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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 with in 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

quality of life is family efficacy. The specific objectives of the study are:

-To assess the family efficacy of MR children.

-To assess the difference if any, in family efficacy of MR girls in comparison to that of MR boys

METHODOLOGY

Therty moderately mentally retareded children between ages 15-18 years were selected on purposive basis from two institutions catering to the education of MR children in Jodhpur city. Sample comprised of father or mother of these 30 moderately mentally retarded children. Most of the families were from low socio-economic status.

To study the different measures selected for the study, following tools were used.

Back ground Information Sheet :

A self constructed sheet in Hindi was developed to collect information on the socio demographics of the samples.

NIMH family efficacy scale (2000) :

Developed by Dr. Rita Peshawaria National Institute for Mentally Handicapped for assessment of family of the MR children. As such the scale assesses the following:

-Strength of the Indian families.

-The uniqueness and typical characteristics of the families.

-The family climate and functioning of the families.

-The thrust area for family intervention.

Fifteen major themes / areas of family efficacy were developed with the help of professionals working in the field, parents of the MR individuals and parents of intellectually normal individuals.

Based on each of these themes a situation is given. The subject is asked to respond to the given situation by choosing one out of the three given options. A system of rating of 3,2, and 1 score was adopted. Higher the scores, higher the efficacy.

Interview method was used for this test. Appointments were made with the available parent according to their convenience. After getting familiarized and establishing rapport with the subjects, the interview was conducted, so that the respondents feel comfortable enough to share their thoughts with the interviewer. Instructions given in the test were read out and explained in detail to ensure that the respondent has understood the intention of the assessment, which was purely for academic research. Scoring was according to the given key. Since the respondents were basically Hindi speaking, the tool was translated into Hindi with the help of 5 subject experts.

RESULTS AND DISCUSSION

Family efficacy means the strength and unique functioning style of the family. The result shows that more than 60 percent of families (Table1) have high level of family efficacy. None of the families in the present group have scored low on the composite family efficacy. This may be because of the strong family system in the city. It is observed that more families are joint families and even when they are nuclear, they maintain close ties. There is high emotional attachment to one another and members give full support to each other in adverse situations. Such support has been reported to have positive influence on family efficacy.

Table 1 : Showing Percentage of level of composite family efficacy

Level of FE.	Percentage on Level of Composite Family Efficacy		
Family efficacy	Total	Boys	Girls
Low	Nil	Nil	Nil
Medium	36.67	38.89	33.33
High	63.33	61.11	66.67

However when analyzed for significance of difference between the two groups, as shown in Table 2, the difference is not significant. It indicates that families with MR boys and families with MR girls do not differ in their efficacy.

When percentages of all the families is observed (Fig. 1) in individual areas of family efficacy an interesting picture emerges. Most of the families i.e. above 50 percent fall in the range of medium level efficacy in six areas out of the fifteen included in the FES namely, Sacrifice, Health, Social support, Independence, Crisis and Roles and responsibilities.

In the area of Communication, Optimism and Values as high as 60 or more percent of families have high level family efficacy. Families feel that living life with dignity is as important as to earn money and material goods. All

Table 2 : Showing significance of difference on gender in composite family efficacy

Gender	N	Mean	Std. Deviation	t	df	Sig. (2-tailed)
Boys	18	32.22	5.37	-0.69	28	0.495
Girls	12	33.58	5.12			

