COMMUNITY CARE OF MENTALLY RETARDED CHILDREN: AN EXPLORATORY STUDY OF SUPPORT SYSTEMS

by

ESTHER NOZIZWE CHINKANDA

Submitted in fulfillment of the degree

DOCTOR OF PHILOSOPHY

in

SOCIAL WORK

in the

FACULTY OF ARTS

at the

UNIVERSITY OF THE NORTH

STUDY PROMOTOR: PROFESSOR M. BOPAPE

PIETERSBURG

AUGUST 1987

[redacted]

[redacted]

ACKNOWLEDGMENTS

Throughout my many setbacks and disappointments during the course of this study I was blessed with the assistance and support of many people who went out of their way to help me. I can mention but a few by name, but I am thankful to all:

- To my promotor Professor M. Bopape, who sacrificed many hours of his time to guide and support me throughout this project: this will always be appreciated.

- The President of the Human Sciences Research Council for his permission to use, in this study, data collected by the author in a HSRC study on support systems of mothers of mentally retarded children.

  The opinions expressed and conclusions reached here are those of the author however, and should under no circumstances be regarded as representing the opinions or conclusions of the Human Sciences Research Council.

- The Human Sciences Research Council and the University of the North for financial assistance.

- I am grateful to the friendly and helpful staff of the Pretoria and Northern Transvaal Mental Health Society who made their confidential records available for this study. A special word of gratitude to Mrs S. von Staden, the Director, and Mrs A. Dube (social worker), for availing themselves for interviews and again to Mrs von Staden for reading a portion of the manuscript.

- I am likewise grateful to my friends and colleagues and more especially to Chris van der Burgh, Rhoda Muller, Annatjie Paul and Tebogo for their fruitful suggestions and support.

- To Margaret Bennetts and Xandra de Fortier for their personal interest and for checking the language.

My special thanks to Elize Beukes who typed the manuscript with care, speed, accuracy and patience.

A final word goes to my mother and sisters for listening to my complaints and sharing in my triumphs and to my daughter Niki for her love, patience and encouragement.

ESTHER NOZIZWE CHINKANDA

August 1987

ABSTRACT

As the population of any country increases as in South Africa, so the number of mentally retarded children who require care and the use of specialized services also multiplies. Governmental departments and welfare organisations cannot continue to carry the financial responsibility of caring for these persons on their own indefinitely. There is a need for the different communities to share in the responsibility of caring for the mentally retarded.

Community care of the mentally retarded refers to the care of these persons within their own families in conjunction with support from the community. The persons who assume the responsibility of this supervision are the mothers or any female member of the family assigned to the task. The mothers/caregivers of mentally retarded children have to cope with the daily tasks of caring for the children as well as to supervise their other needs such as health, education and welfare.

There is a stage beyond which the mothers of these children cannot cope on their own and then require the assistance of those within their own families as well as outsiders. These sources of assistance (support) are referred to as formal and informal support systems.

This study was aimed at identifying the specific systems which proffered support to black mothers of mentally retarded children in Atteridgeville and Mamelodi; assessing the size and composition of the mothers' social network, identifying those systems which had a negative effect, ascertaining the level of the mothers' knowledge of community services and finally, identifying those cases where the institutionalization of the children was preffered by the mothers/caregivers.

A sample of 80 mothers was drawn from a population of 148 mothers of mentally retarded children who formed part of the case records of the social worker of the Pretoria and Northern Transvaal Mental Health Society assigned to Mamelodi and Atteridgeville. The sampling method employed was the non-probability quota sampling technique.

The data was collected through a literature study, interviews held with the Director of the Pretoria and Northern Transvaal Mental Health Society and the social worker assigned to the area and interview schedules administered to the sample by the researcher and five qualified social workers.

The main findings of the study were that mothers of mentally retarded children were in need of material (financial) and instrumental (practical) aid and that their main sources of support were the mothers' siblings and grown-up children. The main types of support received were emotional and instrumental. Bathing, dressing the children and doing laundry were the main tasks with which help was required.

EKSERP

Namate die bevolking van 'n land aanwas, soos in Suid-Afrika die geval is, neem die aantal verstandelik gestremde kinders wat versorging en die benutting van gespesialiseerde dienste benodig ook toe. Staatsdepartemente en welsynsorganisasies kan nie onbepaald voortgaan om die finansiële verantwoordelikheid vir die versorging van hierdie persone alleen te dra nie. Die behoefte bestaan dat die gemeenskappe die verantwoordelikheid van die versorging van verstandelik gestremdes moet deel.

Gemeenskapsversorging van die verstandelik gestremde impliseer die versorging van daardie persone binne hulle eie families, met die ondersteuning van die gemeenskap. Die persone wat die verantwoordelikheid van hierdie toesig aanvaar is die moeders of enige vroulike familielid aan wie die taak opgedra is. Die moeders/versorgers van verstandelik gestremde kinders moet benewens die behartiging van die daaglikse versorging van die kinders ook toesien dat in ander behoeftes met betrekking tot gesondheid, opvoeding en welsyn voorsien word.

'n Stadium word bereik wanneer die moeders van hierdie kinders net nie meer alleen die mas kan opkom nie en hulle die bystand van ander familielede sowel as van buitestanders benodig. Na hierdie hulpbronne word verwys as formele en informele ondersteuningsnetwerke.

Die oogmerk van hierdie studie was om die spesifieke ondersteuningsnetwerke wat bystand aan swart moeders van verstandelik gestremde kinders in Atteridgeville en Mamelodi verleen, te identifiseer; om die grootte en samestelling van die moeders se maatskaplike netwerke te bepaal; om daardie netwerke wat 'n negatiewe uitwerking het te identifiseer; om die moeders se mate van kennis aangaande gemeenskapsdienste te bepaal en laastens om daardie gevalle waar die moeders verkies dat die kinders in 'n inrigting opgeneem word, te identifiseer.

'n Steekproef van 80 swart moeders is uit 'n groep van 148 moeders van verstandelik gestremde kinders getrek wat deel uitgemaak het van die gevallerekords van die maatskaplike werker van die Pretoria en Noord-Transvaal Geestesgesondheidvereniging aan wie die Mamelodi en Atteridgeville-area toegewys is. Die steekproefmetode wat gebruik is, is die nie-waarskynlikheidskwota steekproef tegniek.

Data is versamel by wyse van 'n literatuurstudie, onderhoude met die direkteur van die Pretoria en Noord-Transvaalse Geestesgesondheidsvereniging en die maatskaplike werker aan wie die area toegewys is asook deur onderhoudskedules wat deur die navorser en vyf gekwalifiseerde maatskaplike werkers in die steekproef gebruik is.

Die belangrikste bevindinge van die studie was dat daar 'n behoefte aan materiële (finansiële) en diensbare (praktiese) ondersteuning by moeders van verstandelik gestremde kinders bestaan en dat hulle hoofbron van hulp dié van hul eie broers en susters en volwasse kinders was. Die belangrikste tipe van bystand wat ontvang is, was van emosionele en praktiese aard. Die bad en aantrek van die kinders en die was van hulle wasgoed was die belangrikste take waarmee hulp benodig is.

TABLE OF CONTENTS PAGE

CHAPTER I

INTRODUCTION

CHAPTER 2

MENTAL RETARDATION : AN OVERVIEW

CHAPTER 3

AN OVERVIEW OF THE PRETORIA AND NORTHERN TRANSVAAL MENTAL HEALTH SOCIETY WITH SPECIFIC REFERENCE TO SERVICES IN MAMELODI AND ATTERIDGEVILLE

TABLE OF CONTENTS (continued) PAGE

CHAPTER 4

THE RETARDED CHILD AND HIS FAMILY

CHAPTER 5

SOCIAL NETWORKS AND SOCIAL SUPPORT SYSTEMS : AN OVERVIEW

CHAPTER 6

SOCIAL NETWORKS AND SUPPORT SYSTEMS FOR MOTHERS OF MENTALLY RETARDED CHILDREN

CHAPTER 7

FINDINGS AND CONCLUSIONS

TABLE OF CONTENTS (continued) PAGE

CHAPTER 8

SUMMARY AND RECOMMENDATIONS

TABLES IN THE STUDY

TABLES IN THE STUDY (continued)

CHAPTER 1

INTRODUCTION

1.1 MOTIVATION FOR THE CHOICE OF SUBJECT

The researcher's interest in the care of the mentally retarded was aroused in 1980 when she was doing a study in an agency dealing with mentally ill and mentally handicapped clients (Chinkanda 1981). In this study mention was made of the fact that social work treatment of the mentally retarded involved the family to a very large extent because of the nature of the ailment the client was suffering from. The case records did not specify the nature and extent of the family's involvement.

