasing number of special education classrooms in public schools. Although many visionary ideas such as deinstitutionalization and standards for residential facilities were espoused, in reality change was slight because institutions continued to be primarily holding facilities providing at best, custodial care.

Some authorities, such as Blatt, Ozolins, and McNally (1979), advocate closing all residential institutions and moving toward smaller community based facilities. The fact that large investments of money have been made in the physical plants of large institutions make this unlikely, however. It is more likely that smaller facilities will be built as the larger ones become obsolete. These facilities will probably have slightly different missions than strict residential care, however. For example, in 1982 the Kentucky Association for intellectually disabled Citizens went to court to prevent the rebuilding of an obsolete residential facility. The judge ruled that the institution could be rebuilt, but its size was drastically induced. In addition, however, he ruled that the facility should provide space for emergency temporary care of intellectually disabled
people when their parents or legal guardians had to travel or pursue business that would be impossible if the had to maintain responsibility for the people in their charge.

Today, residential placement of intellectually disabled children and adolescents clearly focuses on relatively small, community placements when services are insufficient to maintain children in their natural homes (Thaw, 1986). The number of intellectually disabled in these types of settings is on the rise, and funds are increasingly being allocated to community services and placements (Braddock and Fujjura, 1987). It also appears that this move toward smaller community placements will be accelerated if legislation introduced in the U.S. senate (S.1673) by Senator Chafee (RI) is passed. This Chafee bill seeks to redirect Medicaid funding available for residential treatment for the intellectually disabled away from large institutional settings toward community services and smaller community residences. Passages of this bill would force to state to greatly enhance their community programs or risk the loss of federal support. This emphasis on community treatment at the expense of institutional care is the result of the normalization and humanistic legalism movements discussed above rather than empirical evidence that intellectually disabled people achieve maximum habitation in such settings.

A broader approach to residential treatment was discussed by Thaw (1986), who advocated a community-oriented continuum of care. This continuum would consist of a variety of services that focus on the needs of the intellectually disabled person as opposed to the nature of the residential placement of the individual. Many different types of residential settings would be generated, ranging from institutionalization to individualized, independent placement in the community. This would provide a broader array of placements created to match the needs of the individuals served rather than
having one type of placement and requiring all persons to fit that program. In this type of approach, the larger facilities would represent only one place along the continuum, which because of their concentration of residents and professionals, could provide a variety of interdisciplinary services and training efforts for community residences in addition to residential care.

1.09 INSTITUTIONS FOR THE INTELLECTUALLY DISABLED IN INDIA

In 1934, the oldest existing facility in the form of psycho-medical rehabilitation was establishment at “the Central Nursing Home” at Ranchi in Bihar. Though this institution primarily provided facilities for the non-intellectually disables, it also opened the doors to the intellectually disables as well. In 1941, a home specially for the intellectually disabled known as the “Home for the Mentally Deficient Children” was established by Children’s Aid Society in Mumbai. This was the first home of its kind in India. The first special school to provide special education was the “School for Children in need of Special Care,” at Sewri in Mumbai which was established in 1944.

There were about 162 known institutions in the country providing 10,000 beds for a population of about 20 million intellectually disabled people. These institutions or organizations are engaged in the care and training of the intellectually disabled and they are run by Government or voluntary organizations. The picture has changed now. There are around 482 institutions for the intellectually disabled children in India, out of which 83 institutions at the most are in Maharashtra. Many of them are residential. Hence very few studies have been considered to find out whether the residential facility really benefits the child or causes adverse effects on intellectual, psychological, and physical development, due to restricted environment. (Rehabilitation Council of India, 2000).
According to the Mental Health Act (1959), a patient is subnormal by reason of arrested or incomplete development of mind, which includes sub-normality of intelligence. He requires or is susceptible to medical treatment or other special care or training. Further, the legislative framework for the protection of the rights of disabled people is covered by four acts in India (Thomas 2005a):

- Mental Health Act 1987
- Rehabilitation Council of India Act 1992
- Persons with Disabilities Act 1995
- The National Trust Act 1999

*The Mental Health Act 1987*

(http://www.disabilityindia.org/mentalact.cfm) - Mental Health Act came into effect in all the states and union territories of India in April 1993 and replaced the Indian Lunacy Act of 1912. This Act consolidated and amended the law relating to the treatment and care of mentally ill persons and to make better provision with respect to their property and affairs. The objectives of the Act include to:

- regulate admission to psychiatric hospitals or psychiatric nursing homes of mentally ill-persons who do not have sufficient understanding to seek treatment on a voluntary basis, and to protect the rights of such persons while being detained;
- protect society from the presence of mentally ill persons who have become or might become a danger or nuisance to others;
- protect citizens from being detained in psychiatric hospitals or psychiatric nursing homes without sufficient cause;
regulate responsibility for maintenance charges of mentally ill persons who are admit ted to psychiatric hospitals or psychiatric nursing homes;
provide facilities for establishing guardianship or custody of mentally ill persons who are incapable of managing their own affairs;
provide for the establishment of Central Authority and State Authorities for Mental Health Services;
regulate the powers of the Government for establishing, licensing and controlling psychiatric hospitals and psychiatric nursing homes for mentally ill persons;
provide for legal aid to mentally ill persons at State expense in certain cases.