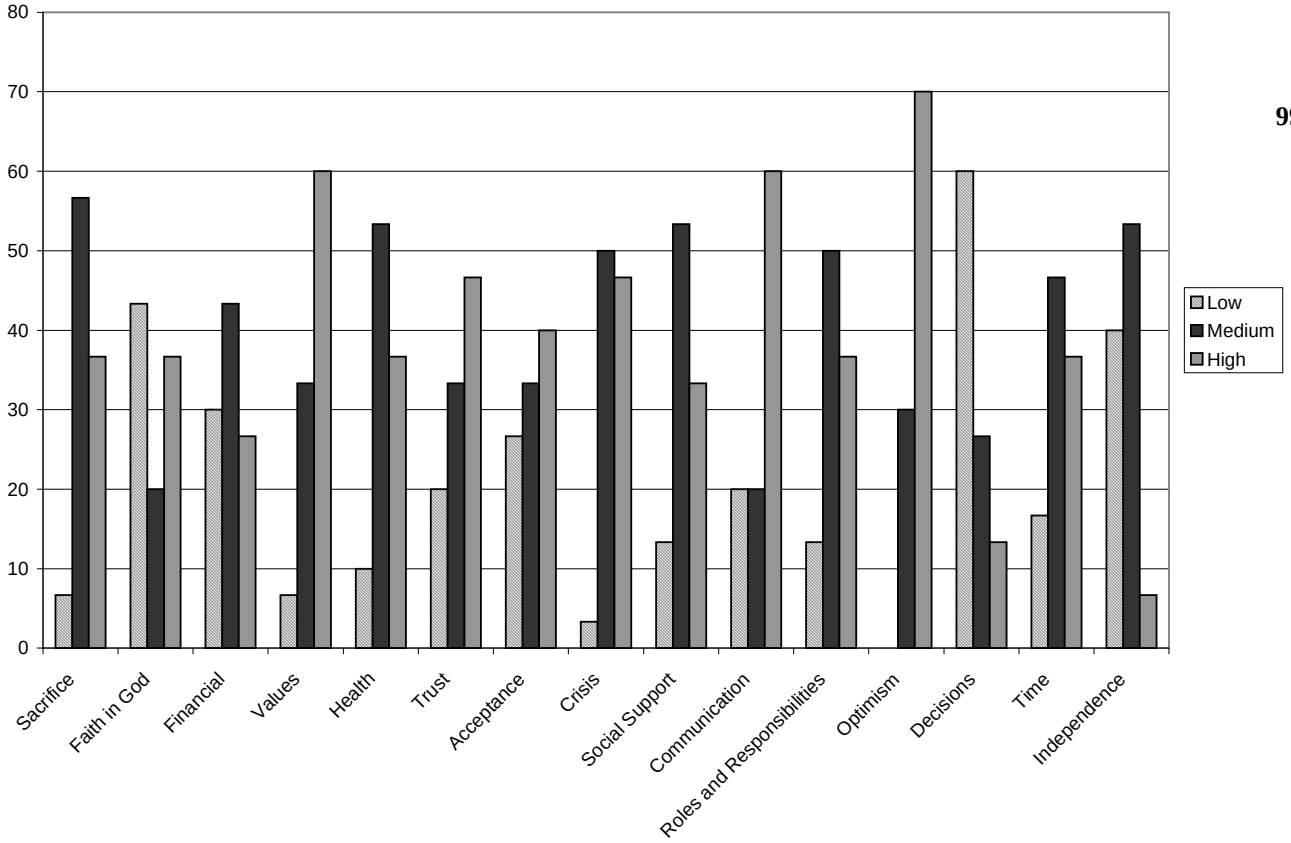

Fig. 1 : Showing percentages on level of family efficacy (parent) in specific areas of total sample.

members share experience and tension with each other. Communication is good amongst all the family members. It appears that since the families in the present sample are high in the area of Trust, Acceptance, Social support, and Sacrifice, they are high in Communication too.

It also points towards the dominance of familial orientation over individualistic orientation of the family members. They feel that family, as a whole is more important than any one member so they are willing to sacrifice personal profit for family. Watson & Keith (2002) too report similar views when they say that families of disabled child give more priority to the needs of handicapped child than a non-handicapped child in the family.

Health and social support too has similar trends. As for social support, the present study shows that more than 50% of families reported that their neighbors give full support and help to the family. Here again the close family, kinship ties and the small town traditional values of cooperation with each other seem in operation.

As much as 40 per cent families have low level of Family Efficacy in the area of Independence meaning that families here still do not hold individuals' independence over family in high esteem. However, with increasing exposure to wider world through various media, a good enough per cent of families (53.33 per cent) have medium level efficacy in this area meaning in some areas family members have full freedom and in others strict restrictions are imposed.

