INTRODUCTION
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Family in society is the smallest social unit, which consists of components, which are interdependent. Components in a family are the members in the family, who have set of obligations and expectations towards each other, which are framed according to their socio-cultural background.

No matter what type or form of family, belonging to any socio-cultural background, every member in the family is important and is assigned a role depending on his status in a family. Only when this role is conformed to, and compromise is maintained between the obligations and expectations of the family members, can they have harmonious co-existence. Children are God’s gift and they form an integral part of this co-existence.

The list of complications, inconveniences, expenses, and changes in life-styles brought on by a new child is endless, but many of these negative aspects of parenthood are often overshadowed by the sheer joy and pleasure that the child brings to the new parents. The displeasures of diaper changing and the sleepless nights caused by the infant’s crying may fade away with the first smile, the first step, and the first spoken word. With these first accomplishments, parents may begin to envision a fruition of their dreams and hopes of parenthood – healthy, bright, capable, beautiful children doing all the things that the parents did or wished they could have done.

But in a family, which has a child with mental handicap then these sets of obligations and expectations change, keeping in view the nature and severity of individuals, condition.

The extent to which the newborn is divergent from the family’s hopes and expectations is stressful. Reactions to having a child with a disability both within and between families are highly individualistic and depend on the severity of the child’s handicap, supports available to the family, and the cultural context of the family as well as other factors.

Wolfensberger (1967) mentioned three types of crisis patterns in families with a mentally retarded child.
a) The novelty shock crisis or the shock of initial diagnosis,

b) The crisis of personal values characterized by a reaction of anguish and chronic sorrow stemming from the destruction of their over determined expectations of the child; and

c) The reality crisis stemming from external forces related to difficulties of raising the child such as physical demands and social pressures.

Definition of Mental Retardation:

Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. (AAMR 2002)

Currently the classification based on IQ is:

- 90 – 110 Average Intelligence
- 70 – 90 Borderline Intelligence
- 50 – 69 Mild Mental Retardation
- 35 – 49 Moderate Mental Retardation
- 20 – 34 Severe Mental Retardation
- Below 20 Profound Mental Retardation

While providing a classification, it is also cautioned that IQ alone should not be the deciding criteria and that adaptive behaviour deficits should be given consideration. In addition, every cut off IQ is given a 5 points overlap. For instance 70 – 75 can be considered mild mental retardation if adaptive behaviour assessment is suggestive of such a decision. Mental retardation (MR) occurs in 2-3% of the general population.

CAUSES OF MENTAL RETARDATION

Causes of mental retardation can be before, during or after birth.

Biological risk factors and environmental risk factors:

The causative factors of mental retardation are varied and widespread. There are factors which affect the fetus at conception or even before conception, such as age
of the mother, health of the mother, and/or chromosomal and genetic disorders. The causes may be broadly classified under biological risk factor and environmental risk factors.

Therefore the causes of MR are classified as

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(A) Genetic causes are purely biological
(B) There are some biological causes which are enforced with environmental influences
(C) There are some environmental causes which are purely psycho social in nature

**Biological risk factors** – are those that develop within the body as part of one’s basic biology and organic make up. They include genetic and other inborn features (characteristics) metabolic aspects and interaction of varied complex systems of the body. Many biological risk factors are genetic.

**Environmental risk factors** – are health related risks that exist outside the person and over which the individual has little or no control. These includes social and physical factors.

(a) **Social environmental risk** for disability are a function of the expectations and opportunities that accompany specific socio cultural environment. Attitudes, assumptions, preferences or prejudices encountered throughout society help create
social environmental disability risks, for instance occupational settings, certain physical
skills, abilities and characteristics. Because of the physical demands and socio cultural
expectations of that environment the likelihood or risk of a functional limitations
becoming a disability is greater than in cultural setting that assigns less value to these
characteristics. Socio environment risk for disability is when individuals are required
to perform tasks that exceed their physical or mental abilities.

(b) Physical environment risk – injury or disease can trigger a process that
leads to disability. They place individuals in circumstances leading to impairment and
functional limitations.

