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DEVELOPMENT OF LIFESTYLE AND COPING PATTERNS IN FAMILIES OF MENTALLY HANDICAPPED CHILDREN

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A thesis submitted to the Faculty of Arts, University of the Witwatersrand, Johannesburg in fulfillment of the requirements for the degree of Doctor of Philosophy.

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ABSTRACT

The development of lifestyle and coping patterns in families with a mentally handicapped child is the subject of this study.

More specifically, four main issues have been explored:

a. Parental process of adaptation to having a mentally handicapped child.

b. Parents' willingness to acknowledge the influence of the child on the family as a whole, and/or on a particular member of it.

c. The impact of the mentally handicapped child on his parents' relationships with community support networks (relatives, friends, neighbours and professionals).

d. Parents' attitudes and plans in regard to the mentally handicapped child's future.

A descriptive longitudinal cross-sectional design was adopted to facilitate analyzing the long-term impact of the mentally retarded child on the development of his family lifestyle and the parents' coping patterns.

Two groups of parents were identified according to the age of the mentally retarded child. Group A consisted of thirty couples with a pre-schoo[illegible]hild (aged two to six) and group B which comprised thirty [illegible]ples with a mentally retarded adolescent or young adult (aged 16-30).

Mothers and fathers were interviewed separately by the researcher, who used two research tools: the Questionnaire on Resources and Stress and a specially designed interview schedule.

Comparisons were made between the two groups of parents (i.e. the parents of the younger and the older children) and for mothers versus fathers. The influences of child and family characteristics on parents' opinions in regard to the four main areas of the research study were explored.

While many of the study findings served to confirm the results of earlier investigations, they, in addition, provided data for the researcher to postulate a longitudinal model to illuminate the process of family adaptation to the presence of a mentally handicapped child. Thus, on the basis of the findings and in the light of earlier theory proposed by past researchers, the writer advances a model which combines McCubbin and Pattersons double ABCX framework (1983) and Blacher's stages formula (1984).

The new combined model suggests three phases through which parents of a mentally handicapped child have to pass in the process of adapting to having such a child.

Firstly, the initial crisis response. Results of the research study reveal that the presentation into the family system of the mentally handicapped child was such a stressor event that existing resources could not avoid a severe crisis for the majority of the parents. Shock and disbelief, which were the most common feelings amongst parents, represent their severe emotional situation at this initial stage. Although as already mentioned, parents' initial reactions were similar, their ability to overcome the acute crisis differed.

The second phase seems to start when the parents begin to assimilate the reality of their child's problem and to develop a more realistic approach to the situation. This may be considered as their first attempt to accomodate to the new demands. Such an approach creates a change in parents' feelings: from shock and disbelief, to anger, disappointment and guilt feelings or denial. Thus, parents who overcame the initial crisis still tended to deny

the reality of the child's problem by believing in his 'cure'. Moreover, the parents of the younger children (compared to the parents of the older ones) tended to deny the impact of the child on their family as a whole, or on a particular member of it. However, the recognition at this stage of the full meaning of the child's problem facilitated the growth and development of parental coping patterns and thereby enabling the parents to achieve a certain degree of adaptation (phase three - adjustment and acceptance).

The findings of this study have revealed what appears to be a sequential linkage between parental coping patterns. It was found that parents of adolescents and young adults who already perceived the reality of the child's problem, were also aware of its impact on the family as a whole. In an attempt to meet the child's special needs, a reorganization of roles and expansion of tasks occurs in the family in order to meet these needs. The family comes to increasingly perceive the importance of social support networks and when these services are not available in the community, a process of the stresses and strains occurs in the family. These are reflected among other things in the parents' attitudes towards using professional help. For instance, unsatisfactory social and health services affects parents' attitudes towards the child's future and their ability to plan realistically for it. Although it was found that the majority of the parents expressed worry in regard to the child's future, only a small minority take practical steps by saving money or by registering the child for an institution. Planning for the future seemed to exacerbate stress for many parents although the reasons are different according to the child's age. Thus, whatever the child's age they prefer to avoid doing so.

The findings of the study also manifest an apparently sequential linkage from one parental coping pattern to another. Moreover, each coping pattern seems to have an influence on family lifestyle. It was found that the atmosphere in the families of the older children tended to be melancholic and the general attitude to life was pessimistic. The attempt to cope with the child's problem seems to

intensify the family interrelationships. It also stimulates an inward-focus of the family's activities and goals. Moreover, the burden of care for the child which contributed to the development of the foregoing lifestyle characteristics, also influences parents' relationships with the outside world. Being dependent on professional help limits parents' social and geographical mobility. There is also a tendency among the parents of the older children to avoid social contacts.

The study findings also reveal the difficulties that the parents of the older children have in maintaining external relationships. It was found that over the years of rearing the mentally handicapped child within the family, the parents, instead of utilizing external support networks, tend to rely on familial internal resources. This situation probably creates a strengthening of the internal resources. However, at the same time, it limits the parents' ability to accept outsiders' help and support, and thus, increases their feeling of loneliness.

DECLARATION

I declare that this thesis is my own, unaided work. It is being submitted for the Degree of Doctor of Philosophy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in any other University.

Mia Bergan

6 day of April, 1987.

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CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

The impact of mental retardation is never restricted only to mentally retarded individuals. Members of the immediate and extended family are also affected to varying degrees, the effect being both reciprocal and circular in terms of the child and family.

Whilst families are affected by the presence of retarded children so too are the children affected by their families' reactions and responses to the situtation. Indeed, satisfactory emotional development of mentally retarded children may be dependent among other things upon the parents' reactions to them.

An overview of the relevant literature reveals that after a long period of attention focused on the mentally handicapped child himself, shift was recently made towards recognition of the need to study the effects of the child on those who have personal relationships with him, namely his family members.

Existing knowledge on the impact of the mentally retarded child on his family may be obtained from three main sources: 1) studies, diaries, articles and books written by parents of mentally handicapped children (Wilks, 1974; Hannam, 1975; Featherstone, 1980; Boston 1981); 2) clinical observations and experiences; 3) empirical studies (Blacher, 1984).

Data derived from the abovementioned sources may be grouped according to some main characteristics:

a. In many studies the information was obtained only from mothers of mentally retarded children. Fathers and siblings were not included in the samples and the mothers were considered to represent the ideas of the whole family. (Farber, 1960; Cummings et.al., 1966; Kennedy, 1970; Mercer, 1974; Voysey, 1975; Holroyd et.al.,1976; Glendinning, 1983; Beckman, 1983).

b. The focus in the majority of past studies tended to be on the attitudes and reactions of parents of young (pre-adolescent) children (ages 2-16), (Farber, 1960; Fowle, 1968; Hewett et.al., 1970; Gumz and Gubrium, 1972; Voysey, 1975; Friedrich et.al., 1983; Beckman, 1983).

c. Perhaps because dysfunctional families are particularly noticeable in social and health services, much of the literature on families with handicapped children is centred around the catastrophies that can occur in such families. Only a few recent research studies focus attention on parental competence in coping with the described crisis situations. (Hewett et.al., 1970; Voysey, 1975; Patterson and McCubbin, 1983; Kazak et.al., 1984; Zollinger Giele, 1984; Patterson, 1985).

d. The variations which were found in parents' reactions to having a mentally handicapped child led some researchers to classify the various attitudes and patterns of behaviour into clusters each one of them representing certain related parental reactions. These clusters helped to clarify differences between parental reactions which sometimes appeared to be similar for all the parents of mentally retarded children (Farber, 1960; Hutt and Gibby, 1965; Ian Mink et.al., 1983).

e. The clusters, although helping to emphasize the differences in parental reactions to having a mentally handicapped child, did not facilitate dynamic description of the changes in parents' attitudes, once a parent has been classified according to his reactions at a certain defined cluster. Some researchers, however, adapted a developmental approach to this subject and made an attempt to describe the various changes in parental reactions over the years. Most of these studies held the idea that parents' reactions to having a mentally handicapped child represented a stage in their efforts to adjust to the situation. Thus, it was postulated that certain reactions are typical of each particular stage and when analysing these reactions one can

identify the stage in which a particular parent finds himself in an ongoing process towards a certain degree of adaptation. These studies can be seen as the forerunners of a more dynamic developmental approach which, instead of stressing the negative influences of a mentally handicapped child on his family, have tried to positively illuminate parental ways of coping with the situation (Blacher, 1984).

An overview of the various studies, which were classified according to their main characteristics, clearly reveal that while certain issues have received quite a lot of attention, other areas seem to have been neglected:

(a) There are only a few studies in which both parents participated and were separately interviewed.

(b) Even when parents of older children were included, the maximum age of the child was around 20 years. No evidence could be found of a study on the reactions of parents of young adults (above twenty years old) who still live with the family.

(c) "Despite the acknowledged importance of the family, we know relatively little about the functioning of families of retarded children. Perhaps the most critical shortcoming is the lack of prospective longitudinal investigations detailing familial adaptation and functioning from the time at which retarded children are identified" (Crnic et.al., 1983, p.125). In spite of the development of certain research tools for measuring stress and coping patterns in families with an exceptional child (Holroyd, 1974; Patterson and McCubbin, 1982) it seems as if these research tools have not yet been used in studies designed to measure the lifelong impact of the mentally retarded child on his parents.

The present study was designed as an attempt to fill the above described void in this particular area. Its overall and specific aims will be discussed in the following section of this chapter.

1.2 AIMS OF THE STUDY

The overall aim of this research study is to investigate the long-term impact of a mentally retarded child on the development of parental coping patterns, and on the lifestyle of his family. In an attempt to systematically investigate this overall aim, special attention was invested in the following areas:

(a) The stages in the process of parental adaptation to the stressful event of having a mentally handicapped child.

(b) Parental acceptance of familial special needs or problems resulting from having a mentally retarded family member.

(c) The impact of the mentally retarded child on his parents' reciprocal relationships with familial, informal and formal social supportive networks.

(d) The nature of parents' attitudes and practical plans for the mentally retarded child's future.

It was suspected that a relationship exists between the age of the mentally retarded child, the reactions and behaviour of his family and the ways in which the child is treated. Families with mentally retarded toddlers and pre-school children were suspected to be in a stressful crisis situation. This situation may change over the years towards increasing adaptability to the fact of having such a child.

The decision about research methods must be related, of course, to the aims and assumptions of the particular study. In addition, the theoretical concepts on which the study is based must be taken into consideration. In the following section of this chapter, two relevant issues will be briefly discussed:

* Characteristics of moderately retarded children, adolescents and adults;

* *The family lifecycle.*

1.3 THEORETICAL CONCEPTS FOR STUDYING FAMILIES OF MENTALLY HANDICAPPED CHILDREN

1.3.1 Characteristics of moderately retarded children, adolescents and young adults

In order to discuss some of the characteristics of the moderately retarded child, adolescent and young adult, and the implications of such children for parents, some basic concepts in the field of mental retardation must be defined.

(a) Mental Retardation

The term is used to refer to a variety of physical and mental conditions. However, there is lack of agreement throughout the world regarding the designation of persons who are mentally handicapped. This confusion applies to the collective term for mental retardation as well as to the terms for its different levels. For instance the terms "mentally deficient", "mentally handicapped", "mentally subnormal", "mentally retarded", "feeble minded" etc. are mentioned when referring to the total group whose intelligence quotient falls under a certain defined level. (Report of the Committee of Inquiry into the case of mentally deficient persons, 1967).

The most widely used definition of mental retardation was published in 1977 by the American Association on Mental Deficiency. Mental retardation according to the AAMD definition "refers to significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period" (The upper age of the developmental period is set at eighteen).

The most common British definition, based on the Mental Health Act of 1959, refers to severe subnormality (rather

than mental retardation) which is described as a state of arrested or incomplete development of mind which includes subnormality of intelligence and is of such a nature and degree that the patient is incapable of leading an independent life or of guarding himself against serious exploitation or will be incapable when of an age to do so." Less severe retardation is referred to as subnormality defined as a condition "which includes subnormality of intelligence and is of a nature or degree which requires or is susceptible to medical treatment or other special care or training of the patient" (Edgerton, 1979, p.12).

In South Africa, the term Mental Retardation refers to a specific and limited aspect of the man's mental function as specifically defined in the Report of the Commission of Inquiry on Mental Handicap, (1965): "A mentally handicapped person is someone who by reason of an arrested or incomplete development of mind has a marked lack of intelligence and either temporarily or permanently inadequate adaptation to his environment". This definition presupposes that there are three essential features of mental handicap, namely: 1) arrested or incomplete development of mind; 2) a marked lack of intelligence; and 3) inadequate adaptation to the environment.

It presupposes too that the characteristics of mental handicap are not necessarily all permanent. It is well known that in the general sense in which the concept is used, no cure for a mind which has not developed adequately, nor for a marked lack of intelligence can be expected. Nevertheless, it is an accepted fact that many of these mentally handicapped persons (especially the subnormal ones) overcome their handicaps to such an extent that they are able to adapt themselves to their environment reasonably well. (The Committee of Inquiry into the care of Mentally Deficient Persons, 1967).

(b) Types and levels of retardation

There are systems of classification based on symptoms and others based on causation, but the most widely used classification refers to the severity of the intellectual handicap. According to the AAMD system which is used throughout the world, the following categories exist:

mild retardation (IQ 55-69) moderate retardation (IQ 40-54) severe retardation (IQ 25-39) and profound retardation (IQ less than 25) (Edgerton, 1979). The differences in opinion regarding the grading of intelligence levels depend on the tests used, the subjective opinion of the person making the assessment and some other factors. In South Africa the following classification (based on the tests used by the National Bureau of Educational and Social Research) was suggested by the Committee of Inquiry into the care of Mentally Deficient persons, (1967): "Our definition of mental handicap applies to the group of children with IQ's that fall between 0 and approximately 79. The IQ's of the mentally deficients fall between 0 and approximately 49. In other words all mental deficients are mentally handicapped but only some mentally handicapped children are mentally deficient" (p.2). The classification of intelligence according to the abovementioned Committee was: Subnormal (50-79) Imbecile (25-49) Idiot (0-24). However, today in South Africa the AAMD classification is commonly used by professionals in the field of mental retardation. It must be kept in mind that classifications based on IQ levels, although most commonly used, represent only a specific aspect which does not always have the same meaning for different individuals. Thus, another classification is suggested by the Committee (1967). This classification is based on habilitation possibilities of the individual.

However, not all mentally deficient children can be educated or trained. There are children with higher IQ's who are unable to profit by the scholastic training provided by

special schools. These children are classified as "trainable" rather than "educable". The Committee report (1967) states: "When the term "trainable child" is used, it has a definitive meaning that implies different aims from those involved in so-called "educable children", whose educational objectives are linked up with the learning of subject matter of a more academic nature" (p.4).

(c) Pathological causes

Another classification of the AAMD which has been widely accepted is the medical classification system based on physical and aetiological factors. The categories are as follows:

(i) Retardation caused by infection

(ii) Retardation associated with disease or intoxication

(iii) Retardation associated with trauma or a physical agent

(iv) Retardation associated with disorders of metabolism

(v) Retardation associated with growth

(vi) Retardation associated with prenatal condition (Hutt and Gibby (1965).

A category relating to the time of the occurrence of the condition is another way of identifying factors related to cause. The three categories are:

(i) Prenatal factors (Infections, Drugs, Radiation Genetics, Metabolism)

(ii) Perinatal factors (Prematurity, Complications of labour and delivery)

(iii) Postnatal factors (Acute illness, Trauma, Progressive disorders, Lead poisoning, Deprived environment) (Fleming, 1973).

Finally, it should be noted that it is not always possible to identify a specific biological aetiology for a clinically retarded child. There are still many cases where the determining cause is difficult to identify and even after a careful clinical assessment, tests and observations, the cause remains unknown.

(d) Incidence and Prevalence

It is not possible to give an accurate account of mental retardation due to the difficulties involved in making a definite diagnosis of this condition early in a child's life. However it has been accepted that most cases of severe mental retardation should normally have come to light by the ages of fifteen - nineteen years and that their total number then closely approximates to the true prevalence of that condition. In England, surveys which were done in 1977 suggest that the prevalence rate for all ages is between two and three per thousand (Heaton Ward, 1977). Mercer (1966) found the following rates in her case finding survey: ages 0-4, 0.7 percent; ages 5-9, 0.54 percent; ages 10-15, 1.15 percent; ages 15-19, 1.61 percent; ages 20-24, 0.90 percent; ages above 25, 0.13 percent. The Committee of Inquiry into the care of Mentally Deficient Persons (1967) estimated the number of mentally retarded persons who are six years old and over as three to four per thousand. The total number was between 10,608 - 14,144 mentally deficient whites. Using their estimation means that if the white population in 1984 was approximately 4,500,000, then the estimated number of mentally deficient whites will be between 13,500 - 18,000 persons. In 1967 only 5,516 persons have been formally traced and the Committee states that "the fact must be faced that the actual number of mentally deficient children and adults is far larger than the number known to us" (p.11). Surveys have tended to show a higher prevalence among the male population than among females. The only clearcut diagnostic category possible in most of these surveys was Down's syndrome. The incidence rate of Down's Syndrome in England was 1.8 per 1000 births. In 1971 8.5% of all retarded people in England were Down's Syndrome cases (Heaton-Ward, 1977).

(e) Characteristics of moderately retarded children, adolescents and young adults

Mentally retarded children are not equally deficient in all areas. Not only is there general variability among the children in a certain category, but there is also considerable variability within the same child in terms of various characteristics (Hutt and Gibby, 1965). "As all measurements are based on a continuous dimension, individuals in the upper range of one category are hardly distinguishable from those at the lower level of the next category. Some of the moderately retarded therefore, demonstrate behaviour patterns similar to those of some of the severely retarded, while others more closely approximate the mildly retarded" (Begab, 1963, p.24). In the following section, special attention will be given to the characteristics of the moderately retarded child (as the mentally retarded children of the parents who participated in this study were defined as moderately retarded).

According to Begab (1963) the "average moderately retarded "trainable" or semi-dependent child reflects growth and behavioural characteristics that differ in some respects from the other retarded subgroups. Most of these children can be identified as retarded in infancy or early childhood. Usually the family physician or the mother is first to recognize the lag in development. The young child is slow in learning to walk, has poor motor coordination, minimal speech and little communication skill. As they grow older, if appropriate training is provided, they acquire language and communication abilities and are fairly capable in areas of self-care.

Functional academic skills are generally beyond their capacities, however some have sufficient manual abilities which enable them to contribute towards their self-support

through sheltered employment. "Moderately retarded individuals usually achieve their maximum potential if they learn the basics of self-care, a degree of social behaviour and some semblance of independence under structured supervision" (Fleming, 1973, p.57). "Trainable" persons evidence a wide range of behaviour, sometimes organically induced, at other times functionally determined. For example, where there is brain damage, behaviour is often excitable, unpredictable and difficult to control. Others can be highly tractable and responsive and can be taught acceptable conduct.

When the behavioural characteristics of the moderately retarded child are noticeable, and when in addition the child has physical problems, he might suffer from a lack of self esteem. Generally, the moderately retarded child is capable of developing a self concept; thus it is important to help parents to understand that their attitudes toward the child will affect his feelings about himself (Fleming, 1973). It is difficult for moderately retarded children to reasonably judge their emotional feelings and attitudes towards others. Thus, many of them are self-centred, tend to seek immediate satisfaction and have low tolerance for frustration. The behaviour of moderately retarded adolescents and adults is childlike: some are bedwetters, thumb suckers, some masturbate often or strive constantly for attention.

According to Begab (1963) one of the most pressing of parental concerns is the fear that the moderately retarded adolescent or adult will engage in delinquent behaviour or social misconduct. Actually, moderately retarded persons are seldom involved in crimes and although they are mature in the physical sense they seem to have little interest in the opposite sex. Sometimes gestures of affection are misinterpreted as sexually motivated when engaged in by trainable youngsters and adults.

Begab (1963) concludes his discussion about moderately retarded persons stating: "most significant in cases of successful adjustment was the extent to which parents accepted their retarded child. Those who are given the help they need gain in self confidence, show a greater tolerance for frustration, and evidence a much wider and more constructive interest in the world about them" (Begab, 1963, pp. 27-28).

1.3.2 The Family Lifecycle

One of the most impressive features of family interaction is its complexity and variety. Moreover, family behaviour varies across social-cultural groups and among families within a given demographic category. The family is looked upon also as the basic unit of emotional development where phases can be identified and predicted. Thus, the family developmental approach views the family as a small group system, intricately organized internally into paired positions of husband - father, wife - mother, son - brother and daughter - sister. Norms prescribing the appropriate role behaviour for each of these positions, specify how reciprocal relations are to be maintained, as well as how role behaviour may change with changing ages of the occupants of these positions. This intimate small group has a predictable natural history designated by stages beginning with the simple husband - wife pair and becoming more and more complex as members are added and new positions created.

The family is an arena of interactive personalities each striving to obtain satisfaction of his desires. In some stages of development parents and children are good company, at other stages their diverse developmental strivings may be strikingly incompatible (Hill, 1965).

Within the past generation, the changes in family lifecycle patterns have escalated dramatically, due especially to the

lower birth rate, longer life expectancy, the increasing divorce and remarriage rate, the changing role of women, and immigration. The recent changes in these patterns make the task of defining the normal family lifecycle even more difficult, (McGoldrick and Carter, 1982). Thus, one can find a variety of ideas about the stages occurring in the family lifecycle among various researchers. Among the various ideas, Hill's stages in the family lifecycle stress the parental aspect in family life and therefore will be introduced here. Hill (1965) mentions that of all the children the oldest child's development is the most significant for the shift in role content in the parents' positions since the parents experience new and different problems at each stage of the development of this child. He suggests the following stages:

(a) Establishment (A newly married childless couple)
(b) New parents (Infant 3 years old)
(c) Pre-school family (Child 3-6 years old and possibly younger sibling)
(d) School age family (Older child 6-12 and younger siblings)
(e) Family with adolescent (Oldest child 13-19)
(f) Family with young adult (Oldest child 20, until first child leaves home)
(g) Family as launching centre (From departure of first to last child)
(h) Post-parental family, the middle years (after children have left home until father retires).
(i) Aging family (After retirement of father).

The view of the stages of the family lifecycle as distinctive role complexes makes it possible to anticipate the content of family interaction for each of the stages.

During the first three stages the family tends to be future oriented, living with rapidly expanding needs for shelter space facilities, durable goods and means of transportation. Needs press heavily on resources as the ratio of dependents to earners

mounts and the volume of plans for the future is very high. The willingness to accept help from the outside is also greater at this period. In stages 4-5, the family is more oriented to the here-and-now, achieves some equilibrium of interaction but is still pressed with high needs and inner conflicts resulting from the complicated relationships with the adolescent son or daughter.

In stages 6-7, a slow decline in pressure of needs on resources occurs as the mother can more easily return to work outside the house and sometimes the young adults are also contributing to the family maintenance.

Stages 8-9 are the longest and seem to be considered very problematic. Although in many cases the family at this stage (especially in stage 8) enters into a period of financial recovery, the "empty nest" represents a new situation for the parents who after a long period of raising children have to concentrate again on the husband - wife role. Thus, at this stage the family is mainly oriented to the past, and if the shift from old to new tasks is hard, the parents will try to maintain their old tasks by intervening in the lives of their offspring who are sometimes already married and have their own families. The atmosphere in the family at this stage is characterized as being depressive, unless the elderly couple adjust to the change and a new balance is created. Caplan (1982) adapts Bunlding's ideas, stating: "The family as a unit is continually in transition from one stage of the family cycle to the next, so that it can never be in a static condition. Family life is a swiftly moving series of identity crises as members of various ages are socialized into new roles. In addition to the identity crises that stem from aging and individual pathologies, there are externally-triggered crises. The "group cultures" created by every family unit that lives together through time, provide some security and stability for individual members" (Caplan, 1982, pp. 207-208).

In conclusion, variation in lifestyle of families can be caused by the stages of family development, or social class. Buying patterns, saving patterns and mobility patterns can be expected to vary greatly over the family life span. Internal and external relations and patterns of child rearing are also expected to vary at each stage in the family lifecycle. "We can see the family as a workshop in social change", (Caplan, 1982, p.206).

1.4 DEFINITION AND USAGE OF TERMS

The following terms either have a specialized meaning or need to be operationally defined for this study:

(a) Lifestyle - in this study refers to general and emotional atmosphere, manners and patterns of behaviour, attitudes, expectations, norms and values.

(b) Coping patterns - problem-solving efforts made by an individual or a group when the demands of a given situation tax adaptive resources, (Schilling et.al., 1984). In this study coping patterns refer specifically to the parents' efforts directed towards solving problems resulting from having a mentally handicapped child.

(c) Stress - Catechis (1978) introduces English and English's definition of stress as "a force applied to a system sufficient to cause strain or disorientation in the system, or when very great, to alter it into a new form" (p.12).

(d) Resources - according to Holroyd (1974) resources refer to an individual's ability to utilize his or her coping skills in a supportive manner for both self and family.

(e) Mentally handicapped young children - in this study this term, as well as the terms "mentally retarded", "mentally deficient", "disabled" or "trainable" refers to toddlers and pre-school children (ages 2-6) with moderate to severe retardation (55-35 IQ).

(f) Mentally handicapped older children - in this study this term as well as the abovementioned terms used for the young children refers to adolescents and young adults (ages 16-30) with moderate to severe retardation (35-35 IQ).

Unless otherwise indicated, when reference is made to a "child" in the body of this thesis, it means a mentally handicapped child; similarily, unless otherwise indicated, any reference to parents means parents of a mentally handicapped child.

(g) Family - in the present study this term refers mostly to mothers and fathers of the mentally handicapped children who were interviewed.

(h) Group A - parents (mothers and fathers) of the young mentally handicapped children (term e).

(i) Group B - parents (mothers and fathers) of the older children (term f).

(j) Training Centre - In this study refers to the three day-care centres attended by the mentally handicapped children of the parents who were interviewed (Sunshine Centre, The Hamlet and the Selwyn Segal Hostel).

(k) QRS - Questionnaire on Resources and Stress. In this study, the QRS is used as an instrument to measure maternal and paternal stress resulting from having a mentally handicapped child, and ways of coping with such a situation (see section 1.5.4.1 on research tools).

(l) Schedule - A research tool constructed for the purpose of this study, used for the structured interviews with the parents of mentally handicapped children who took part in this study. (See section 1.5.4.2 on research tools).

(m) High skilled fathers - fathers whose occupation is defined as professional qualified and high administration, managerial and executive or inspectory supervisory and thus non manual (Higher and lower grade).

(n) Low skilled fathers - fathers whose occupation is defined as skilled manual.

1.5 METHODS

The research methods will be described in the following sections:

(a) The Research Design
(b) Demarcation of the Study
(c) The Sample
(d) The Research Tools
(e) Procedures

1.5.1 The Research Design

"Researchers who study families encounter perplexing methodological problems, especially if they try to trace the influence that family members have on one another. They confront the practical obstacles inherent in any attempt to record behaviour of human subjects in their daily routines, and they also grapple with several problems that arise from the singular character of family life" (Hess, 1981, p.207). The confusion in the field of family studies is frequently mentioned in the literature and the criticisms applying to almost every aspect of research methods used (Riskin and Faunce, 1972).

Reid and Smith (1981) stress the importance of the experimental approaches as the most direct and powerful means that research can provide. However, a review of the literature reveals that many if not most of the studies in the field of

family interaction and family development fall under the category of "naturalistic descriptive". Some of the widely described shortcomings such as subjective evaluations or a lack of comparison groups, are built into these kinds of studies.

Nevertheless, the important role that descriptive research plays in social work is frequently mentioned, (Reid and Smith, 1981). Naturalistic descriptive studies enrich knowledge about client needs, problems and attitudes toward service, the nature of services provided, and the use of services. Mainly, descriptive studies provide information about the presence of associations among factors; however, speculation about causality could be another outcome of the research. Yet, although possible cause and effect relationships that hold, when a number of variables are controlled, gain some probability of providing valid explanations, such relations may be regarded as "best guesses" and in need of further testing.

Explanations are inadequate for many social phenomena, particularly those in which variables are likely to have reciprocal effects on one another. Interactions within social systems such as families, provide the most obvious example. Thus, parental attitudes and the behaviour of children clearly affect one another often in an escalating series of exchanges. "Moreover there may be simultaneous interactions among numerous variables within social systems or impinging on these systems from their environments", (Reid and Smith, 1981, p.78).

In the attempt to overcome some of the abovementioned problems inherent in family studies, a developmental approach as a conceptual framework was introduced by Hill and associates (1964). They state: "Family development studies at the descriptive level place their emphasis less on what the behaviour is than on when it occurs; more on the

timing and sequence of family behaviour than on the content of behaviour alone. The charge is to discover what behaviours can be expected to change predictably over the natural history of families as against behaviours which are more or less constant, or which are adventitious and/or situational", (Hill, 1964, p.189). This approach goes beyond the understanding of family behaviour as relating to family characteristics, to specify the relative contribution of developmental time to the formula of explanation. As the stages of family development had been sufficiently defined by hundreds of descriptive studies, it became quite obvious that any research which seeks to generalize about families without taking into account the variation due to the stages of family development, represented in the sample, will have tremendous variance unaccounted for, just as studies which ignore social class differences leave much unexplained (Hill, 1964; Riskin and Faunce, 1972; Hess, 1981).

In addition to the importance of time in family developmental studies, Riskin and Faunce (1972) suggest that more attention should be devoted to relating family interaction processes to other kinds of processes. For example, the problem of conceptualizing the relationship between the family as a unit and the individual as a unit, or the relationship between the family as a unit and the family interacting in other contexts (schools, hospitals, training centres' have not been explored well in their opinion. In order to explore family processes and to take the full advantage of the conceptual framework of family development the need to use a system of longitudinal data collection and analysis is essential.

The longitudinal study is a controversial topic. The long term study in which changes (or maturation) are measured for the same people periodically over many years is often mentioned as an ideal (Baldwin, 1960; Hill, 1964). However, it seems that many researchers are aware of the difficulties

inherent in this method. Difficulties of sampling, of securing the cooperation and commitment of the research subjects over such a long time period and many other organizational and personal changes lessen the chances of research continuity. Beside the high cost of these studies some serious methodological problems like the inability to control the environment of a child or a family over any reasonably long period, or to avoid the ongoing impact of the researcher from creating changes in the family's attitudes and behaviour, are commonly mentioned (Baldwin, 1960; Hill, 1964; Riskin and Faunce, 1972; Reid and Smith, 1981). Hill (1964) concludes "the major objection to the longitudinal method in family study has been financial and organizational cost and awkwardness rather the looseness of research design intrinsic in the method" (p.196). In the attempt to overcome the shortcomings of the longitudinal method, Hill (1964) suggests five alternatives:

(i) A synthetic pattern of development constructed from cross sectional data.

This method is most frequently used. A cross section of the population is taken by sampling categories like "years married/child's age". The method is based on a comparison of groups of subjects representing a different stage of development. The formation of groups within a study and across studies needs to be carefully designed in order to avoid biases resulting from a poor design when some important factors (like socioeconomic status, level of education, kind of diagnosis, sex and age) are not taken into consideration. Hill (1964) calls for attention to be paid to generational differences in value orientations and styles of life which can also create differences between groups, and influence the study findings. The cross-sectional study although avoiding many of the costs and organizational problems of the truly longitudinal study, is considered to provide data which can rarely be more than suggestive of developmental patterns.

(ii) Restrospective history taking

"This is a method for manipulating the time machine backward in time through the device of recall by the respondent", (Hill, 1964, p.196).

The ability of people to recall past events and feelings has been investigated in many longitudinal research projects, and results show that the content of the material and the span of development has an important effect on accuracy of recall. Requests for quantitative information and concrete events are answered more reliably than inquiries about attitudes and feelings (Fontana, 1966). The advantages of the method of retrospective history over some other compromises are, firstly, that the data is not wedded to the stages of development established in advance by the researcher and thus does not reveal new points of significant change in family development. Secondly, it is a relatively inexpensive way of operating the time machine, since years and decades may be covered in a two hour interview. But, it does require families as respondents that are far enough along in the life-span to have a history to recall (Hill, 1964; Riskin and Faunce, 1972).

(iii) Segmented longitudinal studies

Studies which deal with a segment of the family life-span to test hypotheses about family changes at selected points in development time, fall under this category. These studies are based on the principle of the longitudinal method over short periods, moving forward or backward in time using retrospective and prospective methods. Many theorectical questions cannot be answered in studies designed in this fashion, especially in regard to continuity and discontinuity of change in family development.

