Impact Of disability of mentally retarded persons on their parents

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ABSTRACT

Mental retardation is a permanent condition unlike many other diseases. It is a highly prevalent and highly disabling condition. In this study an attempt has been made to study both positive and negative impact on parents so as to help manage this problem in the best possible way. The study was conducted at the out patient department of P.G.I. Behavioral and Medical Sciences, Raipur and two special schools of mentally challenged children and it was done by purposive sampling method. Using specially designed semi structured socio demographic and clinical data sheet, information was gathered about mentally challenged children and their parents. Vineland Social Maturity Scale (V.S.M.S) and Developmental Screening Test (D.S.T) were used to assess their intelligence. Parents fulfilling inclusion and exclusion criteria consenting for the study were selected. National Institute for the Mentally Handicapped Disability Impact Scale (2003) was then administered on them. The results are reported and discussed.

Key Words: Mental Retardation, Disability.

INTRODUCTION

Mental retardation is a highly prevalent and highly disabling condition. Depending on the severity of their disability Mentally retarded (MR) are more and more dependent on their caregivers. Previous studies have focused either on positive or negative (Zuk, 1959[26]; Worchel and worchel 1963[25]) impact on the parents. In this study an attempt has been made to assess both positive and negative impact on the parents of such persons so that they could be helped to manage there problems in the best possible way.

DEFINITION OF DISABILITY AND MENTAL RETARDATION

Disability may be defined as disturbances in performance of social roles that would normally be expected of an individual in the habitual milieu, arising in association with diagnosable mental disorder (Jeblensky, Schwarz and Tomov 1980)[13]. The terms disability, impairment and handicap are often used in a confusing and interchangeable fashion. Recently, the World Health Organization (WHO, 1980)[24] has given the following definitions: “An impairment is an anatomical defect, or absence or loss of a specific psychological or physiological function that can arise from a disease or from an intrinsic pathological state”.

⇒A *disability* is a restriction in the ability to perform a task or activity within the range normally expected or someone of the same age or level of maturity.

⇒A *handicap* is a social disadvantage preventing the fulfillment of a normal social role.

According to Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995

"Disability" means -

1. Blindness;

2. Low vision;

3. Leprosy-cured;

4. Hearing impairment;

5. Loco motor disability;

6. Mental retardation;

7. Mental illness;

"Person with disability" means a person suffering from not less than forty per cent of any disability as certified by a medical authority”.

Mental Retardation is a highly prevalent and highly disabling condition. It is generally considered that two percent of the Indian population constitutes persons with mental retardation. In India prevalence of mental retardation varies from 0.22 percent (ICMR, 1983)[12] to 32.7 (Shalini, 1982)[21] per thousand population.

According to American association of Mental deficiency (AAMD, 1983)[3], *"Mental retardation can be defined as a significantly sub average general intellectual functioning, resulting or associated with concurrent impairment in adaptive behavior and is manifested during the developmental period"*

Need for Study: -

Mental retardation makes a person incapable of living an independent life. In India, family bears the main burden of caring for such persons unlike in the developed world. Family members particularly parents are more affected by the condition. Normally the people in the society and the professional workers do not feel the actual stress and the burden to the extent it is experienced by the family members of the mentally retarded child. There is need to find out how disability due to mental retardation is affecting parents of such persons in order to help those who are having negative impact and to find out how they are positively affected so that others can be helped in the same manner. Aim of this study is to know the type of impact of having a mentally retarded child on the parents.

CLASSIFICATION OF MENTAL RETARDATION

The two major classificatory systems ICD-10 and DSM-IV have classified mental retardation into four degrees of severity as shown in the table below -

Level of Retardation	I. Q. Level		Mental age	Proportion of MR group percent
	DSM-IV	ICD-10		
Mild Mental Retardation	50-55 to approximately 70.	50-70	9-12yrs	85%
Moderate Mental Retardation	35-40 to 50-55	35-49	6-9yrs	10%
Severe Mental Retardation	20-25 to 35-40	20 to 34	3-6yrs	3% to 4%
Profound Mental Retardation	below 20 or 25	less than 20	Less than 3yrs	Approximately 1% to 2%

- (Volkmar & Dykens, 2002)[23]

AIMS:

1. To assess the level of disability in Mentally Retarded Children

2. To see the impact of disability of mentally challenged children on their parents.

NULL HYPOTHESIS:

There will be no impact of disability on parents.

