

THE IMPACT OF MENTAL RETARDATION ON
FAMILY FUNCTIONING

BY

NGOAKOANA EMMA PILUSA

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE:

MAGISTER ARTIUM IN SOCIAL WORK
(MANAGEMENT)

IN THE FACULTY OF HUMANITIES
DEPARTMENT OF SOCIAL WORK
UNIVERSITY OF PRETORIA

SUPERVISOR: DR. J.D. TRIEGAARDT

JULY 2006

TRUST IN THE POWER OF HOPE

Hope deferred makes the heart sick, but when the desire is fulfilled, it is a tree of life.

Proverbs 13:12

DON'T GIVE UP

Let us not be weary in well doing: for in due season we shall reap, if we faint not.

Galatians 6:9

- ✓ DEDICATION
- ✓ ACKNOWLEDGEMENTS
- ✓ DECLARATION
- ✓ SUMMARY
- ✓ OPSOMMING

DEDICATION

THIS DISSERTATION IS DEDICATED TO THE FOLLOWING:

- **My mother, Virginia Kgaphela Leshaba, for the love, care and support received throughout the study.**
- **My grandmother, Dimakatjo Maggie Leshaba, for the encouragement I have always received. Her dream was to see her only surviving grandchild being educated and independent in life.**
- **My husband, Victor Pilusa, for the moral support, motivation and assistance received throughout the study.**
- **My three daughters, Kgothatso, Amanda and Puseletso for their understanding and motivation during the period of study.**

ACKNOWLEDGEMENTS

I would like to express my greatest gratitude and appreciation to the following people for their support and cooperation during this project:

- My supervisor, Dr J.D. Triegaardt, for her guidance, support and understanding.
- My colleagues, Glen Mhango, Johanna Mokonyama, Mercy Mukhovha and Narena Fick.
- My cousin, Maureen Mailula (Saasa) for her support.
- Francina Thema and Balebogeng Kekana for typing this work and for information search on the internet.
- The three day care centres that participated in the research, **Mahwelereng centre of hope, Thobela centre for the mentally handicapped and Bangwanate disabled centre.**
- Rev. Richard Selepe for the grammatical editing of the dissertation.

DECLARATION

I would like to declare that this dissertation is the result of my independent work, and that all the sources used have been acknowledged by means of complete references.

SUMMARY

TITLE : The impact of mental retardation on family
Functioning

NAME : Ngoakoana Emma Pilusa

SUPERVISOR : Dr. J.D. Triegaardt

DEPARTMENT : Social Work

DEGREE : M.A. (S.W.) Management

The aim of this study is to establish the impact of mental retardation on family functioning. The researcher conducted the research in the Waterberg district of the Limpopo province. The lack of insight on the part of the family on how to cope with such circumstances motivated the researcher to conduct the study. Most families do not have the experience of caring for a mentally handicapped member and therefore need information and support on how to cope with the condition.

The study is qualitative and exploratory in nature. The research question was; “What is the impact of mental retardation on family functioning”? A simple random sampling was used in the study. The sample was selected from all the registered children attending three different day- care centres in the Waterberg district for the past three months prior the investigation. Ten parents (one per household) of children with mental retardation were interviewed using a semi structured interview schedule.

A phenomenological design was used and participants' experiences of family life and reactions to the realization that they have a child with mental retardation are discussed.

Data consisted of audio taped and written interviews. The data collected was transcribed and analyzed according to qualitative methods.

The research findings show that mental retardation has an impact on family functioning. Families had to make new adjustments to accommodate the child and his/her special needs. The researcher recommends that service providers should receive training on issues related to mental retardation so as to provide the much needed services to these families. It was found that the burden of caring, financial constraints, lack of community support, the manner in which the disclosure was handled and the lack of services, all had a negative impact on the family.

KEY WORDS:

- ◆ Mental Retardation
- ◆ Family
- ◆ Family Functioning
- ◆ Disability
- ◆ Support
- ◆ Disclosure
- ◆ Caring
- ◆ Coping
- ◆ Information
- ◆ Skills
- ◆ Needs

OPSOMMING

TITEL	:	Die invloed van verstandelike gestremdheid op die funksionering van die gesin.
NAAM	:	Ngoakoana Emma Pilusa
SUPERVISOR	:	Dr. J.D. Triegaardt
DEPARTEMENT	:	Maatskaplike Werk
GRAAD	:	M.A. (S.W.) Bestuur

Die doel van hierdie navorsing is om die invloed van verstandelike gestremdheid op die funksionering van die gesin vas te stel. Die navorser het die navorsing in die Waterberg distrik van Limpopo Provinsie uitgevoer. Die gebrek aan insig van die gesin om sulke omstandighede te hanteer, was die motivering om die studie aan te pak. Die meeste gesinne en families het nie ondervinding of vaardighede vir die versorging van 'n verstandelik gestremde gesinslid nie, en het daarom inligting en hulp nodig om so 'n toestand te hanteer.

Hierdie navorsing is kwalitatief en ondersoekend van aard. Eenvoudige lukraak steekproef is gebruik vir die navorsing. Die steekproef is geselekteer vanuit al die geregistreerde kinders wat drie verskillende sentra in die Waterberg distrik bygewoon het gedurende die drie maande wat die ondersoek voorafgegaan het. 'n Semi gestruktureerde skedule is gevolg om onderhoude te voer met tien ouers (een per huishouding) van kinders met verstandelike gestremdheid. 'n Fenomenologiese plan is gevolg en die deelnemende ervarings van gesinslewe en die reaksies op die bewuswording dat hulle 'n verstandelik gestremde kind het, is bespreek.

Data bestaan uit oudiologiese en geskrewe onderhoude. Versamelde data is getranskribeer en geanaliseer volgens kwalitatiewe metodes.

Die ondersoekbevindings toon dat verstandelike gestremdheid 'n impak het op gesinsfunksionering. Gesinne is verplig om aanpassings te maak om 'n

kind met spesiale behoeftes te akkomodeer. Die navorser beveel aan dat diensverskaffers opgelei behoort te word in sake rakende verstandelike gestremdheid om sodoende die broodnodige dienste aan die gesinne te kan lewer. Daar is gevind dat die las van versorging, finansiële beperkings, gebrek aan ondersteuning van die gemeenskap en die wyse waarop die onthulling plaasgevind het, 'n negatiewe impak op die gesin het.

Die ondersoekvraag was: “Wat is die invloed van verstandelike gestremdheid op die gesinsfunksionering?” Hierdie vraag was ten volle onderskryf deur die bevindinge van die navorsing.

SLEUTELWOORDE:

- ◆ Verstandelike gestremdheid
- ◆ Gesin
- ◆ Gesinsfunksionering
- ◆ Gestremdheid
- ◆ Ondersteuning
- ◆ Onthulling
- ◆ Versorging
- ◆ Hantering
- ◆ Inligting
- ◆ Vaardighede
- ◆ Behoeftes

TABLE OF CONTENTS

CHAPTER 1

GENERAL ORIENTATION

1.1 INTRODUCTION	1
1.1.1 Classification in terms of degrees of severity	1
1.2 PROBLEM FORMULATION	7
1.3 PURPOSE, GOAL AND OBJECTIVES OF THE RESEARCH	9
1.3.1 Purpose of research	
1.3.2 Goal of the study	
1.3.3 Objectives of the study	
1.4 RESEARCH QUESTION	10
1.5 RESEARCH APPROACH	11
1.6 TYPE OF RESEARCH	11
1.7 RESEARCH DESIGN AND METHODOLOGY	12
1.8 PILOT STUDY	14
1.9 DESCRIPTION OF THE RESEARCH POPULATION, BOUNDARY OF THE SAMPLE AND THE SAMPLING METHOD	15
1.10 ETHICAL ASPECTS	16
1.11 DEFINITION OF KEY CONCEPTS	17
1.11.1 Mental retardation	
1.11.2 Family	
1.11.3 Family functioning	
1.11.4 Limpopo province	
1.12 CONTENTS OF THE RESEARCH REPORT	20

CHAPTER 2	
MENTAL RETARDATION IN THE FAMILY	
2.1 INTRODUCTION	22
2.2 CAUSES OF MENTAL RETARDATION	26
2.2.1 Genetic Factors	
2.2.2 Biological Factors	
2.2.3 Environmental Factors	
2.3 THE PREVALENCE OF MENTAL RETARDATION	29
2.4 TREATMENTS AND EDUCATION	29
2.5 FAMILY NEEDS	31
2.5.1 A comprehensive system of care.	
2.5.2 Information	
2.5.3 Skills	
2.5.4 Support	
2.5.4.1 Informal and formal support networks	
2.5.4.2 Benefits of social support	
2.5.4.3 Dimensions of social support	
2.5.4.4 Implications for intervention	
2.5.5 Meaningful Involvement in Intervention	
2.5.6 Managing the Process of Individual and Familial Adaptation.	
2.5.7 Contacts with Other Families	
2.5.8 Assistance in Handling Problems in the Larger Society.	
2.6 MENTAL RETARDATION AS A FAMILY SYSTEMS PHENOMENON	36
2.6.1 Parental Sub-System	
2.6.2 Marital Sub-System	
2.6.3 The Siblings Sub-System	
2.6.4 Extra Familial Subsystem	
2.7 MAJOR FUNCTIONS OF A FAMILY	40
2.8 PARENTAL REACTIONS TO THE HANDICAP	41
2.8.1 Uniqueness of each family	
2.8.2 Generalized expectations associated with the birth of a child.	
2.8.3 Generalized reactions to the birth of a child with disabling conditions	
2.8.4 Parental expectations related to the type and degree of disability	

2.9 GUIDELINES FOR THE DISCLOSURE OF DIAGNOSIS	47
2.10 THE IMPACT OF DISABILITIES ON SIBLINGS.	49
2.10.1 Positive reactions	
2.10.2 Negative reactions	
2.11 SPECIAL NEEDS OF SIBLINGS	50
2.11.1 Mature, informed parents	
2.11.2 Information, Skills and Support groups	
2.11.3 Self-identity	
2.11.4 Planned involvement	
2.11.5 Future plans	
2.11.6 Close and meaningful relationship	
2.12 EXTENDED FAMILY'S REACTIONS	52
2.13 THE IMPACT OF CARING	53
2.14 THE NEEDS OF CARERS	54
2.14.1 The need for a break and practical support	
2.14.2 Need for information.	
2.14.3 The need for training in caring skills.	
2.14.4 The need for emotional support	
2.14.5 The need for improved communication and problem solving.	
2.14.6 The need for stress management.	
2.15. CHRONIC STRESSES UNIQUE TO FAMILIES WITH A CHILD WHO HAS A MENTAL HANDICAP	55
2.15.1 Stigmatized social interactions	
2.15.2 Increased and prolonged burden of care	
2.15.3 Lack of information	
2.15.4 Financial concerns	
2.16 COPING AND ADAPTATION	57
2.16.1 The process of family adaptation	
2.16.1.1 Defence	
2.16.1.2 Coping	
2.16.1.2.1 Individual and familial coping strategies	
2.16.1.3 Resilience	
2.17 CONCLUSION	59
CHAPTER 3	

ANALYSIS AND INTERPRETATION OF DATA

3.1 Introduction	61
3.2 Research methodology	61
3.3 Research findings	62
3.3.1 Understanding mental retardation	62
3.3.2 Disclosure of the disability	63
3.3.3 Reactions to the disclosure of the disability	65
3.3.3.1 Parental reactions	
3.3.3.2 Siblings reactions	
3.3.3.3 Extended family members reactions	
3.3.4 Financial implications	68
3.3.5 The impact of care giving	70
3.3.6 Services and support	71
3.3.6.1 Services	
3.3.6.2 Support	
3.3.7 Coping effectiveness	75
3.4 Summary	76

CHAPTER 4

CONCLUSION AND RECOMMENDATIONS

4.1 Introduction	78
4.2 Summary	78
4.3 Conclusions	79
4.4 Recommendations	80
4.5 Future research	80
References	81
Annexure	88
Annexure 1 – Permission to conduct research	89
Annexure 2 – consent form	90
Annexure 3 – semi-structured interview schedule	91

1.1 INTRODUCTION

Disability is defined by the World Health Organization (in Oliver and Sapey, 1999: 38) as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. Mental retardation is one form of disability, and for the purpose of this study, the researcher will confine the investigation to mental retardation. Mental retardation and mental handicap will be used interchangeably by the researcher through out the study as various authors also use different terminology to refer to people with mental retardation.

According to Nicholas (2003: 307) mental retardation is a label given to anyone who has been assessed to have an IQ score of 70 or less on a psychological test of intelligence. However, mental retardation not only affects performance on tests of general mental functioning, but places limitations on one's capacity for self-care, language and speech ability, social educability and vocational proficiency. According to Batshaw (1997:344) there is a general agreement that a person with mental retardation must have significantly sub average intellectual functioning; an impairment resulting from an injury, disease, or abnormality that existed before age 18; and an impairment in adaptive abilities. Mental retardation is divided into four degrees of severity; mild, moderate, severe and profound mental retardation.

1.1.1 CLASSIFICATION IN TERMS OF DEGREES OF SEVERITY

- ◆ The following table lists the degrees of severity of mental retardation with their corresponding level of functioning (Nicholas, 2003: 307-308).

CATEGORY	IQ RANGE	LEVEL OF FUNCTIONING
Mild mental retardation	50-70	Individuals educable. Can be minimally self supporting. Can acquire basic social and vocational skills.

Moderate mental retardation	35-49	They are trainable. Able to perform academic activities comparable to a child in grade two.
Severe mental retardation	20-34	They are seriously impaired in their motor and speech development, and only learn basic language and practice hygiene after age six. Usually permanently dependent on others and therefore spend their lives with family, in community homes or in institutions.
Profound mental retardation	20	Fully reliant on caregivers. Often diagnosed with a neurological disorder and epilepsy, spasticity and mutism. Locomotive, speech and self care skills are impaired to the point that makes institutionalization inevitable.

Early references to persons with intellectual impairments have been traced to the Romans, who sometimes kept “fools” for the amusement of the household and its guests (DSM–IV 1994:230).

According to DSM-IV (1994:230-231) the prevailing misunderstanding and mistreatment of those with mental retardation began to change toward the end of the 18th century. Until the mid 19th century, children and adults who today would be diagnosed as having mental retardation were often lumped together with

those suffering from mental disorders or mental conditions.

