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**THE EFFECTS OF THE
MILDLY OR MODERATELY
RETARDED CHILD ON THE FAMILY**

by

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**SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE
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DEDICATION

This study is dedicated to the greatest woman I know who through all the tough times is always there, and to the good man who is no longer here, yet remains alive in my heart and mind!

KATE and ISAAC

I salute you both, Dear PARENTS.



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ABSTRACT

In hierdie navorsingsprojek is 'n eksplorasië van die effek van die matig- of gering verstandelik-gestremde kind op die gesin ten doel gestel. Ten einde hierdie doelstelling te bereik is 'n ondersoek na die volgende aspekte nagestreef:

- (a) die aanpassingsproses van die ouers
- (b) die psigo-sosiale funksionering van die verstandelik-gestremde kind
- (c) die huweliksverhouding van die ouers
- (d) die verhouding tussen die gesinslede en die verstandelik-gestremde kind
- (e) die effek van die verstandelik-gestremde kind op die sibbes
- (f) die sosio-ekonomiese status van die gesin

Die navorser het 'n kwalitatiewe navorsingsmetodologiese benadering gevolg en deur die benutting van 'n onderhoudskedule data versamel. Die steekproef is saamgestel uit vyf gesinne in die geografiese area van Vosloorus - 'n swart gemeenskap in Boksburg.

Die grootste beperking van die studie was die klein steekproef wat benut is, want dit het veralgemenings en die algemene betroubaarheid van die bevindinge beïnvloed. Desnieteenstaande het interessante bevindinge na vore gekom en kan soos volg opgesom word:

- (a) Ten opsigte van die aanpassingsproses van die ouers

Dit blyk asof die ouers gevoelens beleef het wat gewissel het van woede, skok en hartseer tot ontkenning en uiteindelik aanvaarding, nadat hulle ingelig is oor hul kind se gestremdheid.

(b) Ten opsigte van die psigo-sosiale funksionering van die verstandelik-gestremde kind

Dit het na vore gekom dat hierdie kinders in feitlik alle opsigte bygestaan moes word aangesien hulle beide vergeetagtig en motories "lomp" was, wat hulle nie in staat gestel het om alle funksies self te verrig nie.

(c) Ten opsigte van huweliksverhouding van die ouers

Drie van die vyf gesinne het 'n stabiele huweliksverhouding gerapporteer, terwyl twee gesinne gestel het dat hulle probleme ondervind.

(d) Ten opsigte van verhouding tussen die gesinslede en die verstandelik-gestremde kind

Geen definitiewe uitspraak oor probleme is in die verband deur enige van die gesinne gemaak nie. 'n Gelatenheid in terme van aanvaarding van 'n situasie waaraan niks verander kan word nie is inteedeel aangetref.

(e) Ten opsigte van die effek van die gestremde kind op die sibbes

Beide positiewe en negatiewe invloede is gerapporteer. Wat wel duidelik na vore gekom het is dat die sibbes nie gerus is om verduidelikings te verskaf as portuurgroeplede of buitestaanders vrae begin vra oor hul gestremde gesinslid nie.

(f) Ten opsigte van die sosio-ekonomiese status van die gesin

As gevolg van die feit dat die gestremde kinders addisionele insette benodig, soos byvoorbeeld dienste van sielkundiges of selfs praktiese insette soos oorskakeling na 'n nuwe skool, het die gesinne almal buitengewone finansiële druk ondervind.

Hierdie resultate stel die navorser en ander belangstellendes in staat om beter tot die leefwêreld van gesinne met matig of gering verstandelik-gestremde kinders toe te tree.

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CHAPTER I

THE EFFECTS OF THE MILDLY OR MODERATELY RETARDED CHILD ON THE FAMILY

1.1 Introduction

The theme of this study is "*The Effects of the Mildly or Moderately Retarded Child on the Family*". The premise is that retardation is not primarily a problem that resides in an individual but rather is an event that occurs in a family and in a community. The effects of the mentally retarded child are mostly felt or experienced by the people who have to care and look after him.

Families with a child who has mental retardation are at risk for greater stress and adjustment difficulties than are families with a child who is developing normally (Blacher, 1984, Crnic et al, 1983 and Waishren et al, 1980). According to Bodgan, in Wishart (1981) the birth and rearing of a child with a disability can be traumatic and stressful for the families. Most families who have a mentally retarded child have difficulty in coping with normal daily activities and are subsequently socially isolated. These authors concluded that, despite the hardship socially imposed and otherwise that may be experienced in caring for a child with disabilities, families can and often do come to accept their disabled members.

Professionals who work with families of developmentally disabled children have brought about an awareness of the impact that these children have upon each member of the family system. The presence of the child in the family who is mentally retarded is potentially detrimental to the self-esteem of the family as a whole, and is also an increased burden on the emotional and material resources of the family system. The impact is felt by parents, brothers, and sisters in all social classes in the relatively affluent Western world (Gath, 1985).

Generally, the focus of this research investigation is to get a clear picture as to how the families of a specific community who have mentally retarded children are affected in different areas of their functioning. The type of children that were looked at were the ones who did not make no progress at school, but are also not profoundly or severely retarded to such an extent that they need institutional care.

They are the children who since infancy have caused their parents much concern because their development was slower than that of their peers.

1.2 Statement of the problem

The care of the mentally retardation child, and especially the mildly or moderately retarded child, appears to be undertaken by the family in most cases. Mental retardation does not only affect the person concerned but has effects on the family as a whole. In order for social workers to deal with this situation effectively, it is of utmost importance to have extensive knowledge about the effect of the children on their family functioning.

1.3 Motivation for the research project

Social work is a helping profession aimed at helping the clients to help themselves in their daily problems and assist them to gain insight into their daily encounters.

Brown in Grinnell (1981:35) stated that....the topic for social work research should come from day-to-day activities and interactions on the job....thus research topics result from a critical review of professional social work activities and the ends to which they are directed.

In this project the researcher has been motivated to choose the mildly or moderately retarded children because from personal observation it is clear that parents do not want to accept the fact that their children could not progress at school and had to be shifted to the school for the mentally retarded. The parents would come to the social worker's office to report that their children had been dismissed from the schools for the normal children and did not believe or understand that their children are mildly or moderately retarded. To help them gain insight, the social worker need to have extensive knowledge - hence the undertaking of the research.

According to the reasons stated by Mouton & Marais (1988) why persons undertake research, it can be stated that it was out of wonder that the researcher's topic was undertaken, in order to explore and gain more insight of the effects of the retarded child on the family.

1.4 Aims of the project

Mouton and Marais (1988:42) states that "research goal provides a broad indication of what researchers wish to attain in their research". Grinnell (1985:50) states that.. "*many problem areas studied within our profession never occur in isolation*". Therefore, the main objective at hand is to determine the effects of the mildly or moderately retarded child on the family.

To achieve the objective of this study, the following aspects in the family functioning will be explored:

- (a) The adaptation process of the parents to the diagnosis of mildly or moderately mental handicap.
- (b) The psycho-social functioning of the mildly or moderately retarded child.
- (c) The marital relationship of the parents of the mildly or moderately retarded child.
- (d) The relationship between the mildly or moderately retarded child and the family members.
- (e) The effects of the mentally handicapped child on the siblings in the home.
- (f) The socio-economic status of the family.

The research was conducted in the black township of Vosloorus and the respondents will be family members of the retarded child.

As the goal of the practitioner is to gain insight of how the mentally retarded child affects family members in their daily interaction, the methodological is basic or exploratory research. More details on the sample and research methodology will be discussed in Chapter 4.

1.5 **Methods of investigation**

The researcher adopted a qualitative approach to methodology in this study. Schurink and Schurink (1988:21) state the following in this regard.

"A qualitative methodology is viewing the world as a whole (gestalt), made up of various elements interrelated to each other in such a manner that the pattern gives meaning to the element, thus increasing the research capability for generalization, across actions or behaviour of the individual client, being studied."

The qualitative approach is thus an attempt to understand reality from the situational meaning that human subjects give to their world. Again, Bogdan & Taylor, (1975); Walizer & Wienir, in Grinnell (1985:264) state that in qualitative research emphasis is placed on fully describing and comprehending the subjective meanings of events to individuals and groups caught up in them. As this is the context of this research qualitative methods will be utilized

In this research, the interview schedule, which is a qualitatively oriented data gathering method has been chosen. Mindel in Grinnell (1981:156) referred to the interview schedule as an instrument used to collect data by means of face-to-face interviews. During the data collection phase, the researcher made use of field notes and a diary. More detail on the data collection and analysis will be discussed in Chapter 4 and 5.

1.6 **Definition of concepts**

1.6.1 **Retardation**

The American Association on Mental Deficiency describes retardation as "subaverage intellectual functioning which originate during the developmental period and is associated with impaired adaptive behaviour and manifested during the developmental period. Thus, subnormal intelligence is no longer the sole determinant of mental retardation, but the inability to adapt behaviourally to the world in which the person lives must exist concurrently as well" (Thain, Castro & Peterson, 1980:3).

1.6.2 **Disability**

Lees Shaw in Thain, Castro & Peterson (1980:6) define disability as a limitation of performance in one or more activities which are generally accepted as essential basic component of daily living, such that inability to perform them necessitate dependence on another person.

1.6.3 Handicap

Mittler in Thain et al (1980) made distinction between disability and handicap. He described handicap as a cumulative result of the obstacles which disability interposes between the individual and his maximum functional level.

1.6.4 Family

There are many types of families, and many definitions of what the family is. Schulz (1982:18) defines the family as "a social institution that has the primary personal function of providing nurturance and support for its members, and the primary social function of reproduction and replacement of members."

Minuchin (1974:47) defines a family as a social system that faces a series of developmental tasks. Consequently the family system is organised around the support, regulation, nurturance and socialisation of its members. He notes that "human experience has two elements: a sense of belonging and a sense of being separate. The laboratory in which these ingredients are mixed and dispensed is the family. the matrix of identity."

According to Minuchin (1974) the family must meet the challenge of both internal and external change. In the early process of socialisation, families mold and programme the child's part to the family group and from the transactional patterns in the family structure that are consistent throughout life events. The sense of separateness and individualization occurs through the participation in different family subsystems in different family contexts as well as through the autonomous participation in extra-familial groups. Consequently, as families develop, the accommodation of the family to the child's needs delineate areas of autonomy that he experiences as separateness (Minuchin, 1974).

For the purpose of this study and from the above, it is clear that the family is essentially a micro-society or small social system. As such it develops norms, values, and expectations for its members, and establishes rules and procedures to maintain and perpetuate itself. From the above it is clear that the family's goals are to procreate and raise children, to socialise them and provide for their education, to gratify personal needs, maintain and protect its members, and to provide social status in the larger society (Shea & Bauer, 1985).

In the family unit, each subset or member affects and is affected by every other member of the system, hence the main focus of this research - on how does a mentally retarded child affects the family.

1.6.5 Effect

The results accomplish or occur: The concise Oxford Dictionary (1984:328).

1.6.6 Child

Any person under the age of 18 years - Child Care Act 1983. (In this research, it is the mentally handicapped child).

1.7 Overview of the study

The study is limited to the geographical area of Vosloorus. Vosloorus is a black area and the study is also limited to one race group namely black.

Interviews were conducted with the normal members of the families who have a mildly or moderately mentally retarded member.

This report is divided into six chapters namely:

- Chapter One:** General orientation to the study, where the problem has been stated, motivation for the study, research goals and the method of investigation are outlined.
- Chapter Two:** An overview of literature on the present study.
- Chapter Three:** Level of development of the study.
- Chapter Four:** Research Methodology.
- Chapter Five:** Data Analysis and interpretation.
- Chapter Six:** Conclusions, Recommendations and Summary.

CHAPTER 2

THEORETICAL FOUNDATION

2.1 Introduction

Caring for a mentally retarded child often places considerable burden on the main carer and their family, including physical and mental strain and in many cases a need to give up paid employment.

Walter in McCubbin et al, (1989) maintains that the social cost for caring for a mentally retarded relative has led to a greater emphasis on the need for formal services, not only to replace informal assistance from those who lack close relatives, but also to act in partnership with the informal carers to reduce their burden of care. Lack of suitable facilities to care or look after the mentally handicapped children has caused much strain to their parents and families because these children cannot be admitted in school for normal children. If ever admitted, the parents will not get rest because they will be told about their children's lack of achievement at school.

2.2 The history of mental retardation

During the primitive time, the mentally handicapped were regarded as "*possessed by evil spirits*" and were shunned tortured or killed. Even the "civilized" Greeks and Romans a few hundred years before Christ, referred to them as "fools" or monsters. The Spartans who abhorred any form of handicapped or abnormality frequently put them to death. (Steenkamp & Steenkamp in Glendinning 1983)

The same authors further disclosed that during the Middle Ages, mentally handicapped people were often murdered, humiliated or taunted as village idiots, whilst others were kept as court jesters. The rise of Christianity in the Western world brought a better dispensation and their fellow men acted with more responsibility and compassion towards them.