ALTERNATIVE HYPOTHESIS:

There will be positive and negative impact on parents.

SAMPLE:

The sample consisted of parents of 65 mentally challenged children. The study was conducted at the study was conducted at the out patient department of Post Graduate Institute of Behavioral and Medical Sciences and two special schools of such children in Raipur. The samples were selected by purposive method.

INCLUSION CRITERIA:

1. Parents of persons with I.Q. below 70.
2. Those who gave their consent for study

EXCLUSION CRITERIA:

1. Person having chronic physical illness.
2. Person having mental illness.
3. Mentally challenged parents.

TOOLS USED:

1.Developmental Screening Test (D.S.T.) (J. Bharatraj 1977; 1983)[5]

DST was used to assess intelligence of children. Developmental schedule are inventories for the purpose of assessing the level of development reached by the children. D.S.T. is also a development schedule like that of other developmental schedule such as Vineland Social Maturity Scale, Gessel's Developmental Schedule (1989)[9]etc. The Developmental Screening Test (D.S.T.) was developed by Dr. J. Bharatraj 1977 and revised in 1983[5].

2.Vineland Social Maturity Scale (V.S.M.S., A.J. Malin, 1992)[9]

The Vineland Social Maturity Scale was originally devised by E.A.Doll in 1935.And since then this test is being used in many parts of the world. The first Indian adaptation was done by Rev.Fr.Dr.A.J.Malin while working at the Nagpur Child Guidance Centre. This scale is being used at many clinics, university departments and institutions for mentally retarded persons. It has high co-relation with Binet Scale (0.85-0.96).VSMS gives a profile on development in areas viz, self-help general, self-help eating, self-help dressing, self direction, socialization, occupation, communications and loco motions. The social age and social quotients can be computed from the person's scores.

3.National Institute for the Mentally Handicapped Disability Impact Scale (2003)[19]

This scale was used to asses the impact of disability on caregivers of the mentally challenged children. N.I.M.H.disability impact scale (N.I.M.H.-Dis) has been developed as part of the research project on "Family intervention and support programmes for persons with mental retardation" funded by the U.S.-India rupee fund (1998-2003). Parents and the family are known to get impacted because of having a child with mental retardation.

This is a culture specific tool which could be used to identify and assess the following:

a. The nature and degree of impact on the parents (both positive and negative) because of having a child with mental retardation.

b. The nature and degree of impact on the family members and the relationship within the family.

c. The nature and degree of impact with regard to relationships outside the family.

d. To identify trust area for family intervention programmes.

e. To objectively evaluate family intervention programmes.

The 11 areas of impact included in the scale are as follows:

1. Physical care
2. Health
3. Career
4. Support
5. Financial
6. Social
7. Embarrassment/Ridicule
8. Relationships
9. Sibling effects
10. Specific thoughts
11. Positive effects

METHODS:

65 Mentally retarded children, fulfilling the ICD-10 criteria of mental retardation, were selected from special school and O.P.D. of Post Graduate Institute of Behavioral and medical sciences (PGIBMS)., Raipur. Information was gathered about mentally retarded children and their parents on specially designed semi structure socio demographic and clinical data sheet. Mentally retarded children were administered D.S.T. and V.S.M.S. to assess their intelligence. Parents of such children fulfilling inclusion and exclusion criteria and consenting for the study were selected for the study. Disability impact scale was then administered on the parents to assess the impact of disability of mentally challenged person on them.

RESULTS.