(iv) Segmented longitudinal panels with control

Feldman (1962) describes this design which involves careful sampling of categories of the population according to the stage of family development in which they were located, undertaking interviews in two or more waves at present and again at a subsequent point later enough to enable families to change stages. Families who have not changed stages are considered a control group in comparison with families where changes have occurred.

(v) The intergenerational panel, combining retrospective histories and panel interviews forward in time.

This design, which combines retrospective histories and panel interviews forward in time, enables the researcher to follow the process of change in family development through the past and present and with orientation to the future.

To conclude, reference can be made to Reid and Smith's (1981) statement: "Most researchers probably do not conceive of the purpose of their research as exploration, description, explanation and the like. They are more likely to regard the purposes of their research as answering questions, testing hypothesis or acquiring specific kinds of data. These purposes often comprise some combination of knowledge-building functions. Categorizing a study only in terms of a single function might tend to make both researcher and consumer insensitive to other functions of the study" (p.79).

In the light of the foregoing detailed review and Reid and Smith's statement, an attempt is made to define and describe the design of the present study.

The overall aim of this study called for the use of a descriptive longitudinal design as it seeks to delineate and to analyse the long-term impact of a mentally retarded child on the development of his family lifestyle and his parents' coping patterns. Noting the shortcomings of the pure longitudinal method, a combination of the alternatives suggested by Hill (1964) was comprised for the purpose of this study. A cross-sectional sample was formed according to the age of the mentally retarded child, and in regard to some other variables (like socioeconomic status, level of education, religion, cause of mental retardation). One of the research tools (the schedule) was aimed at gaining retrospective data from the time the mentally handicapped child was born. The groups, which were constructed according to the child's age, represented certain segments of the family life span (with high relevance for understanding the process that parents have to go through when having a mentally handicapped child).

The research tools in this study, although administered in the same interview were constructed to enable the collection of data on parents' current reactions and behaviour, as well as their attitudes towards the child's future.

Lastly, it is noteworthy to quote from De Wet's (1984) summary on the choice of a research design: "We should not be so quick to judge severely and to negate research results obtained through a variety of sampling methods: rather we should discuss them in terms of their assets and liabilities. We need to accept studies on their merits however limited they are and build them up through replication. The methodologist should be sympathetic enough to recognize that everyone makes mistakes, vigilant enough to guard against

taking the occasional error as an indicator of overall quality and objective enough to understand that the most visible target is provided by the best research. In return he can hope that other methodological critics will appraise his work in the same spirit" (p.9).

1.5.2 Demarcation of the Study

The population of the study was defined as parents of mentally retarded children from three day centres in Johannesburg: "Sunshine Centre", "The Hamlet" and "Selwyn Segal Hostel". The children were all diagnosed as being trainable and their level of retardation was defined as moderate to severe (35-35 IQ).

The abovementioned day centres cater only for whites living in the Johannesburg area (including Edenvale, Randburg, Germiston and some other small municipalities). The reasons for excluding other race groups were:

(a) To narrow the influence of cultural differences.
(b) To avoid the need to translate the research tools into other languages.
(c) To avoid technical problems which might reduce parents' cooperation. (The only time that both parents could be available for interviews was during the evenings).

For the purpose of studying the long term impact of a mentally retarded child on his family, only parents who had raised their child within the family from the time of his birth were included. The idea that parental attitudes, reactions and behaviours are influenced by the degree of severity of the child's mental handicap has frequently been mentioned in the literature (Farber, 1960; Tizard and Grad, 1961; Begab, 1963; Bayley, 1973; Chinn et.al., 1978, Featherstone, 1980; Glendinning, 1983, Drew et.al., 1984).

Although severely retarded children have the greatest impact on their families, it was decided to study parents of moderately to severely retarded (or trainable) children because of the possibility of tracing them through the day centres. The severely retarded cases are not always known to the authorities and more of them are or have been in residential care (Tizard and Grad, 1961; Fotheringham et.al., 1971).

The three day centres from which the population of the study was drawn were chosen in regard to the following categories:

(a) The range of children's ages.
(b) The children's level of retardation.
(c) The common language of the parents. (Most of the parents are English speaking at a level that enabled them to be interviewed in this language). A short description of the three day centres follows.

1. Sunshine Centre

"Sunshine Centre" is a voluntary welfare organization working in the field of early intervention, in respect of mentally handicapped pre-schoolers and their families. The services provided are:

(a) A pre-school centre in Johannesburg - twenty children (ages 1 1/2 - 6 years).
(b) A pre-school centre in Germiston - twenty children (ages 1 1/2 - 6 years).
(c) A home programme called S.T.A.R.T for people throughout South Africa and beyond.

"Sunshine Centre" was established in 1976 by a group of mothers of mentally handicapped children. As enrolment increased the mothers decided to introduce professional services to the centre. With the

assistance of public service groups, professional service was gradually introduced and the school maintained full partnership between professional staff, parents and volunteers. "Sunshine Centre" is a registered welfare organization (in terms of the National Welfare Act No. 100 of 1978). It receives referrals from the Johannesburg Hospital, the Department of Health and Welfare, from private and government nurseries and from parents. The philosophy employs a three cornered approach: a) Early intervention services are offered from birth or diagnosis; b) intensive stimulation - highly structured, goal directed programme; c) parental involvement - parents, usually mothers, work actively in the classroom, do home exercises participate in support groups and both mothers and fathers serve on committees.

The methods used in the "Sunshine Centre Five-point programme" are: 1) Socialization; 2) Activities of daily living; 3) Fine motor coordination; 4) Gross motor coordination; 5) Perceptual stimulation. The professional staff consists of teachers, speech therapist, occupational therapist, physiotherapist, social worker and paediatrician.

II. The Hamlet Training Centre

A day care centre for trainable mentally retarded children. One hundred and six children attend the day care centre's school. The children (ages 6 - 18) are defined as trainable moderately retarded. Ten severely retarded children are in a special unit. Thirty five trainable adolescents and adults (ages above 16) attend a workshop affiliated to "The Hamlet". "The Hamlet" was established in 1954 by parents of mentally retarded children. The parents of the first ten children paid for the teacher. In 1964 The Hamlet Society for the Mentally Handicapped, which is affiliated to the South African National Council for Mental Health, bought the house in which the day centre has operated until today.

In 1976 the Department of National Education took over the day centre which until then had been administered by the welfare organization. The basic concept behind the programme is that all children are, if not educable, trainable in many avenues, and the training programme embraces all aspects of the individual's personality. The aim in teaching is to give the child a feeling of competence and confidence to cope with the demands of daily living. The school consists of seven classes. The children are grouped into classes according to their mental health and physical appearance.

The workshop is subsidized by the Department of Health and Welfare and is productive to a certain extent. The professional staff includes the principal, teachers, a social worker and a speech therapist. The children are referred from schools, welfare agencies, the hospital, etc. They are assessed and according to the results accepted into one of the programmes.

III. Selwyn Segal Hostel and Day Centre

The hostel is named after the child of Leon and Fanny Segal and is affiliated to the Society for the Jewish Handicapped which is a voluntary organization. The hostel was founded in 1967. The need for a day centre, which was felt in the community, led to its establishment. As the sample for this research study was taken only from the day centre, its programmes shall be focused upon. Although the hostel accepts only Jewish mentally handicapped, the Day Centre is open to all trainable and untrainable mentally retarded between the ages four to thirty one. In the Day Centre, which is attached to the hostel there are fifty children and adults. Their IQ level ranges from "too low to be assessed up to borderline intelligence". The children and the adults in the Day Centre take part in the hostel's programmes; they attend its school or workshop according to their age and special needs.

The referrals come from physicians, through friends, parents and official authorities. Every child is assessed in the clinic (which is part of the "Selwyn Segal Hostel") and classified into one of four groups; a) low potential achievers; b) junior academic group; c) junior workshop and academic group; d) senior academic group. The overall aim of the "Selwyn Segal Hostel" is to train the mentally handicapped to "take their place in society". The professional staff includes teachers, social worker, speech therapist, physiotherapist, occupational therapist, clinical psychologist, craft instructors and medical staff. The parents pay fees, and expenses are covered by the government's subsidy and through fund-raising.

1.5.3 The Sample

In order to study the long-term impact of the mentally retarded child on his parents two groups of parents were drawn from the previously described population, representing two developmental stages in the mentally retarded child's life.

As previously mentioned the level of retardation for all the children was defined as moderate to severe (55-35 IQ). The allocation into groups was therefore according to the child's age and in regard to the nature of his handicap (his mental and physical condition).

The first group (A) consisted of parents of toddlers and pre-school children ages two to six. The decision to choose this stage in the child's life was based on two assumptions: a) only in a very limited number of cases in which mental retardation is suspected, is it possible to expect a final diagnosis in the first two years after the birth of the child. Actually, in most cases, the parents accept such a diagnosis later on, during the pre-school years; b) as a

result of the above and because of the objective difficulties of the burden of care for a "perpetual baby", this period was suspected to create strain and stress for the parents who firstly have to face such a problematic situation, and then cope with it.

The second group (B) was composed of parents of mentally retarded adolescents and young adults, ages sixteen to thirty. The reasons for choosing this stage in the life of the mentally retarded child were: a) it was suspected that after a period of relatively less tension (inbetween the ages six to sixteen), when the mentally retarded child reaches adolescence his behaviour and needs and the reactions of the outside world toward him create new hardships and difficulties for the parents who have to adjust to these new demands; b) it was suspected that the oldest mentally retarded persons who might be still living with both parents would be around their thirtieth year. After this age, in many cases either the retarded person is institutionalized, or there are fewer instances in which both parents are still alive. Out of the population attending the three day-care centres, children were firstly selected according to their ages, level of retardation, and their physical condition (children with severe physical handicap were not included). Selecting the children according to their sex was impossible as it significantly reduced the number of potential cases, since it was desirable to try to locate at least thirty couples of parents for each group (to facilitate the use of statistical procedures).

The importance of group comparability has already been mentioned. However, the total number of potential cases was too small to enable a full match of the two groups. Yet, in addition to the already mentioned characteristics of the child which guided the first selection, an attempt was made to take into consideration some of the important background characteristics of the parents.

Children whose parents were not living together were excluded. The socioeconomic status of the parents (in regard to their occupations) the father's level of education and the religious background were considered when composing the two groups. Taking into account factors like parental age, family size and place of the child in the family was impossible as a result of the major difference in children's ages. (For example, it was obvious that the younger children generally had younger parents and smaller families). Another selection was done in regard to parents' ability to communicate in English.

After taking into consideration all the abovementioned factors, there were forty families suitable for each group. It was decided to firstly approach thirty couples (with both parents) for each group. From group A - nine families refused to cooperate and in one family, the mother was out of the country for a long period. In group B- ten families refused to participate and in one family, the father was hospitalized for a long period. The parents who refused were replaced by others with similar background characteristics. However, the limited number of cases made it impossible to have thirty couples in each group and so it was decided to include in group A two single parent families (the fathers in these two families left the city after the birth of the mentally retarded child and rarely had contact with him). In group B, six widows were included (the husband had died at least five years before). Thus the total number of research subjects was one hundred and twelve (sixty mothers and fifty two fathers) in both groups. Group A consisted of thirty mothers and twenty eight fathers. In group B there were thirty mothers and twenty four fathers. The ages of the child of these parents were: In group A, thirty percent of the children were two to four years old and seventy percent, five to six years old. In group B, fifty six percent were sixteen to twenty one years old and forty four percent were between twenty two to thirty years old.

A description of the research subjects according to some of the child's and parents' characteristics follows:

1.5.3.1 Child's Characteristics

Table 1

Frequencies of children in schools according to groups (A & B) (in percentages)

Name of the School	Group A	Group B
1. Sunshine Centre	51.7	-
2. The Hamlet Training Centre	31.0	72.3
3. Selwyn Segal Hostel	17.3	27.7
Total	100.0	100.0
	N=30	N=30

Table 2

Frequencies of child's sex according to groups (A & B) (in percentages)

Child's Sex	Group A	Group B
1. Male	44.8	74.0
2. Female	55.2	26.0
Total	100.0	100.0
	N=30	N=30

The differences between groups in regard to child's sex are significant. The frequency of males and females in Group A shows a similar ratio between sexes. However, in Group B the difference in number of males and females is noticeable.

Table 3

Frequencies of cause of child' mental retardation according to groups (A & B) (in ercentages)

Cause of Mental Retardation	Group A	Group B
1. Unknown	18.9	12.9
2. Genetic anomalies	39.7	33.3
3. Infections	-	9.3
4. Disorders of metabolism or nutrition	-	3.7
5. Seizure disorders (epilepsy)	7.4	7.4
6. Brain damage	34.5	29.7
7. Cerebral palsy	3.5	3.7
Total	100.0	100.0
	N=30	N=30

The differences between groups are less than ten percent and therefore cannot be considered significant (see section 1.5.5.2 of this chapter). The frequencies for cause of mental retardation are quite similar in both groups.

Table 4

Frequencies of physical condition of the child according to groups (A & B) (in percentages)

Physical Condition of the Child	Group A	Group B
1. Generally good	72.4	83.3
2. Generally fair	27.6	16.7
3. Generally poor	-	-
Total	100.0	100.0
	N=30	N=30

The differences between groups in regard to child's physical condition are less than ten percent. The two groups can be considered similar. It is important to notice that the majority of children were considered to be in a good physical condition, thus their problems result mainly from their mental deficiency.

To sum up this section on the child's characteristics, the children's level of retardation and physical condition similar in both groups. Sex freqencies are significantly different among and within the groups.

1.5.3.2 Parents' Characteristics

Table 5

Frequencies of mothers' occupation according to groups (A and B) (in percentages)

Mothers' Occupation*	Group A	Group B
1. Professionally qualified and high administration.	6.9	-
2. Managerial and executive.	-	3.7
3. Inspectory supervisory and other non-manual (low and high grade).	8.7	12.9
4. Routine grades of non-manual workers.	20.7	14.9
5. Skilled and semi-skilled manual and routine.	3.4	11.1
6. Housewife.	60.3	57.4
Total	100.0	100.0
	N=30	N=30

* Oppenheim (1966)

The frequencies for mothers' occupation are similar in both groups as the differences are less than ten percent. The majority of mothers in both groups are not working outside the house.

Table 6

Frequencies of fathers' occupation according to groups (A & B (in percentages)

Fathers' Occupation*	Group A	Group B
1. Professionally qualified and high administration.	28.6	20.8
2. Managerial and executive.	14.3	20.9
3. Inspectory supervisory and other non-manual (low and high grade).	35.7	41.7
4. Skilled manual	14.3	8.3
5. Not working (on pension)	7.1	8.3
Total	100.0	100.0
	N=28	N=24

* Oppenheim (1966)

Frequencies for fathers' occupation are similar in both groups as the differences are less than ten percent.

Table 7

Frequencies of fathers' formal education according to groups (A & B) (in percentages)

Father's Formal Level of Education	Group A	Grou, B
1. Post-matric training.	42.9	33.3
2. Matric.	21.4	29.2
3. Under matric.	35.7	37.5
Tota'	100.0	100.0
	N=28	N=24

Frequencies for fathers' level of education should be considered similar in both groups as the differences fall under ten percent.

Table 8

Frequencies of parental religious affiliation according to groups (A & B) (in percentages)

Parents' Religious Affiliation	Group A	Group B
1. Protestants	65.5	61.1
2. Catholics	17.5	16.7
3. Jewish	10.8	22.2
4. Others	6.8	-
Total	100.0	100.0
	N=58	N=54

The differences in frequencies for parental religious background are generally too small to be considered significant. A slight difference can be noticed between the Jewish parents in both groups (more than ten percent). It is important to notice that in the Johannesburg area, religious background often represents a different cultural sector of the population.

Most of the Protestants come from originally English and Afrikaans families, and probably were born in South Africa. The Catholics, however, are mostly first or second generation families who immigrated from Italy, Portugal, Spain and Greece. The origins of most of the Jewish families in Johannesburg is in Eastern European countries (Unterhalter, 1968). Thus, religious background here represents different beliefs and different cultural backgrounds as well.

To conclude: As far as parental occupation and fathers' level of formal education may be considered indicators of family's socioeconomic status, the two groups should be regarded as similar from those points of view. Differences in religious background seem to be small and in this case represent also, a certain similarity in cultural background, of both groups of parents.

Certain other characteristics of parents which were judged to be of less than central importance to the study (such as child's age, birth order, the size of the family, parents' age, mothers' level of formal education and having a mentally handicapped relative) are reflected in Tables 1A, 2A, 3A, 4A, 5A, 6A, 7A in Appendix 4.

1.5.3.3 Sample Bias

The sample in this research study should be considered purposive as it consists of elements deliberately chosen for the study's purposes. "Like other non-probability sampling plans, it is risky to use purposive sampling for generalizing to large populations, for we do not know to what extent the samples are representative of population of interest" (Reid and Smith, 1981, p.173).

The fact that the sample was not going to represent the population of parents of moderately retarded children, adolescents and adults in Johannesburg area, was taken for granted when choosing subjects for the groups. Moreover, an absolute matching of the two groups was impossible due to the small population from which the subjects for the sample were drawn. Yet, an attempt was made to achieve a certain degree of similarity between groups at least in some of the more important child and family characteristics. An attempt to match the groups also according to child's sex was not possible (especially for group B) because of the ratio between males and females in the population. Thus, from this point of view, the differences between groups are significant and probably will have an effect on the results.

1.5.4 The Research Tools

Obtaining data in an interview focused upon one point in time would not have served the purpose of this study, which aimed to explore a developmental process.

In order to be able to gain information on the various stages of this process, there was a need to adopt a retrospective method. As two segments in the child's age were to be compared, prospective data was also needed. Thus the two research tools which will be described here facilitated collecting data retrospectively, prospectively and at a certain point in time.

1.5.4.1 The Questionnaire on Resources and Stress (QRS)

The Questionnaire on Resources and Stress (QRS) is a true-false item questionnaire designed by Holroyd (1974) to measure variables pertinent to families caring for chronically ill or handicapped family members. Holroyd (1974) states: "This project developed

a multidimensional objective, self administered test to measure not only the burden imposed on the family but the family's emotional response to that burden" (p.92). The QRS has been used in several studies during the last few years.

Holroyd (1974), in three pilot studies, compared mothers to fathers of children from an outpatient psychiatric setting, mothers of mentally retarded children with mothers of emotionally disturbed children, and mothers living with a husband and mothers living alone. In 1975 Holroyd and associates compared parents of institutionalized and non-institutionalized autistic children.
A comparison of stress on parents of Down's Syndrome and autistic children was done by Holroyd and McArthur in 1976. Catechis (1978) conducted a study aimed to determine whether the QRS differentiates between mothers of mentally retarded and mothers of non-mentally retarded children. Fridrich and Fridrich (1981) used the QRS to compare parents of handicapped and non-handicapped children. Two years later, after a short form of the QRS was developed, Fridrich et.al. (1983) used this form to discriminate between the families with and without a handicapped child.

In a study on the influence of selected child characteristics on stress in families of handicapped infants, Beckman (1983) used the QRS among other research tools. In all the abovementioned studies the ability of the QRS to discriminate between the reactions of different groups under long term stress was proved. However, as far as is known, a comparison between parents of younger and older mentally retarded chilren has not yet been done, or at least not yet reported.

The QRS originally consisted of 285 items designed to measure factors relating to families who care for a chronically ill or handicapped member. The two hundred and eighty five items are intercorrelated. Those items with the largest number of significant correlations ($r = .30$), together with other items in the same rational scale, were selected to form new scales. This resulted in the fifteen shorter, more homogenous scales using two hundred and six non-overlapping items (Holroyd, 1982).

The fifteen scales are as follows: 1) Poor health/mood; 2) Excess time demand; 3) Negative attitude toward index case; 4) Overprotection/dependency; 5) Lack of social support; 6) Overcommitment/martyrdom; 7) Pessimism; 8) Lack of family integration; 9) Limits on family opportunity; 10) Financial problems; 11) Physical incapacitation; 12) Lack of activities for index case; 13) Occupational limitations for index case; 14) Social obtrusivess; 15) Difficult personality characteristics.

The fifteen face valid subscales measure three broad categories: parent problems (scales 1-7), problems in family functioning (scales 8-10) and problems the parent sees in or for the child (scales 11-15).

Scores (representing the degree of stress in families) can be obtained from the 15 separate scales that can also be summed to yield a total stress score.
In this study the QRS with the two hundred and six non overlapping items was used to measure differences in stress and family resources (or coping patterns) between parents of young mentally retarded children (ages 2-6) and adolescents and young adults (ages 16-30) at a certain point in time (when interviewed) (see Appendix 1).

The validity and reliability of the QRS has been proved in previous studies. Nevertheless, four families (representing the two formed groups, but not included in the sample) answered the QRS in order to assure a full understanding of the questions, which were originally written in a simplified way (Holroyd, 1982).

1.5.4.2 The Interview Schedule

"An interview schedule is simply a guide used by the interviewer in conducting the interview .. As in all other forms of measurement, one is concerned that the interview schedule be so designed that comparable, relevant and precise data are most likely to be obtained" (Polansky, 1960, p.142). Reid and Smith (1981) mention the importance of the researcher administering the interview himself for the purpose of obtaining data on topics which are complex, highly sensitive, emotionally laden or relatively unexplored. A schedule helps the interviewer in conducting a semi-structured interview.

Such a semi-structured interview schedule "might consist of open-ended questions and probes and the order in which the questions are to be asked are pre-determined, but the response categories are not" (p.211). A semi-structured instrument might contain both fixed alternatives and open ended questions and may or may not allow the interviewer some flexibility in the wording or rephrasing of questions or in asking additional probes. "Because of its versatility in being able to combine many of the advantages of both completely structured and unstructured interviews, the semi-structured interview is probably used more often by social work researchers than any other type of

interview (Reid and Smith, 1981, p.211). A semi-structured schedule was used in this study in order to create a certain degree of homogeneity in administering the interviews. The schedule was aimed mainly at gaining retrospective information (from the time of the mentally retarded child's birth) and prospective data (by asking future oriented questions). The schedule consisted of thirty three open ended questions. Fourteen questions sought retrospective information, nine questions probed for present feelings and reactions and ten questions were future oriented. (See Appendix 2).

Thus, the schedule enabled the interviewer to gain information covering the different stages in the developmental process.
The schedule was administered four times (to four families representing the two research groups, not included in the sample) in order to pretest its ability to gain the desired information. Two or three questions which seemed to need further clarification were changed in order to be better understood by those interviewed.

1.5.5 Procedure

The following section will be divided into two parts:
(a) The interviews
(b) Data analysis

1.5.5.1 The Interviews

After the selection of the subjects for the two groups (A,B) a letter was mailed to every selected family informing them of the research study and requesting their agreement to be interviewed. (See Appendix 3). In the letter, it was mentioned that both parents would be interviewed by the researcher at their homes.

They were requested to reply only if they refused the interview. The parents who refused to be interviewed were replaced by other parents with similar background. A telephone call was made to each family to arrange the date for the interview. Most of the interviews were conducted in the evenings (when both parents could be at home and free from their other obligations).

Riskin and Faunce (1972) raise the question: "On whose territory is the family being studied?" (p.374). They mention that only few investigations have studied the differential effects of home versus laboratory setting. They conclude by stating that in avoiding a mixture of home, offices, etc. one introduces fewer uncontrolled variables. In this study all the parents were interviewed at their homes by the same person (the researcher). According to Riskin and Faunce (1972) "The effects of the interviewer and the context are there; they cannot be eliminated. Therefore, it is essential to be aware of them and to control for them to whatever extent is possible" (p.377). It was assumed that if all interviews were conducted by the researcher, fewer uncontrolled variables would be introduced.

As already mentioned, both parents were interviewed. However, in order to be able to compare mothers' to fathers' reactions, they were interviewed separately (during the same evening). One parent was asked to leave the room where the interview was taking place and to answer the Questionnaire on Resources and Stress (QRS) which is a self administered tool.
At the same time his spouse was interviewed according to the semi-structured schedule. When the interview with the first parent was over he was asked to leave the room and to answer the QRS and his spouse was interviewed.

Each interview lasted approximately one hour, leaving enough time for answering the QRS. The semi-structured interviews were recorded (unless the parents refused to be taped). After both parents were interviewed, they answered some informative questions in regard to objective details. As it was assumed that reacting to one research tool (either the QRS or the schedule) might affect parents' reactions to the other tool, it was decided to change the order so that if the mother was the first to be interviewed, in the following family the interview started with the father. Lastly, it is important to notice that subject families who were in treatment or "labeled" (in this case families with a mentally retarded child) may have had certain expectations from the research study and even more from the interviewer (especially when they knew that he or she was a professional social worker - as she was in this case). This situation no doubt had an affect on the interviewees and on the general atmosphere during the interview. Such an atmosphere may have helped the parents to open up and increased the ability to collect data; however, there is a certain risk that the investigator's behaviour and attitudes will create bias towards pathology. (Riskin and Faunce, 1972).

1.5.5.2 Data Analysis

As previously mentioned, data was obtained by the use of the QRS and the interview schedule.
The QRS has an answering sheet and answers can be computerized to obtain scores according to the Draft Manual (Holroyd, 1982). This procedure yields individual scores (for each of the fifteen scales). A mean score for each group (A,B) was then calculated. Mean scores were also calculated for all the fathers in both groups as well as for the mothers. Calculations of mean scores for mothers and fathers within groups (mothers A, fathers A, mothers B, fathers B) were also obtained. Comparisons between the mean scores in the

abovementioned groups were done by using the t-test in order to determine to what extent differences between groups can be regarded as statistically significant.

Statistical analyses were made for each scale separately. When analysing the results, scales were grouped according to the main aims of the study (see section 1.2 in this chapter).

The data obtained by the interview schedule was recorded or immediately written up after the interview. In order to be able to use quantitative methods, it was necessary to develop categories for answers to each question in the schedule. Reid and Smith (1981), when discussing ways of categorization, state: "Consequently, we start from the broader guidelines stemming from the purpose of the study and try to develop more specific questions or working hypotheses based on the data collected ... to enhance reliability in coding unstructured data, it is particularly important to define categories as clearly as possible" (p.247-248). After writing down the recorded data an attempt was made to categorize the data in a way which reflected the variety of parental attitudes and reactions. However, because of the small number of cases, defining more than six or seven categories for answers to each question may have created difficulties when using quantitative methods.

When the categories were developed and numbered, the raw data were assigned numbers corresponding to the appropriate category. The categorized data was computerized in order to firstly obtain frequency distributions. When the number of cases allowed further analysis, the Chi square test was used. However, when the number of cases in each cell was too small the Chi square test could not be considered a valid test. Thus, it was arbitrarily decided that a

difference of more than ten percent would be considered as notable one in this study. Two kinds of comparisons were made. Firstly, according to groups (A,B) and within the groups (mothers versus fathers); then between mothers and fathers from both groups and between mothers of groups A and B and fathers of groups A and B.

Secondly, further analyses were made to investigate the impact of child and family characteristics on parents' reactions and attitudes.

1.6 OVERVIEW OF THE STUDY

The following chapters cover the four main areas which were focused upon in this reasearch study. Each of these four chapters contain an overview of relevant literature and past research, a presentation of the findings of this study, and a discussion of these findings in the light of available theory. The four chapters refer to the following subjects: 1) The process of adaptation and its impact on parental attitudes and feelings toward the mentally handicapped child (chapter 2); 2) The effect of the child's mental handicap on the family as a whole (chapter 3); 3) The influence of the mentally handicapped child on his parents' relationships with the outside world (chapter 4); 4) Parents attitudes and plans for the child's future (chapter 5).

In the last chapter (6), an integration of theory and findings regarding the four abovementioned areas is presented by using a model for delineating and analysing the long-term impact of a stressor event (having a mentally retarded child) on the development of parental coping patterns and family lifestyle.

1.7 LIMITATIONS OF THE STUDY

The inherent limitations of this study were:

(a) The small sample of parents in the study meant that when multiple responses were given to questions, the numbers of responses within each cell were often too few to permit conventional statistical analyses. This had been anticipated, and prior to the analysis of results, the relatively arbitrary decision was taken to regard variations of ten percent or more as notable or of "significance". The inability to use statistical procedures constitutes a limitation.

(b) A criticism which may be applied to previous, similar research studies, which were based on small samples, is relevant also to this research study. Blacher (1984) states: "While the non-structured interview method is relevant to the development of theoretical formulations, it may be subjective, limiting the generalizability of the findings" (p.64). Although an attempt was made to at least structure part of the interview (by using the QRS) it is still important to keep in mind the shortcomings of the small sample and the partially semi-structured interview.

(c) The problems of group comparability have already been mentioned. The fact that a full matching of the two groups was not achieved (especially in regard to child's sex) probably effected the research findings.

(d) It must be kept in mind that the sample included only parents who agreed to be interviewed. Although an effort was made to replace parents who refused to take part in the study with parents with similar child and family characteristics, it is possible that there is a

major difference between cooperative and non cooperative parents. The ones who seem to be readier to open up and share their emotional feelings and reactions in regard to such a sensitive issue (having a mentally retarded child) may represent a more adaptive attitude to the situation. On the other hand, the difficulties of non-cooperative parents in sharing their problem with others may represent among other things their lesser ability to adjust to having a mentally retarded child.

(e) It is difficult to discriminate between reactions and lifestyle patterns which would have occurred in the family regardless of whether or not they had a mentally retarded member, as against such patterns which may be attributed to the existence of such a member in the family.

CHAPTER 2

THE PROCESS OF ADAPTATION AND ITS EFFECT ON PARENTAL ATTITUDES AND FEELINGS TOWARD THE MENTALLY HANDICAPPED CHILD

2.1 PERSPECTIVES FROM THEORY AND PAST RESEARCH

2.1.1 Introduction

The birth of a mentally handicapped child is a devastating experience. It follows a period of preparation and joyful anticipation which is suddenly brought to a full stop. Usually it is an event totally outside the experience of everyone concerned. It threatens the whole being of the parent and shatters the hopes vested in the unborn child. The fears and anxieties dormant in all prospective parents are suddenly seen to have foundations.

Anderson (1982) states that nothing in our culture prepares young parents for the arrival of a damaged child. It would be even truer to say that our society works very hard to repress from consciousness the dark hints that it may occur. We treat pregnant women as if they were in danger, but the conscious message is that babies are good, birth is a happy event, motherhood gives status, fathering is power. Parenthood typically offers an adult a series of opportunities for enriching his own identity, for concrete affirmation of his generativity, for increased self-knowledge, for vicarious approximation of his ego ideals and for experiencing his effectiveness in bringing a production situation to fulfillment (Cummings et.al., 1966).

Comparisons of their children's prominent characteristics with prevailing value systems both cultural and personal, yield data to parents which contribute to their evaluation of themselves and others.

Chinn et.al. (1978) mention that babies and children have such a positive connotation in our society that much of the literature neglects to describe the negative aspects of parenthood. Thus, most parents are not only unprepared for a bad event: they are especially keyed up for a good one. Normally parents develop strong social and psychological attachments with and commitment to their children. They build up hopes and desires taking special pride in their children's accomplishments. However, when they realize that such goals will not be achieved their very private feelings are dashed. Glen Vinning (1983) quotes a mother who participated in her study: "I think subconsciously that whenever you have a child born to you, you have certain dreams and ambitions for what you want your child to be. And all of a sudden the child doesn't measure up to those dreams and ambitions and you have to start from scratch" (p.21).

There is a common tendency among parents to see a great deal of themselves in their children. Very often parents consider their children as an extension of themselves and displace upon them many of their own feelings and needs. Sometimes, the parent is so closely identified with the child that he cannot see the child as having any separate existence in his own right. When the child does something that is approved, the parent takes pride in the child's performance. But when the child fails, the parent feels as if it is his own failings (Hutt and Gibby, 1965).

According to Chinn et.al. (1978) and Howard (1978) parents will react to the birth of a mentally retarded child or to the diagnosis of a handicap in many different ways that are not always predictable. Howard brings evidence from a few previous studies that parental reactions to the recognition of having a disabled child is, in general, the same whether this disability is recognized at birth or during the early years of development. Yet, there is no typical reaction. It

seems from many studies that the variations in parental reactions to the birth of a mentally handicapped child are due to the parents' characteristics and personality, their past experiences and their expectations and hopes for the future. Differences in reactions can also be related to the child's characteristics and the nature of his handicap in regard to his parents' expectations of him. Kurtz (1977) suggests that "parental reaction may not be to the retardation per se but to a demolition of expectancies when they first learn that their child is mentally retarded" (p.97).