During the eighteen century there was no clear distinction between mental illness and mental retardation. It was only in the 19th century that the theories of philosophers such as Rousseau and Locke led to the recognition

of the rights of the child, including those of the mentally handicapped. It was the work of Dr Jean Itard that gave rise to the more scientific approach to, and care of these children. The number of institutions increased but little attention was given to real education. As there was no possibility of recovery or a "cure" most mentally handicapped persons had to spend their entire lives in institutions and gradually public interest in their fate waned (Steenkamp & Steenkamp in Glendinning, 1983).

At the beginning of the 20th century Dr Binet of France designed an intelligence scale and since then children who are moderately mentally handicapped have been catered for in special classes. The main distinction remained between those children who could be placed in a special class and those who were handicapped to the extent that they needed institutional care (Glendinning, 1983 & Oliver, 1983).

The increasing emphasis on welfare services since the second world war resulted in the flourishing of the social sciences and the parents of mentally retarded children began to fight for the education rights of their children. Since 1950 day care centres were developed (Pfouts, 1976).

The shortage of facilities for mentally retarded made South African National Council for Mental Health to have interest in mental retardation and in 1960 a National Division for the Mentally Handicapped child under the chairmanship of Dr V.M.Grover was created. This Division was instrumental in obtaining a grant in respect of day care centres for white retarded children from the Department of Health. It also pressurised the Government to appoint a Committee of Inquiry into the care of Mentally Retarded children. The committee was appointed in 1965 under the chairmanship of Dr A.J. van Wyk superintended of Weskoppies Hospital.

The investigation was confined to Whites and the completed report was presented to the minister of Health in December 1967. (Pfouts, 1976)

The report was published in 1969 and reflected the following recommendations.

- that the mental Disorder Act be revised in the light of recent knowledge about mental retardation.

- that clinics of genetic examination and counselling be introduced.
- that wards for mentally retarded in psychiatric hospitals be closed.
- that day care centres for children provide separate nursery sections.
- that the Department of Education be responsible for the accommodation of trainable children between the ages of 6 and 18 years and that such training be compulsory
- that the care of trainable adults be placed under the supervision of the Department of Social Welfare and Pension and that suitable subsidy schemes for hostels and protective workshops be introduced.
- that a national organization be formed to stimulate, co-ordinate and give direct to the activities of private welfare initiative in the field of mental retardation.

Since 1976, The Mentally Retarded children's Training Act, 1974, (Act 63 of 1974) has led the state subsidisation of day centres controlled by the Department of National Education (for White children). It is said that other population will receive state aid within the near future and it is to be expected that compulsory day-centre attendance will be instituted for all trainable children in this country. (Pfouts, 1976)

2.3 Classification of mental retardation

Steenkamp & Steenkamp (1981:6) maintain that it is impossible to determine anyone's IQ with absolute accuracy. Usually the following approximate IQ classification are used to assess educability.

145 + Highly gifted

130 - 144 Superior

115 - 129 Above average

85 - 114 Average

70 - 84 Below average, with poor scholastic progress.

- 50 - 69 Mentally moderately handicapped and needs special education to make any progress.
- 25 - 49 Severely mentally handicapped and can only adjust in a day centre.
- Below 25 Profoundly handicapped - normally dependent on institutional care.

The World Health Organization (WHO) regards children with an IQ below 70 as severely mentally handicapped and labels the day - centre child as mildly or moderately handicapped.

The behavioural classification of mental retardation according to Adams in Thain & Castro & Peterson (1980:102) is as follows:

- Borderline intelligence :IQ ranging between 83 & 68
- Mild retardation :IQ 67 to 52
- Moderate retardation :IQ 51 to 36
- Severe retardation :IQ 35 to 20
- Profound :IQ below 20.

The functioning capacity of the above-named mental retardation varies considerably. It depends on the level in which that person is classified. A brief discussion of the different levels of functioning follows:

The mildly retarded may show some developmental lag in early childhood, which becomes more pronounced in the school place when the demands of normal education impose standards that are too high. The mildly retarded can benefit from special education and can achieve academic skills to the sixth grade by their late teens. Thain, Castro & Peterson (1980). The most of the mildly retarded make satisfactory adjustment to adult life, if they are given special education and helped to find suitable work, unless they are exposed to an undue degree of stress, either in their personal life or through some more generalized social hazard such as chronic and unwidespread unemployment. (Fine, Mayhew & Hanson, 1984)

Gast, et al in Longo & Bond (1984) maintain that the moderately retarded show conspicuous developmental lag as babies, and have very limited capacity for academic learning but they are capable of being trained in concrete tasks and of achieving some level of independence in self-care, though this depends on the sustained support of concerned adults. The same authors further maintain that these children in their adulthood, if they do not have marked physical handicaps - can be trained to be quite productive in routine industrial tasks in a sheltered workshop setting and to participate in a limited range of social activities under supervision.

Severe retarded individuals are capable of achieving some of the training and social skills of the moderately retarded group, but they require closer supervision and direction in most aspect of their life. Some of the severely mentally retarded individuals have a more restricted existence resembling that of a pre-school child in dependency needs and achievement of self-help skills.

The profoundly retarded are dependant on other people for their care and survival, and most of them have gross central nervous system pathology with severe physical handicaps, their capacity for any level of social interaction is extremely limited Davids (1992).

In the mildly retarded group, only the higher levels of adaptive behaviour tend to be affected - that is their perceptual capacity, attention span, impulse control, judgement, memory, thought and language process.

While the moderately, severely and profoundly handicapped show a progressive involvement of the total nervous system in their malfunctioning patterns, until with the profoundly retarded the primitive involuntary mechanisms are affected, and the child or adult does not develop even basic physical adaptive behaviour such as motor skills and sphincter control. Between these two polarities are differing levels of adaptive competence, with corresponding need for an increasing complexity of medical, educational and social services (Donnelly, et al in Davids 1992).

Concerning services for the retarded people, the mild and borderline grades have been catered for by special education within the public school system. Miller (1988) however, state that the three lower grades of retarded people are much less served, while the public schools in most states have established classes for trainable children (who usually fall within the moderate or severe ranges). There are still some areas in which these facilities have to be maintained privately. There are few services available for the seriously disabled in our society and these people are viewed as quasi- invalids who could neither benefit from social rehabilitation nor expected to become part of normal society.

In the present study the researcher has looked at the services available for the mildly or moderately retarded in Vosloorus and found that the service that is being offered leaves much to be desired. There are no trained teachers nor any professional person to look after the needs of these children.

2.3.1 Educability

Few years ago any child who could not benefit from ordinary education was described as "ineducable". Such a child would be kept at home and wait for the year when he/she will qualify for a disability grant. In the the Black community such a child would no even attend stimulation group because there are none.

Barrett and Cipani in Buckley (1993) maintain that the day care child (mildly or moderately handicapped) would derive little benefit from school-subject teaching and cannot be regarded as teachable, but he should be seen as educable. He should be seen as teachable in the sense that he is amenable to some personality development, discipline, maturation of social behaviour and in general to becoming more of an independent and responsible person.

The children who could not benefit from normal school were described as "uneducable" but recently the term uneducable has been changed to "trainable" because *this child can be trained to behave in a socially acceptable way and become very much aware of what* (his family or his community would regard as "wrong" "naughty" or nice). This child can be trained to participate in a group to perform useful tasks, to clothe feed and wash himself. He can be trained to realise what is dangerous, which situations should be shunned and what activities he may

enjoy without giving offence to others. It is possible to help him to become less clumsy in his movements, to adjust to routine and show respect for property and privacy of other people.

In this sense the child may be considered as "educable" and particularly as "trainable". The term training would include elements of educating, teaching and washing (Barrett; Cipani in Buckley 1983). The moderately or mildly retarded child can be trained at home to behave in a normal and acceptable manner. Where there is lack of formal institutions which caters for such children, the family must take full responsibility to mould the child and prepare him or her to be independent.

2.4. Causes of retardation

Information about the causes of mental retardation has increased in the last decade or two (Steenkamp & Steenkamp, in Glendinning, 1983). Mental retardation can be caused by certain infections and intoxications. Since much new information has accumulated about the causes of mental retardation, major known or suspected causes can be divided into medical, organic, emotional and situational factors. Often the causes are a combination of the above mentioned factors (Thain, Castro & Peterson, 1980).

2.4.1 Medical Conditions

Major medical causes known to cause or suspected of causing mental deficits are:

- (i) **Maternal infections during the early stages of pregnancy**
- (ii) **Poor nutrition of the mother**
- (iii) **Prematurity of the infant often related to maternal conditions and lack of adequate pre-natal care.**
- (iv) **Meningitis and encephalitis.**
- (v) **Ingestion of drugs who seem to be harmless.**

- (vi) Blood type incompatibility.
- (vii) Injury through accident before or after birth or at any other time of life. (Guide to Genetic Disorders, 1988).

2.4.2 Organic Conditions

A variety of hearing, visual or perceptual difficulty may create problems in a person's orientation to his environment, regardless of his mental equipment. They may also make an intelligent child to appear dull because they interfere with his ability to interpret actions and expectations of his environment. (White & White, 1980).

A child with a partial hearing loss may respond eagerly to the ice cream bell outside because he can hear the high tickle, but at the same time may be unable to hear his mother's voice and be punished because of his "obvious" selectivity.

Another child may be unable to see shapes and pictures clearly enough to perceive their meaning. He may be slow in recognising people that come into his field of vision and he may appear odd in his orientation to space. The plight of these children is profound because they appear stubborn and intellectually clumsy (Denchack, Schoen & Stanovich 1990).

2.4.3 Motor Problems

Longo & Bond (1984) state that it is often difficult to judge the mental ability of the person whose responses are seriously hampered by lack of control over his muscles. He may fail routine tests because he lacks the necessary muscle control to produce speech, to control eye movement, to point at an object. Such children have difficult time keeping up with contemporaries and are frequently left out of daily activities.

2.4.4 Situational Problem

Some children become retarded because of cultural deprivation. There is lack of human and intellectual stimulation in his daily life. There is also lack in

parental love and responsiveness. A child who has suffered lack of attention during periods of special sensitivity, fails to provide experiences for practice for later skills. Satisfaction permits the child to move on to the next stage.

If those satisfactions are interfered with, either by a crippling condition or by environmental intervention (e.g. making body contact unpleasurable) the critical period may irrevocably pass (Longo & Bond, 1984).

Many causes of mental retardation still remain unknown (Steenkamp & Steenkamp in Glendinning, 1983). Their origin is not known up to this day despite the standard of modern technology which is prevalent.

According to Mee (1989), at least 80% of retarded individuals are mildly retarded, and the overwhelming majority of these cases have unknown etiologies. He listed synonyms for unknown causation as unpathological, clinical, endogenous, and cultural-familial. He further stated that "Persons making up the small group with known etiologies are spread across the full IQ range for retardation, but are concentrated among the moderately, severely, and profoundly retarded.

He further states that (Mee 1989) the majority of the mildly retarded are cultural-familial retardates. Cultural-familial implies that the condition stems from a complex interaction of both environmental (cultural) and hereditary (familial) factors. Although there is no conclusive evidence concerning the causation of cultural-familial retardation, it believed that the majority of cases are caused by early cultural and social inadequacies.

2.5 Overview of the literature on the impact the mentally retarded child has on the family.

2.5.1 Family as a whole

- ;** The focus of this research is the effect that the mildly or moderately retarded child has on the family. Therefore, in order to get the clear picture of the effects this family undergo, it is clear that the whole family system has to be taken into account.

Whatever the position of the family may be, there will of necessity be a crisis in the family causing tension and disturbing the smooth functioning of the family when a handicapped child is born or when the doctors diagnose that the child who has been growing up normally is handicapped.

The official diagnosis of a handicapped child marks the occurrence of the family crisis, which affects the family on many levels. Fortier & Wanlass (1984) list the following levels of reaction when the diagnosis of a handicapped child is made:

- On the affective level, family members, especially the parents, begin working through feelings of grief, anger, guilt, helplessness and isolation.
- On a physical or sensory level, somatic symptoms may arise as a result of the stresses caused by the crisis experience.
- On a behavioral level, the family may need to provide immediate care for the handicapped child, arrange transportation to medical treatment, alter previous methods of scheduling time and meet new financial needs.
- On an interpersonal level, the family may have to deal with labelling and stereotyping, handling "helpfulness" and advice from interested friends, and providing support for other family members, especially the siblings. While every family member does not go through all of these experiences, each will go through several of them (Fortier & Wanlass, 1984). The manner in which each family member reacts to the crisis will in turn affect the responses of other family members. As the child develops the family must begin coping with long term uncertainty regarding the child's present and future functioning. The successful growth and development of the handicapped child requires the restructuring of roles for the entire family system.