Causative factors in mental retardation include genetic, biological and environmental factors. The more severe forms of retardation often result from genetic or biological disorders. In most cases, the causes are unknown (Nicholas, 2003:308). According to Dell Orto and Marinelli (1995: 458-459) three types of prevention are commonly referred to in the literature; primary, secondary and tertiary. Primary strategies prevent the occurrence of mental retardation, secondary strategies prevent the full expression of the disorder and tertiary strategies are directed at optimizing the potential of a person who has already manifested mental retardation. Primary and secondary prevention efforts are commonly focused before conception, before birth, or shortly after birth. Prior to or after conception, the likelihood of some chromosomal and gene abnormalities can be determined through family information, physical examinations and chromosomal studies. Early intervention and special education are forms of tertiary prevention aimed at the infant and young child.

Some people suffering from mental retardation are institutionalized while others live with their families. According to Burke and Cigno (1996:29) it seems probable that most caring is likely to take place within the immediate family household. With deinstitutionalization, more and more people are cared for in their homes. It is therefore important to realize that disabled people do not function in isolation.

According to Seligman and Darling (1989:7) people live within a context of the family and when something happens to one member of the family, everyone is affected.

Within a family there are four sub-systems, namely, marital, parental siblings and extra familial (extended family and friends). When a professional, for example, intervenes in one sub-system, consideration of other systems should be made.

The birth of a child with mental retardation can be a traumatic and shattering

event for a family. The feeling of grief and loss that the family goes through is caused by the realization that the anticipated, normal child they waited for nine months was never born. These parents experience chronic sorrow which affects their reaction to their child and affects overall coping ability (Oliver and Sapey, 1999:79-80). According to Marsh (1992:14-15) there is much evidence that family members experience a range of powerful emotions in response to a diagnosis of mental retardation, including denial, shock, anger, grief, guilt, embarrassment, depression, withdrawal, ambivalence, disillusionment, and fear. Alper, Schloss and Schloss (1994:59) note that parents do not accept a diagnosis and continue shopping for a new diagnosis or cure. They may also minimize the seriousness of the disability as they develop coping mechanisms. Parents may experience regret about some of the things they think they should not have done. They feel helpless and unable to change the disabling condition, and this helplessness often develops into either anger or pity.

The White Paper for Social Welfare (1997:58) states that the financial, social and emotional resources of families are also taxed when they have to care for members who have special needs and problems. Marsh (1992:16) indicated that as a consequence of the mental retardation of a family member, families have a number of central needs:

- For a comprehensive system of care for their relative;
- For information about the disability;
- About intervention and about services and resources;
- For skills to cope with the mental retardation and its sequelae for the family;
- For support;
- For meaningful involvement in intervention;
- For managing the process of individual and familial adaptation;
- For contact with other families and
- For assistance in handling problems within the larger society.

The researcher conducted the study because she observed problems from her

daily contacts with families of people with mental retardation. Problems such as learning difficulties, one or both parents denying the child, blaming one another, divorce and guilt feelings among parents, were attended to by the researcher as part of social work. Schools and day care centres often referred such cases needing social work intervention.

The lack of insight, on the part of the family, on how to cope, also motivated the researcher to conduct the study. Families do not have the experience of caring for a mentally handicapped member and therefore need information and support to cope with the condition. Lea and Foster (1990: 219) state that many researchers working in this area have noted that social support is instrumental in parent's adjustment to and acceptance of the child. They propose a distinction between formal (or public) and informal (or intimate) sources of support. The former sources include the general public, medical professionals and social services, while the latter include spouse, siblings, family and friends.

With the exception of those individuals who have had a mentally handicapped person in their own family, most people have had little contact with people with mental retardation (Webb and Tossell, 1991:97). According to Lea and Foster (1990: 217-220) a number of researchers have postulated that the presence of a defective child in the family will have an effect on the parent's marital relationship.

The second factor which has received some attention from investigators is that of religious conviction. Parents interpret the event positively or negatively, that is, either being blessed or punished by God depending on their frame of reference. The third set of factors referred to by researchers pertains to the personal characteristics of the handicapped child. The primary characteristics identified as influencing the degree of stress parents experience and their ability to cope include the child's age, diagnosed condition, physical appearance, degree of retardation, number of associated handicaps and level of social skills. It would seem that the closer the child approximates normality in terms of appearance

and social behaviour, the less stress the parents experience.

A child with a disability is usually the only family member with a disability, or at least with that particular disability. Thus, the stigma of the disability may be experienced both from outside and within the family (Olkin, 1999:95). The White Paper on Transforming Public Service delivery (1997:19) notes that information is one of the most powerful tools at the customer's disposal in exercising his or her right to good service. The consultation process should also be used to find out what customers and potential customers need to know, and then to work out how, where and when the information can best be provided.

The provincial manager of the field on disability in Limpopo province supported the personal interest shown by the researcher on the subject as it is also work related. The results of the study will provide guidance to social workers and other professionals on how to provide necessary services needed by people with mental retardation and their families. This is in line with the White Paper for Social Welfare (1997:61) that indicated that families in need should receive comprehensive protection and support from the State and organizations of civil society.

The researcher was able to talk to the provincial manager of the Office on the Status of People living with Disabilities, Mr. Selaelo Makgato, who mentioned that, the study will not only benefit the Waterberg district but the entire Province since there was no research conducted in the area of mental retardation in the Province. The Provincial director of Limpopo Mental Health Society indicated that families of children with mental retardation have been neglected and it is hoped that the study will help all service providers with the provision of appropriate services in the district. The Mental Health Society will therefore utilize the findings of the study to the benefit of people with mental retardation and their families. The society is rendering services to eight (8) centres/units in the Waterberg district.

The researcher is currently coordinating the field on disability in the Department of Health and Social Development - Waterberg district, Limpopo province, and the results of the study will help in the development of relevant intervention programs in the district.

It was therefore, the intention of the researcher to explore the impact that mental retardation has on family functioning in an attempt to enhance professional intervention.

1.2 PROBLEM FORMULATION

This study proposed to establish the impact of mental retardation on family functioning.

The researcher observed that mentally retarded children are born to families in every strata of society, to the very poor and the very rich, the illiterate and the highly educated.

Alper, *et al.* (1994:58) note that most prospective parents are faced with excitement, the task of planning for the future and learning the meaning of being parents.

Birth, for most families, is a time for rejoicing, for pride, for gathering together loved ones and sharing with them in the celebration of a renewal of life. For other families, birth may not be as joyful an occasion. On the contrary it may be a time for tears, despair, confusion and fear for those who become parents of children with mental retardation. It may demand a totally new life of all involved, full of mysterious and unique problems (Alper, *et al.*, 1994:58). Hales (1996: 58) states that the birth of a baby changes the ethos of the members of any family. Parents have to develop a new routine, siblings have to learn to accept the new addition to the family and often they may discover feelings of loss which come as a result of parents being so involved with the baby. When the new baby is born with a disability there can be a different sense of loss for the parents as they discover that their expectations for the

child have to be modified.

Those who become parents of children with mental retardation need to make huge emotional adjustments as they endeavour to come to terms with the feelings brought by a sense of overwhelming disappointment and loss. They experience guilt and shame at having produced a child with special needs because it is not seen as perfect by the rest of society (Webb and Tossel, 1991:101). The situation is even more difficult in communities where having a handicapped child is seen to represent a divine punishment and the family will have to carry the stigma. Some families are embarrassed by the child and consider hiding him/her.

One of the primary stressors of life with a severely handicapped child is day to day care, feeding, dressing and toileting. Often the emotional and physical demands of that care leave the caregiver with no strength for other relationships or activities (Alper, *et al.*, 1994: 74). The White Paper on an Integrated Disability Strategy (1997:9) mentions that experiences in the United States, United Kingdom and Europe have shown that a move away from institutionalization often results in people with mental disabilities becoming homeless and living on the streets, with little or no community support.

One area in which disablement makes its impact is that of family finances. Disability usually involves extra expenses, for example, medical care, special school, teaching aid and domestic help. For an unemployed single mother who must take care of her child, poverty is almost inevitable. Another area of concern centres on the reactions and adaptation of siblings of the child with a handicap. Younger children with a disabled sibling may take the role of an older child, assuming increased responsibility than would a child his/her age in a family without a child with special needs. For a younger disabled child,

parents may tend to overprotect this child to the point of neglecting other children in the family (Helton and Jackson, 1997: 126).

According to the South African census (1996) there were 22 578 persons with a mental handicap in Limpopo province, 192 553 in the Republic of South Africa as at October 1996. Seven percent (7%) of the South African population was classified as disabled. Forty percent (40%) of black/Africans were found to be the highest in terms of age and mental handicap. The census report for 2001 reported 26 223 people with a mental handicap in Limpopo province and 206 451 in the Republic of South Africa (Statistics South Africa, 2001). The number of people with a mental handicap has grown by 3 645 in Limpopo province between 1996 and 2001.

Nothing prepares parents and other family members for the arrival of a mentally retarded child. All parents see themselves in their own children and a mentally retarded child fails to reflect the image that its parents project.

Family members experience a range of powerful emotions in response to a diagnosis of mental retardation, including denial, shock, anger, guilt, embarrassment, depression, withdrawal, ambivalence, disillusionment, and fear.

The focus of the investigation was on the impact that mental retardation has on family functioning and the unit of analysis for the study was the individual parent (one per household) of persons with mental retardation.

1.3 PURPOSE, GOAL AND OBJECTIVES OF THE RESEARCH

1.3.1 PURPOSE OF RESEARCH

The Reader's Digest Oxford Complete Word finder (1996: 1240) defines a purpose as the reason for which something is done or made. Exploratory research was conducted to gain insight into the impact of mental retardation on family functioning. Grinnell (1993: 136) indicated that an

exploratory study explores a research question about which little is as yet known.

1.3.2 GOAL OF THE STUDY

The terms goal, purpose and aim implies the broader, more abstract conception of the end towards which effort is directed (Fouche, 2002: 107). The researcher's goal in this study was to investigate the impact that mental retardation has on family functioning.

1.3.3 OBJECTIVES OF THE STUDY

Objectives denote the more concrete, measurable and speedily attainable conception of the end towards which effort or ambition is directed. It is the steps one has to take within a certain time span in order to attain the dream (Fouche, 2002: 107-108). The objectives in this study were as follows:

- ◆ To provide a broad theoretical framework on mental retardation and family functioning.
- ◆ To explore the impact of mental retardation on family functioning in the Waterberg district, Limpopo province.
- ◆ To make recommendations based on the results of the study on the provision of services to families of persons with mental retardation.

1.4 RESEARCH QUESTION

Research always commences with one or more questions or hypothesis. Questions are posed about the nature of real situations while hypotheses are statements about how things can be. A good research question is one that can be answered by collecting data and whose answer cannot be foreseen prior to the collection of data (De Vos, 1998: 115-116). The researcher decided on a research question because it is more relevant in an exploratory study than a hypothesis. The research question in this study was as follows:

What is the impact of mental retardation on family functioning in the Waterberg district, Limpopo province?

1.5 RESEARCH APPROACH

Fouche and Delpont (2002: 79) identified two types of approaches namely, the qualitative and the quantitative approaches. They define qualitative research as research that elicits participant's accounts of meaning, experience, or perceptions. The qualitative researcher is therefore concerned with understanding rather than explanation, non-statistical methods and small samples often purposively selected. In this study the researcher made use of the qualitative approach.

The researcher therefore made an effort to understand and interpret the meaning that parents put forward as representing their experiences and feelings regarding their children's handicap and how it impacts on the functioning of the family.

1.6 TYPE OF RESEARCH

Looking at the nature of the research the applied type of research was found to be the most suitable type. Applied research is defined by Bless and Higson-Smith (2000:153) as social research which has the primary aim of finding solutions to specific concerns or problems facing particular groups of people by applying models or theories developed through basic social research. According to Neuman (2000: 23), applied research is aimed at solving specific policy problems or at helping practitioners accomplish tasks. The recommendations of the study will serve as a guideline to professionals on how to help families of people with mental retardation. This study is therefore an applied type of research.

1.7 RESEARCH DESIGN AND METHODOLOGY

The qualitative research strategy differs inherently from the quantitative research design in that it does not usually provide the researcher with a step-by-step plan or fixed recipe to follow (Fouche, 2002: 272).

The researcher followed the phenomenological design for this study. This design aims to understand and interpret the meaning that subjects give to their everyday lives. As interviews were conducted, the researcher was in a position to understand participant's experience of family life or reactions to the realization that they have a child with mental retardation, as expressed in their own words.

A research project stands or falls on the quality of facts on which it is based. The importance of constructing an appropriate and accurate instrument for measuring and collecting data is an absolute necessity (Bless and Higson-Smith, 2000: 97).

As a qualitative approach was followed, the researcher opted for a semi-structured interview. According to Greeff (2002: 292), interviewing is the predominant mode of data or information collection in qualitative research.

The semi-structured interview gives the researcher and participants much more flexibility and this will allow the researcher an opportunity to probe further on issues emerging during the interview, and the participant is able to give a fuller picture. The participant shares more closely in the direction the interview takes and he/she can introduce an issue the researcher had not thought of (Greeff, 2002: 302).

Data analysis is the process of bringing order, structure and meaning to the mass of collected data (De Vos, 2002: 339). Qualitative data analysis is therefore a search for general statements about relationships among categories of data.

In this investigation, the researcher made notes and recorded all the interviews on a cassette. Transcripts from ten interviews were analyzed by reading through them, organizing the data, generating categories, themes and patterns and the writing of a report. The researcher in the analysis of data followed the following steps:

◆ **Collecting and recording data**

According to De Vos (2002:340) the researcher should plan for recording in a systematic manner that is appropriate and will facilitate analysis, before data collection commences.

Data collection was done using the semi-structured interview schedule and notes were kept in an organized manner, clearly marked and intact. The researcher utilized a tape recorder and labelled all the audiotapes for easy access and completeness of the data.

◆ **Managing data**

This is the first step in data analysis away from the site (De Vos, 2002: 343). Data was organized into manageable units to allow for manual analysis.

◆ **Reading and writing memos**

The researcher is expected to read the transcripts several times, trying to get a sense of the interview as a whole before breaking it into parts (De Vos, 2002: 343). In this investigation the researcher read through the data to familiarize her with the data and made notes of the key concepts or ideas found in the transcripts.

◆ **Describing, classifying and interpreting**

The process involves noting regularities in the setting or people chosen for the study (De Vos, 2002: 344). Classifying means taking the text apart and looking for categories, themes or dimensions of information. Interpretation

involves making sense of the data, the lessons learned. The researcher searched for explanations for these data and the linkages among them.

◆ **Representing and visualizing**

In the final phase the researcher presents the data, a packaging of what was found in text, tabular or figure form (De Vos, 2002: 344). The researcher presented the results from the investigation in a text form.

1.8 PILOT STUDY

1.8.1 Pilot test

Pilot study is defined by Bless and Higson-Smith (2000: 155) as a small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequately appropriate.