The researcher's curiosity was further aroused with regard to what support was available to the family to enable them to cope with caring for a disabled child at home. This curiosity is reflected in the researcher's writings in the field*.

Until recently, most mentally retarded children were cared for only in institutions. This caring activity is increasingly being attended to by the community specifically by the families involved. Within the family the mother is the one who carries the actual responsibility of the day to day caring activities. Wilkin (1979:28) explains the situation by stating that "community care rests very heavily on the family, and family care rests equally heavily on the assumptions about the role of women in the home and in society at large ..." In some societies these roles may have undergone changes but in black families in South Africa, there is still a very clear division of domestic work

---

* 1. Chinkanda, E.N. Prejudicial attitudes towards the mentally retarded: A challenge for social work. Social Work/Maatskaplike Werk Vol 19(3), 1983:138-141.

2. Chinkanda, E.N. Caring for a mentally retarded child at home. Maatskaplike-Praktyk/Social Work Practice Vol. 31, 1986:6-9.

with the female doing most of it irrespective of whether she is in a full-time job or not.

There has been a great deal of concern expressed both locally and abroad concerning the increasing number of persons dependent upon the state for care on the one hand, and on the other hand there is concern regarding the gradual depletion of the resources of the state. The helping professionals and government departments have increasingly come to realize the importance of the role played by social networks and their supportive roles or their potential for support (Froland, Pancoast, Chapman, Kimboko 1981(b)).

Again community involvement in the case of the handicapped and the integration of the handicapped in the community can only occur if they are cared for within their own communities and not in remote institutions.

Community supports, when given their rightful recognition by helping professions as being basic structures and sources of help have a great potential for innovation and commitment in maintaining health and providing needed human services (The Presidents Commission on Mental Health 1978). Helping professions and government departments can ill afford to waste such valuable resources.

1.2 PROBLEM FORMULATION AND HYPOTHESIS

There has been an almost incredible awakening of the public conscience in the past decade concerning mental retardation. Not only was the care of the mentally retarded focused upon but there was a change of direction away from institutionalising these persons to having them live within the community (Ayer, Alaszewski 1984; Glendinning 1986).

More and more families care for their mentally retarded members themselves because of dissatisfaction with institutions. This dissatisfaction is often a result of the following:

(i) In most cases institutions are situated far away from the homes of the residents.

(ii) There are only a few institutions available, especially in the case of Blacks in this country. This often leads to overcrowding viz. large numbers of residents being cared for by one person who cannot cope adequately with all the needs of her charges (in 1984 there were four institutions for black mentally retarded persons in South Africa).*

(iii) Due to the lack of sufficient institutions a family sometimes has to wait for long periods before their disabled child is admitted to an institution. The family remains in a transitional period pending the placement of their disabled child and such a situation is not conducive to adjustment to and acceptance of the disabled child. This can cause much stress in the family.

(iv) Institutions tend to promote the isolation of the disabled and to accentuate the fact that they are different.

Parents who undertake to raise their mentally retarded child at home accept an enormous responsibility. The actual daily caring activities are attended to by the mother because of her socially prescribed role. She provides the majority of the labour and tends to take on extra work involving caring for the handicapped child.

Due to the enormity of the task, there is a point beyond which the mother of the retarded child can no longer assume her expected role towards the said child and toward the other family members without aid. This help should be forthcoming both from within her family and from the wider community. The mother needs support in order to cope with the child and make it possible for him to live as full a life as his disability will allow while she and the rest of the family also live a satisfying and healthy life.

The following questions are then raised:

---

* Facilities for mentally retarded persons 1984. South African National Council for Mental Health. Johannesburg.

(i) What sources of support are available to the mother of the mentally retarded child?

(ii) In which areas does the mother require aid and with what tasks does she need help?

(iii) What types of support does she receive and what are the sources of the support?

(iv) Who gives most of the support?

It is hypothesized that there are certain persons and institutions who form part of the social network of the mother/caregiver of a mentally retarded child who give certain types of social support to enable her to care for the mentally retarded child at home.

1.3 AIMS OF THE STUDY

The study aims at:

(a) Identifying the social support systems utilized by black mothers/caregivers of mentally retarded children in the Atteridgeville and Mamelodi areas;

(b) assessing the size and composition of the mother's social network and those network members who can be perceived as potential social support systems;

(c) ascertaining the level of the mother's/caregiver's awareness of formal support systems and the extent to which they are utilized;

(d) identifying those systems which have a negative effect, and

(e) identifying those cases where the mothers preferred institutionalisation of their children.

1.4 RESEARCH DESIGN AND METHODOLOGY

This study is essentially exploratory in nature. It aims at finding out about the broad issues concerning the help required and received by mothers who care for their mentally retarded children at home. According to Babbie (1983) exploratory studies are done to satisfy the researcher's curiosity and desire for better understanding and to test the feasibility of undertaking a more careful study. The third reason given by Babbie (1983) for doing exploratory studies is to develop the methods to be employed in a more painstaking study.

One can safely say that this study was undertaken for the first two reasons and that those objectives have been realized. The study has raised questions about family/community care as an alternative to institutionalisation and the actual support available for the mother of the mentally retarded child with regard to successful family care.

The methodology of the study encompassed not only the empirical component but also additional activities in which the researcher engaged in order to endeavour to expand her knowledge of the following : the field of mental retardation and the issues surrounding the care of a mentally retarded child at home; the concepts of social support systems and social networks; social science research and social work research. The purpose was to lay a sound foundation on which the investigation is based.

Another activity engaged in was the conducting of an interview with the Director of the Pretoria and Northern Transvaal Mental Society and the social worker of the society assigned to Mamelodi and Atteridgeville.

The empirical component of the study included an interview schedule for the mothers of mentally retarded children in the sample.

1.4.1 Pilot study

A pilot study was conducted by the researcher two months prior to the main study and this exercise provided valuable material which led to adjustments not only to the interview schedule but also to the times at which respondents should be visited.

Because the questions were in English and had to be translated into two black languages,* after the pilot study was completed some questions had to be rephrased so that they could be translated while retaining their original meaning. An example of such a question was: "What is your present marital status?" In the local black languages one cannot speak of marital status without specifically mentioning whether the person is married or not. This question was then re-phrased to read: "Which of the following best describes your situation? Married, Never married, Divorced/Deserted, Widowed."

A sensitive question such as (Question 72): "Describe how you felt/reacted when you discovered/were told of the child's impairment" was altered from its original place under the section: "Mother's Experiences" towards the end of the interview schedule (see Annexure A; Chinkanda 1985).

It also became clear that certain questions would require verification questions for example question 38(j) verifies questions 38(a) to 38(i); question 39(j) also verifies questions 38(a) to 38(i), question 50 column 67 verifies all the columns for question 50; question 51 column 76 verifies all the columns in questions 51; and question 53 column 17 verifies all the columns in question 53.

1.4.2 Main study

The interviews were conducted by the researcher and five qualified social workers who were deemed to be experienced in their different fields of practice and were familiar with the area in which the study was undertaken.

---

* Although several black languages are used in the Pretoria area, the questionnaire was translated into Zulu and Northern Sotho.

Two training sessions for the fieldworkers were held during which the entire interview schedule was dealt with.

The assistance of the Indigenous Languages staff of the Opinion Survey Centre of the Human Sciences Research Council was invaluable in standardising the translation of the questions. The questions were translated into Zulu and Northern Sotho which are the major languages used in the relative areas.

