# ANALYSIS AND INTERPRETATION

# ANALYSIS AND INTERPRETATIONS

The problems associated with mental retardation are on the rise throughout the world. However, it is the attitude of the family and the society that has a direct impact on the upbringing and training of the mentally retarded. Therefore, it is important to study the attitude of the family and its effects, since such knowledge will be valuable in planning the social work intervention and effective remedial programmes which can be implemented in our cultural setting. This situation has made it mandatory to become more closely associated with families and gather adequate information about them. Information about parents and siblings can be extremely useful in developing optimal intervention plans for the handicapped persons, as the influence of the family may be more substantial on the handicapped persons than others as stated by Robinson (1976). \( \frac{1}{2} \)

# 3.1 PROFILE OF THE FAMILY MEMBERS

The present study focuses on the families of the mentally retarded and their attitude.

The following tables show the social, demographic and cultural background of the families which may have direct impact in the formation of attitude.

TABLE 3.1

AGE GROUP OF PARENTS.

|                | FREQUENCY  |            |            |  |  |
|----------------|------------|------------|------------|--|--|
| AGE<br>in Yrs. | FATHERS    | MOTHERS    | TOTAL      |  |  |
| 25-35 yrs.     | 2<br>(5)   | 17<br>(30) | 19<br>(20) |  |  |
| <=36 yrs.      | 38<br>(95) | 40<br>(70) | 78<br>(80) |  |  |
| TOTAL          | 40         | 57         | 97         |  |  |

Note: Figures in brackets represent percentages.

Out of the 57 families interviewed, all the mothers were present at the time of interview while only 40 fathers could be interviewed. This is because in 9 families the fathers were dead and in 8 families the fathers were not present at the time of interview inspite of having taken prior appointment. The table reveals that 80 percent of the parent's were above 36 years and had grown up retarded children are due to which the parent's experience of handling a retarded child is well established. All the fathers in all families were elder than the mothers.

**TABLE 3.2** 

AGE GROUP OF SIBLINGS.

| AGE        | BROTHERS | SISTERS | TOTAL |
|------------|----------|---------|-------|
| 12-17 yrs. | 12       | 10      | 22    |
|            | (44)     | (32)    | (38)  |
| 18-24 yrs. | 5        | 19      | 24    |
|            | (19)     | (62)    | (41)  |
| 25-35 yrs. | 10       | 2       | 12    |
|            | (37)     | (6)     | (21)  |
| TOTAL      | 27       | 31      | 58    |

NOTE: Figures in brackets represent percentages.

Out of the 58 siblings interviewed, 27 were brothers and 31 were sisters of the mentally retarded children. Only siblings above 12 years were considered for the interview since they are matured enough to answer the questions. Nearly 44 percent of the brothers belonged to the age group of 12 to 17 years while 37 percent belonged to the age group of 25 to 35 years. Amongst the sisters, 62 percent of them belonged to the age group of 18 to 24 years and only 6 percent of them belonged to the category of 25 to 35 years. The table also reveals that out of 58 siblings, 46 of them were below 24 years while only 12 of them were above 25 years and independent.

**TABLE 3.3** 

# **EDUCATIONAL STATUS OF PARENTS**

|                              | PARENTS    |            |       |  |  |
|------------------------------|------------|------------|-------|--|--|
| EDUCATION                    | FATHERS    | MOTHERS    | TOTAL |  |  |
| Illiterate                   | 2<br>(5)   | 10<br>(17) | 12    |  |  |
| Primary<br>(I-V Std.)        | 5<br>(13)  | 9<br>(16)  | 14    |  |  |
| Secondary<br>(VI-VIII Std.)  | 8<br>(20)  | 18<br>(32) | 26    |  |  |
| High School<br>(IX-XII Std.) | 8<br>(20)  | 11<br>(19) | 19    |  |  |
| Graduates                    | 17<br>(43) | 9<br>(16)  | 26    |  |  |
| TOTAL                        | 40         | 57         | 97    |  |  |

NOTE: Figures in brackets represent percentages.

The table shows that nearly 43 percent of the fathers are graduates and 53 percent have under education from the primary level to the high school level. Only 5 percent of them were illiterates.

With regard to the mothers, 32 percent of them have undergone secondary education from VI to VIII standard. However, 10 percent of them were not educated.

The overall picture regarding the educational status of the parents shows that except for 12 parents the remaining parents have the basic education which may be a contributing factor in the formation of attitude.

TABLE 3.4

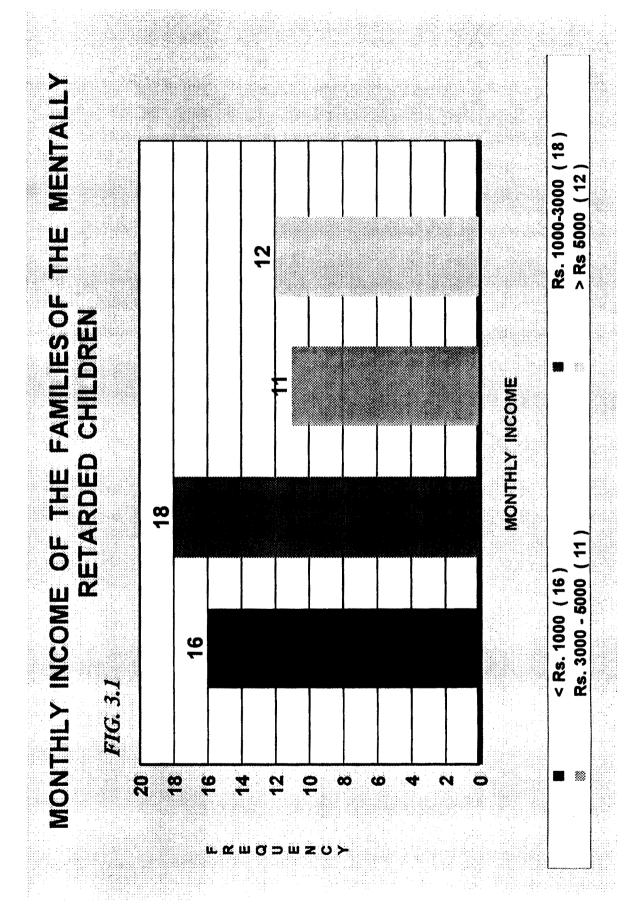
EDUCATIONAL STATUS OF SIBLINGS.

|                              |            | PARENTS    |       |
|------------------------------|------------|------------|-------|
| EDUCATION                    | BROTHERS   | SISTERS    | TOTAL |
| Illiterate                   | 0 (0)      | 1 (3)      | 1     |
| Primary<br>(I-V Std.)        | 1 (4)      | 1 (3)      | 2     |
| Secondary<br>(VI-VIII Std.)  | 6<br>(22)  | 5<br>(16)  | 11    |
| High school<br>(IX-XII Std.) | 9<br>(33)  | 14<br>(45) | 23    |
| Graduates                    | 11<br>(41) | 10<br>(32) | 21    |
| TOTAL                        | 27         | 31         | 58    |

NOTE: Figures in brackets represent percentages

The table reveals that none of the brothers were illiterates. 41 percent of them were graduates while the rest were taking education from the primary to the high school level. As for the sisters, a majority of them amounting to 45 percent were under going high school education while 32 percent of them were graduates. Only 3 percent of them were not educated.

The overall picture regarding the educational status of the siblings, shows that, 44 out of the 58 of them have been educated above IX standard.



The figure 3.1 shows that the families belonging to the income of under Rs. 1000 per month are 28 per cent. Thus, these families are living below the poverty line. However majority of the respondents belong to the middle income group of Rs. 1,000 - 5,000, while 21 per cent of the them belong to the highest income group.

TABLE 3.5

RELIGIOUS BACKGROUND OF THE FAMILIES.

| RELIGION | FREQUENCY | PERCENTAGE |
|----------|-----------|------------|
| HINDU    | 55        | 96         |
| MUSLIM   | 2         | 4          |
| TOTAL    | 57        | 100        |

Although the researcher was interested in comparing the attitudes of the family based on their religious background, it could not be done due to the lack of sufficient number of samples. The table above reveals that there were 4 per cent Muslims and the remaining were Hindus. There were no other religious background people in the sample taken for study.