For numerous reasons, according to Loeb (1977) fewer mentally handicapped children are being institutionalized. Instead they remain at home as an integral part of the family structure. This places the parents under many special and sometimes chronic stresses.

The above statement is concurred by Chinkanda (1988) who stated that the care of the mentally handicapped is mostly undertaken by the family instead of institutions. According to Wikler (1981) types of stress that are unique to families of mentally handicapped children include the prolonged burden of care the child demands, stigmatised social interactions and a lack of knowledge in child management. These stresses are exacerbated by the unique physical, emotional and caretaking needs of each specific handicapped child and families are required to cope with each stress one at a time as they occur over the family life cycle.

The presence of the handicapped child places the family at a higher risk for marital conflicts, siblings rivalry and ongoing stress and frustration (Turner, 1980). With reference to the literature, and impact and effects of the handicapped child on the parent subsystem and on the sibling subsystem will be further discussed.

Ballard in Thomas (1982) perceives the presence of a handicapped child as a definite threat to its family members. He argues that because the family is a system, if one member is affected by a handicap, then all the members will be affected to a certain extent. The extent to which the entire family will be affected will differ from family to family according to the level of integration. Glendinning (1983) also reported that some mothers have admitted that they have suffered a great deal of stress and strain.

Not all families experience insurmountable problems when making changes because of the handicapped child. Those families that have been well integrated prior to the birth of the mentally retarded child do not experience major problems and they easily make changes to adapt to the child. One should, however bear in mind that individual family members do not necessarily make a good job of adjusting to the handicapped child. Anderson (1982) contends that in those cases where the parent of a handicapped child shows a neurotic reaction, there usually have been some underlying problems prior to the birth of he child.

Some of the adjustments that have to be made by the handicapped family are due to the amount of time which the mother devotes to the care of the mentally retarded child. This will affect not only her physical energy to perform tasks for other persons in the family but it may also affect her mental and emotional

ability to care for their other needs. This will obviously have an effect on her relationship with her family especially her husband.

In some families the presence of a handicapped child brings about difficulties that have been suppressed for a long time. One parent may have more difficulty in accepting the child than the other and he may gradually stay away from home for longer hours or in the case of the mother she may over identify with the handicapped child to the exclusion of other children. "In case like these the handicapped child plays an important part in the family drama, and the fulcrum around which much of the action takes place" (Anderson, 1982).

The concepts of the family life cycle and its developmental tasks are relevant to a discussion of families with handicapped children, since such children almost invariably contribute to an arrest in their family's life cycle.

The developmental psychology states that the family can be conceived as having a life cycle. The family life cycle is defined by Duvall (1977, 1985:485) as "the sequence of characteristic stages beginning with family formation and continuing through life of the family to its dissolution" and describes the typical life cycle of an intact family in terms of eight stages. Each stage requires changes and redefinitions in relationships with the external environment and struggles with one's self definitions and self identity. The individual member of the family must accomplish certain crucial tasks at specific stages of its life cycles (development). Successful mastery of the tasks in one stage leads to success in later tasks (Duvall 1985; Germain & Gitterman, 1980).

Duvall's (1985) stages of life cycle are stated below

2.5.2 Duvall's stages of family life cycle

1. Married couples without children	Establishing a mutually satisfying marriage. Adjusting to pregnancy and the promise of parenthood. fitting into the kin network.
2. Childbearing families (oldest child birth-30 months)	Having, adjusting to, and encouraging the development of infants. Establishing a satisfying home for both parents and infants.
3. Families with pre-school children (oldest child 2 years)	Adapting to the critical needs and interests of pre-school children in stimulating, growth-promoting ways. Coping with energy depletion and lack of privacy.
4. Families with children (oldest child 6 - 13 years)	Fitting into the community of school age families encouraging children's educational achievement
5. Families with teenagers (oldest child 13-20 years)	Balancing freedom responsibility. Establishing post parental interests and careers.
6. Families launching young adults (First child gone to last child leaving home)	Realising young adults with appropriate rituals and assistance Maintaining a supportive home base
7. Middle-aged parents (Empty nest to retirement)	Rebuilding the marriage relationship. Maintaining kin ties with older and younger generations.
8. Aging family members (retirement to death of both spouses).	Coping with bereavement and living alone. Closing the family home or adapting it to aging. Adjustment to retirement.

The concepts of the family life cycle and its developmental tasks are relevant to a discussion of families with handicapped children, since such children almost invariably contribute to an arrest in their family's life cycle. Most families generally do go through the life cycle in fixed pattern.

Families form when people marry, separate from their parents and learn to accommodate each other as marital partners, and then assume the role of parents with the arrival of their first child. Each addition to the family not only increases its size but reorganises the family structures, its living pattern and its life style (Thomas 1982). The family cycle must accommodate itself to the expansion phase, and later it must adjust itself to the contraction phase. Each stage in the family life cycle is accompanied by special problems that relate to this process of accommodation, and each family must find a suitable and effective way to resolve these problems so that the family unit and individual family members can move on to the next stage of growth and personal development (Thomas 1982).

The parents of normal children have to endure many problems, trials and moments of despair associated with development, almost all these parents know that ultimately the child will become a self-sufficient adult. By contrast, the parents of handicapped child may have less to look forward to and be burdened by the child's unrelenting demands and unbeatable dependency.

The literature is consistent in identifying numerous stresses confronted by families of the developmentally disabled. These include additional physical care, medical, educational and other support services, and financial strain resulting from the needs for special treatment and equipment (Bulbolz & Whiren, 1984; Holroyd, 1974). Other problems reported in the literature by parents include isolation, and decreased social mobility and a variety of emotional problems such as depression, guilt and anxiety (Bulbolz & Whiren, 1984; Gallagher et al, 1983; Holroyd, 1974; Marcus in Brantley & Clifford, 1988).

In the light of the family life cycle and family's developmental tasks, a detailed discussion of the effect the mentally handicapped child has on the parents follow.

2.5.3 The parents

When it dawns upon parents that their child is to grow up handicapped sometimes evident at birth or shortly thereafter, but perhaps only after several years of normal development - parents face nearly overwhelming psychological problems (Nihira & Meyers, 1987).

Depending on the time the parents became aware of their child's handicap their reaction is bound to pass through the following stages:

- * A suspicion that something is wrong with the child.
- * Becoming aware of the problem.
- * Searching for a cause.
- * Blaming someone or something.
- * Searching for a solution
- * Accepting the problem
- * Finding and accepting assistance for the child (Oliver, 1983).

When parents become aware of the problem, the parent is often dazed and unable to think of any way out of the dilemma. Being faced with having a retarded child is a major psychological stress, and parents confronted with such a situation-though well adjusted are likely to manifest a diversity of responses, some of which may interfere with optimum coping (Featherstone, 1980).

As soon as the parents become aware of the handicap a state of shock will follow from which various emotions will emerge especially feelings of frustrations, loss of self-esteem, ambivalence, depression, self-sacrifice and defensiveness.

2.5.3.1 Loss of self esteem

The birth of a retarded child shatters parental ambitions. Most parents dream of having a healthy child who will grow up and be independent. When a retarded child is born or when the child become retarded at later stage, life goals of parents may be abruptly and radically altered, including loss of fantasy of immortality through once's children (Featherstone, 1980).

2.5.3.2 Shame

According to Wilker et al (1983) parents may anticipate social rejection, pity or ridicule and related loss of prestige. They do not want to speak about this affliction or they may try to conceal it from friends, family and neighbours, some believe that the miracle will occur and the child will recover. This parent will travel far and wide with the child to consult various specialists. They clutch at every straw and visit faith healer or go to the water Lourdes, or believe well-meaning laymen who tell them that the child will outgrow the condition. When the state of the child's condition does not change social withdrawal may be a common consequence.

2.5.3.3 Ambivalence

Parents of retarded children experience mixed feeling towards the child namely: feelings of love and hate, acceptance and denial yet the child belongs to them and must be accepted and recognised as such, it is yours and yet not yours.

The retarded child's lack of achievement and tendency towards irritating behaviour are likely to be the sources of continuing parental frustration. When parents are frustrated by the child, anger and resentment are generated towards the child and sometimes the parents wish that the child may die. Again, inconsistent behaviour, sometimes altering between rejection and overprotection, can be expected (Dyson et al in Rivers 1983).

2.5.3.4 Depression

Chronic feelings of sorrow are to be anticipated as another pathological reaction to having a retarded child. (Featherstone, 1980). Most parents are disappointed in their child and concerned about his future. To some mental retardation symbolizes the child's death, reaction similar to that associated with the loss of loved ones.

2.5.3.5 Self sacrifice

Some parents' sacrifice all personal pleasure for the child and he may become the focus of such parents' total interests, often to the detriment of other family members. Family disruption including marital conflicts, may accompany this pattern. The retarded child may become the focus of mutual blame and criticism by the parents (Smith, Neisworth & Hunt, 1983).

Families have reported that subjective marital tension increases after the birth of the handicapped child (Gath, 1972 & Featherstone, 1980:91) notes that:

"a child's handicap attacks the fabric of 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 grounds for conflicts". Since the coping styles of men and women are known to differ, and their rates of adaptation may be quite in compatible with one another, the quality of the marriage will directly influence the experience of stressful situations. Because the perspectives and attitudes of mothers differ from fathers, marital discord is the outcome in many relationships (Sherman & Coccozza, 1984). They further stated that there is a substantial proportion of parents with handicapped children who report that the marriage and families have strengthened and brought together by having a disabled family member. However, Matteson in Gath (1972) claims that while there may be some truth in such statements, those attitudes assist the parents, and the siblings as well, in hiding from themselves the sad and resentful emotions related to their unique burden in life.

2.5.3.6 Defensiveness

Parents may deny the existence of retardation, rationalize the child's shortcomings, and seek professional opinions to substantiate their own contention that "there is really nothing wrong" with him (Gath, 1972).

2.5.3.7 Negative Behaviour

When the parents realise that their child is retarded whatever the reaction may be, there will be a crisis in the family causing tension and disturbing smooth functioning of the family. In other families the child is rejected and may receive harsh treatment. When the child is rejected it is always better to remove the child from this atmosphere (Wayman, 1984).

In other cases the handicapped child is pampered and over protected. As a result of pity and guilt feelings this child may receive everything at the expense of other siblings such behaviour on the part of parents usually encourages dependency on the part of the handicapped child, instead of being trained to do things for himself, the parents do everything for him.

The total dependency of this child may provide the neurotic mother with a feeling of satisfaction or importance. Sometimes the mother overprotectiveness may conceal her deepseated feelings of guilt or rejection. As a result of the parents inclination to encourage dependency on the child, he does not get the opportunity to fully develop his potential, he remains dependent and acquires very few skills. Due to the parents behaviour the other siblings forfeit much parental attention and have to struggle on their own. They become very frustrated because the handicapped child receives every consideration on their cost.

Also parents may hold back some or all their negative feeling from the handicapped child, and consistently take them out on one of their healthy siblings (San Martino & Newman, 1974).

2.5.3.8 Positive Behaviour

As soon as the parents realise that their child is handicapped, they must work through their emotional reactions and obtain guidance as to the best approach and methods of handling the child (Aldenferer & Blashfield, 1984).

Acceptance of the fact that the child is mentally handicapped has a positive effect because the child would not view himself as different from other siblings in the family. The child should be appreciated, not pitied. The more severe his handicap, the less he realises that he is "different" (Darling 1979). She further states that he is much less sensitive than his parents are, he is often totally unaware of his own deficiencies or the problems he is creating for others.

The retarded child should be encouraged to master certain activities, to do things for himself and parents should show their joy when he succeeds. Patience must be exercised when dealing with the handicapped child and encourage him to become more self - sufficient.

Birenbaun (1982) states that the handicapped child should be encouraged to play with friends who are not inclined to bully him and enjoy playing with him.

He must learn the meaning of "no" (discipline must be firm) and what behaviour is socially unacceptable. Unacceptable behaviour should not be permitted, he should not be spoiled or overprotected. Reward for good behaviour is more effective than punishment, but consistent handling is imperative. Feartherstone (1980) states that "his yearning for love, acceptance and protection should provide the framework for teaching discipline". To assist the child to become as independent as possible, training should be consistent, persistent, patient stimulation and discipline in a pleasant atmosphere. Duvall & Miller (1985) states that when training the handicapped child, an infinite variety of activities and situation could be utilized, depending on the parents' ingenuity.

Parents should learn not to hide the disability of the child from friends and relatives. Of importance is that, the family social life should remain as intact as possible and friends should still be invited and welcomed at home (Waisbren & Townsend, 1980:130). They further state that parents should avoid to make their child a central point of discussion but talk about him as they would about any of the other children, each with his own perculiarties and lovable traits. Another important factor is that the parents should never create the impression that they ignore the problems of the child, neither should they bore other people with details of his behaviour.

