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Chapter 1
INTRODUCTION

Mental retardation and mental illness were considered as one and the same in earlier times. During nineteenth century pioneering researchers Itard (1801), Seguin (1837) in Paris and Howe (1948) in Boston; began to draw attention to the group now known as the mentally handicapped. Superstitious thinking, exorcism and fear of the retarded began to dissipate with the advent of the Renaissance. Most important was the contribution of Binet (1905) who founded the intelligence testing movement. Since then, various attempts at improving the quality of life of the mentally retarded began to emerge. Also in the 1970s the philosophy of "normalization" came to the fore, stressing that the lives of mentally handicapped people should be as similar as possible to those of the non-handicapped. This philosophy has given impetus to the movement away from hospital care and to the growth of alternative community- accommodation and training (Youngson 1986). In India, such realization appeared much later. One example is the Indian Lunacy Act - 1912, in which, lunatic means an idiot or person of unsound mind. Mentally retarded were considered as mentally ill and there was provision to keep them in mental hospitals. Only in the Mental Health Act - 1987, mentally retarded were excluded from the group of mentally ill (Bholeswar Nath 1989). Mental retardation is now considered as disability and they are covered under 'The Persons with Disabilities Act' or PWD Act – 1995 (Seema 2003).

Concept of mental retardation

Though the mentally retarded have always been in the Indian communities, the problem was not recognized in its scientific sense for a long time. Many of us are acquainted from our school days with some unfortunate
boys and girls who just could not do mathematics and always performed poorly in school. Some would have known the more severe degree of retardation and remember the traditional village idiot in their locality (Sen. A, 1992). The concepts of intellectual dullness and retarded development are prevailing in Indian communities as a common sense understanding.

Mild deficits may lead only to poor scholastic performance, but more severe deficits affect all aspects of living. Shanley (1986) suggests that the degree of severity is always an important variable. A mildly retarded child may not have any physically distinguishing characteristic and parents may not realize that the child is retarded until academic failure occurs in the schools. For parents of severely retarded children, awareness appears at an early stage.

Even though people recognized retardation fairly well, they were unaware of its nature and cause. Concept of mental retardation is important in deciding how people treat them. For example, perceiving retardation as some kind of illness leads to treatment seeking or ‘shopping behaviour’ in parents of such children.

Krush (1964) reported a case of parents, who were in search of magic key that would restore the severely retarded boy to normalcy. In their search, they contacted 18 physicians, 7 schools, 4 teachers, 2 hospitals, 2 clinics and a chiropractor. Prabhu (1968) analyzed 320 cases during 1965 and 1966 and reported that majority of parents did not consider retardation as the primary problem and they were concerned with the seizure, general poor health, delayed development of speech, etc. In two thirds of the cases, it was the physical problems that troubled parents. The parents of severely subnormal children accepted the presence of retardation better, because the severity of the condition makes the parents to accept it. Prabhu noted that 83 % of parents, at one or the other time, had sought help from quacks or religious people. Hewett (1970) and Keirm (1971) reported very low percentage of such problem (about 8% and 3%
respectively). Narayan (1979) found that out of 48 parents of mentally retarded children; 36 parents consulted different medical professionals in the hope of getting a cure or information about the cause of the child's retardation. 22 families had visited religious places and amount of money spent by the families appear to be higher than their resources. Chaturvedi & Malhotra (1984) found that 60 % of parents tend to view mental retardation as an illness with a probability of cure. They (1982) studied parents of 30 mentally retarded children and reported that 45 % seek no help from medical practitioners, but in the others who seek help more include educated parents, those belonging to higher economic class, and the parents of younger children, of female children, of severe and profoundly retarded children and parents of children with severe psychiatric and organic problems. Venkatesan (1996) studied parents of 97 mentally retarded children and found that parents of moderately retarded children, of female children, of children with multiple diagnostic complaints and those from nuclear families had more frequent consultations or the so called shopping behaviour.

When scientists viewed mental retardation as a form of mental handicap in the same sense as a physical handicap, society supported training techniques and special schools. Even though some parents still carry the disorder concept, in general the concept of handicap is getting more accepted. Tredgold (1963) noted that people have come to understand the essential features of mental retardation. They are convinced that mentally retarded person is fundamentally the same as the normal person who is operating at a lower level of intelligence. He also has potential abilities, which can be further developed by appropriate education and training.

Characteristics of persons with mental retardation

Mentally retarded individuals have different characteristics and no single individual may have all the characteristics. Slow development since birth in all
areas, discrepancy between physical and mental age, poor school / academic performance with repeated failure at school, dependence on others for carrying out day-to-day activities like dressing, bathing etc, appearance of being dull, and being slow in understanding, memory, attention-concentration, thinking, problem-solving, decision making. History of delay in developmental milestones, difficulties in expression / control of feelings / emotions, disturbances in communication skills (expressive / receptive), difficulties in managing money and time concepts, incompetence in performing vocational activities or lack of social skills, associated features like behaviour problems, epilepsy, sensory handicaps, are some important characteristics of a mentally retarded person (Venkatesan 2004).

"Idiot savants" – the seriously retarded persons may show a high level of skill in some specific aspect of behaviour that does not depend on abstract reasoning. Thus a retarded may be able to remember the serial number on every dollar bill he is shown or has ever seen, or he may be able to tell the day of the week of a given date in any year, without resorting to paper and pencil, or even to making other numerical calculations. In other exceptional cases, a retarded person may show considerable talent in art or music. However such unusual abilities among mental retardates are rare (Coleman 1976).

**Definition of mental retardation**

Mental retardation is not something that one has, like blue eyes or a bad heart. Nor is it something that one is, like short or thin. It is not a medical disorder, nor a mental disorder. Mental retardation is a particular state of functioning that begins in childhood, and is characterized by limitation in both intelligence and adaptive skills (Venkatesan 2004).

The term mental handicap indicates either that the normal intellectual functions of the brain have not fully developed for whatever reason, or that
acquired functions have been lost, due to disease or damage occurring during the developmental period (Youngson 1986).

There are two approaches to the problem of defining mental retardation (Girimaji, 1993). The medical / psychological or the clinical approach makes use of the pathological and statistical criteria and it is possible to diagnose mental retardation irrespective of whether or not any individual is identified by his or her milieu as retarded or abnormal. According to the sociological approach, the labeling of an individual as a mentally retarded person is a response to his or her inability to conform to the role expectations of the usual status. Professionals tend to use both these models together in defining mental retardation.

Definition formulated by the American Association of Mental Deficiency (AAMD) has been considered as the most comprehensive one (Grossman G, 1972) and the most widely accepted and currently used definition (Tanguay & Russel, 1991) which incorporates the essence of both of the above said models. According to the AAMD-1983 version, mental retardation refers to significantly sub average intellectual functioning, resulting in or associated with concurrent impairments in adaptive behaviour and manifested during the developmental period.