TABLE 3.6

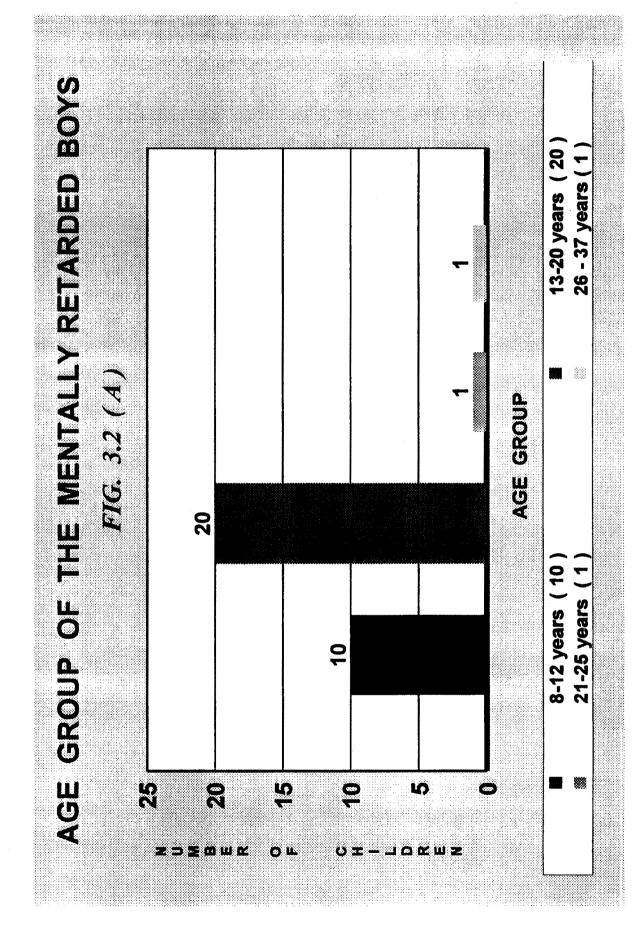
THE TYPES OF HOUSES IN WHICH THE FAMILIES LIVE.

| HOUSE      | FREQUENCY | PERCENTAGE |
|------------|-----------|------------|
| KUTCHA     | 6         | 11         |
| SEMI-PUCCA | 13        | 23         |
| PUCCA      | 38        | 67         |
| TOTAL      | 57        | 100        |

Majority of the families of the mentally retarded amounting to nearly 67 percent were living in pucca houses wherein the houses were made of concrete structures. In semi-pucca houses made just out of mud, 23 percent of them were living. Nearly 11 percent of them were residing in Kutcha houses which had thatched roofs and huts.

## 3.2 PROFILE OF THE MENTALLY RETARDED CHILDREN

The families of 59 mentally retarded children were taken for this study. Since two families had two mentally retarded children in each of them, the total number of families taken for the study was 57. The following graphs gives a vivid picture of the profile of the mentally retarded children under study, regarding their age, level of retardation and other illness the child may be having.



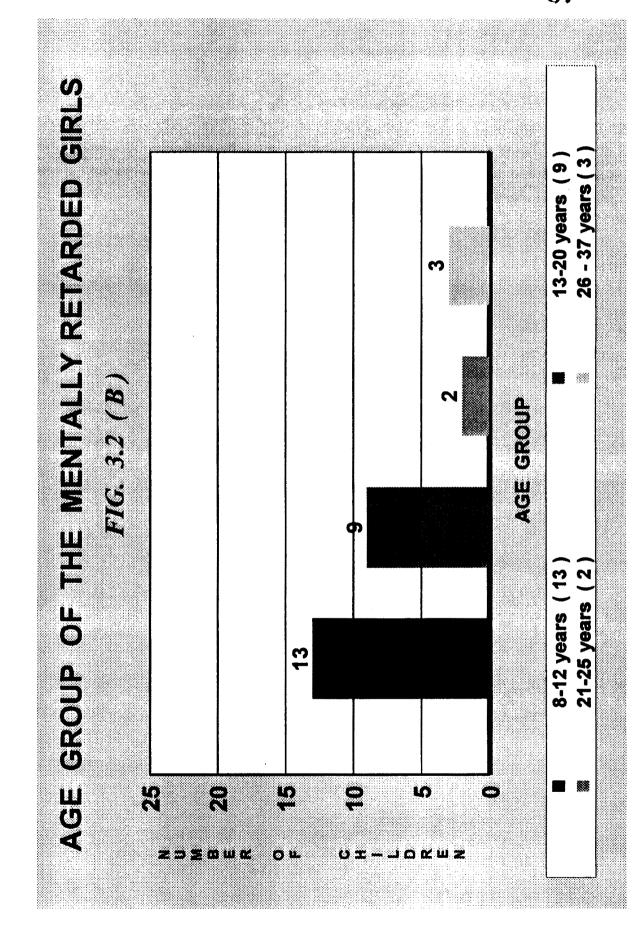
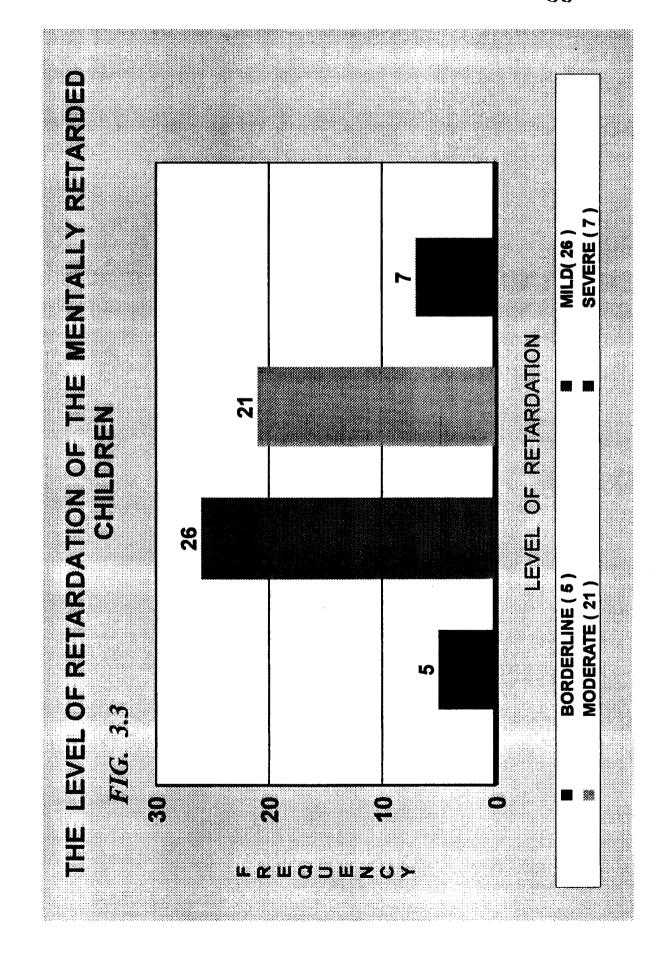
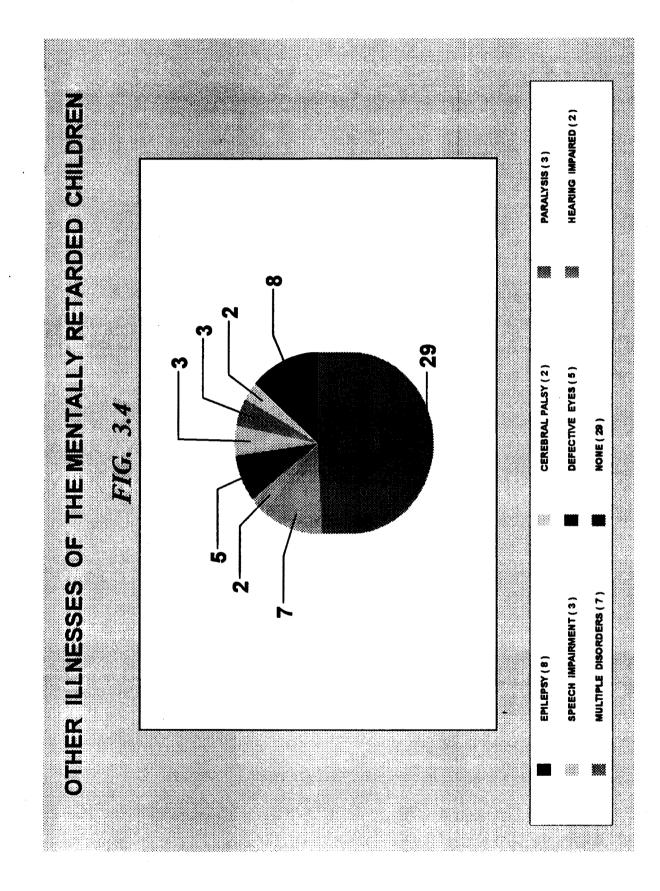


Figure 3.2 (A) & (B) reveals that amongst the 59 mentally retarded children, boys were more than the girls and numbered to 32 of them. The boys (10) who belonged to the age group of 8-12 years were mostly new entrants to these specialised course. The largest number of boys (20) belonged to the age group of 13-20 years. These boys were in their adolescent stage and had developed secondary characteristics of growth. On enquiring, teachers and parents complained that certain boys of this catagory and above did exhibit certain deviant sexual behaviour. The strength of the boys in the age group of 21-25 years and 26-37 years was only each.

This declining strength in the older catagory may be attributed to the fact that these specialised schools were started only after 1980 and hence most of the children belong to the younger catagory. Moreover, the provision of vocational training and occupational training is not available in all these schools and therefore, parents prefer to keep the children at home instead of unnecesserily incurring the expenses of transportation of the child to these schools.

The girls were nearly 27 of them out of the 59 mentally retarded children. The highest number of them who belonged to the age group of 8-12 years were about 13 girls. 9 girls belonged to the age group of 13-20 years. The strength of girls who belonged to the age group of 21-25 years and 26-37 years were 2 and 3 respectively and thus had a lower strength compared to the other groups. The menstrual cycle had started in 17 girls and these girls belonged to all the age groups.