The New Dictionary of Social Work (1995:45) defines the pilot study as a process whereby the research design for a prospective survey is tested. Grinnell (1993:446) agrees by saying that a pilot study is the administration of a measuring instrument to a group who will not be included in the study to determine difficulties respondents may have in answering questions and the general impression given by the instrument. A pilot study is therefore designed to determine whether the intervention will work out or not.

In this study, the researcher tested the semi-structured interview schedule on two individual parents (from different families) who did not form part of the final sample.

1.8.2 Feasibility of the study

De Vos and Fouche (1998: 101) note that all proposals address the resources that are available and that are needed to carry out the study. The researcher is coordinating services for people living with disabilities at

Waterberg district and this study easily formed part of the researcher's daily activities. The recommendations of the study will be made available to the employer so that social workers can use them to improve service delivery. A letter of permission to conduct the study was obtained from the Department of Health and Social Development, Limpopo Province and the organizations for children with mental retardation. (Annexure 1).

1.9 DESCRIPTION OF THE RESEARCH POPULATION, BOUNDARY OF THE SAMPLE AND THE SAMPLING METHOD.

Population is a specific pool of cases that need to be studied (Neuman, 2000:210). Bless and Higson-Smith (2000: 85) defines a population as the set of elements that the research focuses on and to which the obtained results should be generalized. The population in this study comprised of families who have children with mental retardation who also attend day care centres in the Waterberg district, Limpopo province.

A sample is a subset of a population of individuals, objects, or events chosen to participate in or to be considered in a study. Probability sampling is based on randomization, while non-probability sampling is done without randomization (Strydom and Venter, 2002:203). For the purpose of this study the researcher made use of probability sampling and a simple random sampling was followed. According to Strydom and Venter (2002:204) when a simple random sampling is followed, each individual case in the population has an equal chance to be selected.

In this case, ten individual parents (one per household) of children who have mental retardation were included in the sample. The ten individual parents were interviewed using the semi-structured interview schedule at Waterberg district, Limpopo province. They were selected using a probability; simple random sampling and the sample was drawn from a list of all the registered children in three day care centres for mentally retarded

children in the Waterberg district. The registered children have been attending the day care centres for the past three months before the interview.

1.10 ETHICAL ASPECTS

According to Babbie (1998:438) if one is going to do social scientific research, he/she needs to be aware of the general agreements shared by researchers about what's proper and improper in the conduct of scientific inquiry. The following were some of the most important ethical aspects which were considered in this research.

1.10.1 HARM TO EXPERIMENTAL SUBJECTS

The nature of the investigation may lead to emotional harm. The researcher therefore informed respondents beforehand about the potential impact of the investigation. Subjects in this investigation were informed that they are part of a research project to avoid creating unnecessary expectations as they may have thought that the researcher had a package of solutions for their problems. The researcher arranged for a debriefing session for all the participants. This was done in the form of a structured group that allowed for each group member to ventilate their feelings and reactions to the interview. Debriefing was done within seventy (72) hours of the interview.

1.10.2 INFORMED CONSENT

Obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed,

as well as the credibility of the researcher, be rendered to potential subjects or their legal representatives (Strydom, 2002:65).

The researcher informed participants of the purpose of the research, the time that will be needed to conduct the interview and all other important activities required to carry out the study. The researcher also provided respondents with a consent form which outlined what the research was all about. This was done prior to the interview.

1.10.3 VIOLATION OF PRIVACY/ANONYMITY/CONFIDENTIALITY

Privacy is defined by Strydom (2002:67) as that which normally is not intended for others to observe or to analyze. The researcher did not use any hidden apparatus in this investigation. Permission to use a tape recorder was sought from participants. Individuals were not singled out in the research report for readers of the report to identify them. Their identity was not revealed. The researcher did not reveal any confidential information obtained during the course of the study without the consent of the participant.

1.10.4 DECEPTION OF SUBJECTS AND /OR RESPONDENTS

According to Strydom (2002: 66) deception involves withholding information, or offering incorrect information in order to ensure participation of subjects when they would otherwise possibly have refused it. The researcher informed all the respondents of the goal of the research so that they should participate freely. The researcher also identified herself to the respondents correctly as a student from the University of Pretoria.

1.11 DEFINITION OF KEY CONCEPTS

1.11.1 MENTAL RETARDATION

According to the American Association on Mental Retardation, quoted

in the policy guideline for psychosocial rehabilitation of persons affected by mental disability (2000: ii), mental retardation refers to substantial deficits in certain aspects of personal competence. It is manifested as significantly sub average abilities in cognitive functioning, accompanied by deficits in adaptive skills.

Mash & Wolfe (2002:39) refer to people with a mental handicap as people with a significantly sub-average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skills areas: communication, self care, home living, social or interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health and safety. The onset must occur before age 18 years. Four degrees of severity can be specified, reflecting the level of intellectual impairment: mild, moderate, severe and profound.

The Mental Health Care Act (2002:12) defines severe or profound intellectual disability as a range of intellectual functioning extending from partial self-maintenance under close supervision, together with limited self protection skills in a controlled environment through limited self care and requiring constant aid and supervision, to severely restrict sensory and motor functioning and requiring nursing care.

According to the researcher, mental retardation is a permanent intellectual impairment that manifests itself at an early age. It is not something a person has or something a person is. It is not a medical disorder or a mental disorder. It is a particular state of functioning that begins in childhood and is characterized by limitations in both intelligence and adaptive skills. Mental retardation is therefore a result of the tension between a person's capabilities and limitations, and the prevailing demands and values of society.

1.11.2 FAMILY

According to The New Book of Knowledge (1995:37) the family is the most important group to which most people ever belong. Most people, but not all of us, are born to parents who have set up a home and are ready to welcome children. There are many different kinds of families besides the mother-father-children family. Some of the other kinds are families without children, families made up of one parent and a child or children and families with a parent, a step-parent, and children. A family is therefore defined as a small group of people related to one another by birth, adoption, or marriage, sharing a household, and caring for one another.

The White Paper for Social Welfare (1997:93) notes that the family is comprised of individuals who either by contract or agreement chooses to live together intimately and function as a unit in a social and economic system. The family is the primary social unit which ideally provides care, nurturing and socialization for its members. It seeks to provide them with physical, economic, emotional, social, cultural and spiritual security.

According to the researcher a family is a group of related people and serves as a unit for the care taking of its members.

1.11.3 FAMILY FUNCTIONING

According to Kavanagh (1992: 258), family functioning is defined as the expected good relationship and interaction occurring amongst the family members.

A disabled child residing with the family, especially a severely impaired child, can increase consumptive demands without proportionately increasing the family's productive capability. As a result, a disabled child residing in the least restrictive environment, namely, the family may unintentionally generate a restrictive environment for all family members.

It is furthermore conceivable that a disabled child can change the family's self-identity, reduce its earning capacity, restrict its recreational and social activities, and affect career decisions (Seligman and Darling, 1989:10).

According to Hornby (1994:36), all families differ regarding the priorities they attach to the various functions and with respect to which family members are assigned to perform specific roles within the family. Family functions refer to the different types of needs for which the family provides such as economic, physical care, recuperation, socialization, affection, self-definition, educational and vocational needs. However, caring for a member of the family with a disability is likely to affect these family functions in certain ways.

Family functioning is viewed by the researcher as the appropriate way in which members of the family should relate, interact and share life experiences in a harmonious way.

1.11.4 LIMPOPO PROVINCE

The Constitution of the Republic of South Africa, Act 108 of 1996, section 103, indicates that the Republic of South Africa is divided into nine provinces. Limpopo, formally known as the Northern Province, is one of the nine provinces. The Constitution further stated that the boundaries of the provinces are those that existed when the Constitution took effect.

1.12 CONTENTS OF THE RESEARCH REPORT

The research report is the final product of the long research process that has been completed. Without the completed report there is no indication that any research has been done (Strydom, 2002: 248). The report in this study consists of four chapters which are divided as follows:

CHAPTER 1

This chapter will include the introduction, goals and objectives of the study, research methodology and definition of concepts.

CHAPTER 2

The theoretical framework on mental retardation and family functioning will be presented in this chapter. This will include the causes of mental retardation, treatment, reactions of family members, family needs, functions of the family, guidelines for the disclosure of diagnosis, impact of caring, needs of carers and coping and adaptation.

CHAPTER 3

In this chapter the researcher focused on the empirical study, the analysis and the interpretation of data. The findings were presented in a text form.

CHAPTER 4

The final chapter will present the conclusions and recommendations of the study which are based on the literature review and the empirical study.

CHAPTER TWO

MENTAL RETARDATION IN THE FAMILY

2.1 INTRODUCTION

The arrival of a new baby has a massive effect on any family, but there is a qualitative difference when the baby has a disability or special needs. Most parents expect that their children will be attractive, smart, and socially successful (Wicks-Nelson and Israel, 1997: 260).

For many years parents of children with special needs were left largely unsupported and received little help from professionals. The focus was predominantly on the child (Dale, 1996: 8). The researcher will provide the historical background of mental retardation in an attempt to explain the subject further.

According to Marsh (1992: 21), the historical context provides an essential dimension for understanding mental retardation in the present. Three evolutionary phases in the history of mental retardation have been identified (Marsh: 1992: 21-24).

- The era of institutionalization and segregation.
- The era of deinstitutionalization and community development.
- The current era of community membership, which is marked by an emphasis on functional supports to enhance community integration, quality of life and individualization.

Each of these eras has had an impact on families as well as people with mental retardation.

2.1.1 The era of institutionalization and segregation

Historically people with mental retardation have been devalued or neglected, receiving inferior opportunities for learning and participating in society. Such individuals have been largely assigned places in society that are essentially devoid of value and esteem. Many families who served as

primary caregivers for their relatives in the past were subjected to the pervasive devaluation and segregation that often accompanied a diagnosis of mental retardation. Following World War II, there was increasing recognition of the debilitating and dehumanizing effects of large institutions.

2.1.2 The era of deinstitutionalization and community development

While the reasons for deinstitutionalization are complex and vary across national political contexts, one common factor is the embrace by advocates of the concept of normalization and the rejection of segregation of people with intellectual disabilities from the rest of society. Institutions became both the symbol and instrument of separation and the consequent stigmatization of people with intellectual disabilities. Closing the institutions is the means by which residents can obtain the benefits accruing to all of living and participating in normal communities (Mansell and Ericsson, 1996: 9).

Marsh (1992: 23) has identified a theoretical process that defines deinstitutionalization:

- Preventing institutional admissions by developing alternative community-based services.
- Returning institutional residents to community settings following preparations for community life and
- Maintaining an environment that protects the civil rights of residents who remain institutionalized and facilitates their return to the community. During this era, the development of community resources has resulted in improved services and support for the lifetime community residents as well as those who were transferred from institutions.

2.1.3 The current era of community membership

The White Paper on an Integrated Disability Strategy (1997: 5-6) noted that the majority of people with disabilities in South Africa have been excluded from the mainstream of society and have thus been prevented from accessing fundamental social, political and economic rights. The exclusion experienced by people with disabilities and their families is the result of a range of factors including;

- The political and economic inequalities of the apartheid system;
- Social attitudes which have perpetuated stereotypes of disabled people as dependent and in need of care;
- A discriminatory and weak legislative framework which has sanctioned and reinforced exclusionary barriers.

The present era is distinguished by a commitment to full community participation and integration for all people with disabilities, including those with the most severe limitations. The overarching objective is to build a community that respects the rights of people with disabilities, to dignity, status, respect, freedom, and security; that affirms the potential of all citizens, including those with disabilities, for growth and self actualization; and that maximizes opportunities for them to contribute their talents and gift. Mansell and Ericsson (1996: 11-12) also identified the following four major attributes of the new paradigm;

- The primacy of the community. The new paradigm rests on the fundamental belief that people with disabilities can and should live in communities as full participating members. The role of service providers is to identify and remove barriers to full community participation.
- Emphasis on relationships. People with disabilities have the same needs for social connectedness as do any other persons living in the communities. The fundamental task of service providers is to ensure that people make social connections and become fully integrated into the life of the community. These social relationships make it possible

for people with disabilities to make use of natural supports in their communities.

- Person-centred support. This view of services for people with disabilities eschews the notion of fitting people into available programme ‘slots’. People with disabilities should live in homes, not in programmes and they should work in jobs, not in workshops.
- Choice and control. The new paradigm rejects the notion that the professionals know best. Instead, it recognizes the right of consumers to make choices about where and with whom they live, how they spend their time and how they want their supports configured. The task for community support workers is to assist consumers in making informed choices and to ensure that meaningful choices are available.

2.1.4 Families and the historical context

Each of these evolutionary phases has had an impact on families. During the institutional era, families whose members resided in institutions were often estranged both from the system and from their relatives. Those whose family members remained at home were often faced with pervasive segregation and stigmatization.

During the era of deinstitutionalization and community development, families benefited from improved community services and resources for their relatives, although there was little attention to the impact of this movement on families or to their needs, feelings and concerns.

Finally, during the era of full community membership, families are likely to benefit indirectly from improved services for their relative; they are also likely to benefit directly from the availability of family - oriented services. Marsh (1992: 141) further noted that in this era of community integration, the most normalized residential setting for people with mental retardation is the family.

It is important to note that families have always been more prevalent than institutions as caregivers for people with disabilities. Thus, although families have been affected by the vicissitudes of history, their needs have remained essentially the same; to receive acknowledgement and to have access to a comprehensive and coordinated system of community-based care for their relative; and to reside in a society that accepts people with disabilities and assists them in fulfilling their potential.

The history of people with mental retardation has also been a history of their families. The perceptions, attitudes, treatments, values, beliefs, services, resources, and ideologies that have defined and circumscribed the lives of people with mental retardation throughout history have had a commensurate impact on their families (Marsh, 1992: 25).

2.2 CAUSES OF MENTAL RETARDATION

According to Nicholas (2003: 308), causative factors in mental retardation include genetic, biological and environmental factors. The more severe forms of retardation often result from genetic or biological disorders. In most cases, the causes are unknown. Because of the severity of mental retardation, and the heavy burden that it imposes on affected individuals, their families and the health services, prevention is extremely important (World Health Report, 2001: 1). Lea and Foster (1990: 187) noted that a detailed knowledge of causative factors of mental handicap in a community forms the basis for instituting preventative measures. This statement is supported by the World Health Report (2001:1) by saying that in view of the variety of different etiologies of mental retardation, preventive action must be targeted to specific causative factors. Preventative strategies at each of the three levels (genetic, biological and environmental) can work to curb the incidence of mental retardation (Nicholas, 2003: 308-310).

2.2.1 GENETIC FACTORS

More than a hundred genetic causes of mental retardation have been identified. For instance, Down's syndrome, fragile x syndrome and phenylke tonuria are genetic disorders usually characterized by moderate to severe mental retardation. Down's syndrome is characterized by an abnormality of the 21st chromosomal pair. Fragile x syndrome results from a mutation at a "fragile" site on the X chromosome, whereas phenylke tonuria is a result of a metabolic defect involving phenylalanine, an essential amino acid.