Although parents of mentally handicapped children cannot be considered a homogeneous group, and as mentioned earlier parental reactions vary to a great extent, one can still find in the existing literature recurring themes and emerging patterns in the difficult adjustment process that the parents face. Generally speaking, the literature contains numerous descriptions of fairly discreet sequential stages of adjustment experienced by parents in response to the birth of a mentally handicapped child. The resulting patterns of behaviour may vary from a more constructive form of adaptation (such as a realistic acceptance of the child's condition) to a more destructive and maladaptive form (as in rejection or denial of the retardation). The multitude of individual parental reactions may be grouped into a number of major categories of behaviour according to the type of acceptance of the child's handicap. (Hutt and Gibby, 1965).

It is of considerably great importance to understand the feelings and values of the parents with whom the child is growing up. According to Feder (1978), clinical experience has shown that satisfactory emotional development of the handicapped child depends as much way in which his parents relate to him as o cap itself. The parents' feelings about the child handicap will be a major determinant of the child's self image, whether he will

be motivated to improve as much as he can, or to what extent he will perceive himself as defective and rejected and become increasingly negativistic towards all efforts to help him. Whether the parents' expectations of the child are realistic or not will determine how much pressure he experiences, and whether they can cope with their shock and disappointment will determine whether they will tend to withdraw from him or be emotionally available to help him.

The purpose of the following chapter is to describe the dynamics of the process the parents go through in their attempt to adjust to the fact of having a mentally handicapped child, and the nature of the various kinds of parental reactions at each particular stage. The chapter will also refer to the effect of parents and child characteristics on parents' reactions to the birth of a mentally handicapped child and on their ability to fulfill their parental role.

2.1.2. The process of parental adaptation to mental retardation and to the child.

It may be stated categorically that all parents of mentally retarded children are likely to show some undesirable personal reactions to the fact that their child is retarded. Such reactions vary both in degree from one parent to another and in their particular nature, depending upon a multiplicity of intricate and closely interwoven factors. They also vary from one time to another in the life-span of a given parent. For example, the emotional reactions of a parent when he first becomes aware of his child's problem may be somewhat different from those he manifests ten years later, or the pressure of the stress situation to which he may be subjected by the retardation of the child may

increase and become more devastating over time (Hutt and Gibby, 1965). The process of accepting a handicapped child may be a very long one. It is likely to continue long after the birth of the child. The literature consists of many studies which have tried to describe the process parents have to work through in their attempt to adjust to the fact of having a mentally handicapped child. Certainly, the idea that parents experience several "stages of adjustment" in coping with the birth of a handicapped child is not new, and has appeared intermittently in the professional literature since the mid-1950's.

Blacher (1984) provides an overview of a range of studies, each one of which defines these stages and describes the parental emotional reations at each stage. He states: "this body of literature does indeed suggest that many authors are describing the same, or similar phenomenon using different terminology" (p.55). The differences in terminology are due, according to Blacher (1984) to the discrepancy between the manifest evidence concerning stages of adjustment in the empirical data and in clinical experience. Differences in terminology are also a result of the way "stages" are defined (whether they are time bound, invariant, culture bound, person-specific, etc.).
When dealing with the "stages model" one can find different opinions with regard to the idea that parents of handicapped children go through an ordered sequence of discrete stages of adjustment, before they do indeed attain a final stage of acceptance.

Wikler et.al., (1981) mention that there are two incompatible notions about the adjustment process of parents of retarded children - that parents work through their grief over time, or that sorrow is chronic. However, a stage according to Wikler et.al., (1981) is time bound.

Blacher (1984) believes that the most important factor in defining a stage is not time but the change in parental reaction. He states: "The length of time one spends in a stage is irrelevant, movement from stage to stage is defined by a noted change in parental reaction" (p.56). There is, however, great variation in the pace in which parents may move from one stage to another.

Thus, Anderson (1982) notes that some parents may go through these stages very quickly or even omit some of them; others may get stuck at any stage. Moreover, stage-like reactions may, according to Blacher (1984), occur repeatedly or to be triggered by types of crises related to the handicapped child or to stressful life events (Van Mink et.al., 1983).

The stages therefore have also been differently conceived by various investigators. Blacher (1984) in his overview of the literature, mentions that early investigators made an attempt to delineate parental reactions to a birth of a mentally retarded child by using Bowlby and Freud's theories of the phases of grief, a process which is analogous to the stages of adjustment. For example, Bowlby identified the phases as grief, despair and withdrawal, while Kennedy (1970) also describes three stages (protest, despair and withdrawal) in mothers' reactions to having a mentally handicapped child. More recently Huber has adapted Kubler-Ross' stages regarding death and dying when defining the stages which he found that the parents go through: denial, anger, bargaining, depression and acceptance (Blacher, 1984).

In order to overview the literature which refers to the stages model and to review some ideas on this issue, Blacher's grouping of the various taxonomies (1984) will be used. Blacher divides the studies into three major groups.

Each group represents a particular stage in the process of adaptation and parents' typical reactions in regard to that stage.

2.1.2.1 Initial Crisis Responses

Most investigators have identified a stage representing initial reactions that parents experience upon the birth of their handicapped child or when they first learn about the diagnosis. This stage is generally regarded as one of crisis, or strong emotional reaction as a result of becoming suddenly exposed to a reality of which the parents were previously unaware; however, other investigators suggest that formal diagnosis only affirms what parents already know.

A writer of the latter persuasion is Kurtz (1977) who asserts that in many cases the diagnosis of mental retardation is actually a confirmation of parental suspicion rather than a new and surprising finding, since many parents draw their own conclusions before the child is examined by a diagnostician. In fact, it is possible that the same child has been evaluated many times, since the parents may visit many clinics in their search for 'the golden key'. Consequently it may be the confirmation of retardation which is a shock to some parents rather than its revelation.

In similar vein, Featherstone (1980) suggests that during the period of suspicion when the parents are aware that something is wrong but the diagnosis is not yet clear, the most typical parental reaction is fear which presents itself as an inner dialogue. One inner voice calls the parents to admit that something is wrong with the child, but a more reassuring voice tries to deny this suspicion. Fear of the unknown or of the

possibility that these suspicions may be confirmed is the most typical reaction at this stage.

Despite the views of writers such as Kurtz and Featherstone, the predominant theme in the literature is that a crisis occurs when parents first authoritatively learn that their child is mentally retarded. (Michaels and Schuman, 1962; Mercer, 1966; Gumz and Gubrium, 1974; Margalit and Raviv, 1983; Blacher, 1984). Mercer (1966) defines crisis as "A situation in which there is a wide divergence between role expectations and role performance" (p.19). Margalit and Raviv (1983) use Kaplan's definition of crisis in the family - "A situation in which the families' normal problem-solving skills lose their previous efficiency and the usual support resources are not longer adequate". (p.163).

Blacher (1984) suggests that the most typical parental reactions during the period of the initial crisis are forms of shock, denial and disbelief. As a mother in Glendinning's study (1983) states: "It was terrible when we first knew that it was like this. It was a terrible shock". (p.26).

This mother and the other parents in Glendinning's study clearly had no doubts that it was preferable to know about the child's problem as soon as possible. They felt that the later they found out, the more difficult it would be for them to adjust to the knowledge of their child's disability.

In a situation of shock when the individual feels his security threatened, he defends against the offensive force. Denial is a defence mechanism that may arise in reaction to this threat (Chinn et.al., 1978).

Denial is a common reaction, providing a form of self protection against painful realities. Parents may deny the reality of retardation and claim that the child is lazy or unmotivated, or they may search for a cure or some kind of therapy to relieve the problem.

Mourning or grief reactions, feelings of detachment and bewilderment or withdrawal are all typical of the initial stage, each representing different individual parental responses to crisis. (McMichael, 1971; Howard, 1978; Chinn et.al., 1978; Featherstone, 1980; Blacher, 1984; Drew et.al., 1984). Howard (1978) mentions that the mourning process cannot be totally effective when the damaged child survives. Other researchers look upon the grief reaction as a result of a loss of a dream and a hope, or as a reaction to the 'death of the normal child' (Chinn et.al., 1978). Rarely are the reactions described above viewed as positive or adaptive. However, Blacher quotes from a few previous studies which view this initial stage positively. These studies regard the abovementioned parental reactions as part of a long-term coping process which is common and normal to these parents. "Following the initial stage of shock, denial, or disbelief there appears to be a stage characterized by a continuum of these earlier reactions. Again however, a specific sequence of stages is merely implied. If it is not so, one might expect some form of regression characterized by movement of a parent from a stage representing greater adjustment to a stage representing less adjustment" (Blacher, 1984, p.65).

2.1.2.2 Continuous feelings and responses

The broad rubric of "emotional disorganization" is frequently used to describe the stage whereby parents

emotionally react to the realization that they have a child who is not "normal". Such feelings as guilt, disappointment, anger or lowered self esteem are common (Blacher, 1984).
When the handicapping condition is very evident guilt and projection of blame are probably the most common typical reactions. At this stage the parents may find that denial is not a viable means to protect their ego. Projection of blame is another commonly used defense mechanism against guilt feelings. (Chinn et.al., 1978; Howard, 1978; Drew et.al., 1984; Blacher, 1984).

Guilt can serve a useful purpose in such cases if it prevents the recurrence of certain inappropriate behaviours. However, assuming the blame will not make the handicap disappear, intense feelings of guilt can erode the parents' positive self-concept. In some cases it is even possible that the parents unintentionally may be responsible for the handicapping condition. However, according to Feathersone (1980) even parents who assume the responsibility for the situation may feel angry. Anger can be directed to oneself but also to other people, mostly professionals who are involved in the situation. Some parents direct their anger towards God as Featherstone (1980) states: "Some religious people may feel that if a healthy child is a perfect miracle of God, who creates the imperfect child, why would God create imperfection?" (p.33).

When parents are aware of their child's situation, besides guilt and anger they feel disappointed by the handicapped child. Thus, resentment and aggression may follow. "I never hated the baby, just what she was, I didn't care if she died" (Blacher, 1984, p.63). The stereotype of a good parent is warm, loving and accepting. Rejection tends to carry strong negative

overtones. It is a fact that every parent sometime rejects his or her normal child. We reject behaviour that we find unacceptable and displeasing. Very often we reject not only the behaviour but the source of the behaviour as well. When it is so easy to develop feelings of rejection toward a normal child, it is understandable why parents of handicapped children may develop such reactions.

According to Feder, 1978), guilt and overprotection may evoke resentment of the handicap, which can turn into resentment and rejection of the child. Parents often feel the child is a stigma. The child is a profound blow to the parents' self-esteem. The lowered self-esteem may create feelings of sorrow and depression, detachment in relationships and even physical symptoms.

2.1.2.3 Adjustment or acceptance

The second state of emotional disintegration is characterised by depression, denial, anger and sadness and is followed by a period of adjustment or equilibrium. The parents report gradual lessening of both anxiety and emotional reactions. There may be partial acceptance and partial denial of the handicapping condition (Howard, 1978).

The literature reveals that writers about this final stage are not unanimous in their understanding of it. Some view it as a definite stage, involving two, three or four sub-stages; others see full parental acceptance as a chimera, and suggest a permanent pattern of chronic sorrow; while yet others conceive of a continuum ranging from constructive to maladaptive parental adjustment. A final group of writers advance

the suggestion that the reactions of parents of mentally retarded children are little different from those of parents with "normal" children.

Blacher (1984) is in the first group. He asserts that even within the final stage various sub-stages have been identified. These sub-stages are those of reconstruction and reorientation. The sub-stages allow both the needs of the family and the child to be met. At this stage parents start to channel their energies into solving realistic problems of the child and the family (Michaels and Schuman, 1962).

After a gradual process parents may reach a stage of acceptance (Rosen, 1955; Howard, 1978; Chinn et.al., 1978, Drew et.al., 1984; Blacher, 1984). According to Blacher (1984) acceptance refers to parents accepting the child as well as others and themselves. The process of acceptance can be broken down further. Chinn et.al. (1978), for example, suggest that acceptance can develop in three areas:

(a) Accepting that the child has an handicap.
(b) Acceptance of the child.
(c) Acceptance of self.

Featherstone (1980) identifies four interrelated stages. She believes that acceptance "Refers to one of four parallel processes, or sometimes to an amalgam of several. First, parents acknowledge the existence of the handicap and its long term significance. Second, they begin the long, difficult task of integrating the child and the disability into their lives. Third, they learn to forgive their own errors and shortcomings. Fourth, they search for meaning in their loss" (p.215). When the parents learn to accept the situation it is a

major critical step in the healing and growing process. This step implies a recognition of the value of the child for who he is and sometimes enables parents to develop a very special and unique attachment to their child.

There is a considerable variation in the timing, duration and the behaviour characteristic of this stage of parental adjustment, as described in the literature. Blacher (1984) refers to a few studies (Rosen, 1955; Turnbull and Turnbull, 1978), that after interviewing, parents are not able to delineate any definite points in time which marked a "phase of acceptance". It seems, according to these studies, that there is a life-long need to make continual adjustments and re-adjustments to one's child who has mental retardation. Bayley (1973), who interviewed parents of adolescents and young adults, found that after living with the child for so long the parents in many cases were unaware that they had created a structure within which the family could cope with its subnormal member. This care was only possible within this structure which Bayley called "a structure for coping". Thus, even when the process of adaptation had not reached its final stage, the development of the structure for coping enabled the parents to at least adjust their lives to the daily grind resulting from the child's problem. Featherstone (1980), too, is careful to point out that parents may never reach an absolute stage of acceptance but that they are likely to experience positive feelings in a step by step movement in that direction. Similarly, Blacher (1984) points out that it is important to recognize that there is not an abrupt end to the stages of parental reaction.

The belief that adjustment is not time-bound is fundamental to the second group of theorists such as Wikler et.al, (1981) who found that parents of mentally handicapped children experience chronic sorrow rather than some kind of time bounded grief and eventual adjustment. The term "chronic sorrow" (Olshansky, 1962) refers to a clinical picture of the continuing sadness experienced by parents of mentally handicapped children and creates stress and sadness over time. Wikler et.al. (1981) and Blacher (1984) have described Searl's ideas that feelings of shock or guilt never disappear but stay on as a part of the parents' emotional life. Parents, in Searl's view, do not "adjust to" or "accept" the fact and conventional assumptions about progressive stages towards acceptance do not seem to apply.

A third variation in understanding acceptance is provided by Hutt and Gibby (1965), who prefer to describe patterns of parental behaviour which range from a more constructive form of adjustment to a more destructive and maladaptive form of adjustment. They have grouped parental reactions into a number of major categories of behaviour according to the type of acceptance of the child's retardation. The three defined categories are:

I. The accepting parent - this category of parental reaction may be regarded as being constructive and adaptive. The "accepting parent" acknowledges and accepts the reality of his child's disability in a mature manner. Such an acceptance of the child leads to many positive benefits for the child and the family unit. The child is accepted as he is and the parent perceives his own role clearly and deals with the child's problems in a realistic manner.

II. The disguising parent - this category includes modes of behaviour which attempt to disguise the child's condition. Such a parent perceives that there is "something wrong" with the child to some extent, but he cannot admit that the child's problem is a result of limited intellectual capacities. Thus, he may see the child himself as being at fault or as being a form of punishment to his parent.

III. The denying parent - the parent who as a severe emotional reaction to the stress situation, denies both to others and to himself the reality of the child's disability. This pattern of behaviour may be a result of the general maturity level of the parent and his life history. For the immature parent, greater stress creates more extensive defensive reactions and consequent maladaptive behaviour.

Finally, it must be noted that some researchers have produced clinical evidence to suggest that parents of mentally retarded children, or sub-groups of them, do not fit into any of the conceptual frameworks discussed above. (Hewatt et.al., 1970; Hart, 1970; Voysey, 1975; Kurtz 1977).

Hart (1970), for example, describes an atypical group of parents (highly educated, in a high socioeconomic status and strongly religiously oriented) who had already altered the reality of their condition so that they perceived themselves as being chosen, for a special purpose, by God to raise a special child. These parents usually emphasized the retarded child's good qualities and his special contribution to the family life.

It is of note that Hewett et.al., (1970); Voysey (1975) and [illegible] (1977) found that the vast majority of parents of a mentally handicapped child do not differ to a great extent from parents of ordinary children.

Hewett et.al., (1970) report on some studies which clearly suggest that reactions like anxiety, guilt and rejection may also be generally found to a marked degree in parents of normal children. The common tendency to relate these kind of reactions specifically and solely to parents of mentally handicapped children is considered by these researchers as creating a completely biased and prejudiced impression of such parents.

Hewett et.al.'s views are backed by other researchers. For example, Kurtz (1977) reports on Birenbaum's findings which showed that mothers of young mentally retarded children made an attempt to maintain a normal appearing family life-style, and that maintenance of such life- style seemed extremely important to these mothers. Similarly, Voysey (1975), when summing up her interviews with parents states: "Overall, the majority of parents claim that their disabled child has not had deleterious effects on their family life" (p.27).

To sum up, two main groups of approaches have been described: The first and the most common approach indicates that although parents of mentally handicapped children cannot be considered a homogeneous group, they do share some common reactions to disability. According to the second approach, which is held by only a small number of researchers, although parents of mentally handicapped children face some difficulties as a result of the child's situation, the reactions of many of them do not differ a great deal from the reactions of parents of normal children and they try to, and succeed in maintaining a 'normal' life style in spite of their difficulties.

2.1.3 The effect of parental reactions to their mentally retarded child upon their attitudes and feelings towards him

The professional literature stresses the importance of mutual bonding between parents and infant. Howard (1978) mentions a small number of studies which reveal that a mother's or father's behaviour towards the infant derives from personal family experiences, cultural background, genetic endowment and previous pregnancies. These studies also indicate that the infant's and parents' behaviour both contribute to the establishment of a life long relationship. When parents are depressed and anxious about their abnormal child's condition, it is obvious that their interaction with him will be disturbed. The mother, out of her sense of shame and grief, may reject the child and not respond to his early attempts to communicate. She may handle him perfunctorily and isolate him from others as well as from enriching experiences.

According to Feder (1978) it is difficult for parents of a disabled child to perceive the positive aspects in their child's personality. When the mother-child interactions are satisfying the mother will feel rewarded for her efforts and a reciprocal love relationship is easily facilitated. However, when the child is difficult to handle and his reactions toward his mother are poor, a vicious cycle is often set in motion as the child - in his mother's eyes - seems to be rejecting the mother by his unresponsiveness. Thus, she, in defense, often unconsciously begins to feel rejecting of the child. As a result of this continually unrewarding relationship, the mother may find herself spending only the minimal amount of time with the child. Thus, the disabled child who often needs maximum and intense stimulation if he is to progress and become aware and responsive to his environment, gradually receives less and less stimulation and becomes even less responsive and rewarding to the mother as his overall isolation and sensory deprivation increases.

Cummings et.al. (1966) found in their study that mothers of mentally handicapped children clearly derive less pleasure in relating to their retarded children than in relationships with their normal children. The fact that they bear a burden of anxiety, depression and conflict in modulating hostile feelings seems to produce tendencies towards rejection of the retarded child at the same time as overprotection is manifested.

The abovementioned studies clearly reveal that the difficulties in the parental process of adaptation have a negative impact on parents' ability to fulfill their roles in regard to their child's special needs. However, other studies (Michaels and Schuman, 1962; Hart, 1970; Hewett et.al., 1970; Bayley, 1973 and Kurtz, 1977) suggest that on the whole, parents who are able to adjust to the fact of having a mentally retarded child develop a realistic approach to the child and are able to emphasize their child's strengths and minimize his weaknesses. Accepting the child for what he is makes it easier for these parents to overcome the day-to-day difficulties of raising a mentally handicapped child and in many cases parents even find some advantages to having such a child.

2.1.4 The impact of family and child characteristics on parental adjustment to having a mentally handicapped child

Many studies on parents' reactions to the birth of a mentally handicapped child indicate that there are differences between mothers' and fathers' reactions, the way they adjust to the fact of having such a child, and to their attitude towards the child himself.

It seems to be widely agreed that family and child characteristics also play an important role and influence parental

reactions to mental retardation as well as on the parents' attitudes towards their child. In this connection the following elements will be discussed:

I. Mothers' versus fathers' reactions.
II. The family socioeconomic status and the parents' level of formal education.
III. Parental religious background.
IV. Child's age.
V. Child's sex.
VI. The severity of the handicap or the cause of the mental retardation.

2.1.4.1 Mothers' versus fathers' reactions

It is commonly accepted that both mothers and fathers are deeply affected by the presence of a mentally handicapped child in the family. Mothers, however, have been found to be more vulnerable (Cummings et.al., 1966; Cummings, 1976; Egan and Daneel, 1980; Margalit and Raviv, 1983), since they carry a greater burden of caring for the child and often lack the adaptive advantage of spending much of the day at an outside job, a situation which both interrupts the continuity of stressful contacts with the child and provides an area for self-actualization.

In their studies, Cummings et.al., (1966) and Cummings (1977) compared patterns of personality traits of mothers of different kinds of deficient children and mothers of normal children. The same comparison was made in respect of the fathers. Findings from these studies indicate that mothers of mentally retarded children differ from those of normal children in the seven following areas:

I. Increased occurrence of depressed feelings.
II. Increased preoccupation with the involved child.
III. Increased difficulty in handling anger towards the child.
IV. Feelings of increased possessiveness towards the child.
V. Decreased sense of maternal competence.
VI. Decreased enjoyment of the child.
VII. Feelings of rejection towards the handicapped child.

Crnic et.al., (1983) refer to evidence from studies which in most cases were not able to relate the mothers' depressive reaction, or their preoccupation to the severity of the child's handicap, although mothers of severely retarded children tend to be more overprotective. It seems from a few existing studies that maternal education, and even more so maternal age, are important factors affecting mothers' feelings and attitudes towards the mentally handicapped child. "Older mothers felt that their increasing age made them more susceptible to anxiety and stress, partly because they had less energy and resilience to help them to cope." (Glendinning, 1983, p.78).

As mentioned before, mothers of mentally retarded children have been found to be more depressed and preoccupied compared to fathers of such children. It may be postulated that the mothers are more emotionally aware of their feelings of depression and resentment and able to express their feelings, while the fathers are less emotionally aware and less able to express such feelings, or else they are highly defended against revealing their true feelings (Esnal and Daneel, 1980).

In this regard it is interesting to note that women have been found to be more accepting of handicapped children than are men (Crnic et.al., 1983). Yet, when compared to fathers of normal children, the fathers of mentally handicapped children demonstrated eight characteristics that were different from those in fathers of normal children.

They:

I. Were more depressed.
II. Were more preoccupied with the involved child.
III. Experienced decreased enjoyment of the child.
IV. Had decreased self esteem.
V. Experienced decreased interpersonal satisfaction with their wife and other children.
VI. Had a need for more order and routine.
VII. Were less assertive.
VIII. Had less sexual interest in the opposite sex. (Cummings, 1976).

Howard (1978) suggests that the father, relative to the mother, has fewer opportunities to help his handicapped child directly, which leads to fewer opportunities to counter-balance the sense of loss, frustration and anger. Less confrontation with the child's handicap probably creates more psychological stress for the fathers as much as it enables them to run away from the daily reality of the child.

The differences between mothers' and fathers' reactions to their mentally retarded child may create difficulties because of disagreements over the handling of the child. For example, spouse (usually the father) may blame the other one (usually the mother) for being over-anxious or overprotective (McMichael, 1971).

Glendinning (1983) concludes her findings about mothers' and fathers' reactions to their mentally handicapped child by stating that in each of the two-parent families that she studied, the father was the breadwinner for the household, even when the mother had a paid job. Conversely the mother took primary responsibility for the care of the child and the home. What was crucial, certainly to the mothers' experience of stress, was the amount of flexibility in these two roles. Sharing of the various economic and domestic commitments between parents provides a better adjustment of the parents to the situation and enables coping patterns to emerge.

2.1.4.2 Socioeconomic status and parents' level of education

The socioeconomic status and the intellectual level of the parents may affect their attitude to mental retardation and to the child. Certain lower socio-economic groups may place a greater value on physical attributes than other groups. Occupations in these groups may involve manual labour and physical disabilities may be a greater disadvantage than in groups where there are more vocational alternatives. Higher socioeconomic groups, on the other hand, tend to place a greater emphasis on education and intellectual achievements. The level of education of the parents in these families is often higher and their expectations emphasise cognitive development. Children in these families whose handicap causes limitation of cognitive skills may frustrate their parents because of their inability to achieve goals set for them by the parents. (Feder, 1978; Chinn et.al., 1978; Drew et.al., 1984).

However, Hart (1970) found that among parents with an above-average level of education and socioeconomic status, there was a tendency to consider themselves as

being chosen for the special task of raising a mentally handicapped child. These parents seem to create situations which result in their own hostility being directed toward someone other than the child.
In spite of their continuing sorrow, most of these parents consider caring for a retarded child as an enobling experience and they feel that they have gained something - usually in terms of their own character development - which otherwise they would have missed.
Using Farber's definition of crisis, Gumz and Gubrium (1972), state that mothers of retarded children who were of high socioeconomic status tended to react as if bereaved, while in lower status mothers, role crisis and difficulty in organizing self concepts for an extended period of time occurred.

Farber (1968) concludes his research study by mentioning that the higher the socioeconomic status of the family, the greater the impact on the family's emotional reaction when a child is labelled as mentally retarded. For lower socioeconomic status families, the label of retardation matters less than the child-care problems associated with the condition.

2.1.4.3. Parental religious background

The religious background may be a variable related to the degree of the effect of mental retardation on the family (Drew et.al., 1984). For some who do not believe in God, the arrival of a handicapped child may reinforce their disbelief, or they may simply accept it as a medical fact without relating it to any philosophical or religious view.

However, other parents have said that prayer played an important part in helping them to come to terms with their child's condition. Some go so far as to believe

that God has given them this child to challenge or test their faith or that they have been chosen because their faith equipped them to provide for the special needs of the child (Hart, 1970; Worthington, 1982).

Deep religious faith can, however, be a drawback if a mother feels that she is being punished for some imagined fault. Fortunately the improvement in understanding about the causation of handicap means that most people realize that "it can happen to anyone". Nevertheless in a vulnerable state when the mother suffers guilt feelings, she may find help and support from a minister or a priest. (Voysey, 1975; Worthington, 1982).

Zuk's (1959) study on mothers' guilt feelings revealed that Catholic mothers with young children were more accepting than non-Catholic mothers with older retarded children. When Catholic mothers were compared to Protestant mothers, the former again seemed to have less difficulty in accepting the child. Some other studies mentioned by Farber (1968) suggest that religion is an important factor in accepting the child and that it sometimes affects the way parents treat their children ("The martyr or chosen people syndrome", p.157).

Although there is evidence that religion is a factor which has its effect on parental attitudes towards the mentally retarded child, previous investigators have failed to explore and compare specific belief systems, and this issue remains unclear.

2.1.4.4 Child's age

Accepting the fact that from the birth of the mentally handicapped child the process of parental adaptation to mental handicap and to their particular child

starts, it is obvious to assume that parents' reactions will differ according to the child's age.
In studies where the interviewed parents had very young children, like those of Backman (1983) and Cummings et.al. (1986), the child's age and sex bore no relationship to the amount of stress felt by mothers. However, researchers who included in their sample children of different ages found evidence that parents' attitudes and feelings differ in regard to the child's age, and sometimes also according to his sex. (Farber, 1968; Bayley, 1973; Worthington, 1982; Glendinning, 1983).

Most studies reveal that over the years a more realistic, practical attitude towards the child develops. A mother of a thirty year old mentally retarded daughter states "The only thing I can say is that you've got to accept it. It's hard, isn't it, but you have to accept it" (Bayley, 1973, p.186).

Worthington (1982) notes that when the other children in the family grow up and become less dependent while the retarded child remains the only one who is still dependent on the parents; he becomes so much a part of the family that the parents never doubt their love for him and cannot imagine life without him. In fact many parents speak with great pride about the behaviour of their adult son or daughter and they feel that their effort and perseverance paid dividends. In spite of the abovementioned, when reviewing the literature on this issue one may find that the most commonly held view is that more family stress tends to occur in families of older handicapped children. (Farber, 1968; Feder, 1978; Backman, 1983).

Wikler et.al (1981) compared social workers' and parents' views in regard to difficulties experienced

by parents as a result of raising a mentally retarded child at home. The social workers tended to overestimate the distress of the parents' early experiences yet, they underestimated the distress of the later experiences. Glendinning (1983) quotes a mother saying "I could manage her when I was younger. I didn't get depressed as easily as I do now." (p.79).

It seems from the foregoing studies that the most common reaction among parents of older children is depression which according to Olshansky (1962) is "chronic sorrow" or with regard to the findings of other studies can be explained as a consequence of the development of a realistic approach to the situation.

2.1.4.5 Child's Sex

Beside Farber's findings (1960) that the ability of the father to cope was related to the child's sex and that mothers of boys were confronted with more severe problems, other studies in this respect (Cummings et.al., 1966; Backman, 1983; Margalit and Raviv, 1983) could not find significant relationships between child's sex and parents acceptance of his mental handicap.

Nevertheless, Crnic et.al. (1983) report that sex of the child was important to marital integration, as retarded male children had a more significant negative impact on the marriage.

2.1.4.6 The severity of the child's handicap

The degree of severity is another important variable affecting parental reactions to the child with a handicap. A mildly retarded child may have no distinguishing physical characteristics that suggest

retardation, and it seems from studies that the physical appearance of the child is important to the parents. (Howard, 1978).

The mildly retarded child may not only have all the outward appearances of a normal child, but his behaviour may also be more like than unlike that of a normal child. When the parents feel that the child is not rejected by the outside world it will help them to accept the child easily (Chinn et.al., 1978).

According to Begab (1963) the nature of the child's behaviour as a result of his handicap will also influence the ability of the parents to accept him. "Much depends on the family's definition of acceptable behaviour" (P.55). Worthington (1982) supports this contention by stating: "A child who is of pleasant temperament, co-operative behaviour and is socially acceptable is usually described as no trouble at all or a real blessing, even though he may be severely retarded in the intellectual sense. On the other hand, those whose children display bizarre or wild behaviour, who have aggressive or hyperactive outbursts, who seem totally unresponsive to the request of others or prohibit outings feel their lives are dominated by stress" (p.43).

Another opinion on the degree of severity and its impact on parental acceptance of the child's problem has been suggested by Chinn et.al. (1978). They found that although the initial effect of the more severely handicapped child on his parents is great, the fact that in many cases the parents are aware of the problem at an earlier stage helps them to adjust to it. Conversely, when the parents are aware that something is wrong, but are only at a later stage, faced with a final diagnosis, the process of adjustment that they have to go through may be even harder.

To sum up: It seems that the nature of the child's problem and the way it influences his behaviour influences parents adjustment to the situation and their attitudes to the child more than the degree of severity *per se*.

The findings of the present study in regard to the former discussed issues are introduced in the next section of this chapter.

2.2 FINDINGS OF THE PRESENT RESEARCH STUDY

2.2.1 Introduction

This section introduces the findings of the research study in regard to the process of parental adaptation and its impact on parents' attitudes toward their child. The section will be divided as follows:

I. A comparison between the parents of the younger and the older children (Group A versus Group B).
II. A comparison between mothers and fathers.
III. A comparison between mothers and fathers in regard to child's age (mothers A versus mothers B, fathers A versus fathers B).
IV. A comparison of mothers versus fathers within groups A and B.
V. The impact of child and family characteristics on the parental process of adaptation to the child and parents attitudes towards him.

The presentation includes results of both research tools - the QRS and the interview schedule.

2.2.2 A comparison between parents of the younger and the older children (Group A versus Group B)

Eight out of the fifteen QRS scales deal with issues which may be related to the subject of parental acceptance of the child's mental handicap and the influence of the handicap on the parents' feelings, behaviour and attitude towards the child. The eight scales compose of two parts. Firstly there are scales which deal with the influence of the child's problem on the parents' views about their way of life, their feelings towards themselves and the child and their behaviour as a result of the child's problem.
The scales are:

1. Poor health/mood.
2. Excess time demand.
3. Negative attitudes towards index case.
4. Overprotection/dependency.
6. Overcommitment/martyrdom.
7. Pessimism.

Secondly, there are two scales which cover the parents' views on the child's problems arising from his special situation.

The scales are:

11. Physical incapacitation.
15. Difficult personality characteristics.

Results for scales 1, 2, 3, 4, 6 and 7 are presented in Table 9.