In the area of Crisis 50 per cent respondents are of the view that in some situations families give full support to solve the crisis but in some other situations crisis are faced by one's own self.

In the area of Roles and responsibilities the family members take over responsibilities of each other in problematic situations and if needed they play roles of other family members but for limited time because they themselves have so many responsibilities.

In the area of Trust, the high level of Family Efficacy of 46 per cent of Ss points towards the fact that families have high trust on their family members. All members trust other members and are ready to help every time because they are closely attached.

It appears that total faith in God, trust, acceptance and high belief in fate encourage optimism and positive thinking.

Most of the families have notable low level of Family Efficacy in only two areas, which are Faith in God and Decision making. Low level of family efficacy points towards the belief of people that every thing is God's

doing and that man has no role to play. Majority of the Ss are illiterate and semi – literate in the present study and for them, with complete responsibility on God, it is easy to accept their circumstances. It is almost like a coping mechanism. Brown *et al.* (2003) in their study on families of children with mental disabilities showed that spiritual and cultural beliefs and family relationship were rated highly, while support from others and support from disability related services were rated quite low.

In the area of Decision making also, low level of Family Efficacy, means more families in the present study let only elders make the decisions rather than taking the views of all the family members while taking decisions.

In the area of Time and Finance, the percent distribution is almost equal in the three levels of Family Efficacy. Since in the present sample of families of low income levels, resources are limited, each family tries to expand it according to their ways. They have to spend money on most preferable demands. A big part of money is spent on childcare like hospital appointments and in travelling. According to Sheshadhari *et al.*, 1983, (Shanmugavelyuthm, 1999) the mentally handicapped child has less impact upon family interaction in a high socio-economic status than in low socio-economic status families.

Time spent together by family members indicate good family efficacy. In the present study, 46.67 per cent families have medium level of Family Efficacy and 36.67 per cent have high level of Family Efficacy pointing towards the tendency of families with a MR child to spend a lot of time together. Research provides evidence that the family members who spend time together are emotionally and socially better placed than otherwise.

To find out about sex differences, when obtained data was split on gender there was no significant difference observed in the level of Family Efficacy of the boys' and girls' families. Therefore it can be said that it does not make a significant difference in the efficacy of the families if the child with MR is a boy or a girl.

Verdugo (2002) supports the result of the present study, as he too did not find gender difference in the quality of life of boys and girls.

CONCLUSION

From the results of present study on family efficacy it can be concluded that children with MR in this city are enjoying a satisfactory quality of life, but there is a scope of improvement by way of initiating educational programs for parents for making them more sensitive, aware and resourceful towards improving the quality of life of their MR children.

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REFERENCES

Brown, I., Anand, S., Issacs, B., and Nehama (2003). Family quality of life. *Journal of Developmental and Physical Disabilities,* **15** (3), 207-230.

Chintamanikar, (1992). Exceptional children: Their psychology and education. New Delhi, Sterling Publisher private Ltd. 41-44.

Demarle and Daniel, J. (2001). The life cycle and disability": Experiences of discontinuity in child and family development. *Journal of Loss and Trauma,* **6** (1), 29-43.

Kaur, J.P., Shome, M.K., and Sen, A.K. (1996). Parental Attitude toward Children with Mental Retardation: A Psycho-social Study, Indian Journal of Psychology, **71** (1&2), 29-36.

NSSO Survey (1991). The Indian Child: A Profile 2002. Department of Women and Child Development, Ministry of HRD, Govt. of India.

Shankar and Uday (1978). Problem children. Lucknow, Atmaram and Sons. 4-5.

Shanmugavelyuthm, K (1999). Mentally retarded children and their families. New Delhi, Mittal Publications, 1-9, 19-30.

Sukumaran, P.S. (2000). Parental involvement in the education of mentally handicapped children. New Delhi, Discovery Publishing House. 13-20.

Verdugo, M., and Sabeh (2002). Evaluation and perceived quality of life assessment in childhood. Psicothema, **14** (1), 86-91.

Watson, S., M.R. and Keith (2002). Comparing the quality of life of school age children with and without disabilities. *Mental retardation* **40** (4), 304-312.