Causes before conception

Age of the mother: The best period for conception is between 20 and 30 years
of age. A very young teenage mother is likely to have problems due to biological
immaturity. There are high risk group for abortions, premature deliveries giving birth
to low birth weight babies, or babies with chromosomal abnormalities etc. Above 30
years of age, as the maternal age advances they are the candidates for high risk
pregnancy and deliveries. They may face problems of difficult, delayed deliveries,
babies born with chromosomal and other physical abnormalities. Thus age of the
mother plays an important role in the delivery of a healthy, normal baby.

Nutrition and health status of the mother before pregnancy are very important
for conception and development of the foetus. A healthy mother brings forth a healthy
child.

Large families: Limiting of the family size is good for the health of the mother
and the well being of the child. As the birth order of the child increases, there is a
possibility of increase in the risk factors.

Addictions: Any addictions such as drug abuse, smoking & chewing of tobacco
and alcohol consumption can jeopardize the health status of the mother and influence
the developing foetus adversely (microcephaly, low birth weight etc.)
Prenatal causes (during pregnancy)

No or poor antenatal check ups, Abortions – repeated, attempted, threatened, Poor nutritional status of mother, Diabetes, Rh. Incompatibility, Hypertension (high blood pressure), Convulsions (fits), Infections – (Toxoplasmosis, others, Rubella, Cytomegalo virus, Herpes), STD (Sexually Transmitted Diseases), Physical trauma/injury, Emotional stress/trauma, Drugs, Irradiation, Addictions – Tobacco / Nicotine – Alcohol, Potentially harmful medication, Multiple pregnancies (twins, triplets), Maternal mental illness, System pathology – heart, kidney, liver diseases, Bleeding during pregnancy.

Natal causes (during delivery)

Premature (born before full term), Post mature (born after 42 weeks pregnancy), Multiple pregnancies (twins, triplets), Difficult and prolonged labour (labour for more than 24 hours), Forceps/instrumental delivery/vacuum extraction, Caesarian (delivery by surgery), Bleeding during delivery, Abnormal presentation – Buttocks, Breech, Brow/face, Hand/shoulder, foot/leg., Prolapsed cord/kinking/knotting, Cord round the neck, Unhygienic delivery – place, instruments, handling, Convulsions during delivery.

Natal causes:

The process of delivery of the baby should be one of ease and smooth passage of baby with no harm caused either to the baby or to the mother. Certain conditions which cause difficult labour should be identified early and treated and complications averted, Abnormal foetal positions or presentation, Abnormally narrow birth passage, Abnormally large head, Bleeding during delivery, Physical manipulations, Instrumental deliveries, Multiple Pregnancy (twins, triplets), Unhygienic delivery.

Post natal causes (from birth upto 18 years of age)

Delayed birth cry – birth cry after 5 minutes, Low Birth weight - <2500 gms, Prematurity / post maturity, Colour of the baby – pale, yellow, blue, plethoric., Activity of the baby – dull, lethargic, jittery irritable, convulsions, Obvious congenital anomalies – Microcephaly, Hydrocephalous, abnormality of limbs, cleft lip/palate, visual/auditory impairment, system involvements Cardio vascular system, Respiratory system, Infections / Septicaemias (Infection in the blood), Trauma / Injury, Feeding
problem – (vomiting, colic, spitting, difficulty in sucking and swallowing), Convulsions (fits), Jaundice, Nutritional deficiencies, Developmental delays.

**Psycho social causes**

Psychosocial causes refer to the environmental influences. These also can lead to mental retardation.

**Prenatal factors :**

- Relative infertility, Repeated abortions, Conception after many years of marriage,
- Large family, lack of family planning, Poor spacing between births, Illegitimate unwanted child, Only child – a child born after a long period after the earlier pregnancy, Difficulties in previous pregnancy.

**Child**

Premature baby, Low birth baby, Difficulties & problems in the newborn period such as illness, prolonged stay in hospital, surgery, Severe congenital abnormalities, Feeding problems.

**Parents**

Very young or very old parents, Mental illness, Unpreparedness for the arrival of the baby, Poor general health, Addictions (drugs and alcohol), Poverty, Single parent (divorce, separation, bereavement), Marital disharmony, Poor family resources, Poor personal relationships with family, Poor family support.

All the above mentioned conditions play an important role in the development of the child and contribute to causation of mental retardation.