The translations were part of the training sessions which included tuition in coding and transferring codes into the appropriate columns. Other aspects discussed during the training sessions were research ethics, mode of dress and differences between a research interview and a therapeutic interview.

The interviews were conducted over a period extending from 8 to 10 months during the second half of 1985 and early 1986.

1.5 SAMPLING

The sample for the study was drawn from the files of the social worker of the Pretoria and Northern Transvaal Mental Health Society. This social worker is assigned to Mamelodi and Atteridgeville townships.

There were 148 files available from which a 54 % sample was drawn.

The sample drawn consisted of 48 cases in Mamelodi and 32 in Atteridgeville. The sampling technique employed was the non-probability quota sampling technique. This technique is an equivalent of stratified sampling but here there is an added requirement in that each stratum is represented in the sample to the same proportion that it is represented in the population.

This sampling technique was chosen because the candidate wished to obtain a sample that would contain mothers of different age groups, mothers of different marital statuses; children of different sexes and age groups. This was done to ensure that older as well as younger mothers of different marital statuses were included in the sample as well as children of different age groups and both sexes. During the original planning the child's level of retardation was considered as a characteristic to be included, but while drawing up the sampling matrix for the pilot study the candidate realized that not all the files had this information available. The same applied to the educational background of the mothers. These characteristics were excluded and the information was obtained at a later stage (see Tables 1.1 and 7.1).

The following is the sampling matrix constituted for drawing up the sample:

TABLE 1.1 : MATRIX FOR DRAWING OF THE SAMPLE

Mother		Child			
	Marital	Male		Female	
Age	Status	14 and above	Below 14	14 and above	Below 14
	Single				
	Married				
	Living together				
	Widow				
	Divorced/ Deserted/ Separated				
	Single				
	Married				
	Living together				
	Widow				
	Divorced/ Deserted/ Separated				

A matrix such as this was drawn for each area. If a category consisted of one or two children these were included in the sample. Where there were three children the middle one was included and in the case where there were four or five every second one was included. In categories with six or more children, every third child was included.

A number was placed against each name and address and the numbers were used for drawing the sample. If a given category had the following numbers, for example, 7, 15, 16 and 30; the numbers 15 and 30 would be included in the sample.

The final sample drawn was as follows:

TABLE 1.2

SAMPLE DRAWN IN RELATION TO UNIVERSE AND RESIDENTIAL AREA

Area	Universe	Sample
Mamelodi	95	48
Atteridgeville	53	32
TOTAL	148	80

1.6 CONCEPTUALISATION

The following are the major concepts used in the study:

1.6.1 Mentally retarded child

Throughout the entire study the terms mentally retarded, handicapped or disabled child are used interchangeably to refer to a child whose intellectual development has been arrested at a certain stage of life and is therefore not corresponding to his chronological age; such a condition having led to his inability to function independently in society. Such children have also been referred to in the study as 'the retarded' or 'retardates'.

A detailed definition of mental retardation, its causes and a description of the behaviour characteristics of the different groups is given in Chapter 2.

1.6.2 Social network

In this study the concept social network is used to refer to persons whether related to the respondent or not and to persons attached to certain community institutions with whom the focal individual is in contact. A further explanation of the concept is found in Chapter 5.

1.6.3 Social support systems

Social support systems or simply support systems are defined as those individuals, groups or professionals who may or may not be related to the focal person or who may or may not be attached to a governmental agency who provide certain forms of assistance to enable the focal person to cope with a problem.

The support provided may be instrumental, emotional or it may take the form of giving advice or feedback on behaviour. The support is aimed at making the recipient feel loved and needed.

A further discussion of the concept will be found in Chapter 5.

1.6.4 Mother

The terms 'mother' and 'caregiver' are used interchangeably to refer to an adult female who may or may not be the biological parent of the mentally retarded child who normally assumes the role of caring for this child.

1.6.5 Community care

The meaning of 'community care' has undergone changes since it was first used at the turn of the century. Community care has been defined as:

(a) an alternative to institutional care through the development of small-scale residential facilities administered by local authorities. This type of care is for those handicapped persons who can no longer be cared for by their families;

(b) integration of the mentally handicapped within the community. The focus is on societal reaction to and the labelling of a person who is different. Integration is seen as offering the handicapped an opportunity to gain self-confidence and the socially required skills for dealing with non-handicapped people;

(c) care by the community made possible by the development of a network of mutual aid and by teaching self-help (Ayer, Alaszewski 1984; Glendinning 1983, 1986; Wilkin 1979).

For the purpose of this study community care is defined as care of the mentally retarded child within his family (by his mother/caregiver) with support from formal and informal networks in the community. This form of care aims at integrating the mentally retarded child in the community.

1.7 LIMITATIONS OF THE STUDY

In any study the researcher is forced to deal with a variety of unexpected problems. The very selection of a research design involves the sacrifice of some desiderata in order to retain others.

In this study the extent of the representativeness of the sample and that to which generalisation can be applied has been limited by the selected sampling technique. While the candidate concentrated on the different characteristics of the mothers and of the children which she wanted to consider for the sampling matrix, the aspect of randomness was sacrificed in drawing the sample.

The study universe itself is not necessarily a reflection of the number of mentally retarded children in the two areas. Only those who are known to the social worker were in the case files.

Not all the case files had information on the level of the child's retardation and on the educational level of the mother and this information was thus excluded from consideration for the sampling matrix. This situation therefore resulted in the final sample consisting of a high proportion of mildly retarded children. This has had an effect on the findings whereby the impression gained was that a large number of the mothers did not require help and this notion is due to the high level of independence of children who are mildly retarded.

1.8 DATA ANALYSIS

Each record (interview schedule) consisted of four cards i.e. there was a total of 320 cards.

The data were cleaned by possible-punch cleaning and contingency cleaning (Babbie 1983:346-348). Possible-punch cleaning ensures that only those codes assigned to particular attributes appear in given columns. Contingency cleaning on the other hand is a process of checking to see that only those cases that should have data on a particular variable do have the data. For example in this study if the response to question 33 was code 7 then the response to question 34 could not be code 1 or code 2.

The size of the sample precluded advanced statistical analysis of the data and the presentation is therefore a descriptive one.

1.9 PRESENTATION

With the exclusion of chapter one, the study is presented as follows:

Chapter 2 gives an exposition of the history, treatment and care of the mentally retarded. Mental retardation is defined in detail and the various causes are also discussed. The different levels of retardation and the behavioural characteristics of each level are outlined.

Chapter 3 consists of background information on the agency from which the case files for drawing the sample was obtained. Services rendered by the branches in Atteridgeville and Mamelodi are singled out for detailed discussion.

Chapter 4 discusses the family of a mentally retarded child and the problems which they have to cope with.

Chapter 5 consists of a detailed discussion of the major concepts used in the study, i.e., social networks and social support systems.

In Chapter 6 the support systems of the mother of a mentally retarded child are identified.

Chapter 7 outlines the findings of the empirical study.

Chapter 8 presents the discussion and recommendations flowing from the findings.

Included in the description of the findings are several tables.

CHAPTER 2

MENTAL RETARDATION : AN OVERVIEW

2.1 INTRODUCTION

Mental retardation has been in existence for as long as human beings have inhabited the earth. The unfortunate humans who are known as the mentally retarded have been given various labels throughout the centuries. At first they were regarded with a lot of superstition which resulted in harsh treatment. Due to advancement in research and technology the mentally retarded person is now regarded as a being as human as any mortal. It is now recognised that he is entitled to basic human rights and is allowed to live as comfortably as any other normal person in as far as his condition will allow.

The mentally retarded individuals are often subjected to treatment which reflects that they are misunderstood by society in general. Societal attitudes have demonstrated a gradual change due to better understanding of these individuals.

In this chapter we shall study the history of the care and treatment of the mentally retarded which is then followed by the definition and various classifications. Issues pertaining to labelling, etiology and prevalence will be discussed later in the chapter.

