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Development of lifestyle and coping patterns in families of mentally handicapped children

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2015-01-08
http://hdl.handle.net/10539/16266

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CHAPTER 5

PARENTS' ATTITUDES AND PLANS FOR THE MENTALLY HANDICAPPED CHILD'S FUTURE.

5.1 PERSPECTIVES FROM THEORY AND PREVIOUS RESEARCH

5.1.1 Introduction

The future of each individual is a matter of great uncertainty. Even parents of a normal child are worried about what will happen to their child if anything happens to them. However, parents of normal children can rely on their child's ability to cope with his future roles. They know that by giving the child the opportunity to get an education or to be trained for a job, they can assure his chances of becoming an independent, well adjusted adult. Parents of normal children may have dreams, hopes and expectations in regard to their child's future and even if not all dreams come true, there is still a hope that the child will play his part in society successfully, and will thus enable his parents to feel that they have succeeded in their parental role by rearing a child who is equipped to deal with his future.

When a child has been diagnosed as mentally retarded, the anxiety and the fear of the parents is understandably greater compared to the way parents of normal children feel about their child's future.

"Family worries about the retarded child at home do not cease even when the family has successfully adapted its living patterns or the individual has achieved a reasonable degree of social usefulness. For those who must always have someone to look after their welfare and protect their interests, the future seems full of uncertainty: 'Who shall care for my retarded child after I am gone or am too old to do so myself?' (Begab, 1963, p.43).

Worthington (1982) notes that if there is one thing that worries parents more than being told that they have a mentally retarded child, it is the prospect of having a mentally handicapped adult.

Almost as soon as their young child is diagnosed, parents ask themselves "what kind of adult are we going to be responsible for?" They realize that the responsibility will last for the whole of their lives whether the child remains at home or goes into residential care. What is certain is that he will be unlikely to make his own way in the world, leaving home for a career and marriage as a natural process, voluntarily and with their blessing. It is impossible not to wonder what the future will be like.

Parents of mentally handicapped children express their great concern about the child's future and as mentioned before, it is an important issue for them. Yet, it seems that this particular subject has not received enough attention in the past; life expectancy of the mentally handicapped was in many cases short and they were considered as having no future. The prolonged life expectancy of many severely handicapped individuals today strongly suggests that an increasing number of parents will be faced with the anxiety-provoking prospect that the retarded child may survive them and will be dependant upon others for his continued well being.

The studies which have dealt with the attitudes and feelings of parents in regard to their child's future have described the nature of parents concern and the way they plan for the future. However, the available information concerning the impact of child and family characteristics on parents' ability to plan for the future is insufficient. Yet, it seems that some of the child and family characteristics play an important part in understanding the nature of parents' attitudes and their plans for the child's future.

This Section will concentrate on three subjects:

I. Parental concern for the child's future.
II. Parents' plans for the future: the various alternatives.
III. The influence of child and family characteristics on parents' attitudes and plans for the child's future.

5.1.2 Parental Concern for the child's future

"All being well we would like to die in ripe old age, knowing that our children are settled, happy and secure. When there is a mentally handicapped child in the family another dimension is added: If the child has survived into adulthood, there is a good chance that he will outlive his parents. There is also a possibility that by then the family will no longer be united or that one parent will already be dead. One thing is certain: when the parents die, someone else will have to look after the child. We live from day-to-day and manage as best we can but we are always fearful that there might be a crisis when we would not be able to support each other. Old age and incapacity come to be doubly dreaded" (Hannam, 1975, p.153). When the child is still young, parents are often concerned about his future development. They want to know how and when the child will develop and what the prognosis is for the future. In order to get answers to those questions, the parents sometimes develop "information seeking behaviour" which helps them to master their anxiety and feelings of helplessness (Chinn et.al., 1978).

The fear of the unknown is also described by Drew et.al. (1984). In his early years, the child usually lives at home and is usually entitled to attend public school until the maximum attendance age is reached. At this age the retarded individual may not function socially and intellectually as an adult, but the responsibility of the schools has ended. If vocational rehabilitation and employment services are available then there is some further assistance. The main parental concern centres around where and how the child's needs will ultimately be met. The thought of 'forcing' the child into an institution, after spending a large number of years in a community and family setting, may be difficult for parents to accept.

The long-term future of the child seems to worry the parents even when the child is still young. Glendinning (1983) concluded her research study on 17 families of disabled

children by mentioning that parents of both younger and older children were emphatically determined to continue caring for their child at home as long as possible, in spite of the strain and sacrifice. She suggests that despite having practical assistance from family members, friends or neighbours when the child was young, parents nevertheless cannot avoid having concerns about the short and long term future. According to Gumz and Gubium (1972) and Howard (1978), among other anxieties expressed by parents in regard to their child is the fear about the future, the child's role in the family and his ability for social adjustment. In a research study on parental areas of concern in regard to the mentally handicapped child, the third area mentioned by parents (fifty families) dealt with the child's future. There were differences between mothers' and fathers' concerns about the child's future. Mothers' main concern was that the child should be accepted by others, protected from emotional stress and be happy, regardless of academic or job success. Most of the fathers, however, reported being concerned about the family budget and the cost of providing help for the child. Their next area of concern had to do with the child's eventual role as a leader, his ability to be a breadwinner and to assert himself outside the home. The fathers' concern involved hopes that the child would become academically successful, would have the ability to obtain training for a good job and would be able to support himself.

Anderson (1982) describes the parents' concern as relating to their doubts about the ability of their child to find his place in society. Planning for the future in many cases is a crucial opportunity to test fantasy against reality. It is also a time when the willingness of society to tolerate, care for and recognize the child's limits is put to the test. With the question "What happens when we have gone?", the full meaning of mental handicap comes out more vividly for the parents.

Eden's (1976) views give weight to the abovementioned ideas. He suggests that apart from the immediate question of how to handle the baby, parents face long term questions such as

"How will he live?, Will he be able to look after himself?, Will he be able to marry?". These various kinds of questions sometimes reflect the parents' difficulties in accepting reality, which in some cases also involves a reluctance to think about the future. The difficulty of thinking about the future is also described by Minde et.al. (1972). Based on information obtained in interviews, they report on the changes in the general pattern of thinking among parents of physically handicapped youngsters over an eight year span. In the first interview the parents could not deal with thoughts concerning the long term development of their children. Out of forty one, twenty five families avoided the issue entirely and most of them believed that handicapped children ran no higher risk of psychological difficulties than normal children. Eight years later, sixty percent of the parents could not discuss the child's future occupation and they assumed that their child did not think of it either. Only four percent of the parents were concerned about the child's future.

Gottlieb (1972) mentions that until circumstances force the parents to think about the future, they prefer to avoid planning for the future. But at this stage when they begin to worry about their health, advancing age, and eventual death, this attitude changes and the ability to live each day at a time is no longer an option for the parents.

For some parents, thinking about the future is such a threat that one of the results may be that a very close emotional relationship develops between the parents and the child. The relationship sometimes is so close that it interferes with the child's independence. In such cases, it seems that other relationships are nonexistent for the parents and child, even to the exclusion of siblings. Moreover, it is very hard for the parents to foresee the possibility of their child living outside the family, and it impacts upon the parents' ability to consider the various alternatives for the child's future. In many cases the result is that even for the older children, the parents prefer to postpone their decisions about the future, although they cannot avoid being concerned about it.

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5.1.3 Parents' plans for the future: the various alternatives

Lurking in the back of parents' minds is the knowledge that one day their son or daughter will probably have to go into residential care - either during their lifetime, or after they die. Most parents are adamant that their other children should not be pressurised into taking over the care of their handicapped brother or sister, so they wish to make other provisions to avoid it (Worthington, 1982).

The main decision for the parents is whether to place the young adult in a residential setting before they become too old, so that when they become elderly or die he will not have to be uprooted into a strange environment on top of the loss of his parents. Or, should they keep the child until the end of their lives, so as not to deprive him of their care any longer than necessary.

According to Worthington (1982) the parents' decision will be influenced by the following factors:

- The personality and the behaviour of the child. If the child does not present the parents with undue stress and his personality is pleasant, it will be harder for them to send him away.

- When the child becomes an important part of the parents' life or plays a key role in the family, some parents come to depend on their mentally retarded child as much as he depends on them. Sometimes, the child keeps the parents together, and for some parents the child is their only and the closest companion (especially if they are widowed). The more able adult can be of practical help in the house, the less able can provide company and affection, and perhaps most of all, can give the parent the assurance that he or she is still needed and important. Parents are inclined to feel guilty about a decision to institutionalize their child, even when the case for this is overwhelming. In many cases, they feel that they must try to cope and that they are selfish in seeking to hand over the

responsibility. After years of adjusting their lives to help the child, they feel that they are giving up. Such feelings interfere with their ability to plan and to carry out their planning to a logical or practical conclusion.

- Parents' decision to keep the child or to place him is also influenced by the alternatives they have. In many cases parents choose not to impose the responsibility and care of their mentally retarded child on his siblings or other members of the family. As Chinn et.al. (1978) mention: it is a choice of the family, of the normal sibling(s) whether they want to care for the mentally retarded brother or sister, and they should not be condemned should they choose not to accept this responsibility. The other alternative is to institutionalize the child. Lack of sufficient information. and the feeling that their child will never get the affection, attention and care he has had at home, make it hard for the parents to decide to place their child in residential care. Sometimes, if the decision is not made at an earlier stage, and the child remains at home, it becomes increasingly harder over time for the parents to admit that they can no longer care for the child and to seek other solutions. If eventually a decision is made to institutionalize the child, the trauma that is usually involved can be curtailed through careful planning.

Chinn et.al. (1978) suggest that the whole family should be involved in the decision-making, including the mentally retarded person himself (if possible).

A trend towards alternative placement has lately developed in some countries with the evolution of community based group homes and hostels. These solutions enable those mentally retarded persons who can cope to stay in the community. The group home operates similarly to a family and it is a good arrangement for the mentally retarded adult who seeks some degree of independence from his family. At the same time, such solutions assure parents that their son or daughter will be adequately provided for.

However, when parents have ideas and information about the alternatives which are available to them, it seems that the process of making a decision can cause a crisis in the family, and raise a great deal of uncertainty and anxiety. This is probably why most parents prefer to live day-by-day, and to plan only on a short-term basis. Hannam (1975) mentions that "Like making a will we put off the evil day of doing something positive about the future because just as the will reminds us of the inevitability of our death, so doing something positive about the future of a mentally handicapped adult is also a reminder of impending mortality, of the relative helplessness of the handicapped and of the need to look at other alternatives" (p.156).

Yet, Drew et.al. (1984) suggest that it may be in the best interest of the child if parents are able, before it becomes too late, to make necessary arrangements for continued maintenance and other matters through carefully planned provision.

Suelzle and Keenan (1981) found in a research study that parents of older children were more likely to plan residential and occupational alternatives for their children. Farber (1975) proposes that it becomes increasingly difficult for parents to cope with the retarded child as the lifecycle develops, and according to Birenbaum (1970), as a result of the increasing discrepancies in age - appropriate behaviour, the parents of young adults become more aware of non-availability of many types of living alternatives within their community. This situation indicates that extra familial environmental factors are also an important consideration in understanding pa[illegible] attitudes towards the child's future and the difficulti[illegible] they have to face in the attempt to plan in this respect.

Bayley (1973), when dealing with parents' attitudes and plans for the future, concludes his findings by saying: "If they could be given a sure knowledge that their subnormal child would be looked after in a way that would satisfy

them, a great load would be lifted for them and they and probably the subnormal child as well, would be much happier" (p.261).

5.1.4 The influence of child and family characteristics on parental attitudes and plans for the child's future

Only a few studies could be found that dealt with the impact of child and family characteristics on parents' attitudes and plans for the future. When dealing with child's characteristics, most studies refer to child's age, the severity of his handicap, and his behaviour as indicators influencing parents' attitudes and ability to plan for the future. As to family characteristics, the socioeconomic status of the family and the health of the parents are commonly considered to have an impact on the way parents feel about the future of their child, and how they plan for it.

5.1.4.1 Child characteristics - age, the severity of the handicap and the nature of child's behaviour

Birenbaum (1970), Farber (1975), Sueizle and Keenan (1981) and others found in their studies that when the child is still young, the parents, in spite of being worried about his future, prefer to live day-by-day and avoid planning for his future. Yet, as the child grows older, the parents are more willing to have tentative plans either by thinking about placement or by finding occupational and living alternatives in the community.

Nevertheless, Bayley (1973) found that even parents of older children still prefer to avoid thinking about the future. As one mother said: "We just live from day-today - you know - and don't look too far into the future. One year is much like another year" (P.258). Another commented: "No, you can't think of the future, or you're punishing yourself. As far as I am concerned,

we've got faith in God and I've had help. If we started worrying about what was going to happen to Lilian, we'd worry ourselves stiff" (P.256).

Tizard and Grad (1961), in their study, also had difficulties in obtaining information about plans for the future, because many parents had not faced the problem of what would happen to a severely mentally retarded child should he survive them. Twenty three percent of the mothers in their study were not willing or able to discuss this problem or did not know what might happen.

In Bayley's study (1973) thirty four out of fifty three families (of mentally retarded adults) did not have any clear idea about what would happen to their children when they would no longer be able to look after them. It seems from the results of several studies that although parents start to worry about the child's future soon after the child is still young, and live with these worries at the back of their minds, it is very difficult for most of them to take practical steps for the future and they prefer to wait until circumstances force them to make a decision.

Bayley's findings also indicated that some parents hoped that the child would die before them, and one mother even said: "If I came to be ill and I knew I couldn't get better, I'd give him a bottle of tablets" (p.256). Such an attitude reflects the difficulties parents have when they think and plan for the future and they have to face the fact that future care for their children is bound by a very limited range of options, none of which offers an attractive or easy solution. This is why many parents avoid thinking ahead. Therefore, suggests Glendinning (1983), putting off planning for the future may not be a totally unrealistic strategy even for the parents of a mentally handicapped adult, since the alternative is a determination to go on, doing what is possible while it is possible, motivated by deep-rooted concern.

When considering the various alternatives for the child, Drew et.al. (1984) suggests that the family is viewed as a primary socializing agent, and there is evidence that the retarded child benefits if he is able to stay within the family. Sometimes placement of the child is justified as being a good solution for him and for the family as well.

According to a few previous studies (Tizard and Grad, 1961; Fotheringham et.al., 1971; Bayley, 1973; Worthington, 1982), the severity of the child's handicap and his difficult behaviour can force the parents to make decisions even before the child reaches adulthood. Sometimes the stress on the members of the family becomes so great that it is impossible to keep the child at home, and parents have to start considering residential care or other alternatives for the child. Tizard and Grad (1961) mention that the main reason for parents asking for placements is their feeling that they cannot cope with the child any longer, mostly because of increasing difficulties in his behaviour.

Fotheringham et.al. (1971) found that institutionalized children had more stressful characteristics compared to children in the community. Although it is difficult to tell whether the family's functioning affects the child's behaviour, or whether the child's behaviour affects the family functioning, these results demonstrate the reciprocal relationship between child and family functioning which sometimes leads to the child's placement.

Gottlieb (1972) suggests that as the gap between physical and mental development widens, parents are inevitably forced to recognize limitations which were not apparent earlier. This is because the young retarded child is likely to be virtually insulated from the outside world, and his difficult behaviour will interfere less with family life. However, when he matures, his bizarre and strange behaviour may become much more noticeable to others.

Chinn et.al. (1976) sum up this issue by mentioning that there are situations in which the presence of the child may have such a disrupting influence on the stability of the family unit that institutionalization is the best solution for both the child and the family.

5.1.4.2 Family characteristics - the socioeconomic status of the family, parents' age and health

The relationship between the socioeconomic status of the family and parents' feelings and plans for the future is mentioned in only a few previous studies. According to Begab (1963), the low status families have fewer expectations from their children and it is easier for them to accept the child as part of the family. When the child is considered part of the family, and no other alternative exists, there is no need to plan for his future, and many of the low status parents rely on their relatives to care for the child if something happens to them.

Tizard and Grad's findings (1961) support Begab's idea, suggesting that families of low social status are most resourceful in creating roles for their mentally retarded member, and this situation influences their plans for the child's future. In these families, the best adjustments to the child and to his handicap were due to low family expectations, *so that it seems easier for them to face hardships as* they come. In a large family, the members may come to take the task of caring for a mentally handicapped member for granted, and no one individual has to bear the whole of the burden unaided.

However, in their studies, Tizard and Grad (1961) and Fotheringham et.al. (1971) could not establish differences in respect to social class between families of institutionalized and noninstitutionalized mentally retarded children.

Begab (1963) when discussing the reasons for parents' decisions in regard to the child's future, mentions that for many high status parents placement of the child is accepted as a good solution for the other family members and for the child himself. He describes the dilemma highstatus parents have when considering the possible alternatives for their child's future by mentioning that these parents, when they dedicated their lives to keeping the child at home, were frequently reluctant to consider institutional placement as the ultimate plan. They also hesitated to impose the burden of a retarded adult on their other children, and they feared relying on strangers whom they felt may lack the personal interest and understanding needed. Thus, the alternative for these parents was not to plan for the future until the time came when decisions had to be taken, either because of the child's needs or because the family could no longer cope with the child at home.

Tizard and Grad's (1961) findings support this idea. In their study, *fifty one out of one hundred and fifty* parents who were asked why they decided to place the child said that they could no longer cope with the mentally retarded child at home. The management *problems had usually been aggravated by death*, illness, pregnancy, or housing difficulties. Other reasons mentioned by parents were the birth of another child or a deterioration in the mother's health. *Bayley (1973) strengthens these findings by stating:* "The most likely cause of the break-up of the structure within which the sub- normal child is cared for, is the death or illness of the mother or person looking after him". (P.234). Under such circumstances a decision about the future must be taken. However, according to Bayley's findings, only in six out of the fifty four families who participated in his study was the mentally retarded kept at home after the death of the mother.

To sum up, the social status of the family helps to predict how parents will feel and plan for the future of their child. However, it seems that the child's behaviour and the severity of his handicap, together with the age and health of the parents, are important factors that may influence parents' attitudes and plans in regard to the child's future.

Although most parents prefer to postpone thinking about the future, the time comes when the combination of increasing difficulties in the child's behaviour and the deterioration in the parents' health, or their advancing age, prevents further avoidance and forces the parents to make decisions.

The findings of the present research study in regard to the abovementioned issues are presented in the next section of this chapter.

5.2 FINDINGS OF THE RESEARCH STUDY

5.2.1 *Introduction*

The present research study findings in regard to parents' attitudes and their plans for the child's future is introduced in this section. Firstly, there is a comparison between the opinions of parents of the younger and the older children (Group A versus Group B). Secondly, there is a comparison between mothers' versus fathers' views, regarding this issue. Finally, there is a presentation of results on the impact of child and family characteristics on parents' attitudes and plans for the child's future.

5.2.2 A comparison according to child's age (Group A versus Group B)

Two out of the fifteen QRS scales introduce items which probe parents' opinions in regard to certain future oriented aspects. The scales are: Scale 12: "Lack of facilities" and scale 13: "Occupational limitation of mentally retarded child).

A comparison of parents' reactions to these scales, by Groups A and B, is presented in Table 56.

Table 56

Means, SD, Df and probabilities for scales 12 and 13 of the QRS, by Groups A & B (t test)

Scale	Group A				Group B			
	Mean	SD	Df	P	Mean	SD	Df	P
12. Lack of activities	1.1	1.2	89.5	0.002	2.1	1.8	107	0.002
13. Occupational limitation	3.6	1.0	102.5	0.003	4.2	1.1	105	0.002
	N=58				N=54			

Results of the comparison between the groups according to scales 12 and 13 of the QRS reveal statistically significant differences between views held by parents of younger and older children. The parents of the older children are much more worried about the lack of activities and the occupational limitations of their mentally retarded son or daughter, than the parents of the younger children.

Parents' answers to a more direct question about their worries for the child's future are presented in Table 57.

Table 57

Frequencies of answers to the question: "Are you worried about your child's future?" by Groups A & B (in percentages)

Answers	A	B
1. No.	20.7	14.2
2. Sometimes, not very much.	24.1	24.7
3. Yes.	55.2	61.1
Total	100.0	100.0
	N=58	N=54

The differences between the groups are too small to be considered meaningful. However, it must be noted that many of the parents in both groups are worried about the child's future.

Parents were asked to recall at which stage they started to become worried about their child's future. Results of the comparison between parents according to Groups (A & B) are presented in Table 58.

Table 58

Frequencies of answers to the question: "When did you first become worried about the child's future?" by Groups A & B (in percentages).

Answer	A	B
1. I am not worried.	27.6	24.0
2. In the last few years.	3.4	55.6
3. Since I knew about the problem.	63.8	18.5
4. Since I saw that the child's development was slow.	5.2	1.9
Total	100.0	100.0
	N=58	N=54

It is of note that the frequencies of "I am not worried" answers in the above table varies from those in the table that preceded it. The reason is that data for each of the tables was drawn from answers to different questions, in this case, questions 25 and 25 of the schedule, (see Appendix 2) respectively.

The findings illustrate two major differences between the parents of the younger and the older children. More of the parents of the younger children recall being worried about the child's future from the time they learnt that he was

mentally handicapped. However, the parents of the older children recall being worried only in the last few years.

Parents' main worries in regard to their child's future are illustrated in Table 59.

Table 59

Frequencies of parents' worries in regard to the child's future, by Groups A & B (in percentages).*

Parent's worry	A	B
1. I am not worried.	24.1	18.5
2. What will happen when we are not able to care for the child.	25.9	50.0
3. How is the child going to develop and how are we going to care for him.	41.4	1.9
4. That there will be a good place for him.	8.6	13.0
5. Will the child be able to leave home.	-	7.4
6. Will he/she be able to make a living.	-	9.2
Total	100.0	100.0
	N=58	N=54

* Based upon responses to question 28 of the interview schedule (see Appendix 2).

Results reveal two meaningful differences between the parents of the younger and the older children. The main worry of parents of the older children is uncertainty about what will happen to the child when they are not able to care for him. Parents of the younger children, on the other hand, still wonder how their child is going to develop over the years.

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Frequencies of parents' worries in regard to the child's future. by Groups A & B (in percentages).*

Parent's worry	A	B
1. I am not worried.	24.1	18.5
2. What will happen when we are not ab' to care for the child.	25.9	50.0
3. How is the child going to develop and how are we going to care for him.	41.4	1.9
4. That there will be a good place for him.	8.6	13.0
5. Will the child be able to leave home.	-	7.4
6. Will he/she be able to make a living.	-	9.2
Total	100.0	100.0
	N=58	N=54

* Based upon responses to question 28 of the interview schedule (see Appendix 2).

Results reveal two meaningful differences between the parents of the younger and the older children. The main worry of parents of the older children is uncertainty about what will happen to the child when they are not able to care for him. Parents of the younger children, on the other hand, still wonder how their child is going to develop over the years.