Table 9

Means, SD, Df, and Probabilities for Group A versus Group B according to Scales 1, 2, 3, 4, 6, 7, of the QAS (t test)

Scale	Group A				Group B			
	Mean	SD	Df	P	Mean	SD	Df	P
1. Poor Health/Mood	3.1	2.3	105.3	0.1	3.8	2.6	109	0.1
2. Excess time demand	4.6	2.5	106.	0.7	4.5	2.3	106	0.7
3. Negative attitudes towards idex case	9.6	3.5	105.5	0.2	8.8	3.0	106	0.2
4. Overprotection/ Dependency	5.5	1.9	90.	0.3	5.9	2.7	102	0.3
6. Overcommitment/ Martyrdom	3.7	0.9	108	0.9	3.7	1.1	109	0.9
7. Pessimism	3.0	2.2	99.4	0.01	4.1	2.	100	0.01
			N=58				N=54	

Results from the comparison between the two groups reveal that the differences in scales 1, 2, 3, 4, 6 are not statistically significant. However, the mean scores for Group A in 2 and 3) are higher compared to Group B. This suggests that the child's problem has slightly more of an impact on the feelings, way of life and behaviour of the parents of the younger children compared to the parents of the older ones. With regard to pessimism (scale 7) which is also related to this subject, it is demonstrated that the difference between the groups is statistically significant (p=0.01). The parents of the older children are more pessimistic compared to the parents of the younger ones. This is the only aspect in which the influence of the child's situation is stronger for the parents of the older children.

A comparison of the QAS scales which relate to parents' views on the child's special problems is presented in Table 10.

Table 10

Means, SD, Df, and Probabilities for Group A versus Group B according to Scales 11, 15 of the ORS (t test)

Scale	Group A				Group B			
	Mean	SD	Df	P	Mean	SD	Df	P
11. Physical incapacitation	5.1	2.3	101.2	0.0001	[illegible]	1.7	107	0.0001
15. Difficult personality characteristics	13.2	4.2	90.8	0.0001	10.0	3.4	97	0.0001
	N=58				N=54			

A comparison of the parents' views on the child's situation and his special problems according to the two groups reveals that the differences in both scales (11 and 15) which relate to this area are highly statistically significant (p=0.0001). Parents of the younger children are more intensely aware of their child's physical incapacitation and difficult personality characteristics compared to the parents of the older children.

When responding to the schedule the parents were asked to recall the initial period when they suspected that the child had a problem or they were told about it. For a comparison between the younger and the older parents' initial reactions, see Table 11.

Table 11

Frequencies of timing of parents' first suspicions of the child's problem by groups (A & B) (in percentages)

Timing of parent's suspicion	Group A	Group B
1. I didn't suspect anything.	44.8	51.8
2. During pregnancy.	1.7	3.6
3. At birth or a few days after.	15.5	13.3
4. After 4 - 8 months.	20.8	20.3
5. From 1 - 2 years.	15.5	5.5
6. From 3 - 4 years.	-	5.5
7. When the child had to go to school.	1.7	-
Total	100.0	100.0
	N=58	N=54

Results show that the parents of the younger children recalled learning about the problem, at an earlier stage than did the parents of the older children. More of the younger children were tested before the diagnosis was made, in most cases by a physician, than were the older children. (See tables 8A, 9A in Appendix 4).

Parents' initial reactions to the child's diagnosis are presented in Table 12.

Table 12

Frequencies of parents' initial reactions to the child's diagnosis by groups (A & B) (in percentages)

Parents' reaction	Group A	Group B
1. I knew something was wrong and was upset.	5.1	7.4
2. Shocked, couldn't believe it.	46.5	44.6
3. Confused, felt bad about the way they told us, was angry.	17.2	14.8
4. Upset but accepted it after sometime.	31.2	27.7
5. I was worried.	-	5.5
Total	100.0	100.0
	N=58	N=54

As the differences are less than 10% they cannot be considered meaningful. Results reveal that many of the parents in both groups were shocked and could not believe that their child could be labelled as mentally retarded. However, when the parents were asked to describe their current feelings, there were some marked differences between groups as presented in Table 13.

Table 13

Frequencies of parents' current reactions towards the child's handicap by groups (A & B) (in percentages)

Parents' reaction	Group A	Group B
1. The child will grow out of it.	25.8	1.8
2. I have accepted. The child will improve.	48.5	37.0
3. You have to accept it.	15.5	37.0
4. I am worried about the future.	6.8	20.5
5. It has changed my lifestyle.	1.7	-
6. It has enriched our family life.	1.7	3.7
Total	100.0	100.0
	N=58	N=54

This table reflects that among the parents of the younger children there were some who still believed that "the child will grow out of it"; only a few of the parents of the older children had the same hope. The optimists among the parents of the older children did not lose hope for improvement, but many of them reacted with "you have to accept it".

When asked about the timing of sharing their problems with other people, and whom they chose to tell about it, there were no marked differences between the groups. The majority of the parents told the relatives immediately after they learned about the child's problem. The parents of the older children, more than the other group, reported that the relatives were initially shocked but learned to accept it. On the other hand, the parents of the younger children felt that, like themselves, the relatives were shocked and it was hard for them to accept the fact. (See Tables 10A, 11A in the Appendix 4).

2.2.3 A comparison between mothers and fathers

A comparison between mothers and fathers according to the eight relevant QRS scales did not reveal any statistically significant differences for any of the scales. It seems that the parents' views on these subjects are quite similar. (See Table 12A in Appendix 4). However, when responses to the schedule were analysed the reactions of the two parent groups to the information received from the physician differed. (See Table 14).

Table 14

Frequencies of mothers versus fathers initial reactions to the child's diagnosis (in percentages)

Parents' reaction	Mothers	Fathers
1. I knew something was wrong and was upset.	8.3	3.8
2. Shocked, couldn't believe it.	53.3	36.5
3. Confused, felt bad about the way they told us, I was angry.	18.3	13.4
4. Upset but accepted it after sometime.	18.5	42.5
5. I was worried	1.6	3.8
Total	100.0	100.0
	N=60	N=52

Results reveal that mothers more so than fathers reported being shocked and unable to believe it, while fathers reported more about feeling upset and coming to accept it after some time.

When asked about their current feelings there were no marked differences between the parents. A large group of mothers and fathers reported that they accepted the fact and hoped that the child would improve (See Table 13A in Appendix 4).

Results show no marked differences about the timing of when parents felt that they were able to confide their problem to others and also in whom to confide. They also felt relatively the same about the reactions of the people with whom they chose to share their feelings. A large group of parents reported that they had told their own parents or siblings immediately after they heard the news. The fathers more than the mothers felt that their relatives accepted the fact and were supportive. (See Tables 14A and 15A in Appendix 4).

2.2.4 A comparison between mothers and fathers in regard to child's age.

2.2.4.1 A comparison between mothers of Group A versus mothers of Group B.

When mothers of Group A were compared with mothers of Group B there were no statistically significant differences in five of the six QRS scales relating to part I (parents' feelings and behaviour towards the child). In scale 7-pessimism - the difference between the two groups of mothers is statistically significant ($p=0.05$). Group B's mothers are more pessimistic.

In the two scales concerning the parents' views on the child's incapacitation (scale 11) and difficult personality characteristics (scale 15), the differences are also statistically significant.

Scale 11 - $p=0.0001$

Scale 15 - $p=0.002$

Table 15, presents further information in regard to the above-mentioned results.

Table 15

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

Scales	Mothers A				Mothers B			
	Mean	SD	Df	P	Mean	SD	Df	P
1. Poor Health/Mood	3.2	2.3	54.7	0.2	4.1	3.0	57	0.2
2. Excess time demands	4.7	2.7	53.7	0.4	5.2	2.1	56	0.4
3. Negative attitudes towards index case	9.9	3.9	56.0	0.1	8.6	3.1	57	0.1
4. Overprotection/ Dependency	5.5	1.8	48.2	0.4	6.0	2.8	55	0.4
6. Overcommitment/ Martyrdom	3.7	0.8	54.9	0.6	3.8	1.0	1	0.6
7. Pessimism	3.0	2.5	52.0	0.05	4.1	1.9	54	0.05
11. Physical incapacitation	5.3	2.5	49.8	0.0001	2.6	1.7	56	0.0001
15. Difficult personality characteristics	13.3	4.1	50.0	0.002	10.0	3.6	52	0.002
	N=30				N=30			

Results regarding mothers' attitudes towards the child's handicap reveal that mothers of the younger children experienced the effect of the child's physical incapacitation and difficult personality characteristics on their daily life more acutely than mothers of older children.

2.2.4.2 A comparison of fathers of Group A versus fathers of Group B.

Results of the comparison between the fathers in both groups show that in the six QRS scales relating to the impact of the child's problem on the parents' feelings and behaviour, the differences between the two groups of fathers are not statistically significant but in the two scales concerning the child's physical incapacitation (11) and difficult personality characteristics (15), the differences are statistically significant.
Scale 11 - p=0.0001
Scale 15 - p=0.01

Fathers of the young children score higher in these two scales. (See Table 16A in Appendix 4).

2.2.5 A comparison of mothers versus fathers within Groups A and B

2.2.5.1 Mothers A versus Fathers A

A comparison between mothers and fathers in Group A did not reveal statistically significant differences for any of the QRS scales discussed in this chapter. It seems that the experiences of the parents of the young children are similar when it comes to these issues. (See Table 17A in Appendix 4).

2.2.5.2 Mothers B versus Fathers B

A comparison between the parents within Group B gave almost the same picture as Group A.
The experiences of both parents were similar regarding these issues except for scale 2 (Excess time demand), in which the difference is statistically significant (P=0.02) The mothers more than the fathers of the older children still felt that they had to spend a lot of time with their child in spite of his older age. (See Table 18A in Appendix 4).

2.2.6 The impact of child and family characteristics on the parental process of adaptation and attitudes to the child

This section includes results of the research study in regard to the impact of child and family characteristics on parental acceptance of the child's problem, and on their attitude to the child. The following characteristics will be discussed:

I. Child's sex.
II. The causation of the mental retardation and the child's physical condition.
III. Child's birth order.
IV. Parents' level of formal education.
V. Parents' occuption.
VI. Parents' religious background.
VII. The existence of a mentally handicapped relative in the family (beside the child).

2.2.6.1 Child's Sex

In respect to children's sex, it must be kept in mind that there were more males among the older children and that this might have an influence on the results discussed below. A comparison between parents of males and females in regard to timing of the initial learning about the child's problem is presented in Table 16.

Table 16

Frequencies of answers to the question: "When was the first time you were told that your child is mentally handicapped?" by child's sex, (in percentages)

Answer	Males' Parents	Females' Parents
1. At birth or a few days after.	13.6	32.6
2. When the child was 4-8 mths old.	33.3	26.0
3. When the child was 1-2 yrs old.	27.3	21.7
4. When the child was 3-5 yrs old.	6.2	13.2
5. When the child was 6 or more years old.	19.6	6.5
Total	100.0	100.0
	N=66	N=46

Results show that parents of females learnt about their daughters' problem at an earlier stage than parents of males. However, the parents of females felt that they had a less detailed diagnosis, while more males' parents received the information that the child had no future and he would die young. (See Table 19A in Appendix 4).

Parents' initial reactions to the child's diagnosis seem to differ in regard to his sex. The results are presented in Table 17.

Table 17

Frequencies of parents' initial reactions to child's diagnosis by child's sex (in percentages)

Parents Reaction	Males' Parents	Females' Parents
1. I knew that something was wrong, and was upset	9.2	2.7
2. Shocked, couldn't believe it	48.4	41.3
3. Confused, felt bad about the way they told us. I was angry.	16.7	15.2
4. Upset, but accepted it after some time.	21.2	40.3
5. I was worried	4.5	0.5
Total	100.0	100.0
	N=66	N=46

It seems that generally it was easier for the female's parents to accept their child's diagnosis, yet among them there were still parents who believed that the child "will grow out of it"; while with the males, parents' initial reaction was disbelief and shock, although over time they developed a more realistic attitude towards the situation. (See Table 20A in Appendix 4).

When the parents shared their problem with others, the reactions of the people who received this information were also quite similar, yet more parents of girls felt that their relatives and friends accepted the fact easily (See Table 21A in Appendix 4).

2.2.6.2 The cause of the child's mental retardation and his physical condition

The cause of the child's mental retardation may affect some of the parents' perceptions of how they learnt about the child's problem.

The timing of parental suspicions about the child's problem seems to be influenced by the causation of the child's mental retardation, as can be seen in Table 18.

Table 18

Frequencies of timing of parents' first suspicions of the child's problem, by the cause of the mental retardation (in percentages)

Timing of Parent's Suspicion	Unknown	Genetic disorders	Brain Damage
1. I didn't suspect anything	55.5	56.3	33.3
2. During pregnancy	-	4.8	2.7
1. At birth or a few days after.	0.3	19.5	13.8
2. After 4 - 8 months	5.5	12.2	33.3
3. From 1 - 2 years	27.7	4.8	13.8
4. From 3 - 4 years	5.5	2.4	2.7
5. When the child has to go to school.	5.5	-	0.4
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Results reveal that many of the parents of children with genetic disorders and mental retardation of unknown actiology did not suspect that something was wrong with the child, while parents of brain damaged children more than other parents did suspect something was wrong with the child as a result of his slow development. The minority of parents of children with genetic disorders and mental retardation of unknown actiology who did suspect a problem developed this feeling as a result of the fact that the child looked sick or different or because of his slow development. (See Table 22A in Appendix 4).

The causation of the child's mental retardation bore a relationship to the time when the parents were first confronted with the diagnosis. The differences in timing are presented in Table 19.

Table 19

Frequencies of answers to the question: "When was the first time you were told that your child is mentally retarded?" by cause of the mental retardation. (in percentages)

Answer	Unknown	Genetic disorders	Brain damage
1. At birth or a few days after.	5.5	41.4	16.6
2. When the child was 4-8 mths.	11.3	34.3	33.5
3. When the child was 1-2 yrs.	33.3	19.5	30.5
4. When the child was 3-5 yrs.	22.2	4.8	5.6
5. When the child was 6 or more.	27.7	-	13.8
Total	100.0	100.0	100.0
	N=18	N=41	N=36

The first to be told were the parents of children with genetic disorders, while in cases where the reasons were unknown, it took three or more years until many of the parents received an initial diagnosis.

Parents of children with mental retardation of unknown aetiology more than others were told that the child was "slow but will grow out of it". They were also told that the child would need special schooling. The words "mental retardation" were mentioned more frequently when the child suffered from brain damage or genetic disorders. (See Table 23A in Appendix 4).

Parents' reaction when they first learnt about the child's problems seem to differ according to the cause of the mental retardation, as shown in Table 20.

Table 20

Frequencies of parents' initial reactions to the child's diagnosis, by the cause of the mental retardation (in percentages)

Reaction	Unknown	Genetic disorders	Brain damage
1. I knew something was wrong, and was upset.	11.3	-	11.1
2. Shocked, couldn't believe it	33.3	63.5	33.3
3. Confused, felt bad about the way they told us. Was angry.	16.6	14.6	11.1
4. Upset, but accepted it after sometime.	38.8	21.9	36.2
5. I was worried.	-	-	8.3
Total	100.0	100.0	100.0
	N=18	N=41	N=36

The parents' initial reaction when learning about the child's retardation differs according to the cause of mental retardation. In cases were the reason was unknown the parents tended to accept the facts more easily. The parents of children with genetic disorders were most prone to be shocked, and could not believe it, but over the years some of them became more realistic and learned to accept the fact.

When asked about the reactions of people with whom they decided to share their problems, parents of children who suffer from genetic disorders felt more than other parents that they were accepted by their relatives and friends. Parents of brain damaged children reported about being supported by their relatives and friends (See Table 24A in Appendix 4). In addition to the causation of the child's mental retardation, his physical condition also influenced parents' attitudes toward him and their ability to accept the situation.

Parents who had perceived their child's physical condition as fair tended to suspect that there was something wrong with him earlier than parents who had perceived their child's physical condition was good. Those parents who reported 'fair' physical condition felt that the child looked strange or was very sick, whereas the children in 'good' health only gave rise to their parents' concern when their development was slow. (See Table 25A in Appendix 4).

The impact of the child's physical condition on the parents' initial reaction to the diagnosis is presented in Table 21.

Table 21

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

Reaction	Good physical condition	Fair physical condition
1. I knew something was wrong, and was upset.	5.7	8
2. Shocked, couldn't believe it	43.6	52
3. Confused, felt bad about the way they told us. Was angry.	13.7	24
4. Upset, but accepted it after sometime.	33.6	16
5. I was worried.	3.4	-
Total	100.0	100
	N=87	N=25

Results reflect that the parents whose children's physical condition was fair, were generally shocked or could not believe the bad news. They also felt confused about the way they were told about the child's problem. When the child's physical condition was good it seemed to help the parents to accept the situation, nevertheless some of them were worried about their child's future.

2.2.6.3 Child's birth order

In considering the results in regard to child's birth order, it must be noted that there are more third or subsequently born children among the older group. Findings of the study reveal that the child's birth order had no marked effect on parents' initial reactions when they first learnt about the child's problem. A large group of them were shocked regardless of the child's birth order. (See Table 26A in Appendix 4).

When asked about their current feelings, the parents of the first born child seemed to be more optimistic about improvement in the child's situation than parents of the third or subsequently born children who mentioned "you have to accept it" and focused on their worries about the future. (See Table 27A in Appendix 4).

2.2.6.4 Parents' level of formal education

Results of a comparison according to the parents' level of formal education did not show any marked difference between parents with lower or higher education with regard to the time that they first suspected that there was something wrong with the child. However, the more highly educated parents recalled that they were told about the problem at an earlier stage (at birth or a few months later) while the parents with lower education recalled being told only when the child was six or more years old. (See Tables 28A, 29A in Appendix 4).

The more highly educated parents mentioned more frequently that when they first heard about the child's problem, they recalled being shocked and that it was hard for them to accept it. (See Table 22).

Table 22

Frequencies of parents' initial reactions to the child's diagnosis, by their level of formal education (in percentages)

Parents' reaction	Under Matric	Matric and Post
1. I knew something was wrong, and was upset.	3.2	9.8
2. Shocked, couldn't believe it.	39.3	52.9
3. Confused, felt bad about the way they told us. Was angry.	18.3	13.7
4. Upset, but accepted it after sometime.	36.0	21.7
5. I was worried.	3.2	1.9
Total	100.0	100.0
	N=67	N=51

It seems from the results that for parents with lower education it was much easier to accept the fact of having a mentally handicapped child. These parents were also more optimistic about the ability of the child to improve. When asked about the reactions of the people with whom they decided to share the problem, the parents with lower level of formal education felt that their relatives and friends were supportive to a greater extent than did the more highly edu ated parents. (See Table 30A in Appendix 4).

2.2.6.5 Parents' occupation

A comparison between working mothers and housewives revealed that more of the working mothers than the housewives suspected that something was wrong with the child. Their suspi ons arose from the child's slow development. (See Table 31A in Appendix 4).

Differences in mothers' initial reactions to the child's diagnosis can be noted in Table 23.

Table 23

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

Reaction	Working Mothers	Housewives
1. I knew something was wrong, and was upset.	6.5	6.0
2. Shocked, couldn't believe it.	36.9	51.5
3. Confused, felt bad about the way they told us. Was angry.	10.8	19.7
4. Upset, but accepted it after sometime.	45.8	18.3
5. I was worried.	-	4.5
Total	100.0	100.0
	N=23	N=33

Results reveal that for the housewives it was harder to accept the child's mental handicap and they were in a shock situation to a greater extent than the working mothers. These housewives were also worried about the child's future to a greater degree. However, when asked about their current feelings the results reflect that the housewives were able to overcome the initial shock and they accepted the situation. (See Table 32A in Appendix 4).

When fathers of lower skills were compared to those with higher skills it was found that the former recalled being told about the child's problem at a later stage. (See Table 33A in Appendix 4).

There were no marked differences in fathers' initial reactions to the diagnosis, in regard to their occupation. (See Table 34A in Appendix 4).

2.2.6.6 Parents' religious background

In analyzing the results regarding the relationship between parental religious background and their ability to accept the child and his situation, it must be borne in mind that there were slightly more Jewish parents among the parents of the older children.

Results of the comparison between parents according to their religion illustrates that the Jewish parents suspected earlier than the Catholics and the Protestants that something was wrong with the child. (See Table 35A in Appendix 4).

The major reason given for the Jewish parents' suspicions were the slow development of the child. They also felt that the physician gave them many diagnoses before the final one. These findings are presented in Table 24.

Table 24

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

Answer	Catholics	Protes-tants	Jews
1. The child is slow but will improve in the future.	5.2	4.2	-
2. We received many diagnoses before the final one.	5.2	14	27.7
3. The child is mentally retarded.	47.3	30.9	22.2
4. The child will have to go to a special school.	21.3	23.9	33.3
5. The child must go into residential care.	10.5	7.3	5.5
6. The child has no future, he will die early.	10.5	19.7	11.3
Total	100.0 N=79	100.0 N=71	100.0 N=18

The Catholics, more than the others, recalled that the only thing they learned from the physician was that the child was mentally retarded.

When asked about their reaction at the time when they first learned that the child had a problem, it seems that for the Catholics it was the most difficult to accept the fact. The Jewish parents and the Protestants felt angry about the way they had been told about the child's problem. As to their present feelings, among the Catholics there were more parents who still believed that the child could be cured. The Jewish parents were more realistic and felt that "one has to accept it". The Protestants were the most worried about the child's future. (See Tables 36A, 37A in Appendix 4).

Results reflect a marked difference in the reactions of the people whom the parents chose to tell about the child's problem. The Catholics felt that for their relatives, as for themselves, it was hard to accept the fact. The Protestants recalled that their relatives after the first shock learned to accept the fact. The relatives of the Jewish parents advised them to place the child in an institution to a greater extent than did the relatives of the other groups. (See Table 38A in Appendix 4).

2.2.6.7 A mentally handicapped relative

The fact that there were more parents with a mentally handicapped relative in the group of the older children must be borne in mind when analyzing the following results

Differences in parents' initial reactions to the child's diagnosis in regard to having a mentally handicapped relative are shown in Table 25.

Table 25

Frequencies of parents' initial reactions to the child's diagnosis, by having a mentally retarded relative (in percentages)

Reaction	A mentally retarded relative	No mentally retarded relative
1. I knew something was wrong, and was upset.	9.2	5.5
2. Shocked, couldn't believe it.	27.2	50.0
3. Confused, felt bad about the way they told us. Was angry.	22.7	14.4
4. Upset, but accepted it after sometime.	40.9	26.6
5. I was worried.	-	3.5
Total	100.0	100.0
	N=22	N=90

It seems from the results that having a mentally handicapped relative helped the parents to accept the facts about the child's problem. For the parents who did not report having a mentally handicapped relative, it was a shock and among them there were many who could not believe that the child was not normal. These parents also reported that their relatives and friends were shocked at hearing about the child's situation. Parents who had a mentally handicapped relative prefered not to share their problem. (See Table 39A in Appendix 4).

A summary and a discussion of the research study's findings described in this section is contained in the following part of this chapter.

2.3 SUMMARY AND DISCUSSION

Parents' reactions to the birth of a mentally handicapped child, or when first facing the fact that their child is mentally retarded, have often been described in the literature as important factors influencing the development of a unique family lifestyle.

Many studies have made the effort to dynamically delineate parental emotional reactions using a "stages model". These studies have tried to link typical emotional reactions to each stage and thereby to illustrate the ongoing changes in parents' attitudes and feelings towards their mentally handicapped child and his problems. (Rosen, 1955; Turnbull and Turnbull, 1978; Howard, 1978; Chinn et.al 1978; Drew et.al., 1984; Blacher, 1984).

In addition to the "stages model", Hutt and Gibby (1965) have suggested three patterns of behaviour which are common among parents of mentally retarded children, and which represent the degree of adjustment to the child and his problems as manifested in parents' behaviour and attitudes towards him.

Sections of the two research tools used in the present study were aimed at finding out whether differences occurred over the years in parents' feelings and attitudes towards their child and his handicap. Thus, the QRS referred mainly to parents's present feelings in regard to these issues, and in addition, by reacting to the interview schedule, the parents had to recall their initial feelings when they were first confronted with the child's problem. A comparison of parents's initial reactions with their present feelings may lead to a dynamic description of the various stages parents went through in the process of adaptation.

When the parents were asked to recall how and when they first learnt about the child's problem, there were some marked differences between the experiences of the parents of the younger and the older children. The former recalled being confronted with the bad news at

an earlier stage. A physician told them about the situation, in most cases after testing the child. Among the older children there were fewer parents whose children were tested before the diagnosis was made, and moreoever this usually took place at a later stage.

Beside the fact that recall must have been easier for the parents of the younger children, the differences may be due also to the development of medical and social services and the improvement of the diagnostic process in recent years. For the young parent who suspects that something is wrong with his child there are more and better services currently available in his community which makes it much easier to obtain professional help at an earlier stage.

Although, as mentioned before, there were differences in the timing and circumstances under which the parents of the younger and the older children first learnt about the child's problem, the emotional reactions of the majority of them (in both groups) seemed to be similar. Chinn et.al. (1978) and Howard (1978) have mentioned that, in general, parents initial reactions to the fact of having a disabled child are the same whether the diagnosis is made immediately after the birth of the child or later, after a few years. The above-mentioned researchers also stress the idea that no single typcial reaction could be found. Such reactions depend on parents' past experiences, their personality and personal characteristics. However, in this study the majority of parents described two main reactions - shock, and disbelief. Shock and disbelief are typical emotional reactions in a crisis situation.

It seems that, as has been found in many previous studies (Michaels and Schuman, 1962; Mercer, 1966; Gumz, 1972; Margalit and Raviv, 1983; Blacher, 1984), the majority of the parents who participated in this study experienced a crisis situation as a result of learning about their child's problem.

While parents' initial reactions seem to be similar regardless of the child's age, results reveal some differences in parents' opinions

about their present feelings in regard to the child's problem and its impact on their life.

Although the differences in parents' reactions to the relevant QRS scales are in most cases not statistically significant, the fact that the mean scores for the group of the parents of the younger children are relatively higher suggest that the child's situation has probably, at that stage, a greater emotional impact on their life and is a strong influence on the nature of their attitude to the child and his problem, compared to the older parents, whose life although still greatly influenced by the child's situation is affected to a lesser degree.

The most striking difference was found in parents' reactions to the seventh scale of the QRS - Pessimism. The older parents seemed to be much more pessimistic than the younger ones, and the difference was statistically significant ($P=0.01$).

Parents' reactions to some of the interview schedule questions in regard to this issue, illuminate the differences in their opinions, in relation to the child's age, to the impact of the child's problem on their life, and their ability to adjust to the situation.

Overall, it seems that the differences in attitudes between the parents of the younger and the older children represent the fact that each group had reached a different stage in the process of adaptation.

The general attitude of the parents of the younger children reveals that many of them have not yet overcome the initial crisis. (Blacher, 1984). There are some among them who still believe that the child "will grow out of it". They feel the strong impact of the child's problem on their mood and health. Their attitude to their child reveals their mixed feelings of anger and hostility, together with guilt, which sometimes leads to overprotection and over-commitment to the child. Such an emotional state is considered by

most researchers to be typical of the first and second stages in the process of adaptation (Blacher, 1984).

The predominant feeling among the parents of the older children is their pessimistic general attitude to life, and to their child's situation in particular. The findings of both research tools show that in this group more parents probably reached the third stage in the process of adaptation, adjustment and acceptance (Blacher, 1984). In their attempt to adjust to the situation, these parents have developed a more realistic approach.

The optimists among them still have some hope that the child's condition will improve, but many feel that "you just have to accept it". This realistic approach probably created the pessimistic attitude which was found to be so common among the parents of the older children. This is probably the "price" the parents "pay" for their ability to adjust to the child and his problem.

The development of the aforementioned pessimistic attitude to life has been described in some previous studies, which referred to Olshansky's (1962) concept of "Chronic sorro . (Olshansky, 1962; Featherstone, 1980; Wikler et.al., 1981; Blacher, 1984). The commonly held view of these researchers is that parents of mentally handicapped children experience chronic sorrow which is not time bound, and which over the years, becomes part of their emotional life and creates a particular atmosphere in the family.

The degree to which parents can adjust to having a mentally handicapped child was found to have a relationship to two important issues, namely:

the ability to share the problem with others; and
their attitude towards the disabled child.

According to the findings of this study, the majority of the parents in both groups were able to share their problem with their relatives shortly after they learnt about it. However, while the

parents of the younger children felt that their relatives, like themselves, were shocked and could not accept it, the older parents felt that their relatives, after the first shock, were able to accept the child. Here again, the parents' beliefs about others' reactions resembled their own feelings, and it seems that improved adjustment to the situation by the parents facilitates acceptance by others, and/or vice-versa.

Results from the two research tools (the QRS and the interview schedule) reflect a highly statistically significant difference in parents' attitudes towards the mentally retarded child, in regard to his age. The younger parents are much more bothered by the child's difficult personality characteristics and his physical incapacitation while the parents of the older children seem to become resigned to their child's special features. The relationship between parents' emotional reactions to the stressful event of having a mentally retarded child and their attitude to the child himself, has already been discussed in previous studies (Howard, 1978; Feder, 1978). These studies stress the difficulties that parents of disabled children experience in relating to the positive aspects of their child's personality.

The burden of care for a child with special needs together with the feeling of being rejected by him (as a result of his poor ability to interact) affects the parents' ability to relate to the child and to enjoy parental tasks. However, when beginning to adjust to their special child, the parents learn to accept him for what he is. It becomes easier for them to overcome the day-to-day difficulties of raising him and they are able to appreciate the positive aspects of his personality. The findings of the study indicate that, in spite of the better adjustment of the parents of the older children, and the lesser dependency of their growing child, mothers of the older children feel strongly the impact on their lifestyle of the burden of caring for a disabled child. In this, they are similar to the mothers of younger children.

As can be noted in the findings of some past studies (Cummings et.al., 1966; Cummings, 1976; Egnal and Dancel, 1980; Margalit and Raviv, 1983), mothers (compared to fathers) were found to be more deeply affected by the presence of a mentally handicapped child in the family. It seems that for the mothers it was much more difficult to deal with the reality of their child and their emotional reactions represented a serious state of crisis. The burden of care for a handicapped child has a great impact on the mothers' lifestyle and opportunity for self realization.

Therefore, as the results indicate, it was easier for the fathers to admit that "they learnt to accept the child and his problem". The fathers also reported fewer difficulties in sharing their problem with others. This result lends further weight to the view, already mentioned, that better adjustment facilitates an attitude of increased openness towards other people.

In order to fully understand the nature of the process of adaptation, further analysis was conducted on the impact of selected child and family characteristics on parental adjustment to having mentally retarded child.

The influence of the child's age upon differences in parents' ability to adjust to the situation, and in their attitudes towards him, have already been mentioned. However, some differences between parents were found according to the child's sex and the severity or the nature of his handicap.

Cummings et.al. (1966); Beckman (1983) and Margalit and Raviv (1983) could not delineate a relationship between child's sex and parental acceptance of his problem. However Farber (1960) and Crn: et.al. (1983) found that it was harder for parents to accept the male and that mothers of boys were confronted with problems of a more severe nature. Males were also found to create more difficulties regarding family interelations, and had a significantly negative impact on marital relations. The findings of this study support these findings.

Parents of females had fewer difficulties in accepting their daughters. and it was easier for them to share their problems with others. The fact that there are more males among the older children (whose parents as aforementioned seemed to be more adjusted to the situation) lends greater weight to the relationship between child's sex and parents' acceptance of his problem. Apparently, many parents seem to expect more of their son (who carries the name of the family) and thus, the disappointment is greater when the male child happens to be mentally retarded. Farber (1960) and Begab (1963) found that males were regarded by their parents as creating more behavioural difficulties. The implications of the child's behaviour and the nature of his handicap were also found to influence parental acceptance of the situation.

Begab (1963), Howard (1978), Chinn et.al., (1978) mention that when a child's handicap is not distinguishable by his physical appearance or behavioural characteristics he is easily accepted by others. Such an attitude on the part of the outside world helps the parents to adjust to their exceptional child and enables them to share their problem with others. The findings of this research study are consistent with the abovementioned ideas. For parents whose children suffered from brain damage, or whose physical condition was only fair it was much harder to accept their disabled child, in comparison with parents of children with an unknown reason of mental retardation, or when the child's physical condition was good. The initial reactions of parents whose children suffered from Down's syndrome represented a situation of a critical crisis. However, after the first shock it was much easier for those parents to adjust to the situation. The severity of the initial crisis and the ability to overcome such a shock are probably due to the Down's Syndrome child's characteristics (Robinson and Robinson, 1976).