2.2 BRIEF HISTORY OF THE CARE AND TREATMENT OF THE MENTALLY RETARDED

For the purpose of this discussion, the history of the care and treatment of the mentally retarded will be divided into five eras. The time periods of these eras overlap and the latter part of this section concentrates mostly on the American scene as this country seems to have the most outstanding legislation pertaining to the mentally retarded (Gearheart, Litton 1979:1). The five eras are as follows:

I. Early history : the era of superstition

II. Nineteenth century : the era of institutions

III. Early twentieth century : the era of public school special classes

IV. The 1950s and 1960s : the era of legislation and popular concern for the retarded

V. The 1970s : the era of normalization, litigation and comprehensive legislation

2.2.1 <u>Early history : the era of superstition</u>

The Spartans of ancient Greece (1552 BC) and the Romans (449 BC) were the first to make mention of the fact that there were 'fools', 'idiots' or 'monsters' in society. The mentally retarded were referred to in these terms and during that period there was little knowledge to guide towards the differentiation between the mentally retarded and the deaf mutes. In both Sparta and Athens the mentally retarded were treated very harshly because the Greeks at that time strongly emphasized physical and mental fitness. The mentally retarded were regarded as societal rejects and were either left to die of exposure, or were thrown off mountains or even drowned in rivers.

In Rome the retardates were used as court jesters for the entertainment of nobility. All mentally retarded and deformed persons were often chained and kept in dungeons where they eventually died.

During the fourth century, Christianity provided hope for these less fortunate members of society. The name of St. Nicholas came to the fore as the patron of the retarded. In Belgium, many idiots migrated to a place called Gheel where they received good treatment and there was talk of being able to cure the condition. When the miraculous cure did not materialize many of the local wealthy took these 'idiots' into their homes and cared for them.

From the thirteenth century onwards, most Catholic churches in Europe took the mentally retarded into their care and provided asylums for them. The Protestant Reformers on the other hand had a different view of the mentally retarded. They saw them as being demon-possessed and 'filled with Satan'. Both Luther and Calvin saw the retarded as

Godless (Gearheart, Litton 1979). These notions often led to the harsh treatment of the retarded. Many were tortured, punished and tormented; the intent being to exorcise them.

The attempts at education undertaken by the Catholic monks were aimed mostly at training them to care for themselves. This however was a step forward from just custodial care and viewing the retarded as wards of the church who could not do anything for themselves.

2.2.2 Nineteenth century : the era of institutions

The change in attitude towards the mentally retarded in Europe led to an awakening from medieval superstition. This in turn led to attempts by Pinel to treat the mentally ill and insane as curable patients; to Pereire's scientific instruction of the deaf mute; to the education of the visually handicapped by Braille and to Itard's scientific individual educational approach towards the mentally retarded.

Gradually society adopted the idea of institutionalisation of the mentally retarded. This shift in attitude towards the care and treatment of the mentally retarded with a focus on education was a result of the work of Itard. In 1799 Itard made attempts to educate a boy (later known as Victor or the Wild Boy of Aveyron) who had lived like an animal in the forest. Itard devoted five years towards the education of this boy because he would not accept an earlier diagnosis by Pinel that the boy's condition was incurable and irreversible.

Itard devised a five-point programme which concentrated on the development of the functions of the senses, training of the intellectual skills and control of emotions (Gearheart. Litton 1979). He eventually admitted to the incurability and irreversibility of Victor's condition but he had made minor strides in the boy's social behaviour. The work of Itard was seen as significant to the educational science of the time (Levinson 1967:46).

Sequin, a student of Itard, continued with work on the mentally retarded by also educating a single boy. He attained success in his venture and in 1842 he was made director of a school for idiots -

Bicêtre in Paris. Seguin's work attracted attention from all over the world, especially the United States. In 1846 his book 'The Moral Treatment, Hygiene and Education of Idiots and Other Backward Children', was published.

The socio-polictical spirit of the day had a profound influence on the success of Sequin's work. Charitable organizations were formed to protect the interests and rights of all individual human beings as a result of the work of Henri Saint-Simon. There was also a gradual change in the traditional educational practices of the day. The names of Rousseau, Sicard and Condillac were foremost during this period.

In 1850 Sequin emigrated to the United States when Louis Napoleon came into power. He played a major role in establishing new residential facilities for the mentally retarded in New York, Massachusetts, Pennsylvania, Ohio and Connecticut. In 1876 he served as the first president of the newly established Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons which was later to evolve into the American Association on Mental Deficiency.

Further developments in Europe took place in Switzerland. A Swiss physician, Jacob Guggenbühl, took an interest in cretins. He had read extensively about cretins but observed that little mention was made of the remediation of the condition. He was given a piece of land near Adendberg where he built several structures and provided therapeutic care, which included healthy and beautiful surroundings, physical care of the body and a good diet.

His work was hailed as a new approach towards the care of cretins, and it attracted a lot of attention from Germany, Austria, Great Britain, the Netherlands and the Scandinavian countries. Although he became internationally known through his publications it was realized, however, that not one of the cretins was ever cured. Many sponsors withdrew their support and complaints poured in which led to an investigation. The Center was eventually closed. Although he, like Itard, operated on an erroneous premise,

> ... Guggenbühl must be acknowledged as the indisputable originator of the idea and practice of the institutional

> care for feebleminded individuals. The hundreds of institutions now in existence derive in direct line from the Adendberg (Kanner 1964:6).

From the 1840s, both private and public institutions were established in countries across Europe (Germany 1845, England 1846, Netherlands 1855, Hungary 1875 and Italy 1889), and as far as Japan in 1900.

On the American scene, things happened a little faster because as early as 1650 colonial America (Maryland) had a law authorizing the appointment of guardians for feeble-minded children. Funds were made available to those who cared for the feeble-minded, but as yet there were no facilities available. Prior to 1848. the feeble-minded were housed together with the deaf and dumb in an asylum in Hartford, Connecticut.

The first institution set up exclusively for the care and education of the retarded was in Massachusetts. Pioneering work here was done by Wilbur of Barre, who took a keen interest in the works of Seguin. He became head of the first New York State Training School in Albany. Later, Howe, after visiting Guggenbühl's Adendberg and probably Seguin's Bicêtre, reported that there was a need for private and state-supported institutions for the mentally retarded (Gearheart, Litton 1979).

This led to the founding of the second state institution in New York in 1851. Several institutions followed thereafter - Illinois 1865, Iowa 1877, Indiana 1879, California 1885, Maryland 1888, Montana 1896, et cetera. The major goal for the founding of these institutions was the remediation of mental deficiency so that patients might return to the community. Most of these institutions employed Seguin's physiological methods for treatment.

Seguin's influence on the American care of the retarded is overwhelming. He actively participated in the establishment of the first four institutions; he provided many excellent instructional techniques for the education of the retarded, and he served as the first president of the group of institutional superintendents.

2.2.3 Early twentieth century : the era of public school special classes

It was not until 1894 that the first special class was formed in an American public school system. Germany was the first to establish such classes in 1870. The establishment of these classes was not exempt from the problems which often accompanied the plight of the mentally retarded. The running of such classes was more expensive than that of regular classes.

Because the Stanford-Binet test was not widely used prior to 1916, this resulted in the inclusion of children other than those with intellectual problems in these classes. The use of these tests led to the grouping of the pupils according to their level of intelligence and this soon produced modified curricula and the use of different teaching materials by teachers with specialized training.

As school attendance became compulsory, many states enacted statutes designed to promote the establishment of special classes for the mentally retarded in public schools.

Gearheart and Litton (1979:9) mention the following factors which influenced the development of special classes for the mentally retarded:

a. The total number of children for which provision must be made is relatively large;

b. the instructural costs were high compared to normal classes;

c. there were enormous administrative costs especially in small rural areas;

d. in the early stages it was common to confine special classes to elementary level because few pupils went beyond this level. Most schools did not provide for or did not know what programmes were required for adolescents;

e. the establishment of parent groups in the late 1940s and early 1950s also affected public school development of special classes for the retarded, and

f. compulsory education legislation led to school districts being accountable for school attendance of the mentally retarded in their respective areas and this led to a boom of special classes.

While the number of classes for the retarded increased considerably in the 1920s, it decreased during years of World War II and then rapidly increased again in the 1970s.