In addition to their worries, parents were also asked about their specific plans, if any, for the child's future. A comparison between the parents of the younger and older children is presented in Table 60.

Table 60

Frequencies of parents' plans for the child's future, by Groups A & B (in percentages).

Parent's Plans	A	B
1. No specific plans.	39.7	20.4
2. I hope the child will be able to go to a "normal" school.	3.5	-
3. I want to keep the child at home.	31.0	13.0
4. I want my family to care for the child.	3.4	16.6
5. I want to place the child in a "home".	22.4	50.0
Total	100.0	100.0
	N=58	N=54

Results reveal three marked differences between parents of younger and older children; among the parents of the younger children, there are more who have no specific plans. More of these parents also intend to keep the child within the family. However, more of the parents of the older children plan to place the child in a "home".

In regard to planning, parents were also asked if they had taken any practical steps. The majority of the parents of both groups had not taken any practical steps for the child's future. As for the parents who mentioned taking practical steps (such as saving money, putting the child's name on a waiting list for residential care), no differences could be found in respect of Groups A and B. (See Table 90A in Appendix 4). Parents were also asked when they intended to

implement any plans that they might have for their child's future. Results are illustrated in Table 61.

Table 61

Frequencies of answers to the question: "When do you intend to take practical steps in regard to your child's future?" by Groups A & B (in percentages).

Answer	A	B
1. It is too early to tell.	51.7	9.3
2. When the child is 7-8 years old.	6.9	-
3. When it becomes impossible to keep the child at home.	19.0	58.9
4. When the hostel (Hamlet) is ready.	-	13.0
5. We have already taken practical steps.	22.4	18.8
Total	100.0	100.0
	N=58	N=54

Results indicate that more parents of the younger children felt that it was still too early for them to consider actually taking practical steps for their child's future. Many of the parents of the older children prefer to postpone taking practical steps until they are no longer able to care for the child.

5.2.3 A comparison between mothers versus fathers

A comparison of mothers versus fathers according to scales 12 and 13 of the QRS is presented in Table 62.

Table 62

Means, SD, Df and probabilities for scales 12 and 13 of the QRS, *mothers versus fathers* (t test)

Scale	Mothers				Fathers			
	Mean	SD	Df	P	Mean	SD	Df	P
12. Lack of activities	1.7	1.5	106.1	0.4	1.4	1.5	107.0	0.4
13. Occupational limitations	3.9	1.1	105.0	0.9	3.9	1.1	100.7	0.9
	N=60				N=52			

The differences between mothers and fathers are not statistically significant. However, both parent groups were strongly aware of their child's occupation limitations. When mothers of the younger children were compared to mothers of the older group according to scales 12 and 13 of the QRS, results were not statistically significant. However, a comparison between the fathers of the younger and the older children according to the same QRS scales (12,13) revealed statistically significant differences. The fathers of the older children were much more worried about the lack of activities for their son or daughter and their occupational limitations (see Tables 91A, 92A in Appendix 4). A comparison between mothers and fathers within each of the groups (A,B) in regard to scales 12,13 of the QRS did not reveal any statistically significant differences between them. Parents' opinions in regard to lack of activities of their child and his occupational limitations seem to be similar for mothers and fathers of the same group. (see Table 93A in Appendix 4).

Mothers and fathers were asked about their general concern for the child's future. The differences in their opinions are illustrated in Table 63.

Table 62

Means, SD, Df and probabilities for scales 12 and 13 of the QRS, mothers versus fathers (t test)

Scale	Mothers				Fathers			
	Mean	SD	Df	P	Mean	SD	Df	P
12. Lack of activities	1.7	1.5	106.1	0.4	1.4	1.5	107.0	0.4
13. Occupational limitations	3.9	1.1	105.0	0.9	3.9	1.1	100.7	0.9
	N=60				N=52			

The differences between mothers and fathers are not statistically significant. However, both parent groups were strongly aware of their child's occupation limitations. When mothers of the younger children were compared to mothers of the older group according to scales 12 and 13 of the QRS, results were not statistically significant. However, a comparison between the fathers of the younger and the older children according to the same QRS scales (12,13) re statistically significant differences. The fathers of the children were much more worried about the lack of activities for their son or daughter and their occupational limitations (see Tables 91A, 92A in Appendix 4). A comparison between mothers and fathers within each of the groups (A,B) in regard to scales 12,13 of the QRS did not reveal any statistically significant differences between them. Parents' opinions in regard to lack of activities of their child and his occupational limitations seem to be similar for mothers and fathers of the same group. (see Table 93A in Appendix 4).

Mothers and fathers were asked about their general concern for the child's future. The differences in their opinions are illustrated in Table 63.

Table 63

Frequencies of answers to the question: "Are you worried about your child's future?" for mothers versus fathers (in percentages)*

Answers	Mothers	Fathers
1. No.	11.6	25.0
2. Sometimes, not very much.	25.1	23.1
3. Yes.	63.3	51.9
Total	100.0	100.0
	N=60	N=52

* Based upon responses to question 25 of the interview schedule (See Appendix 2).

Results reveal that mothers are more worried about their child's future than are fathers.

A comparison was also made between the kind of worries mothers and fathers have, as indicated in Table 64.

Table 64

Frequencies of answers to the question: "What are your worries in regard to the child's future?" for mothers versus fathers (in percentages)*

Answer	Mothers	Fathers
1. I am not worried.	16.6	26.9
2. What will happen when we are not able to care for the child.	41.6	32.6
3. How 's the child going to develop and how are we going to care for him.	23.3	21.4
4. That there will be a good place for him.	10.2	11.5
5. Will the child be able to leave home and us.	3.3	3.8
6. Will he/she be able to make a living.	5.0	3.8
Total	100.0	100.0
	N=60	N=52

* Based upon responses to question 28 of the interview schedule (Appendix 2).

Mothers seem to be most worried about the far future; what will happen to the child when the parents will no longer be able to care for him.
When asked whether they had taken practical steps in regard to the child's future, fathers more than mothers mentioned saving money for the child's future. (See Table 94A in Appendix 4).

5.2.4 The impact of child and family characteristics on parents' attitudes and plans for the child's future.

Child's sex, the cause of his mental handicap and his physical condition seem to have an influence on parents' attitude to his future, and on their ability to plan and take practical steps in this regard.
The influence of the child's sex on parents' worries is presented in Table 65. (It must be kept in mind that there are more males among the older children).

Table 65

Frequencies of answers to the question: "Are you worried about your child's future?" by child's sex. (in percentages)

Answer	Males' Parents	Females' Parents
1. No.	18.2	17.3
2. Sometimes, not very much.	18.2	32.6
3. Yes.	63.6	50.1
Total	100.0	100.0
	N=66	N=46

Males' parents seem to be more worried about their child's future compared to females' parents.
Results also reveal that males' parents are readier to consider placement of the child as a solution for his future while females' parents prefer to keep their daughter at home for as long as possible (See Table 95A in Appendix 4).
The cause of the child's mental retardation also seems to have an impact on parents' plans for his future.
(See Table 66).

Table 66

Frequencies of parents' plans for the child's future, by *cause of child's mental retardation* (in percentages)

Parents' plan	Unknown	Genetic Disorders	Brain Damage
1. No specific plans.	44.6	21.9	30.5
2. I hope the child will be able to go to a "normal school".	-	4.8	-
3. I want to keep the child at home.	16.6	29.2	16.6
4. I want my family to take care of the child.	-	17.3	2.7
5. I want to place the child in a "home".	38.8	26.8	50.2
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Data from Table 66 reveals that the parents whose child's mental handicap is due to unknown *causes have fewer specific* plans for the child's future. A child who suffers from genetic disorders is more likely to stay at home. Parents of a brain damaged child are most likely to consider placement as a solution for the child's future.

When the parents were asked when they intended to take practical steps for the child's future, results show that parents of children whose mental handicap is due to unknown causes felt that it was difficult to start taking practical steps at the stage they were interviewed.

Parents of children who suffer from genetic disorders or brain damage were most likely to say that they will take practical steps only when it is impossible to keep the child at home. (See Table 96A in Appendix 4).

In addition to the cause of the child's mental retardation his physical condition also influences parents' worries about his future as can be noticed in Table 67.

Table 67

Frequencies of answers to the question: "Are you worried about your child's future?", by child's physical condition (in percentages).

Answer	Generally Good	Generally Fair
1. No.	19.5	12.0
2. Sometimes, not very much.	26.4	16.0
3. Yes.	54.1	72.0
Total	100.0	100.0
	N=87	N=25

Results reveal that when the child's physical condition is only fair, parents tend to be more worried about his future. However, no differences according to child's physical condition could be found in parents' willingness to take practical steps for their child's future. (See Table 97A in Appendix 4).

In addition to characteristics of the child, some family characteristics seem to have an impact on parents' worries and plans for the child's future. The child's birth order seems to influence parents' plans for his future. Parents of the first born child plan to raise the child at home to a greater extent than the other groups. Parents of the third or sequentially born children more than the others prefer to place the child in residential care. (See Table 98A in Appendix 4). (It must be noted that there are more first born children among the group of the younger children (A).

Parents tendency to worry about the child's future is influenced by the level of formal education (See Table 68).

Table 68

Frequencies of answers to the question: "Are you worried about your child's future?", by parents' level of formal education (in percentages).

Answer	Under Matric	Matric and post
1. No.	22.9	11.8
2. Sometimes, not very much.	27.8	19.6
3. Yes.	49.3	68.6
Total	100.0	100.0
	N=61	N=51

More of the highly educated parents seem to be worried about the child's future. The difference is especially meaningful, as there are fewer highly educated parents among the parents of the older children, and it was this latter group who were found to be more worried about the child's future (see Table 57).

When asked whether they had taken practical steps to plan for the child's future, the majority of the parents responded "No". However, among the lower educated parents there were more who had not taken any practical steps, while more of the higher educated parents mentioned that they save money or that their child's name is already on a waiting list for an institution (See Table 99A in Appendix 4).

Results reveal that working mothers to a greater extent than housewives are worried about the child's future. (See *Table 100A in Appendix 4*). *Highly* skilled fathers were compared to lower skilled fathers in regard to their plans for the child's future. Results are presented in Table 69.

Table 69

Frequencies of fathers' plans for the child's future, by fathers' occupational category (in percentages).

Parents' plan	Highly Skilled	Lower Skilled
1. No specific plans.	28.3	40.0
2. I hope the child will be able to go to a "normal" school.	2.7	-
3. I want to keep the child at home.	21.6	23.3
4. I want my family to care for the child.	5.6	16.6
5. I want to place the child in a home.	41.8	20.1
Total	100.0	100.0
	N=36	N=12

More of the lower skilled fathers have no specific plans for their child's future while the higher skilled are going to consider placement of the child in the future. In spite of the abovementioned differences, it seems that the majority of the fathers had not taken practical steps for the child's future, regardless of their occupational status (See Table 101A in Appendix 4).

Parents' religious background seems to have no noteworthy impact on their worries about the child's future. Many of them, regardless of religious background, do worry. (See Table 102A in Appendix 4).

However, when they were asked about their specific plans, the Jewish parents were the most likely to consider placement of the child as the best solution for his future. (See Table 70).

Table 70

Frequencies of parents' plans for the child's future, by parents' religious background (in percentages)

Parents' answer	Catholics	Protestants	Jews
1. No specific plans.	26.3	30.9	33.3
2. I hope the child will be able to go to a "normal" school.	-	2.8	-
3. I want to keep the child at home.	15.7	23.9	16.6
4. I want my family to take care of the child.	21.2	8.6	-
5. I want to place the child in a "home".	36.8	33.8	50.1
Total	100.0	100.0	100.0
	N=19	N=71	N=18

When analyzing the results of Table 70 it must be kept in mind that there are slightly more Jewish parents of older children.

Having another mentally retarded relative had no marked influence on parents being worried about the child's future. (See Table 103 in Appendix 4).

A summary and a discussion of the aforementioned results is presented in the following section of this chapter.

5.3 SUMMARY AND DISCUSSION

When a child is diagnosed as being mentally retarded many of his parents' worries seem to be related to his future, and how they are going to prepare the child and themselves for the unknown.

The fact that the majority of the parents who participated in this study, from both groups (parents of younger and older children) reported being worried about the future, clearly reveals that besides the day-to-day concerns which the parents face during the years of rearing the child, a constant worry about his future exists. Similar results were also reported by previous studies (Gottlieb, 1972; Bayley, 1973; Eden, 1976; Wortnington, 1982; Glendinning, 1983; Drew et.al., 1984).

It seems from the findings of the present study that the nature of the parents' worries about the future changes during the years. The main worry of parents of younger children is "how the child is going to develop", and among them there are some who still hope that "the child will grow out of it". Over the years, a more realistic approach develops and it changes the nature of the worries. The older parents fear the moment when they will no longer be able to care for their son or daughter, and thus more of them are worried about his or her occupational limitations and about the lack of activities for their child. It was also found that parents of older children no longer hold a belief that the child can be cured.

Anderson (1982), when describing parents' worries, mentions that parents' attitude toward the future is related to the degree of acceptance of the child's problem. Thinking about the future is an opportunity to test fantasy against reality.

Results from some other studies (Minde et.al., 1972; Eden, 1976; Chinn et.al., 1978; Howard, 1978) also describe the changes in the nature of parents' worries about the future over the years. The belief that the older parents are more realistic and thus more pessimistic when they think about their child's future is common among those researchers.

In a comparison between mothers and fathers, it was found that mothers more than fathers express their worries about the child's future and that the most pessimistic are the mothers of the older children. No marked difference could be found in regard to the kind of worries that mothers and fathers within the same group expressed. However, the fathers of the older children more than the fathers of the younger ones had the ability to specify their concerns in regard to their child's ability to find his place in society and to be able to support himself. These findings lend weight to the idea which was mentioned by Gottlieb (1972). When the parents become older, circumstances force them to change their attitude to their child's future. The possibility of living each day separately is no longer an option for them, and a more realistic approach raises practical and emotional difficulties.

Gumz and Gubrium's (1972) findings in regard to the differences between mothers' and fathers' worries about the future are in the same direction as the findings of this study. Mothers' worries are less specific, mostly related to the child's ability to be accepted by others. Fathers, generally, tend to be more practical when they express their concern about their child's ability to support himself in the future.

The research findings reveal that thinking about the future often includes planning. Here again, some differences were found between the groups. When the child is still young, the parents find it very difficult to consider any other alternatives to the family, even for the far future. Yet, as he matures, thinking about such alternatives is unavoidable. Thus it was found that among the parents of the older children there are more who search for a solution outside the family. Worthingtons' (1982) findings also indicate that the older parents more than the younger ones think about the possibility of placing the child when planning for the future. According to her findings, when the parents become older, their main dilemma is whether to wait until the end of their life or to place the child before, so that he will not be uprooted into a strange environment on top of the loss of his parents.

The findings of this research study show that although many of the older parents plan to find a solution for the child outside the family, when they were asked if they had taken practical steps, no marked differences could be found between them and the younger parents. The younger parents reported that it was too early for them to take any kind of practical steps in regard to their child's future. The older parents, although having tentative plans, preferred to delay taking practical steps until the time that it is impossible for them to care for the child.

Bayley's (1973) findings about parents of adolescents and adults resemble the findings of this study. In his study thirty four out of fifty three parents did not have practical plans and did not take practical steps for the future. Hannam (1975) mentions that parents tend to put off the evil day of doing something positive about the future because just like a will, it reminds them of the inevitability of death. Begab's (1963) ideas about this issue explain the dilemma parents have to face when planning for the future. If they dedicate their lives to keeping the child at home, they are frequently reluctant to think about any other alternative and thus, even when they are theoretically aware that they have to find a solution for the future, practical planning is too difficult for them.

The literature contains mention (Farber, 1975; Howard, 1978; Suelzle et al., 1981; Worthington, 1982) of the idea that child and family characteristics also have impact on parents' attitudes toward the child's future and on their preparedness to plan and to take practical steps in this respect. Beside the fact that there are marked differences between the attitudes of parents of younger and older children, it seems that child's sex also has its effect on parents' attitudes towards the child's future. Results of this study show that males' parents are more worried about the future, and that more of them plan to place the child in an institution. Parents of females are less worried about the future and plan to keep their daughters at home. These results are probably influenced by the fact that the group of the older children consisted of more males, while among the younger children there were more females. However, Mercer

(1966) and Farber (1968), when dealing with the same issue, have mentioned that males' parents seem to have more severe problems with their children and that males create more stress for the whole family. It seems that the child's behaviour and the severity of his handicap more than his sex per se influences parents' attitudes toward the future. The study results show that parents of children who have more physical problems are more worried about the child's future. It was also found that when the cause of the mental retardation is a genetic disorder, the parents of these children prefer to keep their child at home and plan to continue to do so. Yet, when the child is brain damaged, more parents prefer to find a solution outside the family. Robinson and Robinson (1976) mention that parents of Down's Syndrome children usually face less severe behavioural problems compared to parents of children who suffer from brain damage, and this may partly contribute to the foregoing finding.

Tizard and Grad (1961), Fotheringham et.al. (1971), Bayley (1973) and Worthington (1982) describe similar findings. When the stresses on the members of the family are such that it is impossible to keep the child at home the parents are forced to plan and to take practical steps in regard to his future.

It is important to note that the study's results about parents' ability to plan for the child's future are consistent with past studies. However, even in this study, most of the parents of children with severe physical problems and behavioural difficulties, although having plans, had not taken any practical steps in regard to their child's future.

According to some previous studies (Begab, 1963; Gottlieb, 1972; Chinn et.al., 1978), family characteristics also play an important role in understanding the differences in parents' attitudes towards their child's future. Findings of the present study indicate that more of the highly educated parents express worries about their child's future. However, no differences between parents according to

their level of education were found in regard to parental ability to plan and to take practical steps for the future. The highly educated parents express their greater concern for their child's future but like the lower educated parents are not yet ready for practical planning.

The common idea among researchers is that the lower educated parents seem to have fewer expectations from their children, and therefore it is easier for them to accept the child as he is and his integration into the family system often does not represent any severe problems for the parents. The highly educated parents are probably more aware of the impact of the child on the whole family. The child is more of a threat to the family's social status and its mobility, and his integration into the family system seems to be impossible for many of these parents. Thus, finding a solution for the child outside the family is essential (Begab, 1963; Bayley, 1973).

Findings of the present study are consistent with Begab's and Bayley's results. They are contrary to Tizard and Grad's (1961) and Fotheringham et.al. (1971) findings which do not show differences in parents' plans to place the child in regard to their socioeconomic status and level of education.

The ability of the parents to plan practically for the child's future is also influenced, according to Worthington (1982), by the alternatives they have. When parents were compared according to their religion it was found that although religious background does not differentiate between parents in regard to their worries about the future, when it comes to practical planning, the Jewish parents more than the others plan to place the child, are prepared to not wait and to take practical steps in the short term future. This difference can be explained by the fact that the Jewish parents have a reliable alternative in their community (a Jewish hostel - "Selwyn Segal Hostel"), and under such circumstances practical planning becomes an easier task for the parents.

To sum up: the results of this study strengthen findings of previous studies about the intensity of parental worries in regard to their child's future. However, it was found that although the majority of the parents express considerable concern about the future, most of them, even when they plan, are not yet ready to take practical steps. The same trend is described in some other previous studies. According to Chinn et.al. (1978) and Worthington (1982) this may probably be explained by the fact that the decision to search for a solution outside the family sometimes creates guilt and feelings of failure which the parents cannot deal with. Therefore, they prefer to delay their decision into the far future. The fact that there are only a few and not always satisfactory alternatives available in the community makes it even harder for parents to be practical when planning for their child's future.

Child and family characteristics also seem to be related to differences in attitudes towards the future. The results of this study resemble the findings of some previous studies which clearly reveal that the child's age and the severity of his handicap are indicators which strongly influence parents' views in regard to the child's future and their preparedness to plan for it.

Parents' socioeconomic status and level of formal education were found in this study, and in some others former investigations, to have an impact on the degree of parental concern for the child's future. However, according to the present study, the ability to plan practically for the future does not always seem to be affected by these factors.

It seems that parents' attitudes towards the child's future and their ability to plan for it are influenced by a combination of various factors, which are related to some of the child's and family characteristics as much as to parents' personality, the way they have adjusted to the fact of having a mentally handicapped child, their general expectations of life and from their child in particular and the alternatives that are available to them in the community.

CHAPTER 6

STRESS, CRISIS AND THE DEVELOPMENT OF COPING PATTERNS IN FAMILIES OF MENTALLY HANDICAPPED CHILDREN

6.1 INTRODUCTION

This chapter will begin with a discussion of some methods and models that may be used to delineate the long-term impact of the mentally handicapped child upon his family.

Thereafter, an attempt will be made to discuss the dynamics of parental process of adaptation by presenting the double ABCX Model (Burr, 1982; Patterson and McCubbin, 1983).

The presentation of the double ABCX Model, which enables analysis of stress and crisis situations in the family and highlights the development of coping patterns,will create a framework for an understanding of the research findings with regard to the various subjects discussed in the previous chapters.

Finally, the role of community supportive networks and the impact on parental adaptation of reciprocal relationships between external systems and the family will be discussed.

6.2 TYPES OF FAMILY ORIENTATION, PATTERNS OF PARENTAL BEHAVIOUR AND THE STAGES MODEL-AN OVERVIEW OF THE DIFFERENT APPROACHES REGARDING THE IMPACT OF THE CHILD ON HIS FAMILY

Research on the impact which the mentally handicapped child has on his family has had a long history, with social and behavioural studies searching to understand the difficulties and the hardships these families experience when raising the child at home.

While bearing in mind the idea that families' reactions to having a mentally handicapped child vary to a great extent, and that each family develops its unique lifestyle, an attempt has been made to describe some typical reactions which are common among these families.

The tendency of many past studies has been to stress the differences between families of mentally handicapped children and families without such a child.

The general trend in those studies was to emphasize family problems and difficulties in adjusting to the situation and to describing the child's negative impact on the various aspects of family life, such as family inter-relationships, social contacts and most commonly, the daily burden of care for a disabled child (Farber, 1960; Tizard and Grad, 1961; Begab, 1963; Hutt and Gibby, 1965, Bayley, 1973, Howard, 1978, Chinn et.al., 1978, Worthington, 1982; Drew et.al., 1984).

Only a few previous studies have represented a contrary idea, namely, that the child's problem has its impact only on limited aspects of family life, and that on the whole, differences in lifestyle between families of mentally handicapped children and families without such a child are small due to the attempt of many parents of mentally handicapped children to cope with their hardships and to maintain a "normal" family lifestyle (Birenbaum, 1970; Hewett et.al., 1970; Voysey, 1975; Featherstone, 1980).

The idea that in spite of many difficulties, parents of mentally handicapped children seem to cope with their problems led to a more recent tendency among researchers to concentrate their efforts upon examining parents' patterns of coping, instead of describing the problems and hardships placed upon them by the child's situation. This tendency represents a more dynamic and optimistic attitude which emphasises people's ability to cope with stressful life events and to adjust to such situations.