In 2002, the Act was implemented in 25 out of 30 states and Union Territories. Under the Mental Health Act 1987, each state is required to constitute a State Mental Health Authority (SMHA) to ensure effective and equitable enforcement of the provisions of the Act. The primary role of the SMHA is in planning, implementation and monitoring of mental health programme/activities (WHO 2006).

*The Rehabilitation Council of India Act 1992*

([http://rehabcouncil.nic.in/pdf/about_rci.pdf](http://rehabcouncil.nic.in/pdf/about_rci.pdf))- This Act sets out to regulate the training of professionals in rehabilitation and sets out a framework for a Central Rehabilitation Register. Specifically it sets out:

1. training policies and programmes;
2. to standardise the training courses for professionals dealing with persons with disabilities;
3. to grant recognition to the institutions running these training courses;
4. to maintain a Central Rehabilitation Register of the rehabilitation professionals;
5. to promote research in Rehabilitation and Special Education.
In order to give statutory powers to the Council for carrying out its duties effectively the Rehabilitation Council of India Act was passed by the Parliament which came into force with effect from 1993. The amendment in the Act in 2000 gave the additional responsibility of promoting research to the Council. The major functions of the council include the recognition of qualifications granted by Universities in India for Rehabilitation Professionals and also the recognition of qualification by Institutions outside India.

*The Persons with Disabilities (Equal Opportunities, protection Of Rights And Full Participation) Act 1995* (http://www.disabilityindia.org/pwdacts.cf) This act provides 3% reservations for disabled people in poverty alleviation programmes, government posts, and in state educational facilities, as well as other rights and entitlement. The specific objectives of the Act are:

- Prevention and Early Detection of Disabilities
- Education
- Employment
- Affirmative Action
- Non-Discrimination
- Research And Manpower Development
- Recognition of Institutions for Persons with Disabilities
- Institution for Persons with Severe Disabilities
- The Chief Commissioner and Commissioners for Persons with Disabilities
- Social Security

A study conducted by *Disability Knowledge and Research Group* in India assessed the impact of this Act and tried to evaluate its implication (Thomas 2005a). It was found that those eligible had difficulties in obtaining disability certificates, benefit
entitlements varied across the India and that only 3% per cent had received monetary support from the government on a regular basis (UNNATI 2004).

**The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999**

(\[http://www.disabilityindia.org/trustact.cfm\]

This Act provides for the constitution of a national body for the Welfare of Persons with Autism, Cerebral Palsy, intellectual disability and Multiple Disabilities. The main objectives are:

- to enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong;
- to strengthen facilities to provide support to persons with disability to live within their own families;
- to extend support to registered organization to provide need based services during the period of crises in the family of persons with disability;
- to deal with problems of persons with disability who do not have family support.

**National Policy for Persons with Disabilities Act (PWD Act,2005)**

(\[http://www.disabilityindia.org/nationalpolicyfordisable.cfm\]

The National Policy, released in February 2006 recognizes that Persons with Disabilities are valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society. Its aim is to ensure better coordination between various wings of the State and Central Governments (Kumar 2005). The focus of the policy is on the following:

- Prevention of Disabilities
- Rehabilitation Measures
Physical Rehabilitation Strategies
Early Detection and Intervention
Counselling and Medical Rehabilitation

In addition to the legal framework, extensive infrastructure has been developed in India for disabled persons under this Act and includes the establishment of the following institutions:

- Institute for the Physically Handicapped, New Delhi.
- National Institute of Visually Handicapped, Dehradun
- National Institute for Orthopaedically Handicapped, Kolkata
- National Institute for Mentally Handicapped, Secunderabad.
- National Institute for Hearing Handicapped, Mumbai
- National Institute of Rehabilitation Training and Research, Cuttack.
- National Institute for Empowerment of Persons with Multiple Disabilities, Chennai

1.11 EMERGENCE OF THE PROBLEM

After considering the degrees of retardation, it was found that the mild intellectually disabled can reach to a particular level of social and psychological development, whereas the severe and profoundly intellectually disabled due to some organic and physical causes need intensive training. The focus of this study is on the 10% of this population i.e. moderate group. It has been observed that the number of intellectually disabled children admitted in most of the residential institutions belong to moderate group. Many moderate intellectually disabled can develop optimally, if provided with opportunities. After working for two years as special educator in one of the residential institution for the intellectually disabled it was observed by the researcher that the psychological and social environment of the institution is not
conducive for optimal development of the students. It was also found to be essential to study the effective psychological intervention strategies for the development of moderate intellectually disabled in residential institutions.