2.2.4 The 1950s and 1960s : the era of legislation and popular concern for the retarded

A new type of treatment for the mentally retarded emerged out of the educational movement. Numerous vocational programmes were designed during the 1940s to develop the abilities of handicapped people in selected vocational areas (Payne, Mercer 1975). These programmes were designed for those who were later classified as TMR (trainable mentally retarded). It was estimated that about 87 % of the mentally retarded were employable and that they could benefit from these special programmes.

Public awareness of the mentally retarded was provoked by President Kennedy, who appointed a panel in 1961 to which he gave a mandate to prepare a national plan to help meet the complex problem of mental retardation. The panel presented its 200 page report in 1962. This report had over 90 recommendations in the areas of research, prevention, clinical and medical services, law, education; local, state and federal organization.

In 1966 President Lyndon Johnson appointed a President's Committee on Mental Retardation to promote national planning and to mobilize basic programmes in the field of mental retardation.

An abundance of legislation was passed during this era (1954-1963) to ensure the care, treatment and education of the retarded.

2.2.5 The 1970s : the era of normalisation, litigation and comprehensive legislation

The era of the 1970s saw a great deal of improvement in the care of the mentally retarded. Legislation and litigation on behalf of the mentally retarded led to the recognition of the fact that the mentally retarded have a rightful place in society and not in confining institutions.

The principle of normalisation and the principle of the least restrictive environment led to major changes in the care and treatment of the mentally retarded. Briefly, the principle of normalisation required that services for the mentally retarded be provided at community level; that educational and training programmes be integrated with those of normal individuals; that the mentally retarded be provided with residential facilities in small units resembling homes; and that there be daily contact between the mentally retarded and normal persons on the social as well as vocational level.

In 1971 the U.N. adopted a seven point Declaration of the Rights of Mentally Retarded Persons. This declaration further enhanced the principle of normalisation in as far as its concentration on the rights of the mentally retarded to proper education, care, security and legal representation was concerned.

The principle of the least restrictive environment as applied to education means that:

> ... in every case, students should be provided an educational program in a setting which is the least different from the program provided all other students and least restrictive (environmentally and experientially) of all the program alternatives which are available and appropriate to his/her educational needs (Gearheart, Litton 1979:13).

A series of procedures designed to ensure litigation was being mandated by law. Parents and guardians are fully involved in decision-making to ensure that school authorities do not take arbitrary or unilateral action against mentally retarded children.

The issue of child advocacy became of public concern when in 1971 President Nixon directed the Office of Child Development of the Department of Health, Education and Welfare to establish a National Centre for Child Advocacy. Child Advocacy is mainly concerned with intervention on behalf of children in those services and institutions that affect their lives. Child advocacy may be carried out by interested individuals, parents, guardians or professional organizations. The mentally retarded became the main beneficiaries of this move.

Several publications began to appear which focused on the mentally retarded and their legal position. This opened a doorway for litigation which was mainly aimed at forcing local, state or federal governments to provide education and treatment for the mentally retarded. It became clear that the courts were deciding in favour of the plaintiffs and this led to more and more hearings. The major areas of concern were: architectural barriers, classification, commitment, custody, education, employment, guardianship, protection from harm, sterilisation, treatment, voting and zoning (Gearheart, Litton 1979).

The dedicated work of concerned individuals and organisations led to the passing of the Rehabilitation Act of 1973 and the Education for all Handicapped Children Act of 1975. Amongst others the Rehabilitation Act provides for non-discrimination, guarantees in areas such as employment, programme accessibility and post-secondary education. The Education for all Handicapped Children Act provides amongst others for state and local educational agencies to take responsibility for providing education for all handicapped children (Gearheart, Litton 1979; Report-President's Commission on Mental Health 1978).

2.3 DEFINITION AND CLASSIFICATION OF MENTAL RETARDATION

Persistent confusion prevails in attempts to define mental retardation. So far no single definition coined has been seen as acceptable to all those concerned with mental retardation, especially the various professions.

Robinson and Robinson (1976) feel that the same situation which pertains to the definition of mental retardation prevails in the various attempts to define intelligence - multiple controversies exist.

To begin with, the term mental retardation as applied to those patients who are mentally subnormal is not universally used. While in the United States the condition is referred to as 'mental retardation', 'mental deficiency', 'mentally defective' and 'mentally handicapped', in England 'feeble-mindedness' is the general term used. In Russia, France and the Scandinavian countries, the term 'oligophrenia' is used. The World Health Organization (WHO) recommends the term 'subnormality' (Gearheart, Litton 1979).

The reasons why no single accepted definition exists to describe the condition of mental retardation are seen by Gearheart and Litton (1979) as the following:

a. Definitions typically reflect the current socio-cultural standards of a given society, and these change constantly.

b. The different disciplines (that is education, psychology, medicine, law, et cetera.) have coined terms or definitions to suit their own area of function. A good definition for one discipline may be a poor one for others.

c. Mental retardation is an extremely complex area with a multitude of opposing theoretical views, and a wide variety of etiologies.

d. Western civilization prizes intellect so highly that any definition descriptive of persons with low intelligence would have negative connotations.

The most accepted definition so far is the one provided by the AAMD (American Association of Mental Deficiency). Although in itself this definition leaves a number of questions unanswered, it is currently the most widely used.

This AAMD definition, published in 1973, is preceded by various other definitions, some of which were coined as early as 1937. We shall make mention of some of the definitions briefly to obtain an idea of the trends that preceded the 1973 definition.

Tredgold (Robinson, Robinson 1976:26) defined mental deficiency as:

> ... a state of incomplete mental development of such a kind and degree that the individual is incapable of adapting himself to the normal environment of his fellows in such a way as to maintain existence independently of supervision, control or external support.

Doll came with a somewhat specific definition in 1941. He stated that:

> We observe that six criteria by statement or implication have been generally considered essential to an adequate definition and concept. These are (1) social incompetence, (2) due to mental subnormality, (3) which has been developmentally arrested, (4) which obtains at maturity, (5) is of constitutional origin and (6) is essentially incurable (Robinson, Robinson 1976:26).

In 1957 Kanner (Robinson, Robinson 1976:26) introduced another definition in which he differentiated between two classes of mentally deficient adults. He distinguished between what he termed 'absolute' and 'relative' feeble-mindedness. He stated:

> 1. The one type consists of individuals so markedly deficient in their cognitive, emotional, and constructively conative potentialities that they would stand out as defectives in any existing culture ... They would be equally helpless and ill-adapted in a society of savants and in a society of savages. They are not only deficient intellectually but deficient in every sphere of mentation.
>
> 2. The other type is made up of individuals whose limitations are definitely related to the standards of the particular culture which surrounds them. In less complex, less intellectually centred societies they would have no trouble in attaining and retain-

> ing equality of sizeable ambitions. Some might even be capable of gaining superiority by virtue of assets other than those measured by intelligence tests ... But in our midst their shortcomings, which would remain unrecognized and therefore non-existent in the awareness of a more primitive cultural body, appear as soon as scholastic curricular demand competition in spelling, history, geography, long division ... It is preferable to speak of such people as intellectually inadequate rather mentally deficient.

All the above definitions seem to reflect concern with adults only. Those working with children had no basis for their work.

The most widely used definitions were those flowing from the use of the Stanford-Binet Intelligence Scale and the Wechsler Intelligence Scale for Children. The fact whether one was mentally subnormal or not was assessed according to the above scales, based on one's scores in an IQ test. An IQ score of 70 was popularly used as a cut-off score for the retarded group. The various classifications coined later were based on IQ's lower than 70.

Various problems accrued from this kind of definition because IQ scores were based on sampled behaviour at a given time in a controlled environment. Robinson and Robinson (1976:27) contend that:

> ... no cutoff score will ever be adequate to define mental retardation independent of the setting in which the individual finds himself. Different skills and different abilities are required at different ages and in different environments. Retardation must therefore be gauged in large part against current environmental demands.

The latter part of this contention seems to agree in part with the latter part of Doll's definition when he describes the group falling under "feeble-mindedness".