Identification of mental handicap was based on intelligence scores earlier, but since 1960s, however, more attention has been given to other measures that reflected a person's level of competence in performing skills such as eating, dressing, communication and social skills (Shanley 1986)

Polloway (1997), while discussing the revised 1992 definition holds that this definition has a multidimensional focus. Other than the basic points of IQ and the adaptive skills, the lives of mentally retarded persons are seen as significantly affected by other variables like physical wellbeing, psychological and behavioural factors, family and community supports and medical conditions.
Another important definition is the one given in ICD (International Classification of Disorders) -10 (1992). Mental retardation 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 contributes to the overall level of intelligence, i.e., cognitive, language, motor and social abilities. The ICD-10 and DSM (Diagnostic and Statistical Manual) -IV definitions are similar except that DSM-IV also specifies the age of onset as below 18 years of age (Chadda 1999).

Mental retardation is also defined as a disability characterized by significant limitations, both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before the age of 18 (AAMD 2002). The five assumptions essential to the application of this definition are: (1) Limitations in present functioning must be considered within the context of the community environments typically of individual's age peers and culture. (2) Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and communication factors. (3) Within an individual, limitations often coexist with strengths. (4) An important purpose of describing limitations is to develop a profile of needed supports. (5) With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation will generally improve.

Classification of mental retardation

Various terms namely feeble minded, moron, imbecile and idiot, were used earlier. At the present terms namely mentally retarded, mentally handicapped, mentally deficient, mentally disabled, or mentally challenged are used. The term mental retardation is widely accepted (Baroff 1986, Reber 1992, Batshaw 1993).
Depending on the purpose, mental retardation has been classified differently. From the medical and psychological standpoint, it has been classified as mild, moderate, severe and profound; based on the Intelligence Quotient (IQ) (Zigler, Balla & Hodapp 1984, Sturmey 1993). There are certain problems in labeling and categorizing mental retardation strictly on the basis of IQ. For example, there is a standard error of measurement, which is 3 or 4 points over or under the score obtained on a particular test. Thus an IQ of 70 may actually mean an IQ of 66-74, called as the “zone of uncertainty”. One has also to take into consideration the “adaptive behaviour” of the patient. Thus, for making a diagnosis, both the intellectual level as well as the adaptive behaviour should be assessed, especially if the IQ falls within the zone of uncertainty (Chadda 1999). The scales commonly used for measuring the adaptive behaviour are the Vineland Social Maturity scale and the AAMD Adaptive Behaviour Scale (Kaplan, Sadock & Grebb, 1994). A definition of mental retardation based on social competence would be preferable to definition based on psychometric criteria (Greenspan & Granfield 1992). However, sub classifications based on IQ is helpful in predicting outcome and determining educational program (Chadda 1999). Considering the educational and functional aspects of their behaviour and abilities, it has been classified as educable, trainable and custodial (Kulkami 1999).

The two main components of mental retardation, namely low cognitive ability and diminished social competence, are profoundly affected by social and cultural influences and so clinical diagnostic criteria that can be used internationally for research cannot be specified. A specially designed multi axial system is required to do justice to the variety of personal, clinical and social statements needed for the comprehensive assessment of the causes and consequences of mental retardation (ICD-10, Diagnostic criteria for research, WHO, 1993). In ICD-10 mental retardation is classified in to four levels- mild (IQ 50-69), moderate (IQ 35-49), severe (IQ 20-34) and profound (IQ less than 20).
Psychological assessment of mental retardation

Definition of mental retardation has two important criteria, namely sub-average intellectual functioning and problems of social adaptive behaviour. Therefore, psychological testing becomes crucial in diagnosing the presence and degree of mental retardation. There are many problems in assessment as the mentally retarded have associated sensory motor deficits, communication problems, behaviour problems, poor attention, poor concentration and lack of motivation and cooperation. Use of psychological testing is not only for diagnosis, but also helps in providing a profile of abilities and disabilities, which helps in training, to evaluate therapeutic effects and in providing vocational guidance. Important areas of assessment are assessment of general intelligence, assessment of adaptive behaviour and assessment of individual abilities and deficits. Gessell's Developmental Schedule, Vineland Social Maturity Scale, Binet-Kamath Test, and Seguin Form Board are some of the important psychological tests which are commonly used.

Prevalence of mental retardation


A few sample surveys have estimated approximately 3% of the general population as mentally retarded. About 2% of the total population are mentally retarded with a net annual increase of 0.35 million (Venkatesan & Vepuri 1995). The present total birth rate in the country translates in to one mentally
handicapped infant being born every minute in one more family (Kulkami 1999). Ganguli (2000) reports the rate per 1000 as 3.7 in rural areas and 9 in urban population. The once widely used figure of 3% prevalence of mental retardation has lately come under stringent medical scrutiny and the latest estimation indicates 1-2% (Tarjan, Wright, Eyman & others 1973, Baroff 1986, Zigler, Balla & Hodapp 1984, Greenspan & Granfield 1992, Reber 1992, Batshaw 1993). Those with severe degree of retardation would be 3 to 4 per 1000 in the population. 85% of the mentally retarded persons fall into the mild category and the remaining 15% belong to moderate, severe and profound groups (Szymanski and Crocker 1989, Zealley 1993, Baird & Sadovnick 1985). In the Indian setting, 75% of the mentally retarded persons are considered to be belonging to the category of mildly retarded (Prabhu, Verma, John, Daniel & Elizabeth 1985). Epidemiological study by Baird and Sadovnick (1985) at British Columbia (Canada) reported a closer figure to the current figure of one percent prevalence than to the older figure of three percent.

Etiology of Mental Retardation

There are two types of causes: (1) Biological and (2) Socio-cultural.

(1) Biological causes

Biological abnormalities can be detected in approximately 25% of the cases of mental retardation on extensive investigations (Zealley 1993). Mental retardation due to biological causes is usually recognizable at birth or in the early childhood; the severity in such patients is generally moderate to profound (Chadda 1999). Clinicians need to detect such causes as they help in genetic counseling, family management and recognition of associated handicaps (Szymanski & Crocker 1989). The retardation due to socio-cultural causes is usually mild in nature. Taft (1987) classified the causes as organic and non-organic and McQueen, Spence, Winsor, Gamer & Pereria (1986) classified the biological causes as prenatal, perinatal and postnatal. According to Chadda
(1999) some of the important prenatal causes are – (i) Inborn errors of metabolism, (ii) Chromosomal aberrations and hereditary disorders (iii) Complications of pregnancy and (iv) Maternal infections during pregnancy; some of the important perinatal causes are – (i) Prematurity, (ii) Intra uterine growth retardation, (iii) Birth injuries and (iv) Kericitus (a defect in bilirubin metabolism) and some of the important postnatal causes are – (i) Infections, (ii) Malnutrition, (iii) Lead poisoning, (iv) Cerebral palsy, (v) Heller’s disease and (vi) Head injury.