Among the first attempts to identify parents' attitudes to having a mentally handicapped child and to describe a few clusters of typical reactions, is Farber's classification, which is based on types of family orientation (Farber, 1960).

By using three types of family orientation (child oriented, home oriented and the parent oriented family), Farber tries to explain the differences in the impact of a severely mentally retarded child on the family, both as a whole and on particular members of the family (each parent and the siblings).

The three types of family orientation generate some basic ideas which help in understanding the differences in parents' basic attitudes to life. Such attitudes probably have their impact on the nature of family lifestyle and on parents' ability to cope with stress and crisis situations placed upon them by the child's problems and special needs.

Hutt and Gibby's (1965) study represented another effort to cluster parents' reactions and attitudes to having a mentally handicapped child. They tried to classify the various reactions into three patterns of behaviour, each one describing different typical parental reactions to the situation.

The three patterns of behaviour (the accepting, the disguising and the denying parent) vary according to the degree of parental acceptance of the child's problem. Thus, each pattern represents a parental reaction to the stressful situation caused by the child, and delineates the form of their adjustment, (constructive or destructive). The advantage of Hutt and Gibby's patterns of behaviour approach over Farber's types of family orientation, is in its attempt not only to describe the problematic situation in the family and the reactions of the parents to having a mentally retarded child, but also to classify these reactions by focusing on the degree of parental adjustment as represented in their patterns of behaviour.

The tendency to focus on parental adjustment behaviour rather than on descriptions of the families' problems and hardships caused by the child, is represented also in many studies which have used the "stages model" when discussing the child's impact on the family.

The contribution of the "stages model" to the understanding of parents' reactions to having a mentally retarded child lies in its dynamic approach, which stresses the developmental aspects of the process of parental adjustment. Coping with a mentally retarded member in the family means coping with a long-term problem which has its on-going effects on the family throughout the various stages of its lifestyle.

The "stages model" helps to clearly differe ciate between the crisis reactions which are typical of the initial period following parents' awareness of the child's problem, and later on to the reactions which represent different levels of parental adjustment to the situation.

In his overview of the studies which have tried to describe parents' reactions to having a mentally handicapped child, Blacher (1984), using the various taxonomies mentioned in these studies, defines three main stages (the initial crisis responses, continuing feelings and responses, and adjustment or acceptance).

Although the basic tenet of such a model seems to be positive, since the process which the parents go through leads to adaptation, not all the reactions which are typical to each stage can be viewed as positive or adaptive. Blacher (1984) refers to evidence from some studies (Wright, 1976; Sieffert, 1978) which view reactions like shock, denial or disbelief in a positive way, explaining that such feelings are normal or typical to a crisis situation and therefore can be considered as helping the parents to overcome the crisis. The abovementioned formulation reveals another important contribution of the "stages model" to the understanding of the process of adaptation. By linking certain typical reactions to each stage, one may identify the differences between the stages, which illustrates the idea that moving from stage to stage represents a noted change in parental reactions.

Overall, when compared to approaches that emphasize the types of family orientation or the patterns of parents' behaviour, the great advantage of the "stages model" is in its dynamic approach. Instead of the idea that parents' ability to cope with the situation of having a mentally handicapped child is related mainly to the nature of the child's problem and some other family and child characteristics, the "stages model" describes the parents' struggle to cope with the problem as a developing process comprising an ordered sequence of discreet stages which the parents have to go through until they reach a certain degree of adjustment that enables them to respond to their child's special needs, and to minimize his negative impacts on the whole family.

As already mentioned, a description of the stages in the process of parental adaptation stresses the uniqueness of the long-term impact of a mentally retarded member on his family. Such an on-going impact creates new reactions at each stage of the lifecycle, but at the same time, there appears to be a certain degree of continuation of earlier reactions typical to a former stage overlapping into the new one. The "stages model", although referring to the different periods of the lifecycle, concentrates on describing the direct parental reactions to a defined stressor event-having a mentally handicapped child. However, beside the stresses and strains created by the child's problem, the family experiences stressful life events which are part of the changes in the lifecycle of each family (like the birth of a child, the illness of a family member, etc.) (McCubbin et.al., 1982).

The double ABCX Model (McCubbin and Patterson, 1982; Patterson and McCubbin, 1983) provides a better understanding of the different sources of the on-going stress created by the existence of a mentally handicapped child, as well as the additional life events and changes during the family lifecycle. The above-mentioned model "provides also a way of viewing family efforts over time to adapt to multiple stressors through the use of various family resources and perceptual factors as the components for a coping process aimed at achieving family balance" (Patterson and McCubbin, 1983, p.26). The double ABCX is presented in the following section of this chapter.

6.3 THE DOUBLE ABCX MODEL

The ABCX Model developed by Hill and later modified by other researchers, can be seen as one of the major formulations in the family crisis literature which helps in studying and examining the process of adjustment that families have to go through when facing a crisis situation (Burr, 1982). By using the ABCX Model and its extended variation (The Double ABCX Model), an attempt can be made to focus on aspects of family adjustment or ways of coping with stress and crisis situations, rather than merely describing the difficulties and hardships resulting from such a state.

The main idea in this model is that a crisis situation (The X factor) is influenced by several other phenomena. Burr (1982), using Hills' theory, tries to define crisis in order to examine the variations of the X factor. Hills' basic definition of crisis was "any sharp or decisive change for which old patterns are inadequate" (Burr, 1982, p.6). Later investigators viewed crisis as a continuous variable when suggesting that crises vary according to their severity. In studies which viewed the family as a system, crisis was *defined as a "disruption in the routine* operation of the family social system. The less disrupted the system is, the less severe is the crisis; the more disruptive the system is, the greater is the crisis" (Burr, 1982, p.6)

Burr (1982) stressed the importance of the amount of crisis but at the same time he states that even in situations when it seems that no crisis exists, it does not mean that there are no stresses or problems in the system. It merely connotes that the problems are of a routine rather than unusual nature.

A situation of crisis results from a stressor event which produces a change in the family system (The A factor). Anything that changes an aspect of the system, such as boundaries, structure, goals, processes, roles or values, can produce some amount of crisis in the system and is called the "stressor event" (Burr, 1982). The intensity of crisis is positively related to the degree of the changes in the system resulting from the stressor event.

Hill's model identifies another two variables which influence the relationship between the stressor event and the intensity of the crisis. The B factor refers to the crisis-meeting resources of the family. Burr (1982) concludes that the B factor represents the vulnerability of the family to stress influences, or the ability of the family system to prevent a stressor event from creating some crisis or disruptiveness in the system. The degree of family vulnerability to stress is positively related to the amount of crisis caused by a stressor event.

The C factor is another variable which influences the relationship between the stressor event (A) and the nature of the crisis (X). The C factor is defined as the family's perception of the stressor event. Burr referring to Hill's ideas, highlights the differences in the ways in which objective observers (professionals), the community, and the family define and relate to a stressor event. The main difference among these definitions seems to be whether the family defines the change in the system as easy or difficult. When the family defines the stressor event as a severe one it means that the event creates a serious change in the system. Such a situation will probably be influenced by the family's vulnerability to stress, and thus have its impact on the ability to cope with the crisis situation. The ABCX Model is summarized in figure 1:

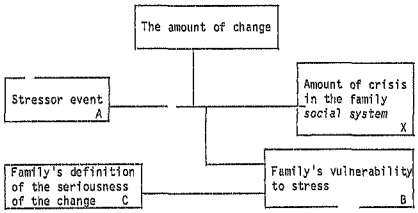


Figure 1: The ABCX Model (Burr, 1982, p.10)

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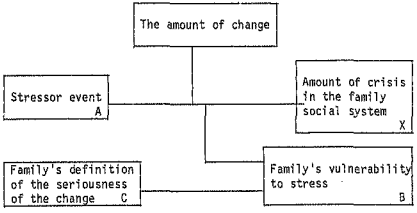


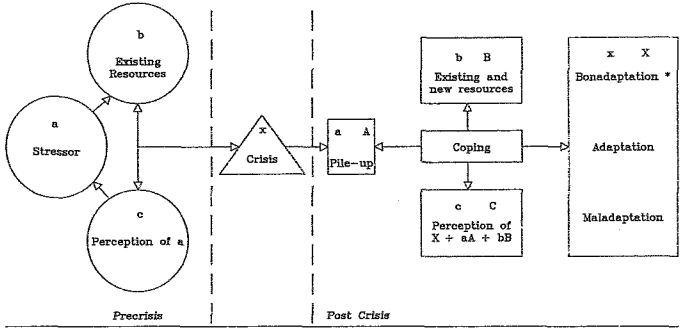
Figure 1: The ABCX Model (Burr, 1982, p.10)

Later investigators tried to identify some aspects of the two variables (B and C) but, the most important and major goal of these studies has been to identify factors that are related to whether or not the families recover from the disruptive effects of stress.

Burr (1982) adds further insight about the relationships between the level or reorganization and various specific factors such as amount of adaptability, integration or affection. Using Hansen's definition Burr (1982) refers to the family's regenerative power as a factor which will indicate the level of reorganization which can be achieved after a period of crisis. Another factor which according to some studies seems to have an influence on the nature of the crisis and on crisis recovery is related to the extent to which the stressor event can be anticipated. A sudden or unanticipated stressor event seems to create greater disruptiveness in the family system and therefore probably more difficulties in recovery.

The ABCX Model formulated a conceptual framework for studies which were basically designed in order to analyze the outcome of the interactions between the stressor event, the nature of the crisis and the factors which influence the family's response to such a situation. However, a more comprehensive paradigm was needed to describe observations from longitudinal investigations of families responding to a prolonged stressor (McCubbin and Patterson, 1982). McCubbin and Patterson (1982), by the addition of postcrisis variables to the original ABCX Model, facilitated the understanding of the long-term impact of stress on the family system and the adaptation process to crises events.

The Double ABCX Model is represented in Figure 2:



* Bonadaptation means optimally satisfactory adaptation

Figure 2 – The Double ABCX Model (McCubbin and Patterson 1982, p.46)

Clinical observations and the data from longitudinal studies revealed that the coping efforts that the family has to make in order to adjust to long-term stress produces additional stressors.

In addition, such a family has to simultaneously adjust to other life changes that happen in families over time and occur independently of the initial stressor which caused the crisis. In other words, over time and in an effort to manage a crisis situation, these families experience a pile-up of stressors as a result of (a) the hardships inherent in the initial stressor which caused the crisis, (b) normal change and development of family members and the lifecycle of the family and (c) the trial and error efforts to manage the situation (McCubbin and Patterson, 1982). The pile-up of the different stressors is represented in the Model by the double A factor.

The double B factor stands for the two general types of family resources. The first are those resources that are already available to the family before the crisis occurred and that minimize the impact of the initial crisis or reduce the probability of the family entering into crisis. The second are the coping resources (personal, family and social) strengthened or developed in response to the crisis situation. Such coping responses were defined by McCubbin and Patterson (1982) as "(a) self reliance and self esteem, (b) family integration, (c) social support, and (d) collective group supports, which include social action" (p.45).

Another factor which influences the family's ability to cope with a long-term stressor is related to two different forms of family perceptions. The first is the family's perception of the stressor event (c) and the second is the family's perception of the crisis (C) which involves not only the initial view of the stressor but also the pile-up of life events and the meaning that the family attach to the total situation.

According to McCubbin and Patterson (1982) the family's perception postcrisis appears to involve "(a) religious beliefs (b) a redefining of the situation and (c) enclosing the situation with meaning" (p.45).

When the initial stressor event has long-term impact on the family (as in situations of chronic illness or handicap) the initial crisis appears to be but one phase in the continuum of family adjustment to stress over time. McCubbin and Patterson (1982) introduce the concept of "family adaptation" as one possible outcome for the family course of adjustment following a crisis. "Adaptation involves the processes of stimulus regulation, environmental control and balancing to achieve the family system and member growth and development. Balancing the various dimensions of family life is a difficult process involving assimilation, accommodation and compromise" (pp.45-46).

The main contribution of the double ABCX Model lies in its definitions of the various aspects which describe and explain family's coping behaviour in terms of a process the outcome of which is a certain degree of adjustment not only to the initial crisis but also to postcrisis prolonged stress events. By referring to precrisis and postcrisis periods the double ABCX Model provides a formulation for improved understanding of the long-term effects of stressful events on the family's life and a developmental approach to the process of family adaptation to such events.

Thus, the double ABCX Model appears to have value in studies which try to explore the impact of long-term stressful events on family's reactions and ability to develop coping patterns in order to adjust to the situation.

Patterson (1985) in a study on families of children with Cystic Fibrosis introduced the "Family Adjustment and Adaptation Response Model" (FAAR) which is another variation of the double ABCX Model. The FAAR Model focuses on the family variables of demands, resources

family perception and coping which interact over time to result in a level of adjustment or adaptation.

The adjustment phase is characterized by family resistance to move into a crisis. However, there are occasions when the demands require major systematic family change or when the resources or coping patterns are inadequate or exhausted and the family moves into crisis.

The crisis situation creates major systematic changes in the family structure or interactions which call for new or additional resources, perceptions and coping behaviour in order to restore balance to the family system. Family adaptation, then, describes the outcome of family efforts to achieve a new level of homeostasis which was upset by the crisis (Patterson, 1985).

The advantage of the FAAR Model over the double ABCX Model is in its more dynamic approach to the various stages of the process of family adjustment and especially to the precrisis period. The basic concept of the model stresses the family's struggle to avoid disequilibrium in the system and, if it occurs, to achieve a new level of homeostasis which can be viewed as family adaptation.

In the following section an attempt is made to discuss and integrate the findings of the present study in the light of the double ABCX Model and its previously mentioned variations.

6.4 COPING WITH STRESS - THE PROCESS OF FAMILY ADAPTATION TO HAVING A MENTALLY HANDICAPPED CHILD

When the parents first learn that their child is mentally handicapped they are also confronted with the nature of this phenomenon and among other things they have to face the fact that basically mental retardation is an irreversible, chronic situation. Their child may become better or worse at times but always will remain less than a normal healthy child and will be dependent on them to a certain degree. Being mentally retarded, the timing by which the child will move through different developmental stages will be influenced by the level of his intellectual achievements, his emotional reactions and his social relationships.

The birth of a mentally handicapped child is usually an unanticipated event which creates considerable disruption in family life. The extent of the first shock influences the nature of the crisis in these families; however, the chronicity of the phenomenon has a far-reaching impact on the whole family and calls for an on-going process of adaptation creating differences in the lifestyle of these families.

In order to understand the long-term impact of the mentally handicapped child on his family, a developmental approach is needed. Such an approach provides a longitudinal follow-up through the different stages of child development and family lifecycle. While stressing the on-going accumulative impact of the child on the family such an approach also highlights the different reactions and attitudes typical to each stage, and the general tendency of the family to try to achieve at least a certain degree of equilibrium which will finally lead to adjustment, or acceptance of the mentally handicapped child.

In order to illustrate the dynamics of the process of family adaptation to having a mentally retarded child and to facilitate a further discussion of this issue the writer has developed a combination of Blacher's stages Model (1984) with McCubbin and Patterson's double ABCX Model (1982) (See Figure 3).

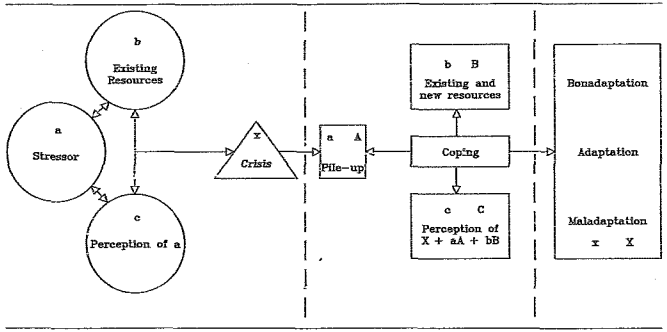


Figure 3 – Phases in the Family Process of Adaptation

6.4.1 Phase I - The initial crisis response (abcx)

As already mentioned, the birth of a mentally handicapped child is in most cases unanticipated but, even before the parents learn about the diagnosis of their child they often start to suspect that something is wrong, usually as a result of his slow development and abnormal behaviour or appearance. Results of this study reveal that suspecting that the child has a problem is a stressful situation in itself, and that for some parents receiving the diagnosis was a relief. The longer the period between the time of first suspicions and receiving the diagnosis, the greater the initial stress, especially when it was hard for the parents to obtain a definitive diagnosis of the child's problem from professionals. "My feelings were changing from day to day. Some days I looked at her and thought - there is nothing wrong with her. The other day I was sick and I was depresssed again" (A mother of a three year old daughter). "When they first told me, I was shocked and scared. Even after I already suspected that something was wrong I used to push it into the back of my mind, but after I heard it from the doctor I couldn't deny it and it was hard to accept" (A mother of a four year old son). "The most frustrating thing was that they couldn't tell what the cause was. Nothing was definite" (A mother of a seventeen year old son).

The circumstances under which the parents were first confronted with the diagnosis also have considerable impact on the amount of stress they felt, and as a result on the nature of the initial crisis. As with some previous studies (Bayley, 1973; Voysey, 1975; Worthington 1982; Glondinning, 1983), results of the present study show how significant the situation of initial signs or indications of the child's problem was for the parents and how much it influenced their responses.

The differences in parents' initial experiences with professionals which were found in this study show that professionals today are much more aware of the traumatic on-going influences of diagnosis for the parents, and they try to create an atmosphere which will help the parents to come to terms with the bad news. Although the parents' reactions in both groups (the younger and the older children) were similar, the parents of the younger children were more satisfied with the way in which they were told about the problem, and also with the general attitude of the professionals.

This is clearly illustrated from statements made by parents of the older and younger children. The following are typical: "They did not give me much hope. They even said that he will probably die young. They did not tell me anything about his future only not to be too optimistic" (A mother of a twenty two year old son). "The doctor did some tests and then told us that something is wrong with the chromosomes. He didn't tell us what to do with her. Actually they didn't tell us anything and I felt very bad. I didn't want to talk about it with anybody at that time" (A father of a twenty five year old daughter).

"Dr. W. told us that he is mentally handicapped, his brain is not functioning well and it is early to tell how he will develop. She said that his brain was damaged because he was born premature and because of lack of oxygen during the birth. It was not a surprise-I knew before that there were problems but I was shocked!" (A mother of a three year old son).

"I learnt a lot at the hospital. We had a lot of information from the doctor. She also told me about another mother who had a child with the same problem and I learnt a lot from this mother. You hear it but you can't accept it; it is a shock, I felt so upset" (A mother of a three year old daughter).

Yet, the stressful situation of learning about the child's problem can only partially explain parents' responses. When facing such a problem a new period of family life starts for the parents, and their ability to rely on already existing internal and external resources, as much as their subjective perception of the child's problem, its impact on their own life, and the family as a whole will determine how much of a crisis such a situation will create.

Findings of the study show some marked differences between parents in regard to their existing resources prior to the occurrence of the stressor event. The differences in the availability of external resources were due to the child's age (i.e. better and more services today).

There were fewer differences in parents opinions about the initial reactions of their relatives. Relatives were generally regarded by the parents as an available helping resource. The existing internal resources did not receive enough attention in this study as families' interrelationships prior to the stressor event were not explored. However, some differences in internal resources can be related to family characteristics like the parents' level of formal education, their religious background and the mentally handicapped child's birth order in the family which were found to influence parents' rections and probably to impact the family's internal resources as well.

Child and family characteristics were found to be noticeably related to parents' perception of the stressor event. This study strengthens the findings of some past studies (Farber, 1960; Begab, 1963) concerning the differences in parents' attitudes to the child's problem according to his sex, and the nature of his handicap. Differences in parental subjective perception of the child's problem were found to be related also to parents' level of education and religious

background. A wide gap between parents' expectations and child's performance created more disruption for the whole family.

Altogether it seems that in spite of variations in existing resources and subjective perception of the stressor event, a crisis situation was unavoidable for these parents. The dominant emotional feeling of most of the parents in the initial phase was shock and disbelief, and even the older parents, when recalling their initial reactions, described typical crisis responses.

These findings emphasise the uniqueness of the stressful event caused by a mentally retarded member in the family. The disruptive impact of such an event on family life is so great that it is impossible to avoid a crisis situation.

The research findings clearly show that the majority of the parents who participated in the study faced a crisis situation during the initial period after learning about the child's problem. The dominant emotional reactions of these parents were very similar regardless of the differences in factors a, b and c which were already mentioned. Although most of the parents described similar emotional responses - shock and disbelief, the amount of stress and the nature of parental coping patterns was related to the crisis intensity and to the ability to overcome such a situation.

6.4.2 Phase II - Continuing feelings and responses (aAbBcC)

The following comments by subjects of the study reflect the events following the initial crisis.

"The first years were bad because she was sick many times. She also developed slower than a normal child. I used to go to the doctor almost every week. When she was five she started to go to the training centre. It became easier to manage her and I didn't have many problems. Now, that she is an adolescent, I sometimes feel that I have less problems

than some of my friends with normal girls. Yes, I accepted the fact that she is limited but to me she is like a normal child because she is so good and easy to manage" (Mother of a seventeen year old daughter).

"When she was young we used to spoil her too much because we thought that *being as she is she needs more than other* children. She became hard to manage and it was very difficult to keep her at home. When she was six years old the doctor told us to send her to the day centre. Since then it has been much easier to manage her and she has improved a lot. You start to accept the fact that she is this way and you learn to live with it" (Father of a sixteen year old daughter).

"During the first period I still believed that he would overcome it. He developed slowly but not too slow. The main problem was and still is communication. It is hard to have a baby who doesn't show any kind of affection. Slowly, slowly I started to accept the fact that my child has a problem. I still can't use the words "mentally handicapped". When I was advised to take him to the day centre I went there. When I saw the place I couldn't put him there. Only when I became pregnant again it was hard to care for him and I felt that I couldn't give him what he needs so I decided to put him in the day centre" (Mother of a three year old son).

"*The first one and a half years I couldn't accept* it. I didn't want to see anybody or to speak to anybody. I was depressed and isolated. He was developing slowly but without too many problems. I was working with him all the time teaching and playing with him. *I still hope* that one day he will be able to go into a "normal" school, that will be enough for me" (Mother of a four year old son).

As already mentioned, having a mentally handicapped child seems to be such an event that a crisis reaction by the parents is unavoidable. The research findings show that as a result of the child's problems many changes occurred in the

family system. The parents had to reorganize their lives and to devote a lot of their time to handling the child's needs. They had to give up recreational and social activities and it seems as if the child's problems and needs became the focus of their lives. Such a situation caused a pile-up of stressors since at the same time many of the parents had not yet overcome the initial crisis and were struggling with their natural tendency to deny the situation, with guilt feelings and general emotional disorganization.