According to the D.S.M. -III- R classification, the mentally retarded were classified as mild, moderate, severe and profound. In this study, none of the children were profoundly retarded but 5 of them belonged to the category of borderline retardation. These children are commonly referred to as "slow learners" and have an I. Q. ranging between 70 to 75. They are mostly recognised as being mentally retarded only when the child is unable to cope up in a normal school curriculum.

The census conducted periodically shows that the highest percentage of mentally retarded belonged to the mildly retarded category. Figure 3.3 also shows that nearly 26 children were mildly retarded, which was the highest percentage in the whole group. About 21 children were moderately retarded while 7 were severely retarded.

It is not unusual to find that most of the mentally retarded children had other illnesses too. These children under study were suffering from epilepsy, cataract, paralysis of any part of the body, speech and hearing impairment or a combination of two or three disorders. Figure 3.4 shows that 8 out of the 59 children had history of epileptic attacks while 5 of them had defective eyes. 7 children suffered from multiple disorders such as heart diseases and fits, hearing impairment and cataract, obesity with defective speech and the like. As can be seen from the figure, 29 children did not have any other kind of illness.

#### 3.3 ATTITUDE OF THE FAMILY TOWARDS MENTAL RETARDATION

Attitude is the way one perceives certain objects, qualities or relations. The way in which one's views or attitudes are formed is influenced by certain set norms or experiences. Therefore, both social learning and innate factors contribute to the formation of an individual's attitude. In the case of mental retardation or other disabilities, familial attitude

and relationships are basically a sociological problem and virtually all rehabilitation workers recognise the significance of these in carrying out rehabilitation efforts.

As a result of fragmentary acquaintance, without the benefit of scientific understanding it is inevitable that people have held many erroneous beliefs and conceptions about mental retardation. The common misconception existing in the community are:

- 1) Mental retardation and mental illness are the same and could be cured.
- 2) Mental retardation is always hereditary.
- 3) The mentally retarded cannot become useful to the society.
- 4) Marriage of the mentally retarded, alleviates the mental retardation.
- 5) Theory of 'Karma' and acceptance of the inevitable.

(Channabasabanna, Bhatti and Leny Prabhu, 1985)<sup>2</sup>.

Although some of the misconceptions are still popular, with the recent developments in the diagnosis there has been a positive approach in the treatment, training, rehabilitation and involvement of the families of the mentally retarded with the help of psychiatry and psychiatric social workers. It is important to know the knowledge levels of the families regarding mental retardation its management, while studying their attitude and analysing their perception regarding the impact of the presence of the mentally retarded child in the family.

The working definitions of these attitudes has already been explained in the methodology chapter. It is important to bear in mind that although these attitudes may be overlapping in the family members actions at certain point of time, the researcher has assessed the most predominant attitude that has comeforth during the

course of the interview and other observations made. Moreover, the attitude of each family member may vary from person to person and thus only one attitude that is explicitly seen has been attributed to each family member.

# 3.3.1 Family's attitude based on the relationship to the child

The attitude of each person in the family depended on the status of the relationship with regard to the mentally retarded child. It is natural that the basic parental concern will always create an attitude of worry, depression, overprotection or resentment. Parental attitudes towards the mentally retarded children were reported as negative by Chaturvedi and Malhotra (1984)<sup>3</sup> and Rastogi (1981)<sup>4</sup>. Rastogi also observed that mothers had more negative attitudes than fathers.

On the other hand, siblings may not be as concerned as their parents about the retarded child but develop an attitude of embarrassment, acceptance or disgust. The attitude formation in siblings was very much influenced by the way in which the parents treated the retarded child.

TABLE 3.7:
FAMILY'S ATTITUDE WITH RESPECT TO THEIR RELATIONSHIP TO THE
RETARDED CHILD.

# [A] Parent's Attitude

| ATTITUDE      | RELAT      | IONSHIPS   | TOTAL      |
|---------------|------------|------------|------------|
|               | FATHER     | MOTHER     |            |
| DEPRESSED     | 3          | 6          | 9          |
|               | (8)        | (11)       | (9)        |
| RESENTMENT    | 6          | 5          | 11         |
|               | (15)       | (9)        | (11)       |
| WORRY         | 7          | 19         | 26         |
|               | (18)       | (33)       | (27)       |
| EMBARRASSMENT | 0<br>(0)   | 0 (0)      | 0<br>(0)   |
| ACCEPTANCE    | 19         | 15         | 34         |
|               | (48)       | (26)       | (35)       |
| DISGUSTED     | 0          | 6          | 6          |
|               | (0)        | (11)       | (6)        |
| OVERPROTECTED | 5<br>(13)  | 6 (11)     | 11<br>(11) |
| TOTAL         | 40<br>(41) | 57<br>(59) | 97         |

 $\chi^2 = 10.52$ 

df = 6

Level of significance = 0.005

Note: Figures in bracket indicate percentages.

The above table brings forth the fact that the parent's attitude towards the retarded child is based on the status of relationship with the child. It was found that the table is statistically insignificant.

Out of the 40 fathers, 19 of them had accepted the child while none of them were disgusted with the presence of the child. In contrast, 15 percent of them resented that their child is retarded and 13 percent of them overprotected the child. In comparison to the fathers, the percentage of mothers who were depressed and worried about the child was more. Amongst 57 mothers, only 15 of them had accepted the child and surprisingly 6 of them were disgusted with the presence of the child. None of the parents were embarrassed to acknowledge that they had a retarded child.

Thus, it can be implied from this table that the mothers were more anxious about the child than the fathers. The mother's disgust with the child may be attributed to the fact that they being the primary caretaker of the child, were overburdened with the household chores and the child's daily routine. These negative attitudes of mothers is consistent with the earlier findings of Rastogi (1981) <sup>4</sup>.

TABLE NO. 3.7

**B: SIBLING'S ATTITUDE.** 

| ATTITUDE      | RELATION   | ONSHIPS    | TOTAL      |
|---------------|------------|------------|------------|
|               | BROTHER    | SISTER     |            |
| DEPRESSED     | 0 (0)      | 0 (0)      | 0 (0)      |
| RESENTMENT    | 1<br>(4)   | 1 (3)      | 2<br>(3)   |
| WORRY         | 0<br>(0)   | 0 (0)      | 0<br>(0)   |
| EMBARRASSMENT | 6<br>(22)  | 9 (29)     | 15<br>(26) |
| ACCEPTANCE    | 11<br>(41) | 15<br>(48) | 26<br>(26) |
| DISGUSTED     | 9 (33)     | 6 (19)     | 15<br>(45) |
| OVERPROTECTED | 0 (0)      | 0 (0)      | 0<br>(0)   |
| TOTAL         | 27<br>(46) | 31<br>(53) | 58         |

$$\chi^2 = 1.75$$

df = 6

Level of Significance = 0.005

Note: Figures in bracket indicate percentages.

The above table reveals that the sibling's attitude towards the retarded child is based on the status of relationship of the child. It was found that the table is statistically insignificant.

Majority of the siblings have accepted the presence of the retarded child in the family. These siblings played a active role in teaching retarded child its daily routine, take them for outings or even assured their parents of undertaking the retarded child's responsibility in future. On the contrary, 33 percent of the brothers and 19 percent of the sisters were disgusted with the presence of the retarded child at home. They felt that these retarded siblings always spoilt the things that belonged to them or they were neglected by the parents and more attention was given to the retarded child. Moreover, due to the physical and financial strains in having to bring up a retarded child, the healthy siblings were deprived of family tours and other luxuries. The table also shows that 22 percent of the brothers and 29 percent of the sisters were embarrassed to reveal that they had a retarded sibling especially in front of peers and friends. They were apprehensive that they may be outcasted from the peer group or the retarded sibling's actions may be ridiculed in the group. Such siblings preferred that the retarded child stays indoors when their friends visited their homes and even refused to take the child along with them for outings.

The percentage of the sisters accepting the retarded child was more than that of the brothers. Also the level of disgustment was less in sisters as compared to brothers which implies that the sisters are more considerate and affectionate to the retarded child.

## 3.3.2 Attitude Based On The Educational Status Of The Family.

It was thought necessary to investigate the correlation, if any, between the family's attitude and the educational status of the family members.

TABLE 3.8

ATTITUDE TOWARDS THE RETARDED CHILD BASED ON THE EDUCATIONAL STATUS OF THE FAMILY.

| ATTITUDE       |            | EDUCATIONAL STATUS |            |                |            |           |  |  |
|----------------|------------|--------------------|------------|----------------|------------|-----------|--|--|
|                | Illiterate | Primary            | Secondary  | High<br>School | Graduate   | TOTAL     |  |  |
| Depressed      | 1          | 3                  | 1          | 2              | 2          | 9         |  |  |
|                | (8)        | (19)               | (3)        | (5)            | (4)        | (6)       |  |  |
| Resentment     | 0          | 1                  | 6          | 3              | 3          | 13        |  |  |
|                | (0)        | (6)                | (16)       | (7)            | (6)        | (8)       |  |  |
| Worry          | 3          | 6                  | 7          | 7              | 3          | 26        |  |  |
|                | (23)       | (38)               | (19)       | (17)           | (6)        | (17)      |  |  |
| Embarrassment  | 0          | 0                  | 6          | 5              | 4          | 15        |  |  |
|                | (0)        | (0)                | (16)       | (12)           | (9)        | (10)      |  |  |
| Acceptance     | 3          | 3                  | 8          | 21             | 25         | 60        |  |  |
|                | (23)       | (19)               | (22)       | (50)           | (53)       | (39)      |  |  |
| Disgusted      | 4          | 3                  | 4          | 4              | 6          | 21        |  |  |
|                | (31)       | (19)               | (11)       | (10)           | (13)       | (14)      |  |  |
| Overprotection | 2<br>(15)  | 0<br>(0)           | 5<br>(14)  | 0 (0)          | 4 (9)      | 11<br>(7) |  |  |
| TOTAL          | 13<br>(8)  | 16<br>(10)         | 37<br>(24) | 42<br>(27)     | 47<br>(30) | 155       |  |  |

$$\chi^2 = 48.35$$

df = 24

Level of significance = 0.005

Note: Figures in brackets indicate percentages

This table was found to be statistically significant which implies that the attitude depends on the educational status of the family members.