It is known that autosomal recessive conditions are seen in greater prevalence in families with consanguineous marriages. Studies carried out at Vellore (Centerwall & Centerwall 1966, Joshua 1974), Bangalore (Rao & Padmashree 1986 b,) and Hyderabad (Uma, Jyothi, Reddy, & Reddi1982; Jyothy, Shobha Rani, & Reddy 1986) have shown 30-40 % prevalence of consanguinity. In north India where social customs do not encourage consanguineous marriages, the rate of consanguinity is less than 10% (Sinclair 1972).

In an Indian study on causes of mental retardation, Rao, Narayan & Reddy (1971) found most being idiopathic. In another study, the same investigators (1974) found in a sample of 1234 mentally retarded children that the etiological factors could not be determined in 27 to 48% of mental retardation cases. Sinclair 1972, Subramanya, Agarwal & Jaiswal 1974 and Joshua (1974) reported that 47% of mental retardation is due to genetic origin. Steel (1982) found that 20 to 30% of mental retardation is genetic in origin. Comer & Ferguson (1987) have reported that 55% of mental retardation is due to genetic causes. Kusuma Kumari, Sujatha, Usha Rani, Isac & Reddy (1990) reported genetic or partly genetic causes in 81.8% of cases and in 44.2% cases exact etiology was not known.
Mathew (2002) studied 98 cases belonging to 0-10 years of age level. Detailed case history was taken and intelligence and adaptive behaviour were assessed. Various causes have been analyzed and it was found that prenatal psychological stress turned out to be an important causative factor in 15.3% of the cases. There was no significant etiology reported by 30.6% of cases.

(2) Socio-cultural factors

Large percentage of mentally retarded comes from lower socioeconomic groups where many factors like adverse social, economical and cultural conditions (Nanda 1978), environmental deprivation and familial influences play a role. Malnourishment of the prospective mother, improper care, dietary deficiencies during pregnancy, untreated maternal infections, pre-maturity and obstetric complications due to the above reasons, health hazards for the baby, and the nutritional problems in children (Llyod 1976; Winnick & Rosso 1979) are some of the important causes. Poverty and large size of the family are reasons for improper care of the child. Poverty and lack of stimulating environment in childhood cause retardation usually of mild variety, but children so affected often are not able to complete regular schooling (Naik 1992). Sensory stimulation, play experiences and pleasure are lacking as the mother is often busy in looking after a number of children besides acting as an earning hand. Stimulating environment has been shown to lead to a remarkable improvement in enhancing the intellectual level.

Shift from institutional care to family care

The late Victorians in Britain were so haunted by a decline in national intelligence that they ruthlessly segregated mentally retarded people and kept them in asylums and colonies, of course later converted into hospitals, to prevent them from multiplying and increasing their number.(Sen 1992).
Institutionalization was the trend for a long time. Parents were advised to place their severely retarded children in institutions at an early age (Aldrich 1947), but, as studies showed the adverse effects of institutionalization (Goldfarb 1945, Bowlby 1951, Farel 1956) the trend changed gradually to family care. Centerwall & Centerwall (1960) found that retarded children brought up at home had better outcome compared to those brought up at institutions. Community care was strongly advocated by Younghusband (1970).

Carr (1974) reviewed effects of severely retarded children on their families and concluded that, most families want to keep their children at home, but the situation becomes difficult when the child is more severely retarded, has behaviour and management problems and comes from a large family which has multiplicity of other problems. Saha (1982) found that the mentally retarded children become social isolates who require greater parental involvement. Balchandran (1985) emphasized the role of family in promotion of mental health. Cole (1986) opined that when faced with excessive demands, the family may cope by eliminating the stressor, which is nothing but the child itself, by placing the child out of home. Rowitz (1992) noted that mental retardation is a family affair and what is in the best interest of the family is generally in the best interest of the individual with developmental disabilities. Mink (1993) holds that the shift in focus from the individual to the family is important because what affects one family member will affect all members. Blacher & Baker (1994) reported that despite public policy supporting home care for children with mental retardation, some families still seek out of home placement. Rimmerman & Duvdevani (1996) found that 5 predictors are important in out of home applications—high parental stress, lower social support, favourable attitudes toward normalization, lower family climate and higher age of the child. Hanneman & Blacher (1998) found that the more normative the child’s appearance, the less likely caregivers were to seriously consider placement. Higher socio economic standing of mothers promoted more serious consideration of placement, as did larger number of
siblings in the family. Stress on caregiver contributed to both placement intentions and actual placements.

Even though this is the era of family care, still institutionalization is continued partially due to difficulty in management of the child and, of course some parents do so with an idea that training may improve their children. It is inevitable to institutionalize when there is no facility for a day school in their locality. The magnitude of institutionalization is small because most of the residential care centers are private and costly and so, many parents cannot keep their child in such centers even if they want.

Prabhu (1995) noted that the founding of the Children’s Aid Society and starting of the facility in her home with two mentally retarded children by Jai Vakeel in the early 1940s is noteworthy. From this small beginning the number has gone up to 700. The home for mentally deficient children in Bombay established by Children’s Aid society in 1941 is claimed to be the first voluntary agency in India. In the 1950s eleven more schools were started in various parts of India. Another sixty centers were added during the 1960s (Venkatesan & Vepuri 1995). Kamath (1978) reported that for such a vast country like India there are only 150 day care and about 65 residential care institutions. Dhoot (1992) noted that in 1966 there were 51, in 1973 there were 91, and in 1987 there were 146 institutions. The National Institute for the Mentally Handicapped (NIMH) has compiled a Directory of Institutions in India (Reddy 1988, 1989 and 1992) and listed 485 institutions.

Caring for the mentally retarded individuals

Institutional care is one way of rehabilitation and the other way is to set up day-care centers or special schools for the mentally retarded individuals. Yet another approach is to take professional advice from rehabilitation experts located in their consultation chambers either in a hospital, counseling center or in
child guidance center. Most common and popular method adopted by many is approaching counselors or rehabilitation experts. As discussed in the previous section, there is shortage of all such facilities and due to this; the role and responsibility of parents and families of persons with disabilities get increased (Venkatesan 2003).

In 1978 a workshop on development and strengthening of mental retardation programs recommended that – (1) Each country should identify a resource group of persons familiar with mental retardation and charge them with the task of planning preventive and rehabilitative services and training programs. Their plan should be coordinated at a high level, within the national plan of development. (2) Day care facilities for retarded children should be set up and assistance given to families in greatest need. Cooperation with voluntary associations in these activities is strongly recommended. (3) Prevention should be advanced by strengthening family health services, extending immunization programs and developing genetic counseling. (4) Estimates should be made, based on survey and research, of the magnitude of the problem, and the main causes, especially in the rural areas. (5) Anachronistic laws dealing with mental retardation should be revised.