An older than average age mother and exposure to x-ray radiation are predisposing factors causing increased incidence of chromosomal disorders. According to Wicks-Nelson and Israel (1997: 249) it is believed that advancing maternal age is related to failure of the chromosome pairs to divide in meiosis, with trisomy 21 being a result. Prevention at this level focuses primarily on the genetic counselling and education of prospective parents. The Choice of Termination of Pregnancy Act, 1996 (Act No. 92 of 1996) provides parents with a choice to terminate the pregnancy if early identification of genetic abnormalities occurs.

2.2.2 BIOLOGICAL FACTORS

According to Nicholas (2003: 309-310) mental retardation can result from in-utero exposure of the foetus to diseases such as rubella, syphilis, and acquired immune deficiency syndrome. Excessive consumption of alcohol by the pregnant mother may also result in foetal alcohol syndrome in the child. Birth trauma and injury resulting in severe lack of oxygen to the brain, called anoxia, can result in neural cell death, causing permanent brain damage.

Prevention at this level focuses primarily on the education of prospective parents regarding the mother's physical, psychological and nutritional health during pregnancy. Immunization is important to prevent maternal

rubella. A healthy diet and recommended supplements can reduce the percentage chance of abnormalities in neurological development in the fetus. Education about the dangers of excessive alcohol, drug and nicotine consumption also constitutes important primary prevention.

2.2.3 ENVIRONMENTAL FACTORS

Deprivation of stimulation is the primary environmental precursor of delayed development, which can lead to cognitive disabilities. Mild mental retardation is significantly prevalent in low socio-economic groups, where cognitive stimulation is limited. Such environments are often characterized by exposure to poor medical and nutritional care, family instability and inadequate caregivers. Wicks-Nelson and Israel (1997: 254) on the other hand noted that, severe social isolation can result in serious retardation, but even a milder lack of stimulation might lead to intellectual deficits. Educationally and economically deprived parents may lack skills and knowledge to stimulate children's language and cognitive development. Parents of any social class who are stressed and lacking social support undoubtedly find it difficult to provide their offspring with continuous sustenance and achievement motivation.

Prevention at this level needs to occur in various areas, e.g. socio-political petitioning for government to alleviate poverty and lack of basic necessities, provision of basic nutrition and health care for newborns, community education of parents, and provision of adequate schooling facilities.

The World Health Organization (2001:1) came up with the following methods of prevention;

- Iodization of salt to prevent iodine-deficiency mental retardation (cretinism);

- Abstinence from alcohol by pregnant women to avoid foetal alcohol syndrome;
- Dietary control to prevent mental retardation in people with phenylketonuria'
- Environmental control to prevent mental retardation due to poisoning from heavy metals such as lead;
- Prenatal genetic testing to detect certain forms of mental retardation such as Down's syndrome.

2.3 THE PREVALENCE OF MENTAL RETARDATION

According to the World Health Report (2001:4) it is estimated that the overall prevalence of mental retardation is between 1% and 3%. It is more prevalent in developing countries because of higher incidence of injuries and deprivation of oxygen at birth and early childhood brain infections. Statistics South Africa noted that the number of mentally handicapped people was 206 451 in the 2001 census.

2.4 TREATMENT AND EDUCATION

No matter where children and adolescents with retardation reside, the need for treatment must be addressed. According to Wicks-Nelson and Israel (1997:264) medications are not known to strengthen intellectual functioning in cases of retardation but are employed widely for medical and behavioural symptoms. Psychotropic medications can alleviate the numerous behavioural problems that coexist with retardation, including, anxiety, affective disorders, over activity, aggression, self abuse, stereotypes, eating disorders, and psychotic behavior. Children and adolescents with retardation can also benefit from psychotherapies that aim to reduce behavioral/psychological problems. The single most important innovation in treating retardation has been the application of behavioral techniques (Wicks-Nelson and Israel, 1997:

265). The acquisition of daily living skills was recognized as crucial. Consistent with the behavioral approach, efforts have been made to train caregivers, whether the setting is the home, community programs, or residential institutions.

The World Health Organization (2001:2) has identified the following treatment goals:

- Early recognition and optimal utilization of the intellectual capacities of the individual by training, family education and support;
- Vocational training and opportunities for work in protected environments;
- Training of parents to act as teachers and trainers of daily life skills;
- Support groups for parents.

Historically, special education for the mentally handicapped typically had meant assigning them to special classes or schools, thus drastically limiting contact with normal children (Wicks-Nelson and Israel, 1997: 266). Inclusion in regular classrooms can avoid stigmatization and encourage the modelling of academic and social skills. Most importantly, integration in regular school settings can put the child on a path to playing a full role in society in adulthood (Wicks-Nelson and Israel, 1997:268). In an inclusive education and training system, a wider spread of educational support services will be created in line with what learners with disabilities require (Education White Paper 6, 2001: 15). The place of these children is not one of isolation in dark backrooms and sheds. It is with their peers, in schools, on the playgrounds, on the streets and in places of worship where they can become part of the local community and cultural life, and part of the reconstruction of our country (Education White Paper 6, 2001:4). According to the researcher, children with mental handicap are undervalued and they are less likely than their siblings to attend school. As a result they become disempowered adults who are unable to integrate normally in the community.

2.5 FAMILY NEEDS

Marsh (1992: 56-66) indicated that families have needs for the following:

2.5.1 A comprehensive system of care.

A central family need is for a comprehensive system of care for their relative. According to Marsh (1992:56), the burden of families would be significantly reduced if such a system of care were available throughout the lives of their family member. Medical services include acute care, developmental remediation, maintenance therapies and monitoring. Financial services include acute care and special needs, as well as routine cost of care. Educational services include appropriate assessment and placement, as well as special programs. Psychosocial and vocational rehabilitation are also necessary. In addition to their need for services for their family member, families need the following support services for themselves;

- Respite care (temporary relief from care giving responsibilities).
- Case management (a single individual to assist in identifying needs).
- Rehabilitation services (training in self-care and independent living skills).
- Homemaker services (routine household care, laundry etc).
- Home health aides (assistance with health and disability related matters).
- Nursing care.
- Parent training (e.g. in medical or therapeutic procedures).
- Financial aid for equipment, training, transportation etc).

In light of the demands of primary care giving, respite care is an essential family support service that has been described as a lifeline for parents. Four major approaches to providing respite care have been identified; home-based care by community providers in the client's home, group day care, group residential care and respite as an adjunct service (community

residences, residential treatment facilities, nursing homes, state institutions). Respite care can make a significant difference in the lives of families, especially when it is supplemented by other family resources.

2.5.2 INFORMATION

One of the most important family needs is for timely and complete information that can facilitate the process of family adaptation. It is likely that many parental difficulties reflect the fact that parents are informationally deprived rather than emotionally overwhelmed (Marsh, 1992: 60-61).

2.5.3 SKILLS

As primary caregivers, families are faced with formidable demands for coping and adaptation. One of the prerequisites for effective coping is development of the necessary skills. These skills are needed for coping with the mental retardation, with the system and with the personal and familial consequences of mental retardation. There are two kinds of skills that are needed by families; paraprofessional skills that will enable them to meet the specialized needs of their child and general skills that enhance coping effectiveness.

2.5.4 SUPPORT

A diagnosis of mental retardation often seems to serve as a familial membrane that quarantines the family from mainstream society. Social support generally refers to the protective role that relationships can play in mitigating the effects of stress, and in enhancing physical and psychological health. The potentially protective functions of social support include the provision of positive affect and emotional support; of expressions of agreement; of opportunities for ventilation of feelings; of information and advice; and of material aid.

A priority in community care services must be to support families in caring for their handicapped offspring. Family care is the most cost-effective community service (Fraser, Sines and Kerr, 1998:80-81). There is widespread agreement internationally as to the form these should take:

- Short-term breaks

The child or adult is cared for outside of the family to give the parents a break. This could occur regularly or for a set period each year while the family takes a holiday.

- Day care.

Although most developed countries provide schooling for children with special needs, the same opportunities are not always available to families in the adult years. Hence the provision of out-of-home facilities is most important, especially when the adult has behavioural or intensive care needs.

- Counselling and advice.

Families need access to medical and psychological advice both in regard to their child and for their own wellbeing. Therapists and social workers can provide much useful practical guidance and assistance.

- Financial support.

The additional costs of rearing a child with disability are well established, in clothing, medicines, diet and laundry. A range of benefits is now available to families both from the State and from charities.

2.5.4.1 Informal and formal support networks

The informal support network includes the nuclear family, the extended family, friends and acquaintances, neighbours, co-workers, and other families who have children with disabilities. This network can meet many family needs, including those for emotional ventilation and sharing; for

skills and coping strategies; for acceptance and validation; for information and advice; for substitute care giving; for transportation; for financial assistance and for practical care.

The formal support network includes professionals and service providers, social institutions and the government. This network complements the informal support network and can also meet many family needs, including those for services, for information, for skills, for support, for meaningful involvement in intervention, for assistance in managing the process of family adaptation, for contact with other families, and for assistance in handling problems in the larger society.

Benefits of social support

There are many potential benefits of social support, which may be the most valuable resource for families, e.g. that there is a positive relationship between social support and personal, family and child functioning, and that social support may enable parents to maintain a sense of normalcy and coping effectiveness.

Dimensions of social support

According to Marsh (1992:64) this may refer to some of the following structural characteristics of social support network;

- network size, which refers to the number of individuals perceived as offering support.
- network density, which provides a measure of the interrelatedness of the network and the linkages among members.
- boundary density, which reflects the membership overlap between two or more individuals.

Implications for intervention

It is important for professionals to assist families in utilizing the informal support network and to increase the responsiveness of the formal support network. When professionals do take a few minutes to allow parents to discuss their feelings and to respond in an empathic and caring manner, it can make a significant difference to them.

2.5.5 MEANINGFUL INVOLVEMENT IN INTERVENTION

Families have a need for meaningful involvement in intervention designed to assist their relative. After all, they do not work regular hours, and their care giving responsibilities often continue for a lifetime.

2.5.6 MANAGING THE PROCESS OF INDIVIDUAL AND FAMILIAL ADAPTATION.

One of the major needs of families is to handle the personal and familial consequences of the mental retardation. As family members come to terms with the mental retardation and its sequelae, they need to work through powerful feelings of loss, to resolve family problems and conflicts, to manage the emotional climate within the home, and to achieve a balance that meets the needs of all family members.

2.5.7 CONTACTS WITH OTHER FAMILIES

Families also need contact with other families, who often serve as their most valuable resource.

2.5.8 ASSISTANCE IN HANDLING PROBLEMS IN THE LARGER SOCIETY.

People with disabilities and their families continue to be subjected to corrosive stigmatization by a society that sometimes denigrates and devalues those who deviate from its norms. As a result, families need assistance in dealing with problems in the larger society.

2.6 MENTAL RETARDATION AS A FAMILY SYSTEMS PHENOMENON

Marsh (1992:130) noted that mental retardation is a family systems phenomenon. The presence of a member with mental retardation irrevocably changes the family unit and affects all individual members. Many areas may be affected, including family relationships, finances, and social and recreational life, household functioning, care giving demands and siblings (Marsh 1992: 135).

Fraser, *et al.* (1998:18) agrees by saying that the individual influences his/her context and is influenced by it in constantly recurring sequences of interaction. The individual who lives within a family is a member of a social system to which s/he must adapt. His/her actions are governed by the characteristics of the system and these characteristics include the effect of his/her past actions. The individual responds to stresses in other parts of the system to which s/he adapts; and s/he may contribute significantly to stress in other members of the system. The physical, social and emotional functioning of the family members is profoundly interdependent, with changes in one part of the system reverberating in other parts of the system.

2.6.1 PARENTAL SUB-SYSTEM

According to Marsh (1992:152-157), all family members are affected by the presence of disability; however, the mental retardation of child undoubtedly poses special challenges for mothers. The care giving role has been assumed to be fundamental for women, who have traditionally had primary responsibility for the needs of others, including men, children, and older persons. As a result, they are likely to assume the primary care giving burden for children of any age with mental retardation, whatever their other responsibilities inside or outside of the home. Fathers may be placed in a peripheral role that offers little validation and support; they are

prone to experience problems in resolving the powerful emotional burden and they are likely to experience frustration in fulfilling such traditional male roles as protector and provider .

2.6.2 MARITAL SUB-SYSTEM

Under the best of circumstances, contemporary marriages are faced with a host of individual, intrafamilial, and extra familial obstacles to stability and persistence. Although the marital partners may be confronting a mutual tragedy, they may differ significantly in coping styles and adjustment patterns. Mothers may be more likely to seek emotional expression and support, and to become enmeshed in the demands of primary care giving. Fathers may be more likely to deny and inhibit their feelings, and to detach themselves from the painful familial reality. However, the mental retardation of a child may have positive consequences for the marital relationship, including better support and understanding between partners (Marsh, 1992:158-160).

2.6.3 THE SIBLINGS SUB-SYSTEM

According to Marsh (1992:164-167), siblings share in the experiences of their parents. Although they share many of the experiences and feelings of their parents, their attitudes, beliefs, and perceptions are also shaped by their own unique experiences. Some of these include the absence of a normal family, which may colour their perceptions of family relationships; their own immaturity, which may interfere with their ability to understand and cope with their feelings; and the quality of their relationships with their parents, the child with the disability, the other siblings, and the outside world. As a result of these experiences and concerns, siblings have a number of central needs. Some of these needs are:

- Ø Information about mental retardation and the consequences for them,
- Ø An opportunity to express the strong feelings aroused by the condition,

- Ø Sufficient parental attention,
- Ø Appropriate care giving responsibility
- Ø Reasonable expectations that are not based on compensation for the disability of their brother or sister.

2.6.4 EXTRA FAMILIAL SUBSYSTEM

According to Marsh (1992:172-174), this system consists of all relatives aside from parents and siblings. They also share in the experiences of the nuclear family. These family members may offer valuable support to the nuclear family or may add to their existing burden. Grandparents can serve as supporters and helpers for their adult children, and as nurturers for their grandchildren. They may provide invaluable emotional support and instrumental assistance, including advice about child care, access to community resources, coping strategies, assistance with care giving, and respite services. When they are confronted with the mental retardation of a grandchild, however, grandparents are likely to experience powerful feelings of loss, which can add to the problems of their children.

Grandparents may, however, respond in a number of ways; by denying the nature or severity of the disability, by placing blame usually on the partners; by continually searching for a cure; by insisting that everything will be fine; by attributing the disability to punishment by God; by assuming responsibility for the child; by becoming more or less protective than the parents; and by withdrawing from the family.