The IQ classification is used world-wide and in some countries it is written into existing laws. However, it generated a lot of criticism when it was used alone without consideration of other factors. Some of the criticisms are that the IQ factor has been misused, in that other sources of information about a given child have been ignored. IQ scores, when used in conjunction with other aspects of behaviour, have proved to be very useful.

Some contemporary definitions are Mercer's definition according to a social system perspective and Bijou's definition according to an experimental analysis point of view (Robinson, Robinson 1976).

According to Mercer's social system perspective, an individual is retarded if he has been labelled as such by a given social system. He sees 'mental retardate' as a given status and 'mental retardation' as the accompanying role. He sees the school as the one social system that uses this label freely (Robinson, Robinson 1976).

Bijou, on the other hand, has suggested that "a retarded individual is one who has a repertory of behavior shaped by events that constitute his history and that the stimulus-response which contribute to retarded behavior should constitute the focus of investigation" (Robinson, Robinson 1976:29). Bijou rejects the biological or medical definition of mental retardation. He sees mental retardation as a symptom of an underlying condition. He emphasizes patterns of development in relation to whatever stimulation or reinforcement the child is exposed to. He maintains that:

> ... the coordination of the individual as a total functioning biological system and the environmental events which impinge upon him determine the success or failure of development of serviceable behavioral repertoires (Robinson, Robinson 1976:29).

This definition did not have a widespread impact but it drew attention to the experiential history of the individual and to the role of reinforcement in behaviour. One could say that the present attempts at the treatment of the mentally retarded through behaviour modification may have part of their origin in Bijou's work.

The Presidents' Committee on Mental Retardation defined the mentally retarded as being "... significantly impaired in their ability to learn and adapt to the demands of society" (Payne, Mercer 1975:30).

The AAMD definition by Grossman (1973) - referred to earlier - is in fact an improvement on Heber's (1961) definition which reads as follows:

> Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior" (Heber 1964:1).

The AAMD definition (coined by Grossman) will be given more attention in this chapter for the reasons outlined earlier and also because the researcher will base this study on the AAMD version of mental retardation.

The AAMD manual defined mental retardation as

> ... significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period. (Gearheart, Litton 1979:30; Robinson, Robinson 1976:30).

Various aspects of the definition will be discussed.

Mental retardation - in the manual, mental retardation denotes a level of behavioural performance. The definition does not mention etiology or levels of retardation and it also does not distinguish between the retardation associated with psychosocial influences or the one associated with biological deficit.

Intellectual functioning - this may be assessed by one or more of the standardized tests which have been developed specifically for this purpose.

Significantly sub-average refers to a score that is two standard deviations below the mean i.e. an IQ of 67 and 69 on the Stanford-Binet and Wechsler tests respectively.

Developmental period - the upper level of this period has been given as 18 years of age.

Adaptive behaviour refers to the effectiveness or degree to which the individual is able to meet standards of personal independence and social responsibility according to his age and the norms of his culture.

In 1965 the AAMD developed a project to study the broad dimensions of adaptive behaviour. This study produced two adaptive behaviour scales; one is for children aged 3 to 12 and the other was designed for children aged 13 and older. The 1974 manual states that these scales must not be used in isolation to determine an individual's level of adaptive behaviour.

According to this definition the designation of mental retardation refers to current behaviour and leaves no room for possible future changes or the improvement of the intellectual level of the individual. The definition however views mental retardation as a reversible condition unlike the definitions that preceded Heber's and Grossman's (cf. Doll's definition).

Because of their behaviour and the various causes of their condition, retarded children constitute a very heterogenous group. It is common for lay people to overlook this fact and club the retarded into one homogeneous group. The various definitions do not delineate the characteristics of the retarded by degree, therefore to gain a better understanding of the various differences in behaviour, one needs to classify the retarded into different groups according to their intellectual development.

Gearheart and Litton (1979) cite three basic reasons why a classification system is important. They state as their first reason the fact that it facilitates research because it enables one to discuss data of incidence, prevalence and educational strategies for the various groups. It also facilitates communication between the various professional groups concerned with the retarded; and finally it aids in the understanding of the behaviour of a given child or group of children.

Because new information becomes available over a period of time concerning mental retardation, issues pertaining to classification are as extensive as those concerning the care and treatment of the mentally retarded. Gearheart and Litton (1979:31) contend that "... classification systems must be subjected to continuous revision because even today they can only be considered tentative".

In 1947 Straus and Lehtinen spoke of exogenous (brain-injured) and endogenous (non-brain injured) types of mental retardation (Robinson, Robinson 1976:34). In 1949 Kanner proposed absolute, relative and apparent feeble-mindedness and in 1933 Lewis employed pathological and sub-cultural classifications (Gearheart, Litton 1979:32).

Classification systems have been coined in terms of the etiology of the illness, clinical variety or symptom constellation, severity of symptoms as well as the purpose for which the classification system is to be used. Mention has therefore been made of the legal, the educational, the medical and the behavioural classification systems.

We shall concentrate on the behavioural classification system for the following two reasons: firstly, this study concerns itself with the mother who is coping with the daily behaviour manifested by a child with a low level of intellectual development; and secondly, we have selected as our definition the AAMD definition which mentions two essential parameters, i.e. sub-normal intelligence and impairment in adaptive behaviour.

Before the development of intelligence tests, social incompetence was the criterion used as the determinant of whether a person was mentally retarded or not. Grossman, in his definition implies that adaptive behaviour exists concurrently with, but independent of intelligence. Heber, before Grossman, also suggested a connection between adaptive behaviour and intelligence (Robinson, Robinson 1976). Payne and Mercer (1975) feel strongly that there must be impairment in adaptive behaviour before an individual can be technically classified as mentally retarded regardless of whether adaptive behaviour is part of intelligence or not.

Problems in adaptive behaviour are therefore classified into four degrees of severity:

	Stanford-Binet IQ	Wechsler IQ
mild	52-67	55-69
moderate	36-51	40-54
severe	20-35	25-39
profound	<20	<25

The IQ levels differ from author to author but almost all fall within the ranges given above. Grossman acknowledged the difficulty of measuring adaptive behaviour when he emphasized that:

> Measures of adaptive behavior cannot be administered directly in offices, but must be determined on the basis of a series of observations in many places over considerable periods of time. For this reason rating scales or interview data usually make up the data from which levels of adaptive behavior are inferred (Payne, Mercer 1975:96).

The AAMD behaviour scale is divided into two major parts. Part one consists of questions pertaining to the individual's development and to the evaluation of individual skills. Part two concerns maladaptive behaviour related to personality and behavioural disorders.

Just like the intelligence tests, the AAMD Behaviour Scale must not be used on it's own to conclude that a person is mentally retarded. It should be used in conjunction with other tests.

Gearheart and Litton (1979:34) have the following to say as a final word on the use of classification systems:

> Any classification scheme based on a single criterion has inherent difficulties because of the complexity of the condition of mental retardation. In addition, no one criterion can supply sufficient information about the individual to effectively fulfill the requirements of the multidisciplinary approach to mental retardation. Therefore, we must use the system or combination of systems that best facilitates planning or programming for a specific purpose.

For a better understanding of the classification, a brief outline of the characteristics of the different groups is given:

The mildly retarded

This group comprises approximately 85 % of all retarded persons. They have few if any physical characteristics which point towards mental retardation. Their development in walking, talking, toilet-training and feeding themselves is slow. Eye-hand co-ordination is also slow and remains below normal expectancy. A diagnosis of retardation is often made after a year or two of school experience.

This group can develop social and communication skills in special structural classes and they can also benefit from arts and crafts classes. While they can benefit from primary school education, they cannot complete secondary education. In the schools where this group attends regular classes, there may be problems such as the exhibition of anti-social behaviour, demands on the teacher's attention and the inability to conform to the social standards of the class.

Many of these individuals are able to hold down jobs in certain industries but with the rapid switch to automation, as is the case today, many will end up without jobs. Some of them marry and have families. They, however, encounter problems in managing their own affairs and so are often found as clients in welfare offices.

Some have emotional and behavioural problems which often cause them to be in a state of conflict with the authorities. Therefore they are often placed in residential care in order to protect both them and their families.