Table-1 Socio-Demographic details of Parents

Variable	**N**	**Range**	**Mean**	**S.D.**
Age	**65**	**21-63**	**37.43**	**8.78**
Variable			**N**	**Percent**
Sex	Male		32	49.20%
	Female		33	50.80%
Education	Up to Vth		8	12.30%
	Up to XIIth		20	30.80%
	Up to graduation		27	41.60%
	Illiterate		10	15.40%
Parents Living status (singly or together)	Single/widow/widower/divorcee		3	4.60%
	Living together		62	95.40%
Occupation	Unskilled worker		13	20%
	Business		9	13.80%
	Service		15	23.10%
	Housewife		28	43.10%
Domicile	Rural		24	36.90%
	Urban		41	63.10%
Income	900-5000		28	43.10%
	5001-10,000		20	30.80%
	10,000 and above		17	26.20%
Types of family	Nuclear		41	63.10%
	Joint		24	36.90%
Informant's relation With the child	Mother		31	47.7%
	Father		34	52.3%

Table-1: shows that the total number of parents was 65, the age range was 21 to 63 with the mean of 37.43 and standard deviation 8.78. With regard to sex, there were 49.2% of male parents and 50.8% of female parents. Most of the parents (41.6%) were educated up to graduation or more, 30.8% were educated up to XII

th, 12.3% up to Vth (Primary level) while 15.4% were uneducated. Most of the parents (95.4%) were living as couple, only 4.6% were living singly. In occupation, majority of i.e. 43.1% were house wives, 23.1% were doing service, 13.8% were business persons and 20% were labour and farmers. Most of them belonged to urban background (63.1%) while 36.9% hailed from rural background. Income wise, majority of them i.e. 43.1% parent were earning less than 5000. 30.8% were in the income range of 5001 to 10,000 per month, while 26.2% were earning more than 10000. Most of the parents belonged to nuclear family i.e. 63.1% and remaining 36.9% belonged to joint family.

Table-2. Clinical variables of the Parents.

Variable	**N**	**Range**	**X**	**S.D.**
Age	**65**	**21-63**	**37.43**	**8.78**
Variable			**N**	**Percent**
Father's age at the time of child's birth	Below 20 years of age		2	3.10%
	21 to 35 years of age		51	78.50%
	Above 35 years of age		12	18.50%
Mother's age at the time of child's birth	Below 20 years of age		15	23.10%
	21 to 35 years of age		47	72.30%
	Above 35 years of age		3	4.60%
Any infection during first three months of pregnancy	No		62	95.40%
	Yes		3	4.60%
Any history of Maternal disease	Absent		61	93.80%
	Present		4	6.20%
Any attempt to induce abortion	Yes		8	12.30%
	No		57	87.70%
Any history of Repetitive abortion	Yes		7	10.80%
	No.		58	89.20%
Duration of Pregnancy	Full term		55	84.60%
	Premature		4	6.20%
	Post-mature		6	9.20%

Table-2: shows the clinical variables of parents. The maximum percentage of fathers (78.5%) were in the age range of 21 to 35 years at the times of birth of the child, 3.1% father's were under 20 years of age, 18.5% of fathers were above 35 years at that time. The majority (72.3%) of mothers were in the age range of 21 to 35 years, 23.1%. were below 20 years and only 4.6% were above 35 years of age at the time of bird of the child. 95.4% mothers did not have any infection during first three months of pregnancy and 4.6% had infection during first trimester of pregnancy. Most of children didn't have any history of maternal disease (93.8%) and only 6.2% of children had history of maternal disease. Maximum number of mothers (87.7%) did not attempt to induce abortion and 12.3% of mothers attempted to induce abortion and 10.80% had history of repetitive abortion. Most of the children were born out of full term pregnancy(84.6%), 6.2% were premature and 9.2% were Post-mature babies.

Table-3. Showed Socio-demographic variables of mentally retarded children.

Variable	**N**	**Range**	**Mean**	**S.D.**
Age	**65**	**5-28**	**11.38**	**5.76**
Variable			**N**	**Percent**
Sex	Male		43	66.20%
	Female		22	33.80%
Birth order time of birth	First		28	43.10%
	Between		23	35.40%
	Last		14	21.50%
Education	Not going to school		29	44.60%
	Pre primary/K.G./Nursery		21	32.30%
	Primary		12	18.50%
	Pre Vocational/V, VI		3	4.61%

Table-3: This table shows the Socio-demographic variables of mentally retarded children. It shows that there were 65 children in the age range of 5 to 28 years. The mean age was11.38 standard deviation 5.76.The majority of children were males i.e. (66.2%) and the female were only 33.8%. Maximum number of mentally retarded children were first born children (43.1%), 21.5% were last born children and 35.4% were born in between. With regards to education,

maximum numbers of mentally retarded children were not going to school (44.6%), 18.5% were educated up to primary level, 32.30 up to pre primary level and 4.61% were educated up to prevocational level.