The fact that the parents of a Down's Syndrome child almost always learn about his problem immediately after his birth, may also have its impact on parents acceptance of the handicap (Drew et.al., 1984). The parents of the Down's Syndrome children, who were confronted with the child's problem earliest, had fewer difficulties in adjusting to their child's problem.

Results reveal that the child's place in the family had no impact on parents' initial reactions to the diagnosis. Yet later parental reactions differed according to the child's birth order. It was harder for parents of the first or second born child to adjust to his handicap. As there were more parents of third to sixth born children in the older group, the increased ability to adjust to the situation is probably a result of the child's age as much as of his place in the family.

In addition to the order of birth, some other family characteristics were found to influence parents' ability to adjust to their child. Results reflect some differences in the parental process of adaptation, according to their level of education. As with the findings of some previous studies (Farber, 1960; Begab, 1973; Bayley, 1973; Chinn et.al., 1978) the findings of this study show that parental level of formal education has no impact on parents' initial reactions to having a disabled child, and the parents had to go through a period of crisis. However, the lower educated parents seemed to overcome the crisis situation better and they developed an attitude which helped them to adjust to the child and to accept others' support and help. The higher educated parents, who were much more aware of the difference between their child and "normal" children in regard to physical and emotional development, had more difficulty accepting the fact that their child is exceptional. Similar findings have been reported in some past studies (Feder, 1978; Chinn et.al., 1978; Drew et.al., 1984). Nevertheless Hart's (1970) findings describe a different attitude which was found among highly educated parents. These parents believed that they were divinely chosen for a special task of raising a mentally retarded child and thus it was easier for them to accept their child and the burden of care resulting from his special needs.

Religious background is another factor which was found to influence parents' attitudes to their mentally retarded child and their ability to adjust to their special situation. Results show

that for the Catholic parents it was harder to accept the child and his handicap and they felt it was similarly difficult for their relatives with whom they shared their problems. These results are contrary to Zuk's findings (1959). Farber (1968) suggests that religious background should be considered an important factor influencing parents attitudes. However, no other past studies which dealt with this issue could be found.

The differences between Zuk's and the present study's findings could be a result of the influences of some other interlinked variables which could not be statistically analysed because of the small size of the sample.

Results show that having a mentally handicapped relative beside the child probably helps the parents to adjust to their problem. But, as there are more parents of older children who have mentally retarded relatives, and as these parents were also found to have a more adjusted attitude towards their child, the impact of the child's age could be the operative variable, rather than having a mentally retarded relative per se.

In conclusion the findings of the present research study lend support to the concept of stages in the process of adaptation which the parents have to go through when raising their mentally retarded child at home. The initial reactions of the majority of the parents are typical of a crisis situation.

The differences which were found in regard to child's age show that over time, the parents develop a more adjusted, realistic approach to the situation. However, this realistic approach creates a special atmosphere in the family. The parents seem to develop a pessimistic attitude to life and "chronic sorrow" (Olshansky, 1962). The need to cope with the ongoing changes in the child's special needs becomes part of the process of adaptation which creates fundamental differences in the lifestyle of those families.

CHAPTER 3

THE EFFECT OF THE CHILD'S MENTAL HANDICAP ON THE FAMILY AS A WHOLE

3.1 PERSECTIVES FROM THEORY AND PAST RESEARCH

3.1.1 Introduction

A new child in the family may have a positive or negative effect on the relationship already existing between husband and wife. The child may draw the parents closer together with a commitment towards a common goal. On the other hand, the child's presence may result in discord and conflict. The arrival of the new child usually represents a dramatic change in lifestyle for a couple.

Chinn et.al. (1978), refer to Reiss who found in his study that a large percentage of couples reported a decline in the positive aspects of marriage with the passage of time. The decline was greatest among couples with children. The new child had an impact on the recreational and social activities of the parents. Travel over extensive distances or time may become difficult owing to expense, inconvenience and sometimes difficult behaviour of the child. Financial problems may also result from the fact that the wife must relinquish a job in order to care for the child.

Couples with children at times find that their childless friends lack sympathetic understanding about the needs and nature of children and parenthood and this may result in change in friendship patterns, putting an end to a relatively independent, carefree lifestyle.

The list of complications, inconveniences, expenses and changes in lifestyle introduced by a new child is endless. Many if not all of these negative aspects of parenthood are

often overshadowed by the sheer joy and pleasure that the child brings to the new parents. The displeasure of diaper changing and the sleepless nights owing to the infant's crying may tend to fade away with the first smile, the first step, and the first spoken word. With these first accomplishments, parents may begin to envision a fruition of their dreams and hopes of parenthood - healthy, bright, capable, beautiful children doing all the things that their parents did or wished they could have done. (Chinn et.al., 1978).

Parents of mentally handicapped children may find that although the child's handicap does not necessarily preclude the pleasures of parenthood, the satisfaction that may be realised by accomplishments of the child may be overshadowed by the frustration they have and experience during the years of rearing him. Retarded children are born to families in every stratum of society - to the very poor and the very rich, the filiterate and the highly educated, the unskilled labourer and the scientist. Whatever the status of the family, whatever the cause or the severity of the child's handicap, the retarded child will have a significant and lasting effect on the lives of the other family members. Even when the effect of these families is not emotionally traumatic, the limited capacities of the child may engender conflicts with schools and other social institutions or may be an inhibiting factor in the family's social operations. (Begab, 1963).

In studying the impact of the mentally handicapped child on the family as a whole, it must be kept in mind that families vary considerably in their reactions to the birth of a retarded child and in their ability to adapt their living patterns to the child's special needs. The early life experience of the parents, their educational and cultural backgrounds, their religious and ethnic values, their economic resources and the stability of their marital

relationships may influence their feelings and attitudes and their approach to the problems presented. The physical appearance of the child, the severity of his mental handicap and the nature of his behaviour will also contribute significantly to the family's long range adjustment.

The multidimensional aspects of mental retardation have tended to obscure the fact that it is first and foremost a family problem. How efficiently the family can adapt to and handle the problem determines to a large extent how much responsibility society will need to assume in the case, management and treatment of the retarded individual. Only as parental functions are properly discharged can the retarded child make maximum use of the community resources and realize a socially useful role for himself within the outside world. (Begab, 1963).

Of course, it is unlikely that anyone would assume that having a disabled child is just like having a normal child, that it is anything but undesirable, or that it does not present problems that parents would not otherwise face. The fact that the parents do claim that their family life is congruent with the normal order may be then taken as evidence of "strength of character" or a "deeper understanding" of life.

The tendency to deny the impact of the mentally handicapped child on the whole family is mentioned by a few researchers. Wolfsey (1975) found in her research study that parents sustain their predominantly calm and cheerful appearance by ascribing other interpretations to their situation which deny its undesirability and legitimize any suffering on their part.

According to Schild (1976), the effect of the mentally retarded child on the family is not always negative. Studies

like Holt's have concluded that the families often gained improved spiritual and ethical values.

In spite of the fact that in some cases the child's handicap contributes some positive aspects to the atmosphere in the family, most researchers put an emphasis on the fact that a family with a mentally handicapped child is at greater social and psychological risk, and that there is a real danger to the marital relationship and to the normal development of other children in the family.

This chapter will discuss the following issues:

I. The effect of the child on family interrelationships and atmosphere.

II. The effect of the child on his parents' marital relationships and on the siblings.

III. The daily burden of care for the child.

IV. The relationship between child and family characteristics and parental willingness to acknowledge the impact of the child's problem on the family.

3.1.2 The effect of the child on family interrelationships and atmosphere

Ongoing family life may depend on the fulfillment of a thousand mutually anticipated acts but it is, of course, experienced as routine in most important respects. The management of children in encounters with others is perhaps usually the most problematic area for the parents. Nonetheless, such management can be largely routine and it may be instructive and rewarding for parents as for others.

However, for parents of a disabled child, all activities may become problematic. In general, the advent of a disabled child may be seen as breaching the institutionalized order of family life. When the child is kept within the family the basic constitution of the family life is not challenged, but to the extent that the appropriateness of the old rules and recipes for action are called into question, parents are uncertain both as to how they should best perform their everyday tasks and what new tasks may be necessary (Voysey, 1975).

Families with a child who is mentally retarded must be able to maintain normal functioning as much as possible. There are many problems that may hinder such functioning, such as guilt feelings which may produce the need to dedicate one's life to the child's welfare. Intense feelings of obligation may interfere with normal interactions of the parents with other people. The additional financial burden of the retarded child may hinder normal expenditure for recreation and other activities and necessities. The difficulty of finding somebody else who will be able to care for the child because of his special needs, may limit the parents' outside activities. At times, parents are so intensely engrossed with the care for the retarded child that they become oblivious to the needs of other members of the family including their own. (Featherstone, 1980).

Such a situation brings to the surface the question of the reflection of the child's problem on the family as a whole. To what extent do the parents accept the fact that having a mentally handicapped child presents a problem to each member of the family and to the family unit?

Dickerson (1981) mentions that parent[illegible]embers of the family should regularly assess and [illegible]ne patterns of interactions that develop within the [illegible]nold. As the

years go by, emotional and value conflicts that are not always related to the presence of the mentally retarded child may develop around any family members. Nevertheless, some of these conflicts or unresolved problems may be brought to the surface by the daily difficulties caused by the mentally handicapped child.

Drew et.al. (1984) found in a research study that the ability of the family to maintain some degree of normal socialization may be partly a function of the degree of acceptance by the extended family, neighbours, and the community. Chinn et.al. (1978) mention that it is not uncommon for these parents to feel that they are all alone with their problems. They feel that they are the only ones who face such a problem. It is true that each family has its unique problem but at the same time, similar conditions can be shared by other families with a handicapped member. The integration of the family unit into the social structure of the community and the extended family, will greatly enhance the family's opportunity to develop and maintain mental health for all its members. The family's basic attitude to the situation can greatly enhance its prospects for acceptance by others. If the parents view themselves as inferior and stigmatized as a result of the child, others are likely to share similar views. If, however, the family can maintain its pride and dignity believing in its worth and the worth of the handicapped child, these attitudes are likely to have a positive influence on others.

In addition to the attitudes of the outside world, internal processes which occur during the different stages of the family lifecycle are also influenced by the existence of the child.

According to Farber (1968) factors relating to the family lifecycle provide an impetus for revising adaptations. What may be merely an impropriety at one phase of the family lifecycle, becomes offensive in another. The adaptation to a stage of the family lifecycle is insufficient to handle offensive behaviour that may emerge at a later stage.

Farber considers minimal family adaptations as an attempt to handle the offensive child within the existing arrangements of family roles and norms. The maintenance of deviance within the normal scheme of things despite the family consensus that something is amiss occurs in several ways:

- When some family members may suppress their perception about the existance of a problem.
- Some members may convince others to change their perceptions.
- The family members may pretend that all is well.

As long as the deviant person and his family can carry off the fiction of normality, there is no need for further adaptations in family roles or norms. Only when the fiction of normality cannot be sustained, more complex adaptation must be sought.

A few researchers have tried to describe or to construct unique clusters, or modes of adaptation developed by parents to cope with the presence of a retarded child. Farber (1960) describes the three following types of family organization:

I. A parent oriented family: In these families, the focus is upon the parents' occupational and social careers with a secondary position given to the mentally retarded child in determining life chances of family members.

II. Child oriented families: Families who subordinate parents' activities to the maximization of the life chances of children. In these families the division of labour is that the husband would specialize in work activities while the wife cares for the home and the family. Great expenditure of time and effort compensates for the depressing effect of the retarded child on upward family mobility.

III. Home oriented families: These families sacrifice parental life chances for those of the children. The life chances of all those family members may be markedly affected. In a large proportion of the families there is a disagreement between parents with regard to the family orientation, and the orientation itself is not crystalized.

In regard to the aforementioned three types of families Farber (1960) defines "social destinies" as the social concept of life chances or the probability of the individual achieving a successful social and economic position in the society. He refers to evidence from a study by Calver that showed that the time of the birth of the mentally handicapped child in relation to the family lifecycle had an impact on the upward and downward social mobility of the parents. He also concluded that parents who keep their child at home are more often downwardly socially mobile compared to parents who prefer to place the child in residential care.

Tan Mink et.al. (1983) have constructed five clusters describing the impact of the mentally handicapped child on the lifestyle of his family, in terms of division of roles and relationships between family members. The five clusters are:

I. Cohesive harmonious. In these families they found the lowest percentage of working mothers, absence of negative child influence on the marriage and the lowest occurrence of stressful life events.

II. Control oriented, somewhat unharmonious. Here the majority of the mothers were employed, the fathers assisted with child care. These families had the highest socioeconomic level and a significantly low occurrence of stressful life events.

III. Low disclosure - unharmonious. In these families the father helped to care for the child. Most of the mothers were employed and were educated beyond high school. These families had the highest occurrence of stressful life events and negative impact of the child on the family.

IV. Child oriented - expressive. Among these families Tan Mink et.al., found the lowest percentage of father figures. When the fathers were present, they assisted with child care. The influence of the child on the family was negative only in very few cases.

V. Disadvantaged with low morale. Most of the fathers in these families did not assist in child care. Most of the mothers were not employed. The level of education of both parents was low. Many stressful life events were found in those families and the child's impact on the whole family was regarded by them as being negative.

Gumz (1972), like Tan Mink et.al. (1983), has stressed some differences between mothers' and fathers' perceptions of the impact of the child on the family as a whole.

He found that mothers are more concerned about the functioning of the family as a system and about the relationships between the family and other systems. The mothers were also more concerned (than the fathers) about

the emotional crisis involved in having a mentally handicapped child, the emotional strain and the ability to maintain family harmony and integration. In Gumz's study less than 33 percent of the fathers were concerned about these issues.

The tendency to exaggerate the extent of the problems faced by parents of mentally handicapped children is criticized by some researchers. Schild (1976) and Kapaport et.al. (1975) object to the stereotyped trend which describes the parents as a pathological group. Instead, they stress the central problem of family dysfunction as relating to the changes in roles and to the strain and conflicts placed on family members as a result of the child. However, changes in the division of roles and flexibility in the family will avoid strain and stress. The parents in these families have a complicated role in relation to their normal children and the retarded child. The feeling of having a long-term burden in caring for, managing the child, and the isolation and extra care, time and money, creates a great risk for crisis in these families.

According to Schild (1976) the family's approach to mental retardation and to the child will influence the nature of relationships among family members and the role responsibilities and expectations of them. When the child is viewed as an integral part of his family, a better integration will be found among family members, and each one of them will be able to contribute to the dynamics of the family unit and to its better functioning.

The basic responsibility of these parents is not massive input of psychiatric help for themselves to enable them to adjust, accept and resolve their guilt feelings. They want to be treated as ordinary people who have a considerable practical problem: "In talking to those parents what struck

us was not their difference from but their likeness to ordinary families". (Newson and Newson in Dickerson, 1981, p.59).

In an attempt to further delineate the affect of the child on particular aspects of family interrelationships, the next section will refer to parents' marital relationship and to the impact of the child on his siblings.

3.1.3 The effect of the child on his parents' marital relationships and on the siblings

(a) Parents' marital relationships

The child's handicap attacks the fabric of a marriage in four ways:
It excites powerful emotions in both parents. It acts as a dispiriting symbol of shared failure. It reshapes the organization of the family. It creates fertile ground for conflict (Featherstone, 1980).

In an attempt to study the effect of a handicapped child on his parents' marital relationship, one can find on one hand studies which suggest that the child's problem influences this relationship in a very negative way. Yet, other studies come to the conclusion that marital relationships in many cases are not affected by the child's problem to a significant degree and some have even found that a "good" marriage can be strengthened because of the child's disability, rather than to be weakened as a result of it.

Farber (1968), when describing findings from Kennedy's study, states that families of the retarded show a greater prevalence of instability through divorce and desertion. Farber compared 120 educable mentally

retarded children to sixty normal children from families of comparable income and occupational status, and found among other things that in the families of the mentally handicapped, marital relations reflected instability which was represented by a greater amount of divorces and remarriages.

Gath (1972) reports on the effects of Down's syndrome children on their families. According to his findings, in the two years following the birth of the handicapped child, two-thirds of the families either had a parent with depressive psychiatric illness or they displayed obvious marital conflicts. Feder (1978) refers to a mother saying: "We quarrel. Marriage relations are not what they used to be." (p.7).

Nevertheless, some other researchers were not able to determine the negative impact of the child on his parents' marital relationships. Howard (1978) describes D'Arcy's findings which showed that out of ninety mothers who had Down's Syndrome children only three reported that happy marriages changed for the worse. Another fourteen mothers had unhappy marriages to begin with, and the marital relations remained unhappy for them. Seventy three out of ninety mothers claimed that their marriages remained happy and unchanged.

McAndrew (1976) and Fowle (1968) found no difference in marital integration between parents of the mentally handicapped who cared for the child at home, and families who placed him in an institution. Featherstone (1980) when describing some of the problems in marital relationships in these families, concludes by saying that despite all the problems, most marriages survive.

In Voysey's study (1975) the mothers admitted changes in their relationships with their husbands but in all cases these were defined as desirable. Often this was expressed as "It brought us closer together" or "We've sort of come through it together".

It seems from a small number of studies that mothers more than fathers perceive the child as having affected their marital relationships. According to Howard (1978), the mothers felt that they were withdrawing from the child in an attempt to maintain their marital relationships. In Voysey's study (1975), husbands were generally presented as being worried but not showing their feelings. The mothers, in the attempt to maintain good marital relations, sometimes felt that they needed the child for this purpose. As one of them said, "We could never leave each other now because of her". (p.143). Fowle (1968) when using Farber's marital [illegible] index, also found differences between mo[illegible]d fathers, the marital role tension being greater for the mothers.

Tizard and Grad (1961) have described four patterns of family relationships in regard to the degree of integration in these families.

I. Families with good relationships which were thought to be fairly closed units, normally happy and not disrupted by jealousies or dissatisfactions.
II. Families with satisfactory relationships - families with minor signs of strain.
III. Disturbed relationships - where there was a great deal of quarrelling or interference from outside relatives, or unhappy sexual relations.
IV. Very disturbed relationships - families which have broken up or are about to do so, or when the parents live separately though sharing a dwelling, or where marital disharmony seemed abnormally great.

Tizard and Grad, using this rating scheme, compared the relationships in families who kept the child at home to the ones who placed him in an institution. Their findings show that sixty two percent of the families who kept the child at home and forty four percent of the families of the institutionalised children were rated as having good relationships. This suggests that the better adjusted families were more easily able to handle the problems imposed by the child. This evidence is not so convincing because when combining the "good" and "satisfactory" categories and the "disturbed" and the "very disturbed" ones, the difference between the families with the child at home and the families where the child was put in residential care is too small to be considered a significant one. Thus they conclude that according to their data, there is no evidence that keeping the mentally handicapped child at home has any marked effect upon the pattern of family relationships. However, it is notable that some families in their study claimed that the child had strengthened the ties between family members.

According to Begab (1963), the high incidence of broken homes among institutionalized retarded children can not be attributed primarily to the effect of the retarded child on the family. There are some families where the mother's devotion to the child may cause her to neglect her husband and create a rift in the marital relationships that might otherwise not have developed. For the most part however, divorce or separation ensues, and factors unrelated to the child's retardation are responsible. Unquestionably, though, retardation may aggravate an already precarious relationship and perhaps precipitate an eventual break.

Finally, it is important to note the conclusion reached by Farber (1960), who refers to the degree of integration achieved prior to the introduction of the handicapped child as a dominant feature determining the degree of marital integration after the birth of the child. The stability of the marital condition has obvious bearing on parental adequacy and family adjustment to retardation. Some problems presented by retarded children are a lesser threat to family stability than others, and this can provide an explanation of the differences in findings of the various studies that have dealt with this subject.

(b) The Siblings

The presence of a handicapped child in a family affects all the members of the family, not only the parents. The siblings' whole social life may have to be adjusted to the handicapped child. The parents' attitudes to the mentally handicapped child and to the other children in the family will have an impact on the siblings' reaction to the fact of having such a brother or sister, as well as their attitudes towards him or her. In some of the studies regarding this issue, one can note a tendency to emphasize the siblings' difficulties and emotional strain resulting from the handicapped brother or sister. Others reflect the opinion that the impact of the mentally handicapped child on his siblings is not so negative and sometimes is even a positive one. Most of the studies agree that the atmosphere in the family, the attitude of the parents towards the child, and some other factors like the age of the siblings and the child's birth order, will all indicate the kind of influence the mentally handicapped child has on his siblings, and on the parents' attitudes towards their special problems and needs.

The family's general approach to mental retardation will enable its members to understand the nature of the roles, responsibilities and expectations they have of each other. Schild (1976) refers to Kelman's opinion that the retarded child must be viewed as an integral part of his family group, having distinct relationships to its members. The mentally handicapped child, the parents and the siblings mutually influence one another's functioning and contribute their respective influence to the dynamics of the family unit functioning. If the family relationships are good and the mother is able to meet the needs of her handicapped child and still have time for her other children, the siblings are more likely to develop a friendly, protective attitude and be more accepting of the limitations imposed by the handicap. (McMichael, 1971).

Schipper (1959) found in his study of forty three families that in thirty three of them the normal siblings adjusted to the retarded child with minimal adverse effects, and several teenage siblings were more realistic than their parents in accepting the limitations of the defective child. This is echoed by Howard (1978), who found that the young sibling with positive family relationships is often capable of enduring the emotional hurt and anxiety of having a retarded sibling without severe disruption of his or her social and family life.

Farber (1968) refers to findings which revealed that the retarded child had little influence on siblings who were considerably older (a ten years difference in age). These findings suggest that "when the normal siblings are much older than the retarded child, there is little need to modify the birth order role in the family.

Without this revision of roles apparently the normal siblings are not profoundly affected by the presence of the retarded child." (p. 159).

Voysey (1975) found that parents generally denied any negative affects that a disabled child had on their siblings. If they admitted it, it was defined as past and action as having been taken to avoid its recurrence. In McMichael's study (1971) in four out of thirty seven cases where there was a severe failure of the siblings to adjust, the mothers admitted that they neglected the siblings in favour of the handicapped child. In another two cases, the sibilings appeared to resent the handicapped child quite strongly but were themselves much less affected. In twenty four out of thirty seven families, the siblings showed normal reaction towards the handicapped child.

However, contrary to the foregoing, some other past studies have stressed the negative influences of the child on his siblings.

Farber (1968) describes the result of a study of 240 families with severely retarded children. He found that the retarded child's siblings were affected by his degree of dependancy, which adversely affected the sibling's relationships with their mother. When the children were young, interaction between the normal and the retarded brothers and sisters tended to be on an egalitarian basis. As they grew older, the normal sibling(s) frequently assumed a sub-ordinate position in the relationships. However siblings who did not interact frequently with their retarded brother or sister, generally were affected less than those who interacted frequently. In another study, Farber (1975) found that siblings of about the same age as the mentally retarded child were more affected than older brothers or sisters.

Farber (196[illegible] therefore stresses the age of the siblings and the family birth order as important factors determining the ability of the siblings to accept and to adjust to the fact of having a mentally handicapped brother or sister.

In this respect, Howard (1978) reports on Rutter, Tizard and Whitmore findings indicating that the increased amount of behavioural disturbances found in the eldest sisters of handicapped children is related to their parents' expectations of them that they assume more responsibility to help in the home.

Schrieber and Feeley (196[illegible]) also mention the concern expressed by parents of mentally handicapped children about the normal child's feelings of being overburdened by the care of the retarded sibling. The healthy child may feel an obligation to make-up to the parents for what the mentally retarded brother or sister could not give them, and may even experience guilt for being a normal child.

McMichael (1971) considers the severity of the handicap as a main factor affecting siblings' difficulties in emotional adjustments. Another important factor, in his opinion, is the extent of maternal anxiety and the handicapped child's own emotional difficulties. When the handicapped child receives the extra care, time and attention he needs, correspondingly less can be given to the other children, and so natural jealousies become intensified and the handicapped child may be resented by siblings who see him as "the favourite". In some cases the siblings may not be allowed to bring friends because of the fear of the friends' reactions to the mentally handicapped brother or sister. Curtailment of the family's activities (going for holidays, etc.) or

financial problems will have its effect on the siblings as members of this family.

The parents' concern about the influence of the mentally handicapped child on their healthy children is sometimes a reason for them placing the child in an institution. In some families, the parents use the siblings' situation as an excuse for seeking a solution for the mentally handicapped child outside the family even though the strain and stress is not always to be found in the siblings' reactions to the mentally retarded brother or sister.

Howard (1978) refers to Fowle's study which compared the siblings' role tension when the retarded child was at home or in an institution. He found that keeping the retarded child at home raised the role tension for the siblings. The oldest female sibling was more adversely affected by the presence of the retarded child than the oldest male sibling. According to Howard the same results were reported by Gath.

In Tizard and Grad's study (1961) only three out of fifty admissions to instititional care were requested by the parents because of their concern about the adverse effect on their other children. In a study by Fotheringham et.al., (1971), twenty three percent of the families who placed their children in institutional care were irritated by constant interruption of the siblings' homework, reading or rest during the night. When they were asked about changes in their life after they institutionalized their child, seventy nine percent of them said among other things that "His brother and sister no longer have to fear his dangerous behaviour". Fifty one percent said: "His brother has got a new friend and is doing better at school" or "the children

get on better and quarrel less". Thirteen percent of these families described a general decline in family functioning and the fact that the healthy siblings miss their mentally retarded brother or sister: "She was her youngest sister's best friend and helped care for her"; "George's brother talks about him constantly and is always asking when we are going to visit him "(p.49).

Brothers and sisters of handicapped children feel the tug of what almost amounts to two different cultures. They stand with one foot in the world of normal classmates and the other in their exceptional family. They live among ordinary children, they long for simple fellowshi; with others their own age. Yet playmates sometimes treat a handicapped child cruelly. Forced to mediate, to explain and sometimes to choose between conflicting loyalties, brothers and sisters can end up angry at the normal world, the disabled child and themselves. (Featherstone, 1980).

After describing the various problems of the siblings, Featherstone concludes by mentioning that despite all the problems of growing up with disability, most families function adequately and normal children usually develop into normal adults. As for the parents, she states: "We want to believe that our normal children have grown wiser and more compassionate through the family trial. If we must acknowledge that they suffered too, we would like to believe that this suffering is not our fault." (p. 152).

Farber and Jenne's study (1963) on life goals of the siblings of mentally retarded children who were aged ten to sixteen years, indicate that the siblings who interacted frequently with their mentally retarded brother or sister displayed interest in goals related to personal

relations rather than success. In performing the duty of continued contact with their mentally handicapped sibling, they internalized social welfare norms and it directed their career towards the improvement of mankind or the achievement of goals that require dedication and sacrifice. Farber and Jenne's findings, therefore, illustrate the great impact that a handicapped child has on his normal siblings' socialization.

3.1.4 The family's burden of care for the mentally handicapped child

There is a general consensus among researchers that the birth of a mentally handicapped child represents a crisis in the life of the parents and of the family as a whole. The novelty crisis (as a result of lack of understanding of the problem), and the crisis of personal values is followed by a reality crisis which represents the need for help in solving daily problems. Dickerson (1981) notes that all surveys have shown that families of mentally retarded children have a considerable burden to bear. In part it stems from the practical difficulties in rearing such a child. From the emotional point of view, there is evidence that these parents feel differently in certain respects about their children and about their role as parents as compared to parents of normal children.

Among the common problems of these families, is the financial problem which has been described in many studies as a central one for many families who keep the child at home.

Glendinning (1983) refers to the fact that many disabled children create extra financial pressures. These extra expenses put a financial burden on the other members of the family who must sometimes give up plans or activities

which are beyond the family's budget. Among the other difficulties described by the parents in Gumz's study (1972) are the financial problems with which the parents must cope. The fact that mothers in many cases are unable to work outside the house (because of difficulties in finding someone who will care for the child) limits the family's possibilities of gaining better financial resources which might cover the special expenses caused by the mentally handicapped child.

Featherstone (1980) mentions some other differences in daily life between families with a mentally handicapped member and those without, referring to the difficulty "to survive holiday seasons and festival times" when the child must be kept at home all day long.

Tizard and Grad (1961) and Hannam (1975) describe the difference between families with differential access to resources. On the one hand, there are those who have enough internal resources to cope with the problem, and in most cases can rely on other members of the family or friends. On the other hand, there are families who need help from welfare agencies in order to cope with day-to-day difficulties. The main burden, according to Hannam (1975), falls on the mother because the father can at least get away to work, and by immersing himself in it can forget the problems at home for a while. For the mother, there is no escape unless outsiders come in to help or the child is placed in a residential unit occasionally. Unless there is somebody who can care for the child, "normal" activities such as shopping, hair cutting and going to the library, all become unpleasant. In many cases, the family's activities must be geared to the mentally handicapped child's capabilities and it creates limitations on outside activities for the family members and most of all, for the mother.

Tizard and Grad (1961) found that some women could only do the housework after the mentally retarded child had been put to bed. Some had to get their shopping done by neighbours or husbands, some were prevented from going out to work or were unable to comply with medical treatment which would have involved attendance at an outpatient clinic.

Mercer (1966) compared families who released their mentally handicapped member from institutional care to families in which this member was a resident patient. She found that 68 percent of the families of resident patients reported one or more problems in the "burden of care" category, while only 20.6 percent of the families of released cases reported such a problem. She concluded that although practially all kinds of problems showed a higher percentage of the families of resident patients reporting the problem, the significant differences were concentrated in one area - "burden of care". Resident families more often reported that the mother was ill or working, the family could not afford the cost of the mentally handicapped member's support, and had other problems which she defined as the "crisis of the burden of care". These findings illustrate the significance of the burden created by the special needs and problems of the mentally handicapped member, on the family's day to day life.

It seems from the various studies discussed above that in many cases the main reason for parents choosing to place the child is their feeling that the burden of keeping him at home is too heavy with regard to the daily reality for each family member and for the family unit. Hart (1970) describes the limitations placed on the family's activities caused by the child and concludes that there are two alternatives from which the family can choose: limit themselves or leave the

child at home or somewhere else. In the beginning the parents may not be too bothered about being tied down with a retarded child, but they become increasingly so, as time goes on and they begin to realize that they may never again be able to do anything spontaneously.

It seems that the child's age has a considerable impact on the way parents view the "burden of care". Although the older child can sometimes be regarded as less dependent on his parents, it has been found in some studies that his special needs and problems create a recognizable hardship for the parents.

According to Schriber and Feely (1965) after the initial parental response of emotional disintegration, there evolves a period of adjustment and reorganization of the family's daily activities and plans. In many families the crisis occurs during the retarded person's adulthood. There may be more involvement with professionals and ultimately recognition of the chronicity of the handicap. Family roles may not develop along conventional lines as the individual family members will have to adjust to the problem posed by a handicapped child. Because of this situation, the handicapped person's adolescence is probably the worst crisis situation for the family unit.

With regard to the period of adolescence of the mentally handicapped person, parents experience the burden of care and the impact of the child on the whole family due not only to the arrest in the development of the family lifecycle caused by the child. According to Featherstone (1980), when forty four parents of institutionalized mentally handicapped children were interviewed, results showed that the parents failed to recognize the changing needs of the maturing child and it increased the problems of the family as a whole. The

mentally handicapped adolescent found it hard to adjust his social behaviour and reacted in strange and unfamiliar situations, in an infantile way.

In spite of the burden of care for their mentally retarded child Birenbaum (1970) found that mothers of young moderately retarded children made an attempt to maintain normal appearing family lifestyles, which was extremely important for their value system. But when they were asked to project such activities into the future, they were reluctant to make predictions indicating that they could manage only on a day-to-day basis. These mothers had to change their expectations in response to a reality of continuing dependence. As the child grows older the appearance of conventional family life must be modified by the particular types of problems that are presented by the retarded member.

3.1.5 The impact of child and family characteristics on parental willingness to accept the influence of the child on the family as a whole

In studies of the impact of the child on the whole family, one may find that amongst other factors, characteristics of the child and family are important variables in determining the extent to which the parents acknowledge that the child's situation has an influence on the whole family.

This section refers to:

(a) Child characteristics (sex, and the severity of the mental handicap)

(b) Parents' social status, level of education, religious background and the size of the family.

(a) Child Characteristics

The relationship between the child's age and parents' willingness to accept his impact on the family as a whole have already been discussed in the previous section. In this section, attention will be paid to the child's sex and to the nature of his handicap.

