

A Case Study :

QUALITY OF LIFE OF CHILDREN WITH MENTAL RETARDATION

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ABSTRACT

Family is the first and lasting environment to which a child is exposed to and in turn it is his presence which impacts the family. Like all children the quality of life of children with mental retardation (MR) is affected by how effectively the family takes care of its children. Each family has a unique climate, characteristic strengths and weaknesses and different ways of meeting stress situations. The level of family efficacy of MR children was assessed in the present study with the aim of exploring the quality of life of MR children residing in the city of Jodhpur. Standardized scale on Family Efficacy by Peshawaria (2000) was used on either parents of 30 MR children. The obtained results are presented in tabular and graphical format and are discussed in the light of reviewed literature and personal observations.

Key words : Children, Mental retardation, Family Efficacy

Mental Retardation (MR) is a universal phenomenon and is found in all classes, races, socio-economic levels, castes, gender, region and localities

The AAMR, in 1982 defines mental retardation as significantly sub average general and intellectual functioning, resulting in association with concurrent impairments in adaptive behaviour and manifested during the developmental period of a person (Chintamanikar, 1992).

More and more research evidence indicate that MR is quantitative rather than qualitative. The problem and magnitude of MR is no more a hidden reality. The NSSO survey (1991) on children in India, with delayed mental development reports that among children up to 14 years of age, the incidences of delayed mental development are 3%. Out of these 20 to 22 million individuals, more than 95 percent can be helped to function very near to normal with necessary help. Early intervention, training centers, day care centers, integrated schooling and sensitization, awareness and education of the parents are some of the measures, which could prove effective in helping these children of lesser good.

Since the family provides a socially acceptable vehicle to bring children into the world, giving birth to a mentally handicapped child has a profound effect on the structure, functioning and development of a family (Demarle and Daniel, 2001). On the other hand it is the family that helps to shape the personality characteristics and determines the quality of life of these children (Sukumaran, 2000)

As retarded children grow older, they become lonely and unable to adjust in society. Their psychological and social needs are frustrated. Parents of such children develop a guilt complex. Overprotection and denial by the parents invite adjustment difficulties in such type of children (Shankar and Uday, 1978), whereas positive and warm climate within the family is conducive to happy, healthy and positive quality of life. Therefore it is easy to understand that the effect of having a MR child is not a unidirectional process. The quality of life of children with disability is affected by the type of family and family members one has, and the presence of these children in turn affects the climate within the family and the quality of family life. (Brown, *et al.* 2003). The situation may be complicated by factors such as poverty, family size, and absence of social support.

Since the family climate has most expansive, intensive and enduring influence on the quality of life of growing children the quality of life of MR children can be gauged by the climate and efficacy within their family (Shanmugavelyuthm, 1999).

In Indian culture boys and girls are brought up differently and it may be true in the case of MR children too. The parent's perception of stigma is higher in the case of a boy (Waisber, 1980 in Kaur *et al.* 1996.). It seems that "a greater degree of sub-normal behavior may be tolerated for females than males" (Kaur *et al.* 1996). However, it is reported that in disabled children there is no gender difference in the quality of life (Verdugo, *et al.* 2002).

The study has been taken with the definite objective of broadening the horizons of understanding the quality of life of MR children. The measure selected to denote