As is the case for members of the nuclear family, the consequences of mental retardation for other extended family members are likely to include both positive and negative components. For example, there may be negative feelings among aunts, uncles and cousins if a grandparent is more involved with the child with a disability than with the normal grandchildren. Conversely, the parents of a child with a disability may feel

envious of the normal nieces and nephews, and of the time that grandparents spend with them.

Kahana, Biegel and Wykle (1994:333) also believe that the family does not operate or function in a vacuum, but is a system in interaction with its wider context. The *social ecology model* views the family as a system nested within a number of other societal systems in a hierarchical manner.

Microsystems. In this context this system represents the family, its patterns of activities, roles and interpersonal relationships. Within the Microsystems one can examine parent-child interactions and the development of sibling bonds. Understanding the nature of parent – child or sibling interactions in such families elucidates ways in which they are like other families but also provides insight into substantive differences associated with having children with special needs (Kahana, *et al.*, 1994:333).

Mesosystem. This comprises a wide range of contexts in which a family actively participates at a personal level. This would include medical and health care workers who may be involved intensively with the person with disability. Also included would be the extended family, friends, neighbours, work colleagues, school, etc.

Exosystem. This comprises such things as the media, the planning and provision of health care systems and social care systems. Given the importance of care giving for children with mental retardation and the fact that the vast majority of care giving is provided by parents, understanding the social context in which parents function is critical. For example, the extent to which family and friends are supportive of care giving demands can impact on the child and family (Kahana, *et al.*, 1994:335). It is composed not so much of individuals but of organizations and policies.

Macrosystem. This represents the ideological belief system inherent in social institutions of the society in which the family lives. It includes ethnic/cultural, religious and social elements as well as political and economical factors.

The implication of the social ecological model is that changes in the systems at higher hierarchical levels affects and changes those systems at lower hierarchical levels. The implications of this for families is that changes in cultural beliefs, neighbourhood or the nature and provision of social care will have effects on the interactions of the family with those systems and also upon the relationships within the family (Kahana, *et al.*, 1994: 335) .

2.7. MAJOR FUNCTIONS OF A FAMILY

According to Alper, Schloss and Schloss (1994:78-79) the following are specific areas in which families are responsible for each of their members;

- The economic responsibility to generate income and provide financial support for living costs and related payments.
- The domestic and health care responsibility to meet the daily needs of food, clothes, health and medical care and safety.
- The recreational responsibility to provide leisure environment and activities.
- The responsibility for self- identity to increase each family member's sense of belonging.
- The affectionate responsibility to show and share love, care, emotional feelings and companionship.
- The responsibility for socialization to develop social skills and enhance interpersonal relationships.
- The educational and vocational responsibility to assist and support schooling and career selection and preparation.

2.8 PARENTAL REACTIONS TO THE HANDICAP

According to Dale (1996:48-51), parents rarely expect their child's disabling condition or life-threatening illness. The confirmation or diagnosis, whether at birth or later, often creates an immense crisis of changed expectations and hopes, and parents may experience intense reactions during the early days. Breaking the news about disability is one of the most stressful tasks for medical professionals. The researcher has observed that in some cases professionals do not inform parents of the disability and leave it for the parents to discover for themselves. Anticipating the interview may evoke feelings of anxiety, distress, inadequacy or defensiveness, with worries about how best to communicate the news, what to say about the child's prognosis, and how to handle the parents during their first shock. The news may be so difficult to take in that some parents will refuse to accept it for a while and may reject the person conveying the news.

In the search for meaning for their situation, some parents may resort to traditional beliefs and see their child as the consequence of a misled or misfortune of their own, or as a blessing in disguise from God, sent to test their faith and fortitude. Fraser, *et al.* (1998:22) noted that parents must mourn the loss of their desired normal child before they can accept their real defective child. Like mourning this is seen as a process that goes through a number of stages, which are as follows:

- shock
- denial
- sadness
- adaptation
- reorganization.

The implications of this conceptual framework are that families and parents in particular, pass through these stages in a sequential nature following the birth or diagnosis of a disability in a child. According to the

researcher, parents may not go through the same sequence as suggested by the framework. Reactions will differ from one parent to the other.

A main communication task during the diagnostic period is to communicate information about the child's condition and special needs to the parents in terms that can be understood and remembered and which will enable the parent to start adjusting to the reality of the child's condition. This includes specialized knowledge on the causes of the child's condition, its characteristics, and some of its potential consequences and future prognosis. Adequate information probably reduces the stress and anxiety of uncertainty and meaninglessness.

Effective communication depends not only on the successful transmission of the information, but also on a discerning awareness of the parent's understandings and other factors which may affect the communication process. A final point to consider is that the communication of the child's diagnostic condition should not be seen as a discrete or short term exercise. Some parents achieve a full understanding of what the professional is trying to communicate only through direct experience and learning from their own child and situation. This may take months, if not years in some cases (Dale, 1996: 53-54).

Although there are similarities in the ways parents react to the birth of a child with a disability, there are also many other factors that mitigate a wide range of parental responses. The following are some of the factors mentioned by Alper, *et al.* (1994:55-64).

2.8.1 Uniqueness of each family.

Each family should be viewed individually because of its specific members, structure, social and cultural backgrounds and life experiences. There are no two families alike and each family has its own unique ethnic

values, and special goals and objectives that the family members agree upon and work together to achieve. Families of children with disabilities are unique, normal families in the community, not “handicapped families”.

2.8.2 Generalized expectations associated with the birth of a child.

Most prospective parents are faced with excitement, the task of planning for the future, learning the meaning of being parents, and, in the case of giving second or further birth of a child, preparing older brothers and sisters. The disclosure of the diagnosis of mental handicap will destroy most, if not all, of the expectancies about the future, albeit with a range of options. It is important to note that all parents need help during and shortly after the birth of their child.

2.8.3 Generalized reactions to the birth of a child with disabling conditions.

Alper, *et al.* (1994:58-59) noted that parental reactions at the birth of a child with disabilities are based upon the belief that the grief they experience is the result of the loss of an expected “normal” child. The type and degree of parental reactions are highly related to the degree to which the child’s birth deprives the parents of their dreams and fantasies relating to the child. As a result, parents pass through a sequence of feelings and reactions.

Failure to believe – parents do not accept a diagnosis and continue shopping for a new diagnosis or cure. They may minimize the seriousness of the disability as they develop coping mechanisms.

Self blame - an overwhelming feeling of guilt may often be initiated by the parent. Parents may experience regret about some of the things they think they should not have done. Mothers might worry about anything they may have done during pregnancy that might have caused the handicap to occur.

Anger and self - pity - parents feel helpless and unable to change the disabling condition, and this helplessness often develops into either anger

or pity. Parents will displace their anger onto the professional, the spouse, or the institution. Self-pity and/or depression can be expected from parents of children with disabilities and should be permitted as parents wrestle with how to cope with their problems.

Giving and sharing - a common type of parental reaction that usually takes place following failure to believe, self blame, anger and self pity, is seen as parents volunteer to help other parents of children with disabilities.

2.8.4 Parental expectations related to the type and degree of disability.

Parent's expectations relating to their child may be influenced by different types and degrees of disabling conditions. Mental retardation may be one of the most difficult conditions for parents to accept. Parents may be devastated by this diagnosis, especially when they realize that their child is going to carry a stigma that has been highly related to isolation, dependency and institutionalization in our society. Many disabling conditions may have associated conditions or secondary/multiple conditions, such as speech, language impairments, social disabilities and behavioural disorders. The impact of having a child with a disability may be more difficult when the child displays maladaptive behaviours as well as when there are other family conflicts. The severity of disability is another factor with specific implications for parents. Children with mild conditions may not be identified until school readiness screening. This might cause parents to regret not having had the opportunity for early intervention. The advantage would be that these children have been treated as normal throughout their infant, toddler, and early childhood years. Once of school age, another advantage for children with mild disabilities would be a greater opportunity to be mainstreamed and integrated among other children without disabilities in the least restrictive environment. On the other hand, parents of children with moderate disabilities may face ambiguity and feel puzzled or stressed. Generally,

families of a child with severe disabilities tend to experience more stress than those of a child with mild disabilities.

Accurate information provided for parents may decrease ambiguity, help parents to set appropriate goals and expectations and start home intervention activities as early as possible.

The following is a classification of common feelings experienced by parents as seen by Fraser, MacGillivray and Green (1991:245);

Ø **Biological reactions**

These will include feelings of protectiveness toward a vulnerable newborn. In the case of handicap this can become over-protectiveness with an increased sensitivity to any implied suggestion of criticism or negativism toward the child. Conversely the protection might extend toward the existing family and result in the rejection of the newborn. Resentment and revulsion are common feelings toward the abnormality. Many parents may oscillate between these feelings and the apparently conflicting feelings of protectiveness.

Ø **Feelings of inadequacy**

According to Fraser, *et al.*, (1991:246) serious doubts regarding parent's reproductive adequacy can arise, often affecting sexual relationships. There is a fundamental desire in human beings to see their children as an extension of themselves. These feelings of a reproductive inadequacy may affect many other members of the family. Rifts may occur with arguments regarding whose side of the family the handicap is on. Siblings may also be affected with fears about their own reproductive inadequacy. The arrival of a child who is different and who, it would be anticipated, will cast serious self-doubt about the ability to cope.

Ø **Feelings of embarrassment**

When parents are forced to go public with their child, they may come across reactions in other people that will only serve to compound their own sense of embarrassment. They may find avoidance in friends and neighbours. Similar reactions may be found in siblings, the other parent and grandparents. Avoidance of prolonged discussion regarding the child may well be experienced from professionals in the paediatric service. This embarrassment from others communicates to the parents that they have done something wrong. Reaction to this might be to adopt stances of defiance, curtness or even to become apologetic (Fraser, *et al.*, 1991: 246).

Ø **Feelings of guilt**

These might be related to the embarrassment and feelings of inadequacy. Ideas may surface surrounding blame for the handicap occurring; mothers especially might worry about anything they may have done during pregnancy that might have caused the handicap to occur. For example, smoking, drinking, and working too hard. However, it is more likely if these feelings are present that they are related to the belief in the parents that they are not doing enough to help their child, or the other children in the family are suffering. Guilt is usually related to the perception of what has been required in terms of rearing and the related perception of the adequacy of the efforts made.

Ø **Feelings of fear**

The sudden destruction of expectancies leads to the introduction of many uncertainties. These uncertainties generate fear of what the future may hold for their child. With a sick child with a poor life expectancy, parents may be afraid to develop an attachment. They may also be frightened of the power of their own feelings. These emotions may be alien to them, such as feelings of rejection towards the child, bitterness and anger toward others.

Ø **Feelings of bereavement**

The loss of the “hoped for child” is often compared to the process of bereavement. This model has proven to be useful to some parents to understand their own reactions. However, its wholesale adoption by professionals has served to perpetuate the ideas of inevitable pathology.

According to Fraser, *et al.* (1998:23) the following areas may be useful to explore in understanding parents’ reactions:

- Ø Prior knowledge about disability;
- Ø Parental reaction to pregnancy;
- Ø The experience of delivery;
- Ø The early parent/child bonding experience;
- Ø The circumstances as to the disclosure of the diagnosis;
- Ø The nature of the prognostic information given surrounding the diagnosis;
- Ø Availability of treatment;
- Ø The need for emotional support;
- Ø The reactions of others.

2.9 GUIDELINES FOR THE DISCLOSURE OF DIAGNOSIS

According to Fraser, *et al.* (1991: 245) the guidelines for the disclosure of diagnosis are:

- Ø Parents must be told as soon as possible.
- Ø Parents should be told together.
- Ø The child should be present. This conveys the message that it is thought that the baby is valuable.
- Ø The discussion should be private.
- Ø The news giver should be a well-informed person, for example the paediatrician concerned.

- ∅ The news giver should explain the facts as simply as possible and be wary of influencing decision making.
- ∅ A subsequent interview should be arranged so that the parents can ask questions and seek practical advice.
- ∅ Follow-up should be arranged at home with a key worker, usually a health visitor, general practitioner or social worker who can offer continuing support, practical information and advice.

Kahana, *et al.* (1994:78-80) agrees by noting that the person breaking the news should have time to prepare as carefully as possible before actually meeting the parents and the following points should be considered:

- **Who should give the information?**

This should preferably be someone who knows the parents, and has appropriate communication skills and relevant knowledge. No other staff should be present unless they have a clear role, and their presence is explained or negotiated with the parents.

- **To whom should the information be given?**

Parents usually want to be told together, and prefer their baby to be present if it is a congenital problem identified at birth.

- **What should be said?**

All relevant information should be available if necessary, but decisions should be made about what parents should be told, the priorities, and the order in which to give it, and the terminology to be used. Only what is absolutely essential information should be given at this stage, unless specifically requested by the parents, as the shock will inhibit both their understanding and retention.

- **Where should they be told?**

The most appropriate venue should be selected, but privacy is the essential factor. Arrangements should be made to avoid all interruptions, including the telephone. Tissues should be made available, and chairs positioned appropriately to enable physical comfort to be given if necessary.

2.10 THE IMPACT OF DISABILITIES ON SIBLINGS.

Having a brother or sister with a disability in the family provides siblings with special expectations and causes specific reactions. Being the sibling of a handicapped child evokes a range of emotional responses, from pride to enjoyment to irritation and resentment.

2.10.1 Positive reactions

Siblings may develop greater empathy and understanding for people with disabilities. They become more tolerant and patient with others and learn how to be helpful to others. Snyman (1993:33) further stated that the attitudes of the parents play a key role in the development of the siblings' attitudes towards the retarded child. When parents work through their own feelings and adopt a positive outlook, it is likely that the siblings' attitudes will follow suit.

2.10.2 Negative reactions

The presence of a mentally retarded child can exert negative effects on non-retarded sibling's individual functioning; high degrees of anxiety and conflicts with parents; lower sociability; and adoption of life goals involving dedication or sacrifice (Snyman, 1993:33). Alper, *et al.* (1994:98-99) added by saying that without well informed parents and a functional family, siblings run the risk of dealing with their natural feelings in an unhealthy fashion. As a result, they may develop inappropriate behaviours and long lasting emotional problems related to the experience. Siblings may feel a

myriad of feelings including resentment, jealousy, guilt, grief, fear, shame, embarrassment, and rejection.

2.11 SPECIAL NEEDS OF SIBLINGS

Siblings need a variety of things to ensure a positive experience with a brother or sister who has a disability. The most prominent ones are; mature, informed parents; information, skills and support groups; an opportunity to grow and develop as an individual; positive involvement in the programme for the child with a disability and clarification of the sibling's role; and a close, meaningful relationship with the child who has a disability (Alper, *et al.*, 1994:108).