Mats (1982) mention that other siblings should be explicitly told about the handicapped child, they should not get the information from friends and neighbours. In order for the reciprocal relationship to exist between the handicapped child and his siblings, the parents should assist them to accept him, but not to do things for him.

If parents accept the problem and the child, and if they live a full family life and are intergrated into society, they will experience gratification in their efforts to educate this child and they will get satisfaction from assisting other parents who have handicapped children.

The family acceptance of the handicapped child is usually dependent on the parents (Smith, Neisworth & Hunt, 1983).

A discussion on the effects the mentally retarded child has on the siblings follows:

2.5.4 The Siblings



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Holroyd in Fredrich, Wiltura & Cohen (1990) states that siblings of the retarded children are often adversely affected when they hear about their brother or sister's condition from friends. The siblings experience their own problems. They all soon surpass the handicapped one, they go to school develop different interests, have their own friends but often feel rejected by them, are teased about, or feel ashamed of the handicapped one or may reject or even hurt him.

The siblings are often told to love the retarded child. They are not permitted to retaliate against him. When such an attitude is enforced by the parents, then the normal siblings view the retarded one as an "odd one" for whom they can make allowance but who is not good as playmate. Consequently, the good relationship between the siblings and the retarded child is strained.

Siblings who have handicapped brothers or sisters are often expected to compensate for the deficiencies of the "different" child. Parents may exert great pressure on the normal siblings, who may be obliged, implicitly or explicitly to accomplish at higher level than is possible for them (Suran & Rizzo, 1983).

Parents may have unrealistically high aspirations for them to compensate for the limitations of the handicapped child, and may come to expect their normal children to be more independent, understanding tolerant and generous than is reasonable (Schild, 1971; Smith, Neisworth & Hunt, 1983).

From the above, it can be postulated that adolescent siblings will be subjected to more pressure to achieve socially and scholastically than other siblings.

Again, parents may hold back some or all of their negative feelings from the handicapped child, and consistently take them out on one of their healthy siblings (San Martino & Newman, 1974).

According to Smith, Neisworth & Hunt (1983) and Suran & Rizzo, (1983); normal siblings may have smaller peer group network due to the stigma of having a handicapped sibling. The limitations of the special child may create difficulties for normal siblings, especially young adolescents who begin to experience doubts about socially acceptability, and who fear that different brother or sister may be an additional source of stigmatisation. Many siblings are unable to explain their special brother or sister to their friends, and they also have to explain things that they themselves often cannot understand or accept. They report that they are frequently subjected to ridicule and gossiping, which is not uncommon amongst children.

Another problem area for the siblings of the retarded child is when they wish to bring friends home. In those homes where the retardation has been openly discussed, the young man or woman will be able to explain to the boyfriend or girlfriend that they have a retarded sibling and not let the visitor find out on his/her own. In such cases the friend have been prepared ahead of time and may even decline the invitation to visit if they fell uncomfortable in the presence

of handicapped persons. In cases where they have not been prepared ahead of time, they may not know how to handle the situation. This type of occurrence may spell an end to a promising friendship.

Another source of resentment for the non-handicapped children may be when their parents expect them to help with the care of their retarded sibling. McCormack in Glendinning (1983) both report that most of the mothers they studied were not in favour of their other children assuming the great responsibility of helping to care for the handicapped child unless they volunteered to do so of their own accord. Even some mothers ensure that this does not interfere with other aspects of their children's lives e.g. doing homework, visiting friends etc.

The consequence of living with a handicapped sibling have been discussed extensively in the literature (Robinson, et al in Glendinning 1983). The manner in which the other children will respond to the handicapped child is often determined by how the parents handle the situation.

According to Ballard in Gable & Kotsch (1981) children are likely to take their lead from their mother and father, and the way in which they see them managing their relationship in dealing with the crisis. If the parents' attitude is more or less optimistic and accepting one, it will probably be taken up by the children in a way which is sensible and essentially adaptive.

If, on the other hand, their example is ambiguous and it seems to the children that what has happened poses an unmanageable threat to the marriage and expected life style of the family, then problems and unhappiness may arise.

2.6 Overview of the Literature on the Various Problems That Are Experienced by the Families Who Have Mentally Retarded Children

2.6.1 Finances

Parents of handicapped children experience increased financial difficulties resulting from the needs for special medical care and special programmes. Fathers are

reported as being seen as most involved with financial concerns with mothers assuming the role of caregivers Howard in Hymovich & Baker (1985). Fathers are usually concerned about the handicapped child's ability to learn a trade and become an independent adult. A handicapped child often causes considerable strain by forcing the family to find an adequate source of income (Smith, Neisworth & Hunt, 1983). In most cases mothers of mentally handicapped children do not seek employment because they feel restricted by their responsibilities toward the disabled child. This means that only one parent will be able to meet the needs of the family. The amount of money which can actually be spent will be limited by the household's total income and by other demands on the family budget. In addition to this, fathers have little opportunity to do things directly helpful to their handicapped child because occupational roles require that fathers are absent from home during the day (Cummings 1976).

There are instances when the retarded child incurred additional expenses because of his extra needs. Some parents identify extra expenses like buying extra toys and games specially for the retarded child's stimulation and education as a burden in their income (Bell, et al in Turner, 1980).

Children who have been diagnosed as retarded put extra costs on the finances of the family. He has to attend clinical psychologists and special doctors and this places an extra burden on the financial aspects of the family. Travelling to and from the hospitals and clinics demands money from the very limited money that is earned by the parents.

With the mildly or moderately retarded children, the families try to apply for disability grants or single care grants for the children with no avail. The single care grants is only awarded to the parents of severely and profoundly retarded children.

2.6.2 Social Factors

Farber & Rowitz in Chentwyad (1985), revealed the dilemma that is faced by parents of handicapped children when they decide to "mainstream" their handicapped children, that is place them in settings with normal children viz: They may:

- (a) Face a daily reminder of discrepancy between their child and normal children around them.
- (b) Share the "stigma" of handicapped with their child and may not feel respected or accepted by other parents.
- (c) Reveal a lack of interest in common with other parents.
- (d) Be deeply concerned with the difficult social adjustment of their handicapped child.
- (e) Worry that normal school setting may lack that supportive service available when the program is focused on the handicapped.

The mainstream may be in the interest of the child, it may also increase stress felt by parents when placing their handicapped child with normal siblings.

2.7. Summary

Chapter two attempted to give an overview of the different problems, strains and pressures that the families who have mentally retarded children are faced with.

Though a retarded child places a considerable demands upon family, if viewed as human beings with human emotional needs who can learn and who will learn if given the proper opportunity, the majority of retarded children can become useful, productive, and at least partially self - sufficient adults.

In our black communities there are few institutions who admit mentally retarded children. These institutions are characterized by long waiting list and the child end up being cared for at home permanently.

The impact of the mentally handicapped child has on the family, has been highlighted and discussed in detail in this chapter.

Chapter three will concentrate on the development of research on the "Effect of the Mildly or moderately retarded child on the family". It will focus on the research development of this subject in South Africa and overseas.

CHAPTER 3

LEVEL OF DEVELOPMENT OF THE STUDY

3.1 Introduction

It is recognised from the previous chapters that if there is a mentally handicapped member in the family, that particular member will effect its members in one way or another. With reference to the literature, specific research findings will be noted in this chapter.

Families of children who have handicapping conditions are often faced with unique sets of problems as they attempt to adapt to the presence of handicapped children within the family unit. Parents of handicapped children are faced with the task of meeting the needs of the child and other family members (Gardner & Eheart in Luiz & Fullard, 1991).

Research on the impact of the handicapped child on siblings has also indicated several sibling's vulnerability to stress and other problems. (Vadasy, Fewell, Meyer & Schell, 1984). Therefore empirical research findings conducted in South Africa and overseas on this topic will be briefly presented below.

3.2 Research findings on the effects the mentally handicapped child has on the family

Breslau, Weitzman and Messenger (1981) conducted a study on the effect of the handicapped child on the "normal" children at home.

The researcher studied 239 families with siblings between the ages of 6 and 18 years. Their mothers were asked to complete the Psychiatric Screening Inventory. The data obtained showed that among siblings younger than the disabled children, male siblings had greater psychological impairment than females, whereas the reverse was observed in older siblings. Breslau et al (1981) found that 27% of the young male siblings were severely psychologically impaired compared to 6% of the younger female siblings. Among the older siblings 13% of the male siblings and

27% of the female were found to be seriously impaired. On two scales measuring interpersonal aggression, siblings of the disabled children scored significantly higher than the control group, indicating greater pathology in these behavioural domain.

There is a popular belief that having a mentally handicapped child will have long-term deleterious effects on the family, the marriage and the siblings (Martino & Newman, 1989 & Bulman & Brymann 1990).

Research conducted by Farber (1988) and Gath (1985) indicate that the marital relationship may suffer when a handicapped child forms part of the family. De Meyer (1979) found that while general ratings of marital happiness did not suffer in families of autistic and normal children, the parents of autistic children had more extremely happy marriages. This finding is similar to Gath's observation that it is the weak or shaky marriages that suffer most when there is a Down syndrome baby in the home.

Marital satisfaction is considered to be an important dimension in the family of the handicapped child. Tew, Payne & Lawrence (1977) in their empirically sound study note that the birth of a spina bifida child seems to present a serious challenge to the stability of marriages relationships. Fifty nine families with a spina bifida child were studied from 1964 to 1966. The quality of the marital relationship in the index families was found to have deteriorated over the years, but to have improved slightly in the control families. The divorce rate of the index families was twice of the controls and of the national average. Only one in four marriages appeared to be unaffected or free of marital difficulty. The results of the study seems to confirm that more often than not, the family with a handicapped child is a handicapped family.

Claims, Clerk & Smith (1979) conducted a study in which school-aged cancer patients and their healthy siblings from 71 families, were given the Piers-Harris Children's self-concept scale, the Bene Anthony Family Relations Tests, and the Thematic Apperception Test.

The Piers-Harris Children's self-concept scale assessed the children's perception of themselves, the Bene Anthony Family Relations Test evaluated perceived roles in the family, and the Thematic Apperception Test elicited other concerns central to the children. The study revealed that the siblings of children with cancer have significant anxiety, fear for their own health, social isolation and experience other stresses once thought to be peculiar to the cancer patients themselves. The study also demonstrated that siblings feel very isolated from their parents and from other family members and friends. They know that the parents' time and attention, as well as the financial resources of the family, are directed towards the patient rather than towards their own needs. The parents postpone attending to the needs of their other children in their distress. In addition, the siblings' anxiety and fear of illness are often not attended to, and they remain at home alone, worried and cut off from emotional support.

The authors concluded that these results indicate that siblings, like cancer patients, experience severe stress when confronting a life-threatening illness such as cancer, and that in recognising and attending to their needs, one can practice primary intervention by facilitating their healthy adaptation to a very difficult situation.

Burten (1986) conducted a study on how the handicapped child affects the non-handicapped children in the home. He found that although siblings older than the sick child understood the child's special needs, they resented the extra attention required and felt responsible for the sick child's well-being. On the other hand, younger siblings were uprooted and side placed as the ill child eventually dependent role.

Another study which was conducted by Grossman (1972) on the same topic noted that most students used as subjects were embarrassed by handicapped siblings of the same sex. Older siblings of both sexes received higher coping scores than siblings overall social adaptation, relationship with the retarded child on the self esteem. Younger brothers of mentally retarded males appeared to be greatest at risks and this finding prevailed across all social classes. Grossman's findings on the effect of birth order were similar to those reported by Breslau et al (1981).

Breslau et al (1981) conducted a research to investigate psychological problems among mothers and siblings of handicapped children. Breslau et al (1981) found that, as a group, mothers of handicapped children reported being more depressed than mothers of non-handicapped children. The best predictor of maternal distress was the amount of help that the child needed with activities of daily living such as eating, dressing and grooming.

Ogle (1987) and Mattle, et al in Breslau et al (1981), studied the quality of siblings relationships. They found that mothers rated siblings dyads higher and, thus, more positively, when the dyad contained a handicapped child than when both children were non-handicapped.

Ogle's (1987) study used 3 to 12 year old siblings of severely handicapped children, while Moltale's study was of 9 to 15 year old mentally retarded and autistic children and their siblings. Ogle determined that there were no significant differences in the rating of the pairs as a function of the age spacing, sex composition of the dyad, or the care giving demands of the handicapped child.

Another important study on the effects of the mentally retarded child on the siblings was conducted by Lobato & Tlaker (1982). They studied a group of 83 non-handicapped college-aged siblings of retarded children. Approximately 45% of the subjects surveyed reported that they had benefited from the experience. The benefit that they have cited included increased understanding of other people, more tolerance and compassion and greater appreciation of their own health and intelligence. However, 45% also reported negative experiences including guilt, shame, or a sense of being neglected, and negative feelings toward their retarded sibling. The findings emphasised each family's unique responses to a handicap, influenced by family social class, family size, birth order, age and sex of the sibling.