National Institute for the Mentally Handicapped, Secunderabad, India has come out with training manuals for different personnel like village rehabilitation workers, multi rehabilitation workers, guidance counselors and psychologists (NIMH 1988).

More than these professionals, the immediate caregivers in the family are important. If caregivers are educated they can handle the day-to-day problems of the disabled more effectively (Chawla & Neki 1978). An informed parent suffers lesser guilt, reduced psychological stress and all these foster better quality in the retarded and his family (Ember 1979, Harisasara 1981, Dadu 1982, Kaushik 1984a&b, Kohli 1989b, Bhuvsar 1991, Madhvan & Nayan 1992).
The need to improve the quality of early intervention was expressed by many (Akhtar & Verma 1972, Pandit, Vijayalaxmi, Naik & Plumber 1988, Kohli 1989a) which helps in saving the precious time which is otherwise wasted in approaching illusory or quickie treatment by parents. (Singh 1981, Girimaji 1990)

For early intervention, early diagnosis is the most essential step (Jeyawardena 1977, David 1984, Bailey & Simenson 1988, Girimaji 1990, David & Apte, 1991). Estimation of developmental level in infancy in the normal range has poor correlation with the later intellectual functions; whereas, estimates of developmental level in the retarded range, have high correlation with later intelligence. Discussing the problems of diagnosis Girimaji (1990) suggests the system of diagnosis evolved at the MR clinic of National Institute of Mental Health and Neuro Sciences (NIMHANS) as useful in management, which is as follows – Axis I - degree of retardation. Axis II - etiological factors / syndromal diagnosis. Axis II - associated medical disorders / handicaps. Axis IV - associated psychiatric disorders. Axis V – parental and psychosocial factors. Some of the important steps of early intervention are as follows (Girimaji 1990) – (1) Treatment of underlying disorders wherever possible. (2) Treatment or correction of associated medical and psychiatric problems. (3) Counseling parents about diagnosis, prognosis, treatment options and motivating them for training. (4) Planning an individualized training program based on the assets and liabilities in the child, family and environment. (5) Involving parents in training as much as possible and help them to acquire training skills. (6) Referring to appropriate agencies whenever required. (7) Periodic monitoring and discussion with parents. Some of the techniques used in early intervention are (1) sensory motor stimulation, (2) speech and language training, (3) motor training, (4) self-help skills training, (5) social skills training, and (6) cognitive stimulation.

Assessment of parental attitudes and perceptions is an important step to be taken before starting counseling or training program (Devi 1976, Srivastava 1978, Rastogi 1981, Chaturvedi & Malhotra 1983, 1984, Channabasavanna,
In India, parent training programs for the mentally handicapped have been developed by Dr. H.S. Narayan at Bangalore, Dr. Sally Datey at Vellore, Dr. V.K. Varma & Dr. M. Seshadri at Chandigarh, Dr. S.S. Kaushik at Varanasi and Dr. M. Mehta at Delhi. A family model has been tried at NIMHANS, Bangalore and Christian Medical College (CMC), Vellore, where families of the retarded children stay together with their ward and are trained through group interactions to look after their retarded children (Mehta, Bhargava & Pandey 1990).

Brief inpatient family intervention model developed at NIMHANS in 1985, is of great help in meeting the needs of subgroups of families who needed intensive intervention for reasons such as presence of high degree of stress and poor coping skills in the family following the birth of the mentally retarded child (Girimaji 1993). Others have reported such interventions across the country (Damle 1952, Adisheshiah 1972, 1987, Peshawaria & Menon 1991).

Counseling the parents of mentally retarded aims at imparting factual information (which includes proper communication of diagnosis and prognosis), alleviation of parental distress and promoting healthy attitudes and coping mechanisms and equipping them with appropriate skills to optimally bring up and care for their affected child. Parents need to go through a period of “priming” after detailed evaluation during which parents develop sound knowledge of the diagnosis and prognosis and are able to sort out their emotional and other maladaptive reactions (Girimaji, Shobha, Sheshadri, Madhu Rao & Nardev 1990). Parental counseling (both individual and group) as an important tool has been advocated by many others (Bhatia 1964a & b, Akhtar & Verma 1972, Mazumdar & Prabhu 1972, Desoza 1979, Miles 1980, Jayashankarappa & Puri 1984, Mehta and Ochaney 1984, Babusenan 1987, Mehta, Bhargava & Pande 1990, Ramaswamy 1990, Hornby & Peshawaria, 1991).
Barnes (1990) listed the psychological and behavioural problems as (1) cognitive dysfunctions- which includes difficulty in sustaining concentration and lack of alertness, (2) motivational dysfunctions- resulting in laziness, resignation, apathy and anxiety, (3) neurological dysfunctions- owing to brain pathology, (4) other psychological problems such as poor self esteem, disturbed body image, feeling of rejection, emotional and personality hang ups and (5) excessive social and educational demands.


Important disorders appearing in association with mental retardation are listed by Bhatia (1994) as – (a) physical disorders like defects in vision or hearing, motor disorders (spasticity, ataxia and athetosis), and epilepsy and (b) psychiatric disorders like schizophrenia (characterized by poverty of thinking, less elaborate delusions, simple and repetitive hallucinations; also called “Pfropf schizoophrenie”), mood disorders, neurosis (common in less severely retarded), personality disorder, organic psychiatric disorders, autism, over-activity syndrome, behaviour disorders (mannerisms, head banging and rocking, hyperkinetic syndrome, temper tantrums, self stimulation, pica, undue dependency, legal problems) and sexual problems (public masturbation is the most common frequent problem).

Other than the above said interventions, for the associated disorders; drug therapy and behaviour modifications are used frequently. Even though there is no drug for curing mental retardation as such, drugs help to control the
associated psychiatric problems and thus help further management and training. Sell (1984) observed that 75% of mentally retarded children seen in the outpatient department of well known college in northern India are simply being prescribed drugs only. Drugs are used in specific indications like psychosis, depression, anxiety, hyper-kinesis and other severe behaviour disturbances. Anti-psychotics are used when there is psychotic disorder. Other than anti-psychotics; lithium carbonate, carbamazepine, sodium valporate and naltrexone have been used to control aggression and self-injurious behaviour in the mentally retarded (Craft, Ismail, Krishna Murthy & others 1987, Campbell, Anderson, Small & others 1990). Haloperidol and chlorpromazine have been used to control stereotyped motor disorders. Stimulants, such as methylphenidate and amphetamines are prescribed in cases of hyperactivity. In specific behavioural disturbances, use of medications is always an adjunct to the behavioural interventions or other non-physical approaches of treatment. A need for caution is expressed in using antipsychotic drugs wherever definite brain pathology is present (Chadda 1999).