Table-4. Clinical details of mentally retarded children

	Variables	N	Percent
Family history of mental retardation	Present	9	13.80%
	Absent	56	86.20%
Family History of mental illness	Present	7	10.80%
	Absent	58	59.20%
Nature of Delivery	Normal	49	75.40%
	Caesarean	11	16.90%
	Forceps	5	7.70%
Complications Occurring during birth	Present	20	30.76%
	Absent	45	69.23%
Postnatal Complication	Present	10	15.38%
	Absent	55	84.61%
Any co morbidity	Present	59	90.80%
	Absent	6	9.20%
Behavior problems	Present	16	24.80%
	Absent	49	75.20%
Delivery place	Hospital	40	61.50%
	House	25	35.50%
I.Q. level	Mild	9	13.50%
	Moderate	39	60%
	Severe	17	26.20%

Table-4: This table shows that 86.2% of mentally retarded children did not have any history of mental retardation in the family and 13.8% of them were having the history of mental retardation in the family. 59.2% of mentally retarded children didn't have any history of mental illness in the family and only 10.8% of them were having the family history of mental illness. 75.4% of the children had normal delivery, 16.4% had caesarian and rest of the 7.7% had delivery using forceps. With regards to complication occurring during birth, 30.76% of mentally retarded children were having the history of complications, where as 90.80% children included in this study did not have any complication during birth. In postnatal complication, 15.38% of children were having the history of complication and 84.61% did not have any such problem. Maximum i.e. 60% children had moderate level of mental retardation, 13.50% had mild level and 26.20 % had severe level of mental retardation.

Table-5 Impact of mental retardation on the Caregivers.

AREAS	Maximum Scores	Obtained Scores	Percentage (%)
1. Physical care	1430	507	35.45%
2. Health	1040	213	20.48%
3. Career	910	115	12.96%
4. Support	1170	297	25.38%
5. Financial	1040	409	39.33%
6. Social	780	181	23.21%
7. Embarrassment /Ridicule	910	197	21.65%
8. Relationships	1170	294	25.13%
9. Sibling affect	1300	326	25.08%
10. Specific thoughts	910	131	14.40%
Total negative impact	10660	2693	**25.26%**
Positive impact	1170	645	**55.38%**

Table-5 shows the percentage of positive and negative impact on parents. The maximum negative impact on caregivers was on finance (39.33%) and physical care (35.45%), the minimum negative impact on parents was on career (12.96%) and specific thoughts (14.40%), percentage of negative impact on health, support, social, embarrassment and relationships was 20.48%, 25.38%, 23.21%,21.65%,25.13% and 25.08% respectively.

The items measuring positive impact were in the areas of patience, tolerance, empathy, sensitivity, support and better relationships. The overall percentage of positive impact was 55.38 while overall negative impact was 25.26%.

DISCUSSION

This study aims to enumerate the impact of having an intellectually disabled child. Results of this study show that parents reported more positive impact (55.38). They had developed more patience, more tolerance, more empathy, more sensitivity and better relationships among the couple because of having such a child in their family. Reporting of more positive and less negative impact may be due to better coping mechanisms, more awareness & training about the behavioral intervention techniques, various benefits provided by the government and support by various NGO's etc. Similar findings are reported in literature.

Abbot and Meredith (1986)[1] contributed a study on parental strength of the parents of the mentally retarded children. The authors noticed that the parents with retarded children were less critical of family members, and they had fewer persistent family problems than second group. Authors have suggested that those parents with retarded children have been using 'spousal support', 'participation in similar kind of parents groups', 'religious beliefs' as the important resources used to cope with the challenges of rearing a disabled child. Similarly, Stainton & Besser (1998)[22] tried to explore the positive impact of MR children in family. They identified nine core themes, in them viz, (i) source of joy and happiness; (ii) increased sense of purpose and priorities; (iii) expanded personal and social networks and (iv) community involvement; (v) increased spirituality; (vi) source of family unity and closeness; (vii) increased tolerance and understanding; (viii) personal growth and strength and (ix) positive impacts on others/community. Positive Impact has also been reported by various other authors. Gray & Holden (1992)[11] examined psychosocial well being of

parents of ‘autism’ affected children. Parents who had better social support had lesser level of emotional symptoms like ‘depression’, ‘anxiety’, ‘anger’ & parents of older autistic children’s had lower level of depression’, ‘anxiety’, ‘anger’ may be because with passing of time they learn to live with the problem.