The inadequately informed parents can be more harmful to their son/daughter than other. No amount of information is sufficient to respond to the growing worries and issues of parents of today. We need to come out with awareness of building materials that suits the needs of parents of different strata, literate, illiterate, those residing in remote rural and tribal areas and those residing in urban areas, their doubts, worries and concerns are the same, though the form in which it is manifested is different.

The parents of intellectually disabled child have to remain busy throughout life, as these children rarely become independent. Sometimes willingly or unwillingly parents from upper to lower class send their child in residential institutions due to practical difficulties. Parents are more confused whether the residential care facility will benefit their child or not.

The work done by the past researchers in developed countries urged me to do more extensive and systematic studies on the effectiveness of the various psychological intervention Programs on the psycho-social development of both residential and day school moderate intellectually disabled, under more stringent design condition in Indian environment.

1.12 STATEMENT OF THE PROBLEM
1.13 SIGNIFICANCE OF THE PROBLEM

At the national conference on “families having individual with chronic problems” held at TISS, Mumbai, Sen and Tuli (1991) highlighted the agony of mentally handicapped. No other type of disability according to them causes such personal, family, social and psychological problem as mentally handicapped.

The child’s intelligence level is affected by the psychological climate of the house. According to Baldwin (1955) “Homes showing large gains in the IQ are those marked by warmth, freedom of exploration and acceleratory pressure from the parents”. In India the joint family system is slowly giving a way to nuclear family system which assigns the supply of rearing children solely to the parents which makes a difference in warmth and affection children receive. Environmental factors such as increased rate of pollution, population explosion, also have severe effect on intellectually disabled in India.

It is important to know that the development of an intellectually disabled child basically and fundamentally depends on the factor and family members’ attitude towards them and the environment provided. The child should be in a non-stigmatizing and a stimulating environment, where he is accepted as he is and should be receiving a kind of structured assessment and interventions from the professional as needed.

Handicapped children are the integral part of society; they have a right to use maximally their potential that they can function as useful member of society.
From the Indian context, wherein the trained professionals are limited and the need to cater to large number of help is huge, the constraints relating to cost effectiveness of any program are too pressing. Professionals do need to look for effective support system and develop certain innovative models of care which could be feasible and relatively effective. Services to meet the needs of mentally handicapped in India are far from adequate. Only 1% of intellectually disabled individuals are fortunate enough to receive such services. The emphasis should be given on normal peer interaction, community based institutions and implication of psychological principles and therapies for the psychological and social development.

Mental health of intellectually disabled individual should also be focused on. The thoughts, feelings, and behavior established by teacher form a foundation of adult happiness and effectiveness. It is the result of living and learning. There is no other place where mental matters are so important as in the home where the lives of children are taking the shape that will adumbrate future joy or disappointment and will mould destiny.

1.14 RELEVANCE OF THE STUDY IN THE CURRENT CONDITION

At a philosophical level intellectually disabled people are seen as individuals whose environments failed to provide appropriate learning experiences that would produce the development of adaptive behavior and/or contained environmental events that encouraged the development of maladaptive behaviors (Bijou, 1966). In order to manage intellectual disability, from this perspective, treatment needs to involve the establishment of an environment that sets the occasion for learning adaptive behavior and discourages the maintenance of maladaptive responses. This is clearly a very hopeful philosophy regarding treatment, as the suggested causes of intellectual
disability lie outside the individual, in his environment, which can be manipulated to produce the desired behavior change.

At a technological level, behavior modification specifies the procedures required to analyze and manipulate the environment to produce the desired changes in behavior. A body of empirical research exists to support the use of this technology. Although education and training of the intellectually disabled had been advocated before. Initial claims of the extent of effectiveness of behavior modification with the intellectually disabled and the superiority of this technology over other approaches may have been exaggerated (Konarski and Spruill, 1987), but it has nonetheless become the dominant treatment model in working with intellectually disabled persons, particularly in residential settings.

Normalization refers to the use of culturally normative means to produce culturally normative behaviors in the intellectually disabled (Wolfensberger, 1972). McCarver and Cavalier (1983) summarized the major implications of normalization for residential services as

1) They should be integrated in the community with easy access to generic services;
2) They should be small;
3) They should be specialized so that all residents requiring the same degree of supervision and/or care live together;
4) Residents should not live and work at the same place; and
5) There should be continuum of services with individual placement representing the ideal.