Van Rooyen, (1989) studied the marital relationship of the parents who have mentally retarded children. The aims of the study was to identify stresses resulting from the presence of the specifically pervasive developmentally disordered or mentally retarded children regarding marital satisfaction and interactions. To ascertain whether mothers and fathers of pervasive developmentally

retarded and non-handicapped children would have different stress levels regarding marital and family relationships than parents of both mentally retarded and non-handicapped children would differ regarding their marital stress.

He found that the parents of the pervasive development disorder children revealed a higher level of marital stress and the child related matters than parents of mentally retarded and non-handicapped children.

In summary, the picture that emerges from the research findings of different researchers confirms that many families of handicapped children experience intermittent or chronic stress.

Retardation is not simply a defect that occurs to, or resides in, an individual. Rather it is an event that involves and includes the total family unit and often parts of the larger community as well.

3.3 Conclusion



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On the basis of the above, and its relevance to the present study in particular the researcher is bound to believe that the mentally retarded child does affect its members in their daily functioning. This knowledge gives the researcher a basis to work from for the purpose of this study.

In the following chapter the research methodology is presented.

CHAPTER 4

RESEARCH METHODOLOGY AND DESIGN

4.1 Introduction

In this chapter the researcher explains the research methodology that has been used in the collection of data.

4.2 Research Design

Tripodi in Grinnell (1981:210) defines a research design as"logical strategy that plan research procedures and provide evidence for the development of knowledge".

A research design is further explained by Mouton and Marais (1988:193) as "an exposition of plan of how the researcher decided to execute the formulated research problem".

Rubin and Babbie (1989:72) further stated that the term research design can have two connotations namely:

One refer to alternative logical arrangement to be selected. This connotes experimental research designs, correlational research designs and so forth.

The other connotation deals with the act of designing the study in its broadest sense. This refers to all the decisions we make in planning the study, decisions not only about what overarching the type of design to use, but also about sampling, sources and procedures for collecting data, measurement issues and data analysis plans.

Epstein in Grinnell (1988) states that there are two methods in social work research that can be utilized namely: quantitative and qualitative methods. The difference between these two methods is that a quantitive method is used to count and correlate social and psychological phenomena. The qualitative method is used to seek essential character of the social and psychological phenomena.

As mentioned in Chapter 1 the qualitative method will be utilized in this study. The qualitative method according to Epstein in Grinnell (1988) assumes that the subjective dimension of human experience are continuously changing and cannot be studied using the principles of quantitative research methodology. Emphasis is placed on fully describing and comprehending the subjective meanings of events to individuals and groups caught in them. As this is the purpose of this research, the method described here, namely qualitative research seems to be the most applicable method.

The qualitative method has certain characteristics viz:

- Assembly of detailed descriptions of social reality.
- Derive concepts and theory from the social reality being studied.
- Grounded theory suited to the study of relatively uncharted terrain.
- Employed to describe social reality from the points of view of participants within the system studied.
- Employ the research participants natural language.
- Concepts and theories are validated by logical induction and through detailed observation of events and discussion of their meanings with system members.
- These studies rely heavily on participant observation and purposeful conversation.
- Emphasize exploratory research design (Epstein in Grinnell 1988).

The description of the population where the sample was drawn follows:

4.3 Population

Seaberg in Grinnell (1985:133) defines a population as "the totality of persons, events, organizational units, case records, or other sampling units with which the research problem is concerned".

In this study, the population consisted of 35 families who have a mildly or moderately retarded child, attending school at Isipho-Sethu Special School and being the residents of Vosloorus Township in Boksburg.

4.4 Sample

According to Seaberg in Grinnell (1985:133) a sample is a small portion of the total set of objects, events, or persons which together comprise the subjects of the study. The sample has been chosen from the above population (4.3) because, as stated by Huysamen (1994) it is usually not practically and economically feasible to involve all its members in a research project. Consequently, we have to rely on the data obtained for a sample from the population.

There are two types of samples viz probability samples and non-probability samples. For the purpose of this study the non-probability sample has been used because it is less complicated and more economical than probability sample. Again, Seaberg in Grinnell (1988) stated the "non-probability samples are suited to exploratory studies where investigators are merely interested in obtaining as much unique data on a research question". The researcher used the first five families found in the list at Isipho-Sethu Special School as the sample of this study.

The sample was selected from the Isipho-Senthu Special School. The said school caters for the mentally retarded children of Vosloorus.

The supervisor from Isipho-Sethu Special School selected the children who are classified as mildly or moderately retarded. The families of the chosen sample were used as respondents in this research.

The following criteria was used to select the sample:

- The child has to be mildly or moderately retarded.
- He/she must have both parents (father and mother).
- There must be other normal siblings at home.

After the above criteria had been met, letters addressed to parents of the five selected children were posted, requesting the parents to take part in the study together with the normal siblings. The parents were then contacted by telephone and asked if the researchers request has been accepted. The parents were all assured that their names would not be published and that all information gained would be regarded as strictly confidential. Arrangements were made concerning the date and time at which the interview was to take place.

The respondents (parents and normal siblings) consisted of five families all living within the geographical area of Vosloorus. The identifying particulars were given by the respondents on the first day of the interviews.

4.5 Measuring Instrument

With regard to the measuring instruments, it was decided that an interview schedule is the suitable data collection method in this study because of its naturalness and spontaneity, flexibility and control of the environment. The questions in the interview shedule were a combination of close-ended and open-ended so as to allow the respondents to formulate their responses themselves [See Appendix "A"].

The interview schedule consisted of the following sections so as to accomodate the aims of the research:

- The adaptation process of the respondents to the diagnosis of mild or moderate mental handicap.
- The psycho-social functioning of the mildly or moderately retarded child.

- The marital relationship of the parents of the mentally retarded child.
- The relationship between the parents and the mentally retarded child.
- The effect of the mentally handicapped child on the siblings in the home.
- The socio-economic status of the family.
- Future plans.

4.6 Duration of the project

The respondents (parents and normal children) were visited in their homes on weekends especially those families who have employed members. Initially the respondents were interviewed one by one and lastly as a group. The interviews lasted about two hours as a group and in the average of one hour per individual interview. The project was started in November 1993 until April 1994.

4.7 Conclusion

This chapter provide a description of the research design used, sampling, procedure, the measuring instrument and data collection method.

In the following chapter the data analysis is presented.

CHAPTER 5

DATA ANALYSIS

5.1 Introduction

Dauids (1992) researched on "The Effects of a Severely or Profoundly Mentally Handicapped Child on Family Functioning". The present study's main focus is on "The Effects of the Mildly or Moderately Handicapped Child on the family". Dauids' study was conducted with the Coloured families and this study focuses on the Black families in the geographical area of Vosloorus.

Dauids (1992) quotes data analysis as stated by Schurink & Schurink that ... "there is a continuous interplay between the analysis of data and other steps involved in qualitative research: the one cannot really be separated from the other". Data analysis is seen as a continuous process which lasts throughout the research process.

In this chapter the researcher will present the data collected from the respondents in a systematic way linked to the format of the interview schedule.

5.2 Identifying Particulars

5.2.1 Family Composition

Table 5.1: Family Composition

	Number of families		Number of siblings
	Father	Mother	
1st	1	1	4
2nd	1	1	8
3rd	1	1	2
4th	1	1	4
5th	1	1	5
Total	5	5	23

As can be seen from Table 5.1, the family composition of the respondents consisted of two parents in all the five respondent families. The first family have four (4) siblings, the second respondent family have eight (8), the third family have two (2) siblings and the fourth and fifth respondent families have four (4) and five (5) respectively. These all included siblings and the mentally retarded child. On average there were 4.6 children per family.

In the sample, three of the mentally retarded children were females and two (2) were males.

5.2.2 Age of the Respondents

Table 5.2: Age of the Respondents

Age Categories	Fathers		Mothers		Siblings	
	no	%	no	%	no	%
6 - 10					8	34,78
11 - 15					5	21,74
16 - 25					7	30,44
26 - 33					3	13,04
34 - 40	1	20	2	40		
41 - 50	3	60	3	60		
51 - 65	1	20	5		23	
Total	5	100	5	100	23	100

From table 5.2 it can be seen that the ages of one (1) father was between 34-40, the ages of three (3) fathers were between 41-50 and finally the age of one (1) father was between 51-65 years. The ages of two (2) mothers were between 34-40, the ages of the other three (3) mothers were between 41-50 years.

The ages of eight (8) siblings were between 6-10, the ages of five (5) siblings were between 11-15, the ages of seven (7) siblings were between 15-25 and finally the ages of two (2) siblings were between 26-33 years.

5.2.3 Occupation of Respondents

Table 5.3: Occupation of Respondents

	Fathers		Mothers		Siblings	
	no	%	no	%	no	%
Professional					1	4,35
Skilled worker	1	20	1	20		
Unskilled worker	3	60			1	4,35
Domestic worker			2	40		
Unemployed	1	20	2	40	3	13,04
Students					18	78,04
Total	5	100	5	100	23	100

The Table above reflects that the occupation of respondents were as follows:

One father was a skilled worker, three fathers were unskilled workers employed by various factories as general workers and only one father was unemployed.

The occupation of mothers were that one (1) mother was a skilled worker, two (2) mothers were domestic workers and two (2) of the mothers were unemployed.

The occupation of siblings indicated that eighteen (18) were students in different standards, one (1) sibling was a professional (being a teacher in the local school) and one (1) sibling was an unskilled worker. Three (3) siblings were unemployed.

5.2.4 Educational level of respondents

Table 5.4: Educational Level of respondents

Standard	Father		Mother		Siblings	
	no	%	no	%	no	%
Sub a up to 6	2	40	3	60	8	34,78
7 up to 10	1	20	1	20	15	65,22
Degree and above						
Never attended	2	40	1	20		
Total	5	100	5	100	23	100

Table 5.4 indicates that two (2) fathers, three (3) mothers and eight (8) siblings were in the Sub a up to 6 standard of education category. One (1) father, one (1) mother and fifteen (15) siblings were in the standard 7 up to 10 standard of education category, none of the respondents have a degree and two (2) fathers and one (1) mother never attended school. None of the respondent siblings have never been to school.

5.2.5 Religion

At the time of the interview, three families were Protestants and two families were Roman Catholic.

5.2.6 Language

Two respondent families were Sotho speaking and three respondent families were Zulu speaking.

5.2.7 Non-handicapped children

There were twenty three siblings who were interviewed. Five siblings were employed and 18 were attending school.

5.2.8 Mentally Retarded Siblings

All the mentally retarded siblings in the study attended school at Isipho-Sethu Special School in Vosloorus. There were seven mentally retarded children who were classified as mildly or moderately retarded.

A summary of the findings on the identifying particulars indicate that 30% of the respondent parents were skilled workers, 20% were unskilled workers, 20% were domestic workers and 30% were unemployed. Findings of the respondent siblings indicate that 10% were professionals, 10% unskilled, 30% unemployed and 50% were students.

60% of the respondent families were Protestants and 40% were Roman Catholic in their religious affiliation.

60% of the respondent families were Zulu speaking and 40% were Sotho speaking.

5.3 The adaptation process of the parents to the diagnosis of mild or moderate retardation.

5.3.1 The first reaction to the fact that the child was diagnosed as mildly or moderately retarded

The respondent couples reported that their first reaction was shock, grief, denial and helplessness.

Two mothers reported that when they heard about their children's mental retardation they felt helpless and thought of removing their children to the farm. They felt that these children would be better off in the farms rather than in the townships whereby people would enquire about their not attending school. Three mothers stated that they were expecting wonders from their children. When it dawned upon them that their children would never be able to attend school for the normal children, they wanted to kill them.

The five respondent fathers' reaction were very neutral. They never expressed anything concrete as to their reaction when they heard about their children's diagnosis.

The five respondent couples all experienced certain feelings when their children were diagnosed as mildly or moderately retarded.

5.3.2 Feelings experienced when the child was diagnosed

Shock: All the respondent couples reported that they were shocked to learn about their children's mental handicap. They were all shocked because all of their children attended schools for the normal children but could not benefit from them and were all expelled from them due to their mental condition.

Grief: 100% of the respondent couples stated that they were grief stricken when they learnt about their children's mental retardation. Their reaction was as follows: (The reaction of one mother) "I felt numbed the whole body, I could not move nor do anything when the news were broken to me by the Clinical Psychologist. My child was eight years old then and I could not believe him. Fortunately, the Clinical Psychologist was very empathetic and consoled me by saying "your child is not severely retarded, he will be trained in some skilled jobs". His words consoled me, I partially regained my strength and went home".

The five respondent couples reported that their grief was worsened by the fact that their children would not have professions as they wished.

Anger: Two respondent mothers stated that they became angry when they learnt that their children were mildly or moderately retarded. They reported that their children repeated all the standards at school. They both left school in standard one, both mothers maintained that they became angry because the principals of the school where their children attended, only wrote them letters explaining that these children were not doing well and had to be removed to the schools for the mentally retarded children.