The moderately retarded individual

The motor development of this group, though below normal expectation, does approach normal in most cases. Their language and speech is, in most cases, developed. As a group they are viewed as semi-dependent because they can be toilet-trained and can master basic skills like feeding, clothing and bathing themselves.

They can benefit from organized training programmes aimed at self-help and social awareness. A few of them go up to the third grade level in school.

Few are capable of reaching the stage of becoming self-supporting adults in a supervised sheltered work facility.

The severely retarded individual

This group exhibits some of the characteristics of the above group but to a lesser degree. They are viewed as being above the level of total dependency although some still require extensive and intensive nursing and medical care because of organic brain damage.

Motor development as well as speech and language are retarded. While the greater proportion of this group may spend a greater part of their lives in a residential institution, those with IQ's of between 25 and 35 may benefit from training in basic self-help skills. Some of the latter group may also function well in a highly controlled and supervised sheltered employment. Those who do not require a lot of care may live in their own homes without causing a lot of adjustment in the family.

The profoundly retarded individual

These individuals have considerable central nervous system impairment. Organic pathology is also present to an unusual extent. Other handicaps which appear with mental retardation are blindness, deafness, epilepsy and gross physical abnormalities. There is poor motor development. Repeated movements such as head-banging, rocking movements, lipor finger-biting are frequently observed. The life expectation of this group is way below average.

These individuals require life-long supportive residential care because they cannot benefit from any form of training or education. Many of them are bedridden throughout their lives and most families cannot cope with the demands of caring for such individuals.

2.4 ISSUES CONCERNED WITH LABELLING

The labelling of the mentally retarded is an extremely controversial subject because of the effects of this labelling on the persons concerned. Labelling a mentally retarded child is a serious undertaking and therefore all measures to ensure accuracy should be employed. The issue of labelling has many political and social overtones, especially where children from low socio-economic backgrounds are the majority of those being labelled as mentally retarded.

Several hypotheses exist with regard to the effects of labelling (MacMillan, Jones, Aloia 1974). Robinson and Robinson (1976:43) summarized the hypothesized effects of labelling as related to "(1) the child's self-concept, (2) rejection by his peers, (3) his own level of aspiration, (4) teachers' expectations for his achievement, (5) his chances for a healthy adjustment in marriage or employment, and (6) his dislike of bearing the label." Most of the above effects are known to have affected the life of the mentally retarded person at one stage or another. MacMillan, Jones and Aloia (1974) however, conclude that unambiguous research evidence of this occurrence is lacking except with regard to the last aspect. Children and adults dislike being called 'retarded' and they also do not like the other derogatory terms used to describe them.

> It is not at all clear, however, whether the label has changed their concept of themselves and/or their treatment at the hands of peers, teachers, and employers or whether in fact they are fastening upon this label, their membership in a special class, or their admission to an institution, as a convenient target on which to blame their feelings of difference and incompetence (Robinson, Robinson 1976).

Some positive effects of labelling have also been hypothesized. Some of the effects have more to do with the social and educational system than with the individual. The labels enable the individual to qualify for certain services and benefits such as admission to specialized services, eligibility for certain grants, et cetera. This is of value if the services rendered are effective, otherwise labelling serves no useful purpose. MacMillan, Jones and Aloia (1974), have confirmed that labelling sometimes helps to resolve the dissonance which occurs when a retarded adult or child fails to reach certain standards or cope in a given situation. Their peers tend to be more tolerant and understanding. Accurate labels help to put the client in the right programme and they keep a client from being entered into a wrong programme (Schilling, Schinke 1983).

Various recommendations have been advanced pertaining to this sensitive issue of labelling. The procedures for labelling have also been under criticism because, as Robinson and Robinson (1976:44) put it:

> Even in the absence of formal data demonstrating unequivocally the deleterious effects of labeling, sufficient anecdotal reports exist to prove to any doubter that at times labels are associated with injustice, with lowered self-aspirations, and with lowered expectations on the part of parents, teachers and employers.

Some of the recommendations are from MacMillan, Jones and Aloia (1974) who suggested that the meaning of the label be broadened, and that appropriate governmental funds be based on services needed and not on the categories and also that computer technology be used to develop an extensive individual profile.

The National Association for Retarded Citizens (USA) developed some guidelines for the screening and evaluation of school children suspected of being mentally retarded (Payne, Mercer 1975:31,32). This six-point guideline may perhaps help eliminate most of the problems that accrue due to labelling, as well as overcome problems of mislabelling.

Dunn (1973) provides three reasons why a continuous search for appropriate terms with which to designate persons with intellectual inadequacies should be undertaken:

1. Sooner or later negative values are attached to any term used to describe retarded persons. Thus the new terms, at least when they are first introduced, are socially acceptable; however, before long they too acquire negative connotations.

2. The condition of mental retardation is so complex and broad, with so many causes and levels, that it may be virtually impossible to include it's entire scope under one rubric.

3. Many different disciplines are involved and interested in the field of mental retardation, including education, psychology, sociology, medicine, speech pathology, social science, and each develops a definition suited to it's particular orientation.

The various disciplines and schools of thought use various terms designating intellectual sub-normality. Some of the terms used over a period are moron, imbecile, idiot or dull-normal and borderline mentally defective. The American educators use dull normal, educable, trainable and custodial, dependent or low grade to designate the various groups.

2.5 CAUSES

The task of defining the causes of mental retardation is an enormous one. Where the etiology is determined, it is often found that the condition is a result of the multiple interactions of agents, or sometimes one or more crucial elements are found to be absent. This makes the task of determining etiology a rather complex one.

About 250 causes of mental retardation have been defined. The problem in discussing the causes of mental retardation is that most mentally retarded individuals fall under the group of the mildly retarded with unknown etiologies. The known causes are related to the less prevalent cases - the moderate, severe and profound.

The AAMD provides a framework for discussing etiological classifications. Before discussing these etiological classifications, one needs to briefly mention genetics. An understanding of genetics is basic since slight genetic deviations can result in severe impairment of mental functioning.

A normal human cell receives one member of each pair of the twenty three chromosomes it contains from each parent. The complement and arrangement of the chromosomes in this case is normal. If an abnormality occurs here, it can have serious implications for the development of the foetus. Each chromosome has genes which are responsible for the characteristics of the individual. There are dominant genes and recessive genes. The majority of genetic mental abnormalities are caused by recessive genes and they tend to be extremely rare in the population.

Other important aspects of genetics are penentrance and expressivity which Mercer and Payne (1975:53) define respectively as "... the proportion of persons with a given gene who exhibit the related trait" and "... the severity of the trait..." Genes have varying penetrance and expressivity and thus one may find individuals with similar genes having varying physical and mental characteristics.

Payne and Mercer (1975) warn that the AAMD classification of etiologies is not absolutely perfect due to the complexity of causes, individual variations and the difficulty in distinguishing retardation from other conditions. The classification is made up of the following categories: infections and toxins, trauma or physical agents, metabolism and nutrition, gross brain disease (post-natal), unknown pre-natal influence, chromosomal abnormality, retardation following psychiatric disorders, gestational disorders and environmental influences.

The above categories will each be briefly discussed. More attention will be paid to the category on environmental influences because the majority of mentally retarded children belong to this group. Robinson and Robinson (1976) refer to this group as the psycho-social cluster. One may also mention that the AAMD definition shows a totally environmentalist position.

2.5.1 Infections and toxins

Certain maternal infections can cause developmental damage especially during the first trimester of pregnancy. Both viral and bacterial infections can be transmitted to the foetus. Some of these viruses may produce no recognizable clinical conditions in the mother but may affect the foetus profoundly. Viruses which are known to reach the foetus include those causing measles (rubeola), chicken pox, small pox, poliomyelitis, hepatitis; but only rubella (German measles) and herpes are known to have caused defects in the foetus.

Rubella infection has been known to affect growth cells, to cause heart disease, microcephally, deafness, cataracts, glaucoma and other eye problems. Of all the symptoms, deafness is the most frequent. In the most recent rubella epidemic which occurred in 1964, mental retardation was more common.