According to Farber (1968) the initial stress on the parents appears to be somewhat sex-linked, with the mother experiencing a slightly greater reaction when the retarded child is a girl, and the father a markedly greater impact (regardless of social status) when the retarded child is a boy. In the low status families where sex differentiation in family roles is probably greater, mothers were affected to a much greater extent when the retarded child was a girl. With time, however, the nature of the impact on the mother tended to shift; that is, eventually mothers of retarded boys were confronted with more severe problems than mothers of retarded girls. With reference to Farber's studies one can come to the conclusion that the older mentally retarded male may provide more difficult role problems for his parents than a retarded girl, even an older one.

Tallman's study findings mentioned by Kurtz (1977) resemble Farber's. He also found that the sex of the child influences the parents' reactions, in that they tend to react in an extreme manner if the child is a male and in a more limited way if the retarded child is a female.

Beckman (1983), in her study on the influence of child characteristics on stress in families of handicapped infants, refers to some other studies by Farber and Bristol which suggest that more family stress tends to

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occur in families of older handicapped children and that boys tend to be more stressful than girls.

In her study, Beckmon also looked into the cause of the infant's handicap, his behaviour, and its influence on stress in the family. Twenty one mothers were interviewed and results revealed that there was a significant relationship between specific characteristics of the handicapped infant and the amount of stress reported by parents Similarly, Holroyd and McArthur (1976) found differences in the amount of stress reported by families of children who were autistic, had Down's syndrome or were outpatients in a psychiatric clinic. The mothers of the autistic children reported greater interference with normal personal and family life functioning than the mothers of Down's syndrome children.

Tizard and Grad (1961) report a significant relationship between child problems and the placement decision. They found that one third of the institutionalized mentally retarded presented with three or more major problems as compared with only twelve percent of those living at home.

Fotheringham et.al. (1971) mention some child's characteristics which have great impact on the lifestyle of the family. The first group includes physical, health and social maturity factors. These characteristics determine the extent to which the child is dependent on his family, which in turn, determines the amount of effort required for his care. The second group of characteristics includes behaviour problems and mental health disturbances. These characteristics, if present in the child, tend to disrupt family living.

When comparing the characteristics of children who were admitted to institutions with ones who were staying at home, Fotheringham et.al. (1971) found that socially disruptive behaviour by the child put a lot of strain on his family and led them to place the child. The results of their study demonstrate a relationship between child and family functioning and institionalization, as the institutionalized children have more stressful characteristics.

Clearly, child characteristics are not the only potential source of stress for families of mentally handicapped children. Child characteristics may interact with family variables over time to produce differing amounts of stress for the family (Beckman, 1983).

(b) Family characteristics - parents' socioeconomic status, religious background and the family size

Results of Nihira et.al.'s study (1983) indicate that family adjustment and functioning is related not only to severity of the child's retardation and the degree of maladaptive behaviour, but also to family demographic characteristics and to the psychological climate of the home.

Only a few studies refer to the influence of parents' socioeconomic status on their attitude towards mental retardation, their ability to accept the fact and the child, and the way they function in daily life with the child at home.

Kurtz (1977) mentions that most of these studies have described reactions of middle or upper income families. Less information can be found about lower socioeconomic status families, although some studies have come to the

conclusion that retardation is not viewed by these families as a major difficulty. It can hardly compete with their financial and vocational problems in being a focus for the family misery. According to Kurtz, the reaction of the low status family to retardation may therefore be minimal.

Farber (1968) suggests that among low socioeconomic level families, the primary crisis-evoking factor is not the label itself, it is rather the mental and physical disability of the child which might require effort and attention. In an earlier study, Farber (1960) described the "role organization crisis" that low socioeconomic status mothers face in their attempt to organize their activities in ways which would permit them to have an acceptable family life.

According to Mercer's findings (1966) high socioeconomic status parents more frequently agree with the official definition of retardation than do low status parents. Therefore high status families are more pessimistic about any possible changes in the child's condition and about his future. They also tend not to release their children from the institution, and among the released children Mercer found more from low status families. The latter ones were aware that the child would continue to be dependent, but they were willing to accept this dependency and favoured discharge. A child with a problem is not perceived in the same way as a similar child in the high status group.

Fotheringham et.al. (1971), when comparing the socio-economic status and level of education of parents who placed their children, with parents who kept the child at home, found that more of the children who were institutionalized came from families of a lower socio-

economic level. The level of education of the fathers of these children was lower than fathers who kept the child at home.

Tizard and Grad (1961), when comparing the social class, household composition and housing of families who kept the child at home with families who placed him, did not find marked differences between the two groups. But, according to their findings, families of institutionalized children were in a better financial position. Only thirteen percent of them were defined as being "poor" while thirty eight percent of the families with the child at home were defined as such. This situation illustrates the extent to which the mentally retarded child is a financial problem.

According to Begab (1963), upper and middle class parents are characteristically career oriented, and aspirations and expectations for all family members are at a high level. Maintaining or raising the family's social status is assigned great importance and is an important consideration in decisions relating to work, education, housing, social relationships, and civic activities. Parents with these social values, who are able to keep the retarded child at home, are often compelled to make drastic readjustments in their living patterns. It is not uncommon for a father to refuse a promotion opportunity to another city because of lack of resources for his retarded child. Many high status families will not, can not or should not, sacrifice the interest of the entire family for the retarded child. In these cases, placement outside the home may reflect a high degree of family adjustment.

The low social status family generally expects less of its children and is more accepting of deviation, there-

fore the presence of a retarded child does not interfere markedly with parental goals although it may well affect the family in other ways. In these families, the fathers are frequently less involved in matters of child care and the difficult chore of looking after the retarded child usually falls mainly on the mother, or sometimes is offset by the assignment of child care responsibilities to other children.

According to Begab (1963), these differences in child rearing and in the attitude towards retardation affect family adjustment and can cause additional social stress for the family.

Zuk (1959) found that the sex of the child, the socio-economic status and the size of the family were not related to parental acceptance of the child. His findings indicate that Catholic mothers accepted the young mentally retarded child more easily than non-Catholic mothers. According to Zuk, the Catholic mothers' religious background (which has its effect on their lifestyle) enabled them to accept the child's problem more easily compared to Protestant or Jewish mothers.

Tizard and Grad (1961) found that having a mentally handicapped child influences the parents' decision about having further children. In their study seventy five percent of the parents did not want more children after the birth of the retarded child. Farber (1968) refers to some findings from a study by Holt which show that in one hundred and sixty families where additional pregnancies were theoretically possible, one hundred and one of them did not want more children (sixty seven percent).

> "We cannot assume that all families within a given social class, sharing the same religious convictions and economic advantages will respond to the same basic problem with the same strategies. We can assume however that the predominant characteristics and values of the group to which the family belongs, do influence its attitudes and responses" (Begab, 1963, p. 56-57).

3.2 FINDINGS OF THE RESEARCH STUDY

This section presents study findings in regard to parents' perception of the impact of the child on the family as a whole, and particular members of it.

3.2.1 A comparison according to groups and for mothers versus fathers

In the questions relating to this subject, the parents were asked to describe the situation in their family and to compare their family to families without a mentally handicapped child.

In comparing the parents of the young children (Group A) with the parents of the older children (Group B) the results of the two research tools (the QRS and the interview schedule) reflect the same trend. Results of parents' answers to the three QRS scales regarding this issue are depicted in Table 26.

Table 26

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

Scale	Group A				Group B			
	Mean	SD	Df	P	Mean	SD	Df	P
8. Lack of family integration.	2.7	2.3	106.3	0.1	3.4	2.4	107	0.1
9. Limits on family opportunity.	1.1	1.3	106.8	0.9	1.1	1.4	108	0.9
10. Financial problems.	3.5	2.3	99.4	0.7	3.4	3.0	110	0.7
	N=58				N=54			

The differences between parents of younger and older children according to the relevant QRS scales are not statistically significant. However, among the parents of the older children there were more who admitted that the child created special problems or needs for the family as a whole.

Parents' answers to the interview schedule resemble their reactions to the QRS (see Table 27).

Table 27

Frequencies of answers to the question "Do you feel that your family has special needs or problems because of the child?" by groups A & B (in percentages).

Answer	Group A	Group B
1. No.	69	51.9
2. We used to have problems in the past.	1.7	1.9
3. In a way.	15.5	16.6
4. Yes.	13.8	29.6
Total	100.0	100.0
	N=58	N=54

The difference between the groups in parents' answers to "Yes" is more than ten percent and will therefore be considered a marked one. Yet, it is important to take note of the fact that many parents in both groups denied having problems or needs as a result of the child. In another question, parents were asked to give reasons for their denial of the child's impact on the family as a whole. More of the parents of the younger children try to lead a normal life. The parents of the older children although admitting having needs or problems do not feel a strong difference between their family and families without a mentally retarded child. (See Table 40A in Appendix 4).

Comparisons between mothers of the older children versus mothers of the younger ones and fathers of the older children versus fathers of the younger ones in regard to the QRS scales reveal that although the differences are not statistically significant, mothers and fathers (each group separately) of the older children were most likely to accept that their mentally handicapped child had an impact on the whole family. (See tables 41A, 42A in Appendix 4).

These results lend weight to the idea that over the years as the child grows up the parents feel more and more his increased influence on the family as a whole, and/or on particular members of the family (the siblings in most cases).

When comparing themselves to families without a mentally handicapped child, the parents of the younger children concentrated on difficulties relating to the differences in child rearing (having a perpetual baby) while parents of the older children used terms of lifestyle: being more limited and isolated and having a financial burden. These differences are more than ten percent and should be considered noteworthy. (See Table 28).

Table 28

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 Groups A & B. (in percentages).

Answer	Group A	Group B
1. There are no differences.	24.2	33.4
2. Not very much, you have to devote more time to the child.	12.0	5.6
3. Not now because the other children are young or old.	10.4	1.9
4. Yes, its like having a baby all the time.	32.8	11.1
5. Outside activities are more difficult. We are limited, isolated, spend more money on the child.	17.2	42.5
6. We are closer to each other.	3.4	5.5
Total	100.0	100.0
	N=58	N=54

When mothers were compared to fathers, results reflect that the mothers felt more limited in their activities and more socially isolated, while the fathers mentioned having to spend more time with their mentally retarded child. (See Table 43A in Appendix 4).

Parents' opinions in regard to the effect of the child on a particular member of the family were similar for both groups. Many parents of both groups denied that the child had such an effect on other family members. (See Table 44A in Appendix 4).

To sum up the comparisons according to groups A versus B and between mothers and fathers, it is important to note the similarities in opinions when fathers are compared to mothers and that the differences, even when they are not statistically meaningful, are always in the same direction. As the child grows his influence on the family as a whole or on particular members is increasingly felt by the parents.

3.2.2 Child Characteristics

Has the child's sex an influence on the willingness of the parents to acknowledge his impact on the family as a whole?

When comparing the opinion of parents according to child's sex, it must be kept in mind that there is a marked difference in the number of males in the two groups; the group of the older children (B) consists of more males.

Results show that parents of males are more prepared than parents of females to admit that the child's situation affects the family as a whole. (See Table 29).

Table 29

Frequencies of answers to the question "Do you feel that your family has special needs or problems because of the child?" by child's sex. (in percentages).

Answer	Male's parents	Female's parents
1. No.	59.1	63.1
2. We used to have problems in the past.	1.5	3.1
3. In a way.	10.6	23.9
4. Yes.	28.8	10.9
Total	100.0	100.0
	N=66	N=46

The differences in the answers "In a way" and "Yes" are more than ten percent and should therefore be considered meaningful.

When comparing their family to families without a mentally handicapped child, the parents of males also felt to a greater extent that their families are limited and isolated. (See Table 45A in Appendix 4).

As mentioned above, the effect of the mentally handicapped male on his family as a whole is probably greater compared to the effect of the mentally handicapped female (although as mentioned before, these results may be influenced by the fact that there are more males among the older children).

Results of the study indicate that the cause of the child's mental handicap has a slight impact on parents' opinions about the differences between them and families without a mentally handicapped child (see Table 30).

Table 30

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?" by the cause of child's mental retardation. (in percentages).

Answer	Unknown	Genetic disorders	Brain damage
1. There are no differences.	16.9	26.8	30.5
2. Not very much, you have to devote more time to the child.	22.2	4.8	8.3
3. Not now because the other children are young or old.	11.1	9.7	2.9
4. Yes, its like having a baby all the time.	16.6	29.5	22.2
5. Outside activities are more difficult. We are limited, isolated spend more money on the child.	27.7	19.5	36.1
6. We are closer to each other.	5.5	9.7	-
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Parents of children who have mental retardation of unknown aetiology feel that they have to use more time as a result of the child. When the child suffers from genetic disorders his parents look upon him as a perpetual baby.

The parents of a brain damaged child seem to admit having special problems or needs as a result of the child, while parents who have a child suffering from genetic disorders "try to lead a normal life". (See Table 46A in Appendix 4).

When analysing the results about the relationship between parents' acknowledgement of the impact of the child on the family as a whole, and his physical condition, it must be noted that among the younger children (group A) there are more children who were described by their parents as being in only a fair physical condition. This fact probably has an influence on the results.

The child's physical condition has a slight influence on the parents' willingness to accept that the mentally handicapped child affects the family as a whole.

However, parents of children in fair physical condition feel more strongly that they have to spend a lot of time with their special child. This, in their opinion, is the main difference between their family and families without such a child. When it comes to the siblings, in the families where the child's physical condition is only fair, the parents feel that the siblings are closer to each other, and more helpful. (See Tables 47A, 48A in Appendix 4).

3.2.3 Family Characteristics

Results show that birth order has only a slight and insignificant impact on parents willingness to accept that the child has an influence on the family as a whole. Yet the third and subsequent born child is considered by the parents to be a perpetual baby. The parents of a first born child feel more limited by him, compared to the families where the child has older siblings. The second born child seems to have the greatest impact on his or her sibling. (See Tables 49A, 50A in Appendix 4). (It must be noted that there are more first born children in group A and second born in group B).

Parents' level of formal education seems to have a marked impact on certain parental views in regard to the effect of the mentally retarded child on the whole family. However, it must be kept in mind that there are more highly educated parents in Group A.

Table 31

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

Answer	Under Matric	Matric and Post
1. We have problems or needs.	37.7	41.3
2. We try to lead a normal life.	21.4	39.2
3. It hasn't changed our life, we are like any other family.	36.0	17.6
4. Not now, the child is still young.	4.9	1.9
Total	100.0	100.0
	N=61	N=51

The parents whose level of formal education is lower tend to deny the impact of the child on the whole family to a greater extent than more highly educated parents. The difference is more than ten percent and should therefore be regarded as noteworthy. The higher educated parents tend to admit that they "try to lead a normal life", and it is harder for them to state that their life was not changed and that they are like any other family.

The parents who are more highly educated are also more aware of the impact of the mentally handicapped child on his siblings. (See Table 51A in Appendix 4).

The aforementioned differences (see Table 28) in parents' formal education according to the two groups (A & B) demonstrate that parents' formal education has a marked impact on their views. There are more lower-educated parents in group B, but still these parents more than others deny the fact that the child's problem affects the family as a whole.

When comparing the reactions of mothers who are in employment to mothers who are not working outside the house, it was found that the latter ones most strongly felt the impact of the child on the family as a whole. Many of the mothers who work outside the house do not admit that the child's problem changed their lives. (See Table 32).

Table 32

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

Opinion	Working Mothers	Housewives
1. We have problems or needs.	32.6	43.9
2. We try to lead a normal life.	26.2	31.8
3. It hasn't changed our life, we are like any other family.	39.1	19.7
4. Not yet, the child is still young.	2.1	4.6
Total	100.0	100.0
	N=23	N=33

Results show that the housewives seem to experience the burden of care for the child more than the working mothers. (See Table 52A in Appendix 4).

A comparison between higher and lower skilled fathers shows that the former ones are more likely to admit that the child's problem creates problems for their family and that they are different from families without a mentally retarded child. More of the lower skilled fathers could not perceive any change in their life when comparing themselves to families without a mentally retarded child. (See Table 53A in Appendix 4).

A comparison between religious background and parents' opinions about the influence that the child has on his family is presented in Table 33. (It must be kept in mind that there are slightly more Jewish parents of the older children (Group B).

Table 33

Frequencies of parents' answers to the question: "If you have special problems or needs, what are your problems or needs?" by parents' religious background (in percentages).

Answer	Catholics	Protes-tants	Jews
1. We have no needs or problems.	73.6	61.9	44.4
2. We used to have problems in the past.	-	2.8	-
3. We are more limited.	5.2	11.2	11.1
4. It affected the siblings.	5.2	9.8	33.3
5. It put a strain on us, we are worried.	5.5	8.7	11.2
6. We need more professional help.	10.5	2.8	-
7. We are closer to each other.	-	2.8	-
Total	100.0	100.0	100.0
	N=19	N=71	N=18

Results reveal a noteworthy difference between the Jewish parents and the others in acknowledging the impact of the child on family problems and needs.

The Jewish parents were also more willing to admit that a particular member of the family was affected by the presence of the child. The least acceptance of this fact was found among the Catholic parents. The Jewish and the Protestant parents more than the Catholics reported differences in lifestyle - they feel more limited and isolated.

As already mentioned, when comparing the parents according to their religion, it should be noted that there are more Jews among the parents of the older children (group B), and this fact probably has an impact on the nature of the results when groups A and B were compared in Table 28.

Having a mentally retarded relative (beside the child) had no marked impact on parents' willingness to admit the differences between their family and families without a mentally retarded child. (See Table 54A in Appendix 4).

A summary and a discussion of the aforementioned findings is presented in the following section.

3.3 SUMMARY AND DISCUSSION

The effect of the mentally handicapped child on his family has frequently been described in the literature. Some of the studies which have dealt with this issue contend that families of mentally retarded children are strongly affected by the child's problem in terms of their lifestyle and interrelationships. In these studies, the differences between families of mentally handicapped children and families without such a child are strongly emphasized, especially concerning day-to-day life and patterns of child rearing. The general focus in these investigations is characterized by the tendency to describe the child's impact on the family as a whole as being negative (Begab, 1963; Mercer, 1966; Farber, 1960, 1975; Chinn et.al., 1978; Featherstone, 1980; Drew et.al., 1984).

On the other hand, one may find a few studies which oppose the tendency to look upon parents of mentally handicapped children as a pathological group and to over-estimate the stresses and the strains in their lives. (Schild, 1964; Rappoport et.al., 1975; Voysey, 1975;, McAndrew, 1976).

When responding to the two research tools (the QRS and the interview schedule), the parents who took part in this study had to relate to two main areas in which the child's problem might have its influence on the family as a whole. They were asked to estimate the influence of the child's situation on their interrelationships and on the general atmosphere in the family, and to compare their daily life to the day-to-day life of families without a mentally handicapped child in order for them to identify the differences and the similarities.

Data obtained from the two research tools consistently reveal that many of the parents of both groups (parents of the younger and the older children) denied the effect of the child on the family's interrelationships or on the atmosphere in the family. They also denied that the child's situation created problems for the family as a whole or for a particular member of the family.

However the differences in parents' reactions to the interview schedule revealed that the parents of the older children admitted more frequently that the child's situation affected the whole family, or created problems for a particular member.

While it was difficult for most of the parents to acknowledge that as a result of the child they became an exceptional family, when they were asked to compare their daily life to families without a mentally handicapped child, many parents could not ignore the unique burden of care they have to bear as a result of the child's special needs.

It seems from the results that the "burden of care" has a different meaning for the parents according to the child's age. For the parents of the young children it is the daily grind resulting from caring for a perpetual baby who never grows. The older parents, on the other hand, describe the burden of care in terms of the limitations imposed on them by the child's situation, mainly social isolation and financial difficulties. The differences in parents'

opinions clearly reveal that in spite of the fact that the growing child sometimes becomes physically less dependent on his parents, when comparing themselves to parents of normal children the parents still experience the differences in their daily life. When referring to the burden of care, the parents of the older children actually describe the development of clear patterns of lifestyle, like the tendency of some of them to give up social contacts, or to refuse better jobs.

Findings of some previous studies are consistent with the above-mentioned results. Bayley (1973), Voysey (1975) and Glendinning (1983) also found that while it was quite difficult for parents to accept that the child's situation created problems for the family as a whole, they were ready to acknowledge the influence of the child on their day-to-day life.

Parental tendency to deny the influence of the child's problem on the family as a whole can be explained in several ways:

- Sometimes, the family as a whole or members of the family try to suppress their perception of the existence of a problem either for the whole family, or even for their mentally handicapped child. In such circumstances, the parents may totally deny any exceptions in their family life when comparing themselves to families without a mentally handicapped child. (Farber, 1975).

- For some parents, even when adjusting to the fact that their child is mentally handicapped, it is still hard to accept the implications of such a situation on the family as a whole. It might also be seen as the parents' attempt to protect the family's "normal" appearance in order to avoid stigmatization.

- According to Chinn et.al. (1978) when the parents feel that the attitutde of the community towards them does not basically change because of their mentally handicapped child, it becomes easier for them to ignore the differences between themselves and families without such a child.

- Tizard and Grad (1961) and Hannam (1975) have described parents who decide to keep their mentally handicapped child at home as better adjusted to the situation of having such a child. As all the parents who participated in this study preferred to keep the child at home, it can be assumed that for them the child's problem probably created less stress for the whole family and thus it was easier for them to deny the child's impact on their family lifestyle.

Child and family characteristics are also important factors influencing parents' beliefs about the impact of the child's problem on the family as a whole. The findings of the present study are consistent with some previous studies (Tizard and Grad, 1961; Farber, 1968; Fotheringham et.al., 1971) and clearly demonstrate the impact of the child's age, sex and the severity of his mental handicap on his parents' willingness to accept that his situation creates problems for the family as a whole or for a particular member.

It seems that more family stress tends to occur in families of older mentally retarded children and that males tend to be more stressful than females. It was also found in this study, and in some previous investigations (Tizard and Grad, 1961; Farber, 1968; Fotheringham et al., 1971; Beckman, 1983), that the severity or the nature of the handicap indicates how the child will be dependent on the parents, and the extent to which they will feel limited because of his problems. It was found that parents of brain damaged children felt the negative impact of the child on the siblings and on their lifestyle. The Down's Syndrome child had more effect on day-to-day life, and his parents tended to view the differences between them and families without a mentally regarded child around the daily burden of care, and not so much in regard to family interrelationships and social limitations.

However, among the parents of children in only fair physical condition, there were more (in comparison to the parents of children in good physical condition) who described the positive impact of the mentally handicapped child on the siblings who became closer to

each other. Such feelings of togetherness might reflect the tendency of some families to avoid contacts with the outside world. Instead of outside contacts, the family members develop very close interrelationships and tend to emphasize the family unity around its special task; caring for a mentally handicapped member.

Family characteristics were also found to have an impact on parental willingness to accept the child's influence on the family as a whole. Results of this study indicate that when the child is the second born in his family, the parents perceive the impact of his problem on the siblings more strongly. According to Farber (1960), the degree of family integration achieved prior to the introduction of the mentally retarded child is a dominant factor determining what will happen to the family's interrelationships after the birth of such a child. Yet, more important factors are the family birth order and the arrest in the development of the family lifecycle, which is due to the fact that the mentally retarded child's dependency on his parents continues in spite of his growing age. When the retarded child is the last born, the parents experience the arrest in their family lifecycle more acutely, since in their advancing age they still have to care for a child whose needs, in spite of his growing age, resemble the needs of a baby. (Farber, 1964).

Results reveal that besides the order of birth, differences in parental level of education create different opinions in regard to the influence of the child's problem on the family as a whole. The parents whose level of education was lower were strongest in their denial that the child's problem impacted on their lifestyle and family interrelationships. These results stress the great influence of education on parents' views, as among the parents of the older children who were readier to accept the child's impact on the family as a whole, there were more lower educated parents. The higher educated parents were more ready to admit that the child's problem affected his siblings and had a certain impact on the family lifestyle. The fact that mental retardation is not viewed as a major difficulty by families of lower socioeconomic status and education has already been mentioned in past studies. (Begab, 1963; Farber, 1968; Kurtz, 1977).

Mercer (1966) found that the more highly educated parents preferred to keep their child in an institution, while Fotheringham et.al. (1971) found that among the children in institutions, more came from families of lower socioeconomic status and level of education. A common view among researchers is that for the lower socioeconomic and less educated families it is easier to accept the child's mental disability; however, it is much more difficult for these parents, and especially for the mothers, to organize their daily activities in a way which would permit them to have an acceptable family life. (Farber, 1968).

Parental religious background is another factor which was found to have its influence on the degree of acceptance of the effect of the child's problem on the whole family. Results of this study show that the Jewish parents more than the Catholics and the Protestants reported differences in their lifestyle when comparing themselves to families without a mentally retarded child. This result is probably influenced by the fact that among the older children there were more Jewish children, and it has already been mentioned that more parents of the older children were ready to acknowledge that the child's problem had an impact on the whole family. The fact that the Catholics more than the others tend to deny the impact of the child's situation on the family as a whole, could be explained with reference to Zuk's findings (1959) which revealed that Catholic mothers accepted the mentally retarded child as part of the family more easily. Such an attitude probably helped the mothers to ignore the effect of the child on the whole family.

To conclude, the findings of this study reveal that many of the parents who were interviewed were not prepared to accept that their child influenced the nature of their family life. However, when comparing themselves to parents of "normal" children, the parents were readier to acknowledge the differences in daily life which arose from the burden of care for a disabled child. A comparison between mothers and fathers in regard to the abovementioned issue, did not reflect any of the marked differences in opinion which have

been reported in some past studies (Holroyd and McArthur, 1976; Beckman, 1983).

The differences in parents' opinions were due mainly to the child's age. The parents of the younger children are more aware of differences in patterns of child rearing, mainly the need to care for a baby who never grows. The parents of the older children tend to describe more basic changes in their lifestyle which result from the child's special needs.

The influence of the child on parental relationships with community support networks, will be discussed in the following chapter.

CHAPTER 4

FACING OUT; THE IMPACT OF THE MENTALLY HANDICAPPED CHILD ON HIS PARENTS' RELATIONSHIPS WITH THE OUTSIDE WORLD

4.1 PERSPECTIVE FROM THEORY AND PAST RESEARCH.

4.1.1 Introduction

Having a baby is usually an occasion for rejoicing and much public congratulation. The new baby is paraded in the pram, everyone likes to have a look and coo over it, and the parents can glow with pleasure and satisfaction. All babies seem to be beautiful, at least to their mothers and there is the feeling of having created something perfect, a sense of continuity and the belief that a bit of one's self will live on for the future. There is, of course, another side to having babies: depression, anti-climax, and loss of freedom, but these are not the aspects that are accentuated.

In "normal" family life, participation in friendship groups and in wider organizations outside the family, ordinarily supports the norms and values associated with everyday life. For the family in crisis, these ordinary community relationships do not support norms and values pertinent to handling "the problem" (Farber, 1975).

When the child is mentally handicapped this is a tremendous blow to the self esteem of the parents. They feel that they have either failed or been singled out by fate (Hannam, 1975).

It seems that the outside world represents a considerable threat to the parents. From the start they have to confront it in the shape of professionals, relatives, and friends. The professionals, according to Anderson (1982), understand about these things and can see what is coming, but the relatives or friends may have mixed feelings when they get the news.

Although as Farber (1975) notes, other extra-family coalitions do assist family members in handling the crisis,

sometimes people outside the family find it very difficult to react helpfully. Very often the result is either too much sympathy or a denial of any sort of problem. It seems that the parents themselves fear both reactions. Although they hope to not be rejected because of the child, too much sympathy sometimes makes them feel as if there has been a "death in the family", being constantly surrounded by people who are "awfully nice" (Voysey, 1975, p. 144).

Most studies show that the outside world's initial reactions have great significance in determining the parents' attitudes towards other people and organizations in the community, including the services with which the parents must have contact in order to be helped with their new situation. Not only the first reaction parents face, but other factors, affect parents' openness to accept help. Bayley (1973) describes two main reasons. According to his findings some of the families want to suppress the pain that they feel about their subnormal member, and not let the world know about it. They do not want to feel stigmatized. The second reason may be related to the first one, but Bayley did not find clear evidence that this is so: there is a great reluctance on the part of the parents to rely on other people, and especially their other children, to care for the mentally handicapped child. In fact, according to Voysey (1975) parents may report that they have to manage others' expressions of sympathy and advice, and their ability to accept such offers depends on the already existing relationships with people outside the family.

There is no doubt that the ability of the parents to develop mutual extra-family relationships will create a healthier atmosphere in the family and help the parents in adjusting to their problem and its implications on their day-to-day life.

This section will describe the roles played by community support networks, and the reciprocal social relationships between these networks and the parents. It will be divided into two parts:

(a) Parents' relationships with relatives, friends and neighbours;
(b) Parents' relationships with professionals.

4.1.2 Parents' relationships with relatives, friends and neighbours

One of the most consistent research findings described in the literature is the limitation on participation of parents of mentally handicapped children in extra-family relationships such as organizational membership, recreational clubs, visits to other people's homes and other kinds of social activities.

Farber (1968) mentions that findings of various studies suggest that families with mentally handicapped children tend to disengage themselves from community relationships and to focus attention on problems within the family.

Tizard and Grad (1961) have defined three degrees of social contacts which they found among families of mentally handicapped children:

(a) Normal social contacts: When the family had good relationships with relatives, friends, and neighbours, they were friendly and visits were exchanged. The parents seldom went out together but each parent had his own social activities.

(b) Limited social contacts: The parents did not go out without the child, it was difficult to take the child out to crowded places and because of this the parents never went out together.

(c) Severely limited social contacts: Families who cut themselves off completely from social intercourse, lived in social isolation, frustrated and unhappy.

Tizard and Grad's findings (1961) reveal that out of one hundred and fifty one families who participated in their study, sixty percent had normal social contacts, twenty seven percent had limited contacts and ten percent were severely limited. Other studies (like those of Holt, 1958;

Farber, 1968: Rowitz, 1974, Suelzle and Keenan, 1981), report similar findings. It is quite obvious that many parents of mentally handicapped children, when readjusting to their new roles, have difficulty in relying on extra-family resources, more specifically on their social contacts with relatives, friends and neighbours. It seems from a few research studies that the parents do not always find it easy to accept help from these outsiders. (Glendinning, 1983).

Voysey (1975) reports that some parents who had very limited social contacts asserted that they "did not really mind". Such a reaction raises the question of whether these people are basically less social and prefer to spend more time in joint family activities or whether they become accustomed to a different kind of lifestyle imposed on them by virtue of having a mentally handicapped child. Some parents try to emphasize the normal aspects of this way of life saying: "It's like when you have a baby, you stay at home." (Voysey, 1975, p.146).

Some studies have tried not only to describe the nature of the parents's social relationships, but to find out the reasons for the development of such relationships between the parents and the outside world. The reasons which have been described in these studies can be divided into two main categories:

(a) Reasons which derive from the general social reaction to mental handicap, and from specific reactions of people in the parents' immediate community, who have direct social contact with them (relatives, friends and neighbours).
(b) Reasons which are related to the parents' behaviour, feelings, and expectations as a result of having a mentally retarded child.

(a) In a discussion of the mentally handicapped child's impact on parental adaptation, Adams (1971) indicates

that the critical event may be of such a nature that the family problem is labelled first in the community and only afterwards within the family. He suggests that revisions of family relationships with outsiders may occur even while the family still denies the existence of the problem. Farber (1975), in considering this idea, raises the question of adaptation and labelling and the outcome in regard to those who are labelled (the child and his family). Adapting Goffman's (1963) and Birenbaum's (1970) ideas, Farber suggests that the extent that mothers of retarded children are able to perform roles similar to those performed by mothers of normal children is related to the degree that these mothers are affiliated with a stigmatized person. When the consequences of the courtesy stigma that these mothers bear are manageable (which means that others are "considerate" in accepting "the plight of the family with a disabled child", or they "forgive" failures in role performance without needing to negotiate the basis for continuing the relationship), then the failures are seen as improper but not offensive.

According to Farber (1975), in such a situation one can view the situation to be offensive when:

- The failures are no longer seen as unavoidable lapses.
- The failure itself (regardless of basis) produces bitter disappointment, interferes with important goals and is viewed as a permanent state.
- The demands on one's resources exceed one's ability to compensate for these failures.
- The costs of carrying a courtesy stigma outweigh the gains from maintaining the relationships.

In the foregoing conditions there is a need to call for negotiation of the allocation of roles either directly or through intermediates (such as relatives, friends, neighbours or professionals).