Out of the 13 illiterates, 31 percent of them were disgusted with the retarded child where as this percentage is comparitively lesser in educated members. The percentage of the family members who were worried and depressed about the child were the highest in the "Primary' group. The highest percentage of overprotecting the child was found in the "secondary' group. 16 percent of the family members of this group resented that their child was mentally retarded. 17 percent of the family members were worried about the child and 10 percent of them were disgusted with the presence of the retarded child in spite of the fact that their educational qualifications were upto high school level. It is also interesting to note that out of 47 graduates, 25 of them have accepted the child. The other extreme of this picture was 9 percent of these graduates overprotected the child.

From the overall assessment of this table, it can be concluded that the attitude towards the mentally retarded child became more healthy and positive with increasing educational status of the family members. A significant relationship between the knowledge and attitudes of parents is reported by Suma Narayan (1993)<sup>5</sup>.

# 3.3.3 Family's Attitude Based On Their Economical Status

TABLE 3.9 : FAMILIAL ATTITUDE BASED ON THE ECONOMICAL STATUS.

| ATTITUDE   |             | MONTHLY INCOME     |                 |            |           |  |  |  |
|------------|-------------|--------------------|-----------------|------------|-----------|--|--|--|
|            | < Rs. 1,000 | Rs.1000 to<br>3000 | Rs.3000 to 5000 | >Rs.5000   | Total     |  |  |  |
| DEPRESSED  | 2           | 2                  | 0               | 1          | 5         |  |  |  |
|            | (12)        | (11)               | (0)             | (8)        | (9)       |  |  |  |
| RESENTMENT | 0           | 2                  | 1               | 0          | 3         |  |  |  |
|            | (0)         | (11)               | (9)             | (0)        | (5)       |  |  |  |
| WORRY      | 4           | 2                  | 2               | 1          | 9         |  |  |  |
|            | (25)        | (11)               | (18)            | (18)       | (16)      |  |  |  |
| EMBRRASS-  | 2           | 2                  | 0               | 0          | 4         |  |  |  |
| MENT       | (12)        | (11)               | (0)             | (0)        | (7)       |  |  |  |
| ACCEPTANCE | 4           | 8                  | 6               | 9          | 27        |  |  |  |
|            | (25)        | (44)               | (54)            | (75)       | (47)      |  |  |  |
| DISGUSTED  | 2<br>(12)   | 2<br>(11)          | 2 (18)          | 0<br>(0)   | 6<br>(10) |  |  |  |
| OVERPROT-  | 2           | 0                  | 0               | 1          | 3         |  |  |  |
| ECTED      | (12)        | (0)                | (0)             | (8)        | (5)       |  |  |  |
| TOTAL      | 16<br>(28)  | 18<br>(31)         | 11<br>(19)      | 12<br>(21) | 57        |  |  |  |

$$\chi^2 = 17.50$$

df = 18

Level of Significance = 0.005

Note: Figures in bracket indicate percentage

The researcher was interested to find out whether the economical status of the family has any influence in the attitude formation towards the retarded child.

It was found that the above table was not statistically significant. This means that the attitude of the family is independent of its economical status. Even during the course of the interview it was realised that the financial status plays very little role in the attitude formation which is now explicitly proved by the above table.

However, the financial condition of the family plays an important role in fulfilling the specialized needs of the retarded child such as education in specialized schools, vocational, training, medical care (if needed) etc. Parents from the lowest income group expressed the desire of getting certain concessions to the children and the person accompanying them in all the transports. They also expect some funds for the maintenance from the Government as it is given to other physically handicapped and children in Observation homes, Ashram shalas, Orphanages etc. Amongst the parents, fathers preferred to discuss the child's economic and occupational future rather than their own feelings Similar observation is reported earlier by Purnima Mane (1990)<sup>6</sup>.

# 3.4 PERCEPTION OF PARENTS

Having assessed the influence of various parameters like educational status, economical status and the status of relationship with the retarded child on the attitude of the families, it is evident that education has played a significant role in the formation of attitude. Consequently, only the educational status of parents has been considered to find the correlation with the parent's perception about some other factors. It is important to recognise that the way in which the families viewed the mentally retarded child's problems, training and rehabilitation has a great impact on shaping the life of that child. Therefore, the researcher has studied the parent's view regarding the causative factor, the child's marriage and expectations of the child's recovery.

### 3.4.1 Perception of causative factor in relation to parent's educational status

Many parents thought that their child's mental retardation may be due to one or more of the various factors such as heredity, evilspirit, childhood illness and so on. Therefore, the parent's perception was interlinked with their educational status to assess their level of awareness about mental retardation.

700

Heredity was attributed to be causative factor when there is a history of mental illness either in the paternal or maternal side of the child, at least in previous two generations.

The birth of a mentally retarded child in the family was thought of as a punishment from God for the sins committed by someone in the family even from previous generations. This is a blind faith which is prevailing in the society some people even thought that mental retardation was caused due to the performance of black magic up on the family out of enemity.

Childhood illness like high fever, severe dehydration, jaundice, measles etc. were also some of the reasons the parents considered as being responsible in their child becoming mentally retarded.

A mother having a history of many abortions, forceps delivery, consaginous marriage, premature birth of the child are also some of the reasons which are cited by parents on being mostly told by doctors.

PARENT'S PERCEPTION OF THE CAUSATIVE FACTOR
IN RELATION TO THEIR EDUCATIONAL STATUS

| CAUSATIV<br>FACTOR |            | EDUCATIONAL FACTOR |            |                |            |       |
|--------------------|------------|--------------------|------------|----------------|------------|-------|
| FACTOR             | Illiterate | Primary            | Secondary  | High<br>School | Graduate   | Total |
| HEREDITY           | 2          | 3                  | 3          | 1              | 2          | 11    |
|                    | (17)       | (21)               | (11)       | (5)            | (8)        | (11)  |
| EVIL SPIRIT        | 3          | 2                  | 1          | 3              | 2          | 11    |
|                    | (25)       | (14)               | (4)        | (16)           | (8)        | (11)  |
| DON'T KNOW         | 3          | 2                  | 9          | 9              | 11         | 34    |
|                    | (25)       | (14)               | (35)       | (47)           | (42)       | (35)  |
| CHILDHOOD          | 3          | 1                  | 6          | 3              | 0          | 20    |
| ILLNESS            | (25)       | (7)                | (23)       | (16)           | (27)       | (21)  |
| ABORTION           | 0          | 2                  | 2          | 1              | 0          | 5     |
|                    | (0)        | (14)               | (8)        | (5)            | (0)        | (5)   |
| PRE-               | 1          | 1                  | 2          | 0              | 1          | 5     |
| MATURITY           | (8)        | (7)                | (8)        | (0)            | (4)        | (5)   |
| CONSAGINOUS        | 0          | 3                  | 2          | 1              | 2          | 8     |
|                    | (0)        | (21)               | (8)        | (5)            | (8)        | (8)   |
| FORCEPS            | 0 (0)      | 0.                 | 1          | 1              | 1          | 3     |
| DELIVERY           |            | (0)                | (4)        | (5)            | (4)        | (3)   |
| TOTAL              | 12<br>(12) | 14<br>(14)         | 26<br>(27) | 19<br>(19)     | 26<br>(27) | 9.7   |

 $\chi^2 = 23.54$ 

df = 28

Level of Significance = 0.005

Note: Figures in bracket indicate percentage

The above table proved that the parent's perception of the causative factor in relation to their educational status was statistically insignificant.

25 percent of the illiterates thought that mental retardation in their child was due to evil spirit and 25 percent of them thought it was due to childhood illness. The highest percentage of parents who thought mental retardation was because of their consaginous marriage or heredity factors were primary educated. It is ironic to see that nearly 47 percent of the parents who were educated upto the high school level and 42 percent of them who were graduates did not know the reason for their child's mental retardation.

2

During the course of the interviews, there were many things which came to light. Nearly 75 percent of the parents had not taken efforts to find out, from any source, the reasons for their child being mentally retarded. Secondly, the actual causal factor recorded in the case files of the retarded child was refuted by some of the parents and they attributed the mental retardation of their child to some other causal factor. Many of the parents were not frank in disclosing the causative factor especially if they were guilty of having tried to abort during the pregnancy or their's was a consaginous marriage.