**Legislation**

India, being a democratic country, the Constitution and legislation play an important role in the life of every citizen, irrespective of his being abled or disabled.
The preamble of the Constitution of India states, “We, the people of India, having solemnly resolved to constitute India into a Sovereign Democratic Republic and to serve all its citizens.

Until recently, there was no exclusive law for protection of rights of persons with mental retardation. They were governed by the Indian Lunacy Act of 1912. In the year 1987, this act was replaced by Mental Health Act 1987. This act did not include any provision to safeguard the rights and interests of persons with mental retardation rather it totally excluded mental retardation from its purview. As a result a vacuum was created which has been filled by the enactment of comprehensive legislation, i.e., “The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995”. The provisions of the act range from prevention, early detection to education, vocational training and employment, preferential treatment and protection from negative discrimination. The Act ensures equality of human rights and dignity of life to people with disability. It will also strengthen the hands of the government to formulate appropriate programme for education and employment of people with disabilities including those with mental retardation.

Significance of the study

The general assembly of United Nations in its resolution of 3rd December, 1998, showed its concern that no less than 500 million persons are estimated to suffer from disability of one form or another, of whom 400 million are estimated to be in the developing countries. There are 12.9 million disabled in the country, according to census data released by the Registrar-General of India. This is about 2.13 per cent of the total population. Of this, 0.22 percent are ‘mentally’ disabled. (The Hindu, June 3, 2005). But rehabilitation services have barely touched even the fringe of the problem in the rural areas of the third world countries. Experts opined that at least one person out of ten of the population of any country is affected by some kind of physical or mental handicap. The world programme of action states that the problem of disability in developing countries needs to be especially highlighted. As many as 80% of all disabled people live in isolated rural areas in developing countries. In some of these countries, the percentage of disabled population is estimated to be as high as 20 and
thus if families and relatives are included, 50 percent of the population could be adversely affected by disability.

As structured services have not yet reached all corners of the country, supporting and empowering the families of disabled persons is one way of reaching out to assist them. By this, the family will also develop positive attitude towards the disabled persons. In case of mental retardation, it is further stressed that family should be empowered as these persons are dependent on them to a large extent.

A CHILD WITH DISABILITY IN THE FAMILY.

The birth of any child can have a significant effect on the dynamics of the family. The parents and other children must undergo a variety of changes to adapt to the presence of a new member. The effects on the family of the birth of a child who has a disability can be even more profound. In cases in which the condition is not readily apparent at birth, it is only with the passage of time that the condition becomes evident the everyday routines that most families take for granted are frequently disrupted in families with children who are disabled.

Families with children with disabilities not only face the ordinary tasks of family life, but must also confront issues that are idiosyncratic to the specific disability and level of functioning of the child. Factors such as the child’s personality, activity level, attractiveness, and others influence the family. Interactions among family members also influence the way the family unit interacts with society. The impact of the child on the family changes as the child grows. Learning about and adjusting to a child’s disability impacts the entire family system.

Disabilities make different demands on families. It is important to look at how the family perceives the impact of the disability. What might be viewed as a crisis for some is a minor inconvenience or even an asset for others, depending on how the family system is organized to cope with crisis.
The addition of a child produces tremendous change and challenge to the marriage relationship, calling forth effort, resources, and personal maturity, and relationship and communication skills. When the arrival of a child introduces additional factors, such as coping with the unexpected and different, the degree of challenge may increase dramatically. The birth of a baby with a severe disability deeply challenges the couple and their resources. Role differences can be further exacerbated; care giving routines are often more complicated, time-consuming, and stressful as they are to exert tremendous pressure on some couples.

The most important difference between mourning a death and mourning a disability is that the child in question is not dead at all... while death provides a moment's respite from ordinary demands, disability generates new tasks and necessities (Featherstone, 1980).

Most parents report feeling a sense of shock, they feel emotionally "numb", they may even show physical signs of shock. Shock often turns denial; parents deny the disability or the severity of it. For children who look "normal". This denial is easier parents may "shop around" for another opinion that is more optimistic. These reactions may be a way of buying time to adjust. To the extent that reality is acknowledged then, everything must change.