All the above-described stressors were related to the child's mental handicap. However, in coming to terms with mental handicap, the parents started to accommodate the idea that the child's situation was not time-limited, and that during the coming years the growing child would probably create more difficulties and hardships. As a baby the fact that the child development was abnormal was not noticed to such an extent by the parents and others. However, in the long run the gap between the physical and mental development of the child became more and more evident, forcing the parents to search for a solution suitable to the child's state.

The need to search and the difficulties involved in finding an adequate solution at each stage of the child's development caused an additional on-going stress for the parents, as it reminded them again and again that their child would always remain "different".

The findings of the study reveal that the conventional tensions resulting from the changes in the lifecycle of every family, or the stages in the development of all children, created much more intense stress for the parents who were interviewed, yet when they were able to accept their child's special needs and could find a satisfactory solution (a training centre or a workshop), the whole family

felt relieved which enabled the developing of a more positive attitude towards the child.

One of the important findings of this study is the strong dependence of the parents on various kinds of professionals and services. Although many past studies (Farber, 1960, 1968, 1975; Begab, 1963; Bayley, 1973; Featherstone, 1980; Glendinning, 1983) have established that one of the characteristics of families of mentally retarded children is their *intensive relationships with social and health services*, it was striking to confirm how important these kinds of external resources were for the parents. It seems that the degree to which the parents could rely on external resources played an important part in their ability to cope with their serious problems. For the parents of the younger children (and especially the mothers who were generally much more satisfied with the existing services and the professionals' attitudes), the idea that they could rely on such supportive networks helped to reduce the stresses and strains resulting from the intensive burden of care for the young mentally handicapped child.

For the parents of the older children, who were less satisfied with the services in their communities and felt that there was a need for more and better schools, day centres and institutions, the fact that there were not satisfactory solutions for their growing children created additional stress and worries, especially when thinking and planning for the child's future. *For example:*
"I am worried about his future. If he can stay at the workshop its O.K. but I know that they are going to ask me to take him out. Where to? I don't know, what we shall do? I can't tell, I only know that it worries me all the time and I am afraid of the day ...." (Father of a twenty nine year old son).

"I know that when I am not here my son will need care. What is he going to do? I don't know , I don't like to think of that. I believe in God, he will help us" (Mother of a twenty five year old son).

It was quite obvious that the availability of external resources helped the parents to develop internal resources and to reduce the vulnerability of the whole family. External resources included support and help which the parents could get from relatives, friends and neighbours. For the parents of the younger children, and especially the fathers who were still in an acute crisis situation, it was very difficult to maintain their social relationships. Although they had a great need for social support and help, they had difficulties accepting it as a result of their tendency to avoid social contacts and isolate themselves.
"I think that our friends can't understand what it is to have such a child. Some of them say 'Oh, what a burden it is for you' and I don't like it" (Mother of a three year old daughter).
"Most of our friends are very helpful, but we lost some friends because of him. Sometimes we have troubles with the neighbours' kids. They want to play with his sister but they do not come to the house because of him" (Father of a four year old son).

Results of the study show that while the parents of the younger children still try to maintain their social contacts in spite of the difficulties they have to face when going to visit other people or inviting friends to their home, the parents of the older children seem to have fewer expectations from their friends and neighbours. They consider themselves being "not so social". Such an attitude stresses again the relationships between external and internal resources. The parents of the older children seemed to rely on internal rather than on external resources (social and

health services and friendship relationships). The fact that they had ceased to be in an acute crisis helped them to become more self-reliant, and therefore less dependent on external resources. "We must always take him when we go, that's why we don't go so much to visit friends. We stay at home, watch T.V. We are a very closed family, you know" (Father of a nineteen year old son).

The ability to overcome the crisis situtation, as already mentioned, relies not only on the *utilization of existing* and new external and internal resources. It seems that the subjective perception of the crisis and the various kinds of stressor events also have an impact on the process of crisis recovery. Subjective perception of the stressor events and the crisis situation was found to be different for mothers and fathers. Results of the present study are consistent with findings of some past studies (Farber, 1968; Wolfensberger, 1967; Cummings et.al., 1966, Cummings, 1976).

Mothers seem to be more vulnerable than fathers, it is much harder for them to accept the diagnosis and their emotional reactions are much more intense and deep-seated. But, the crisis they face is not only the "tragic" one (Farber, 1960). The nature of the crisis that the mothers have to face involves the need for role reorganization, and their crisis resolution is dependant on the ability to cope with the burden of caring for a mentally handicapped child without giving up other life duties and activities. As a result of *their subjective perception of the stressor event*, the mothers who participated in this study were found to be more worried than fathers about the impact of the child on family interrelationships and on the siblings. The mothers of the younger children seemed to be much more optimistic, or in other words, less realistic.

By devoting a lot of their time and energy to the child these mothers expected a significant, dramatic change in his situation. The growing child, although still very much dependant on his mother seemed to put less strain on her. The experienced, less hopeful mother of an older child was able to develop a more realistic approach to his situation. Such an approach created a more pessimistic attitude towards the child but at the same time helped to reduce the stress caused by the need to respond to the on-going special needs of the growing child.

"In the first two years I refused to accept that something might be wrong. Sometimes I felt that I could kill myself and the child. When the doctor told me that I have to do something for her we started to ask, all over, what can be done for her, but nobody helped us. At that time she was not moving and it was easier to manage her. Now you have to watch her all the time when she is at home. In the day centre she has improved a lot, but still I feel that our whole attitude to life changed because of her. I am worried about her future" (Mother of a four year old daughter).

"The first years were hard because of my husband. He could not accept it. I was forty seven years old when the child was born and my husband said that we are too old. Then, when he heard that the child was mentally retarded it was too much for him. I also could not believe it and I used to send him to private lessons and to a normal nursery school. Until he was ten and his heart was operated on, he was always very sick. When he started to go to a training centre I always had the feeling that they were not doing enough for him. I always felt that there must be a better school. But, when he was there he improved a lot. My daughter and I accepted him for what he was. We used to take him with us to sing in the church choir and he enjoyed it very much. But, for my husband it remained a problem, he couldn't accept it. He wanted to put him in a "home", but I felt that I couldn't leave him alone" (Mother of a twenty two year old son).

As with some other previous studies (Wolfensberger, 1967; Cummings, 1976) the findings of this study reveal some differences between mothers' and fathers' subjective perception of the child's situation and its effect on the family. Although as already mentioned the reactions of most of the parents indicated that a crisis situation was unavoidable, for the fathers the child's problem created a "value conflict" (Farber, 1968). Accepting the disabled child was contrary to their expectations and values. It was even harder when the mentally retarded offspring was a male. However, fathers were able to develop a more remote and objective attitude to the situation. Such an attitude enabled them to control their emotional reactions and develop a more realistic approach.

The changes in the fathers' lifestyle were not so marked as for the mothers. While the mothers in most cases were the main carriers of the burden resulting from the child's special needs, the fathers spent many hours outside the house and their task as breadwinners enabled them to "run away" from many of the hardships caused by the child's situation. Day-to-day difficulties kept the mothers busy struggling to maintain their different roles despite the time-demanding care of a mentally handicapped child. The fathers, however, while developing a realistic approach and a greater ability to control their emotional reactions, were found to be more future-oriented, than the mothers.

In coming to terms with the child's situation the fathers felt "the burden" of responsibility for their child's future. They were worried about the limited opportunities to find a satisfactory solution which would meet the child's needs and at the same time minimize the value conflict for themselves. "I hope that one day he will be able to work and make his own living. I hate the idea that he will spend the rest of his life in a 'home' doing nothing" (Father of a twenty one year old son).

"Maybe, she will get married one day, you never know ..." (Father of a seventeen year old daughter).

Thus, the fathers were more aware than mothers of the practical problems which the child caused for the family at each stage of his development. This practical attitude enabled them to look forward and plan for the future. The mothers' main worries in regard to the child's impact on the whole family concentrated around current family interrelationships and special needs of particular family members.

Differences between mothers' and fathers' subjective perception of the nature of the crisis (x) probably has its impact on the pile-up of stressor events for each parent (aA) and the ability to use existing and new internal and external resources (bB). However, the research findings reveal that beside the abovementioned differences some of the parents' reactions were similar. It seems that there was a general "agreement" between parents (although interviewed separately) to avoid expressing extreme ideas or feelings which might be contrary to the ideas or feelings of the spouse.

Overall, the second phase represents a new stage in the process of adaptation which starts with the trial of recovering from the initial crisis and at the same time overcoming new stressor events caused by the "normal" and unique changes in the development of the mentally handicapped child. The dynamics of the family's ability to utilize existing resources and to create new ones which will meet the new stressors, and changes in basic attitudes to the crisis and its outcomes, lead to the development of adequate coping patterns. The recovery from the initial crisis and the development of coping patterns should be considered as a further step towards adaptation. However, the mixture of the dominant emotional reactions typical of this stage (anger, disappointment, guilt feelings, denial,

resentment and aggression) underscores the significance of this intermediate phase in the developing process from the initial crisis situation towards a certain degree of adaptation.

6.4.3 Phase III : Adjustment or acceptance (xX)

During the second phase, when the parents start to overcome the initial crisis they realize that the child's problem is not time-limited and that in order to cope with it some basic changes in the family system are needed. Reorganization of roles, changes in family expectations and values and in the relationships with the outside world facilitate the growth of coping patterns. "Coping includes both the behavioural responses of family members as well as the responses of the family unit in an attempt to manage the situtation. Moreover, coping is their ability to acquire and use the resources needed for family adaptation" (Patterson and McCubbin, 1983, p.30). The development of coping patterns has already been described in past studies as creating some changes in the lifestyle of those families (Darling, 1979; Patterson and McCubbin, 1983). When summing up parents' reactions to the different issues which were included in the research tools it became quite clear that a *unique lifestyle develops in the family* as a result of parents' attempts to cope with a long-term phenomenon like mental retardation.

Moreover, the various coping patterns were found to be linked sequentially to each other. Each coping pattern seemed to have its impact on a specific aspect of lifestyle. Summing up these various specific aspects illuminates the unique lifestyle which typically develops in families of a mentally handicapped child. The impact of the development of coping patterns on lifestyle characteristics in families of mentally handicapped children is illustrated in Figure 4.

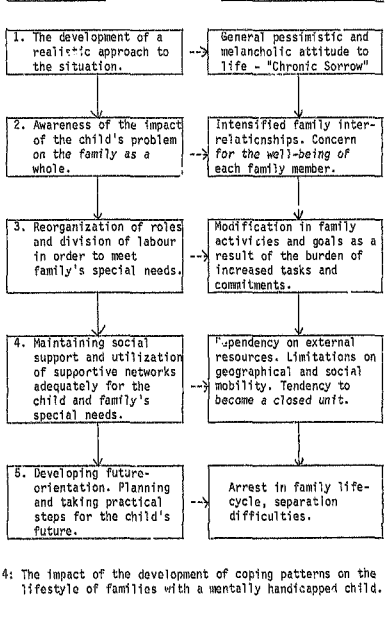


Figure 4: The impact of the development of coping patterns on the lifestyle of families with a mentally handicapped child.

The development of coping patterns and the changes in family lifestyle can be seen as an attempt of the family system to create new balance in order to respond to the child's special needs and at the same time to keep the family unit functioning. McCubbin and Patterson (1982) use Piaget's concepts of cognitive development to describe three additional processes which help the family to create and to maintain a new balance, or in other words to adapt to the situation. First, the family has to assimilate new experiences or demands resulting from the situation created by having a mentally handicapped child. "Assimilation involves making the "new" demands fit existing family structure and functioning" (McCubbin and Patterson, 1982, p.42). Later on, the family accomodates to the demands by changing its dynamics to fit to the new situation. "A family's effort to balance assimilation and accommodation is not a clear-cut course of action with predictable conflict-free outcomes. Because the family faces a host of competing alternatives in what it assimilates and how it accomodates, each of which brings on additional hardships, the best solution is likely to be a difficult one involving the process of family compromise" (McCubbin and Patterson, 1982, p.42).

It seems from the study's results that the sequential coping patterns (described in figure 4) represent the parents' effort to accomodate to the assimilated new demands forced upon them by the child's situation. The changes in the life-style of the family can be seen as a compromise which facilitates the maintenance of a balance in the family's life. This new balance may perhaps facilitate movement to other coping patterns, but this must remain only a suspicion since the findings of this study provide no direct evidence in this respect. Findings of the study indicate that the ability of the parents to develop a realistic approach is connected to a certain degree of acceptance and understanding of the nature of the child's problem (assimilation).

In spite of the new realistic approach, results of the study show how hard it was for the majority of the parents to assimilate the possibility of the child's problem having great impact on the whole family. However, such an approach at least facilitated a better understanding of the situation and its influences on the family unit and each of its members.

The parents' ability to realistically assimilate the child's problem was found also to influence their attitude to th outside world. The better adjusted (or more accepting) parents felt more accepted by others (relatives, friends and neighbours) and less dependant upon them (services and professionals).

Assimilating the meaning of the child's problem and its irreversibility influenced parents' general attitude to the future. Planning for the future was found to be more common among the better adjusted parents (mainly the parents of the older children). However, taking practial planning steps seemed to create objective and subjective difficulties for the majority of the parents who participated in the study. The objective difficulties result from the lack of adequate facilities for mentally handicapped adults. The subjective parental hesitations when planning for the child's future will be explained further on, in relation to lifestyle characteristics.

As already mentioned, the development of a realistic approach to the child's problem was found to influence parents' ability to recognize the possibility of its impact on the whole family.

The degree to which the reality of the problem was assimilated influenced parental expectations from the outside world and their attitude towards the future. Reorganization of roles with its accompanying division of labour (coping

pattern No. 3 in figure 4) represents the process of parental accomodation to the already assimilated changes and demands. Changing of family dynamics, reorganization of roles and the new attitude towards life goals created, according to the study's results, to have a strong influence on the nature of the lifestyle of the parents. The uniqueness of parental lifestyle was found to develop parallel to the process of adaptation, and was also influenced by the specific aspects of the child's different developmental stages and the family lifecycle.

The differences in attitudes and views of the parents of the younger children (age 2-6) and the parents of older ones (age 16-30) in regard to the various subjects which were studied in this research study, highlight the basic assumption about the different stages (or phases) in the process of parental adaptation.

The findings clearly reveal that among the parents of the younger children some were still in an acute crisis situation. These parents had not yet assimilated the full meaning of the child's problem and still expressed hopes that the child would be cured.

Their optimistic attitude to the situation enabled them to reject any differences in their lifestyle when comparing themselves to families without a mentally handicapped child. As they still did not assimilate the full meaning of the child's problem they could not start the process of accomodation to the new demands.
The child's future, for example, did not represent any special problems for these parents as they believed that the child would recover. Nevertheless, in the group of the parents of the younger children there were parents whose reactions were typical of the second phase in the process of adaptation (mainly the parents of the older of the younger children).

The fact that their child (age 5-6) could not be considered a baby any more strengthened their already changing attitude to the situation. Now they were experiencing the difficulties and hardships of the growing child to a greater extent, and in their effort to cope they had to "pay the price" by changing their lifestyle (modification in activities, reduction of free time, etc.). At this stage, it was still hard for the parents to accept the impact of the child on the whole family or to accept that their family had special problems or needs because of the mentally retarded child. However, they had to admit the differences in day-to-day life when comparing themselves to families without a mentally handicapped child.

Yet, these parents still believed that in the long run they would be able to maintain their family life without the need to modify their activities, social relationships, goals or expectations.

"There are no differences at all. We are more together maybe than other families" (Father of a two year old son).

"For my wife it created a lot of strain. She had to put aside a lot of her activities because you must watch her and help her more than with a normal child. She also can't go to a normal school ... A friend left us because of her, I will not consider him a real friend; but I must admit that I am quite an isolated person and I used to be so before her" (Father of a five year old daughter).

"There are not too many differences in our daily life. I have to devote a lot of time to him but I don't mind because I can see that he [illegible]ps and I am sure that he will be fine. He is not physically handicapped so there are no special needs" (Mother of a three year old son).

The fact that parents of young mentally handicapped children make an attempt to maintain the "normal" appearance of

family lifestyle and to avoid changes in day-to-day life as much as possible, has already been mentioned in some past studies (Hewett et.al., 1970; Birenbaum, 1970; Voysey, 1975). The findings of this study strongly support this contention. Although Birenbaum (1970) notes that parents may be unable to continue this "normal appearing round of life" when the retarded child reaches adolescence or adulthood, results of this study indicate that even for the parents of the older children it was still hard to admit that having such a child created a problem for the whole family: the tendency to focus on the child, and define the problems by referring first and foremost to his special needs, was generally maintained.

Yet, when comparing the reactions of the parents of the older children with the younger ones, it becomes quite clear that the former ones had already reached a further stage in the process of adaptation. This situation enabled the establishment of coping patterns needed in order to adjust to the mentally retarded child's special problems and needs. However, as already mentioned, the changes in day-to-day life which were essential in order to accomodate to the new demands, had in the long run, an almost unavoidable impact on the lifestyle of the family. The unique lifestyle which was found to develop over the years should therefore be seen as part of the process of family compromise (McCubbin and Patterson, 1982) which, after all, facilitated parents' ability to adjust to or accept their child and his problem.

As already mentioned, the gap between the child's mental level and his physical appearance became more and more obvious as he grew older. Thus, it created a pile-up of additional stress for the parents of adolescents and young adults. Moreover, after many years of rearing the child and coping with past developmental and specific hardships caused by him, the parents seemed to feel much more competent when facing the problems of the mentally retarded adolescent or young adult.

It therefore seems from the research study results that many of the parents of the older children almost "forgot" what it means not to have such a child. They were no longer surprised when repeatedly confronted with new problems, almost expecting such events to occur. Such an attitude helped them to better accept the possibility that the whole family will have difficulties as a result of the child. Their attitude to the outside world can also be seen as a "compromise", as their realistic approach led them to seek future-oriented habilitation programmes, although their expectations after many years of intensive relationships with services and professionals tended to be low. Sustaining social contacts seemed to create many more difficulties for the parents of the older children, especially with friends. With regard to family and neighbours, the fact that more "reaching out" was done by these people helped the parents to feel more accepted and to maintain the contacts. Yet, to a certain degree many of these parents felt socially isolated; but as it had become such an established pattern of lifestyle. they tended to define themselves "as not so social".

Among the marked differences between the reactions of parents of younger and older children was their attitude to the future. As was expected, the parents of the older children were much more future-oriented and their main concerns were related to the child's future. However, it was striking to find that even the majority of the parents of the older children did not (when interviewed) have any specific plans for the child's future neither had they taken any practical steps in this regard. Moreover, the idea that the "child" would stay with them until they pass away was quite common, and the arrest in the family lifecycle (Farber, 1968) which avoided "the empty nest" probably helped some of these parents to maintain their marital relationship. In such

cases, keeping the young adult at home served first and foremost the parents' needs, and was not necessarily primarily in the interests of the young adult. At this stage the unique lifestyle characteristics were so well established that separation, maybe, seemed to be too much of a threat to the already achieved balance.

"Yes, there are differences in our life but I don't know if it is because of him. We live in a big house with a big yard and we are more like a community than a family. Each one has his activities and the place is big so each one has his corner. We haven't gone on a vacation for a long time and we are too busy to get out of the house. We have become much closer to each other, especially me and my wife. It enriched our family life. Sometimes I think that we were chosen to raise this child" (Father of a twenty three year old son).
"I haven't taken any practical steps yet. Maybe if my husband dies or something happens to me, but I really can't think of it now" (Mother of a twenty six year old son).
"Sometimes I think about the future. Now that we have become older and my wife is not feeling so well I worry what will happen to him. I know that the children will take care of him. I know that I don't want to put him in a 'home'. He will stay with us - this is my plan" (Father of a twenty two year old son).

The reactions of the parents of the older children, already described, strengthens the contentions of some other researchers about the sub-stages of acceptance (Blacher, 1984), or the differences in levels of adaptation which may be found amoung these families.

Blacher (1984) emphasizes the variation in the timing, duration, and behavioural characteristics of the stage of adaptation. Turnbull and Turnbull (1978) stress the lifelong

need to make continual adjustment to having a mentally handicapped child. Olshansky (1962) and Wikler et.al. (1981), when mentioning the "chronic sorrow", lend weight to the contention that even the parents whose behaviour and attitudes show a certain degree of adjustment to the situation "pay the price" emotionally. The findings of this study are consistent with this theory. The older parents were found to have a much more pessimistic, melancholic attitude to life. The sad atmosphere which was experienced during the interviews seemed to reflect common parental emotional reactions.

When discussing the differences in parents' ability to reach a certain degree of adaptation, two important factors must be kept in mind.

I. The uniqueness of each family. In spite of the common behaviour characteristics, attitudes and reactions which have been described by many researchers as typical of parents of a mentally handicapped child, it is important to be aware of the fact that each parent is an individual and his reactions are influenced by his personality, his past experiences and his future expectations. The individuality of each family member and the combination of these individuals into a family system also contribute to variations which could be found in parental reactions to having a mentally retarded child.

II. Child and family characteristics. The impact of child and family characteristics on parental reactions and attitudes to having a mentally handicapped child has already been discussed in previous chapters with regard to the various subjects included in this study. Taking all factors into account, the child's age is the most important factor in determining the degree of parents adaptation. The dynamic approach which was utilized in

this study enabled clarification of the nature of the process of adaptation, strengthening the relationship between the child's stage of development and familial phases in this process. Differences in parents' attitudes, in regard to the various subjects were also found to be related to the child's sex and the severity of his handicap.

It seems that these factors have an impact especially on parents' reactions to the initial crisis when they first learnt about the child's problem. The findings of this study about the impact of socioeconomic status and level of education on parental reactions to having a mentally handicapped child are generally similar to the results of previous studies (Tizard and Grad 1961; Farber, 1960, 1968, 1975; Begab, 1963; Kurtz, 1977; Chinn et.al., 1978; Drew et.al, 1984).

However, findings in regard to the impact of parents' religious background on their reactions were not always consistent with the few past studies which have dealt with this issue (Zuk, 1959). Unfortunately, as a result of the small sample, further analysis on the inter-relationships between more than two variables could not be done. Such analysis could perhaps explain some of the abovementioned differences between this study and previous ones.

To sum up:

The combination of the double ABCX Model (McCubbin and Patterson, 1982) and the stages Model (Blacher , 1984) facilitates the dynamic examination of the process of parental adaptation, and illuminates the growth or coping patterns during the phases of the process. The sequential nature of these phases also enables analysis of the situation for each family of a mentally handicapped child by "placing" it in the appropriate stage of the process of adaptation. After analysing the findings of this

study, it seems that bonadaptation of the parents to the stressor event of having a mentally retarded child should be considered to occur when the parents are able to cope with the child's special problems and needs without too many modifications in their lifestyle. In other words even when objectively it seems (to outsiders) that the parents' lifestyle differs greatly from the lifestyle of families without a mentally handicapped child, the subjective perception of the parents themselves seems more important in terms of understanding the meaning and the outcome of the process of adaptation.