# 3.4.2 Parent's view regarding their child's marriage in relation to their educational status

Even the parents of mentally retarded have a dream to see their child get settled down in life as any other parents. Their view regarding the child's marriage is very much influenced by the cultural norms and their educational status. Some parents felt that the mentally retarded child would become normal as they grow up and therefore they can get

married. Parents who had only one child or one son felt that they should get him married since he is heir to the family. There were some respondents who vehemently refused the concept of getting their mentally retarded child married. They opined that since these individuals themselves require personal attention, they will be unable to lead a normal family life. On the other hand, some of the parents have not even thought about their child's marriage and therefore did not give any response to this question. This reaction was given by the parents whose retarded children were too young for marriage. The above views were interlinked with the parent's educational status as shown in the table below.

Table 3.11: Parent's View regarding their child's marriage in relation to their educational background.

| PARENT'S    | EDUCATIONAL STATUS |            |            |                |            | TOTAL      |
|-------------|--------------------|------------|------------|----------------|------------|------------|
| VIEW        | Illiterate         | Primary    | Secondary  | High<br>school | Graduates  |            |
| ВЕСОМЕ      | 1                  | 3          | 5          | 2              | 1          | 12         |
| NORMAL      | (8)                | (21)       | (19)       | (10)           | (4)        | (12)       |
| HEIRS TO    | 1                  | 2          | 5          | 0              | 1          | 9          |
| THE FAMILY  | (8)                | (14)       | (19)       | (0)            | (4)        | (9)        |
| NO MARRIAGE | 6<br>(50)          | 5<br>(36)  | 6<br>(23)  | 11<br>(58)     | 18<br>(69) | 46<br>(47) |
| NO RESPONSE | 4<br>(33)          | 4<br>(28)  | 10<br>(38) | 6<br>(31)      | 6<br>(23)  | 30<br>(31) |
| TOTAL       | 12<br>(12)         | 14<br>(14) | 26<br>(27) | 19<br>(19)     | 26<br>(27) | 97         |

$$\chi^2 = 17.14$$

df = 12

Level of significance = 0.005

Note: Figures in bracket indicate percentages.

It was noticed that the table 3.10 is statistically insignificant which implies that the parent's view regarding the child's marriage is irrespective of their educational status.

It was encouraging to note that 50 percent of the illiterates refused to get their child married. The highest percentage of respondents who felt that their child would become normal were in the primary group while those who felt that their child being heir to the family should get married, were from the secondary group. However, 69 percent of the graduates were convinced that they will not get their child married. Out of the 97 respondents, 30 of them did not give any response to the question regarding their child's marriage. This is one of the contributing factor for the table being statistically insignificant. Since their children were not in the marriagable age, most of them had not even given a serious thought to this whole issue.

# 3.4.3 Parent's Perception about the child's recovery in relation to their educational status.

It is quite natural that every parent of a mentally retarded child "hope against hope" that their child should become normal if by any means possible. Many a times, parents are misled by doctors about the child's recovery when they are given some tonics or feel overjoyed on seeing the improvement in their child's behaviour at home after having sent them to a specialized school. Thus, the parents feel that their child may get cured as it grows. Parents begin to accept the harsh reality that their child is incurable only when the child is grown up and there seems to be no remarkable improvement in the child's behaviour. On the other hand, some parents were still not sure whether their child would get cured or not because the doctors do not explicitly reveal their child's condition. There were some parents who were reluctant to answer this question.

The researcher realised that many parents thought that their child's disability was mainly due to the other illnesses like epilepsy, other physical handicapness etc. rather than mental retardation itself. Therefore, they felt that once the child is treated for the other illness, it would get completely cured. Thus, it can be seen that parents were in the dark that their child is primarily mentally retarded though other illness can be outwardly seen. The parent's perception regarding the child's recovery from mental retardation was correlated with their educational status.

Table 3.12: Parent's perception about the child's recovery in relation to their educational status.

| PARENT'S<br>VIEW | EDUCATIONAL STATUS |            |            |                |            |      |
|------------------|--------------------|------------|------------|----------------|------------|------|
|                  | Illiterate         | Primary    | Secondary  | High<br>School | Graduate   |      |
| CURABLE          | 4                  | 5          | 8          | 1              | 5          | 23   |
|                  | (33)               | (36)       | (31)       | (5)            | (19)       | (24) |
| INCURABLE        | 4                  | 3          | 9          | 11             | 18         | 45   |
|                  | (33)               | (21)       | (35)       | (58)           | (69)       | (46) |
| DON'T KNOW       | 3                  | 3          | 5          | 3              | 2          | 16   |
|                  | (25)               | (21)       | (19)       | (16)           | (8)        | (16) |
| NO RESPONSE      | 1                  | 3          | 4          | 4              | 1          | 13   |
|                  | (8)                | (21)       | (15)       | (21)           | (4)        | (13) |
| TOTAL            | 12<br>(12)         | 14<br>(14) | 26<br>(27) | 19<br>(19)     | 26<br>(27) | 97   |

$$\chi^2 = 17.01$$

df = 12

Level of significance = 0.005

Note: Figures in bracket indicate percentages.

Statistically, this table is not significant. Hence, it can be concluded that the parent's perception regarding their child's recovery is independent of their educational status.

Amongst the parents who were illiterates, 33 percent of them thought that their would get cured while 25 percent of them did not know whether their child can be cured or not. The highest percentage of parents who hoped that their child's retardation is curable were from the primary group. Nearly 21 percent of the parents who were high school educated did not give any response regarding their child's recovery. It should be appreciated that 69 percent of the graduates felt that their child is incurable.

All the tables on parent's perception about the various issues regarding mental retardation in relation to their educational status are in significant. This implies very clearly that education has not played a major role in moulding parent's perceptions and views. Also, parent's education has not facilitated the real understanding of the problem of mental retardation in its totality. On the contrary, the parent's views and perceptions were ruled or influenced by the set norms, practices and certain prejudices caused from the pressures prevailing in the society. Kolhapur being a semi-urbanised city, the society's thinking processes are still monopolised with its traditional and rigid views. Hence, there is an influence of the society on the parents view which predominantly seen than their educational status.

# 3.5 REACTIONS OF THE FAMILY DUE TO THE PRESENCE OF THE MENTALLY RETARDED CHILD

There are multiple problems in families having a mentally retarded child. The overwhelming problem of these parents is related to the feeling of social ridicule for

possessing a mentally retarded child. The major factors that affect the growth and development of the retarded child are the personality characteristics and perceptions of the parents which combinely leads towards the formation of attitudes. Having discussed about the attitudes of family members in relation to various parameters in the preceding sections, the researcher is interested in finding the reactions and responses of the family members.

The understanding of the intensity of these responses and the variety of reactions of the family members can help the mental health professionals and social workers to make a more appropriate therapeutic approach. A variety of reactions have been described and mentioned in the literature such as alarm, anxiety, bitterness, denial, shame, guilt, frustration, despair, helplessness etc. It was pointed out by Galton et al. (1963)<sup>6</sup> that parents may concurrently be depressed about their disappointment, guilty about their responsibility, angry about narcissistic injury done to them and anxious about the child's future.

In this section, the researcher has tried to find out what were the initial steps taken by the family on realising that the child is mentally retarded and the modes of treatment adopted. Efforts were also made to see if the presence of the child has any kind of effect on the family members and their routine. The interaction pattern between the parents and normal siblings was also studied.

# 3.5.1 Initial Steps Taken By Parents

The initial reaction shown by the family members is always important in determining the stand adopted by them towards the mentally retarded child. The total lack of preparedness for this event confuses, disorganises and immobilises the parents as already mentioned by Parks and Ronda (1983)<sup>7</sup>. It may be, however, noted that parent's initial

negative reactions are often intensified by the insensitive manner in which medical personnel inform them of their child's conditions (Vitello and Soskin 1985, Collins 1986)<sup>8,9</sup>. Many a times, the parents have to develop their own expertise on handling their retarded child due to the lack of knowledge and coping methods. The initial step taken by the parents is the direct consequence of their understanding about the problem.

The following table shows the relation between the initial steps taken and the parent's educational status.

Table 3.13
INITIAL STEPS TAKEN BY THE PARENTS IN RELATION TO THEIR

**EDUCATIONAL STATUS** 

| STEPS<br>TAKEN                       | EDUCATIONAL STATUS |            |            |                |            |            |  |
|--------------------------------------|--------------------|------------|------------|----------------|------------|------------|--|
|                                      | Illiterate         | Primary    | Secondary  | High<br>School | Graduate   |            |  |
| NO STEPS                             | 3 (25)             | 4 (28)     | 6<br>(23)  | 4<br>(21)      | 3<br>(11)  | 20<br>(21) |  |
| DISCUSSED                            | 0 (0)              | 1<br>(7)   | 8<br>(31)  | 5<br>(26)      | 7<br>(27)  | 21<br>(22) |  |
| TOOK TO<br>THE TEMPLE<br>OR MAGICIAN | 1 (8)              | 2<br>(14)  | 1<br>(4)   | 0<br>(0)       | 0<br>(0)   | 4<br>(4)   |  |
| TOOK TO THE<br>HOSPITAL              | 8<br>(67)          | 7<br>(50)  | 11<br>(42) | 10<br>(52)     | 16<br>(61) | 52<br>(54) |  |
| TOTAL                                | 12<br>(12)         | 14<br>(14) | 26<br>(27) | 19<br>(19)     | 26<br>(27) | 97         |  |

$$\chi^2 = 14.44$$
 df = 12

Level of significance = 0.005

Note: Figures in bracket indicate percentages.