Behaviour modification techniques are used in teaching skill behaviours and in treating problem behaviours. Some important domains of skill behaviours in which the mentally retarded children perform poorly compared to the normal children of their age are – (1) Motor skills like running, jumping, walking up and down stairs, riding bicycle, etc. (2) Activities of daily living like eating, toileting, brushing, bathing, dressing, grooming, etc. (3) Language skills like receptive and expressive language. (4) Reading and writing (5) Number and time concepts. (6) Domestic and social skills (7) Prevocational skills and money concept. Some common problem behaviours which are problematic to others or to the child himself are – (1) violent and destructive behaviours (2) temper tantrums (3) misbehaving with others. (4) Self injurious behaviour. (5) Repetitive behaviours. (6) Odd behaviours. (7) Hyperactivity. (8) Rebellious behaviour. (9) Fears (10) Sexual problems. The period of therapy is often longer in the mentally retarded as compared to that in children with normal intelligence and the success rate is

Since mentally handicapped persons can never be 'cured' of their handicap, rehabilitation for them is more specifically defined as full integration or re-integration into community life, and the maximizing of individual potential (Youngson, 1986). Regarding special education, the retarded children can be divided into two groups, depending on the level of retardation: the educable, those capable of grasping the rudiments of academic skills, and trainable, those capable of acquiring only the basic social skills. Early intervention is important as it accelerates the mental and social development and it also prevents the development of faulty learning habits. The principles of operant conditioning are frequently used for imparting education. Early preschool programs have been found to raise the IQ by more than 15 points depending on the nature and intensity of the program (Naik 1992). Every individual (no matter how severely impaired) is capable of learning so long as life endures and he is responsive to the environment. Changes may be fostered towards the maximum development of human qualities by the process of education, socialization and physical care; Services for the mentally retarded persons have the same goals as services for all children and adults (Thakur Hari Prasad, 1990). Rehabilitation depends on the learning potentials and assets of the retarded person. Supported employment, including job placement, is important role in rehabilitation of the retarded (Botuck and others, 1992). Those with multiple physical handicaps, with severe and profound retardation, require physical rehabilitation. Children with sensory handicaps require special training and educational facilities, while those with motor difficulties require orthopedic services and physiotherapy.
Towards Welfare of Mentally Retarded Persons

Most parents of mentally handicapped often ask this question as to what will happen to their mentally handicapped child after they are no more. This was one of the topics discussed at the national meeting organized by Thakur Hari Prasad Institute for Mentally Handicapped Children in Feb. 1987. The Government of India has established National Trust, which can provide guardianship for such mentally handicapped persons. National Trust for welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities has been formed in 1999. The Government of India has given various benefits to the parents of mentally retarded children. Income tax rebate and family pension facility has been given to government servants. The Government of Karnataka has the provision of giving monthly pension to the poor parents of severely mentally retarded children. School-going retarded children are given scholarships. Special insurance benefits are also available. Railway concession is given, not only for the retarded individual but also to the person who accompanies the retarded individual. For the mildly retarded, job reservation and loan facilities for self-employment also have been started. The rights of mentally retarded in India are discussed in Venkatesan (2004).

Prevention of mental retardation

The intention of preventive measures is to reduce the incidence or prevalence of a disorder. The various measures of prevention are classified into three categories - primary, secondary, and tertiary.

Primary prevention includes public education, improving maternal and child care and genetic counseling. Consanguineous marriages, marriage at improper age and marriage of the retarded are to be avoided. Secondary prevention aims at early diagnosis and intervention. Rectification of biological
errors has to be undertaken at an early stage. Tertiary prevention includes treatment of associated emotional and behavioural problems, parental counseling, special education and rehabilitation.

Reactions and attitudes of parents towards the mentally retarded child

Here in this section some studies on reactions and attitudes of parents towards the mentally retarded child are covered. When a retarded child is born in to a family or when the parents come to know that their child is mentally retarded, parents and family members show various reactions like shock, guilt, denial, anger and so on. Parental attitude towards their retarded child is usually formed on the basis of their initial reactions. Attitudes may depend on child characteristics and also on the personality of the parent. These reactions and attitudes play an important role in the perception of stress and in the coping process. Some related studies are reviewed here.

Some studies on reactions and attitudes:

Waterman (1948) and Hastings (1948) studying the psychological factors in parental acceptance of mentally retarded children found that unsuccessful attempts at abortion gave rise to guilt in mothers. Boles (1959) found premarital sex, marriage outside the religion and homicidal wish as important factors. Repond (1955) viewed that when deficiency is obvious at birth or when the realization slowly comes, the most serious problems are aroused by parental guilt at having produced such a child. It was found that well assorted couple who love each other and are bound together by strong mutual sympathy will tend to become even more firmly united to form a close defensive triangle – mother, father and the defective child. On the other hand if the bond between the couple is not strong, has a disastrously disrupting effect. Each tend to blame the other, increasingly find fault and criticize, disruption may lead to separation or family breakup. Zuk (1959) found that Catholic mothers to be more acceptant and they
made quicker adjustment by taking it as a responsibility given to them by God. Kramm (1963) studied parents of Mongol children and found 12% of mothers reported it to be a direct act of God (punishment). Michaels and Schuemen (1962), Ellis (1982), Dodge (1976) and Beck (1962) found denial of the existence of mental retardation in their child. Olshansky (1962) proposed that most of the parents suffer from pervasive psychological reaction identified as chronic sorrow, particularly if the child is severely retarded. Condell (1960) discovered strong emotional reactions like crying, questioning and running from specialist to specialist in the mothers when they realized retardation in their child. Solnit & Stark (1961) did a psychoanalytic study of mourning at the birth of a defective child. They found that mothers of retarded infants on being told that their child was mentally retarded plunged in to a period of despair similar to the sequence of a grief reaction to actual death – denial, anger, despair and finally acceptance. Worchel & Worchel (1961) reported that most of the parents had negative attitude as they considered the mentally retarded child as a taint on the family stock and they had doubt about the heredity. Fortune (1962), Frenklin (1963), Cowie (1966), D'Acry (1968), Berg, Gliderdale & Way (1969) and Carr (1970) noted that mothers wish to know about their mentally retarded child very early and also that parent's satisfaction about how they were told correlates well with being told early in child's life. These studies indicate that awareness has an important role in the development of parental attitudes. Farber, Jennin & Toigo (1960) found that the initial stress in the parents appears to be linked to the sex of the child. Cook (1963) found that regardless of their nature, mildly retarded were, most likely to elicit parental rejection and the severe ones elicited overprotection. Ehlers (1963) examined the perceptions of mothers and revealed that in the case of severely retarded children most of the mothers recognized the slow and atypical condition of the child and made an early decision to seek medical help. Appell, Williams & Fishell (1964) observed confusion and inability to accept the situation in most of the parents who had unrealistic goals and they needed counseling to change it. Goshen and Morgantown (1963) observed depression in mothers. Erickson (1968, 1969) found that the mean profile
patterns on Minnesota Multi-phasic Personality Inventory (MMPI) obtained for the parents indicated neurotic symptoms related to aggression, anxiety and depression. Brinkworth and Collins (1969) found that the first response of parents on being told that the child is mentally retarded is grief. Mackeith (1973) reported parental feelings of revulsion, inadequacy, anger, grief, shock, guilt, bereavement and embarrassment at the birth of a mentally retarded child. Carr & Oppe (1971) reported that grief and guilt tended to predominate in the mothers because they had not only lost the hoped for normal baby, but had given birth to an imperfect one. Grief was expressed in weeping or depressive withdrawal. Guilt was manifested through self-accusation, blaming ones past sins; fate etc. anxiety was exhibited by seeking answers to innumerable questions. Gath (1972) studied families of children with mental and physical handicaps and found that many of the women remembered the bitter feelings they had when they first got the news of the child being mentally retarded. Bentonin (1972) has noted that when a defective child is born the parents get a shock, which disrupts management of the child to some extent unless reinforcement is given by elders in the family or by the family doctor. Drotar, Baskiwitz, Irvin, Kennel & Klaus (1975) described 5 stages in parental response – shock, denial, sadness and anger, adaptation and reorganization. Wing (1975) found that 57% of mothers had mild to severe psychiatric symptoms like anxiety and depression. 84% had worry of having mentally retarded child. The siblings of mentally retarded too had problems, 9% learning problems, 6% antisocial behaviour and 23% had some special problems. Wolfensberger & Kurtz (1969) reported that the society tends to view the mentally handicapped individual as a sick person, a menace to the society, a sub human, an object of pity, a burden of charity, children who will never show up or perhaps capable of development. Srivastava, Saxena & Saxena (1975) assessed the attitude of mothers and found that the mothers fostered dependency in children. Marital conflict, strictness with children, easy irritation with children, suppression of aggression and avoidance of communication were some of the trends observed in families with retarded children. Dodge (1976) studied the family’s reaction to the problem of mental retardation in the child.
Initially feelings of being overwhelmed were observed, but later, denial, anger, intellectual acceptance and finally emotional acceptance of the child. Ehlers, Krishef & Prothero (1977) opined that all parents show one of the three basic responses towards the retarded child. First, the child is accepted for what he is and the parents recognizing the child's limitations try to the best of their abilities to provide the most wholesome environment possible in which the child achieves his highest possible level. Second, the parents either accept or reject the child, with possible shading of acceptance and rejection, but decide to institutionalize him. Third, they reject the child either part or whole. Gath (1978) studying the parents and sibs of Down's syndrome states that the parents project much of their grief upon the people who were present and involved with them when they first came to know about the distressing news of their child's handicap. Prabhu (1978) found that mental retardation is not considered as a serious problem, especially in the agricultural communities, where it is not noticed at all. Sethna (1978) noted that parents tend to treat the retarded child differently and wax from overprotection to shame. Narayan (1979) found that 71% of the mothers felt panicky when they realized that their child was mentally retarded. A variety of reactions was observed such as hostility, feelings of sadness, blaming self, wishing for death, grief etc. Some even felt that it would have been better if they had no children instead of a mentally retarded child. Mothers showed more anxiety and depression. Hariyasara (1981) noted that the initial reaction of parents to the realization of having a retarded child as shock, followed by coping mechanisms. Ishtiag & Kamal (1981) studied 20 moderately retarded children and their families. 72% of the families had marital disharmony as a result of birth of a handicapped child. 56% parents of parents had negative attitude and 88% of the mentally retarded children were neglected by their parents. Rastogi (1981) studied parents of 50 mentally retarded children. Both parents showed negative attitude towards the severely retarded children and mothers exhibited more negative attitude than the fathers. Kalyani Gopal (1985) studied parents of 60 mild, moderate and severe mentally retarded individuals and reported that 70% of parents have positive attitude while 3% had negative attitude. Puri & Sen
(1989) opined that the behaviour of mentally handicapped child was disruptive to the smooth functioning of any group, whether it is the family unit or it is the playground or it is the classroom and could prevent the child’s integration in such groups. The reaction of the group members to such disruption might be one of rejection, exclusion, punishment or the disorganization of the group itself. Ramadevi (1991) in a study of attitudes of rural children towards their mentally retarded siblings indicated that majority of children favoured their retarded sisters to their retarded brothers irrespective of the sex, age, ordinal position and educational level of the sibling of the retarded child. Narayan, Madhavan & Suryaprakasam (1993) studied the impact of professional intervention on the parental perceptions and expectations and showed that expectations in areas like total cure, need for special education and speech development showed significant changes, the number asking for cure reduced and those expecting training increased. Ramgopal & Rao (1994) and Rangaswamy (1995) found that the mothers of mentally retarded children with behaviour problems have high negative attitude with respect of acceptance, education and future home management and hostility. Peshawaria, Menon, Ganguli, Sumith Roy, Rajam, Pillay, Asha, Guptha & Hora (1994) felt that these reactions are not permanent and these reactions are normal reactions to a situation of stress. Parvathi and Vijayakumar (1995) indicated that the family climate for retarded males is not as good as that of females, but that concern shown for their welfare is equivalent for both populations. Behari (1995) found that more marital conflict, rejection of home making role and ascendancy of the mother were evinced more in well educated and upper class mothers than in less educated and lower class mothers. Bruce, Schultz & Smyeansios (1996) found the presence of grief over time and mothers showing higher levels of avoidance behavior and intrusive thoughts about the child, and were more distressed at recalling the time of diagnosis. Ansari (2002) indicated that the parents showed greater acceptance for their disabled children, when the disability was manifest (when the children were deaf, blind or physically handicapped). When the disability was not manifest, as in the case of mentally retarded children, there was no difference
between the non-disabled and disabled children. While gender of the child was not important, the gender of the parent emerged as a significant variable; the fathers showing greater acceptance and the mothers showing relatively greater rejection towards the disabled child. Juyal (2002) found that children show better home and emotional adjustment with attitude of acceptance of their parents and better social adjustment with permissiveness and domination of their father.

**Stress and coping in the families of mentally retarded**

When a mentally retarded child is born in to a family various problems start challenging the family members. Compared to physical handicaps, mental handicap is more problematic. The physically handicapped may be trained in specific ways and may become quite useful, but due to intellectual limitations, specifically when the retardation is severe, a mentally handicapped becomes totally useless as he or she does not learn anything significantly or satisfactorily.