Three mothers reported that they were angry with the teachers who taught their children because they were the ones who labelled their children as retarded whilst they were not doing their work of teaching them. They maintained that no physical deformity could be observed from their children but they are labelled as mentally retarded.

Three fathers maintained that they were angry because they felt their children would be a burden to them. They stated that they were not expecting to have abnormal children who would not be self-sufficient. Two father stated that they were very very angry because there are no sufficient schools for the mentally retarded children in Vosloorus and their not attending school would force these children to roam about the streets aimlessly.

This confirm opinions of reseachers such as Fortier & Wanlass (1984:260). They state that: "it is not towards handicapped children that parents may have feelings of anger, of course. It is natural in the ups and downs of daily living for feelings to fluctuate especially if one has been disappointed in his or her life". The respondent parents never expected their children to be handicapped, hence the feelings of anger at the lack of suitable facilities to care for these children.

- Denial:** All the parents reported that they denied the diagnosis. They could not believe that their children were mentally retarded.
- Acceptance:** All couples eventually accepted the condition of their children. All five couples viewed their children as a gift from God. They all reported that they consulted witchdoctors, prophets and faithhealers with a view that their children would be cured, but did in the end accept the situation.
- Guilt:** Three respondent couples felt guilty about the condition of their children. They reported that they did not give much attention to their children when they were young. They left their children with aged people to look after them while they were working and their children were not well looked after.

They blamed themselves that if they were not poor, their children would have attended proper creches instead of being left in the care of the aged people.

Summarised therefore the findings on this aspect reveal that 60% of the respondent couples felt guilty and 40% did not feel guilty about the diagnosis of their mildly or moderately retarded children. The manifestation of guilt has been found to be the most common response in parents of the retarded children in this study. Their parents felt that they had done something which had contributed to their children's retardation. It was evident from the responses of 60% of the respondents that they felt guilty because they considered themselves to have contributed to the conditions of their children because they did not pay more attention to their children. They left them in the care of the aged people while they were at work.

Blame: Three couples (60%) blamed themselves because they left their children to be looked after by aged people. They reported that if they had given much care to their children during their formative stages, their mental condition would be normal. Two couples (40%) did not blame themselves at all. All five couples did not blame each other about the condition of their children.

The reaction of the 70% of the respondents is confirmed by the Oliver (1983:48) who cited that "when the parents became aware of their child's handicap their reaction is bound to pass through the following stages, blaming someone or something and searching for a cause".

5.3.3. Present feelings about the child's condition

All five couples reported that they had accepted the condition of their children. They mentioned that they had travelled far and wide to try and get cure for their children but to no avail. They reported that they had spent hundred of rands on witchdoctors and faithhealers but they never helped.

5.3.4 Knowledge about the causes of mental retardation

All five couples (100%) reported that they did not know about the causes of mental retardation. It can be asked if their lack of knowledge can be attributed to the fact that only 20% of the respondents had a higher level of education.

5.3.5 Feeling of parents when they meet new people and have to describe the child's condition

From the five respondent couples one mother stated that "it was very difficult for me to tell people about my child's mental condition. If I had visitors in my house, I used to request my son to go to his friends in the street because people would see him that he is not normal. As time went by, I realised that hiding the child's condition would not help me because people sometimes asked about his standard at school and found that he was in the lower grades than his peers. I eventually discussed his condition and his lower grades with the Minister of religion and he told me not to be afraid about my child's well being because I would not be able to change his condition. From that day I am free to discuss my child's condition with who ever asks me questions about him".

The four respondent couples, all stated that they are not afraid to tell people about the condition of their children. They all stated that hiding the disability of their children would not help nor change their mental condition.

According to Waisbren & Townsend (1980) parents of handicapped children should learn not to hide the disability of their children from friends and relatives. In this study 90% of the respondent couples reported that they were not afraid to tell or discuss the condition of their children with people. Only 10% of the respondent couples were afraid to reveal the disability of their children to people but eventually consulted the Minister of religion who counselled them. The findings of this study reveal that all the parents were not afraid to discuss the condition of their children with people.

5.4 The psycho-social functioning of the mildly or moderately retarded child

5.4.1 Problematic areas to the child when it comes to self-care skills, motor development and cognitive development and communication

Table 5.5: Areas of the retarded child's functioning

	Not very good	Good	Very good
Self-care skills			5
Motor development	2		
Cognitive development		5	
Communication			5

Self-care Skills: All five couples reported that their children were capable in that respect:

- all the children are toilet trained
- they all bathed themselves and could dress themselves properly

Motor development: Out of the five respondent families the following was stated:

- two children from different families limped
- one has a deformed arm which is capable only of performing minor or light tasks
- other children were quite normal physically, no conspicuous deformity would be observed.

Cognitive development: From the five respondent families all the retarded children were capable of understanding simple instructions but their attention wanders and they are forgetful.

All five families reported that:

- Their children could not store information for a long time.
- If taught simple instructions, if requested to follow them after few hours they fumbled.
- One mother stated that "I do teach him to write his name and he will write it when I am assisting him, as soon as I remove the page where I have written, he has forgotten even his first initial.

Communication: From the responses received all the retarded children were able to communicate properly with other people.

- Two children from the respondent families were slurred in their speech. Their mothers reported that their slurred speech was attributed to the fact that they started to talk very late at the age of three and four respectively.
- Three respondent families' children were talking and one could not observe or detect any defects from their speech.

5.4.2 Child's attendance of a stimulation group

All five respondent families' children (100%) attended a day-care centre which helps them to remain properly stimulated. In the day-care centre, these children are taught different skills. They are taught to draw and do many simple tasks which are meant for children who are mildly or moderately retarded.

All the respondent mothers stated that nobody has ever taught them skills of stimulating their children. Whatever they do, is simply trial and error. The mothers reported that even the clinics and hospitals they attended never taught them what to do in order to assist their children in the area of stimulation.

All the children from the respondent families once attended schools for "normal" children.

5.5 The marital relationship of the parents

5.5.1 Description of marital relationship

Three respondent couples (60%) reported that their marriages were stable but did experience hard times. The hard times are never attributed to their retarded children. They mention that odd days are there in every normal family and this also applies to them. Two of the couples (40%) did however report problems with their marital relationship.

5.5.2 Reasons for conflict in the marital relationship

Two couples reported that they did fight over the mistakes that were made by their children (retarded). Of these couples, one said "He does not understand that this child is not well and he must be accepted as he is".

From the three respondent couples who reported that they did not fight over anything that concerned their children, one mother reported that "My husband provides everything in the house as a sole breadwinner and I have to look after the retarded child because I am unemployed. There is no reason for me to expect him to help me because he is the head of the family".

5.5.3 Reasons for stability in marital relationship

The three respondent couples who reported that their marriage was stable, attributed their stable marital relationship to God. They reported that God gave them their mildly or moderately retarded children to bind their marriages.

One family reported that God has sealed their marriage by giving them the child. Their child was sent as a blessing because before their child was born their marriage was in trouble and they were on the brink of divorce. When their child was born, and became slow in all his milestones, that brought them together and they learnt to tolerate each other.

One mother stated that "Under no circumstance will I leave my family because of this child. Nobody will accept me with a retarded child and his father has to look after us until I die".

The findings on the marital relationship concurs with the study conducted by Sherman and Coccozza (1984) in which they stated that some families are brought together by having a retarded member. The respondents in this research did reveal that their marriage were bound together by having a retarded child. Mattson (1972) argues that although respondents might claim that there were no conflicts in their marriages, these attitudes assist them in hiding from themselves the sad and resentful emotions related to their unique burden in life.

5.6 Relationship between the parents and the mentally handicapped child

5.6.1 Parents' Relationship with the handicapped child

Table 5.6: Parents' Relationship with the handicapped child

Very Good	%	Good	%	Poor	%
5	100	-	-	-	-

All five respondent couples (100%) reported that there exist a positive relationship with their retarded children. Their reactions were: "We love our child very much".

One mother reported that due to the love of her daughter, she left her employment because she feared that her child would be abused if there is nobody to look after her when she comes from the day-care centre. She fears that abnormal children have unaccounted for pregnancies due to the fact that males tend to take advantage of the mentally retarded children. She further stated that - "My daughter is mentally retarded and I have to protect her from all the bad things that might happen to her. I protect her in all aspects. My over protectiveness towards this child, has led the other children to call her 'Mamas baby'."

The five fathers responded that their children were a gift from God and they had to love them until their last days.

5.6.2 Parents' view of the child with the handicap

All five respondent couples reported that their children are what they are because of God and their handicapped children would be taken away from them by Him only. Their reactions were as follows: "Our children are very special to us. We will stand by our children through thick and thin".

One mother stated that if her husband can die now, she will never get married again because she fears that the step-father would not accept the child who is forgetful and cannot do any constructive assignment without being supervised.

Two families reported that they were sub-tenants for a long time without houses of their own and could not stay for a long time in any place because their mentally retarded children were ridiculed by their landlords.

One mother stated that as a sub-tenant, "I was always under stress because my child was always referred to as a "fool" or all the derogatory names that the landlord could construct. She said, "I always prayed to get a house of my own so that my child could be free and happy". This mother said, whenever the yard was dirty, the dirt would be attributed to her child and they would remark "this stupid has dirtied this yard".

5.6.3 Parents' expectation of change in the child's condition

The response of all the five respondent couples was negative. None of them is expecting miracles. All of them have consulted several witchdoctors but none could assist in changing their retarded children's condition. They all stated that their children are what they are and will never change.

5.6.4 Stress caused by the rearing of the child on the functioning of the family

Out of the five respondent families only one family (20%) reported to have experienced the stress in rearing their handicapped children. This family stated that: "it has been very stressful to bring up children who are slow in their development". The mother stated that: "My children started to walk very late and I have to carry them on my back for a longer time than normal children. My children had to be looked after for a longer time. It has been strenuous for me because my husband never bothered to assist me with the children. He will come back from work and sit and will never lift up his hands to assist me with the children. I do not wish that other mothers can experience the type of strain that I went through and that I am experiencing".

The same couple reported that rearing of their mentally handicapped children has never given them freedom because these children must not leave their sight.

The other four respondent couples (80%) reported that rearing their children did not strain them.

The respondent mothers felt that their children were a blessing from God to test their faith in Him. One of the mothers reactions were "I would wake up day after day for almost three months, go to my child's bedroom, and talk to him trying to find out what it is that the teachers see from my child to label him mildly or moderately handicapped. Why is he not progressing at school while he responds well to me at home". This mother never got to know all the answers she asked herself and eventually accepted that her child will not progress at school.

According to Glendinning (1983) mothers were the ones who experience stress in the rearing of the handicap children. In this study only 10% concurred with Glendinning (1983) findings. Findings of this study revealed that the parents were not particularly experiencing stress..

5.6.5 Feelings of social isolation

All the five respondent reported that they did not experience any isolation. They reported that their friends and families are used to their children. Their friends and families treat their mentally retarded children like any other children. The families were actually integrated in their communities and very close to friends and relatives.

5.6.6 Attitude of other family members towards the retarded child

Table 5.7: Attitude of family members to the retarded child

	Positive	%	Negative	%
Father/Mother	5	100	-	-
Elder brother	6	100	-	-
Elder sister	7	100	-	-
Younger brother	5	100	-	-
Younger sister	5	100	-	-

All five respondent families (100%) reported a good relationship towards their retarded members.

5.6.7 Other family members' feelings of being neglect

From the five respondent families none could report that they felt neglected either by their spouses or their normal children.

5.7 The effects of the mentally handicapped child on the siblings

5.7.1 Feelings of hurt when people made fun of the handicapped children

Eight (8) respondent siblings (34,8%) reported that they felt hurt when people made fun about handicapped people but had no way of retaliating against their comments because they were too young.

Fifteen (15) respondent siblings (65,2%) stated that they felt hurt when other people made fun of handicapped children. They stated that they did not like to hear people make comments about the handicapped people because they felt that they were directing their fun at them indirectly.

5.7.2 Coping with embarrassment

All the respondent siblings reported that they have learnt to cope with embarrassment when strangers stare at them in social gatherings. They all reported that they did not hide their brothers' and sisters' disability because nobody wished to be handicapped.

5.7.3 Discussion of brother's or sister's limitations with friends

Table 5.8: Discussion of Limitations

	YES	%	NO	%
6 - 10			8	47,06
11 - 15	1	16,67	4	23,53
16 - 25	4	66,67	3	17,65
26 - 33	1	16,67	2	11,76
Total	6	30,4	17	69,6

Seven (7) respondent siblings (30,4%) reported that they discussed their retarded siblings' limitations at home. They reported that they grew up with their friends and they knew about the disability of their sister or brother. They reported that their friends were never inquisitive because the majority of them are older than their retarded siblings.