Likewise Kazak and Marvin (1985)[15] pointed that higher levels of stress are found in the families with handicapped children and that despite the presence of high levels of stress, the families were found to have successful coping strategies. Friedrich et al (1985)[8] commented that coping resources like *utilitarian resources*, *energy/moral’*, *general and specific beliefs’* and above all *‘social support from the near and dear one’* were the important sources to overcome the continuous stress to those parents with severely mentally retarded children. Beavers et al (1986)[4] found that family support and cohesiveness were the positive elements to overcome the stress. Canam (1993)[6] talked about the common adaptive tasks and styles of the parents of the children with chronic conditions including mental retardation. Parents of chronically ill or disabled children face a number of common tasks in adapting to their child's condition. Those parents have similarity in managing tasks and coping strategies to overcome the day-to-day stressful situation. Author noticed that effective coping strategies can reduce the menace to them as well as increase the family adaptability.

In the present study negative impact (25.26%) included difficulties in meeting extra demands with physical care of the child, experiencing health related problems, making career adjustments, experiencing loss of support from the spouses etc. Previous studies on similar topics showed that there can be a chance of having negative emotions like ‘despair’, ‘blaming each others’, ‘comparing child with normal children’, ‘marked disruption in parental job activities’, ‘interpersonal relationships’ etc. In the present study it was found that parents’ were having maximum negative impact on the domains like *‘physical care & financial areas’*. Whereas least negative impact has been noticed in the areas of parents’ *‘career activities & specific thoughts’*. It means that the parents’ are having problems in the allocation of funds in the care & training of their retarded children as well as in other necessary domestic requirements. Less negative impact in the area of career may be due to the fact that many respondents were housewives and in India many females remain housewives instead of being career oriented. Negative impact on the parents’ of the intellectually disabled children in the form of financial crisis was also noted by Datta (2002).[7] Parents might develop an antagonistic

attitude towards their retarded children due to failure in reaching balance in meeting the financial needs of the family in general & specific needs of their retarded children. The present study found that in the families of mentally retarded children problems come in the shape of *'negative impact on health of caregivers*, *social embarrassment of the family members*, *'relationship problems among the siblings'* etc. Those problems can magnify the existing problem of having a mentally retarded child.

In the present study parents have reported both positive and negative impact. The enumerated percentage of 'positive impact of having a mentally retarded child outnumbered the level of negative impact of it'. [Positive impact = 55.38% vs. Negative impact = 26.26%]. Kearney & Griffin (2001)[16] also noted the similar phenomenon among the parents of retarded children. They found that the parents had both positive & negative emotions towards their children, such as *'sorrow & joy'*, *'pessimism & optimism'*. Their daily activities evolved around *'positive impact to negative impact'*. These may be due to the fact that parents tend to develop a sense of resilience to meet up the daunting task, i.e., *'fulfilling the needs of their retarded children'*.

Ramey & Keltner (1996)[20] accomplished a study to explore the family adaptation and meeting with the challenges of the families with mentally retarded persons. This study made it evident that both the informal and formal support systems have significant and pervasive effects on parental wellbeing. Similarly, culture and ethnicity exert influences on families through belief systems and culturally endorsed practices. Studies support that families where parents prior to having a mentally retarded child had good marital relationship tend to come even closer to each other to face the situation of having a mentally retarded child. Indian parents report that the major things found most useful in coping up with the situation include getting physical help for looking after the child, financial help, early and timely advice by professionals, their empathic attitude and overall faith in God.