Parents may feel angry at doctors, professionals, and even the child himself. This, too, is part of the grieving cycle. Some feel a kind of mourning, feeling sad about the child they had expected but didn't get' in reality, morning the death of the normal child. Featherstone(1980) compares the death of a child and the birth of a child with a disability. Parents may feel that the child's disability was their fault. The mother may think she has done something she shouldn't have. Hope provides strength even when the hope is unrealistic. Sometimes having some degree of unrealistic hope may actually be helpful to the family if it is all they have to go on. Parents have all these feelings at some time. Some of them are only momentary, others long-lasting.

The initial impact may take several forms. It may result in some sort of a transient stress disorder for the parents, or it may even have a permanent debilitating effect on the entire family unit. Featherstone (1980) suggested that the advent of a handicapped child may attack the very foundation of a marriage by inciting powerful
emotions in both parents, including feelings of shared failure. Fathers and mothers may react very differently to the handicapped child. The mother may take on the role of physical protector and guardian of the child’s needs, while the father is more reserved in his role. He may cope by withdrawing, internalizing his feelings.

The presence of a retarded child need not create a family crisis. How the family defines the event will determine whether or not a real crisis exists. There are few families, however, in which the stigma of mental retardation imposed by our society will not cause the event to be interpreted as a crisis. The professional can help the family to cope with the crisis. By examining the resources of the family, including role structure, emotional stability, and previous experiences with stress, the professional can help the family use its strengths to deal effectively with the situation.

Certain risk factors that contribute to stress:

Stress:

1. Features of the child

Behavior problems in the child; Night time disturbance with the child, including difficulty in settling the child at night, Multiple impairments in the child (a combination, possible including incontinence, immobility, poor communication skills, a sensory impairment); Communication problems in the child; Serious problems with the child’s physical health; More severe learning difficulties in the child; Problems with the child’s appearance; High excitability in the child.

2. Parental and family characteristics

Social isolation in the mother, lacking a close friend, not utilizing available social support; Socio-economic hardship-unemployment, no car, poor housing, low income, money worries, lack of maternal employment; Poor parental education; High levels of strain from current life-events. Marital dissatisfaction; Poor coping strategies by the parent- a low use of practical coping methods; a high use of passive acceptance in dealing with child-related problems, and wishful thinking; Lack of active recreation and leisure in the family; Lack of strong moral-religious emphasis in the family; Lack of family cohesion and closeness.
Pearline et al (1981) were able to describe the stress processes as combining three major conceptual domains, encompassing: (1) manifestations of stress (these include physiological indicators of stress and also perceived stress); (2) stressors (the stress inducing events or conditions that give rise to manifestations of stress); (3) mediators (which may be exacerbating or moderating in their influence within the stress process).

**Family Burden**

The presence of a mentally handicapped child in the family is known to place constraints on its normal functioning and be a source of stress. It is also perceived as a burden on the family as a whole making demands on its coping resources.

The burden of childcare falls squarely on the shoulders of major career who is more often the mother. Since the caring of a mentally handicapped child is more demanding, it is likely to disrupt the routine of the mother and the family as a whole.

Sometimes burden could be due to less favorable attitude of the mothers mentally handicapped children towards the management of these children (Fangri and Verma, 1992). It may be her frustration and irritation, which lead to the disruption in family routine and family interaction in family routine and family interaction rather than the presence of the handicapped child as such.

The birth of a child who is mentally retarded can be a traumatic experience for the family, which requires changes and adjustment in many areas. A number of researchers have stressed the emotional and functional crises and parents of children who are mentally retarded undergo. These stresses include physical and mental health problems, moodiness, demands on time, negative societal attitudes, over protectiveness, dependency, feelings of self sacrifice and reduced personal well being, marital happiness, and social support.
Family Functions

Olson (1979) defined family functioning as family member’s perception of family cohesion and adaptability.

Goldenberg and Goldenberg (1980) state that family is far more than a collection of individuals, occupying a specific physical and psychological space together. Rather it is a natural social system with properties all its own, one that has evolved a set of roles, a power structure, form of communication and ways of negotiation and problem solving that allow various tasks to be performed effectively.

To survive, all families must perform certain tasks. These tasks are designed to meet the needs of all family members, and also have the long-range goal of helping young family members become self-sufficient and independent.