Seventeen (17) respondents (69,6%) reported that they did not discuss their brothers or sisters limitations with friends because their parents taught them to hide their families secrets.

5.7.4 Feelings when introducing brother or sister to friends

All the respondent siblings reported that introducing their disabled brothers or sisters to prospective girlfriends or boyfriends had posed problems to them.

One respondent reported that: "It is very difficult to introduce my sister as disabled to my prospective boyfriend because I do not know how he will react thereafter. I at times fear that he will not come back to me. He can run away from me, because of my sister's condition."

One respondent male-sibling stated that: "I seldom introduce my sister to my girlfriend because her handicap is not conspicuous. She will see for herself when I happen to marry her because she might run away fearing that she might have disabled children herself."

5.7.5 Open discussion of retardation in family.

All twenty-three (100%) respondents reported that they did not discuss retardation in their families. Their families did not sit down to discuss retardation at all.

One respondent sibling stated that "my mother is very protective towards my retarded brother and she treats him like a "king". My mother does everything for him. Instead of teaching him how to do things she does them for him.

5.7.6 Feelings of not being loved

All the twenty-three respondents siblings (100%) maintained that their parents love them equally. They reported that their parents treat them equally because they also love their retarded members.

5.7.7 Expectations to achieve as experienced by siblings

All twenty-three respondent siblings (100%) reported that their parents did not expect them to achieve well at school in order to compensate for their disabled brothers or sisters. They reported that their parents had accepted their brothers or sisters disabilities and did not expect them to compensate for them.

5.6.8 Growth and development of the normal children

All the respondent siblings (100%) reported that they experience a lot of stress because their retarded siblings were unable to do concrete tasks and everything had to be done by them. They reported that their retarded siblings were forgetful and could not store many things in their memories and that forced them to do all the house chores. They reported that they had to teach their disabled members simple things like reading simple stories, etc.

20% of the respondents siblings revealed that they did not feel hurt when people made fun about the handicapped people. Findings postulate that these respondents were young and could not defend the handicapped in any manner. 80% of the respondent siblings reported that they were hurt when people made fun about the handicapped people.

On the whole the attitude of the respondent siblings were very positive towards their retarded members. According to Mats (1982), parents should not hide the disability of their children to their non-handicapped children. From the findings, it is evident that the positive attitude of the respondent siblings was enhanced by the fact that their parents did not hide the disability of their members from them. According to Smith, Nersworth and Hunt (1983) in the homes where retardation is openly discussed, the young man or women will be able to explain to the boyfriend or girlfriend that they have a retarded sibling and not let the visitor find out on his/her own.

Findings of this study reveal that 65% of the siblings were not afraid to discuss the disability of their siblings to friends, while 35% were afraid because retardation was never openly discussed in their families.

5.8 The socio-economic status of the family

All five (5) respondent families (100%) reported that bearing handicapped children has drained them financially. They all reacted as follows:

They had been to various doctors and witchdoctors in an effort to correct the mental condition of their children.

They had consulted clinical psychologists. Two respondent families reported that their retarded sons were taken to the "Sangomas" and were initiated to be sangomas and this did not work to heal their retardation. Their children were taken by these "sangomas" because they believed that they were possessed by their ancestors and they would be normal if they become witchdoctors.

All the respondent families reported that they had travelled to far away places to consult witchdoctors and that had drained them financially. They all reported that their children had to consult clinical psychologists who were expensive and at times did not afford to pay their expenses.

According to Fortier & Wanlass (1984) families who have retarded children spend a lot of money on specialized medical care. Families from the middle class tend to be more financially secure and better prepared to utilize outside help resources such as specialist doctors in securing help for their retarded members needs. Conversely, families of lower socio-economic status often have limited financial resources.

5.9 Other areas affected

- 5.9.1 Social life:** All five respondent families reported that their social life was centred around their immediate families because they understand their retarded children. They seldom went to far places because they could not afford to do so.
- 5.9.2 Support systems:** The five respondent families reported that their immediate families are very supportive. Their grandmothers do look after their retarded children. They all stated that their immediate families are always a source of support and they can rely on them.
- 5.9.3 Future plans:** All respondent families could not say with certainty if their retarded children could pose problems later in life because the day-care centre which their children were attending might open a workshop which would train them in various skills or semi-skilled jobs, and that would make the future much easier.

5.10 Conclusion

The data received from the respondents were analysed in this chapter. It is recognised from the preceding overview of the literature and the discussion of the interview schedule in this chapter that the mildly or moderately retarded children do have effects on their families. The next chapter will deal with the conclusions and recommendations.



CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

The aim of this study was to explore ~~the effects of the mildly or moderately retarded child on the family.~~ The objective of this study has been reached. Through the use of a qualitative method of data gathering, it was possible to develop a holistic picture of how these children affect their families.

6.2 Conclusions

The method of data gathering of this study was highlighted in Chapter 4. The conclusions of this investigation are to be considered tentative, due to the small number of subjects and no control group being involved. Generalization of these results are therefore difficult. For this particular small group of respondents the results showed that the rearing of a mentally retarded child affects all family members both positively and negatively. This can be summarized as follows:

(a) On the adaptation process:

When the parents first learnt about the diagnosis of their children's disability, they were emotionally affected. Feelings of anger, shock, grief, denial and eventually acceptance, were reported.

(b) On the psycho-social functioning of the retarded children:

These children had to be assisted in most areas because they were forgetful, though they could master some activities they were not as perfect as normal children could, due to their mental capacity.

(c) On the marital relationship:

Three families reported their relation as stable and two families reported that they were experiencing problems.

(d) On the relationship between the family and the retarded child:

The families gave no definite opinion on this aspect but the researcher found feelings of lassitude.

(e) On the effect of the retarded child on the siblings:

The siblings were positively and negatively affected by having a retarded member in their families. Important though was that siblings were not equipped with explanations suitable for peers and outsiders if they were asked about their disabled member.

(f) On the socio-economical status of these families:

Due to the fact that these children had to be taken to clinical Psychologists; changed from the schools for the normal children to the school for the mentally retarded, and new school uniforms had to be bought, etc, the families felt drained financially.

It is clear therefore that for the family of the retarded child, the situation is very complicated. The particular handicap of the child, the slowness of his development, the necessity of special arrangements, companionship and adjustment which must be made in the family's expectations for the future combine to create pressure on the parents which tends to disrupt the normal family equilibrium.

The relationship between the retarded child and his family is not only more complex and ambivalent than the ordinary one, but also more intense and prolonged. Parents of a retarded child often need help in dealing with their family situation, in recognizing and accepting the child's handicap, and in handling certain day-to-day problems of living with both the child and his normal brothers and sisters.

The mentally retarded children used as respondents, are cared for in a school which is not adequately equipped. The parents of these children have hope that one day, the day-care centre which their children are attending will open a workshop that will equip their children with skills.

6.3 Recommendations

In the course of this study the researcher was alerted to a number of issues which, in her opinion, warrant further exploration. Brief mention will be made here:

- Early intervention programmes and therapy must be developed to prepare the mentally disabled youngsters for the challenges of later life.
- Mentally retarded people of Vosloorus are not receiving many of the services for which they are eligible and which might help them to improve their level of functioning or reduce their level of disadvantage. Provision and allocation of services for the mentally retarded should be a major priority for policy-makers and planners.
- Group therapy for families who have mentally retarded children must be developed because this kind of group has potential of allowing these families to receive technical advice about coping with everyday difficulties and to deal with stigma of having a disabled member.
- The state must play a stronger role to initiate and take over the responsibility for the erection and maintenance of special schools for the mentally handicapped child instead of placing the onus of the provision of these services solely on the community and private sector.

BIBLIOGRAPHY

- Aldenferer, M. & Blashfield: *Families of Children with Mental Retardation: Comprehensive View From an Epidemiologic Perspective.* American Journal on Mental Retardation, Vol 97, No 3:315-332
- 1984:
- Anderson, D. 1982: *Social Work and Mental Handicap.* London: The McMillan Press.
- Birenbaum, A. 1982: *On managing a courtesy stigma.* Mental Retardation, Vol 30:334-350.
- Blacher, J. 1984: *The school as respite for parents of children with severe handicaps.* Baltimore: Brookes.
- Bogdan, P & Taylor, K : *Families under stress:* London. 1975 : Routledge & Kegan Paul
- Brantley, H. & Clifford, E. 1988: *When my child was born: Maternal Reactions to the birth of a child.* Journal of Personality Assessment, (44):620-623.
- Breslau, N. 1984: *The effects of mentally handicapped children on families. A conceptual review.* Journal of Child Psychology and Psychiatry, 26, (6):367-380.
- Breslau, N. 1984: *Psychological functioning of siblings of disabled children.* Pediatric, 67 (3):369-390.

- Breslau, N. Weitzman, W. & Messenger, K. 1981: *Psychologic functioning of siblings of disabled children. Pediatrics, 67, (3):344-353.*
- Bruininks, R.H; Wolman, C. & Thurlow, M. 1990: *Considerations in designing survey studies and follow-up systems for special education service programs. Remedial and Special Education. 11, (2): 7-17.*
- Buckley, B. 1993: *Invisible children: Siblings of the handicapped. Practice Digest, 1, (2):14-28.*
- Bulbolz, M.M; Whiren, A.P. 1984: *The family of the handicapped: An ecological model for policy and practice. Family Relations, 33:5-12.*
- Bulman, M. & Brymann 1990: *Contemporary Social Research. London Ltd.*
- Burten, L. 1986 : *The family life of sick children: London, Routledge & Kegan Paul.*
- Child Care Act Act 74, 1983.
- Chentwyad, J. 1985 *Factors contributing to stress on mothers caring for an intellectually handicapped child. British Journal of Social Work (15): 295-304.*
- Chinkanda, E.N. 1988: *Community Care of Mentally Retarded child at home. Social Work Practice, (3):6-9.*

- Clairns, N.U; Clark, G.M. & Smith, S.D. 1979: *Adaptation of siblinsg to childhood malignancy. Journal of pediatrics. 95, (3):484-488.*
- Consice Oxford Dictionary - 1984.
- Crnic, K.A; Friedrich, W.N. & Greenberg, M.T. 1983: *Adaptation for families with mentally retarded children: A model of stress, coping and family ecology. American Journal of Mental Deficiency, 91: 226-236.*
- Cummings, S.T. 1976: *The impact of the child's deficiency in the father. A study of mentally retarded and of chronically ill children. American Journal of Orthopsychiatry, 46 (2):246-255.*
- Cummings, S.T; Bayley, B.A. & Rie, H.E. 1976: *Effects of the child's deficiency on the mother: A study of mothers of mentally retarded, chronically ill and neurotic children. American Journal of Orthopsychiatry, 36:595-608.*
- Darling, R.B. 1979: *Families against society. A reaction to children with defects. London: Sage Publications.*
- Davids, M.A. 1992: *The Effects of the Severely or Profoundly Mentally Handicapp Child on Family Functioning. RAU.*
- De Meyer, M.K. 1979 *Parents and children in autism: New York, Willey.*

- Denchack, Schoen,
Stanovich. 1990: *Assertiveness Training for People with a Mental Handicap. Mental Handicap: Vol 20, Sept 1992.*
- Duvall, E.M. & Miller, S:
1985 : *Marriage and family development. New York: Harper & Rowe.*
- Duvall, E.M. 1985 *Marriage and family development: New York: Harper & Rowe.*
- Farber. B. 1988: *Family adaptations to severely mentally retarded children. Baltimore : University Park Press.*
- Farber, B. 1989: *Effects of a severely retarded child on the family. New York. Appelton-Century Crofts.*
- Featherstone, H. 1980: *A difference in the family: Living with a disabled child. New York: Basic Book.*
- Fine, M.J; Mayhew, P. &
Hanson. 1984: *Handbook on parent education. London: Academic Press.*
- Fortier, L.M; & Wanlass,
R.L. 1984: *Family crisis following the diagnosis of a handicapped child. Family Relations, 33:13-24.*
- Fredrich, W.N; Wiltura, L.T. *Coping; Resources and Parenting*
Cohen, D.S. 1990: *Mentally Retarded Children. American Journal of Mental Deficiency, 130-140.*

- Gable, H. & Kotsch, L. 1981 : *Extended Family and Young Handicapped Children: Topics in Early Childhood Special Education*, 29-36.
- Gallagher, J.J. 1983: *Families of handicapped children: Sources of stress and its amelioration: Exceptional Children* 50(1):10-19
- Gath, A. 1985: *Parental reactions to loss and disappointment. The diagnosis of Down's syndrome. Developmental Medicine and Child Neurology*, 27, (3):390-400.
- Gath, A. 1972: *The mental health of sibling of congenitally abnormal children. Journal of Child Psychology and Psychiatric*s, 13:211-219.
- Germain, CB & Gitterman, A 1980: *The life model of social work practice*. New York: Columbia University.
- Glendinning, C. 1983: *Unshared care: Parents and their disabled children*. London: Routledge, Kegan Paul.
- Grinnell, R.M. 1981: *Social Work Research and Evaluation*. USA: Peacock Publishers.
- Grinnell, R.M. 1985: *Social Work Research and Evaluation*. USA: Peacock Publishers.