During the course of the interviews, parents reported variety of initial steps such as discussing about their child's condition with others, taking the child to the hospital, temple or magician or the other extreme of not taking any step. Parents who did not take any steps even after realising that their child is not normal, have a 'wishful thinking' of their child becoming normal as it grows. This is in accordance to the belief that 'each child has its own pace of growth' as reported by Purnima Mane (1990)<sup>6</sup>. On the others hand, some parents discussed with their friends, neighbours or well-wishers about their child's condition. These discussions were mostly based on the information got from literature, mass media or observing other children having similar problems. The Orthodox or religious parents took the child to the magician or temple and made vows or performed some rituals to get the child cured. Most of the parents took the child to the hospital and tried all the measures available to get their child cured.

It was found that the table 3.13 is statistically insignificant. This implies that the initial steps taken by the parents is irrespective of their educational status. From the above table, it can be seen that amongst the illiterates only 25 percent of them did not take any steps and 67 percent of them took the child to the hospital on realising that their child is not normal. Nearly 31 percent of the parents from the secondary educated group discussed about their child's condition with others 14 percent of the primary educated parents took the child to the temple or magician. Incidentally, the percentage of parents who took the child to the hospital was the highest in all educated and illiterate groups.

# 3.5.2 Modes Of Treatment Adopted.

Parents resort to different kinds of treatment on being told that their child is mentally retarded. Although it is a well known fact that mental retardation is not curable, many a

times this truth is not convincingly told to the parents by the health professionals. Therefore, parents do 'doctor - hunting' and try out all the means possible to get their child cured. This process goes on until the parents finally realise that their child can never be cured. Consequently, many years and lot of money is wasted before the parents are channelised to put their child for specialised training.

The modes of treatment adopted by the parents for the child's recovery is based on their understanding about mental retardation. In the following table, the educational status of parents has been interlinked with modes of treatment adopted by them to see the relationship, if any, between these two parameters. The modes of treatment that were commonly adopted by the parents were medical, aurvedic, homeopathic or combination of medical and religious treatment. Religious treatment included taking of some vows, observing fasts and performing certain rituals by parents. Some parents also take the child to Godmen who give 'pudis' which is basically a kind of powder that is claimed as holy medicine by these Godmen.

TABLE 3.14

MODES OF TREATMENT ADOPTED FOR THE CHILD'S RECOVERY IN

RELATION TO THE PARENT'S EDUCATIONAL STATUS.

| MODE OF<br>TREATMENT | EDUCATIONAL STATUS |            |            |                |            |            |  |
|----------------------|--------------------|------------|------------|----------------|------------|------------|--|
|                      | Illiterate         | Primary    | Secondary  | High<br>School | Graduate   | TOTAL      |  |
| MEDICAL              | 2<br>(17)          | 6<br>(43)  | 10<br>(38) | 6<br>(31)      | 16<br>(61) | 40<br>(41) |  |
| RELIGIOUS<br>&       | 9                  | 7          | 11         | 10             | 5          | 42         |  |
| MEDICAL              | (75)               | (50)       | (42)       | (52)           | (19)       | (43)       |  |
| AURVEDIC             | 0<br>(0)           | 1<br>(7)   | 4<br>(15)  | 3<br>(16)      | 3<br>(11)  | 11<br>(11) |  |
| HOMEOPATHIC          | 1<br>(8)           | 0<br>(0)   | 1<br>(3)   | 0 (0)          | 2<br>(8)   | 4<br>(4)   |  |
| TOTAL                | 12<br>(12)         | 14<br>(14) | 26<br>(27) | 19<br>(19)     | 26<br>(27) | 97         |  |

$$\chi^2 = 16.13$$

df = 12

Level of Significance = 0.005

Note: Figures in bracket indicate percentages.

It was found that the statistical difference in the above table was not explicit. The table reveals that 75 percent of the illiterates adopted both religious and medical treatment on realising that their child is mentally retarded. Nearly 61 percent of the graduates resorted to medical treatment to get their child cured. The parents who adopted aurvedic and homeopathic treatment belonged to the secondary, high school and graduate category. The astonishing fact that has comeforth, from the analysis of this data is that, none of the parents have refrained from adopting any means for treating the child inspite of mental retardation being incurable. Ironically, the doctors also try to console the parents by giving "tonics' to improve the capacity of the brain instead of disclosing the harsh reality. Most of the children under study were also suffering from other illnesses as already mentioned. There is possibility of improvement in these other illnesses due to doctor's treatment, which the parents must have misinterpreted as a first step towards the cure of mental retardation.

## 3.5.3 Problems Encountered By Family Members Due To The Presence Of The Mentally Retarded Child.

The problems encountered by the families due to the presence of the mentally retarded child are innumerable. The stress and strain associated with caring for these children often has a disruptive effect on the daily routine, physical and mental health of other family members. It is extremely important on the part of the mental health professionals to know what are the major problems faced by the family members and to study the effect of these problems on psycho-socio-cultural functioning of parents. The table and the subsequent explanation throw light on the above mentioned aspect.

TABLE 3.15

EFFECT OF THE PRESENCE OF MENTALLY RETARDED

CHILD ON THE FAMILY MEMBERS.

| FACTORS                                     | Father     |            | Mother     |            | Brother  |            | Sister    |            |
|---|------------|------------|------------|------------|----------|------------|-----------|------------|
| AFFECTED                                    | Yes        | No         | Yes        | No         | Yes      | No         | Yes       | No         |
| HOUSEHOLD                                   | 0          | 40         | 47         | 10         | 0        | 27         | 12        | 19         |
| ROUTINE                                     | (0)        | (100)      | (82)       | (18)       | (0)      | (100)      | (39)      | (61)       |
| SOCIAL                                      | 9          | 31         | 41         | 16         | 7        | 20         | 13        | 18         |
| ACTIVITIES                                  | (23)       | (77)       | (72)       | (28)       | (26)     | (74)       | (42)      | (58)       |
| CONCENTRATION                               | 15         | 25         | 20         | 37         | 13       | 14         | 19        | 12         |
| ON WORK                                     | (38)       | (62)       | (35)       | (65)       | (48)     | (52)       | (61)      | (39)       |
| PEACE IN THE                                | 22         | 18         | 36         | 21         | 10       | 17         | 9         | 22         |
| FAMILY                                      | (55)       | (45)       | (63)       | (37)       | (37)     | (63)       | (29)      | (71)       |
| INTERACTION<br>WITH OTHER<br>FAMILY MEMBERS | 14<br>(35) | 26<br>(65) | 34<br>(60) | 23<br>(40) | 2<br>(7) | 25<br>(93) | 9<br>(29) | 22<br>(71) |
| HEALTH                                      | 17         | 23         | 39         | 18         | 3        | 24         | 5         | 26         |
|   | (43)       | (57)       | (68)       | (32)       | (11)     | (89)       | (16)      | (84)       |
| TOTAL                                       | 40         |            | 5.7        |            | 27       |            | 31        |            |

Note: Figures in bracket indicate percentages.

The household routine of the fathers and brothers was not affected while 82 percent of the mothers and 32 percent of the sisters opined that they had to re-adjust their household routine to help the mentally retarded child in toilet training, eating habits and others activities. As reported by Batshaw and Parret (1986)<sup>10</sup> "families have to undertake considerable hardship in the management of the child like continued lack of sleep, additional clothes to wash, extra financial cost, special treatment if the child has multiple problems and so on".

The social activities of 72 percent of the mothers and only 23 percent of the fathers were restricted. Few siblings felt that their social activities are restricted because they were deprived of the pleasure of family outings and having other social commitments. The parent's concentration on work at office or any other vocation has been affected to some extent (38 percent of the fathers and 35 percent of the mothers), due to the worry about the child's retardation and future. Comparatively, the percentage of siblings getting affected in their work is higher (48 percent of brothers and 61 percent of sisters). Most of the siblings were in schools or colleges and their studies were affected due to the child's temper tantrums, tearing of books etc.

According to 55 percent of the fathers and 63 percent of the mothers there was no peace in the family because of the mentally retarded child. There were frequent quarrels and misunderstandings between the parents or the parents and other siblings. In a traditional country like ours, family get-together is an important factor in the socialization process. Unfortunately due to the presence of the mentally retarded child, the family's interaction with the relatives and others in the society becomes minimal 60 percent of the mothers confessed that most of their time in spent in looking after this child that they hardly have time for such interactions.

Bringing up a mentally retarded child involves more physical work and more mental strain. This table explicitly reveals 68 percent of the mothers and 43 percent of the parents complained that they were having health problems such as headaches, blood pressure, acidity, backpain and bouts of depression. Siblings also said that they became irritated very easily and emotionally upset for any inadvertent mistake committed by the retarded child.

The overall view of the table gives the idea that the mothers faced the maximum hardships in rearing this child. This may be because she is the primary care taker. Thus, the prolonged burden of care is an important area of stress for the mothers that the other family members. It is consistent with the earlier findings of Suma Narayan (1993)<sup>4</sup> that "This is again an undesirable trend that the care of the handicapped is conceived as the mother's job".