This principle and its implication have had a significant impact on attitudes toward residential treatment for the intellectually disabled. Although normalization
consists of no specific treatment techniques in itself, it has provided the conceptual and philosophical framework for such important advances as deinstitutionalization, mainstreaming, and legislative and judicial forces that have shaped today’s approach to residential treatment.

Humanistic legalism seeks to gain equality and justice for intellectually disabled persons to ensure their right as citizens. This is accomplished through judicial, legislative, and programmatic processes that result in reifying certain philosophical orientations (McCarver and Cavalier, 1983). In recent times, these orientations have been very often covered by the wide umbrella of normalization.

1.15 CONCEPTS AND TERMS USED IN THE THESIS

- **Intellectual Disability**: According to American Association on Intellectual and Developmental Disabilities (AAIDD) Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour which covers many everyday social and practical skills. This disability originates before the age of 18.

- **General intellectual functioning** is now defined by an intelligence quotient (IQ or equivalent) based on assessment with one or more of the standardized, individually administered intelligence test, such as WISC-III, the Stanford-Binet IV and the Kaufman Assessment battery for children. These tests assess different verbal and visual-spatial skills in the child, and mathematical concepts, which together are presumed to constitute the general construct known as intelligence.

- **Adaptive functioning** refers to how effectively individuals cope-up with ordinary life demands and how capable they are of living independently and abiding by the community standards. (Hodapp and Dyken, 1994). It also refers to the effectiveness
of the individual in adapting to the natural and social demands of his environment. Impaired adaptive behavior is reflected in: (1) Maturation, (2) learning and (3) social adjustment.

- **Psychological development:**
  Psychological development is the way individual thinks, behaves and feels in a given situation. It is also related to the intellectual development of an individual. The aspect of adjustment is related to it. Cognitive processes are the aspects of psychological development. It is to self direction and all other personality variables also.

- **Social and emotional development**
  In children with intellectual disability inadequate social abilities are consistently noted. Although cognitive limitations may partly explain these deficiencies, these children vary greatly in their social skills. Inadequate social abilities have been discussed in terms of poorly delineated constructs of social development, including “social competence” and “social skills,” but rarely in terms of development (Peck, Odom, and Bricker, 1993).

  Given a broad domain of social development, the issues of sociability, including emotional and pro-social behavior, and peer relationships are discussed.

- **Special education** is instruction designed to respond to the unique characteristics of children who have needs that cannot be met by the standard school curriculum.

- **Exceptional children** are children who have special physical, mental, behavioural, or sensory characteristics that differ from the majority of children on both the ends such that they require special education and related services to develop to their maximum capacity. The category includes children with communication disorders,
hearing disorders, visual impairments, physical disabilities, intellectual disability, learning disabilities, behavior disorders, multiple handicaps, high intelligence, and unique talents.

Several terms are also used to refer to children who receive special education services. Although the use of varying terminology is quite common in special education, there are technical differences in meaning among a number of terms. Stevens (1962) differentiated the following terms.

- **Impairment** refers to diseased or defective tissue. For example, lack of oxygen at birth may cause brain damage or neurological impairment that result in cerebral palsy. Similarly, a birthmark could be considered an impairment because it is different from the tissues that surround it.

- **Disability** refers to the reduction of function, or the absence, of a particular body part or organ. A person who has an arm or leg missing has a physical disability. Similarly, someone who cannot control muscles required for speech, has a disability in communication. The terms disorder and dysfunction are frequently used as synonyms for disability.

- **Handicap** refers to the problems that impaired or disabled people have when interacting with their environment. A Vietnam veteran who is confined wheel chair put it this way: “Sure I have a disability; but I’m not handicap – until I try to get into a building that has a flight of steps and revolving door as its only entrance.”

- **Normalization** can be defined as the philosophy that all handicapped people should have the opportunity to live lives as close to the normal as possible; patterns and conditions of everyday life as close as possible to the norms and patterns of the mainstream of society should be made available to them (Nirje, 1969).
Normalization has resulted in the greater integration of the handicapped population into business and social activities. Its greatest influence on special education, however, has been the promotion of two practices, deinstitutionalization and mainstreaming.

- **Deinstitutionalization** refers to the movement to eliminate large institutions, particularly those for the intellectually disabled. Wolfensberger (1972), an early advocate of normalization, proposed that long-term total life care institutions be replaced by small, community-based homes that would permit residents to participate in local activities and be closer to their families. The establishment of group homes is being encouraged by many parents and special educators.

*****