2.11.1 Mature, informed parents

Siblings need parents who can be positive role models and who can make them feel loved and cared for. They need to feel that they have their own place in the family and are not an afterthought. Siblings need to know that they are not responsible for their brother or sister who has a disability and should feel free to decline to care for them or to be involved if they wish. Parents need to explain stresses and tensions in the family so that siblings know the sources of them and how to deal with them.

2.11.2 Information, skills and support groups

Alper, *et al.* (1994:109-110) states that siblings who lack information and experience have a hard time putting things into proper perspective. Parents need to provide information about the exceptional child's condition, its etiology, and what can be done about it. Siblings also need some guidance on how to deal with predictable situations. They need basic skills in communications and behaviour management so they can relate to their brother or sister. They need to know about the assessment and planning process and something about the services given to their brother or sister. They definitely need support groups of their own to

provide a forum to learn new information and to share their experiences with one another. Siblings can work out their negative feelings in a supportive environment and without the fear of offending parents and the brother or sister who has a disability. The sharing of experiences and resources can do much for the siblings' self confidence.

2.11.3 Self-identity

Siblings need special understanding, attention, support, and recognition for their unique contributions to the family system. They need to be recognized and affirmed for themselves, independent of achievements and deeds. Their achievements should be recognized and applauded, and not overlooked because of the attention the child with a disability receives. They should be encouraged to have their own friends, games and hobbies, and time to themselves. While it is reasonable to expect siblings to play with and otherwise take care of the child with a disability sometimes, it should not be a fulltime occupation.

2.11.4 Planned involvement

When the individualized family service plan is being developed, it may be appropriate to include siblings in the discussion if for no other reason than that they know what is going on. Their needs should be incorporated into the individualized family service plan and appropriate services provided. Parents should also periodically assess the family environment to see how the needs of family members are being met and what adjustments are needed.

2.11.5 Future plans

For their own peace of mind, siblings need to know about future plans for the child with a disability. If the child's difficulties are so great that s/he will never be fully independent, the question arises of what will happen to him/her when the parents are too old to cope anymore. It is unfair to

assume that the other children will take on the caring role. They have their own lives to lead and parents should make them realize that they do not expect them to take over from them in years to come (Kimpton, 1990: 96).

2.11.6 Close and meaningful relationship

The greatest need that siblings have and the outcome of all the other needs are to have a close, intimate relationship with their brother or sister. Like all the relationships, it has to be established on the basis of mutual trust and understanding. Parents and professionals have to provide guidance along the way and encourage the relationship.

2.12 EXTENDED FAMILY'S REACTIONS

In addition to siblings, other members of the extended family are also affected in varying degrees by the birth of a child with disabilities. Their reactions to the birth and corresponding degree of support for the parents can be a source of comfort or pain for parents of a newborn child with disabilities. Having a child with mental or physical disabilities may cause some negative, or even disruptive, changes between the child's parents and grandparents. Parents may receive less support from the child's grandparents, especially those who are paternal. Grandparents are also (especially) vulnerable by their unique position as parents of the mother and father. They tend to grieve at two levels; first, the loss of the expected grandchild and, second, at the knowledge of the increased burdens placed on their own offspring. The degree to which grandparents are impacted is also reflected by the degree to which they can be supportive and provide encouragement for the parents.

2.13 THE IMPACT OF CARING

Anyone who provides care for another person will find that their life alters due to the responsibilities they have assumed, and those who give substantial and regular care are likely to experience great changes.

According to Heron (1998: 44), caring may involve a real danger of overwork. Physical exhaustion can be a real problem for carers, especially if they are older people or not in good health. Some caring tasks, such as lifting someone who is heavy, pushing someone in a wheelchair and extra washing, all of which are undertaken day in day out, can be physically strenuous.

Besides physical exhaustion, carers who have to undertake a supervisory or monitoring role often experience mental strain due to having to be constantly alert to what the person they are caring for is doing. According to Glendinning (1986: 105), many disabled children need more attention or supervision during the day than would normally be required by a non-disabled child of the same age. Children with mental handicaps may have very short concentration spans or little awareness of danger, or may damage themselves or their surroundings, or may have a tendency to run away.

Another significant factor in caring is the effect which stress can have on relationships between family members (Heron, 1998: 45). This can be manifested in the following manner:

About the time spent with the person needing care.

Lack of privacy.

Insufficient understanding of the nature of the illness.

Disagreement about the way to deliver care, and

Conflict about relative responsibilities.

Such differences cause a background of disharmony which can adversely affect relationships in the family.

A sense of limitation and missed opportunities is often expressed by carers when they talk about their lives. There is a feeling that their life has taken a different course from that which they would have chosen had they not had the responsibility of caring. A number of carers will not have had the opportunity to go to work, or will have had to give up working in order to care.

According to Heron (1998: 49), social isolation can also be a problem for primary carers when the conflicting demands of their families and the cared for person mean that their time is carefully allocated between the two groups, leaving little spare time for making contact with people outside the family boundaries. The lack of someone with whom to talk about the experience of caring can be an extremely stressful factor in a carer's life. Through not talking about the emotional impact of the situation, people may internalize feelings, possibly causing depression or severe anxiety.

2.14 THE NEEDS OF CARERS

2.14.1 The need for a break and practical support.

Appropriate respite will enable a carer to have a break, to enter into employment and in critical cases to regain the strength and will to continue to care.

2.14.2 Need for information.

When people begin caring they are generally uninformed about the condition of the person they are supporting. They also are not aware of what services are available to help that person or themselves.

2.14.3 The need for training in caring skills.

Training provides in-depth information and practical coping skills. The list of areas in which carers can benefit from training is large and will depend on the individual needs of the person requiring support. One important area to carers is skills in rehabilitation to enable the person they care for to learn or relearn skills which would increase their independence.

2.14.4 The need for emotional support

The opportunity to talk about caring, off-load worries and share the problems of caring can be extremely useful for many carers. There are a number of ways of providing emotional support. Individual counselling, self-help groups, and telephone support all have a role to play in relation to this.

2.14.5 The need for improved communication and problem solving.

Heron (1998: 57-58) pointed out that problems facing families are often founded in communication difficulties. These can be between the dependent and the carer, between the carer and their families, or practically any combination of the involved. Most people communicate with each other in an automatic way, based on learned behaviour, which can crystallize into inappropriate patterns within the family.

2.14.6 The need for stress management.

Stress management involves understanding stress and how it operates, examining behaviours and attitudes which can exacerbate stress and learning relaxation techniques.

2.15. CHRONIC STRESSES UNIQUE TO FAMILIES WITH A CHILD WHO HAS A MENTAL HANDICAP

2.15.1 Stigmatized social interactions

According to Fraser, *et al.* (1991:249), the public have a tendency to stereotype all people with a mental handicap as completely lacking in social competence. Parents may face reactions from others that are quite hostile. As the child gets older the discrepancy between their size and apparent age and their mental functioning may tend to increase, thus making the child more noticeable.

2.15.2 Increased and prolonged burden of care

The burden of caretaking is often increased and more prolonged in a child with a mental handicap. There may be secondary problems associated with the mental handicap which increases the workload of the parents. More severe mental handicaps are often associated with multiple physical handicaps. This burden can be seen to be endless; parents of older children cannot look forward with any certainty to relief from the burden of care afforded to parents of normal children. The child's handicap might make respite more difficult to organize. Parents may feel that only a specialized sitting service would be acceptable and the informal baby-sitting networks available to parents of normal children are not an option available to them.

2.15.3 Lack of information

For information and advice most parents rely on their own experiences of being parented, and on advice from friends, relatives and neighbours. These resources are usually inadequate for children with a mental handicap, where most specific information may be required.

2.15.4 Financial concerns

The needs of many handicapped children will have financial implications. Prolonged incontinence will incur costs for laundry, bedding, nappies and clothing. Prolonged crawling, hyperactivity or some problem behaviours will also take their toll on clothing. Many severely handicapped children

may require a special diet, due perhaps to feeding problems or difficulty in swallowing and digestion. Difficulty and mobility of the child might also result in restricting access to shopping facilities with the “best buys.”

The child may require extra stimulation requiring the purchases of extra specialized toys. Travel to clinics will be an extra cost. It is further mentioned that not all parents will suffer from these financial burdens.

2.16 COPING AND ADAPTATION

Parents might achieve some degree of acceptance after the child’s initial diagnosis, yet once again experience coping difficulties when the child fails to reach or is delayed in accomplishing other major developmental milestones such as talking, walking, beginning school, attaining puberty, or reaching adulthood (Helton and Jackson, 1997 :127).

According to Marsh (1992: 73-76), the role of professionals is to empower families in coping with the adaptive demands associated with the mental retardation of a member. Mental retardation is usually an unanticipated event with little previous experience and little time to prepare; there are few sources of guidance and little understanding by those outside of the family, the ‘crisis’ generally lasts for a lifetime, there is a strong sense of helplessness, there is generally a high emotional impact, and there may be dangerousness and medical problems. In response to the stressor of mental retardation, the family undergoes a process of adaptation.

2.16.1 The process of family adaptation

Once a stressor has occurred, the process of adaptation begins. Three adaptational responses to stress will be considered; defence, coping and resilience.

2.16.1.1 Defence

Defences are legitimate strategies of adaptation, since they can offer protection from overwhelming anxiety and assistance in maintaining psychological integrity under conditions of stress. Since defences often involve distortion of reality, however, such strategies do not enhance problem solving or mastery.

2.16.1.2 Coping

Coping is defined by Marsh (1992:85) as efforts to master demands that are appraised as exceeding or taxing an individual's resources. The author described two categories of coping responses: problem-focused coping, which refers to efforts to improve the person-environment relationship by changing things and, emotional-focused coping, which refers to thoughts or actions designed to relieve the emotional impact of stress.

2.16.1.2.1 Individual and familial coping strategies

- Ø Accepting the disability and its consequences for the family.
- Ø Reframing to focus on individual and family capabilities rather than limitations.
- Ø Seeking information about the disability and available services.
- Ø Developing skills related to the disability.
- Ø Assuming an active and constructive role within the family and the social system.
- Ø Understanding the cognitive, behavioural, emotional and social components of the process of family adaptation.
- Ø Developing realistic expectations for the family member and for the family.
- Ø Achieving a balance that meets the needs of all family members.
- Ø Maintaining cognitive and behavioural flexibility.
- Ø Striving to maintain a normal family lifestyle.
- Ø Understanding and strengthening the family system.

- Ø Improving communication, conflict resolution, problem solving, assertiveness, behaviour management, and stress management skills.
- Ø Seeking informal and formal sources of social support.
- Ø Sharing feelings and coping strategies with other families.
- Ø Seeking outlets outside of the family.
- Ø Developing collaborative relationships with professionals.
- Ø Seeking professional counselling when appropriate.
- Ø Moving into advocacy roles.

2.16.1.3 Resilience

Families are also capable of demonstrating an exceptional level of mastery and control in their adaptive efforts, and of prevailing over the circumstances of their lives. Although a diagnosis of mental retardation may involve the disintegration of existing modes of functioning, it also provides opportunities for personal and familial reintegration. This positive response to stress has been called resilience, which involves both the idea of stressors and the capacity to respond, to endure or to develop and master.

2.17 Conclusion

While the upbringing of all children can be taxing, there is no doubt that the care of a severely disabled child frequently makes demands that go a long way beyond what is usually required of parents of non-disabled children. The amount of direct caring work with the child tends to be greater, more exacting and more complex than with other children. Families of children with a mental handicap experience social isolation, live on a restricted budget and lack experience and knowledge of the condition. It is commonly considered that the specific needs of people with severe mental disabilities fall outside the ambit of development. Such

people are likely to be regarded as ill and in need of constant care. They are not therefore, provided with opportunities to participate in society to the best of their abilities.

Having a disabled child necessitates involvement with a multiplicity of different agencies and professionals. This in itself constitutes tiring, time consuming and often frustrating work. According to Read (2000: 62), dealing with service providers is identified as the most stressful part of bringing up a disabled child.

CHAPTER 3

ANALYSIS AND INTERPRETATION OF DATA

3.1 INTRODUCTION

According to Monette, Sullivan and De Jong (1994:365) data analysis refers to deriving some meaning from the observations that have been made during the research project.

The analysis and interpretation of data gathered by the researcher will be presented in this chapter. Data was collected using the semi-structured interview schedule. Although the schedule was written in English, the interviews were conducted in Sepedi as all the respondents were from a Pedi – speaking ethnic group. All the interviews were conducted by the researcher, where ten (10) parents from different families were interviewed. A pilot study was conducted with two parents who did not form part of the sample. The results of the analysis will be presented in a narrative form; taking into consideration the knowledge that a phenomenological design was followed.

The family system has been defined as a network of interpersonal relationships characterized by a continuous interchange between members and by reciprocal causal effects (Nagler, 1990:260). Despite that, parents of children with mental retardation continued to receive little or no help from professionals. It is against this background that the researcher embarked on this study, to establish the impact that mental retardation has on family functioning.

3.2 RESEARCH METHODOLOGY

The researcher made use of applied research in the investigation. The recommendations of the study will be used for the improvement of services to families of children with mental retardation.

Applied research is defined by Bless and Higson-Smith (2000:153) as social research that has the primary aim of finding solutions to specific concerns or problems facing particular groups of people by applying models or theories developed through basic social research.

The population consisted of parents of children with mental retardation in the Waterberg district. The children are registered and attend stimulation classes at three day-care centres in the Waterberg district. Ten parents (one per household) were selected using probability, simple random sampling.

3.3 RESEARCH FINDINGS

The findings of this study will be presented according to themes. Seven themes have consequently been identified and they are presented as follows:

3.3.1 UNDERSTANDING MENTAL RETARDATION

The aim of the question was to establish the respondents' understanding of mental retardation. The question did not require any formal definition of the concept as the researcher disregarded the level of education of the respondents. Their understanding of mental retardation will therefore be based on their personal experiences with the children.

According to Helton and Jackson (1997:126), developmental disabilities are defined as those problems occurring in individuals at birth or before age twenty-two and also affecting three or more areas of functioning, including such skills as receptive and expressive language, mobility, cognitive and self-care. These conditions generally last throughout the individual's lifetime and require multifaceted, long-term care. Types of developmental disabilities include cerebral palsy, Down syndrome, seizure disorder, mental retardation and autism.

The respondents in this study have shown a remarkable understanding of this condition. The description of their children's condition fitted well with the definition provided by the author. Parents indicated that their children did not speak until they were at least two or three years. Some did not walk for the same length of time.

This was confirmed by some of the parents, who reported that,

- “The child with mental retardation does not understand when people talk to him. He talks without thinking. He beats other children and is dependent on other people with things like bathing, eating and clothing”.
- “The child with this condition is slow to think and to understand, and his mental capacity is not compatible with his age. The child is forgetful. He is born with the disability”.