#### Parent's Time

The another area of stress that was observed during the course of this study was the parent's inability to devote sufficient time and attention to their normal children. Most of the families that were interviewed were nuclear families. The parents reported that due to the handicap of one child, their other children suffered a lot, since there was no way they could divide their attention and time equitably amongst all their children. Parents were more guilty about this in cases where the normal siblings were either younger than the retarded child or less than 8 - 10 years at present.

On the other hand most of the elder siblings said that although they felt neglected during their childhood, they were now able to realise their parent's dilemma and have no ill feelings about the situation. The siblings in four families had developed feelings of hostility due to the preferential treatment given to the mentally retarded child by their parents. Such a treatment can have adverse impact on the mentally retarded child because they are often ignored and the responsibility of looking after them is shrugged off by the normal siblings. By and large it has been noted that in families with good understanding of the crisis of having a mentally retarded child is met effectively and ties become closer knit.

# 3.6 BURDEN DUE TO THE FEMALE MENTALLY RETARDED: PARENT'S VIEW

There are not many studies on how parents view the presence of the mentally retarded girl in the family. In India, due to certain old beliefs, the birth of a girl is usually not considered as a happy occasion. Therefore, it is important to examine how the birth of a female mentally retarded is thought of as an additional burden by the parents.

During the course of the interview, parents pointed out some of the additional strains they had to face since their mentally retarded child was a girl. The child's' menstural cycle, financial security, rehabilitation and the undue advantage taken by people because of the child's innocence are some of the reasons for the additional strains. The following table gives the statistical picture of the additional problems faced by parents as they view them.

ADDITIONAL PROBLEMS FACED BY THE FAMILIES OF FEMALE MENTALLY RETARDED.

| PROBLEMS ENCOUNTERED                  | FREQUENCY | PERCENTAGE |
|---------------------------------------|-----------|------------|
| MENSTURAL CYCLE                       | 4         | 15         |
| FINANCIAL SECURITY                    | 5         | 18         |
| REHABILITATION                        | 7         | 26         |
| MENSTURAL CYCLE & FINANCIAL SECURITY  | 3         | 11         |
| FINANCIAL SECURITY AND REHABILITATION | 1         | 4          |
| MENSTURAL CYCLE AND REHABILITATION    | 7         | 26         |

The menstural cycle of the mentally retarded girl child forces the parents to keep the child from going to school. Out of the 27 mentally retarded girls in this study, the menstural cycle had started in 17 of them. These girls are not capable of changing and washing their napkins and are entirely dependent on someone for this purpose. During this period parents have to constantly keep the child clean and restrict their unconscious physical movements. Parents were also apprehensive that the strangers may sexually abuse their daughter especially when she is alone at home or on the way to school. Moreover, they asserted that such gruesome act will always be finally blamed by the society for the parent's negligence.

As for the provisions of financial security and rehabilitation of the child, the parents were not spontaneous in the discussions. Many parents disclosed that they had to make the provision of financial security for their girl from their property or savings only because there was no other alternative in front of them. Rehabilitation by way of training the girl child is some vocation in order to earn some livelihood was not thought of by many parents.

About 26 percent of the parents thought that the girl child is an additional strain because of its menstural cycle and rehabilitation while 26 percent thought it was only with regard to the rehabilitation. Interestingly, 18 percent of the parents thought that the financial security to be provided for the girl child is an additional strain.

A very clear picture that emerges from this table is that the majority of parents considered the menstural cycle of the child to be the most strenuous situation. Therefore, amongst the 17 girls whose menstural cycle had started, 14 parents were seriously considering Hysterectomy. However, many parents whose daughter's menstrual cycle had

not started, were in a dilemma. They were seeking professional guidance regarding this matter because of the recent uproar in Pune. As a result the majority of parents of the female mentally retarded preferred to keep the child in a hostel after their death..

### 3.7. TRAINING AND REHABILITATION: PARENT'S VIEW.

Our concept of the family's role in the training and rehabilitation of the mentally retarded has undergone a dramatic shift over the past few decades. This shift was in the thinking about the family's role, from an etiological agent to that of a coper and responder. Consequently, various efforts are afoot to evolve strategies that could best enlist the cooperation of parents as partners in this care process. Literature also indicates that the success in the care, training and rehabilitation of the handicapped depends on the family involvement (Bradshaw 1978<sup>12</sup>, Bristol et al. 1982<sup>13</sup>, Rinn et al. 1977<sup>14</sup>).

The family's response and actions is a result of its level of competence or its adaptive skills. Although the families expect that their mentally retarded child should improve somehow, many of them do not know whether effective training is available. Some do not believe that specialised training and mental health professionals could help in the child's wholistic development. Still in some other cases, they are helpless as they have exhausted all their resources and do not have money to spend for the training.

In this section, an attempt is made to empirically probe into the measures adopted by the families in the training of the mentally retarded child such as the parental expectations, level of parent's involvement in training and problems associated with training. Efforts were also taken to study the steps taken by parents with regard to their retarded child's after care, parent's view about rehabilitation and the financial security that has been

provided for the child's future. This is important in restructuring the training programmes and identifying new social work techniques to enable the family members to get involved in the training of the child effectively.

#### 3.7.1 PARENTAL EXPECTATIONS FROM TRAINING.

It is natural that the parents of the mentally retarded have certain expectations of their children. These aspirations are the results of the parent's understanding about the intensity of the problem of mental retardation, level of retardation and the counselling, if any, given by the professionals to the parents. By studying the parental expectations, the training and rehabilitation of the child can be channelised.

There were many interesting findings regarding the parental expectations in sending the child for specialised training. Majority (80 percent) of the parents had high expectations, about their child and also "built castles in the air "about its rehabilitation. They hoped that the child will be able to lead a normal life and were contemplating about getting the child married. 3 percent of the parents complained that they were not happy with the academic training given to the child since they wanted to transfer the child to the normal school after some years which was an unrealistic expectation. Only 15 percent of the parents desired that they would be happy if their child is able to become a useful member of the society and not a burden to the society. This can be considered as a reasonable expectation. Nearly 2 percent of the parents with low expectations found the child to be burdensome and useless.

There is an unhealthy view about the parent's aspirations regarding the child because these parents are hardly counselled by the school authorities. On seeing the child's

improvement in its behaviour after putting him in school, parents misinterpret this sign of improvement and hope that the child can master everything in course of time. Such instances are very common especially among the parents of borderline, mild and moderately retarded children.

#### 3.7.2. PARENT'S LEVEL OF INVOLVEMENT IN TRAINING

The parent's struggle to cope up emotionally and physically with the handicap of their child and therefore getting them involved in the training becomes the most formidable barrier. However, in the management of the mentally retarded child, cooperation from parent's side is inevitable. Services from educational, psychological, medical and communication areas required physical, and psychological involvements from the parents. This is because in terms of intensity, frequency and duration of contact, parents have access to their children than the professionals. According to McConckey et al. (1975)<sup>15</sup>, Helm et al. (1986)<sup>16</sup> and Peshwaria (1989)<sup>17</sup>, in the area of mental retardation, professionals dealing with counselling, education and training have strongly emphasized the need for training the parents to deal effectively with the consequences of their child's disability.

Regarding this study, the researcher was able to realise that the parent's involvement in the training was not satisfactory. This has been studied in relation to;

- a) Reasons for not being involved
- b) Relationship between parents and teachers.
- c) Problems associated with training.

Parents felt that they have fulfilled their responsibility once the child has been put in a specialised school except for 3 or 4 parents. This attitude is consistent with the behaviour of parents from semi-urban culture where normal children are also treated this way. Nearly 90 percent of the fathers opined that they were not actively involved in the training due to the lack of time. Some parents did not know how or in what way they were supposed to participate in the child's training. This is because parents were not made to realise the importance and their role in training and what should be their level of expectation at the time of admitting the child in the school by professionals.

Moreover, the skills taught at schools were not practiced at homes due to the lack of proper feedback from the teachers to the parent's or the parent's inability to train the child in mastering these skills. For example, a child who has been taught to button his/her shirt may not or even refuse to do it at home. Yet another problem associated with the training of the child is the unavailability of professionals in certain specialised schools. Certain children besides mental retardation had defective speech, hearing impairment, physical impairment which required specialised professionals in the respective fields. Unfortunately, there is a scarcity of such expertise in Kolhapur city and thus the training of the child become lopsided.

Parents complained that their child had copied certain habits from other children in the school which had an adverse effect on the child's behaviour and training. e.g. some children who could eat on their own became adamant and expected others to feed them when they saw other children being fed.

According to majority of parents, the parent-teachers meetings was a farce. Many of them attended it out of routine and could not identify the role they had to play. Both the parents and the teachers held the view that there is no cooperation from the other side. In fact, it was realised, that the role of parents and teachers in the training of the child was more of the competitive nature than that of the complimentary one.