In the following section of this chapter the role of community supportive networks, and the interplay of parental relationships on these external resources will be discussed. The reciprocal relationships between the parents and the outside world were found to play an important role influencing the nature of the process of parental adaptation. A further understanding of the meaning of these relationships may contribute to the development and the improvement of services and professional intervention programmes.

6.5 THE IMPACT OF SOCIAL SUPPORT NETWORKS AND COMMUNITY RESOURCES ON PARENTAL ADAPTATION TO HAVING A MENTALLY HANDICAPPED CHILD.

The availability of social and community supportive networks is an invaluable resource for families of a mentally handicapped child. "In communities where there is greater tolerance for developmentally disabled persons, families are expected to experience less stigmatization than they would in communities which are less tolerant" (Sherman et.al., 1984, p.99).

Supportive social relationships are important in most forms of coping, and social support can attenuate the subjective perception of a problem and act as a buffer once a situation has been defined as disturbing (Schilling et.al., 1984). The continuous burden of care and the complexity of the problems created by the child's situation forces parents' long-term reliance on social supportive networks. According to McCubbin and Patterson (1982) the process of family adaptation involves efforts to influence the type and quality of the demands to which the family may be exposed and the resources needed to facilitate adaptation. This process is motivated by the family's desire for self direction and autonomy, and the ability to achieve it may depend on the efficiency of the solutions that the community provides. "To the extent that the community is inadequate to the hardships these families face, family disruption may be inevitable no matter how strong the family's interpersonal capacities. The ability of families to maintain interpersonal stability and psychological comfort will depend therefore not only on their cohesiveness and adaptability but also on the social supports available or absent in the environment" (McCubbin and Patterson, 1982, p.40-41). Schilling et.al. (1984) define three levels of social support, namely: (i) nuclear family members; (ii) close friends, relatives; and (iii) other significant persons who are often the most basic, enduring and immediate sources of social support.

Indeed, findings of the research study demonstrated that for many of the parents (of both the younger and the older children), it was the easiest to maintain their contacts with the "first level persons". As for the second and the third levels defined by Schilling et.al. (1984) there were differences between parents' tendency and ability to maintain relationships, and to ask for and accept support and help. The parents of the younger children were still struggling to maintain contacts with more distant friends, while many of the parents of the older children seemed to give up such contacts.

Kazak and Marvin (1984) suggest another three factors measuring social networks and participations and describing their characteristics - (a) network size; (b) network density; and (c) boundary density (p.69-70). As with some previous studies mentioned by Kazak and Marvin (1984) the findings of this study indicate that the social network size tends to become smaller over the years, as a result of the parents' tendency to withdraw from social life. As for network density, results show that for many parents it was quite difficult to sustain intensive social contacts with the outside world. Yet, for the parents of the younger children it was hard to admit losing friends as a result of the child, while the older parents seemed to accept it as part of their unique lifestyle.

In order to illuminate the differences in families' adaptation in terms of "system-environment fit", McCubbin and Patterson's (1982) framework and concepts were used. They define family adaptation as "the degree to which the family system alters its internal functions (behaviours, rules, roles, perceptions) and/or external reality to achieve a system environment "fit". Adaptation is achieved through reciprocal relationships where "(a) system demands (or needs) are met by resources from the environment; and (b) environmental demands are satisfied through system resources" (McCubbin and Patterson, 1982, p.38).

When this model was applied by the writer to the findings of the present study, a clear distinction could be identified between the family/individual/community configurations of families with younger and older retarded children, respectively. This is schematically depicted in figure 5.

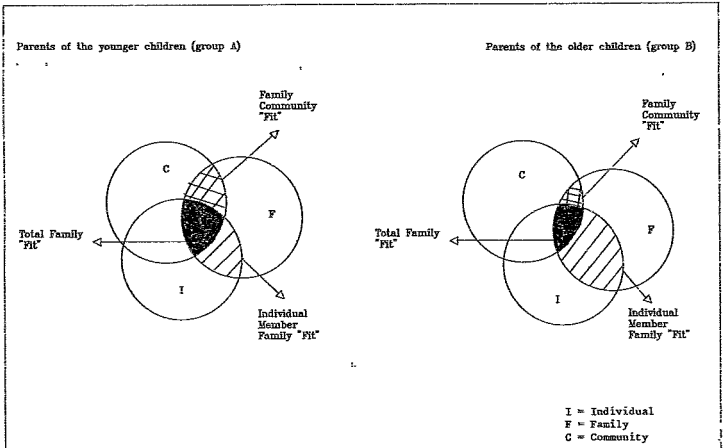


Figure 5 – Differences in Family Environment "Fit"

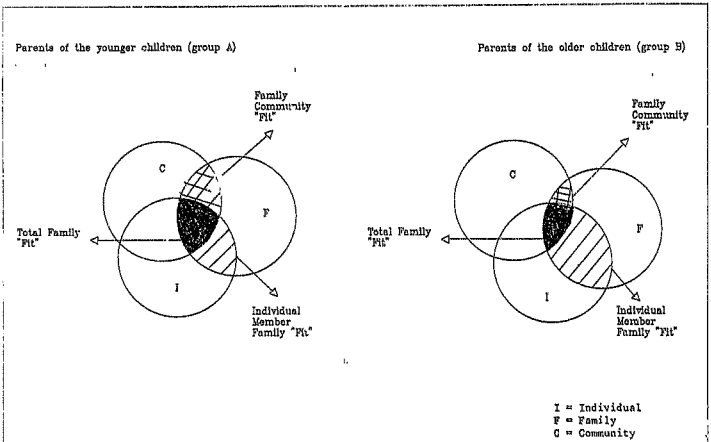


Figure 5 – Differences in Family Environment "Fit"

Results of the study show that the parents of the younger children were much more able (compared with the parents of the older children) to maintain the total "fit" between their family system, each individual member and the environment. As already mentioned, they made a considerable attempt to maintain their social contacts and they were more satisfied with the social and health services available to them in their community. Their basic attitude to professional help was generally positive and they were much more prepared to use it in the future, if needed (mainly for the child, but if necessary also for themselves). The improvement of community services (which may be seen as part of the community effort to improve the "fit" in regard to the family's special needs) and the resultant change in parents' attitude toward them may be attributed to the following factors:

As professionals became more aware of the stress and strains and to the burden of care experienced by parents of mentally handicapped children, they also became more aware of parents' reliance on community supportive networks to cope with these hardships in an adaptive fashion. In addition the trend to avoid institutionalization of the child also led to a greater emphasis on the development of community services. Moreover, the general preparedness of outsiders (relatives, friends and neighbours) to accept the young mentally retarded child facilitated the achievement of a better degree of total family "fit". According to McCubbin and Patterson (1982) minimum discrepancy between the demands of the family unit and the external resources creates the ability to achieve bonadaptation.

The fact that reactions of the parents of the younger children to other issues included in the study (degree of adjustment to child's situation, preparedness to admit the impact on the whole family, and planning for the future) indicated a lesser degree of adaptation (when compared to their attitudes in regard to their relations with the outside world), needs an explanation.

Firstly, as already mentioned, the improvement in social and health services for young mentally handicapped children in the *community created better objective conditions* for these parents.

Secondly, in spite of the objective difficulties these parents had to face in their trial to sustain their contacts with the outside world, they were determined to maintain these relationships and it was important for them to retain the "normal" appearing facade of their family.

Similar attitudes among young parents have also been reported by some previous studies (Hewett et.al., 1970; Birenbaum, 1970; Voysey, 1975). "Our friends are very helpful and we go from time to time to visit them or to play tennis. If I need help I can get it from the neighbours but I haven't got relatives here (in Johannesburg) ... We can get any professional help if it is needed, but now I don't feel the need for much help for myself. For him, there is physio and speech therapy and the day centre" (Mother of a four year old son). "I don't think that it had any influence on our friends, we take him with us wherever we go, all our friends we had before he was born are with us except for one couple. The neighbours like him, they play with him, we can leave him there for a while ... There are many services we can use - the hospital, physio and speech therapy, my wife used to go to a mothers' group in the Toy Library. At the moment we are quite satisfied ... " (Father of a three year old son). "We want to be a normal family, we enjoy every moment with him. He has his own habits and he is developing and for me this is the main thing. Most of our friends were able to accept him. When they do not accept him as part of our family they will cease to be friends ... If we want to go out we can leave him with a babysitter. We are now quite excited because he has started to go to the "centre". I am sure that they can help him"... (Father of a two year old son).

Differences in reactions of parents of younger and older children which were found in this study, indicate two marked changes in parental attitude which develop during the years of rearing the child at home. These changes are clearly depicted in figure 5. The total "fit" between family, individuals and the community decreases over the years while the degree of "fit" between individual members and the family as a whole increases.

These changes can be explained with regard to the objective situation in the community and as a result of parents' subjective reactions and feelings. Although it seems that in the last few years there has been an improvement in services for the mentally retarded, the need for more services for adolescents and adults is still considerable. Results of the study show that the parents of the older children expressed their concern about the lack of adequate solutions in the community or in institutions for their growing sons and daughters. No doubt, this situation led to their difficulties in planning and taking practical steps for the child's future. The parents of the older children were sometimes distressed by the difficulties which their relatives, friends and neighbours had in accepting their adult son or daughter, whose behaviour seemed strange and bizarre to them. Under such conditions it became harder for the parents to rely on external resources which tended to become less and less able to respond to the needs of the growing retarded child.

However, together with the reduction in the availability of external resources, a strengthening of the internal resources occurred. The development of coping patterns, together with the modifications in family lifestyle, faciliated the reliance on internal resources. In some cases the cohesiveness amongst family members even caused a withdrawal from the outside world. Yet, a total withdrawal seemed to be rare, although the general tendency to rely on internal rather than external resources was quite common among parents of older children. "Yes, there are services but they are not given equally to everybody. They give speech therapy only to the people who improve quickly and I think that they are wrong in doing so" (Mother of a nineteen year old daughter).

"There is no club for social life or a place that he can go for a disco. I have to take him with me and he is too old to go with me to a disco place .... Since my husband died only two of my friends keep in touch with me. I am quite lonely ... I have nothing to complain about members of my family. We are close to each other especially since my husband died" (Mother of a twenty four year old son).

"Nobody can help us except ourselves" (Father of a twenty five year old son).

To conclude: findings of the research study indicate that parents' ability to achieve better adaptation improves during the years of rearing the mentally retarded child at home. The constant development of coping patterns enables the parents to rely on internal resources. However, the reduction in the community's ability to meet the demands and needs of mentally handicapped adolescents and adults and their families, together with the tendency of outsiders to withdraw from maintaining social contacts with these families, creates a deterioration in the reciprocal relationships between the parents and the outside world. Under such circumstances, the preparedness of the parents to ask for and to accept social support and/or professional help is limited. Such an attitude probably influences professionals' ability to intervene and to offer assistance, treatment or support when needed, and thus a vicious circle is created.

6.6 CONCLUSIONS AND RECOMMENDATIONS

In this chapter an attempt was made to discuss the various subjects included in the study by integrating the findings into a model based on a combination of the Double ABCX Model (McCubbin and Patterson, 1982) and the stages model (Blacher, 1984).

The main aims of this study were to establish the nature of the impact of long term stresses caused by a mentally handicapped child on his family's lifestyle, and how the family copes with the chronicity and the irreversibility of the child's situation over the years, when deciding to raise the child at home.

The fact that all the parents who participated in this study preferred to keep the child at home (at least until the time of the interview) and raise him within the family, could in itself indicate a certain degree of basic adjustment to the situation.

The parents' decision to try to cope with the child's problem (which sometimes is a result of no other alternatives being available) should therefore be considered as a first step in the process of adaptation, because it involves the preparedness to, at least, start a life-long "mysterious voyage".

The abovementioned basic attitude of the parents who took part in the present study probably had an influence upon their reactions and feelings in regard to the various subjects which were explored and thus may also have some impact on the conclusions. Keeping this contention in mind, an attempt is made here to draw conclusions and to identify the most important findings of the study.

I. A comparison between the parents of the younger and the older children demonstrated that most of them had to face a severe crisis after being confronted with the child's mental handicap. Even if this event occurred many years ago (as it did for the parents of the older children) it was remembered

as a most traumatic one. It seems that McCubbin and Patterson's theory about the strength of existing resources and the ability to avoid a crisis is limited to certain stressor events. Learning about the mental handicap of their child was such a stressor event for most of these families that existing resources were totally insufficient to avoid the traumatic crisis. Thus the intensity of parental reactions when first learning about the problem, and also in the long run, probably created high risk for the family's well-being and/or for particular members of the family.

II. Results of the study indicated differences between mothers' and fathers' subjective perception of the initial crisis, which in turn influenced their subsequent reactions and attitude to the family situation resulting from the child's problem. Having a mentally handicapped child had much more effect on mothers' lifestyle. In order to be able to cope with the situation, mothers tended to give up many more of their activities prior to the birth of the child (jobs, social and recreational activities, etc). Caring for the child was found to be time-consuming even for the mothers of the older children, and all the more so for the younger child. Thus the situation created a role organization crisis for the mother and overcoming such a state was dependent on the mother's ability to modify her daily life, as much as it was on the degree to which other family members were ready for a new division of roles in order to meet the child and the family's needs.

Moreover, it was found that mothers' emotional vulnerability was greater, compared to fathers. Learning about the child's mental handicap created a tragic crisis for them, and it was much harder for mothers to overcome the situation. The extreme nature of maternal initial reactions had its long-term impact on mothers' attitudes to the situation. They were found to be more aware of the impact of the child on

the well-being of the siblings and on the family' inter-relationships. Their concerns in regard to the mentally handicapped child were focused on day-to-day hardships while considering the future seemed to create a lot of stress and was generally avoided. Maternal initial emotional reactions (mainly depression), although becoming less intensive, in the long run became chronic, thus influencing the general atmosphere in the family.

For the fathers, the child's mental handicap created mainly a "value conflict" with its intensity dependent on the nature of the gap between their expectations of the child and his performance. Fathers' emotional reactions, although less expressed, showed that they also had to overcome a crisis situation. However, fathers' ability to repress extreme emotional feelings and their lesser involvement in the daily care of the child, helped them to develop a realistic approach to the situation, which in the long run facilitated their ability to plan practically for the child's habilitation.

III. The linkage between the different but sequential coping patterns which were found to develop when assimilation of the child's situation occurred has already been described in detail. However, it must be noted that for the majority of the parents of younger and older children, even when they were adjusting to their situation it was hard for them to accept that having an exceptional child made them an exceptional family. *Such an attitude can be seen as the* struggle of these families against the labelling attitudes of professionals and society, which ultimately stigmatizes these people.

IV. The dynamics of parental attitudes to social supportive networks which were revealed in this research study can be seen as one of the investigation's most important outcomes.

The tendency to prefer reliance on internal rather than external resources, which develops over the years of rearing the child at home, should be carefully examined by professionals as it seems to result, at least partially, from the limited solutions which the community can offer to a group of people who are in great distress, and who are actually very dependent on external resources for achieving a certain degree of adaptation.

V. The findings of the research study clearly reveal that most of the parents were satisfied with the current solutions they had for their child (the three day centres). However, when expressing their general concern for the child's future, the majority of the parents in both groups (with younger and older children) denied the need to plan practically and to take steps for the future.

For the parents of the younger children who in many cases had not yet assimilated the full meaning of the child's problem, and who still believed that he would be cured, it was difficult to even think about his future in practical terms. For the older parents, who had already developed a much more realistic approach to the situation, and who, compared to the parents of the younger children, were readier to plan, it was still hard to take practical steps for the child's future. These difficulties seem to be caused by the lack of adequate facilities for mentally retarded persons in the community and in the availability of residential care, as much as by the outcome of the lifelong impact of the child on the parents lifestyle. For some parents, avoiding taking practical steps served first and foremost their own rather than their son's or daughter's needs.

VI. Child and family characteristics seemed to generally create differences in parents' reactions to the various subjects included in the research study. The findings indicate that child and family characteristics have a recognizable impact

on parents' initial reactions when first confronted with the child's diagnosis, and thus influence the nature of their process of adaptation. Child's sex, the cause for his mental retardation and the severity of his handicap as much as parental level of formal education, their occupation and religious background were also found to have an influence on general parental attitudes to social support networks. However, child and family characteristics had much less influence on parents' preparedness to ask for professional help for the family as a whole, and to take practical steps for the child's future. In these areas, it seems that parental ideas were greatly homogenous and even child and family characteristics had only a small impact on parents' attitudes and responses.

6.6.1 Recommendations

The following recommendations are based on the foregoing conclusions of the study.

(a) The implications of the impact of the mentally handicapped child on his family's lifestyle, and upon the quality of life at each stage of his development and the family's lifecycle, call for enhanced professional attention in both quality and quantity.

As mentioned, the services for young mentally handicapped children and their families have improved and developed in the last few years. The belief that families with a mentally handicapped child should be considered as being at a great risk, and the long-term impact of the initial crisis on the family system and on particular members, have already been accepted by professionals and have probably created the achieved improvement in services for these families. However, the focus seems to be mainly on developing professional services for the handicapped child himself.

The multiple nature of the child's handicap is met by the development of social and health services such as physiotherapy, speech and occupational therapy, the Toy library, training centres and workshops. Thus, with the emphasis on providing habilitation services for the children, the parents' needs seem to have been neglected, and they have been left aside to struggle with their own difficulties and with the burden of care for the child at home. From the parents' reactions it becomes evident that professionals' preferences are mainly to develop services for younger children, while the services for adolescents and adults and for their families are not sufficient to respond to the growing needs of this population. The lack of adequate solutions (such as social clubs, workshops, hostels and flats) for mentally retarded young adults creates a pile-up of stressors for the elderly parents who at this stage in their life need ever-increasing help to cope with their own problems, as well as to respond to the needs of their mentally retarded son or daughter. The development and improvement of social and health services to meet these needs is essential and urgent and considerably more public resources must be allocated for this purpose.

(b) The differences between mothers' and fathers' reactions to having a mentally handicapped child must be taken into consideration when planning professional intervention programmes for the family as a whole or for individuals.

The fathers' great need for an opportunity to express and share their repressed feelings was strongly felt during the interviews, and had its impact on their ideas about the impact of the child's problem on their lives. Mothers' reactions stress the need for more intensive professional intervention programmes including supportive treatment as much as practical guidance. All in all, professionals must encourage parents to accept

treatment for themselves and to reach out to those who either ignore their difficulties or are afraid to be stigmatized when becoming "a client".

(c) Reaching out towards parents o. mentally handicapped children must become an important aim for professionals and a *variety of programmes* should be offered in order to enable parents' active participation in planning their mentally retarded child's future. Such a situation could avoid the present helpless attitude of the parents of adolescents and adults towards the child's future, and the tendency of some parents to avoid finding a solution for the child's future because of their own needs.

(d) Finally, the findings of this research study should be carefully examined because of the small number of parents who were interviewed, and because these parents could not be considered as representatives of the whole population of parents of mentally retarded children in South Africa or even in Johannesburg. Thus, further studies which will *include more representative, bigger samples* of the population are needed in order to validate the findings of this study. Special attention must be paid to a deeper exploration of the impact the mentally retarded young adult has on his elderly parents, as the information in this specific area seems to be very limited probably because of the short life expectancy of the mentally retarded in the past. However, as a result of the *prolongation of mentally* retarded people's life expectancy in the last few years, more and more of these adults are still living with their old parents at home and the implications of this relatively new situation on the family system, and on each particular family member, should be studied in depth in the future.
A further area which merits special attention in future research is the *possible relationships between family* lifestyles generated by particular coping patterns, and whether or not a new lifestyle stimulates family movement toward a new stage of coping capacity.

APPENDIX 1

QUESTIONNAIRE ON RESOURCES AND STRESS

1. _____ demands that others do things for him/her more than is necessary.

2. _____ understands the idea of time.

3. _____ is cared for equally by all members of our family.

4. It will take us three years or more to pay off our debt.

5. A member of my family has had to give up education (or a job) because of _____.

6. _____ would not resent being left at home while the family went on vacation.

7. Members of our family praise each other's accomplishments.

8. _____ has a pleasing personality.

9. I know _____'s condition will improve.

10. Even if people don't look at _____ I am always wondering what they might think.

11. I take on responsibility for _____ because I know how to deal with him/her.

12. _____ has some unusual habits which draw attention.

13. In our house the whole family eats dinner together.

14. _____ is a very capable, well functioning person despite his/her other problems.

15. I always watch to make sure _____ does not to physical harm to himself/herself or others.

16. The special opportunities needed by _____ are available in our community.

17. Our house if comfortably arranged to meet _____'s needs without making it difficult for other members of the family.

18. I feel that our family situation will get better.

19. Medicine does not have to be given to _____ at a set time.

20. _____ doesn't communicate with others of his/her age group.

21. Other members of the family have to do without things because of _____.

22. _____'s problems or illness do not stand in the way of our family progress.

23. When others are around _____ I cannot relax; I am always on guard.

24. If _____ were more pleasant to be with, it would be easier to care for him/her.

25. Thinking about the future makes me sad.

26. Much of the time I think about _____ dying.

27. If I knew when _____ would die I wouldn't worry so much.

28. Our family agrees on important matters.

29. When _____ is not well, I can't go out.

30. I am afraid that by limiting _____'s activities he/she will not develop on his/her own.

31. Our family's income has dropped over the past 5 years. ____

32. The constant demands for care for _____ limit growth and development of someone else in our family.

33. _____ feels that I am the only one who understands him/her.

34. In his/her own way _____ brings as much pleasure to our family as the other members.

35. I worry about what will happen to _____ when I can no longer take care of him/her.

36. I think in the future _____ will take up more and more of my time.

37. I fear the day when other members of the family leave home and I am left alone with _____.

38. It would be better for _____ if our house could be remodeled.

39. A counselor or a teacher sees _____ at least once a month.

40. I get out of the house to do something interesting at least once a week.

41. I am very careful about asking _____ to do things which might be too hard for him/her.

29. When _____ is not well, I can't go out.

30. I am afraid that by limiting _____'s activities he/she will not develop on his/her own.

31. Our family's income has dropped over the past 5 years. ____

32. The constant demands for care for _____ limit growth and development of someone else in our family.

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36. I think in the future _____ will take up more and more of my time.

37. I fear the day when other members of the family leave home and I am left alone with _____.

38. It would be better for _____ if our house could be remodeled.

39. A counselor or a teacher sees _____ at least once a month.

40. I get out of the house to do something interesting at least once a week.

41. I am very careful about asking _____ to do things which might be too hard for him/her.

42. The attitude of our family makes it impossible for _____ to live with us any longer.

43. _____ is limited in the kind of work he/she can do to make a living.

44. I have accepted the fact that _____ might have to live out his/her own life in some special setting (i.e. hospital, institution, foster home).