The respondents have shown an understanding of the concept of mental retardation, not from any definition provided by someone, but from the interpretation of the behavior of their own children over a considerable period of time.

3.3.2 DISCLOSURE OF THE DISABILITY

Many problems are not noticeable at birth but only develop or become noticeable, as your child grows older (Kimpton, 1990: 7-8).

The question relates to how parents came to know about the disability of their children. The researcher did not however suggest any particular way of disclosure.

The study revealed that parents who took part in the study were not aware of their children's disability until later in life. In one interview the parent said,

- "I send my child to school and he was in the same grade for five years. I was called to the school and the school principal said that my child does not understand what is taught in class. We hit the child at home thinking that he is just playful. The school principal said there might be a problem with the child and recommended that we take him to the hospital. Tests were conducted by the hospital therapists and they confirmed that my child has mental retardation and that he is therefore not responsible for any wrong behavior that we may observe".

Another interview revealed that

- "After the child was born, it was realized that she is floppy. Her milestones were also delayed. The doctor who delivered the baby said that the child's bones are not well developed. He promised that my child would be fine. The child was on treatment from as early as six months. I believed that the condition would be corrected although I suspected that there might be something seriously wrong with my child. I took the child to the doctor periodically for reviews and for further treatment. It was only after eighteen months that the doctor told me that there is nothing more he can do for my daughter as she has a mental handicap and that the God who created her is the only one that can do something about the condition. I was hurt and disappointed."

The interpretation of the findings is that parents were not informed immediately after the birth of their children about the child's disability. Professionals only did the formal disclosure after the parents have communicated their suspicion and uncertainty about the child's condition. Most of them moved from one traditional doctor to another trying to get an explanation of what might be the problem with the child but that did not bring any change.

3.3.3 REACTIONS TO THE DISCLOSURE OF THE DISABILITY

The focus of this question was on the description of the parent's reaction to the disclosure of the disability and their observation with regard to the reaction of other family members.

At the disclosure of the diagnosis, parents often describe a state of shock, numbness or confusion. They talk about not being able to understand what is being said. They are aware that the events with which they are suddenly confronted lie beyond the range of their constructs. Their existing construct system, the way in which they anticipate the world, is suddenly irrelevant; or rather its relevance is uncertain, as the world has suddenly changed (Davis, 1993:17).

3.3.3.1 Parental reactions

The parents who participated in the study expressed the following feelings:

- Hurt,
- Disappointment
- Sadness,
- Uncertainty
- Embarrassment
- Bitterness
- Unhappiness
- Disbelief
- Suffering
- Fear
- Denial.
- Shock One of the parents said;

“I did not believe that my child is handicapped. I told the doctor who broke the news that I am not satisfied with the explanation and therefore do not even begin to imagine that my child will look like that for the rest of his life. I was

afraid that I may have another child with the same disability. This child was the sixth in the family and my husband questioned why it happened with him because it did not happen with any of the other children.”

Another parent indicated that her husband frequently asked why God had to punish him. When he finally thought that he had a son, the child happened to be mentally handicapped. The family went to traditional healers to get an explanation of what might have caused the condition, but they ultimately gave up as no explanation and intervention brought any relief.

It can thus be concluded that parents went through a variety of emotions in an attempt to deal with the realization that they have a handicapped child. There were no follow up visits arranged between the parents and the person breaking the news, as they had to change their life constructions to accommodate new and unforeseen events. They, therefore, had to make it possible on their own to accept the child's condition.

3.3.3.2 Sibling's reactions

According to Glendinning (1983: 90) living with a severely disabled sibling can have a wide variety of consequences for other children in the family. Extra work and extra expenses caused by the disabled child may mean that fewer emotional and financial resources are available for siblings. A sibling who is disruptive or hyperactive may limit their own social lives and their opportunities to read and study at home. Siblings may miss the companionship of a sister or brother; and may themselves be involved from an early age in providing some of the extra attention and care needed by the disabled child.

Siblings were not interviewed during the investigation. Their parents were the only source of information with regard to the question on sibling's reactions to the disclosure.

In their responses some of the parents had the following to say about their other children:

- “My husband died soon after the birth of the child with mental retardation. I had to work in order to support the family. I have nine children and they helped me with household chores, including caring for their disabled sibling. This was treated as part of their routine work and they have never complained about it. Despite the fact that I did not manage to pay for their higher education, they still relate well with the disabled child and all other family members. One of my children is currently a volunteer in a day care centre for children with mental handicap.”

It can be deduced that siblings did not enjoy their childhood as they acted as carers for their brother or sister. They were required to rush home after school to assist their parents with the care of the sibling brother or sister who has mental retardation. Most of them were not allowed the opportunity to further their education due to financial constraints. They were, however, empathetic and understanding towards the child.

3.3.3.3 Extended family member’s reactions

After a lifetime of hard work and worry bringing up their own children, most people look forward to relaxing and enjoying their grandchildren. When their longed-for grandchildren bring sorrow, their dreams are shattered. Although they grieve for their grandchildren, they may even be saddened to see their own children hurt and unhappy. The situation can be particularly difficult for a lone grandparent. As time goes by, they will age and your child will grow taller and heavier. There may come a time when, however willing they are, they will not be able to give as much practical help as they did before (Kimpton, 1990: 98-99).

In a majority of cases it was found that grandparents did not want the parents to take the child to an institution of care or to hear anyone shout at him/her. In one interview, the mother of the child said:

- “My mother in law did not want to hear anyone shout at the child. If it happened that one family member shouts at her, she would be so angry that she would not have her next meal.”
- In another interview, the child’s grandmother did not allow her parents to send her to an institution for children with mental retardation.

It is evident that grandparents were overprotective towards the child. They treated the child differently from other children and saddened when other people treated him/her in a manner they did not approve of. Grandparents sacrificed their resources, time and energy to assist their own off springs. It was mentioned during the interviews that grandparents used their cows, goats and money to pay for services provided by traditional healers to their grandchildren.

3.3.4 FINANCIAL IMPLICATIONS

The aim of the question was to establish how parents handled the financial consequences of rearing a child with a mental retardation. The question was based on the understanding that children with mental retardation may have special financial needs, but it does not suggest that all families with mentally retarded children will experience financial difficulties.

The interviews revealed that the families were engaged in the following activities that needed financial support:

- Visits to traditional healers
- Regular hospital visits
- Clothing due to hyperactivity
- Reorganization of home to suit the needs of the child
- Fees for day care

One of the parents can be quoted saying:

- “I could not make ends meet. I still struggle to close the gaps created by having such a child in the family and it is clear that I will not make it. My other children passed grade twelve but I could not help them to further their education. I did not earn much as I was employed as a general assistant in a shop. We at times went to bed without food.”

It was found that only one parent could be employed while the other assumed the caring role, particularly the mother. This affected the family income and respondents expressed the difficulties they encountered in satisfying the financial needs of their families and those of their disabled children.

The families could not afford to educate their other children adequately due to financial constraints. The spouses of the respondents did not have decent paying jobs and therefore did not earn much to enable them to meet all their financial needs. It was also revealed that the families relied mainly on their own parents (grandparents) for financial assistance.

All the respondents were aware of the Care Dependency Grant, the Child Support Grant and the Disability Grant offered by the Department of Health and Social Development in the Limpopo province. Their children are beneficiaries of either of these grants.

The study therefore suggests that families could not manage to satisfy the financial needs of their disabled children and of the family as a whole. The financial burden of raising a child with a disability may be overwhelming. Most of the children attended the day-care centres for the first time upon receipt of the social grants from the Department of Health and Social Development. These findings are supported by Fraser, MacGillivray and Green (1991:249) when they say that the needs of many handicapped children will have financial implications.

3.3.5 THE IMPACT OF CARE-GIVING

When children are hurt, ill or disabled, they need physical and personal attention, and this has consequences for all members of the family. Anxiety may be the norm, outside commitments may be impossible and childcare duties are increased, including appointments with professionals and even periods away from home for hospital and admissions (Davis, 1993:11-12).

The aim of the investigation was to establish the kind of impact that caring for the child with mental retardation has on families.

The respondents expressed the fact that their lives were affected by the presence of the child with mental retardation. In one interview the parent had the following to say:

- “Caring affected us badly. I cannot visit other people, as he is bedwetting. My fear is that if I leave him when I go visiting, he may use the same wet blankets over and over again. I was forced to stop working as he started walking after three years. My mother in law lived with us and she assisted me with the child. She was very old and could not do heavy duties like carrying him. Despite the fact that he has grown bigger now, I still care for him as if he is a small child.”

According to Webb and Tossel (1991:168), as children grow older the difficulties for their parents increase. The children become physically more difficult to manage, and they may need extra support in coping with the changes brought about by puberty and adolescence. In some communities, parents of adult dependent children are faced with a continuing burden and fears about their children’s futures after they are no longer able to care for them (Nagler, 1990:293).

A parent confirms this during an interview;

- “He is hyperactive and breaks things. We still manage to control him. My family helps me with the care of the child. They bath and give him food when I am not available, as he cannot do that himself. We make use of a pit toilet and it is always locked, as we are afraid that he may throw himself in the toilet. He has often thrown his clothes in the toilet. Family members are therefore always alert not to let him out of their sight. I don’t know what to do because he is growing big. He will one day grow into a big man as I am also growing old. I don’t know what I will do with regards to bathing and feeding him or who will take care of him when I am no longer there. It is not easy to teach him anything as he is very fast and does not listen. We had to build a fence around our home because he goes to the neighbors and disturbs them.”

It is evident through these interviews that caring for the child with a mental handicap has never been easy for the parents who took part in the study. They were faced with a life long battle without a break. The most positive thing about them was that almost all of the parents lived together. In the majority of cases, the existence of the child did not give rise to relationship problems that could lead to marital distress and divorce.

3.3.6 SERVICES AND SUPPORT

3.3.6.1 SERVICES

The researcher needed to find out about the services families of children with mental retardation get from service providers and the support they receive from the community.

Doctors were mainly the first group of professionals mentioned by parents because they give the initial diagnosis, check on the children and serve as a link with other professions.

One of the factors which has a crucial effect on the role played by the general practitioner, is his/her reaction to parents' anxieties about the child's condition. Some of these anxieties had been presented to the GP before the child's condition had been diagnosed, by parents worried over unusual symptoms or unexplained developmental delays. Unsatisfactory responses from general practitioners could apparently have long-term effects on parents' trust and respect (Glendinning, 1986:126-127).

This is confirmed by an interview with one of the children's parents:

- "My daughter was floppy and had strange body movements. Her eyes rolled as she was rocking. She looked like a doll. The general practitioner told me that she would be fine. I believed what he said and honoured all the doctor's appointments. She was under treatment for almost twelve months, after which the general practitioner informed the family that she is not ill. He said that there is nothing more he can do to change her condition as she is mentally retarded. From that day I stopped visiting him because I was hurt and disappointed. I thought that he will bring some change in my child's life."

Other public services that include physiotherapy, occupational therapy and speech therapy are found mostly in hospitals and are not readily accessible because the children and their families live in rural areas, far from the hospitals.

It is apparent from the interviews that where health services are available, parents and their children had to travel long distances to access those services. This made accessibility to services difficult for the families under study and it resulted in many of them missing appointments.

The help available from social development departments to disabled children and their families is of two kinds: practical assistance and personal support

(Glendinning, 1986: 150). The lack of knowledge of what types of services are offered may be of concern:

- “Home-based carers are seen in the community, but I think they only visit the terminally ill patients. They have never visited my family. I came in contact with a social worker once in the hospital. A general practitioner referred me because my child was admitted in the hospital. There has never been any assistance from the department except for the disability grant that my child now receives from them”.

Without clear knowledge and understanding of the kinds of help available, parents could be very hesitant about approaching their social services department. According to Glendinning (1986:151), such knowledge can help parents to define and articulate their needs and problems. It also moulds their expectations of social services departments and, therefore their evaluations and opinions of the help they may actually receive.

The parents interviewed in this study made little reference to services provided by the social development department. Their main contact with this department is when they must apply for the social grant their children qualified for.

The involvement of schools in the lives of children with mental retardation was seen in the early years of their lives. Such children were not seen as being fit for a regular school and were sent home. Most of the parents kept them at home because they did not afford to send them to institutions or day care centres.

According to Helton and Jackson (1997:128), services should be designed to provide optimal benefit to the person with disabilities and his or her family.

The conclusion that can be reached here is that families of children with mental retardation do not see service providers as fully involved in the provision of services mostly needed by these children and their families.

3.3.6.2 SUPPORT

Many families find their social networks positive and supportive. Such support is important in a variety of ways; it provides practical assistance, distraction and has a positive effect on the self-esteem of parents (Davis, 1993: 30).

Most of the respondents in the study enjoyed support from their extended family members. They reported how their mothers and mothers in law assisted them in the care of the children. Those who lived with their mothers in law were able to attend to other family and community commitments because the grandparents looked after the children in the absence of their parents. They were often told that their children are not the only ones in the community and should not feel ashamed. Their own spouses and other children were also found to be very supportive by the respondents.

The community was found to be partially supportive. Respondents emphasized the fact that people are not the same. Some are supportive and helpful whereas others are not and they often make rude comments. The majority of them were found not to be supportive though. Statements made by some of the parents during the interviews support this fact:

- “My daughter had just joined a group of other children who travel in a kombi to different schools in another area. She is attending a day care centre for children with mental retardation. The other children she travels with attend regular schools. The centre is about forty kilometers away from our home. One afternoon, some of the children accompanied my

- daughter home. On arrival they told me that the driver of the kombi was making jokes about the child's condition all the way from school.”
- In another interview a parent indicated that she was walking behind her son and other people did not notice that they are together. She said that she was shocked to hear them pass funny remarks and were also throwing stones at him. In another incident, a community member asked him to dig a pit toilet but paid him R2.00 for the job.

The common view expressed by parents is that families who do not have children with mental retardation will never understand what they are going through. That is, it is almost impossible to get support from those families that do not have mentally retarded children. The families of children with mental retardation lived under stress because they were humiliated and stigmatized by community members.

3.3.7 COPING EFFECTIVENESS

The most common way of challenging people to change is by giving them new information. Professionals do this constantly, in providing a diagnosis, giving a test result or prescribing a treatment. In each case, new information is presented and it is usually assumed that the parent will take it in, accept it and change the way they construe the situation. However, unless the communication is done well, they may attempt to invalidate it, or they may forget much of it. This is frequently what happens, and the result is that the possibility of change is reduced (Davis, 1993:83-84).

The study revealed that families of children with mental retardation, who took part in the study, did not get clear information regarding the type of the disability and how to meet the specialized needs of their children. There was no training offered on how to care for their children. They reported that they have acquired skills on how to handle their children through their direct interaction with these children.