Thus, parents' interpretations of society's attitude to them and to their retarded child will have a great impact on their attitude to social activities in general and on their ability to trust and accept help from people outside the family. Bayley (1973) reports that according to his findings the support and acceptance of the neighbourhood was more directly relevant to the lives of the families than the general tolerance and understanding, or lack of it, of society at large.

Farber's findings (1975) illustrate how important it is for the parents to feel accepted by their neighbours. He mentions that constant presentation of the handicapped child to persons outside the family may be maintained in the neighbourhood and helps the neighbours to get used to the child and accept him and his parents. But, when the neighbours refuse to accept the parents and their mode of presenting the child, it becomes a relevant factor in change of residence.

It seems that the ability of the parents to obtain some degree of normal social interaction may be partly a function of the degree of acceptance by the extended family and by the neighbours within the community. (Tizard and Grad, 1961; Barsch, 1968; Farber, 1968). Drew et.al. (1984), suggest that parents of retarded children appear to be able to maintain positive relationships with the neighbours although some of them have to contend with misperceptions and suspicions regarding retarded children. It appears that successful integration with the extended family, friends or neighbours may well be an outcome of educating people in the community towards acceptance of the mentally handicapped child and his family.

Chinn et.al. (1978) emphasize that the parents' greatest need is for effective communication with

others. Effective communication implies understanding and support, since the parents need to be understood by friends, family and others and to know that they have support from the people who care about them. Appropriate support may be in recognizing the reality of the parents' feelings thereby helping them to resolve problems without causing harm to themselves or others.

It is common to consider supportive community relationships in contrast to isolation, but it can be regarded also in contrast to nonsupportive community relationships. Interactions with groups who do not support the conventional norms and values of the parents, stimulates types of interactions in the family that are disruptive to its internal organization and to the family's ability to satisfactorily adjust to the outcome of having a mentally handicapped member (Farber, 1968). Such a situation causes the family members to adapt their roles and expectations of each other and of the outside world. Evidence from studies demonstrates that the tendency to isolate themselves socially is common among these families. In some cases, isolation causes the parents to feel that the social debt owed them may never be paid off, or that the social interest accruing in this debt is not sufficient to compensate for their sacrifices (Farber, 1975).

Voysey (1975) notes that some parents feel that they must treat others' responses as problematic, so that parents develop skills which enable them to tipify embarrassing situations and predict others' responses. This special competence plays an important role in helping the parents to develop their identity and self-conception, and can avoid the tendency of some families to give up and to become an isolated closed unit.

To sum up, the general ideas and attitudes of society towards mental handicap and the way it is presented to parents of mentally handicapped children by th.. relatives, friends or neighbours, will have a gre.. impact on the ability of these parents to cope wi.. their problems without the need to develop a unique and different lifestyle. Choosing to isolate themselves as an alternative to the attempt to handle the outside world's reactions, will make the burden that these families carry a heavier one.

(b) The tendency of the parents of mentally retarded children to isolate themselves from the outside world serves not only to avoid reactions of other people. According to Chinn et.al. (1978), parents may choose to isolate themselves because of their own feelings of shame and guilt. They may thus unfortunately withdraw from friends, relatives, neighbours and professionals and from any kind of social contact or activity. However, Hewett et.al. (1970) found in their study that even those mothers who felt isolated were not cut off from all social contacts, and that in some cases mothers who had only a few social contacts did not feel lonely. Their conclusion was that feelings of isolation were much more a function of the mother's personality than of the presence of a handicapped child.

Isolated parents or the ones w.. choose to withdraw from social contacts, surround themselves with a protective barrier against outside pain, if not the hurt inside. Staying away keeps the parents protected from the outside world but at the same time impedes their ability to ask for help which is so very needed, or even to receive help (.fered by people in their community.

Voysey (1975), Hannam (1975) and Worthington (1982) have described the parents' first experience of facing others' reactions (after telling them of the problem or

taking the child outside for the first time) as an important, instructive event, which may influence their attitudes and ability to share the problem and to receive help from outsiders. According to Voysey (1975) the first experience may constitute a "turning point" after which it may "never be so bad again". Parents often expect such events to be "the test" of their acceptance. (p.153).

In similar vein, Worthington (1982) describes the mothers who could not tell others about the child or take him out, and who cut themselves off from people, avoiding visiting friends or neighbours. She notes that these mothers regretted this later, recognizing the price they had to pay; becoming isolated and not receiving emotional support and practical help from people outside the family. Worthington concludes by stating: "Talking about the child is harder for some than for others. The sooner the hurdle is overcome the sooner it gets into proportion. Having spoken about it to one person it becomes easier to talk about it to others. It is one step towards acknowledging the problem, involving others and ultimately to coping." (p.68).

Hannam (1975) also mentions that it is essential for parents to be able to openly express feelings of hostility or aggression towards the handicapped child in front of other people. To some parents who have put on a cheerful front, it is a great relief to admit their negative feelings an ill be accepted by others. Anderson (1982) describes the process that some parents go through when they have to interact with the outside world. "There is likely to be a period when a small in-group develops of those who are in the secret and the family becomes in-turned. Then, the first steps back into contact with the outside world may be acutely difficult and painful." (p.78).

If the parents overreact to some of the comments made by other people and turn back to themselves, then every small commerce of daily life can become very stressful. As time goes on, these things fall into a pattern. The situation is known and the relatives, neighbours and friends avoid contact or limit it. Or, sometimes, friendships may strengthen which makes it possible for social life to continue in spite of the difficulties.

When the parents feel that they can relate to the outside world, they express two kinds of major needs:
the need to reduce their anxiety and to obtain emotional support;
the need to minimize the burden incumbent upon them and thus to enable a greater fulfillment of their individual interests and activities.

In regard to these issues, Rappoport et.al. (1975) found that needs felt most strongly were those related to practical day-to-day aspects of living. Glendinning (1983) in her study, asked parents to describe the practical help and the emotional support they received from the extended family. Most of the parents felt that they received very little practical assistance from their relatives, and that they would have liked more. Although the parents wish to receive more practical help from their relatives they accept difficulties emerging from the child's situation or the age of the relatives. Generally, the parents in Glendinning's study felt that although the need for practical help was great, they could not rely too much on others to get it.

Nevertheless, Bayley (1973) found in his study that relatives were the source of a good deal of support. Sixteen out of the fifty three families who took part had 'much' help from relatives; another nineteen families had 'average' amount of help (a regular contact

with the relatives). In some cases the relatives were living far from the family, but occasionally even when the relatives lived further away they offered help.

According to Farber's findings (1968), the attitude of certain relatives is more significant for the parents. He found that when the parents were in frequent contact with the wife's mother, marital integration tended to be high. However, when they were in frequent contact with the husband's mother, marital integration tended to be low. The husband's mother generally blamed the wife for the retarded child. Ordinarily, the wife's mother showed considerable sympathy and understanding for her daughter's situation; as Hewett et.al. (1970) note "maternal grandmothers living nearby are often a tower of strength to their daughters and even when they lived far away were counted as supportive if they kept in constant touch, visited, and often gave practical help" (p.118). It was important for the parents to feel that their child is accepted by his grandparents. Where this did not occur, mothers felt it very keenly and a few even felt that they had to fight their own parents whose views on what was best for the child were contrary to their own (Hewett et.al., 1970).

Extended family members do not always live nearby and therefore are prevented by practical difficulties from providing regular, informal assistance. Neighbours and friends have an advantage over relatives because generally they belong to the parents' community, and therefore are more available. Appell et.al. (1964), Bayley (1973), Glendinning (1983) and others found that parents generally felt that the community accepted their retarded child and that friends and neighbours were willing to support them and offered practical help. In Bayley's study fourteen out of fifty families reported receiving 'much support' from neighbours. Another twenty five families had 'average support'. Glendinning

states that even if friends could not always give informal practical help, their interest and concern was still greatly appreciated. Voysey (1975) found in her study that it was easier for the parents to accept others' offers and advice in time of crisis, or in the interest of the healthy children. In all cases, acceptance of help was premised on the assurance that the disabled child was safely left in another's care. According to Anderson (1982), parents felt that the people who are the most helpful are those who can behave normally; pick up the baby and find out what he or she can do; talk about things of an everyday kind; do not have to express pity or sorrow. It seems from most studies which have dealt with this subject that, as with relatives, parents wish to get practical help and not only sympathy from friends and neighbours. As Hannam (1975) concludes: "A friend or a neighbour who takes the mentally handicapped child for a walk will do more good than one who offers sympathy or compliments the family on how well they are coping" (p.183).

Although, as mentioned earlier, parents generally felt accepted by their neighbours and friends, some situations remained unmanageable and parents had to learn to distinguish 'true' sympathy from mere curiosity, or to manage interactions so that they are not simply at the 'mercy' of others' definitions (Voysey, 1975).

It seems that the child's behaviour and age has a lot to do with the ability of the neighbours and friends to accept him and his parents. Hewett et.al. (1970), Bayley (1973), Hannam (1975), Anderson (1982) and Glendinning (1983) found in their studies that even in the locality where the parents are known, there may be tensions and embarrassments as a result of the child's behaviour. As the child grows older, his behaviour is better known to the neighbours and friends, but it may still be acutely

embarrassing when he makes peculiar gestures or approaches people inappropriately. The mentally retarded child's behaviour, and the reaction of his parents, can cause great embarrassment for the neighbours and friends. Yet, sometimes in their effort to be helpful, neighbours try to deny the problem by giving the parents (and also themselves) a false reassurance that the child "seems so bright" or "is doing marvellously" (Anderson, 1982, p.78). Unsympathetic neighbours and friends increase the stress in the family considerably. Sometimes, parents are made to feel that they have to watch the child every minute of the day or to isolate him from the outside world. They also feel that they must always be prepared to deal with others' reactions and comments and, as Voysey (1975) mentions, "They feel that they have to be rude to some people" (p.153). Parents' emotional feelings in regard to other people's reactions are reflected in their social relationships. Their circle of friends is small when new friendships are looked upon as a potential source of painful and embarrassing questions (Begab, 1963).

Similarly, findings from other studies (Bayley, 1973; Voysey, 1975; Glendinning, 1983) have revealed that there are parents who choose to not have any contacts with their neighbours and friends, either because they want to avoid embarrassment and conflicts or because it is too difficult for them to share their problems with others. It should be remembered, however, that some parents are not so 'social' to begin with, and the lack of social relationships is due more to their personalities than to their mentally handicapped child.

When the parents choose to "keep themselves to themselves" they limit their opportunities to get help from their neighbours and friends. The acceptance and friendship of neighbours is also important for the mentally handicapped child. For the child, neighbours and friends are representatives of the community, and if his parents choose to avoid

social contacts and keep the family a close isolated unit, it will be almost impossible for the child to even try to find his place in his community.

4.1.3 Parents' relationships with professionals

Parents, faced with the realization that their child is mentally handicapped, usually need much of the help that is available to them. Some parents are so bewildered when they encounter the handicap that they may become unaware that they need help, and that help does exist. Other parents may realize that they need help, but they may not be aware of what type of resources exist or where to find them. (Chinn et.al. (1978).

Many studies which have tried to describe the characteristics of families of mentally handicapped children mention that these families have greater contact with social and health services, compared to families without a mentally handicapped child. According to Farber (1968) the long-term reliance on welfare agencies influences the parents' attitudes towards their community and its services and has also a marked impact on the family's lifestyle. Featherstone (1980) states: "Professionals play a big part in the lives of disabled people and their families. It often looks to parents as though outsiders hold the child's future in their hands" (p.177).

On the other hand, it is not uncommon for these parents to feel that they are all alone with their problem. Glendinning (1983) found that parents' opinions on professionals and services were mixed. The professionals received praise from some parents for their conscientious concern and helpfulness but these favourable views were counter-balanced by accounts of services which were considered unhelpful, insensitive and even negligent.

In their studies, Farber (1968), Bayley (1973), Voysey (1975), Featherstone (1980) and Glendinning (1983) tried to find out what creates the differences in parents' opinions, attitudes, and expectations of the various kinds of professionals (physicians, health nurses, social workers, etc.) and the services in the community.
They found that the following factors could explain the difference in parents' views:

I. The way parents experience their first interactions with professionals.
II. The parents' emotional reaction and their ability to cope with the child's problem at the various stages.
III. The extent to which parents understand the various professionals' roles and what may be expected from the services.
IV. The professionals' general attitude towards mental handicap and to the child and parents in particular.
V. The family and child characteristics.

I. Parents initial interactions with professionals

It seems that the parents' initial experiences with professionals strongly influences their further acceptance of help offered to them. The initial interactions between parents and professionals occur mostly when the parents learn about the child's problem. Such an experience is a traumatic one for the parents, and their ability to relate to others in an effective way is sometimes limited by the shock. Hannam (1975) mentions: "All the parents felt that they needed to have more than one meeting with whoever told them of the child's handicap" (p.51). Under shock the parents sometimes feel that they are not ab[illegible]st what they have been told. If they do [illegible]itional meetings with professionals at this st[illegible] feelings of dissatisfaction may grow and misunderstanding will

be inevitable. In the turmoil of this period the parents are often not aware that they have been offered help or even that they were informed about the problem by professionals. Communication between the parents and the professionals is almost impossible sometimes because the parents are overloaded with all kinds of feelings, and in a way they cut themselves off from the outside world. Studies which have dealt with this issue reveal that for most parents, it was difficult to relate to professionals at this stage and they remember almost only the negative feelings which surrounded these first contacts.

As a result, some parents lose hope and refuse to accept professional help. However, most of them subsequently overcome the bad feelings and try to enlist the professionals' help for the benefit of their child.

II. Parents' emotional reactions and their ability to cope with the child's problems

A few studies tried to deal with the relationship between parents' reactions to their child's handicap, and their attitudes towards professionals. Hutt and Gibby (1965) describe "the disguising parent" whose modes of behaviour attempt to disguise the child's condition. They state: "Not only are such attempts made in order to hide his condition from other people but, more important, they are made in order to attempt to hide it from the parents themselves" (p.304). Even if the parents perceive to some extent that there is 'something wrong' with the child, they are unable to recognize or admit that he is mentally handicapped. These parents search very hard for some reality factor to which the child's retardation may be attributed. They 'shop' for doctors and the child is given one medical examination after the other, each time with the hope that a specific remedial cause will be discovered and corrected.

When the professionals are unable to fulfill such expectations, they disappoint the parents. The frustrated parent may place the blame for the child's condition on the professionals. Negative feelings may be justified in some instances but not, of course, for causing the original handicap.

According to Chinn et.al. (1978), parents' attacks on professionals (mostly physicians) are a result not only of their emotional situation, but of poor communication for which the professionals are responsible. Good relationships with the family physician or other professionals are essential to avoid the parents' tendency to project blame on professionals or to become hostile. Hostility may lead to distrust that may impede the ability of the parents to accept professionals' help in the future.

Featherstone (1980) also emphasises how important professionals are for the parents when the diagnosis is made and immediately after. The parents want to know as much as possible about the origins of the disability and its implications for their child's life. Until the child goes to school where he will probably have contacts with professionals, it is up to the parents to what extent they will interact with services. Bayley (1973) found that for the growing child, the family needed less reassurance from their doctor about the care of the handicapped child. He found that only fourteen out of fifty three mothers thought that the general practitioner was "a lot of help" reflecting the amount that these mothers felt that he was needed.

It seems that when the parents feel that they can cope better with the child's problems, their attitudes to, and expectations of professionals change.

III. Parents' understanding of professionals' roles and their expectations of help

Studies by Schwartz (1970), Justice et.al. (1971), Rappoport et.al. (1975), Anderson (1982) and Glendinning (1983) have all described some of the gaps between the way professionals treat mentally handicapped people and their families, and the expectations that parents have of them. Anderson (1982), when trying to explain the reasons for parents' ambivalence about professional help, states: "This can happen with any kind of help but is especially likely when the help involves handing over the care of the child to strangers" (p.79). It seems that it is hard for the parents to trust strangers. Moreover, when they have to ask for increasing amounts of help from professionals, they sometimes also abdicate responsibility for the child. This situation may lead to rejection, and perhaps total responsibility is therefore easier to accept than partial. The fact that strangers may be able to cope better with the child can be perceived by the parents as their failure to do so, which becomes public knowledge when professionals take over these responsibilities. This 'all or nothing' attitude may create difficulties for the parents in using professional help for their sake or that of the child.

Parents' feelings that they do not receive the help they need might also create ambivalent attitudes towards professionals. Sometimes the parents are not aware and have insufficient knowledge about what can be expected from professionals. Unrealistic expectations lead to deep disappointment on the part of the parents. Hewett et.al. (1970) found in their research study that the families were uncertain as to who a mental welfare officer was, and who came from other departments. They also felt that the professionals' home visits were rare but for some families it was hard to see any purpose

for these visits. The fact that they did not know what they could expect from these visits made it difficult for them to find them helpful. Bayley (1973) mentions that one of the reasons that the physicians were considered more helpful than the mental welfare officers or the social workers was probably because the families had a better idea of what the doctor was for. In addition, professionals other than doctors are often not available when parents need them most, and sometimes when they are available, they do not have the specific skills and knowledge necessary. Schwartz (1970) mentions that even when an early diagnosis is made, the way parents are informed about it does not help them to get a clear understanding of the situation, an almost always no concrete help is given about how to handle the problem. In such a situation the parent can feel that, "As regards your own child, you're often a damned sight better informed or aware of the child than the doctor is" (Glendinning, 1983, p.142).

When the physician does not give a clear picture, the parents sometimes consider his behaviour as a disrespectful one: "I got very angry. One of the doctors, at least, knew that I'd had nursing experience, and yet I was still treated as if I didn't know anything" (Glendinning, 1983, p.142).

Schwartz (1970), Bayley (1973), Featherstone (1980), Glendinning (1983) and others have tried to sum up parents expectations of professionals, and mention the most important aspects according to parents's views:

- Parents want to have clear explanations of the child's problem.
- They want to be respected by professionals.
- They want to be informed about everything that has to do with their child's problem and how to handle it.
- They feel a strong need to get concrete help, and when they do get it, they probably consider the professionals as being more helpful.

"If the social worker was unable to do anything about the family's most pressing needs and the parents seemed well adjusted and did not want to talk about 'problems' with the mental welfare officer it is not surprising that contact was dropped" (Bayley, 1973, p.304).

Justice et.al.'s findings (1973) support the above-mentioned ideas. They interviewed one hundred and sixty one parents of mentally retarded children, asking about public and private helping resources used by parents. They found that the parents had not received assistance from public or private resources for most of their problems. Although the parents reported that the services with which they had contact were helpful, they did not seem to generalize the use of these services to their other problems. A large proportion of these parents reported that they did not know of any additional services that might help with their problem. The results of the abovementioned study show how important it is for the parents to be informed about available services and referral procedures, which should result in more effective delivery of services appropriately timed to the needs of the child and the family.

IV. Professionals' attitudes to mental retardation and to the families of the disabled child

As mentioned before, parents of mentally handicapped children need to feel that they and their child are respected by professionals. They also search for competent services which can offer the help needed. Voysey (1975) refers to a study which has shown that parents tend to define the hospital as an irrelevant source of help when they perceive that no medical skills can help their child. No doubt the physician's frequent feeling of helplessness and incompetence when confronted with mental handicap, influences their attitudes towards the phenomenon and to the parents of these children in particular.

According to Voysey (1975) 'breaking the news' is therefore a problematic situation for both sides. The physician feels unhelpful and the parents feel unhelped. In order to solve this situation the parents sometimes tend to take all the responsibilities upon themselves, and reject any kind of medical help offered to them. In an attempt to help the parents, the physician is dependent on the parents for information, since they are in a better position to observe the child's everyday behaviour. Yet, it is hard for the physician to accept this information as reliable for medical purposes, and he may feel limited in his ability to offer professional help. He thus may sometimes resort to verbal reassurances like: "Don't worry" or "Wait and see". Such reactions shake parents' trust in the physician's competence in regard to their child's problems. Hewett et.al. (1970) research findings have shown that only fourteen percent of one hundred and eighty mothers who were interviewed in their study received specific help from general practioners; they therefore had to obtain services from other agencies.

Like physicians, social workers consider the 'special problem' of the mentally handicapped as one that cannot be fundamentally altered or even improved beyond certain limits. Thus, social workers put an emphasis on helping their client to cope with the situation more effectively. In order to be able to do so, the parents need careful and skilled social work help through a close, personal relationship with the worker. The social worker's roles are therefore defined around two major elements:
- The supportive and counselling element.
- The provision of concrete help.

Findings of some studies, such as those of Bayley (1973), Voysey (1975) and Glendinning (1983) reveal some of the difficulties in interaction between social workers and parents which can be explained by the parents' unrealistic expectations, or as a result of the social workers' way of performing their roles.

For some parents it is too difficult to share their feelings with a stranger: "It is not difficult to see why an experienced married woman who has brought up a family and is extremely busy looking after her subnormal child, should be irritated by a young social worker who wants to explore the mother's feelings but has no experience of bringing up children and has no practical help to offer" (Bayley, 1973, p.306).

On the other hand, some parents appreciate practical help, such as help received through training centres. Such structural help is directly relevant to the daily routine of the child and his parents and makes the burden easier to bear. The social workers themselves feel more competent when they can offer practical help together with emotional support, although as Voysey (1975) mentions, practical help may often serve a useful ancillary purpose temporarily in relieving some minor pressures, while the emotional burden is not affected. Material help in some cases may even be an irritant because it does not touch the real issue.

It seems that some parents think that having someone outside the immediate family to whom they can talk from time to time, would reduce their feelings of isolation and tension. These parents appreciated the social worker's help, even though it does not always solve practical problems.

To sum up: relationships between parents of disabled children and professionals seem to be unbalanced. An individual family needs a professional far more than the professional needs them. The professional enjoys higher status than the parents, and has far more power in his hands. The parents' feelings of inferiority and their relative impotence allows welfare services to treat them as patients; consequently a passive, powerless manner of behaviour is almost expected by professionals. In their

struggle to realise their own power and ability, parents sometimes prefer to relate to other parents of mentally handicapped children, instead of using professional help. These parents' organizations, therefore, can be a source of emotional support as well as centres for information dissemination.

Parents involved in these groups are able to share their experiences and feelings. They give one another support while they are able to unify their efforts to secure support for programmes that affect their children (Chinn et.al., 1978). In doing so, they gain the feeling that they are less dependent on the help of professionals and that they can use their own power and influence to shape the services according to their needs.

V. The impact of family and child characteristics on parents' attitudes toward professional help

Only a few research studies could be found which h described the impact of family and child characteristic on the parents' attitudes towards services, and their willingness to utilize offered help. Ehlers (1964) found in his study that working class and lower middle class families did utilize publicly supported community services for the evaluation and treatment of their mentally retarded children. In contrast, upper and upper-middle class families were more likely to make use of private medical services; they were therefore able to have a wider range of options from which to choose. Ehlers f und also that the size of the family, the mother's level of education, and religious or ethnic background are not factors which determine the parents' willingness to utilize professional help, or the kind of professional help preferred by those parents.

Begab (1963) mentions that sometimes lower-class families are better known to welfare agencies because of

other problems beside the mentally retarded child. However, among these families, he found reduced ability to obtain diagnostic, training or therapeutic services, or to purchase private residential care when public resources were not immediately available. Sometimes, even when community resources were not immediately available, Begab found that the lower class families did not have enough information about agencies, or how to obtain help for their particular problems. Begab (1963) and Ehlers (1964) also found that lower-class families, more than middle and higher class families, tended to keep the child at home. The latter ones decide to institutionalize the child when his presence in the family is seen as an interruption to maintained or raised social status, while for the lower-class family, social deprivation is a major factor determining institutionalization.

To sum up: it seems that the social status affects the willingness of the family to use professional help, determines which kind of help will be used (public or private) as well as its purpose (to keep the child at home or institutionalize him).

There is not enough evidence from past studies to make general statements about the influence of the child's characteristics on the parents' attitudes towards professionals. However, Ehlers (1964) found that families with moderately and severely retarded children usually seek out and receive services for them before they are two years of age. Bayley (1973) supports these findings. Among the families who participated in his study, those who had the most severely disabled children could not rely only on the help of relatives, friends or neighbours. They had to utilize formal professional help. While most studies emphasize the parents' considerable need for help when they first learn about the problem, Condell (1966) found that later, when the child grows older, parents still seek

information and have to rely on professionals when planning for the child's future. Condell's results indicate that the child's age has no impact on parents' willingness to use help and that in each stage of the child's life they need to know that professional help is available.

The findings of the present research study in regard to the subjects discussed here, are presented in the following section of this chapter.

4.2 FINDINGS OF THE RESEARCH STUDY

4.2.1 Introduction

The present section includes a presentation of research study findings in regard to the impact of the child on his parents' relationships with support networks. The section is divided into two parts:

(a) Parents' relationships with relatives, friends and neighbours;
(b) The reciprocal relationships between parents, community services and professionals.

4.2.2 Parents' relationships with relatives, friends and neighbours

Two out of the fifteen QRS scales refer to the impact of the child on his parents' social relationships. The scales are: 5, "Lack of Social Support" and scale 14, "Social Obtrusiveness". A comparison between the parents of the younger children (Group A) and the parents of the older ones (Group B) is presented in Table 34.

Table 34

Means, SD, Df and probabilities for Group A versus Group B according to scales 5 and 14 of the QRS (t test)

Scale	Group A				Group B			
	Mean	SD	Df	P	Mean	SD	Df	P
5. Lack of social support.	4.0	1.1	91.1	0.01	3.3	1.6	108	0.01
14. Social obtrusiveness.	2.3	1.0	108.3	0.04	1.9	1.1	110	0.04
	N=58				N=54			

Results of the comparison between the parents of the younger children (Group A) and the parents of the older group (B) on these two scales show a statistically significant difference in both scales.

Group A parents score highter in "Lack of Social Support" and also in "Social "Obtrusiveness". Parents of the younger children felt to a greater extent than the parents of the older group that the child had an impact on their social life.

A comparison of the mothers versus fathers according to the same two scales, did not show statistically significant differences in either scale. (See Table 55A in Appendix 4).

Results of the comparison between mothers of Group A and mothers of Group B and between fathers of Group A versus fathers of Group B are presented in Tables 35 and 36.

Table 35

Means, SD, Df and probabilities for mothers in Group A and mothers in Group B according to scales 5 and 14 of the QRS (t test)

Scale	Group A				Group B			
	Mean	SD	Df	P	Mean	SD	Df	P
5. Lack of social support.	4.0	0.9	45.5	0.1	3.4	1.7	58	0.1
14. Social obtrusiveness.	2.4	1.2	58.0	0.1	1.9	1.2	58	0.1
	N=58				N=54			

Table 36

Means, SD, Df and probabilities for fathers in Group A and fathers in Group B according to scales 5 and 14 of the QRS (t test)

Scale	Group A				Group B			
	Mean	SD	Df	P	Mean	SD	Df	P
5. Lack of social support.	4.1	1.2	43.3	0.05	3.3	1.5	48	0.04
14. Social obtrusiveness.	2.3	0.9	46.0	0.1	1.9	1.0	50	0.1
	N=58				N=54			

When mothers from Group A were compared to mothers from Group B, the differences were not statistically significant. However, fathers of Group A scored higher than Group B fathers in "Lack of Social Support"; the difference being statistically significant. In "Social Obtrusiveness" the difference between the fathers was not statistically significant. These results suggest that while the mothers in both groups had relatively similar opinions about the impact of the child on their social life (according to the two scales), the fathers of the younger children more than the others felt the lack of social support.

Comparisons within each group (between mothers and fathers of the same group) according to scales 5 and 14 of the QRS did not show statistically significant differences. Parents of each group seem to have similar ideas about "Lack of social support" and the child's "Social obtrusiveness". (See Tables 56A, 57A in Appendix 4).

To sum up: Results of the two QRS scales reveal that the child's age has an influence on parents' views about his impact on their social life.

In order to explore in more detail the parents' relationships with their relatives, friends and neighbours, they were asked to estimate the child's impact on these particular social relationships.
The differences between parents' attitudes to those of their relatives according to child's age are presented in Table 37.

Table 37

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.	10.4	14.8
2. It doesn't affect our relationships.	50.0	35.2
3. They accepted the child and helped us.	19.0	27.8
4. We became closer.	10.3	1.9
6. Some relatives cannot accept the child.	10.3	20.3
Total	100.0	100.0
	N=58	N=54

Results show two meaningful differences in parents' opinions about their relationships with relatives. Parents of the older children perceive the child's impact on their relationships with relatives most strongly. They also mentioned that more of their relatives could not accept the child. The parents of the younger children had more positive views about their relationships with relatives.

A comparison between the parents of the younger and the older children attitudes to friends is shown in Table 38.

Table 38

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

Opinion	A	B
1. We are not so social, have not got many friends.	19.0	37.0
2. Some friends have left us because of the child.	19.0	3.7
3. I don't like our friends' attitude towards us.	3.4	-
4. It hasn't affected our relationships.	36.2	31.5
5. They have accepted the child.	22.4	27.8
Total	100.0	100.0
	N=58	N=54

The parents of the older children to a greater extent than the parents of the younger ones prefer to describe themselves as "not so social". However, among the parents of the younger children, there were more who admitted losing friends as a result of their mentally retarded child.
The differences in parents' views (according to Groups A and B) in regard to their relationships with their neighbours are presented in Table 39.

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4. It hasn't affected our relationships.	36.2	31.5
5. They have accepted the child.	22.4	27.8
Total	100.0	100.0
	N=58	N=54

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The differences in parents' views (according to Groups A and B) in regard to their relationships with their neighbours are presented in Table 39.

Table 39

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

Opinion	A	B
1. We have no relationships with them.	34.5	20.4
2. We have problems with them.	3.4	25.9
3. They have got used to the child.	32.8	27.8
4. They have accepted us and are helpful.	29.3	25.9
Total	100.0	100.0
	N=58	N=54

With regard to their views about their relationships with the neighbours, there were two marked differences between the groups. The parents of the younger children more than the others reported having no relationships with their neighbours. Parents of the older children more than the other group had problems with their neighbours as a result of the child.

A comparison between mothers and fathers revealed that the fathers experienced to a lesser degree the child's impact on their relationships with relatives, compared to the mothers. The fathers had the same feeling in regard to their neighbours, as they felt to a greater extent that the neighbours have got used to the child. (See Tables 58A, 59A in Appendix A).

The comparison of the parents' views about the influence of the child on their social life according to the QRS and the interview schedule, reveals a disagreement according to the two research tools. In terms of the QRS results, the child's impact on the parents' social life is experienced by the

parents of the younger children to a greater extent than the other group. The fathers of the younger children score higher on "Lack of social support" compared to the fathers of the older ones. Contrary to these results, according to the interview schedule, the parents of the older children describe more difficulties in their social life arising from the fact of having a mentally handicapped child. The differences between the results of both tools is also noted when fathers, compared to mothers, reflect a stronger tendency to deny having difficulties in their social life as a result of the child's problem. This paradox is further discussed in Section 4.3.1 of this chapter.

4.2.2.1 The impact of child and family characteristics on parents' opinions about the influence of the child on their social relationships

Parents' opinions about their relationships with relatives, friends and neighbours were compared in regard to the child's sex. Results are presented in Tables 40, 41 and 42.

(When analyzing these results, it must be noted that there are more males among the older children).

Table 40

Frequencies of parents' opinions about their relationships with relatives, by child's sex (in percentages)

Opinion	Male's Parents	Female's Parents
1. We have no relatives or no relationships with them.	13.6	10.8
2. It doesn't affect our relationships.	37.8	50.2
3. They accepted the child and helped us.	22.7	23.9
4. We became closer.	3.2	10.8
5. Some relatives cannot accept the child.	22.7	4.3
Total	100.0	100.0
	N=66	N=46

Results show that parents of females felt markedly less negative impact of their daughter on their relationships with relatives. Parents of males were much more inclined to feel that some relatives could not accept their son.

Table 41

Frequencies of parents' opinions about their relationships with their friends, by child's sex (in percentages)

Opinion	Male's Parents	Female's Parents
1. We are not so social, haven't got many friends.	34.8	17.3
2. Some friends have left us because of the child.	15.3	6.5
3. I don't like our friends' attitude towards us.	1.5	2.3
4. It hasn't affected our relationships.	28.7	41.3
5. They have accepted the child.	19.7	32.6
Total	100.0	100.0
	N=66	N=46

It seems from the results that parents of boys, more than parents of girls, consider themselves as "not being social" to begin with. Nevertheless, females' parents seemed to feel more accepted by their friends, or at least that having a mentally retarded daughter did not change their relationships with friends.