**Economic Needs.** Most families must generate income and pay bills. Children with disabilities may add additional expenses. These expenses can range from lost income because parents cannot work, to special food, extra telephone cost, transportation, and so on.

**Daily Care Needs.** All families must perform the daily tasks of living that include cooking, cleaning, laundry, and so on. Children with disabilities may require more care for a longer time. The source of much family stress falls in this area (Beckman-Bell, 1981). The burden of this care impacts parents’ psychological, physical and financial well-being (Seligman & Meyerson, 1982).

**Recreation Needs.** All families need recuperation time; rest and relaxation. Frequently recreation is the family activity most often eliminated under stress. Sometimes families don’t meet recreational needs because of lack of finances; at other times because including a child with a disability makes the activity too difficult. It is important to help families find recreational activities they can enjoy as families as well as individuals.

**Social Needs.** Most families find their social life and outside leisure activities affected by having a child with a disability. Yet families need to be part of the larger
social system. They need an informal support network of friends and neighbors to provide opportunities for children to develop and practice social skills. Some parents get so involved in the education of their child that they forget the importance of this area. Overall, families with good social support networks make it through crises better than those who lack such a system.

**Self – Image Needs.** A positive self-image is important for everyone in the family. All family members need to see themselves as having competence and worth. Parents of children with disabilities may have difficulty seeing themselves as competent parents. Siblings may be at risks regarding self-image if the family revolves around the child with a disability. The child with a disability may have problems in this area also.

**Affection Needs.** Families meet the needs of their members for physical intimacy as well as support and love. A disability may make unconditional love a challenge, and family members may not establish these bonds with children who are terminally ill because of the fear of pain when they are broken. As children grow older the concept of sexuality often becomes confused and confounded with needs for affection.

**Educational / Vocational Needs.** It should be noted that meeting educational needs is only one of many functions of families. Even though it is probably the one in which your interests overlap with families the most, and where you have the greatest interest, this is not necessarily the most important function to the families. Before making an assumption about this, “check it out” with the family.

These tasks that the family performs are referred to as the functions or outputs of the family system. By carrying out its functions the family shares the common goal of serving the collective and individual needs of its members.

Family functions (Skrtic, et al 1984; Turnbull & Turnbull, 1990) include care giving education, guidance, socialization, leisure and recreation, economic, self-definition, affection, vocational, and support functions. We can with some certainty make several general points about parenting a child with a disability. It makes a greater amount of each day’s time. It requires adjustment of family routines. It takes time from
other parent or family pursuits. It sometimes requires specialized knowledge (techniques / equipment). It requires support from professionals and others. It extends loner throughout the child’s lifetime. And it becomes out-of-sync with the family’s life cycle.

**Challenges in the family**

Mental Handicap of the child challenges the family at three levels. First there is the cognitive challenge. The family must learn about the cause of the mental handicap its prognosis, complications, and routines and reasons for the rehabilitation. The family must revise its expectations for the daily life of the child, both for the present and the future, and attempt to match the child’s activities with the limitations of the disability and treatment.

The second challenge is at the emotional level. Finally mental handicap presents a behavioural challenge. Rehabilitation regimens and hospital visits and special educational programme must be incorporated into the family functions and enable the family to carry out other essential tasks. The family must also recognize changes in the child’s ability to perform some tasks and should help where necessary.

Farber (1960) suggests that the advent of the mentally handicapped child need not create a family crisis. How the family defines the event will determine whether or not a real crisis exists. Chinn (1979) states that whether or not an event becomes a crisis depend on three basic conditions: (1) the nature of the event, (2) the resources of the family, and (3) how the family defines the event. There are few families, however, in which the stigma of mental handicap imposed by our society will not cause the event to be interpreted as a crisis.

**CHAPTERISATION**

The detailed report of the study is presented in five chapters. The first chapter focuses on the problem area of the study. It explains the various theories relating to the effect of having a child with mental retardation.
The second chapter gives an account of the available literature on the variables included in the study.

The third chapter describes the methodology adopted for the investigation and includes aspects such as the research design, universe and sampling, tools of data collection and statistical design.

The fourth chapter comprises of the analysis and discussion. It also analyses the hypotheses related to the study.

The fifth chapter contains the major findings of the study. Suggestions for future research have also been offered. The chapter concludes with a summary of the research study.