In India, having female children itself is a stress and if the mentally retarded child is female, it adds to the pathetic condition. When the mentally retarded child is male, then also, due to expectations on the male child, the condition becomes a sensitive issue.

More than that, as medical intervention does not help in most of the cases, a feeling of despair arises. It is noticed how parents and family members react when they come to know that their child is mentally retarded. Such reactions affect the attitudes and these decide the amount of stress experienced and the nature of coping in the family members. Anxiety and depression are commonly noticed.

Parents may avoid social contacts due to fear of embarrassment or rejection. They may hardly find time for recreation or leisure due to caring responsibilities. Some parents may feel rejected or neglected from their own
family members, and some may get adequate support also. Probably the unity, strength and support within the family are important factors, which influence the nature of coping.

In some families the father has to change his job or try to get transfer to such place where services for the retarded child may be available. If the mother is a working- woman she may find it more stressful to put on with her job or may have to leave the job. Financial distress is common in such families due to their shopping behaviour, they have to spend more, borrow money, for the medical interventions or for the training of the retarded child.

Parents and other family members experience burden of caring for the child, mother getting more affected than others. If the child has behaviour problems this burden increases.

Siblings of the retarded child are known to get affected, female siblings getting more affected as they are expected to share the caring burden more than the male siblings. They may feel embarrassed in social situations, have less free time and may experience problems in education. In the process of caring for the retarded child, parents may give less time to the normal siblings and may neglect them. This may lead to emotional and behavioural problems.

Some important factors helping parents, siblings and the family members in coping successfully with the situation are: adequate support from the family members; help in caring for the child by the husband, siblings of the retarded child and grand parents; help from others in the surroundings; financial help; professional help; medical help; understanding attitude of others; social acceptance and above all these, spiritual attitude or belief in God. The role of siblings and grandparents as support to the parents cannot be neglected. Some of the major things which the Indian parents found inhibiting them in coping with the situation include lack of acceptance of the retarded child within the family
especially by the paternal grandparents, other relatives, in the neighborhood and by people in the community. To manage a retarded child having behaviour problems is also found to be a major block. The wrong or delayed advice given by the professionals and their insensitive handling of the whole situation has been reported to be found most upsetting and discouraging to the parents. Other inhibitors include poor physical health of the family members, lack of facilities for training their retarded child and loss of support from family members and relatives (Peshawaria 1994).

Tucker (1982) reviewed literature and opined that it is the absence of support that interferes with adjustment and not the presence of support that facilitates it. Curtrona (1986) holds that the stress-suffering model of social support holds that when stressful life events occur, individuals who have adequate support resources are able to mobilize these resources to help them in coping effectively with challenges posed by the stress. Van (1999) indicates that future research needs to shift the focus from assessing stress and distress, to assessing resilience and adaptation.
Stress refers to the negative feelings generated during the process of coping with problems of life. Cannon's (1932) description of the fight-flight response was one of the important theoretical concepts about stress and Selye's (1956) general adaptation syndrome was the most popular theoretical framework for research. But, both theories were inadequate for understanding the psychological stress. Wolff (1953) proposed the idea that life stress played a role in etiology of disease which gained popularity in the field of medicine.

Any theoretical explanation of stress had to explain how individual differences arose. Lazarus (1966) proposed that individual differences in performance under stress were due to the fact that not everyone perceived potentially stressful situations in the same way. The process of cognitive appraisal psychologically mediates stress and thus an event is only stressful if it is appraised stressful by the individual. When confronted with a problem, individual engage in determining the meaning of the event and their consequences, which is called as primary appraisal. Next the secondary appraisal occurs in which the individual assesses his coping abilities and resources. Subjective experience of stress is a balance between primary and secondary appraisal.

Other than cognitive responses like specific beliefs about the harm an event can cause or about the controllability of the problem, there can be
distractibility and disruption of performance on cognitive task (Cohen 1980). Anxiety, fear, excitement, embarrassment, anger, depression and denial are some of the important emotional reactions to stress (Sarason & Johnson 1979, Batlis 1980). Behavioural responses are limitless, depending upon the nature of stress, including smoking, alcoholism, drug abuse, frequent hospitalization and destructive behaviour. Thus, Lazarus elaborated the idea that some psychological process mediated stress, by the concept of cognitive appraisal and extended the focus on coping. Some other approaches to individual differences focused on the role of personality variables as mediating variables and locus of control (Rotter 1975), self efficiency (Bandura 1977), concept of hardiness (Kobasa 1979) and sense of coherence (Antonovsky 1979) are some such important variables.

Defining stress

The concept of stress is found in physics, physiology and psychology. In physics, stress is a force which acts on a body to produce strain and in physiology; the various changes in the physiological functions in response to evocative agents denote stress (Agarwala, Malhan & Singh, 1979). In psychology, stress refers to a particular kind of state of the organism resulting from some interaction between him / her and the environment (Pestonjee 1992). For Torrington, Weightman & Johns (1985) stress is a demand made on our physical or mental energy. Where this is felt as excessive, it is experienced as stressful and may lead to stress-related physiological problems. Commenting on stress and pressure, Spielberger (1979) states that stress is generated when the pressure begins to do harm. Arroba & James (1987) maintain that pressure and stress are words which are often used interchangeably. They are not in fact the same. Everyone needs a certain amount of pressure. Pressure can lead to stress. No one needs stress. Stress is one's response to pressure, not the pressure itself. Arroba and James hold that both high pressure and low pressure are inappropriate and thus stressful. For Ivancevich & Matteson (1986) stress is
not a response only, but is a stimulus also. Stress as a stimulus has some characteristics, event or situation in the environment that in some way results in a potentially disruptive consequence. The three factors determining what an individual experiencing is likely to result in stress are importance, uncertainty and duration. Holt (1993) defined stress as something associated with tension and anxiety and it can be destructive both physically and psychologically, but it is essential for life. According to Mason (1975) stress can refer to an internal state of the organism (both physiological and emotional), an external event or an experience that arises from a transaction between a person and environment.

**Stress and coping process**

Lazarus & Folkman (1984) conceptualized the stress process as beginning with the occurrence of a significant environmental event, which triggers a process of primary appraisal, followed by secondary appraisal, coping strategies and adaptational outcome, which is the end of the process. An individual assesses the implications and its positive or negative aspects of an event in the primary appraisal. In secondary appraisal, an individual defines what can be done to manage a stressful experience and he tries to trace the resources and supports. Coping is the next stage in stress process in which, actual coping strategies are employed. Adaptational outcomes include physical health (E.g. blood pressure), psychological well-being (E.g. positive emotion, ability to think clearly) and daily functioning (E.g. resuming social activities). Coping refers to changing cognitive and behavioural efforts to manage specific demands that are appraised as taxing or exceeding the resources of the person. Coping involves coming to terms with undesirable outcomes rather than mastering them. There are two dimensions for coping. First is the type of coping effort and the second is the aim of coping effort, which could be targeted toward directly altering the precipitating event, transforming the implications of an event for well being and reducing the negative emotional consequences of a stressful event. The widely
used measurement of coping is Ways of Coping Check List (WCCL) by Folkman & Lazarus (1985).