- Grossman, FK. 1972 : *Brothers and sisters of retarded children.* Syracuse. New York: Syracuse University Press.
- Guide to Genetic Disorders: Down Syndrome (1988) Pretoria: Department of Health, Welfare & Pensions.
- Holroyd, J. 1974: *Manual for the questionnaire of resources and stress.* Los Angeles.
- Holroyd, J. 1988: *Manual for the questionnaire of resources and stress.* Los Angeles.
- Huysamen, G.K. 1994: *Methology for Social Behavioural Sciences.* Pretoria: Stigma.
- Hymovich, D.P; & Baker, C.D. 1985: *The needs concerns and coping of parents of children with cystic fibrosis.* Family Relations (34): 91-97.
- Lobato, D. & Tlaker, A. 1982: *Siblings of Handicapped children: A review: Journal of Autism and Developmental Disorders, 13(4): 347-364.*
- Loeb. R.C. 1977: *Group therapy for parents of mentally retarded children.* Journal of Marriage and Family Counselling, 3(2)L77-85.
- Longo, D.C. & Bond, L. 1984: *Families of the handicapped child. Research and practice.* Family Relations, 33:57-70.

- Luiz, F. & Fullard, W.P. 1991: *Stress Patterns of Families of handicapped children. Exceptional Children. 50(1):3-37.*
- Martino, J. & Newman. 1989: *Handicap and Family Crisis. Bath: The Pitman Press.*
- Mats, N. 1982: *Speed and Accuracy in the choice reaction time of mildly retarded child. American Journal of Mental Deficiency, 1990.*
- Mattson, A. 1972 : (November) *Long-term physical illness in childhood: A challenge to psychological adaptation. Pediatrics, 50(5), 801-911.*
- McCubbin, H.I. 1989: *Action Speaks Louder. New York, Churchill, Livingstone.*
- McCubbin, H.I., Cauble, A.E. 1989: *Family Stress, coping and social support. Springfield, Illinois: Thomas.*
- Mee, H.D. 1989: *Parents needs and how to meet them in Simon, B.G. (ed). The modern management of Mental Handicap. London: University Press.*
- Mee, H.D. 1991: *A Meta-Analysis of Intervention Resource with Problem Behaviour: Treatment Validity and standard of Practice. American Journal on Mental Retardation. 1991, Vol 96, No 3:233-258.*

- Miller, B.C. 1988 : *Family research methods: Beverly Hills Sage Publications.*
- Minuchin, S. 1974: *Families and Family therapy.*
London: Tavistock.
- Mouton, J.C. & Marais, H.C. 1988: *Basic Concepts in the Methodology of the Social Sciences, Pretoria, H.S.R.C.*
- Nihira, K; Meyers, C.E. 1987: *Reciprocal relationship between Home enviroment and development of T.M.R. Adolescents. American Journal of Mental Deficiency*
88:139-149.
- Ogle, M.M. 1987: *Brothers and Sisters. A special part of exceptional families.*
Baltimore, London: P Brookes.
- Oliver, M. 1983: *Research on handicapped children.*
New York: McGraw Hill.
- Pfouts, JH. 1976 : *The Sibling Relations : A forgotten dimension. Social Work, 20:304-310.*
- Rivers, A. 1983: *The problems, needs and concerns of families of retarded children as parceived by their parents. Kent State University.*
- Rubin, A. & Babbie, E. 1989: *Research methods for Social Work Carlifonia: Woodsworth Inc.*

- San Martino, M. & Newman, M.B. 1974: *Siblings of retarded children.* Child Psychiatry and Human Development, 4(3):168-177.
- Schild, S. 1971: *The family of the retarded child.* New York: Mazel.
- Schulz, D.A. 1982: *The changing family.* Englewood Cliffs, New York: Prentice-Hall.
- Schurink, E.M. & Schurink, W.J. 1988: *Developing practice wisdom into theory. The use of qualitative methodology in social work.* The-Social-Work-Practitioner-Researcher, Vol 12:27-37.
- Shea, T.M, & Bauer, A.M. 1985: *Parents and teachers of exceptional children. A handbook for involvement.* Massachusetts: Allyn and Bacon.
- Sherman, B.R. & Cocozza, J.J. 1984: *Stress in Families of the developmentally disabled. A literature review of factors affecting the decision to seek out a home placement.* Family Relations, 33:95-103.
- Smith, R.M; Neisworth, J.T. & Hunt, F.M. 1983: *The exceptional child.* New York: McGraw-Hill.
- Steenkamp, P. & Steenkamp, P.P. 1981: *The trainable retarded:* New York: Plenum Press.

- Suran, B.G. & Rizzo, JV. 1983: *Special children.* Glenview, Illinois: Scott, Toresmann and Company.
- Tew, B.J., Payne, H. & Laurence, K.M. 1977: *Must a family with a handicapped child be a handicapped family?* *Developmental Medicine and Neurology*, 32:95-98.
- Thain, W.S, Castro, G. & Peterson, A. 1980: *Normal and Handicapped Children.* Massachusettes: P.G. Publishing Co.
- The Mentally Retarded Children's Training Act, 1974. (ACT 63 of 1974)
- Thomas, G. 1982: *Helping Troubled Families.* New York: Aldine Publishing Co.
- Turner, A.L. 1980: *Therapy with the Families of a mentally retarded child.* *Journal on Marital and Family Therapy*, 6:167-181.
- Vadassy, P.F, Fewell, RR; Meyer, D.J. & Schell, G. 1984: *Siblings of Handicapped Children: A developmental Perspective on family interaction and family relations,* 33:155-167.
- Van Rooyen, M.S. 1989 : *Pervasive Developmental disorders and mental retardation. A comparison of marital satisfaction and family stress in parents.* University of Port Elizabeth
- Waisbren, S.E. & Townsend, T. 1980 : *Parents' reactions after the birth of a developmentally disabled child* *American Journal of Mental Deficiency.* 84, (4):330-362.

- Wayman, C.C. 1984: *The handicapped member of the family.*
London, Baltimore.
- White, H.D. & White, A. *Pre-school siblings of handicapped children - impact of peers support and training.* *Journal of Autism and Developmental Disorders*, 15(3):345-380.
1980 :
- Wikler, L. 1981: *Chronic stresses of families of mentally retarded children.* *Family Relations*, 30:275-294.
- Wilker, L., Wasow, M. & Hatfield, E. 1983: *Seeking strengths in families of developmentally disabled children.* *Social Work*, 28:310-322.
- Wishart, M.C. 1981: *Parents' report of family life with a developmentally delayed child.* *Child Care, Health and Development*, 7:260-281.

APPENDIX A: LETTER TO PARENTS AND INTERVIEW SCHEDULE

TEL: (011) 906 1009

PO BOX 12091
RUSLOO
1468

Dear Parents

I am a social worker employed by the City Council of Vosloorus. I am presently studying for a postgraduate degree at the Rand Afrikaans University. I am conducting research to explore the effects of the mentally retarded child on the family.

Your child's name has been obtained from the Isipho-Sethu Special School and found to be the ideal candidate for the study. Your family is humbly requested to participate in the study, please.

Your names will not be publised and all information gained will be regarded as strictly confidential. All the interviews will be conducted in the comfort of your home.

Your co-operation will be highly appreciated.

Yours faithfully

TOZI G SOKO

1. FAMILY COMPOSITION

1.2 Age of the Respondents

Age Categories	Fathers	Mothers	Siblings
0 - 5			
6 - 10			
11- 15			
16 - 25			
26 - 33			
34 - 40			
41 - 50			
51 - 65			
Over 66			

1.3 Occupation of Respondents

	Father	Mother	Siblings
Professional			
Skill worker			
Unskilled worker			
Domestic worker			
Unemployed but looking for work			
Pensioner			
Not employed - not looking for work			

1.4 Educational Level

	Father	Mother	Siblings
Sub A up to 6			
7 up to 10			
Degree and above			
Never attended			
Other (mention)			

1.5 Religion

Protestants	1
Roman Catholic	2
Other	3

1.6 Languages

Sotho	1
Zulu	2
Xhosa	3
Shangaan	4
Other	5

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1.7 Number of children
Not handicapped mentally

0
1
2
3
More than 3

1.8 Number of Mentally Retarded children

0
1
2
3
More than 3

2. THE ADAPTATION PROCESS OF THE PARENTS TO THE DIAGNOSIS OF MILD OR MODERATE RETARDATION

2.1 What was your first reaction to the fact that your child was diagnosed as mildly or moderately retarded?

.....

2.2 Did you experience any of the following feelings when you heard the diagnosis?

	YES	NO
Shock		
Grief		
Anger		
Denial		
Acceptance		
Guilt		

If yes, in any of the above, please explain further.

.....
.....
.....

2.3 Did you feel that you were to blame for the fact that your child was mentally handicapped?

YES	NO
-----	----

2.4 Did you feel that your partner was to blame for the fact that your child was mentally handicapped?

YES	NO
-----	----

2.5 What are your present feelings about your child's condition?

.....
.....
.....
.....

2.6 Do you know about the causes of mental retardation?

YES	NO
-----	----

2.7 How do you feel as parents when you meet new people and have to describe the child's condition?

.....
.....
.....
.....

3 THE PSYCHIO SOCIAL ASPECTS OF FAMILY FUNCTIONING OR THE MILDLY OR MODERATELY RETARDED CHILD

3.1 Please state which areas are problematic to your child when it comes to self-care skills, motor development, cognitive development and communication

	Not very good	Good	Very good
Self-care skills			
Motor development			
Cognitive development			
Communication			

3.2 Does your child attend a stimulation group?

YES	NO
-----	----

3.3 Do you as parents make special time in your daily routine to stimulate your child?

YES	NO
-----	----

If yes, has there been an overall improvement in his/her development? Explain.

.....
.....
.....
.....

4. THE MARITAL RELATIONSHIP OF THE PARENTS

4.1 How could you describe your marital relationship?

.....
.....
.....
.....

4.2 If conflict exists in the marital relationship, to what do you attribute it to?

.....
.....

4.3 If you as parents describe your marital relationship as stable, to what do you attribute it to?

.....

5. RELATIONSHIP BETWEEN THE PARENTS AND THE MENTALLY HANDICAPPED CHILD

5.1 How would you describe your relationship with your child?

Very good	Good	Poor
-----------	------	------

5.2 How do you as parents view your child with the handicap?

.....

5.3 Do you think as parents the condition of your child will change?

YES	NO
-----	----

5.4 How stressful has the rearing of your child been on the functioning of the family in your opinion?

.....

5.5 Does the family experience feelings of being socially isolated?

YES	NO
-----	----

5.6 What is the attitude of other family members towards the retarded child?

	Positive	Negative
Father/Mother		
Elder brother(s)		
Elder sister(s)		
Younger brother(s)		
Younger sister(s)		

5.7 Do other family members express feelings of being neglected?

YES	NO
-----	----

6. THE EFFECTS OF THE MENTALLY HANDICAPPED CHILD ON THE SIBLINGS

6.1 Do you feel hurt when people you know make fun of other handicapped children?

.....

.....

.....

.....

6.2 How do you cope with embarrassment when strangers stare at your brother or sister in social gatherings?

.....

.....

.....

.....

6.3 Do you openly discuss your brother's or sister's limitations with friends?

YES	NO
-----	----

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If yes, please comment further:

.....

.....

.....

.....

6.4 How do you feel when you introduce your brother or sister to friends, or to prospective girlfriends or boyfriends?

.....

.....

.....

.....

6.5 Has retardation been openly discussed in your family?

YES	NO
-----	----

.....

.....

.....

.....

6.6 Do you sometimes think that your parents love your mentally handicapped brother or sister more than they love you?

YES	NO
-----	----

.....
.....
.....
.....

6.7 Do you feel that you are expected to achieve well at school, in order to compensate for your brother or sister?

YES	NO
-----	----

.....
.....
.....
.....

6.8 Do you feel that the extra demands made on you, by assisting your parents to care for your handicapped sibling has been stressful?

YES	NO
-----	----

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.....
.....
.....
.....

7. THE SOCIO-ECONOMIC STATUS OF THE FAMILY

7.1 Which of the following areas are most affected by the birth and rearing of your mildly or moderately mentally retarded child?

- finance
- social life
- support system.

7.2 Please explain in which way

.....
.....
.....
.....

8. FUTURE PLANS

(A) To the parents

8.1 Do you think your retarded child's development in future will pose problems to you? Please comment

.....
.....
.....
.....

(B) To the siblings

8.2 Do you think your retarded brother/sister's development in future will pose problems to you? Please comment.

.....
.....
.....
.....