A parent can be quoted as follows:

- “I was told in English that my son has a problem but I cannot remember what the doctor said. I am illiterate and therefore it is not easy to understand and remember what was said”.

Another parent said:

- “My daughter, who is mentally retarded, is very difficult and does not listen to anyone in the family. It happened that she became pregnant and gave birth to a child with mental retardation as well. She and her child always fight. They even threaten to kill each other. My daughter has three children and she is stubborn and cheeks everyone in the family, including her father. We are even considering building a shack for her and her three children because they make an unbearable noise.”

It can, therefore, be concluded that families of children with mental retardation did not receive any form of training to assist them to cope with the disability and its associated specialized needs.

3.4 SUMMARY

The overall findings of the study indicate that mental retardation does have a great impact on family functioning. This is mainly due to the amount of time, energy and material resources put in to cater for the needs of the child with mental retardation. Families were as a result not in the position to educate their other children as attention was given to the child with mental retardation. It was not easy to maintain a balance between the competing needs of the family. It was also difficult for them to honour family and community commitments, as they had to look after the child. Caring for this child is not in the short term. It is a long-term process that made parents anxious as to who will look after their children in the event of their death. Roles played by other family members, like siblings, had to

change. They assumed a caring role instead of playing the role of a brother or sister.

CHAPTER 4

CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

This chapter focused on the summary, conclusions and recommendations of the study.

4.2 SUMMARY

The aim of the study was to explore the impact that mental retardation has on family functioning in the Waterberg district of the Limpopo province. This was achieved by means of a thorough literature study on the subject and the empirical study which was based on the experiences of parents of children with mental retardation.

The objectives of the study were:

- ✓ To provide a broad theoretical framework on mental retardation and family functioning.
- ✓ To explore the impact of mental retardation on family functioning in the Waterberg district, Limpopo province.
- ✓ To make recommendations based on the results of the study on the provision of services to families of persons with mental retardation.

This dissertation is divided into four chapters which are presented as follows:

Chapter 1

The chapter gives a general overview of the research project. This chapter included the introduction, goals and objectives of the study, research methodology and definition of concepts.

Chapter 2

The theoretical framework on mental retardation and family functioning is presented in this chapter.

Chapter 3

The chapter reflected the results of the empirical findings and a discussion thereof.

Chapter 4

The final chapter presents the conclusions and recommendations of the study.

4.3 CONCLUSIONS

The following conclusions are drawn from the literature study and the empirical study:

- Parents of children with mental retardation are not properly informed about the disability of their children by service providers as indicated by Fraser, *et al.* (1991: 245).
- There are no services provided to the children with mental retardation and their families.
- Siblings automatically assume a caring role. The investigation reveals that siblings assisted their parents with the care of the child with mental retardation.
- The needs of many children with mental retardation have financial implications.
- The majority of parents had an understanding of the condition of their children.
- There is no support received from the community.
- Parents enjoy support from their immediate families and other relatives.
- Parents do not have skills to help them cope with the demands and challenges presented by the child.
- The disclosure of the disability is not done soon after the birth of the child.

4.4 RECOMMENDATIONS

- Service providers should be capacitated on Mental Retardation.
- Awareness should be done in the community about Mental Retardation, its causes, treatment and how it can be prevented.
- Provision of adequate information and skills to parents of children with mental retardation to enhance coping.
- Siblings should be well informed about the condition of their disabled brother or sister.
- Service providers should facilitate the establishment of community based care services. This is done in an attempt to support families in caring for their handicapped offspring.
- Families need assistance in dealing with problems in the larger society, e.g. Stigma and isolation.
- Families must be linked with available resources, for example, the Department of Social Development for the application of social grants.
- Families need access to medical and psychological services and social workers and therapists can provide a practical assistance.
- The disclosure of the handicap must be done soon after the birth of the child and follow up visits be made by the service provider.

4.5 Future research

The researcher suggests that future research be conducted on the impediments faced by social workers in service delivery because the results revealed that respondents received little or no help from them.

REFERENCES

Alper,S.K., Schloss, P.J. and Schloss, C.N. 1994. **Families of Students with Disabilities: Consultation and Advocacy.** USA: Allyn and Bacon.

Babbie, E. 1998. **The practice of social research.** 8th Edition. London: Wadsworth Publishing Company.

Batshaw, M. L. 1997. **Children with Disabilities.** 4th Edition. USA: Paul H. Brookes Publishing Company.

Bless, C. and Higson-Smith, C. 2000. **Fundamentals of social research methods: an African perspective.** 3rd edition. Zambia: Juta.

Burke, P. & Cigno, K. 1996. **Support for families.** USA: Avebury.

Dale, N. 1996. **Working with families of children with special needs: Partnership and Practice.** London: Routledge.

Davis, H. 1993. **Counselling parents of children with chronic illness or Disability.** USA: British Psychological Society.

De Vos, A.S., Strydom, H., Fouche, C.B. and Delport, C.S.L. 2002. **Research at grass roots: For the social sciences and human service professions.** 2nd edition. Pretoria: J.L.Van Schaik.

De Vos, A.S. 2002. **Research at grass roots: For the social sciences and human service professions.** 2nd edition. Pretoria: J.L.Van Schaik.

De Vos, A. S., Strydom, H., Fouche, C.B., Poggenpoel, M. and Schurink, E. & W. 1998. **Research at Grass Roots: A primer for the caring professions.** Pretoria: J. L. Van Schaik.

De Vos, A.S. & Fouche, C.B. 1998. General introduction to research design, data collection methods and data analysis. In De Vos, A.S. 1998. **Research at Grass Roots: A Primer for the caring Professions.** Pretoria: J.L. Van Schaik Publishers.

De Vos A.S. 1998. **Research at Grass Roots: A Primer for the caring Professions.** Pretoria: J.L. Van Schaik Publishers.

Dell Orto, A.E. and Marinelli, R.P. 1995. **Encyclopedia of Disability and Rehabilitation**, 458-459. USA: Macmillan Publishing.

DSM-IV. 1994. **Diagnostic and Statistical Manual of Mental Disorders.** 4th Edition. Washington: American Psychiatric Association.

Fouche, C.B. and Delpont, C.S.L. 2002. Introduction to the Research Process. In De Vos, A.S., Strydom H., Fouche, C.B. & Delpont, C.S.L. 2002. . **Research at Grass Roots for the social sciences and human science professions.** Pretoria: Van Schaik Publishers.

Fouche, C. B. 2002. Problem formulation; writing the research proposal. In De Vos, A.S., Strydom H., Fouche, C.B. & Delpont, C.S.L. 2002. . **Research at Grass Roots for the social sciences and human science professions.** Pretoria: Van Schaik Publishers.

Fouche, C.B. and Delpont, C.S.L. 2002. **Research at Grass Roots for the social sciences and human science professions.** Pretoria: Van Schaik Publishers.

Fraser, W.I., MacGillivray, R.C. and Green, A.M. 1991. **Hallas' – Caring for people with mental handicaps 8th edition.** Oxford: Butterworth Heinemann.

Fraser, W., Sines, D. and Kerr, M. 1998. **Hallas' – The care of people with intellectual disabilities 9th edition.** Oxford: Butterworth Heinemann.

Glendinning, C. 1986. **A single door – Social Work with the families of disabled children.** London: Allen and Unwin.

Greeff, M. 2002. Information Collection: Interviewing. In De Vos, A.S., Strydom, H., Fouche, C.B. & Delpont, C.S.L. 2002. . **Research at Grass Roots for the social sciences and human science professions.** Pretoria: Van Schaik Publishers.

Grinnell, R.M. 1993. **Social Work Research and Evaluation.** Itasca: F.E. Peacock.

Hales, G. 1996. **Beyond Disability: Towards an Enabling Society.** London: Sage Publications.

Helton, L.R. and Jackson, M. 1997. **Social Work practice with families – A Diversity Model.** USA: Allyn and Bacon.

Heron, C. 1998. **Working with Carers.** London: Jessica Kingsley Publishers.

Hornby, G. 1994. **Counselling in child disability: skills for working with parents.** London: Chapman and Hall.

Kahana, E., Biegel, D.E. and Wykle, M. L. 1994. **Family care giving Across the Lifespan.** London: Sage Publications, Inc.

Kavanagh, D.T 1992. **Schizophrenia: an overview and practical handbook.** London: Chapman and Hall.

Kimpton, D. 1990. **A special child in the family – Living with your sick or disabled child.** London: Sheldon Press.

Lea, S. and Foster, D. 1990. **Perspectives on Mental Handicap in South Africa.** Durban: Butterworths Professional Publishers.

Mansell, J. and Ericsson, K. 1996. **Deinstitutionalization and community living – Intellectual disability services in Britain, Scandinavia and the USA.** London: Chapman and Hall.

Marsh, D.T. 1992. **Families and Mental Retardation – New directions in professional practice.** London: Praeger.

Mash, E.J. & Wolfe, D.A. 2002. **Abnormal Psychology.** Second edition. USA: Wadsworth Thomson Learning.

Monette, R., Sullivan, T.J. and De Jong, C.R. 1994. **Methods of Social Science Research.** USA: Rhinehart and Winston, Inc.

Nagler, M. 1990. **Perspectives on Disability.** California: Health Markets Research.

Neuman, W.L. 2000. **Social research methods: qualitative and quantitative approaches.** Pearson Education Company.
New Dictionary of Social Work. 1995. Revised comprehensive edition. USA: NASW Press.

Nicholas, L. 2003. **Introduction to Psychology.** South Africa: UCT Press.

Olkin, R. 1999. **What psychotherapists should know about disability.** London: The Guilford Press.

Oliver, M. and Sapey, B. 1999. **Social Work with Disabled People.** 2nd Edition. New York: Palgrave

Read, J. 2000. **Disability, the family and society – listening to mothers.** Philadelphia: Open University Press.

Readers Digest Oxford Complete Wordfinder: a unique and powerful combination of dictionary and the thesaurus. 1996. Oxford: Clarendon Press.

RSA. Ministry for Welfare and Population Development. **White Paper for Social Welfare.** Notice 1108 of 1997. Government gazette, vol. 386 (no. 18166). Pretoria.

RSA. 1997. **White Paper on Transforming Public Service Delivery. Notice 1459 of 1997.** Government gazette, vol.388. Pretoria.

RSA. 1997. **White Paper on an Integrated National Disability Strategy:** office of the deputy president.

RSA. Department of Health. **Policy guidelines for psychosocial rehabilitation of persons affected by mental disability.** 2nd draft (22/11/2000).

RSA. **Mental Health Act.** 2002 (Act no. 17 of 2002) Government gazette, vol. 449. Pretoria: Government Printer.

RSA. Statistics South Africa. 1996. **The People of South Africa: population census.** Census in brief. Report no. 03-01-11.

RSA. **Statistics South Africa.** 2001. Pretoria.

RSA. 1996. **The Constitution of the Republic of South Africa.** Act no. 108 of 1996.

RSA. 2001. **Education White Paper 6 – Special Needs Education.** South Africa: Department of Education.

RSA. 1996. **The Choice of Termination of Pregnancy Act.** Act no. 92 of 1996.

Seligman, M. & Darling, R.S. 1989. **Ordinary families, special children: a systems approach to childhood disability.** London: The Guilford Press.

Snyman, I. 1993. **Children and Families in Distress: Working Papers from a Seminar held on 25-26 July 1991.** Pretoria: HSRC.

Strydom, H. 2002. Ethical aspects of Research in the Social Sciences and Human Service Professions. In De Vos, A.S., Strydom, H., Fouche, C.B. and Delpont, C.S.L. 2002. **Research at Grass Roots for the social sciences and human science professions.** Pretoria: Van Schaik Publishers.

Strydom, H. & Venter, L. 2002. Sampling and Sampling Methods. In De Vos, A.S., Strydom, H., Fouche, C.B. and Delpont, C.S.L. 2002. **Research at Grass Roots for the social sciences and human science professions.** Pretoria: Van Schaik Publishers.

The New Book of Knowledge, 1995. Vol. 6 f. USA: Grolier Incorporated.

Webb, R. & Tossell, D. 1991. **Social issues for carers: a community care perspective.** London: St Edmundsbury Press Limited.

Wicks-Nelson, R. and Israel, A.C. 1997. **Behavior disorders of childhood .3rd** edition. New Jersey: Prentice Hall.

World Health Organization. 2001. **ICD – 10 Guide for Mental Retardation: division of Mental Health and Prevention of Substance Abuse.** Geneva.

ANNEXURE

ANNEXURE 1

PERMISSION TO CONDUCT RESEARCH

ANNEXURE 2

CONSENT FORM

ANNEXURE 3

SEMI-STRUCTURED INTERVIEW SCHEDULE

CONSENT FORM

I (full names) -----
hereby give consent to participate in a research study as a respondent after I have satisfied myself with the following:

1. The title of the study is the Impact of Mental Retardation on Family Functioning.
2. The purpose of the study is to explore the impact of Mental Retardation on Family Functioning in the Waterberg district.
3. I will be asked to respond to questions in an interview conducted by the investigator.
4. This study may lead to emotional harm and I understand that the researcher will conduct a debriefing session within seventy two (72) hours after the interview.
5. There are no financial gains to me for participating in this study.
6. I may withdraw from participating in the study at any time.
7. The investigator may use a tape recorder to capture precisely what I say and I understand that the information will only be accessible to the researcher. My identity will not be revealed in the research report.
8. Should I have questions or concerns about the study, I can call Mrs. N. E. Pilusa at house number 24 Asbestos Street, Chroompark, Mokopane or contact her at the following numbers: (015) 409 2000, during working hours, or 084 466 8212.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Subject Signature

Date

Signature of Investigator

Date

SEMI -STRUCTURED INTERVIEW SCHEDULE

The purpose of this interview schedule is to collect qualitative data from the parents of children who have mental retardation. The parents will be selected from the registers of the children attending three day-care centers at Mahwelereng, ga-Madiba and Tshamahanzi. The children must have been attending the day care centre for the past three months.

1. Will you please explain your understanding of mental retardation?

2. Please tell me how you came to know about the disability of your child.

3. How would you describe your reaction when you first learnt about your child's disability?

4. Can you describe the reaction of other family members to the disclosure of mental retardation?

5. How did you and your partner handle the financial consequences of rearing a child with a mental retardation?

6. May you describe the impact that caring for this child has on the family?

7. Do you find professionals/service providers involved? If so, please explain how.

8. How accessible is a comprehensive and coordinated system of community-based care in your area?

9. Can you describe the form of support you receive from the community?

10. Do you or your families have the necessary skills that will enable you to meet the specialized needs of your child and general skills to enhance coping effectiveness? Explain your answer.

THANK YOU FOR YOUR COOPERATION