**Theoretical models for family research**

Mentally retarded child affects the lives of other people in the family. Earlier research emphasized residential institutionalization as a way of reducing the family problems (Farber 1959, Saenger 1960, Fotheringham, Skelton & Hoddinott 1972b). During the 1980s, because of the deinstitutionalization movement, there was more concern about families with retarded children. Various models came up to explain the relationship between the family and the problem child. The important three models are the functional impact model, the family crisis model and the variant family organization model.

(1) Functional impact model

This model explains the impact of the family context on the quality of the social and cognitive functioning of the mentally retarded child. Mink, Nihira & Meyers (1983) were concerned with distinguishing "growth promoting" families from "growth defeating" families. The Mink model consist variables in three areas: (1) environmental process of reinforcement aspects in the home, (2) the psychosocial climate of the home, and (3) child-rearing attitudes and practices. Another version of this model is the systems model by Turnbull, Summers & Brotherson (1986) and in this model the elements of cohesion, adaptability and communication are the key determinants of successful family interaction. This model may be useful in explaining the impact of the family on the disabled child, but in focusing on a single family member, it ignores the consequences on the other family members. For example, the family may be growth promoting for the retarded child, but may be growth defeating for the non-disabled sibling. Likely, family members are affected differentially by the drain on the time and resources available for home care (Moroney 1983, Perlman & Giele 1983).
(2) Family crisis model

The concept of 'stress' as the tension between an event or situation and the perceived ability to cope with or adapt to it has been developed to explore the effect on family functioning of a person with a disability. This model of family stress developed from a simple stimulus-response model, in which the amount of stress related directly to the antecedent event. An early adaptation was the 'life events' model, in which the stress is seen as a result of a series of major life events, such as divorce or the birth of a child with a disability. The focus was on the event rather than the response and took little account of other factors that may affect the stress felt by the family. Family crisis model considers the effects of the presence of a mentally retarded individual on the quality of functioning of the family. Families proceed in habitual ways until a disruptive event occurs. At that point, the family develops awareness and resolves the crisis, so that it can again continue habitually.

Hill's (1949, 1958) ABCX model is most popular model of this type. In ABCX model, the degree to which a family experiences stress is a function of A-the stressor event, interacting with B-the family's crisis meeting resources, interacting with C-the definition that the family applies to the stressor event to produce X-the family crisis.

McCubbin & McCubbin (1989) focus on the efforts made by the family to resolve the crisis and they focus on the problem solving and coping skills of the family. For Wikler (1986 b) family resources such as social support, financial condition, religiosity and quality of marriage are important factors. Another version of this model of stress that has been widely applied to families is the 'double ABCX' model (McCubbin & Patterson 1983). This model provides a theoretical basis for examining the mediating variables contributing to family stress, such as severity of disability, socioeconomic status and the availability of
support. The conflicting findings have been attributed to differences in population samples, methodology and statistical analysis producing seemingly incompatible results, with differing variables seen as significant contributors to family stress. In addition, most studies have been cross-sectional and only recently have longitudinal studies been undertaken. Research indicates that a family has to respond to a complex array of protective and stress variables to fulfill its caregiving functions alongside its other family functions. No single variable is a predictor of stress, and formal or informal support networks may compensate for deficits in family resources.

Another model of this kind is the stress adaptation model proposed by Farran, Metzger & Sparling (1986), which plays off a description of changes associated with the stressful event against the adaptive capacity of the family members. Implicit in the preceding two types of models – the functional impact as well as the family crisis models – is the assumption that, as an organic social entity, the family strives to regain (or attain) an equilibrium and thereby seeks to restore its previous state of affairs.

(3) Variant family organization model

This model is concerned with how families make adaptations to accommodate the mentally retarded child. This model sees the families as normal even though they depart from the normative conduct (Voysey 1972). The minimal adaptations model assumes that at any given time, family relations are organized to afford the personal growth and autonomy of each member as far as possible. Consequently, when a problem emerges, families will initially make the least amount of change in response to the problematic situation. When the least modification solution fails, the family members go on to the next minimal change and so on. This model is sensitive to the influence of social networks on parents.
The Eco-Cultural model, which is based on the 'social ecology' model developed by Bonfenbrenner (1979), proposes that individuals and families exist not in isolation but in the context of wider relationships within society. The functioning of an individual or family depends on how they relate to the wider context, which exerts influence upon them, and how they influence the wider context. Examples of such relationships include workplace flexibility, which may facilitate the balancing of work and care-giving responsibilities, and how specialist intellectual disability services support a person with an intellectual disability living with his or her family (Ray Jacques 2003). The accommodations made by the family to adapt with stress are not only within the family, but within the wider social context also. Family is the micro system and is influenced by the meso, exo and the macro systems (Bubolz & Whiren 1984; Bonfenbrenner 1977 & 1979). Micro-system: Patterns of activities and interpersonal relationships, e.g. a family. Meso-system: The systems in contact with the family, e.g. neighbours, health workers, workplace, etc. Exo-system: The wider organizational systems such as health or social care agencies; operates more at the level of policy. Macro-system: The wider cultural, religious, economic systems; sets the societal context within which disability is constructed. The parent of a child with a disability may change jobs and even move the family home to improve access to healthcare or schools. Siblings may take on domestic tasks and families may leave or develop new social-support networks, join advocacy groups or develop links with other carers. The accommodations they make depend on the eco-cultural constraints/resources available to them. The eco-cultural model also takes into account the other aspects of family life that have to be maintained in addition to the care-giving responsibilities (Ray Jacques 2003). The functional impact model and the family crisis model both focus on those elements in family life that are abnormal. The variant family organization model is not concerned not so much with focusing on the child as such; rather it asks how does a family with a retarded child deal with the tasks that all families are concerned with. Problems that are considered peculiar to families with
retarded children in the first two models are seen in the variant family organization model as possible analogs for other kinds of problems prevalent in other families. For example the rate of divorce among families of the retarded, controlling for socioeconomic status, does not differ significantly from families with normal children (Sherman & Cocozza 1984). Similarly, although marital satisfaction decreases over time in families with retarded children (Cmic, Friedrich & Greenberg 1983), similar decline also tends to occur in ordinary families (Litwak, Count & Haydon 1960). Perhaps the same predictive factors hold well for ordinary families and for families with a retarded child.