45. I have given up things I have really wanted to do in order to care for _____.

46. My family argues about how to care for _____.

47. _____ is able to fit into the family social group.

48. Some members of my family don't like the way I do things.

49. At times I fear _____ will not be able to function in society if he/she is out of our house.

50. It is difficult for me to stand back and watch _____'s condition get worse.

51. In the future our family's social life will suffer because of increased responsibilities and financial pressure.

52. It doesn't make any difference to _____ if he/she is at home or in a hospital.

53. One of us has had to pass up a chance for a job because _____ could not be removed from a clinic or a special school, ect.

54. Sometimes I avoid taking _____ out in public.

55. Many people simply don't understand what it is like to live with _____.

56. Every member of our family has had to do without things because of money spent on _____.

57. _____ can feed himself/herself.

58. I tend to do things for _____ that he/she can do himself/herself.

59. As the time passes I think it will take more and more to care for _____.

60. I belong to organizations which help with problems I have with _____.

61. There have been serious emotional problems for someone in our family.

62. Our relatives have been very helpful.

63. It is easier for me to do something for _____ than to let him/her do it himself/herself and make a mess.

64. _____ is easy to manage most of the time.

65. I don't think that _____ depends too much on me or other members of the family.

66. I feel that I must _____ from the remarks of children.

67. We can afford to pay for the care _____ needs.

68. Just talking about problems with close friends makes life easier.

69. It bothers me that _____ will always be this way.

70. No one in our family drinks alcohol too much.

71. The community is used to people like _____.

72. _____ has a handicap which prevents him/her from improving.

73. _____ is sometimes too sexual.

74. _____ has a lot of pain.

75. I feel tense whenever I take _____ out in public.

76. _____ is easy to live with.

77. The doctor sees _____ at least once a year.

78. _____ eats his/her meals with other members of the family.

79. An electricity failure would endanger _____ 's life or health.

80. Caring for _____ has been a financial burden for our family.

81. Some friends are very helpful when it comes to _____ .

82. I worry that _____ may sense that he/she does not have long to live.

83. _____ will not do something for himself/herself if he/she knows someone will do it for him/her.

84. I can go visit with friends whenever I want.

85. We enjoy _____ more and more as a person.

86. We have changed our house because of _____ .

87. Taking _____ on a vacation spoils pleasure for the whole family.

88. The family does as many things together now as we ever did.

89. _____ knows his/her own address.

90. _____ gets along very well with others.

91. _____ is aware of who he/she is (for example; male 14 years old).

92. _____ prevents any communication within our family.

93. Sometimes I need to get away from the house.

94. I get upset with the way my life is going.

95. Sometimes I feel very embarrassed because of _____ .

96. Having to care for _____ has enriched our family life.

97. _____ doesn't do as much as he/she should be able to do.

98. Our family has been on welfare.

99. We take _____ along when we go out.

100. It makes me feel good to know I can take care of _____ .

101. Others do for _____ what he/she could do for himself/herself.

102. Because of _____ our family has never enjoyed a meal.

103. I hate to see _____ try to do something and fail.

104. _____ is accepted by other members of the family.

105. I fear _____ might get hurt while playing games or sports.

106. It is difficult to communicate with _____ because he/she has difficulty understanding what is being said to him/her.

107. _____ spends time at a special day center or in special classes at school.

108. _____ is very anxious most of the time.

109. _____'s health is not getting worse.

110. I have no time to give the other members of the family.

111. There are many places where we can enjoy ourselves as a family when _____ comes along.

112. It is hard to think of enough things to keep _____ busy.

113. _____ is overprotected.

114. Our family income is more than average.

115. Caring for _____ gives one a feeling of worth.

116. We have discussed his/her death with _____.

117. _____ is able to take part in games or sports.

118. One of us has had to pass a job because _____ could not be left without someone to watch him/her.

119. _____ has too much time on his/her hands.

120. There is an organization for families who share our problem.

121. I am disappointed that _____ does not lead a normal life.

122. We spend up to 25 percent of our income on medical care (or care for _____).

123. Time drags for _____ especially free t' e.

124. The part that worries me most about _____ going on his/her own is his/her ability to make a living.

125. _____ can't pay attention very long.

126. I worry about what will be done with _____ when he/she gets older.

127. I get almost too tired to enjoy myself.

128. _____ has things to entertain him/her (TV, radio) in his/her room.

129. We owe a great deal of money.

130. _____ is depressed most of the time.

131. If I were healthier, it would be easier to care for _____.

132. _____ can get around the neighbourhood quite easily.

133. _____ wants more freedom than he/she has.

134. One of the things I appreciate about _____ is his/her confidence.

135. I don't mind when people look at _____.

136. _____ will never be any brighter than now.

137. One of the things I appreciate about _____ is his/her ability to recognize his/her own limits.

138. I believe _____ should go places as often as others in the family.

139. I am not embarrassed when others question me about _____'s condition.

140. There is a lot of anger and resentment in our family.

141. Our family has managed to save money or make investments.

142. We own or are buying our home.

143. Information and encouragement is available to those who seek it.

144. We get special funds because of _____'s problem.

145. One of the things I enjoy about _____ is his/her sense of humour.

146. We can have no luxuries.

147. I have enough time to myself.

148. _____ is able to go to the bathroom alone.

149. I am afraid _____ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live.

150. I have too much responsibility.

151. _____ cannot remember what he/she says from one moment to the next.

152. _____ is better off in our home than somewhere else.

153. _____ can describe himself/herself as a person.

154. I am afraid that as _____ gets older it will be harder to manage him/her.

155. It is easy to keep _____ entertained.

156. It makes me feel worthwhile to help _____.

157. _____ wants to do things for himself/herself.

158. In the future _____ will be more able to help himself/herself.

159. I have become more understanding in my relationships with people as a result of _____.

160. The constant demands to care for _____ limit my growth and development.

161. _____ cannot get any better.

162. _____ is very tense in strange surroundings.

163. It is easy to communicate with _____.

164. I feel said when I think of _____.

165. I have had to give up a chance for a job because of _____.

166. _____ accepts himself/herself as a person.

167. Outside activities would be easier without _____.

168. I enjoy church.

169. Caring for _____ puts a strain on me.

170. I often worry about what will happen to _____ when I no longer can take care of him/her.

171. People can't understand what _____ tries to say.

172. I feel that _____ would prefer a professional (nurse, day care helper, etc.) to care for him/her rather than a member of our family.

173. Members of our family get to do the same kinds of things other families do.

174. _____ uses the phone frequently.

175. _____ has many things to keep him/her busy.

176. Sometimes the demands _____ makes drive me out of my mind.

177. _____ could do more for himself/herself.

178. My family understands the problems I have.

179. It is easy to do much for _____.

180. _____ appreciates the interest others show in him/her.

181. It is easier for our family to do things with people we know than with strangers.

182. We can hardly make ends meet.

183. _____ rarely has nightmares.

184. Members of our family are able to discuss personal problems.

185. I am healthy as I ever was.

186. _____ does not dress right.

187. Most of _____'s care falls on me.

188. It is fortunate how _____ has adjusted to life.

189. _____ has his/her own room.

190. _____ is very irritable.

191. We have lost most of our friends because of _____.

192. _____ has an attractive, clean appearance.

193. _____ can ride a bus.

194. _____ will always be a problem to us.

195. _____ is able to express his/her feelings to others.

196. It is easy for me to relax.

197. _____ has to use a bedpan or a diaper.

198. I rarely feel blue.

199. We have good laundry facilities at home.

200. _____ can walk without help.

201. _____ needs help in the bathroom.

202. I have chances to carry on interests outside the home.

203. I am worried much of the time.

204. One of the things I appreciate about _____ is his/her sensitivity to others.

205. _____ likes to follow the same schedule all the time.

206. _____'s needs come first.

Your Name _____ Last _____ First _____ Middle _____

This questionnaire applies to _____ Child's name _____

Your Date of Birth _____ Age _____ Sex _____ Relationship to above person _____ (Father, mother)

	T	F		T	F		T	F		T	F		T	F		T	F
1	_	_	31	_	_	61	_	_	91	_	_	121	_	_	151	_	_	181	_	_
2	_	_	32	_	_	62	_	_	92	_	_	122	_	_	152	_	_	182	_	_
3	_	_	33	_	_	63	_	_	93	_	_	123	_	_	153	_	_	183	_	_
4	_	_	34	_	_	64	_	_	94	_	_	124	_	_	154	_	_	184	_	_
5	_	_	35	_	_	65	_	_	95	_	_	125	_	_	155	_	_	185	_	_
6	_	_	36	_	_	66	_	_	96	_	_	126	_	_	156	_	_	186	_	_
7	_	_	37	_	_	67	_	_	97	_	_	127	_	_	157	_	_	187	_	_
8	_	_	38	_	_	68	_	_	98	_	_	128	_	_	158	_	_	188	_	_
9	_	_	39	_	_	69	_	_	99	_	_	129	_	_	159	_	_	189	_	_
10	_	_	40	_	_	70	_	_	100	_	_	130	_	_	160	_	_	190	_	_
11	_	_	41	_	_	71	_	_	101	_	_	131	_	_	161	_	_	191	_	_
12	_	_	42	_	_	72	_	_	102	_	_	132	_	_	162	_	_	192	_	_
13	_	_	43	_	_	73	_	_	103	_	_	133	_	_	163	_	_	193	_	_
14	_	_	44	_	_	74	_	_	104	_	_	134	_	_	164	_	_	194	_	_
15	_	_	45	_	_	75	_	_	105	_	_	135	_	_	165	_	_	195	_	_

	T	F		T	F		T	F		T	F		T	F		T	F
16	_	_	46	_	_	76	_	_	106	_	_	136	_	_	166	_	_	196	_	_
17	_	_	47	_	_	77	_	_	107	_	_	137	_	_	167	_	_	197	_	_
18	_	_	48	_	_	78	_	_	108	_	_	138	_	_	168	_	_	198	_	_
19	_	_	49	_	_	79	_	_	109	_	_	139	_	_	169	_	_	199	_	_
20	_	_	50	_	_	80	_	_	110	_	_	140	_	_	170	_	_	200	_	_
21	_	_	51	_	_	81	_	_	111	_	_	141	_	_	171	_	_	201	_	_
22	_	_	52	_	_	82	_	_	112	_	_	142	_	_	172	_	_	202	_	_
23	_	_	53	_	_	83	_	_	113	_	_	143	_	_	173	_	_	203	_	_
24	_	_	54	_	_	84	_	_	114	_	_	144	_	_	174	_	_	204	_	_
25	_	_	55	_	_	85	_	_	115	_	_	145	_	_	175	_	_	205	_	_
26	_	_	56	_	_	86	_	_	116	_	_	146	_	_	176	_	_	206	_	_
27	_	_	57	_	_	87	_	_	117	_	_	147	_	_	177	_	_			
28	_	_	58	_	_	88	_	_	118	_	_	148	_	_	178	_	_			
29	_	_	59	_	_	89	_	_	119	_	_	149	_	_	179	_	_			
30	_	_	60	_	_	90	_	_	120	_	_	150	_	_	180	_	_			

APPENDIX 2

A SCHEDULE FOR PARENTS OF MENTALLY HANDICAPPED OFFSPRING

1. When and how did you first suspect that there was something wrong with your son/daughter?

2. When was the first time you were told that your son/daughter is mentally handicapped?

3. How were you told about your son's/daughter's problem?

4. What were you told about your son's/daughter's problem when the diagnosis was made?

5. What was your reaction when you were told about your son's/-daughter's problem?

6. After you knew about your son's/daughter's problem, when was the first time you spoke to a relative, a friend?

7. What was their reaction?

8. Can you recall the various stages you have been through over the years?
   How did you feel in each stage about your child?

   (a) The period before your son/daughter went to nursery school.
   (b) Nursery school and the first school years.
   (c) Adolescence.
   (d) Adulthood.

9. If you didn't ask for professional help at the time when you were first told that your son/daughter was mentally handicapped at what stage did you seek professional help?

10. *How would you describe your feelings now?*

11. Do you feel that there are enough services available to help a parent of a mentally handicapped son/daughter?

12. If yes, which services have you used and why?

13. If not, what kind of services do you think should be available in order to help you with your son/daughter?

14. Do you feel that your family has special needs or problems because of having a mentally handicapped member?

15. If yes, what are the special needs or problems?

16. If not, please give reasons for your answer.

17. Did you seek any professional help for your family?

18. Is there any particular member(s) of your family who has been specially effected by the fact of having a mentally handicapped family member?

19. Has this member(s) had any professional help as a result of this problem?

20. If not, why?

21. Would you consider using professional help in the future for this member(s) of your family or for the family as a whole?

22. Do you think that there are differences in everyday life between your family and families without a mentally handicapped member?

23. If yes, please explain the reason for your answer.

24. Has having a mentally handicapped family member effected your relationships with the followings:
    (a) Your relatives, in the past, in the present.

    (b) Your friends, in the past, in the present.

    (c) Your neighbours, in the past, in the present.

    If so, please explain how.

25. Are you ever worried about your son's/daughter's future?

26. If yes, when did you first become worried about the future?

27. If not, do you think that later on you will become worried about the future?

28. What are your worries for the future regarding your son/daughter?

29. Do you have any specific plans for your son's/daughter's future?

30. Have you taken any practical steps about your son's/daughter's future?

31. If yes, what have you done?

32. If you have not yet taken any practical steps about your son's/daughter's future, when do you think you will do so?

33. What are you going to do?

Information Sheet

1. Child's No. .....

2. Child's birthdate .....

3. Sex .....

4. Cause for mental retardation .....

5. Child's place in the family .....

6. No. of children in the family .....

7. Mother's birthdate .....

8. Father's birthdate .....

9. Mother's formal education:
   (a) Under matric
   (b) Matric
   (c) Post matric training

10. Father's formal education:
    (a) Under matric
    (b) Matric
    (c) Post matric training

11. Mother's occupation .....

12. Father's occupation .....

13. Religion .....

14. Physical condition of the child:
    (a) Generally good
    (b) Generally fair
    (c) Generally poor

15. A mentally handicapped relative beside the child Yes/No.

APPENDIX 3

DIE THE **HAMLET** OPLEIDINGSENTRUM TRAINING CENTRE
01 100131 000 1

Ridgeweg 27
Parktown
Johannesburg
2193
Tel. 642-4694/5

27 Ridge Road
Parktown
Johannesburg
2193
Tel. 642-4694/5

January 19 1984

Dear Mr & Mrs

Mrs Miriam Berson, who is a social worker in the field of Mental Retardation, is undertaking a research project with families who have a mentally retarded child.

I would appreciate it if you would agree to having one interview in the evening with Mrs Berson, at your home.

She will 'phone you for an appointment and wishes to speak to both parents.

If you do not wish to co-operate, please let me know by phoning me.

Thank you for your co-operation.

Yours sincerely,

(Mrs) G Handler
Social Worker

HELP US TO HELP THEM

Society for the Jewish Handicapped

(011) 640-5171

Correspondence to:
P.O. Box 28881
SANDRINGHAM
2131

Fund Raising Act reference no: 01 100 231/000 0

DB/SS September 1983

Dear

Mrs. Miriam Berson is an Israeli social worker with considerable experience in the field of mental retardation. At present, she is undertaking a research project in South Africa about families who have handicapped children. This study is for her doctorate in social work.

Mrs. Berson would like to meet with both of you at your home, on an evening at a convenient time. This should take no more than one and a half hours of your time.

I hope that you will be able to meet with Mrs. Berson. Her work should make a contribution to all of us.

If you are NOT able to see Mrs. Berson, please let me know as soon as possible, otherwise, Mrs. Berson will telephone you to make an appointment.

Thank you for your co-operation,

Yours sincerely,

(Miss) D. BOWMAN,
SOCIAL WORKER

APPENDIX 4

Table 1A

Frequencies of the children's ages by groups (A & B) (in percentages)

Child's Age	Group A	Group B
1. 2 - 3 years	27.6	-
2. 4 - 5 years	31.0	-
3. 6 - 7 years	41.4	-
4. 16 - 18 years	-	27.8
5. 19 - 21 years	-	38.9
6. 22 - 25 years	-	20.4
7. 26 - 30 years	-	12.9
Total	100.0	100.0
	N=30	N=30

Table 2A

Frequencies of child's place in the family by groups (A & B) (in percentages)

Child's place in the family	Group A	Group B
1. First child	46.6	18.5
2. Second child	24.1	40.7
3. Third child	22.4	16.7
4. Fourth child	3.5	11.1
5. Fifth child	3.4	9.3
6. Sixth child	-	3.7
Total	100.0	100.0
	N=30	N=30

Table 3A

Frequencies of number of children in family by groups (A & B) (in percentages)

Child's Age	Group A	Group B
1. One	19.0	3.7
2. Two	31.0	11.1
3. Three	34.5	38.9
4. Four	12.0	33.3
5. Five	3.5	5.6
6 Six	-	3.7
7 Seven	-	-
8. Eight	-	3.7
Total	100.0	100.0
	N=30	N=30

Table 4A

Frequencies of mother's birthdate by groups (A & B)
(in percentages)

Mother's Age	Group A	Group B
1. 20 - 25 years	6.9	-
2. 26 - 30 years	25.9	-
3. 31 - 35 years	32.8	-
4. 36 - 40 years	31.0	7.4
5. 41 - 45 years	3.4	14.8
6. 46 - 50 years	-	31.5
7. 51 - 60 years	-	37.0
8. 61 - 71 years	-	9.3
Total	100.0	100.0
	N=30	N=30

Table 5A

Frequencies of father's birthdate by groups (A & B)
(in percentages)

Father's Age	Group A	Group B
1. 20 - 25 years	-	-
2. 26 - 30 years	14.3	-
3. 31 - 35 years	21.5	-
4. 36 - 40 years	35.7	-
5. 41 - 45 years	25.1	12.5
6. 46 - 50 years	-	20.8
7. 51 - 60 years	3.6	50.0
8. 61 - 71 years	-	16.6
Total	100.0	100.0
	N=28	N=24

Table 6A

Frequencies of mother's formal education by groups (A & B)
(in percentages)

Mother's formal education	Group A	Group B
1. Under Matric.	41.4	68.6
2. Matric	41.4	24.0
3. Post Matric training	17.2	7.4
Total	100.0	100.0
	N=30	N=30

Table 7A

Frequencies of another mentally handicapped relative by groups (A & B) (in percentages)

Another mentally retarded relative	Group A	Group B
1. Yes	10.3	29.6
2. No	89.7	70.4
Total	100.0	100.0
	N=58	N=54

Table 8A

Frequencies of answers to the question: "When was the first time you were told that your child is mentally handicapped?" by groups (A & B) (in percentages)

Answer	Group A	Group B
1. At birth, or a few days after.	25.8	16.6
2. When the child was 4-8 months old.	32.7	27.7
3. When the child was 1-2 years old.	29.3	20.3
4. When the child was 3-5 years old.	6.6	11.1
5. When the child was 6 or more.	5.1	24.0
Total	100.0	100.0
	N=58	N=54

Table 9A

Frequencies of answers to the question: "How were you told about your child's problem?" by groups (A & B) (in percentages)

Answer	Group A	Group B
1. By a doctor or a specialist (without testing the child)	37.9	62.9
2. By a doctor (after testing the child).	46.5	20.3
3. By my wife/husband	12.0	3.7
4. By a Psychologist, Physiotherapist, Educator or Social worker	3.4	12.9
Total	100.0	100.0
	N=58	N=54

Table 10A

Frequencies of answers to the question: "After you knew about your child's problem, when was the first time you spoke about it to a relative or a friend"? by groups (A & B) (in percentages)

Answer	Group A	Group B
1. They all knew already.	20.8	18.5
2. We told our relatives immediately after we knew about it.	63.8	59.3
3. We only told our friends.	1.7	3.7
4. For a long time I didn't speak about it.	13.7	18.5
Total	100.0	100.0
	N=58	N=54

Table 11A

Frequencies of answers to the question: "What were the reactions of relatives and friends when they heard about the child's problem"? by groups (A & B) (in percentages)

Answer	Group A	Group B
1. I didn't talk about it.	8.6	18.5
2. They didn't believe, didn't accept it.	22.4	14.8
3. Shocked, upset but learnt to accept it.	15.5	27.7
4. Told us to put the child in a home.	8.6	1.8
5. Accepted the child and were supportive.	36.2	37.0
6. Accepted the facts better than we did.	8.6	1.8
Total	100.0	100.0
	N=58	N=54

Table 12A
Means, SD, Df, and Probabilities for scales 1,2,3,4,6,7,11,15 of the QRS, mothers versus fathers (t test)

Scales	Mothers				Fathers			
	Mean	SD	Df	P	Mean	SD	Df	P
1. Poor Health/Mood	3.7	2.7	109.0	0.2	3.1	2.3	108.9	0.2
2. Excess time demands	4.9	2.4	106.0	0.08	4.1	2.4	103.6	0.08
3. Negative attitudes towards index case	9.3	3.6	106.0	0.8	9.1	3.0	105.0	0.8
4. Overprotection/ Dependency	5.8	2.4	102.0	0.8	5.7	2.3	99.1	0.8
6. Overcommitment/ Martyrdom	3.8	0.9	109.0	0.2	3.6	1.1	96.8	0.2
7. Pessimism	3.6	2.1	100.0	0.7	3.5	2.2	94.2	0.7
11. Physical incapacitation	4.0	2.5	107.0	0.5	3.7	2.3	106.7	0.5
15. Difficult personality characteristics	11.6	4.1	97.0	0.9	11.5	4.2	93.3	0.9
	N=60				N=52			

Table 13A

Frequencies of parents' current reactions towards the child's handicap, mothers versus fathers (in percentages)

Parents' reaction	Mothers	Fathers
1. The child will grow out of it.	13.6	15.3
2. Have accepted it. The child will improve.	46.6	38.4
3. You have to accept it.	23.3	28.8
4. I am worried about the future.	13.3	13.7
5. It has changed my lifestyle.	1.6	-
6. It has enriched our family life.	1.6	3.8
Total	100.0	100.0
	N=60	N=52

Table 14A

Frequencies of answers to the question: "After you knew about the child's problem, when was the first time you spoke about it to a relative or a friend"? mothers versus fathers (in percentages)

Answer	Mothers	Fathers
1. They all knew already.	23.3	15.3
2. We told our relatives immediately after we knew about it.	63.4	65.3
3. We only told our friends.	-	-
4. For a long time I didn't speak about it.	13.3	19.4
Total	100.0	100.0
	N=60	N=52

Table 15A

Frequencies of answers to the question: "What were the reactions of relatives and friends when they heard about the child's problem"? mothers versus fathers (in percentages)

Answer	Mothers	Fathers
1. I didn't talk about it.	11.6	13.4
2. They didn't believe, didn't accept it.	18.3	19.2
3. Shocked, upset but learnt to accept it.	26.6	15.3
4. Told us to put the child in a home.	5.3	5.7
5. Accepted the child and were supportive.	31.6	42.6
6. Accepted the facts better than we did.	6.6	3.8
Total	100.0	100.0
	N=60	N=52