Golbert & Mukherjee (1999)[10] contributed that professionally oriented training programme to the parents of the disabled children can reduce their feeling of hopelessness, resentment & increase the ability to cope with this chronic stress. Those authors formulated a specially designed training programme for the parents of *'spastic children'* in a centre namely *"Spastic Society of Eastern India"* (now Indian Institute of Cerebral Palsy, IICP). They commented that favourable results can be expected if proper guidance programme is initiated for those parents.

According to Akkok (1994)[2] parent training and education about the nature of disabilities of their children can enhance the development of the children with intellectual disabilities, because parents are the significant contributors to the development of their children. They are the primary caretakers, managers, behavior models,

disciplinarians, and agents of socialization and change for their children. If parents are adequately trained and taught they can be better teacher or trainer to their disabled children than other formal professionals.

Karayanni (1989)[14] tells that if the parents of severe mentally retarded children like *'Down's syndrome'* are adequately counseled about their child's condition and future requirements then they can best be helped to increase their coping mechanism to deal with this chronic stress. The author chooses two Arab families with *'Down's syndrome'* children. He explores the cultural considerations which are to be remembered by the treating team. Aim of this study was to present implications and suggestions to professionals to help parents of children with Down's syndrome to function better and to extend maximum help to their children.

McGaw et al (2002)[18] conducted a study aimed to see the positive results of 'group intervention' to reduce emotional problems of parents of mentally retarded children. Group intervention was provided to 12 parents with borderline or mild intellectual disabilities over 14 weeks. 'Judson Rating Scale and Behaviour Problem Index' was applied on parents to examine the results after 27 week's follow-ups. The immediate and long-term benefits of group interactive process have beneficial effect to reduce parental stress.

Summary & Conclusions:

This study has been carried out to enumerate the level of *'disability associated with mental retardation'* on the parents with the retarded children. Having a disabled child in the family is a continuous source of *'stress'* to the family members. Not only the retarded child but the whole family fabric gets affected to this. But this study shows that it is not necessary that every family of retarded children will have negative impact but in some families this problem can create a positive impact, like *'acceptance of the situation realistically'* , *'standing right behind the retarded child and provide support'* . In this study parents of 65 mentally challenged children were selected. The study was carried out at the out-patient department of Post Graduate Institute of Behavioural and Medical Sciences, Raipur and two special schools in the city for such children. The samples were selected by purposive method. Tools used for data collection were: A) a specially designed socio-demographic & clinical data sheet; B) Developmental screening test (D.S.T.); C) Vineland social maturity scale (VSMS); D) National Institute for the Mentally Handicapped (N.I.M.H.) Disability Impact Scale. Results showed that mean age of the parents was 37.43 ± 8.78. Among the parents males were slightly lesser in number. As per the level of education of the parents are concerned most of them had the education of either pre

university or graduation. Other socio-demographic characteristics noticed were that most of the parents were from urban background, having nuclear family structure; majority of them belonged to lower middle to middle socio-economic status. Clinical data showed that most of the retarded children's mothers did not have the history of 'infectious diseases' during first three months of pregnancy as well as most mothers did not have any history of severe physical illness. Coming to the clinical profile of the children it was found that most of the children were born normally & very few of them were born by caesarian process.

Due to the problem of subnormal intellect to their children most of the parents of the selected sample, i.e., retarded children had problems like *'problem in interpersonal relationship'* & *'communication'*. But this study gives the heartening finding that most of the parents of the selected retarded children viewed that they have more *'positive impact'* than *'negative impact '.This study* shows that the overall percentage of positive impact was 55.38 while overall negative impact was 25.26%. To these parents having a mentally challenged child in the family is not a *'burden like thing'* but they are willing to see the situation more positively & overcome the situation more gracefully.

In conclusion it can be said that having an intellectually subnormal child is not altogether a sign of so called *'bad fate or misfortune'* to everyone, but it can also be a challenge which strengthens the parents of those children. But at the same time it is equally true that having a mentally retarded child is a source of chronic stress to the family members & it can affect them negatively in many ways & more attempts should be made for primary prevention of mental retardation.

Limitations and future directions:

1. Large populations having equal representation of all categories of mental retardation should be included.
2. Technique used for better coping should be assessed so that other parents can also be benefited.

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