Table 42

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

Opinion	Male's Parents	Female's Parents
1. We have no relationships with them.	27.2	28.3
2. We have problems with them.	18.4	8.7
3. They have got used to the child.	27.2	34.7
4. They have accepted us and are helpful.	27.2	28.3
Total	100.0	100.0
	N=66	N=46

There are no meaningful differences between the opinions of parents of boys and girls about the impact of their child on their relationships with neighbours. It seems that the child's sex has a marked influence on parents' relationships with relatives and friends, yet it does not greatly affect their relationships with neighbours.

When parents' views were compared according to the cause of the child's mental retardation results revealed that parents of children who suffer from genetic disorders feel more than the others that they became closer to their relatives. Parents of children with brain damage feel to a greater extent that some of their relatives cannot accept the child. (See Table 60A in Appendix 4).

A comparison of parents' attitudes to friends by cause of mental retardation is presented in Table 43.

Table 43

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

Opinion	Unknown	Genetic Disorders	Brain Damage
1. We are not so social, haven't got many friends.	55.5	14.6	22.4
2. Some friends have left us because of the child.	5.5	9.8	19.4
3. I don't like our friends' attitude towards us.	-	4.8	-
4. It hasn't affected our relationships.	27.7	24.3	56.5
5. They have accepted the child.	11.3	46.3	2.7
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Results reveal some marked differences between parents' attitudes to friends, in regard to the cause of their child's mental retardation. Parents of children who suffer from genetic disorders perceived greatest acceptance by their friends. Parents of brain damaged children denied impact of the child on the relationships with friends while parents of children with unknown aetiology to a greater extent than the others, described themselves as "not so social". It seems from the results that when the reason was unknown or it is brain damage the parents had fewer relationships with their neighbours and in some cases they had problems as a result of the child. The parents of children who suffer from genetic disorders had better relationships with their neighbours. (See Table 61A in Appendix 4).

In addition to the cause of mental retardation, the physical condition of the child seems to have a marked impact on parental relationships with neighbours, as can be seen in Table 44.

Table 44

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

Opinion	Good physical condition	Fair physical condition
1. We have no relationships with them.	25.5	36.0
2. We have problems with them.	17.2	4.0
3. They have got used to the child.	27.5	40.0
4. They have accepted us and are helpful.	29.8	20.0
Total	100.0	100.0
	N=87	N=25

Results reveal that the child's physical condition has a marked impact on his parents' relationships with their neighbours. When the child's physical condition was only fair, the parents seemed to have fewer contacts with their neighbours. However, more of these parents felt that the neighbours became accustomed to the child and they had fewer problems with them, compared to parents whose child's physical condition was good.

After analysing the impact of child characteristics on parental views about their social relationships, further analyses were performed in regard to some family characteristics.

The child's birth order seems to have a marked impact on parents' relationships with their neighbours. Parents of first-born children were more likely to say that their neighbours became accustomed to the child. However, when the child was third or subsequently born, the parents felt that it was easier for the neighbours to accept the family. (See Table G2A in Appendix 4). (It must be noted that there are more first born children among the younger children and more second and third born in the group of the older ones).

Parents' level of education is another characteristic which seemed to have some influence on the impact of the child on parental social relationships. Table 45 presents parents' views about their relationships with their relatives.

Table 46

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

Opinion	Under Matric	Matric and Post
1. We have no relatives or relationships with them.	14.7	9.8
2. It doesn't affect our relationships.	37.7	49.2
3. They accepted the child and helped us.	29.6	15.6
4. We became closer.	4.9	7.8
5. Some relatives cannot accept the child.	13.1	17.6
Total	100.0	100.0

Results demonstrate that while more highly educated parents tended to state that the child made no difference to their relatives, lower educated parents were more inclined to report support and acceptance from their relatives. Level of education had no marked impact on the parents' views in regard to their relationships with friends. (See Table 63A in Appendix 4). As to their relationships with the neighbours, the highly educated parents felt to a greater extent than the lower educated parents that the neighbours accepted them and were helpful. (See Table 64A in Appendix 4). These results reveal that level of education probably has a strong impact on the parents' perception of their social life as there are more lower educated parents among the group of the older children (B) which generally reported a greater impact of the child on their social relationships.

In order to explore the relationships between parents' occupation and their opinion about how the child influenced their social relationships, two analyses were performed. Working mothers were compared to housewives and highly skilled fathers were compared to lesser skilled ones.

The most meaningful differences between working mothers and housewives were in regard to their relationships with their friends. The housewives to a greater extent than the working mothers considered themselves as "not so social". The working mothers, although mentioning that they had lost some friends as a result of the child, generally felt more accepted by their friends. (See Table 65A in Appendix 4).

Like the housewives, the lesser skilled fathers felt more than the highly skilled ones that they are "not so social" when describing the impact of the child on their relationships with friends. However, more highly skilled fathers did not perceive changes in their relationships with friends as a result of the child. (See Table 66A in Appendix 4).

When parents' views about the impact of the child on their social relationships were compared in regard to their religious background, meaningful differences were found in their opinions about relationships with friends and neighbours.

Table 46 presents parents' opinions about their relationships with friends, by their religious background. (It must be kept in mind that there are slightly more Jewish parents among the older children).

Table 46

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

Opinion	Catholics	Protestants	Jews
1. We are not so social, haven't got many friends.	42.2	26.7	11.1
2. Some friends have left us because of the child.	10.5	11.2	11.2
3. I don't like our friends' attitude towards us.	-	2.8	-
4. It hasn't affected our relationships.	10.5	30.9	72.2
5. They have accepted the child.	36.8	28.4	5.5
Total	100.0	100.0	100.0
	N=19	N=71	N=18

Results suggest that the Catholics among the parents considered themselves less social than the others. However, more of them felt that their friends accepted their child. The Jewish parents to a greater extent than the others did not report any difference in their social life as a result of the child. However, fewer of the Jewish parents felt that their child was accepted by their friends. The only marked difference in regard to the Protestants was that they, like the Catholics and to a greater extent than the Jewish parents felt accepted by their neighbours. (See Table 67A in Appendix 4).

Having a mentally handicapped relative in the family had some marked influences on parental attitudes towards the impact of the child on their social relationships. The fact that there are more parents who have another mentally handicapped relative, in the group of the older children (B) may have an influence on these results.

Parents who reported having another mentally handicapped relative in their family felt to a greater extent than those who did not, that the child had no influence on their relationships with relatives and friends. More parents without a mentally handicapped relative mentioned that some friends had left them because of the child. As to the neighbours, the parents who had another mentally handicapped relative felt most strongly that the neighbours became accustomed to the child, while the ones who did not have such a relative tended to report that the child was accepted by the neighbours. (See Tables 68A, 69A, 70A in Appendix 4).

4.2.3 Parents relationships with professionals and services

None of the fifteen QRS scales deals specifically with the impact of the mentally handicapped child on his parents' attitudes towards professionals and services. Therefore, the findings in regard to this issue were obtained solely from parents' reactions to the interview schedule.

Parents were asked about the stage at which they started to seek professional help for their child. A comparison between the parents of the younger (A) and the older children (B) is presented in Table 47.

Table 47

Frequencies of parents' initial contacts with professionals by Groups A & B (in percentages)

Time of First Contact	A	B
1. From birth, from the time I new about the problem.	32.7	33.3
2. We tried to get help but couldn't get it immediately.	20.6	12.9
3. When the child was 1-2 yrs old.	15.5	1.8
4. When the child was 3-4 yrs old.	25.8	25.9
5. When the child was 5 or more years old.	5.1	20.3
6. We haven't asked for professional help (only the day centre).	-	5.5
Total	100.0	100.0
	N=58	N=54

Data from this table reveals that the parents of the younger children recall seeking professional help at an earlier stage than the parents of the older group (B). Differences in parents' satisfaction with the availability of services in the community are presented in Table 48.

Table 48

Frequencies of parents' opinions about the availability of services in their community by Groups A & B (in percentages)

Opinion	A	B
1. Yes, there are enough services.	75.8	51.8
2. No, there are not enough services.	20.8	42.7
3. I don't know.	3.4	5.5
Total	100.0	100.0
	N=58	N=54

The parents of the younger children seem to be much more satisfied with the services available in their community. When asked about the kind of services which are needed in order to help a parent of a mentally handicapped child, the parents of the older children felt a greater need for professional help for the family as a whole, and for mentally retarded adults. (See Table 71A in Appendix 4). Yet, when the parents were asked if they had actually obtained professional help for the family as a whole or for a particular member of the family, the parents of the older children to a greater extent than the parents of the younger ones denied the need for such help. (See Table [illegible] in Appendix 4).

Moreover, as presented in Table 49, the parents of the younger children were more inclined to admit that, if it be needed, they would consider using professional help for the family as a whole in the future.

Table 49

Frequencies of parents' answers to the question: "Do you consider using professional help for your family in the future?" by Groups A & B (in percentages)

Opinion	A	B
1. There will be no need.	43.1	[illegible]
2. I hope not. We will be helped by the family.	6.9	-
3. If it is needed.	27.6	1.6
4. Yes, definitely.	22.4	1.6
Total	100.0	100.0
	N=58	N=62

When mothers' views about professional help and services were compared to the fathers' opinions in regard to this issue, it was found that parents' ideas and attitudes were similar rather than different. Both parents recalled starting to utilize professional help at almost the same

time, however fathers more than mothers felt that it was difficult to obtain help when it was most needed. Both parents were generally satisfied with the services available in their community (See Tables 73A, 74A in Appendix 4). Both parents usually did not feel the need for professional help for the family as a whole. (See Table 75A in Appendix 4).

4.2.3.1 The impact of child and family characteristics on parents' attitudes towards professional help and services

In order to explore the impact of certain child and family characteristics on parents' attitudes toward professional help, further analyses were carried out in regard to child's sex, the cause of his mental retardation, and his physical condition. Some family characteristics, like the child's birth order, parents' level of formal education, their occupation and religious background, were also analysed.

Differences in parents' opinions about the availability of existing services and the need for more professional help in regard to child's sex are presented in Table 50. (When analysing the results in regard to child's sex, it must be noted that there are more males among the older children).

Table 50

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

Answer	Male's Parents	Female's Parents
1. There are enough services.	48.4	58.7
2. There is a need for more information.	16.6	4.3
3. More schools and government support are needed.	18.4	15.4
4. More residential services for adults.	13.6	10.8
6. More services for parents.	3.0	10.8
Total	100.0	100.0
	N=56	N=43

This data reveals that females' parents seem more satisfied with the existing services than males' parents. Males' parents feel the need for more information about services in the community. Parents' views about the need for specific kinds of professional help are similar, regardless of their child's sex.

The findings reveal that when asked about their willingness to utilize professional help for the family as a whole, parents of males reacted more positively to the possibility of doing so in the future. (See Table 76A in Appendix 4).

A comparison between parents according to the cause of the child's mental handicap reveals that when the cause was genetic disorders the parents started to ask for help earlier than in cases where the child suffered from brain damage or when the reason was unknown. (See Table 77A in Appendix 4).

Parents' opinions about services in the community and the need for additional professional help also differ according to the cause of their child's mental handicap. These results are presented in Table 51.

Table 51

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

Opinion	Unknown	Genetic Disorders	Brain Damage
1. There are enough services.	72.3	51.2	47.2
2. There is a need for more information.	22.2	7.3	8.3
3. More schools and government support are needed.	5.5	12.2	27.7
4. More residential services for adults.	-	17.1	11.3
5. More services for parents.	-	12.2	5.5
Total	100.0	100.0	100.0
	N=18	N=41	N=36

Results suggest that parents whose child's mental handicap was of unknown cause were the most satisfied with current services in the community; they also reported the greatest need for more information. Parents of children who suffer from genetic disorders to a greater extent than the others, asked for services for themselves and not on " for the child. The least satisfied group were the parents of brain damaged children, who revealed the greatest need for more schools and governmental support.
It seems from the results that most of the parents do not perceive a need for professional help for the family as a whole and do not intend to ask for such help in the future. However the parents whose children suffer from brain damage seem to consider using help in the future to a greater extent than the others. (See Table 78A in Appendix 4).

In addition to the cause of the child's mental retardation, an analysis was made of the impact of his physical condition on parents' vi- about professional services. Findings in regard to this issue indicate that the parents of children in only a fair physical condition had their initial contacts with services at an earlier stage. (See Table 79A in Appendix 4). However, these parents were less satisfied with the existing services and expressed the greatest need for more schools and support from the government. (See Table 80A in Appendix 4). Parents' opinions about the need for professional help for the whole family are presented in Table 52.

Table 52

Frequencies of parents' answers to the question: "Would you consider using professional help for the family in the future?" by child's physical condition (in percentages).

Answer	Generally Good	Generally Fair
1. There will be no need.	73.5	52.0
2. I hope not. We will be helped by the family.	3.7	4.0
3. If it is needed.	11.4	28.0
4. Yes, definitely.	11.4	16.0
Total	100.0	100.0
	N=87	N=25

Parents of children in only fair physical condition are more willing to consider professional help for the family as a whole if it seems to be needed.

In addition to the foregoing, some other family characteristics were also analysed in order to find out if this appeared to affect parents' attitudes towards professional help. Results reveal that the child's birth order has no impact on parental opinions about the availability of services in the community, as the differences are too small to be considered meaningful. Yet, the parents of the first born child feel the need for more information to a greater extent than the others. (See Table 81A in Appendix 4). There were only slight differences in parents' opinions about the need for professional help for the family as a whole in regard to the child's birth order. The majority of the parents did not report this need. (See Table 82A in Appendix 4).

When the relationships between parents' level of formal education and their attitudes to services was analysed, it was found that this factor like the birth order of the child had no marked impact on parents' satisfaction with services or on their opinions about the need for specific services. Yet, the higher educated parents are more aware of the need to improve the existing services. (See Table 83A in Appendix 4). Differences in regard to parents' willingness to utilize professional help for the whole family are reflected in Table 53.

Table 53

Frequencies of answers to the question: "Would you consider using professional help for your family in the future?" by parents' level of formal education (in percentages).

Answer	Under Matric	Matric and Post
1. There will be no need.	78.6	56.8
2. I hope not. We will be helped by the family.	3.4	3.9
3. If it is needed.	11.5	19.7
4. Yes, definitely.	6.5	19.6
Total	100.0	100.0
	N=61	N=51

Results reveal that the higher educated parents are more prepared to utilize professional help for the family as a whole if and when such help is needed.

In order to explore the impact of parents' occupation on their opinions about professional help and services, working mothers were compared to housewives and highly skilled fathers were compared to those who were less highly skilled.

Results suggest that mothers' occupation had no marked influence on their opinions about the services that are needed to help them with their problems. The differences between the working mothers and the housewives were too small to be considered meaningful. (See Table 84A in Appendix 4). As to their willingness to utilize professional help for the whole family the working mothers seemed more prepared to do so, although the differences are not meaningful. (See Table 85A in Appendix 4).

When highly skilled fathers were compared to lower skilled fathers, there were no meaningful differences in regard to their satisfaction with existing services or in expressed needs about specific kinds of professional help. (See Table 86A in Appendix 4). Fathers' attitudes towards utilizing professional help for the family as a whole are presented in Table 54.

Table 54

Frequencies of fathers' answers to the question: "Did you seek any professional help for your family?" by fathers' occupational category (in percentages).

Answer	Highly skilled	Lower skilled
1. No.	68.6	80.1
2. There was no need.	6.7	3.3
3. We couldn't get help when asked.	4.0	-
4. We were helped.	20.7	16.6
Total	100.0	100.0
	N=36	N=12

Table 54 reveals that the highly skilled fathers were more prepared to utilize professional help for their whole family and not only for the child.

When parents were compared according to their religious background, it was found that the Catholics were the most satisfied group with existing services. The least satisfied were the Protestants. (See Table 87A in Appendix 4). (Yet, when noting these results, it must be kept in mind that there are slightly more Jewish parents of older children).

The differences in parents' opinions about the need for professional help for the family as a whole or a particular member are reflected in Table 55.

Table 55

Frequencies of answers to the question: "Would you consider using professional help for your family in the future?" by parents' religious background (in percentages).

Answer	Catholics	Protestants	Jews
1. There will be no need.	78.9	67.6	72.2
2. I hope not. We will be helped by the family.	-	2.8	11.1
3. If it is needed.	10.6	15.4	16.7
4. Yes, definitely.	10.5	14.2	-
Total	100.0	100.0	100.0
	N=19	N=71	N=18

The differences revealed in Table 55 are too small to be considered meaningful. Most of the parents did not feel that they would consider using professional help for the family in the future, religion, therefore demonstrating no impact on this issue.

Having another mentally handicapped relative had no influence on most of the parents' attitudes towards services as the differences between the parents who reported having such a relative and the parents who did not have one are not meaningful. (See Table 88A in Appendix 4). Having a mentally retarded relative had an impact on parents' willingness to utilize professional help for a particular member of the family. (The parents who have such a relative are more prepared to do so). (See Table 89A in Appendix 4).

A summary and a discussion of the foregoing results is provided in the following section of this chapter.

4.3 SUMMARY AND DISCUSSION

The fact that having a mentally handicapped child has its impact on the nature of parents' attitudes to the outside world is acknowledged in the literature which covers this particular area.

The focus of the present study, in regard to this issue, was on two kinds of parental relationships with community support networks:

I. Relationships with relatives, friends and neighbours.
II. Relationships with professionals and services.

4.3.1 Parents' relationships with relatives, friends and neighbours

In order to explore to what extent and in what ways a mentally handicapped child influences his parents' social life, the parents were asked to react to this issue on two levels. The QRS referred to their social life in general, and to the difficulties they face as a result of the child's problem. When responding to the interview schedule, they had to refer to more specific aspects of their social relationships - with relatives, friends and neighbours. Thus, when

summing up the results one can form a picture of parents' general attitude to their social life as well as their views on some of their specific relationships with others.

Results of the study show that when asked about their general attitude to the outside world, the parents of the younger children to a greater extent than the parents of the older ones, felt the obtrusion of the child on their social life; they also felt the greatest need for social support. Among the parents who participated in the study, the fathers of the younger children experienced the social obtrusiveness of the child to the greatest degree and expressed the greatest need for social support.

However, parents' reactions showed a contrary picture in some respects when they were asked to refer to their specific relationships with relatives, friends or neighbours. In regard to their relatives, the parents of the younger children, more than the parents of the older ones, had the feeling that they and their child were easily accepted. Among the parents of the older children, there were more who felt that for some of their relatives it was hard to accept the child. When asked about their friends, the parents of the younger children were more inclined to report losing some friends as a result of the child, while the parents of the older children often preferred to describe themselves as "not being social". At that stage in their life, it was difficult for these latter parents to discriminate between their basic attitude to social relationships and the reality of their social life which results from having a mentally handicapped child.

When summing up the parents' views about their relationships with their neighbours, two major differences between the groups of younger and older parents can be observed. The parents of the younger children generally had less contact

with their neighbours. The parents of the older children, on the other hand, seemed to experience more problems with their neighbours as a result of the child.

Results obtained from both research tools concerning a comparison between mothers and fathers were inconsistent with each other. While the fathers of the younger children were inclined to feel the impact of the child more strongly on their general social life, when asked about their specific social relationships, results reveal that compared to the mothers, they felt a lesser impact of the child's situation on their particular relationships with relatives, friends and neighbours. Farber's study (1968) refers also to the considerable significance of relatives' attitudes to the child's problem, especially for mothers. It seems that the findings of the present study confirm results from some former studies (Hewett et.al., 1970; Bayley, 1973) which also reveal that the reactions of the outside world and the relatives in particular have great impact on mothers' views about the nature of their contacts with outsiders.

When considering the differences between parents of younger and older children, it is important to note that, as in some former research studies (Tizard and Grad, 1961; Appell et.al.,1964; Bayley, 1973; Voysey, 1975), in this study many parents from both groups felt that their social relationships were not affected by the child's problem and that they were generally accepted by the community. A significant number of parents in both groups felt that they were able to maintain their social contacts in spite of the difficulties they had because of the child.

The differences noted between the parents of younger and older children can be ascribed to the process that the parents go through, over the years, in regard to their social life.

Some researchers (Hannam, 1975; Voysey, 1975; Chinn et.al., 1978) have already described the reactions of parents of young children, mentioning the impact on their attitude to the outside world of their difficulties in adjusting to having a mentally retarded child.

The tendency either to isolate themselves, and by so doing to avoid others' reactions, or to put on a cheerful front and deny any kind of difficulty, helps the parents to run away not only from others' reactions but also from a confrontation with painful inner feelings which they have difficulty in accepting. When running away, the parents sometimes have to pay the price by feeling either isolated or not sufficiently supported by others.

However, in the long run, and through a process of adaptation, a change in parental attitudes to their social life can be noticed. The older child sometimes seems to create more difficulties which prevent others from accepting him. Yet, at this stage, the parents are no longer in a situation which enables them to deny their problem. Thus, they prefer to admit that they are sometimes limited in their social relationships, rather than to pretend that it is not so. While many parents feel that over the years they have found a way to maintain their social relationships and to overcome some difficulties resulting from the child's situation, for others the outside world's reactions and their own feelings will have a great impact on the direction in which their social relationships are going to develop. As has already been mentioned in Farber's (1975), Worthington's (1982) and some other research studies, the findings of this study also indicate that for some parents the costs of carrying a 'courtesy stigma' outweigh the gains obtained from maintaining social relationships. They develop a self concept which enables them to deny the need for social contact. Such an attitude, when it becomes a pattern, will have a great

impact on the lifestyle of the whole family which might become a very closed unit.

The study's findings show that the nature of parents' social relationships is shaped not only by the outside world's reactions, but also by the degree of parental acceptance and ability to share problems with others. Moreover, some of the child and family characteristics are also important factors influencing parents' attitude to the outside world.

The differences between parents according to the child's age have already been discussed. The present study, like some former studies (Hewett et.al., 1970; Bayley, 1973; Anderson, 1982 and Glendinning, 1983), clearly reveals that the child's age has an impact on the ability of the relatives, friends and neighbours to accept him and his parents.
The findings also show that child's sex and the severity or the cause of his handicap affect parental relationships with others. Parents of males feel more strongly than parents of females that it was hard for their relatives to accept them and that their relationships were thus affected. Parents of males also felt more strongly that they lost friends as a result of the child, while parents of females more frequently reported being accepted by their friends.

No specific evidence of the impact of the child's sex on his parents' attitudes to social life could be found in previous studies. However, Begab (1963), Farber (1968) and Glendinning (1983), amongst others, have mentioned that it is harder for parents to accept a mentally retarded male, and that males are looked upon as creating more behavioural difficulties for their parents.

Difficulties in accepting the male child, and the burden of rearing him, can probably explain the differences which were found between the attitudes of males' and females' parents in regard to their social relationships.

As mentioned earlier, the child's behaviour is an important factor influencing parents' ability to maintain their social relationships. Findings of the present study in regard to this issue are generally consistent with results of some past studies (Anderson, 1982 and Glendinning, 1983). The results of the study reveal that the cause of mental retardation or the physical condition of the child has no impact on parents' relationships with their relatives. However, it did affect parents' ability to relate to friends and neighbours. Parents of children who suffer from brain damage feel less accepted by friends, compared to parents of a Down's Syndrome child. When the reason for retardation was unknown, parents of such children preferred to describe themselves as not being social. The behaviour of the Down's Syndrome child is considered less problematic for the parents to cope with, and these children are known to be very sensitive to others' reactions (Robinson and Robinson, 1976). This is perhaps the reason why these parents felt that they could maintain their social relationships more easily. When the child's behaviour creates severe embarrassment for both sides (the parents and other people), the tendency of parents to avoid social contacts will probably become stronger.

It seems from the results that the older male whose behaviour is strange and embarrassing as a result of the severity of his mental handicap, will probably create more difficulties for his parents in their effort to maintain their social contacts especially with friends and neighbours.

The findings also reveal that the lower-educated parents felt more accepted and supported by their relatives, compared to parents whose level of education is higher. As to their relationships with friends, there were no marked differences between parents according to their level of education. The fact that it is easier for families of lower social status and level of education to accept the child has already been mentioned in previous research studies (Begab, 1963; Farber, 1968; Farber, 1975; Chinn, et.al., 1978), and can explain why the less educated parents felt more accepted by their relatives.

When asked about their relationships with the neighbours, the parents whose level of education was higher felt more accepted by the neighbours. In order to explain the differences in opinions about relationships with neighbours, it must be kept in mind that among the parents of the older children there are a greater proportion with a lower level of education, and, as already mentioned, the older parents compared to the younger ones felt that they had more problems with their neighbours as a result of the child's condition.

It seems from this study and from a few former research studies (Bayley, 1973; Anderson, 1982; Glendinning, 1983), that parents' relationships with their neighbours are quite complicated. When the family has been well known in the neighbourhood before the birth of the mentally handicapped child, it is easier for the parents to feel accepted by their neighbours. Yet, when the child matures, and the neighbours are confronted with his strange behaviour, they may change their attitude toward the child and his parents and exhibit mixed feelings towards the parents. The parents may feel the need for help and support, but at the same time they may fear the neighbours' comments and the possibility of being rejected (Voysey, 1975).

To sum up, three major aspects of study findings have been described in an effort to understand the factors which influence parents' attitudes and ideas about their social relationships.

These factors were:

a. The relationship between parents' adaptation to the child's problem and their reaction to the outside world.
b. The outside world's reaction to the child and his parents.
c. Child and family characteristics.

4.3.2 Attitudes towards professional help and services

The fact that parents of mentally handicapped children have more intensive contacts with social and health services, compared to parents who do not raise such a child, is often mentioned in the literature (Farber, 1968; Chinn et.al., 1978, Grendinning, 1983). Many studies which have dealt with this issue have revealed that the way parents experienced their initial interactons with professionals had a considerable influence on their willingness to ask for help and to utilize it - in later years.

The findings of this study indicate that the parents of younger children recalled that they started to ask for help at an earlier stage, compared to the parents of the older children. Although among both groups (the younger and the older children) many parents felt that there are enough services in their community to help in coping with their problem, the parents of the younger children, who started to seek help at an earlier stage, were much more satisfied with the availability of such services for them. (Seventy five percent of these parents had positive views about the accessibility of professional help, compared with 51.8 percent of parents of the older children).

In an effort to understand why the parents of the younger children are more satisfied with social and health services, the following reasons can be suggested:

- As mentioned before, if the initial experiences parents had with professionals were constructive, it will help them to develop a more positive attitude, in general, towards professional help.
- As a result of the development of the social and health services and the growth of the professional body of knowledge and experience, better services are probably available today for younger parents.
- The difference in attitude to services between parents of younger and older children can also be due to the fact that for the latter group it was much more difficult to recall what happened when the child was still young. The difficulty of recall can also be related to some opinions already mentioned in earlier studies (Farber, 1968; Bayley, 1973; Voysey, 1975). When the parents first learn about the child's problem, they are so emotionally stressed that their ability to relate to others and to ask for and accept help is limited. In the long run, what they do recall is that when they needed help most urgently, it was not offered to them. These selective memories can be viewed as a later consequence of former traumatic periods (Featherstone, 1980; Glendinning, 1983).

In spite of the abovementioned differences between the parents of the younger and the older children, the fact that a significant majority of parents of both groups express satisfaction with the services must be noted. In an attempt to explain this phenomenon, one must keep in mind that all the parents that took part in this study had their child in a day centre at the time they were interviewed, and most of them felt fortunate at being able to have such an arrangement for their child.

However, when asked if there are enough services in their community, the parents of the older children, to a greater extent than the parents of the younger ones, stated that there are not enough services and there is a need for more professional help. These findings might reflect the concern older parents have in regard to the future, when it will be impossible to keep the child at home or in the day centre, and the need for an alternative becomes urgent.

The findings of this study clearly reveal that the parents' first priority is to obtain help for the child. From this point of view there were no marked differences between parents of younger and older children - the majority of them did not observe the need for help for the family as a whole, although parents of older children reported more frequently that a particular member of the family (beside the mentally retarded child) was helped by professionals. It seems that these findings strengthen the notion already mentioned by Justice et.al. (1971), Bayley (1973), Voysey (1975) and Glendinning (1983), namely that there is a gap between the way professionals view parents' needs and parents' expectations from services. While the parents express the need for more practical help around the day-to-day problems of caring for the child, the professionals seem to believe that the parents are in such an emotional state that they need professional help for themselves in order to be able to cope with the child's problem. The fact that the majority of the parents in this study denied the need for professional help for themselves can also be explained according to Voysey's (1975) views. Voysey suggests that parents tend to prefer to express their need for practical help because of their difficulties in sharing their emotional problems with strangers, and in admitting that they need professional help. Thus, they declare that their most urgent needs are around practical aspects of raising their child.

When the parents were asked about their willingness to utilize professional help for the family as a whole or for a particular member of the family in the future, more parents of the younger children felt that they might do so, while the parents of the older children were more inclined to deny the need for such help in the future. It is quite clear that as the older parents are much more worried about future arrangements for their children, they first and foremost feel the need to obtain information and practical help in order to solve this problem. After many years of raising their mentally handicapped child, it seems that the older parents feel that they have succeeded in overcoming crisis situations and are able to face their emotional difficulties without the need for professional help. Voysey (1975) found that even when they ask for help for the child, older parents sometimes feel that they are in a better position to observe the child's behaviour and needs, their ability to accept professional advice therefore being limited and they prefer to find their own solutions rather than to rely on professionals' help.

Results of this study demonstrate no meaningful differences between mothers' and fathers' attitudes towards professional help. Only in one area was a marked difference found. Fathers to a greater extent than mothers felt that when they needed professional help it was not available for them. The fact that most of the burden of caring for the mentally handicapped child falls on the mother is mentioned in the literature. Cummings (1976) in a research study on fathers of mentally handicapped children described the need of fathers to be more involved in the child's care. The fact that fathers compared to mothers felt that it was difficult to get professional help may reflect their general feeling of lesser involvement in the child's care, and their wish to take an active part in this task.

Findings of the present study show that the child and family characteristics also have an impact on parental attitudes towards professional help. Among the child's characteristics the most important ones are his age, sex and the cause of mental retardation or the severity of his handicap. The impact of the child's age has already been discussed. As for the child's sex, it was found that the males' parents were more satisfied with professional help. Moreover, males' parents were more ready to use such help for the family as a whole, in the future. This difference is especially marked as there are more males among the older children and their parents expressed less satisfaction with services compared to the parents of the younger children. The fact that parents of males have more difficulty in adjusting to the child's problem and find it harder to raise the child has been mentioned by Begab (1963), Farber (1968) and Glendinning (1983). When the parents encounter more difficulties in their effort to raise the child, their dependence on professional help increases. It is impossible for them to rely on themselves, their relatives or friends, and they must utilize social and health services.

The findings of this study on the relationship between the severity of the child's handicap and parental attitudes to services lends further weight to the abovementioned view. When the child's physical condition was good the parents felt the need for more services, less. Parents of children in only fair physical condition were not satisfied with the existing services. The same attitude was expressed by parents who had a brain-damaged child. It is important to note that parents of Down's Syndrome children felt most strongly the need for help for themselves. It seems that although the Down's Syndrome child's behaviour is often less problematic, and thus the day-to-day care for him represents less practical difficulties for the parents, having such a child creates emotional stress for the parents and they feel the need for professional help for themselves.

In addition to the abovementioned child characteristics, it was found that some family characteristics are also related to parental willingness to accept professional help. Only a few past studies have dealt with this issue. Ehler (1964) could not establish any impact of the family socioeconomic status and level of education, the size of the family or its religious background on parental attitudes towards professional help. However, results of the present study show a marked difference between parents' opinions in regard to services according to their level of education. The highly educated parents compared to the lower educated ones started to ask for help at an earlier stage, they were less satisfied with the existing services and felt the need for the development and improvement of these services. They were also more inclined to consider utilizing professional help for the family as a whole. When evaluating these results, it must be noted that the parents of the younger children generally expressed satisfaction with the services, and as there are more highly educated parents in this group, it might throw light on the strong impact that level of education has on parents' views about services in their community.

Another factor which was found to have its affect on parents' attitudes towards professional help was their religious background. The Catholics to a greater extent than Protestants and Jewish parents seemed satisfied with the existing services, yet, they expressed lesser willingness to utilize professional help for the family as a whole.

To conclude, child and family characteristics were found to have their influence on parental attitudes towards using professional help for the child. As for utilizing such help for the family as a whole, results reveal that the general attitude of the parents was to deny the need for such help, and family characteristics had a minimal influence on this issue.

In the following chapter, parents' attitudes and plans in regard to their mentally handicapped child's future will be discussed.

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