Table 16A
Means, SD, Df, and Probabilities for fathers of Group A versus fathers of Group B according to scales 1,2,3,4,6,7,11,15 of the QRS (t test)

Scales	Fathers A				Fathers B			
	Mean	SD	Df	P	Mean	SD	Df	P
1. Poor Health/Mood	2.9	2.3	49.5	0.3	3.5	2.2	50.0	0.3
2. Excess time demands	4.5	2.4	47.0	0.2	3.6	2.4	48.0	0.2
3. Negative attitudes towards index case	9.2	3.0	46.4	0.7	9.0	3.0	47.0	0.7
4. Overprotection/ Dependency	5.6	2.1	40.6	0.7	5.8	2.6	45.0	0.7
6. Overcommitment/ Martyrdom	3.6	1.1	47.5	0.6	3.5	1.1	49.0	0.6
7. Pessimism	3.0	2.2	43.8	0.1	4.0	2.2	44.0	0.1
11. Physical incapacitation	4.9	2.1	48.5	0.0001	2.3	1.7	49.0	0.0001
15. Difficult personality characteristics	13.1	4.5	38.8	0.01	10.0	3.3	43.0	0.01
	N=28				N=24			

Table 17A
Means, SD, Df, and Probabilities for mothers versus fathers in Group A for scales 1, 2, 3, 4, 6, 7, 11, 15 of the QRS (t test)

Scales	Parents							
	Mothers A				Fathers A			
	Mean	SD	Df	P	Mean	SD	Df	P
1. Poor Health/Mood	3.2	2.3	55.0	0.6	2.9	2.3	54.9	0.6
2. Excess time demands	4.7	2.7	54.0	0.7	4.5	2.4	54.0	0.7
3. Negative attitudes towards index case	9.9	3.9	54.0	0.4	9.2	3.0	53.0	0.4
4. Overprotection/ Dependency	5.5	1.8	51.0	0.9	5.6	2.1	47.0	0.9
6. Overcommitment/ Martyrdom	3.7	0.8	55.0	0.6	3.6	1.1	47.4	0.7
7. Pessimism	3.0	2.2	49.0	0.9	3.0	2.2	48.2	0.9
11. Physical incapacitation	5.3	2.5	54.0	0.5	4.9	2.1	53.6	0.5
15. Difficult personality characteristics	13.3	4.1	46.0	0.8	13.1	4.5	43.0	0.8
	N=30				N=28			

Table 18A
Means, SD, Df, and Probabilities for mothers versus fathers in Group B for scales 1, 2, 3, 4, 6, 7, 11, 15 of the QRS (t test)

Scales	Parents							
	Mothers B				Fathers B			
	Mean	SD	Df	P	Mean	SD	Df	P
1. Poor Health/Mood	4.1	3.0	52.0	0.3	3.5	2.2	51.8	0.3
2. Excess time demands	5.2	2.1	50.0	0.02	3.6	2.4	45.0	0.02
3. Negative attitudes towards index case	8.6	3.1	50.0	0.6	9.0	3.0	48.0	0.6
4. Overprotection/ Dependency	6.0	2.8	49.0	0.7	5.8	2.6	47.2	0.7
6. Overcommitment/ Martyrdom	3.8	1.0	52.0	0.2	3.5	1.1	46.4	0.2
7. Pessimism	4.1	1.9	49.0	0.8	4.0	2.2	42.5	0.8
11. Physical incapacitation	2.6	1.7	51.0	0.5	2.3	1.7	49.3	0.5
15. Difficult personality characteristics	10.0	3.6	49.0	0.9	10.0	3.3	48.2	0.5
	N=30				N=24			

Table 19A

Frequencies of parents' answers to the question: "What were you told about your child's problem when the diagnosis was made?" by child's sex (in percentages)

Answer	Males' Parents	Females' Parents
1. The child is slow but will improve in the future.	3.3	4.3
2. We received many diagnoses before the final one.	13.6	17.3
3. The child is mentally retarded.	25.7	43.7
4. The child will have to go to a special school.	28.7	19.5
5. The child must go into residential care.	7.5	6.5
6. The child has no future, he will die early.	21.2	8.7
Total	100.0	100.0
	N=66	N=46

Table 20A

Frequencies of parents current reactions towards the child's handicap, by child's sex (in percentages)

Parents' reaction	Males' Parents	Females' Parents
1. The child will grow out of it.	7.5	23.9
2. I have accepted it. The child will improve.	51.5	30.4
3. You have to accept it.	25.7	26.3
4. I am worried about the future.	12.1	15.2
5. It has changed my lifestyle.	-	2.1
6. It has enriched our family life.	3.2	2.1
Total	100.0	100.0
	N=66	N=46

Table 21A

Frequencies of answers to the question: "What were the reactions of relatives and friends when they heard about the child's problem"? by child's sex (in percentages)

Answer	Males' Parents	Females' Parents
1. I didn't talk about it.	13.6	10.8
2. They didn't believe, didn't accept it.	19.7	17.6
3. Shocked, upset but learnt to accept it.	16.6	28.2
4. Told us to put the child in a home.	9.0	-
5. Accepted the child and were supportive.	33.6	41.3
6. Accepted the facts better than we did.	7.5	2.1
Total	100.0	100.0
	N=66	N=46

Table 22A

Frequencies of parents' answers to the question: "What made you first suspect that there was something wrong with your child?" by cause of the child's mental retardation (in percentages)

Answer	Unknown	Genetic disorders	Brain Damage
1. I didn't suspect. I was told.	55.5	56.1	33.3
2. Something was wrong during the pregnancy or at the birth of the child.	-	7.3	2.7
3. The child's development was slow.	44.5	19.5	38.8
4. The child was sick and did not look normal.	-	17.1	25.2
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Table 23A

Frequencies of parents' answers to the question: "What were you told about your child's problem when the diagnosis was made?" by the cause of the child's mental retardation (in percentages)

Answer	Unknown	Genetic disorders	Brain Damage
1. The child is slow but will improve in the future.	22.2	-	-
2. We received many diagnoses before the final one.	27.7	4.8	22.2
3. The child is mentally retarded.	11.3	39.2	41.6
4. The child will have to go to a special school.	38.8	21.9	16.6
5. The child must go into residential care.	-	12.2	8.3
6. The child has no future, he will die early.	-	21.9	11.3
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Table 24A

Frequencies of answers to the question: "What were the reactions of your relatives and friends when they heard about the child's problem"? by the cause of the child's mental retardation (in percentages)

Answer	Unknown	Genetic Disorders	Brain Damage
1. I didn't talk about it.	16.6	9.7	19.4
2. They didn't believe, didn't accept it.	22.2	19.8	16.6
3. Shocked, upset but learnt to accept it.	22.2	36.5	2.7
4. Told us to put the child in a "home".	5.5	2.4	8.3
5. Accepted the child and were supportive.	33.5	26.8	44.4
6. Accepted the facts better than we did.	-	4.8	8.6
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Table 25A

Frequencies of parents' answers to the question: "What made you first suspect that there was something wrong with your child"? by the child's physical condition (in percentages)

Answer	Good physical condition	Fair physical condition
1. I didn't suspect. I was told.	49.4	44.0
2. Something was wrong during the pregnancy or at the birth of the child.	1.3	12.0
3. The child's development was slow.	34.4	12.0
4. The child was sick and did not look normal.	14.9	32.0
Total	100.0	100.0
	N=87	N=25

Table 26A

Frequencies of parents' initial reactions to the child's diagnosis by child's birth order (in percentages)

Parents Reaction	First Born	Second Born	3 - 6 Born
1. I knew that something was wrong, and was upset.	-	5.5	12.8
2. Shocked, couldn't believe it.	45.9	36.1	53.8
3. Confused, felt bad about the way they told us. I was angry.	18.9	22.2	7.6
4. Upset, but accepted it after some time.	35.2	36.2	17.9
5. I was worried.	-	-	7.9
Total	100.0	100.0	100.0
	N=37	N=36	N=39

Table 27A

Frequencies of parents current reactions towards the child's handicap, by the child's birth order (in percentages)

Parents' reaction	First Born	Second Born	3 - 6 Born
1. The child will grow out of it.	13.5	22.5	7.6
2. I have accepted it. The child will improve.	54.0	38.8	35.9
3. You have to accept it.	18.9	30.6	28.2
4. I am worried about the future.	13.6	5.5	20.5
5. It has changed my lifestyle.	-	-	2.5
6. It has enriched our family life.	-	2.7	5.3
Total	100.0	100.0	100.0
	N=37	N=36	N=39

Table 28A

Frequencies of timing of parents' first suspicions of the child's problem, by the parents' level of formal education, *(in percentages)*

Answer	*Under Matric*	Matric and Post
1. I didn't suspect anything.	47.5	49.2
2. *During pregnancy.*	1.6	3.9
3. At birth, or a few days after.	11.4	17.6
4. After 4- 8 months.	21.6	19.6
5. From 1 - 2 years.	14.7	5.8
6. From 3 - 4 years.	1.6	3.9
7. When the child had to go to school.	1.6	-
Total	100.0	100.0
	N=61	N=51

Table 29A

Frequencies of answers to the question: "When was the first time *you were* told that your child is mentally handicapped?" by parents' level of formal education (in percentages)

Answer	Under Matric	Matric and Post
1. At birth or a few days after.	14.7	29.4
2. When the child was 4-8 mths old.	29.5	31.3
3. When the child was 1-2 yrs old.	21.5	29.6
4. When the child was 3-5 yrs old.	11.4	5.8
5. When the child *was 6 or more* years old.	21.3	3.9
Total	100.0	100.0
	N=61	N=51

Table 30A

Frequencies of answers to the question: "What were the reactions of *your* relatives and friends when they heard about the child's problem?" by parents' level of formal education (in percentages)

Answer	Under Matric	Matric and Post
1. I didn't talk about it.	16.3	7.8
2. They couldn't believe it, didn't accept it.	14.7	23.5
3. Shocked, upset, but learnt to accept it.	21.3	21.6
4. Told us to put the child in a "home".	3.6	7.8
5. Accepted the child, were supportive	40.9	31.6
6. Accepted the facts better than we did.	3.2	7.8
Total	100.0	100.0
	N=61	N=51

Table 31A

Frequencies of mothers' answers to the question: "What made you *suspect* that there was something wrong with your child?" by the mother's occupation (in percentages)

Answer	Working Mothers	Housewives
1. I didn't suspect. I was told.	71.4	53.0
2. Something was wrong during the pregnancy or at the birth of the child.	-	6.2
3. The child's development was slow.	36.9	24.2
4. The child was sick and did not look normal.	21.7	16.6
Total	100.0	100.0
	N=23	N=33

Table 32A

Frequencies of mothers' current reactions towards the child's handicap, by the mother's occupation (in percentages)

Mother's reaction	Working Mothers	Housewives
1. The child will grow out of it.	8.7	18.3
2. I have accepted it. The child will improve.	34.7	48.4
3. You have to accept it.	32.6	21.2
4. I am worried about the future.	17.6	10.6
5. It has changed my lifestyle.	2.1	-
6. It has enriched our family life.	4.3	1.6
Total	100.0	100.0
	N=23	N=33

Table 33A

Frequencies of fathers' answers to the question: "When was the first time you were told that your child is mentall. handicapped?" by the father's occupation (in percentages)

Answer	High Skilled	Low Skilled
1. At birth or a few days after.	25.6	10.0
2. When the child was 4-8 mths old.	37.8	13.3
3. When the child was 1-2 yrs old.	21.6	30.0
4. When the child was 3-5 yrs old.	8.3	10.1
5. When the child was 6 or more years old.	6.7	36.6
Total	100.0	100.0
	N=36	N=12

Table 34A

Frequencies of fathers' initial reactions to the child's diagnosis by fathers' occupation (in percentages)

Father's Reaction	High Skilled	Low Skilled
1. I knew that something was wrong, and was upset.	8.1	3.3
2. Shocked, couldn't believe it.	44.5	36.6
3. Confused, felt bad about the way they told us. I was angry.	14.8	23.3
4. Upset, but accepted it after some time.	31.3	30.2
5. I was worried.	1.3	6.6
Total	100.0	100.0
	N=36	N=12

Table 35A

Frequencies of timing of parents' first suspicions of the child's problem, by parents' religious background (in percentages)

Timing of Suspicions	Catholics	Protes-tants	Jews
1. I didn't suspect anything.	73.6	47.8	27.7
2. During pregnancy.	5.2	1.4	5.5
3. At birth, or a few days after.	5.2	19.7	5.5
4. After 4 - 8 months.	10.5	15.4	55.5
5. From 1 - 2 years.	-	11.5	5.5
6. From 3 - 4 years.	5.5	2.8	-
7. When the child had to go to school.	-	1.4	-
Total	100.0	100.0	100.0
	N=19	N=71	N=18

Table 36A

Frequencies of parents' initial reactions to the child's diagnosis, by the parents' religious background (in percentages)

Parents' reaction	Catholics	Protes-tants	Jews
1. I knew something was wrong, and was upset.	10.6	5.6	5.5
2. Shocked, couldn't believe it.	63.1	43.6	27.7
3. Confused, felt bad about the way they told us. I was angry.	5.2	18.3	22.4
4. Upset, but accepted it after some time.	21.2	28.3	44.4
7. I was worried.	-	4.2	-
Total	100.0	100.0	100.0
	N=19	N=71	N=18

Table 37A

Frequencies of parents' current reactions towards the child's handicap, by parent religious background (in percentages)

Parents' reaction	Catholics	Protes-tants	Jews
1. The child will grow out of it.	26.3	11.2	5.5
2. I have accepted it. The child will improve.	36.8	47.8	33.3
3. You have to accept it.	31.5	18.3	50.1
4. I am worried about the future.	-	18.3	11.1
5. It has changed my lifestyle.	-	1.6	-
6. It has enriched our family life.	5.4	2.8	-
Total	100.0	100.0	100.0
	N=19	N=71	N=18

Table 38A

Frequencies of answers to the question: "What were the reactions of your relatives and friends when they heard about the child's problem?" by the parents' religious background (in percentages)

Answer	Catholics	Protes-tants	Jews
1. I didn't talk about it.	21.0	7.3	27.7
2. They couldn't believe it, didn't accept it.	26.6	16.9	11.1
3. Shocked, upset, but learnt to accept it	15.7	29.5	-
4. Told us to put the child in a "home"	-	4.2	16.6
5. Accepted the child, were supportive.	36.8	36.6	33.3
6. Accepted the facts better than we did	-	5.6	11.3
Total	100.0	100.0	100.7
	N=19	N=71	N=18

Table 39A

Frequencies of answers to the question: "What were the reactions of your relatives and friends when they heard about the child's problem"? by having a mentally handicapped relative (in percentages)

Answer	A M.R. relative	[illegible] M.R. relative
1. I didn't talk about it.	27.2	8.8
2. They couldn't believe it, didn't accept it.	13.6	20.0
3. Shocked, upset, but learnt to accept it.	9.4	24.7
4. Told us to put the child in a "home".	4.5	5.5
5. Accepted the child, were supportive.	36.3	36.6
6. Accepted the facts better than we did.	9.0	4.4
Total	100.0	100.0
	N=22	N=90

Table 40A

Frequencies of parents' answers to the question: "If you do not have special problems or needs, give reasons for your answer?" by Groups A & B (in percentages)

Answer	A	B
1. We have problems or needs.	31.1	48.2
2. We try to lead a normal life.	37.9	20.4
3. It hasn't changed our life, we are like any other family.	24.1	31.4
4. Not yet, the child is still young.	6.9	-
Total	100.0	100.0
	N=58	N=54

Table 41A

Means, SD, Df, and Probabilities for mothers A versus mothers B according to Scales 8, 9, 10 of the ORS (t test)

Scale	Mothers A				Mothers B			
	Mean	SD	Df	P	Mean	SD	Df	P
8. Lack of family integration.	2.8	2.5	56.8	0.4	3.3	2.3	56	0.4
9. Limits of family opportunity.	1.0	1.1	55.7	0.7	1.1	1.3	57	0.7
10. Financial problems.	3.9	2.4	56.3	0.5	3.4	2.9	58	0.5
	N=30				N=30			

Table 42A

Means, SD, Df, and Probabilities for fathers A versus fathers B according to Scales 8, 9, ... of the QRS (t test)

Scale	Fathers A				Fathers B			
	Mean	SD	Df	P	Mean	SD	Df	P
8. Lack of family integration.	2.5	2.1	45.9	0.1	3.5	2.4	49	0.1
9. Limits on family opportunity.	1.2	1.6	47.9	0.8	1.1	1.5	49	0.8
10. Financial problems.	3.2	2.2	39.4	0.8	3.3	3.2	50	0.8
	N=28				N=24			

Table 43A

Frequencies of parents' answers to the question: "Do you think that there are differences in everyday life between your family and families without a mentally handicapped child?" mothers versus fathers (in percentages)

Answer	Mothers	Fathers
1. There are no differences.	25.3	32.6
2. Not very much, you have to devote more time to the child.	3.3	15.3
3. Not now because the other children are young or old.	5.6	5.7
4. Yes, its like having a baby all the time.	21.6	23.4
5. Outside activities are more difficult. We are limited, isolated spend more money on the child.	36.6	21.1
6. We are closer to each other.	6.6	1.9
Total	100.0	100.0
	N=60	N=52

Table 44A

Frequencies of parents' answers to the question: "Is there any particular member of *your family who has been affected?*" by groups A & B (in percentages)

Answer	A	B
1. No.	48.3	50.0
2. No. They are old enough or too young.	13.8	1.9
3. I was affected.	6.9	3.7
4. My husband/wife were affected.	3.4	3.7
5. It affected the siblings.	25.9	29.6
6. A family member left home.	-	3.7
7. The siblings became closer to each other or more responsible.	1.7	7.4
Total	100.0	100.0
	N=58	N=54

Table 45A

Frequencies of *parents' answers to the question:* "Do you think that there are differences in daily life between your family and families without a mentally handicapped child?" by child's sex (in percentages)

Answer	Male's Parents	Female's Parents
1. There are no differences.	25.7	32.6
2. Not very much, you have to devote more time to the child.	12.2	4.3
3. Not now because the other children are young or old.	1.5	13.0
4. Yes, its like having a baby all the time.	19.7	26.5
5. Outside activities are more difficult. We are limited, isolated spend more *money on the child.*	37.8	17.3
6. We are closer to each other.	3.1	6.5
Total	100.0	100.0
	N=66	*N=46*

Table 46A

Frequencies of parents' answers to the question:" If you do not have special problems or needs, give reasons for your answer", by the cause of child's mental retardation (in percentages)

Answer	Unknown	Genetic disorders	Brain damage
1. We have problems or needs.	33.3	34.1	47.2
2. We try to lead a normal life.	22.3	39.2	22.2
3. It hasn't changed our life.	44.4	24.3	22.3
4. We are like any other family.	-	-	-
5. Not now, the child is still young.	-	2.4	8.3
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Table 47A

Frequencies of parents' answers to the question: "Do you think that there are differences in daily life between your family and families without a mentally handicapped child?" by child's physical condition (in percentages)

Answer	Generally Good	Generally Fair
1. There are no differences.	28.7	28.0
2. Not very much, you have to devote more time to the child.	6.9	16.0
3. Not now because the other children are young or old.	6.9	4.0
4. Yes, its like having a baby all the time.	20.6	28.0
5. Outside activities are more difficult, we are limited, isolated spend more money on the child.	31.2	24.0
6. We are closer to each other.	5.7	-
Total	100.0	100.0
	N=87	N=24

Table 48A

Frequencies of parents' answers to the question: "Is there any particular member of your family who has been affected?" by child's physical condition (in percentages)

Answer	Generally Good	Generally Fair
1. No.	49.4	28.0
2. No. They are old enough or too young.	6.7	16.0
3. I was affected.	5.7	4.0
4. My husband/wife were affected.	2.3	8.0
5. It affected the siblings.	32.3	12.0
6. A family member left home.	2.3	-
7. The siblings became closer to each other or more responsible.	2.3	12.0
Total	100.0	100.0
	N=87	N=25

Table 49A

Frequencies of parents' answers to the question: "Do you think that there are differences in daily life between your family and families without a mentally handicapped child?" by child's birth order (in percentages)

Answer	First Born	Second Born	3 - 6 Born
1. There are no differences.	27.0	33.6	25.6
2. Not very much, you have to devote more time to the child.	13.5	5.5	7.6
3. Not now because the other children are young or old.	13.5	5.5	-
4. Yes, its like having a baby all the time.	18.9	19.4	28.5
5. Outside activities are more difficult, we are limited, isolated spend more money on the child.	27.1	30.5	30.7
6. We are closer to each other.	-	5.5	7.6
Total	100.0	100.0	100.0
	N=37	N=36	N=39

Table 50A

Frequencies of parents' answers to the question: "Is there any particular member of your family who has been affected?" by child's birth order (in percentages)

Answer	First Born	Second Born	3 - 6 Born
1. No.	54.1	50.3	43.5
2. No. They are old enough or too young.	13.5	5.5	5.1
3. I was affected.	2.7	-	12.8
4. My husband/wife were affected.	-	2.7	7.5
5. It affected the siblings.	21.6	33.3	28.5
6. A family member left home.	-	5.5	-
7. The siblings became closer to each other or more responsible.	8.1	2.7	2.5
Total	100.0	100.0	100.0
	N=37	N=36	N=39

Table 51A

Frequencies of parents' answers to the question: "Is there any particular member of your family who has been affected?" by parents' level of formal education (in percentages)

Answer	Under Matric	Matric and Post
1. No.	58.2	37.6
2. No. They are old enough or too young.	4.9	11.7
3. I was affected.	4.9	5.8
4. My husband/wife were affected.	1.6	5.8
5. It affected the siblings.	22.9	33.3
6. A family member left home.	-	3.9
7. The siblings became closer to each other or more responsible.	6.5	1.9
Total	100.0	100.0
	N=67	N=67

Table 52A

Frequencies of mothers' answers to the question: "Do you think that there are differences in daily life between your family and families without a mentally handicapped child?" by mothers' occupation (in percentages)

Answer	Working Mothers	House-wives
1. There are no differences.	39.4	21.2
2. Not very much, you have to devote more time to the child.	4.3	12.2
3. Not now because the other children are young or old.	6.5	6.1
4. Yes, its like having a baby all the time.	17.3	25.7
5. Outside activities are more difficult, we are limited, isolated spend more money on the child.	21.7	34.8
6. We are closer to each other.	10.8	-
Total	100.0	100.0
	N=23	N=33

Table 53A

Frequencies of fathers' answers to the question: "If you do not have special problems or needs, give reasons for your answer?" by fathers' occupation (in percentages)

Answer	High Skilled	Low Skilled
1. We have problems or needs.	40.5	40.0
2. We try to lead a normal life.	35.1	16.7
3. It hasn't changed our life, we are like any other family.	18.9	43.3
4. Not yet, the child is still young.	5.5	-
Total	100.0	100.0
	N=36	N=12