### 3.7.3 PARENT'S EXPECTATION IN REHABILITATION

#### (A) AFTERCARE

Information was elicited from the parents regarding the care of the child when they grow very old or after their demise. This is one area in the sphere of rehabilitation of the mentally retarded, where parents have not seriously thought. Majority of the parents who are actively concerned about the future of the mentally retarded child wanted institutionalization. However, none of the schools in Kolhapur have residential facilities but the parents are keen on making the government or the school authorities to take up the responsibility of looking after their child. Certain, lacunas that can be pointed out for this shifting of responsibility from home care to a residential one are as follows:

- 1) Parents have not taught their normal siblings their responsibility towards the mentally retarded child.
- 2) Parents were apprehensive about the treatment that will be meted out to the mentally retarded child by the sibling's life partners.
- 3) Some parents did not want to burden their normal children with the responsibility of looking after their mentally retarded child and thereby spoil their careers or marital

relationship. This kind of an attitude was observed especially in cases where the mentally retarded child is a girl or is severely retarded.

## B) FINANCIAL INDEPENDENCE

Many parent's primary concern regarding the rehabilitation process of the mentally retarded child was viewed as the child being financially independent. Many parents thought that as the child grows up, it would be able to do something according to its abilities to become independent. Table 3.17 expounds parent's expectation about the child's rehabilitation financially in relation to its level of retardation.

Parents who wanted their children to do business or family business mostly considered them to be "helpless" since these children may not be able to handle the customers efficiently. Children who were expected to take up a job by parents were to be employed as gardeners, peons, home deliverers of milk sachets or newspapers. Some parents opined that they would be happy if their children continued to work in the training center of school's workshop and earn from the profit made through sales of the products like greeting cards, files, candles, etc. There are other modes of earning, the parents have thought regarding the child's financial rehabilitation such as monthly interest from the child's property or other policies taken on their name. Some others expected that the government should provide grants for the child's maintenance.

PARENT'S VIEW REGARDING THE REHABILITATION OF THEIR
RETARDED CHILD WITH RESPECT TO THE LEVEL OF RETARDATION.

| MODE OF                                     | LEVE       | TOTAL     |           |           |            |
|---|------------|-----------|-----------|-----------|------------|
| EARNING                                     | Borderline | Mild      | Moderate  | Severe    |            |
| BUSINESS                                    | 1<br>(20)  | 7<br>(27) | 6<br>(29) | 1<br>(14) | 15<br>(25) |
| JOB   | 2<br>(40)  | 1<br>(4)  | 0 (0)     | 0<br>(0)  | 3<br>(5)   |
| FAMILY<br>BUSINESS                          | 1<br>(20)  | 7<br>(27) | 4<br>(19) | 0<br>(0)  | 12<br>(20) |
| WORK IN<br>TRAINING CENTER<br>OF THE SCHOOL | 0<br>(0)   | 6<br>(23) | 6<br>(29) | 0<br>(0)  | 12<br>(20) |
| NOT YET<br>THOUGHT                          | 1<br>(20)  | 4<br>(15) | 3<br>(14) | 5<br>(72) | 13<br>(22) |
| ANY OTHER                                   | 0<br>(0)   | 1<br>(4)  | 2 (9)     | 1<br>(14) | 4<br>(7)   |
| TOTAL                                       | 5          | 26        | 27        | 7         | 59         |

$$\chi^2 = 29.78$$

$$df = 15$$

Level of significance = 0.005

Note: Figures in bracket indicate percentage.

This table shows that it is not statistically significant. This implies that the parent's view regarding the child's rehabilitation is not in relation to its level of retardation.

According to this table, 40 percent of the parents whose children had borderline retardation, expected the child to take up a job. Amongst the children who were mildly retarded 54 percent of the parents wanted them to do some business or family business. In the category of moderately retarded, 29 percent of the parents thought that their child should work in the training center of the school. It is surprising to note that 14 percent of the parents of the severely retarded also expected that the child should do some job. However, 71 percent of them had not yet thought about this matter while 14 percent of them had other expectations that the child can survive on its property share, etc.

Thus, it can be inferred from this table that the parent's expectation about the kind of rehabilitation the child should have is not in any way related to its level of retardation. Such a view of aspiration can be changed or made more realistic only with the help of professionals who can enable the parents to see the correct picture.

## 3.7.4. MEASURES TAKEN BY PARENTS FOR THE CHILD'S FINANCIAL SECURITY

Parents have a great responsibility to discharge to make arrangements for the child's future by way of financial support. In a country like India, the facilities for the rehabilitation of the mentally retarded after the demise or during the old age of parents is in a bad shape. None of the governmental, non-governmental organisations, siblings or relatives are willing to take up the responsibility of the mentally retarded especially if financial provisions are not made by the parents. The researcher has tried to examine the measures taken by the parents in relation to their monthly income.

TABLE 3.18 :

FINANCIAL SECURITY MADE FOR THE CHILD BASED ON PARENT'S

ECONOMIC STATUS.

| FINANCIAL  | М  | TOTAL         |              |            |      |
|------------|--|---------------|--------------|------------|------|
| SECURITY   | <rs. 1000<="" td=""><td>Rs. 1000-3000</td><td>Rs.3000-5000</td><td>&gt;Rs.5000</td><td></td></rs.> | Rs. 1000-3000 | Rs.3000-5000 | >Rs.5000   |      |
| NO SAVINGS | 11   | 10            | 0            | 0          | 21   |
|            | (69)   | (55)          | (0)          | (0)        | (37) |
| PROPERTY   | 3  | 5             | 2            | 8          | 18   |
| SHARE      | (19)   | (28)          | (18)         | (67)       | (31) |
| SAVINGS    | 2  | 3             | 9            | 4          | 18   |
|            | (12)   | (17)          | (82)         | (33)       | (31) |
| TOTAL      | 16<br>(28)   | 18<br>(31)    | 11<br>(19)   | 12<br>(21) | 57   |

$$\chi^2 = 32.77$$

$$df = 6$$

Level of significance = 0.005

Note: Figures in bracket indicate percentages.

This table shows that it is statistically significant which implies that the financial security made for the child is based on the parent's economic status.

Majority of the parents who were from less than Rs.1000/- income group did not save for their child's future. 55 percent of the parents with monthly incomes between Rs.1000/- to Rs.3000/- have not saved for their child. Amongst the income group of Rs.3000 - Rs.5000/-, nearly 82 percent of the parents have made provision for the child's

future from their savings. Monthly savings, Jeevan-Bima Policy, interest from fixed deposits, recurring deposits are some of the modes of savings adopted by parents. Parents having monthly income more than Rs.5000/- have made financial security for the child from the property share.

#### REFERENCES

- 1] Robinson N.M., "Mentally retarded child: A psychological approach", New York, McGraw Hill, (1976).
- 2] Chanabasavanna S.M., Bhatti R.S. and Prabhu R.Leny, "A study of attitudes of parents towards the management of mentally retarded children", Child Psychiatry Quarterly, Vol. 18,(1985).
- 3] Chaturvedi S.K. and Malhotra S., "A follow up study of mental retardation focussing on parental attitudes", Indian J.Psychiatry, Vol. 26, No. 4, pg. 370, (1984).
- 4] Rastogi C.K., "Attitude of parents towards their mentally retarded children", Indian J.Psychiatry, Vol.23, pp. 206-209, (1981).
- 5] Suma Narayan, "Knowledge, attitude and perception of parents of mentally handicapped children", The Indian J. Social Work, Vol.LIV, No.3, pp.437-447, (July 1993).
- 6] Purnima N.Mane, "Coping with the developmentally delayed child: The trials and tribulations of parents", The Indian J.Social Work, Vol.LI, No.4, pp.553-565, (Oct. 1990).
- 7] Galton, Juanita and Helen Epstin, "Counselling parents of mildly retarded children", J.Social Casework, Vol.44, No.9, pp.523-530,(Nov.1963).

- Parks and Ronda, "Parental reactions to the birth of a handicapped child", Developmental Disabilities, Lynn Wilker and Maryanne (eds.), Washington D.C..NASW,pp.96-101,(19883).
- 9] Vitello, Stanley and Ronald Soskin, "Mental Retardation: Its social and legal context", Englewood Cliffs:Prentice Hall, (1985).
- 10] Collins M.& D., "Kim" Handicap in a social world, Ann. Brechin et al.(eds.), (1986).
- 11] Batshaw, Mark, L.& Yvonne M.Parret, "Children with handicap: A medical primer", (2nd edition) Baltimore: Paul H.Brookes Publishing Co., (1986).
- 12] Bradshaw J. and Lawton D., "Tracing the causes of stress in families with handicapped children", British J.Social Work, Vol. 8, (1978).
- 13] Bristol M.M. and J.J.Gallagher, "A family focus for intervention, finding and educating the high risk and handicapped infant", ed.C.Ramey and P.Trohanis, Baltimore: Univ. Park Press, (1982).
- 14] Rinn R.C. and A Markle, "Parent effectiveness training: A review", Psychological reports, Vol. 41, pp. 95-109, (1977).

- 15] McConkey R. and Jeffree D.M., "Partnership with parents", Special Education Forward Trends, Vol.2, No.13,(1975).
- 16] Helm D.T. and Kozloff M.A., "Research and parent training programmes", J.Autism and Developmental Disorders, Vol.16, pp.1-22, (1986).
- Peshawaria R.,"Parent involvement in training and management of their mentally handicapped children", J. Personality and Clinical Studies, Vol.5, No.2, pp.217-221, (1989).