Table 54A

Frequencies of parents' answers to the question: "Do you think that there are differences in daily life between your family and families without a mentally handicapped child?" by having a mentally retarded relative (in percentages)

Answer	A M.R. relative	No M.R. relative
1. There are no differences.	27.2	28.8
2. Not very much, you have to devote more time to the child.	4.5	10.3
3. Not now because the other children are young or old.	9.3	5.5
4. Yes, its like having a baby all the time.	22.7	22.2
5. Outside activities are more difficult. We are limited, isolated spend more money on the child.	36.3	27.7
6. We are closer to each other.	-	5.5
Total	100.0	100.0
	N=22	N=90

Table 55A

Means, SD, Df, and Probabilities for mothers versus fathers according to Scales 5, 14 of the QRS (t test)

	Mothers				Fathers			
	Mean	SD	Df	P	Mean	SD	Df	P
5. Lack of social support.	3.7	1.4	108	0.9	3.7	1.4	104	0.9
14. Social obtrusiveness.	2.2	1.2	110	0.8	2.1	0.9	109.2	0.9
	N=60				N=52			

Table 56A

Means, SD, Df, and Probabilities for mothers A versus fathers A according to Scales 5, 14 of the QRS (t test)

	Mothers A				Fathers A			
	Mean	SD	Df	P	Mean	SD	Df	P
5. Lack of social support.	4.0	0.9	55	0.7	4.1	1.2	48.6	0.7
14. Social obtrusiveness.	2.4	1.2	56	0.6	2.3	0.9	53.3	0.6
	N=30				N=30			

Table 57A

Means, SD, Df, and Probabilities for mothers B versus fathers B according to Scales 5, 14 of the QRS (t test)

	Mothers B				Fathers B			
	Mean	SD	Df	P	Mean	SD	Df	P
5. Lack of social support.	3.4	1.7	51	0.7	3.3	1.5	50.2	0.7
14. Social obtrusiveness.	1.9	1.2	52	0.9	1.9	1.0	51.7	0.9
	N=30				N=24			

Table 58A

Frequencies of parents' opinions about their relationships with relatives, by Groups A & B (in percentages)

Opinion	A	B
1. We have no relatives or no relationships with our relatives.	10.2	15.3
2. It doesn't affect our relationships.	36.6	50.2
3. They accepted the child and helped us.	28.3	17.3
4. We became closer.	8.3	3.8
5. Some relatives cannot accept the child.	16.6	13.4
Total	100.0	100.0
	N=58	N=54

Table 59A

Frequencies of parents' opinions about their relationships with their neighbours, by mothers versus fathers (in percentages)

Opinion	Mothers	Fathers
1. We have no relationships with them.	31.6	23.2
2. We have problems with them.	16.6	11.5
3. They have got used to the child.	23.3	38.4
4. They have accepted us and are helpful.	28.5	26.9
Total	100.0	100.0
	N=60	N=52

Table 60A

Frequencies of parents' opinions about their relationships with relatives, by cause of mental retardation (in percentages)

Opinion	Unknown	Genetic Disorders	Brain Damage
1. We have no relatives or no relationships with our relatives.	11.3	19.5	8.3
2. It doesn't affect our relationships.	44.4	36.5	52.7
3. They accepted the child and helped us.	27.7	24.3	13.8
4. We became closer.	-	12.2	2.7
5. Some relatives cannot accept the child	16.6	7.5	22.5
Total	100.0	100.0	
	N=18	N=41	N=36

Table 61A

Frequencies of parents' opinions about their relationships with neighbours, by cause of mental retardation (in percentages)

Opinion	Unknown	Genetic Disorders	Brain Damage
1. We have no relationships with them.	38.8	21.9	27.7
2. We have problems with them.	22.2	7.5	16.6
3. They have got used to the child.	27.7	41.4	30.5
4. They have accepted us and are helpful.	11.3	29.2	25.2
Total	100.0	100.0	100.0
	N=18	N=47	N=36

Table 62A

Frequencies of parents' opinions about their relationships with neighbours, by child's birth order (in percentages)

Opinion	First Born	Second Born	3 - 6 Born
1. We have no relationships with them.	27.1	26.3	20.5
2. We have problems with them.	8.1	13.8	20.5
3. They have got used to the child.	46.9	30.5	15.5
4. They have accepted us and are helpful	18.9	19.4	43.5
Total	100.0	100.0	100.0
	N=37	N=36	N=39

Table 63A

Frequencies of parents' opinions about their relationships with friends, by their level of formal education (in percentages)

Opinion	Under Matric	Matric and Post
1. We are not so social, have not got *many* friends.	31.1	23.5
2. Some friends have left us because of the child.	8.2	15.6
3. I don't like our friends' attitude towards us.	-	3.9
4. It hasn't affected our relationships.	36.2	31.6
5. They have accepted the child.	24.5	25.4
Total	100.0	100.0
	N=61	N=51

Table 64A

Frequencies of parents' opinions about their relationships with their neighbours, by their level of formal education (in percentages)

Opinion	Under Matric	Matric and Post
1. We have no relationships with them.	32.7	21.5
2. We have problems with them.	19.7	7.8
3. They have got used to the child.	26.3	35.2
4. They have accepted us and are helpful.	21.3	35.5
Total	100.0	100.0
	N=61	N=61

Table 65A

Frequencies of mothers' opinions about their relationships with friends, housewives versus working mothers (in percentages)

Opinion	Working Mothers	Housewives
1. We are not so social, have not got *many* friends.	19.5	33.3
2. Some friends have left us because of the child.	17.5	7.5
3. I don't like our friends' attitude towards us.	-	3.3
4. It hasn't affected our relationships.	32.6	34.8
5. They have accepted the child.	30.4	21.1
Total	100.0	100.0
	N=23	N=33

Table 66A

Frequencies of fathers' opinions about their relationships with friends, by their occupation (in percentages)

Opinion	Highly Skilled	Lower Skilled
1. We are not so social, have not got many friends.	20.4	40.2
2. Some friends have left us because of the child.	13.5	6.6
3. I don't like our friends' attitude towards us.	2.7	-
4. It hasn't affected our relationships.	37.8	26.6
5. They have accepted the child.	25.6	26.6
Total	100.0	100.0
	N=36	N=12

Table 67A

Frequencies of parents' opinions about their relationships with their neighbours, by their religious background (in percentages)

Opinion	Catholics	Protestants	Jews
1. We have no relationships with them.	31.5	26.7	33.3
2. We have problems with them.	15.7	15.4	11.1
3. They have got used to the child.	26.3	28.4	44.4
4. They have accepted us and are helpful.	26.5	29.5	11.2
Total	100.0	100.0	100.0
	N=19	N=71	N=18

Table 68A

Frequencies of parents' opinions about their relationships with relatives, by having another mentally retarded relative (in percentages)

Opinion	Another M.R Relative	No M.R. Relative
1. We have no relatives or no relationships with our relatives.	9.0	13.6
2. It doesn't affect our relationships.	63.6	37.7
3. They accepted the child and helped us.	9.3	26.6
4. We became closer.	-	7.7
5. Some relatives cannot accept the child.	18.1	14.4
Total	100.0	100.0
	N=22	N=90

Table 69A

Frequencies of fathers' opinions about their relationships with friends, by having another mentally retarded relative (in percentages)

Opinion	Another M.R. Relative	No M.R. Relative
1. We are not so social, have not got many friends.	22.7	28.8
2. Some friends have left us because of the child.	-	14.4
3. I don't like our friends' attitude towards us.	4.5	1.4
4. It hasn't affected our relationships.	54.5	28.8
5. They have accepted the child.	18.3	26.6
Total	100.0	100.0
	N=22	N=90

Table 70A

Frequencies of parents' opinions about their relationships with their neighbours, by having another mentally retarded relative (in percentages)

Opinion	Another M.R. Relative	No M.R. Relative
1. We have no relationships with them.	22.7	28.8
2. We have problems with them.	13.6	14.4
3. They have got used to the child.	50.1	25.5
4. They have accepted us and are helpful.	13.6	31.3
Total	100.0	100.0
	N=22	N=90

Table 71A

Frequencies of answers to the question: "If there are not enough services what kind of services should be available in order to help you?" by groups A & B (in percentages)

Opinion	A	B
1. Yes, there are enough services.	60.4	38.9
2. There is a need for more information.	13.8	18.5
3. More schools and government support are needed.	15.5	14.8
4. More residential services for adults.	-	24.1
5. More services for parents.	10.3	3.7
Total	100.0	100.0
	N=58	N=54

Table 72A

Frequencies of answers to the question: "Did you seek *any professional* help for your family?" by groups A & B (in percentages)

Answer	A	B
1. No.	68.9	77.7
2. There was no need.	10.3	-
3. We couldn't get help when asked.	-	5.6
4. We were helped.	20.7	16.7
Total	100.0	100.0
	N=58	N=54

Table 73A

Frequencies of parents' initial contacts with professionals mothers versus fathers (in percentages)

Time of First Contact	Mothers	Fathers
1. From birth, from the time I knew about the problem.	36.6	28.8
2. We tried to get help but couldn't get it immediately.	11.6	23.4
3. When the child was 1-2 yrs old.	10.2	7.6
4. When the child was 3-4 yrs old.	30.0	21.1
5. When the child was 6 or more years old.	10.0	15.3
6. We haven't asked for professional help (only the day centre)	1.6	3.8
Total	100.0	100.0
	N=60	N=52

Table 74A

Frequencies of parents' *opinions about* the availability of services in their community, mothers versus fathers (in percentages)

Opinion	Mothers	Fathers
1. Yes. There are enough services.	63.3	65.3
2. No. There are *not enough services.*	31.6	30.9
3. I don't know.	5.1	3.8
Total	100.0	100.0
	N=60	N=52

Table 75A

Frequencies of answers to the question: "Did you seek any professional help for your family?" mothers versus fathers (in percentages)

Answer	Mothers	Fathers
1. No.	68.3	78.8
2. There was no need.	6.6	3.8
3. We couldn't get help when asked.	3.5	1.9
4. We were helped.	21.6	15.5
Total	100.0	100.0
	N=60	N=52

Table 76A

Frequencies of answers to the question: "Would you consider using professional help for your family, in the future?" by child's sex (in percentages)

Answer	Males's Parents	Female's Parents
1. There will be no need.	75.7	58.7
2. I hope not. We will be helped by the family.	3.2	4.3
3. If it is needed.	13.6	17.3
4. Yes, definitely.	7.5	19.7
Total	100.0	100.0
	N=66	N=46

Table 77A

Frequencies of parents' initial contacts with professionals by cause for child's mental retardation (in percentages)

Time of First Contact	Unknown	Genetic Disorders	Brain Damage
1. From birth, from the time I knew about the problem.	11.1	41.7	28.0
2. We tried to get help but couldn't get it immediately.	22.2	9.7	28.1
3. When the child was 1-2 yrs old.	16.6	7.3	11.1
4. When the child was 3-4 yrs old.	38.8	24.3	27.7
5. When the child was 6 or more years old.	11.3	12.2	11.1
6. We haven't asked for professional help (only the day centre)	-	4.8	-
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Table 78A

Frequencies of answers to the question: "Would you consider using professional help for your family, in the future?" by cause for child's mental retardation (in percentages)

Answer	Unknown	Genetic Disorders	Brain Damage
1. There will be no need.	72.4	68.4	58.3
2. I hope not. We will be helped by the family.	5.5	2.4	5.5
3. If it is needed.	16.6	9.7	27.7
4. Yes, definitely.	5.5	19.5	8.5
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Table 79A

Frequencies of parents' initial contacts with professionals by child's physical condition (in percentages)

Time of First Contact	Generally Good	Generally Fair
1. From birth, from the time I knew about the problem.	27.5	52.0
2. We tried to get help but couldn't get it immediately.	-	12.0
3. When the child was 1-2 yrs old.	-	4.0
4. When the child was 3-4 yrs old.	2.	16.0
5. When the child was 6 or more years old.	11.4	16.0
6. We haven't asked for professional help (only the day centre)	3.4	-
Total	100.0	100.0
	N=87	N=25

Table 80A

Frequencies of answers to the question: "If there are not enough services, what kind of services should be available in order to help you?" by child's physical condition (in percentages)

Opinion	Generally Good	Generally Fair
1 There are enough services.	56.3	40.0
2. There is a need for more information.	9.3	20.0
3. More schools and support from the government are needed.	12.6	32.0
4. More residential services for adults.	14.9	4.0
5. More services for parents	6.9	4.0
Total	100.0	100.0
	N=87	N=25

Table 81A

Frequencies of answers to the question: "If there are not enough services, what kind of services should be available in order to help you?" by child's birth order (in percentages)

Answer	First Born	Second Born	3 - 6 Born
1. There are enough services.	59.5	50.0	48.7
2. There is a need for more information.	22.7	16.7	15.6
3. More schools and support from the government are needed.	24.3	13.8	12.8
4. More residential services for adults.	10.8	11.2	15.3
5. More services for parents	2.7	8.3	7.6
Total	100.0	100.0	100.0
	N=37	N=36	N=39

Table 82A

Frequencies of answers to the question: "Did you seek any professional help for your family?" by child's birth order (in percentages)

Answer	First Born	Second Born	3 - 6 Born
1. No.	70.2	83.4	66.9
2. There was no need.	8.2	-	7.6
3. We couldn't get help when asked.	-	-	7.6
4. We were helped.	21.6	16.6	17.9
Total	100.0	100.0	100.0
	N=37	N=36	N=39

Table 83A

Frequencies of answers to the question: "If there are not enough services, what kind of services should be available in order to help you?" by parents' level of formal education (in percentages)

Opinion	Under Matric	Matric and Post
1. There are enough services.	54.1	50.9
2. There is a need for more information.	11.4	11.7
3. More schools and support from the government are needed.	13.3	2..5
4. More residential services for adults.	16.3	8.1
5. More services for parents	4.9	7.8
Total	100.0	100.0
	N=67	N=51

Table 84A

Frequencies of mothers' answers to the question: "If there are not enough services, what kind of services should be available in order to help you?" working mothers versus housewives (in percentages)

Answer	Working Mothers	Housewives
1. There are enough services.	56.5	50.0
2. There is a need for more information.	10.8	12.2
3. More schools and support from the government are needed.	13.2	19.7
4. More residential services for adults.	15.2	10.6
5. More services for parents	4.3	7.5
Total	100.0	100.0
	N=23	N=33

Table 85A

Frequencies of mothers' answers to the question: "Would you consider using professional help for your family, in the future?" working mothers versus housewives (in percentages)

Answer	Working Mothers	Housewives
1. There will be no need.	71.7	66.6
2. I hope not. We will be helped by the family.	2.3	4.5
3. If it is needed.	17.3	13.6
4. Yes, definitely.	8.7	15.3
Total	100.0	100.0
	N=23	N=33

Table 86A

Frequencies of fathers' answers to the question: "If there are not enough services, what kind of services should be available in order to help you?" by fathers' occupation (in percentages)

Answer	Highly Skilled	Lower Skilled
1. There are enough services.	64.2	50.0
2. There is a need for more information.	10.8	16.6
3. More schools and support from the government are needed.	20.2	13.3
4. More residential services for adults.	9.4	10.1
5. More services for parents	5.4	10.0
Total	100.0	100.0
	N=36	N=12

Table 87A

Frequencies of parents' opinions about the availability of services in their community, by their religious background (in percentages)

Opinion	Catho-lics	Protes-tants	Jews
1. Yes, there are enough services.	94.7	53.6	66.7
2. No, there are not enough services.	-	40.8	33.3
3. I don't know.	5.3	5.6	-
Total	100.0	100.0	100.0
	N=19	N=71	N=18

Table 88A

Frequencies of answers to the question: "If there are not enough services, what kind of services should be available in order to help you?" by having another mentally retarded relative (in percentages)

Answer	Another M.R. relative	No M.R. relative
1. There are enough services.	50.0	53.6
2. There is a need for more information.	22.7	8.8
3. More schools and support from the government are needed.	18.1	16.6
4. More residential services for adults.	9.2	13.3
5. More services for parents	-	7.7
Total	100.0	100.0
	N=22	N=90

Table 89A

Frequencies of answers to the question: Has a particular member of the family had any professional help"? by another mentally retarded relative (in percentages.)

Answer	Another M.R. relative	No M.R. relative
1. No. It was not needed.	59.0	67.7
2. We could help him by ourselves.	9.3	12.5
3. The other children are too young.	4.5	8.8
4. The member in need of help left home.	4.5	2.2
5. Yes. A particular member of the family had professional help.	22.7	8.8
Total	100.0	100.0
	N=22	N=90

Table 90A

Frequencies of answers to the question: "Did you take any practical steps for the child's future?" by groups A & B (in percentages)

Answer	A	B
1. No.	74.1	68.5
2. We are saving money for the child's future.	20.7	16.7
3. The child's name is on a waiting list for a "home".	5.2	14.8
Total	100.0	100.0
	N=58	N=54

Table 91A

Means, SD, Df, and Probabilities for scales 12, 13 of the QRS, Mothers A versus Mothers B (t test)

Scale	Mothers A				Mothers B			
	Mean	SD	Df	P	Mean	SD	Df	P
12. Lack of activities	1.3	1.4	52.8	0.1	2.1	1.8	53.8	0.1
13. Occupational limitations	2.7	2	53.8	0.1	4.1	1.2	57.0	0.1
		N=30				N=30		

Table 92A

Means, SD, Df, and Probabilities for scales 12, 13 of the QRS, Fathers A versus Fathers B (t test)

Scale	Fathers A				Fathers B			
	Mean	SD	Df	P	Mean	SD	Df	P
12. Lack of activities	0.9	1.0	32.9	0.006	2.1	1.8	46.0	0.006
13. Occupational limitations	3.5	1.1	46.0	0.004	4.4	0.9	46.0	0.004
		N=28				N=24		

Table 93A

Means, SD, Df, and Probabilities for scales 12, 13 of the QRS; a comparison between mothers and fathers within groups A & B (t test)

	Group A								Group B							
	Mothers				Fathers				Mothers				Fathers			
Scale	Mean	SD	Df	P	Mean	SD	Df	P	Mean	SD	Df	P	Mean	SD	Df	P
12. Lack of activities	1.3	1.4	58	0.2	0.9	1.0	52.1	0.1	2.1	1.8	50	0.9	2.1	1.8	47	0.9
13. Occupational limitations	3.7	1.0	54	0.5	3.5	1.1	50.6	0.5	4.1	1.2	49	0.3	4.4	0.9	49	0.3
	N=30				N=28				N=30				N=24			

Table 94A

Frequencies of answers to the question: "Did you take any practical steps for the child's future?" mothers versus fathers (in percentages)

Answer	Mothers	Fathers
1. No.	76.6	65.3
2. We are saving money for the child's future.	13.5	25.2
3. The child's name is on a waiting list for a "home".	9.9	9.5
Total	100.0	100.0
	N=60	N=62

Table 95A

Frequencies of parents' plans for the child's future by child's sex (in percentages)

Parent's plan	Male's Parents	Female's Parents
1. No specific plans.	28.7	32.6
2. I hope the child will be able to go to a "normal" school.	3.3	-
3. I want to keep the child at home.	16.6	30.4
4. I want my family to care for the child.	7.5	13.1
5. I want to place the child in a "home".	43.9	23.9
Total	100.0	100.0
	N=66	N=46

Table 96A

Frequencies of answers to the question: "When do you intend to take practical steps in regard to *your child's future*?" by cause of child's mental retardation (in percentages)

Answer	Unknown	Genetic Disorders	Brain Damage
1. It's too early to tell.	44.4	31.7	25.0
2. When the child is 7-8 yrs. old.	5.5	-	13.8
3. When it becomes impossible to keep the child at home.	16.6	41.6	36.1
4. When the Hostel (Hamlet) will be ready.	22.2	4.8	-
5. We have already taken practical steps.	11.3	21.9	25.1
Total	100.0	100.0	100.0
	N=18	N=91	N=36

Table 97A

Frequencies of answers to the question: "Did you take any practical steps for the child's future?" by child's physical condition *(in percentages)*

Answer	Generally Good	Generally Fair
1. No.	70.2	76.0
2. We are saving money for the child's future.	18.3	20.0
3. The child's name is on a waiting list for a "home".	11.5	4.0
Total	100.0	100.0
	N=87	N=25

Table 98A

Frequencies of parents' plans for the child's future by child's birth order (in percentages)

Parent's plan	First born	Second born	3 - 6 born
1. No specific plans.	32.6	41.6	17.9
2. I hope the child will be able to go to a "normal" school.	-	-	5.3
3. I want to keep the child at home.	45.9	8.5	12.8
4. I want my family to care for the child.	2.7	13.8	12.8
5. I want to place the child in a "home".	18.9	36.1	51.2
Total	100.0	100.0	100.0
	N=37	N=36	N=39

Table 99A

Frequencies of answers to the question: "Did you take any practical steps for the child's future?" by parents' level of formal education (in percentages)

Answer	Under Matric	Matric and Post
1. No.	80.3	60.7
2. We are saving money for the child's future.	13.2	25.4
3. The child's name is on a waiting list for a "home".	6.5	13.9
Total	100.0	100.0
	N=61	N=51

Table 100A

Frequencies of mothers' answers to the question: "Are you worried about your child's future?" working mothers versus housewives (in percentages)

Answer	Working Mothers	Housewives
1. No.	10.8	22.7
2. Sometimes, not very much.	39.1	13.6
3. Yes.	50.1	63.7
Total	100.0	100.0
	N=23	N=33

Table 101A

Frequencies of fathers' answers to the question: "Did you take any practical steps for your child's future?" by fathers' occupational category (in percentages)

Answer	Highly Skilled	Lower Skilled
1. No.	70.2	70.0
2. We are saving money for the child's future.	18.9	20.0
3. The child's name is on a waiting list for a "home".	10.9	10.0
Total	100.0	100.0
	N=36	N=12

Table 102A

Frequencies of answers to the question: "Are you worried about your your child's future?" by parents' religious background (in percentages)

Answer	Catholics	Protes-tants	Jews
1. No.	21.1	16.9	16.6
2. Sometimes, not very much.	21.1	25.4	22.2
3. Yes.	57.8	57.7	61.2
Total	100.0	100.0	100.0
	N=19	N=71	N=18

Table 103A

Frequencies of answers to the question: "Are you worried about your child's future?" by having another mentally retarded relative (in percentages)

Answer	Another M.R. Relative	No M.R. Relative
1. No.	18.1	17.9
2. Sometimes, not very much.	27.2	23.3
3. Yes.	54.7	58.8
Total	100.0	100.0
	N=22	N=90

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Author Berzon Miriam
Name of thesis Development of lifestyle and coping patterns in families of mentally handicapped children. 1987

PUBLISHER:
University of the Witwatersrand, Johannesburg
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