In the recent past, syphilis was also an important cause of foetal deaths and of mental retardation. It's incidence has, however, been reduced by medical advances through treatment and by having women visiting pre-natal clinics being forced to undergo compulsory blood tests.

Lead poisoning is also known to affect mental development. Slum dwellers and those living in buildings which have fallen into disrepair are often exposed to lead-contaminated air. Mortality rates are often high and permanent damage frequently occurs. In children, mental retardation, recurrent seizures and cerebral palsy are common. The exact incidence of lead poisoning is, however, not easy to document because poisoning that goes on for years in underprivileged neighbourhoods may escape attention. Most persons living in these neighbourhoods often do not get timeous and adequate medical care.

Mercury poisoning, which is a rare occupational hazard (common in miners), has also been known to cause kidney and brain damage.

2.5.2 Trauma and physical injury

Brain damage, which leads to learning problems. can occur during the pre-natal, peri-natal and post-natal periods.

Injury to the brain can occur during delivery through the birth canal. Mechanical means to deliver the child are sometimes used if the child's head is too big for the birth canal. These mechanical instruments may injure the infant. The strong muscular contractions of the mother or when the child is lying in a breach position may lead to a disturbance in the supply of oxygen to the placenta. A knotted umbilical cord may sometimes lead to retardation or malformation. Robinson and Robinson (1976:27) contend that these views are, however, controversial.

The most common causes of head injury in children are motor accidents and child abuse. Such injuries often lead to mental retardation. Kanner (Robinson, Robinson 1976:129) classified the serious consequences of head injuries in children as follows:

> (i) acute psychosis immediately after gaining consciousness, with recovery within a month; (2) chronic behavioral disorders ... (3) seizures with or without secondary mental deterioration; and (4) cerebral deficits including aphasia, memory defects and intellectual deterioration.

Evidence, however, exists which points to the fact that the effects of trauma in younger children can be compensated far more easily than those in adults and older children.

2.5.3 Metabolism and nutrition

This category includes those disorders which can be traced to dysfunction in the mechanisms which are responsible for the processing of food or to a lack of nourishment. When the body experiences imbalances in fats, carbohydrates and amino acids in addition to poor nutrition, this can cause both mental and physical retardation.

Tay-Sach's disease caused by a recessive gene is a degenerative disease found more commonly amongst Jews than amongst Gentiles. From a point late in the child's first year, this disease follows a course of severe retardation accompanied by convulsions, blindness, paralysis and eventual death at age four.

A form of carbohydrate disorder known as galactosemia is caused by a recessive gene. It is characterized by the inability to metabolize galactose, a milk sugar. The syndrome manifests itself in varying degrees of mental retardation. Removal of milk from the diet has been found to eliminate the symptoms.

Phenylketonuria (PKU), first described by Folling in 1934, refers to an enzyme deficiency. Damage to the central nervous system, dental deformity, severe and early mental retardation and skeletal defects are associated with the accumulation of phynelalanine. Diet control such as the elimination of fish, meat and eggs from the diet until the age of 4 has produced positive results.

Cretinism is by far the most well-known and easily recognized metabolic endocrine abnormality. The severity of retardation depends upon factors such as the deficiency of the thyroid hormone, the variation in the passage of thyroxin from mother to foetus and the age at which the diagnosis is made. Reversal of symptoms can be attained through treatment which consists of replacing thyroid hormones.

Robinson and Robinson (1976) state that it is not easy to assess the exact effect of nutrition on mental retardation as poor nutrition is often associated with poor living conditions.

2.5.4 Gross post-natal brain disease

Tumours have been found to affect the brain, spinal cord and meninges (membranes covering the brain and spinal cord). Neurofibromatosis is a chronic progressive disease, the common features of which are yellow and brown pigmentations on the back area and also skin tumor (neurofibromas). This disease was first reported by Recklinghause in 1879. Persons suffering from this disease have an intellectual level ranging from normal to severe retardation.

Tuberous sclerosis is caused by a defective dominant gene. The disease is characterized by a triad of mental retardation, epilepsy and potato-like nodules often found on the bridge of the nose and cheeks. Tumours may appear on other parts of the body.

Meningitis and encephalitis are infections of the lining of the brain and of the brain itself. Meningitis, although it can cause death, is treatable. It is caused by bacteria, viruses or tubercular organisms and it usually attacks during infancy.

Encephalitis is usually caused by viruses such as measles, chicken pox, whooping cough, influenza and vaccinia and is therefore impevious to treatment with anti-biotics.

Huntington's chorea is another degenerative disease which attacks the brain and nerve fibres. It's symptoms are involuntary jerky movements often accompanied by mental deterioration. It's effects are not evident until adulthood and therefore it's inclusion as a cause of mental retardation is widely questioned. "Keep in mind that to be technically classified as mental retardation the condition must exist during the developmental period - birth to 19 years of age" (Mercer, Payne 1975:56).

2.5.5 Unknown pre-natal influence

This category is made up of those conditions for which no established cause existed at, or prior to birth. Primary examples are hydrocephalus, microcephaly and Cornellia de Lange syndrome.

In hydrocephalus, progressive enlargement of the cranial vault occurs due to a large blockage in the flow of cerebro-spinal fluid in the skull. The mental effects range from mild to severe, and early death is a common occurrence.

Ecksteen (Gearheart, Litton 1979) indicates that hydrocephalus can occur due to the following different causes:

(1) Excess formation of cerebral fluid;

(2) failure of the absorption of cerebral fluid; and

(3) a block in the circulatory system of the cerebro-spinal fluid.

The latter is by far the most common cause. The most common characteristic is the enlargement of the face. Treatment with surgery has proved successful in a large number of cases.

Microcephaly exists in an individual where the head circumference is very small. This may be attributed to the lack of formation of brain tissue.

Microcephaly is seen to exist concurrently with a variety of environmental factors, acquired conditions and hereditary disorders. Further on it is assumed that factors such as infections, radiations, head trauma, meningitis, chromosomal abnormalities and child abuse could also be causative. Mental retardation ranging from mild to severe is almost always present.

All victims of the Cornellia de Lange syndrome are mentally retarded, with IQ scores of below 50. The syndrome is characterized by multi-involved facial features, a low-pitched cry, some skeletal deformities and a lot of hair growth on the body. The persons afflicted are often found indulging in self-mutilative behaviour such as the pulling of hair and the biting of lips.

2.5.6 Chromosomal abnormality

Aberrations in the number or arrangement of chromosomes is likely to have a damaging effect on the foetus. These effects are seen in Down's syndrome, cri-du-chat syndrome and Klinefelter's syndrome; a result of sex chromosome abnormalities.

Down's syndrome was first described by John Langdon Down in 1856. At the beginning this syndrome was thought to be a result of human degeneration which was often associated with races from the East. It was thus known as "mongolism" from the Mongolian race. Later on the use of mongolism to describe the syndrome was dropped as it was realized that the syndrome occurred even in persons of other races. This disorder is often associated with a suplication of the twenty first pair of chomosomes.

Down's syndrome is often associated with mental retardation in the moderate to severe category. The highest IQ of such persons is 70. There is still some doubt about the correlation between the number of characteristics displayed and the degree of impairment exhibited.

The cri-du-chat syndrome is characterized by a larynx dysfunction which causes a high pitched cry. It is caused by the lack of material in the fifth chromosome and is often associated with mental retardation.

Klinefelter's syndrome is a condition where abnormality in the sex chromosomes occurs. What happens here is that an extra X sex chromosome is received by the male resulting in an XXY arrangement. This syndrome is associated with mild retardation. The male also has characteristics which are the result of this additional chromosome; these are sterility, immature male genitalia and the development of breasts.

In the female the sex chomosome abnormality reflects an absence of one of the X chromosomes (XO). This syndrome is referred to as Turner's syndrome. No direct relationship between Turner's syndrome and mental retardation has been found. the syndrome. however. is often associated with learning problems. Turner's syndrome often produces the lack of secondary sex characteristics and this results in sterility.

2.5.7 Gestational disorders

Premature infants have often been found to have attention rate deficiencies and below normal IQ's. These infants constitute two general groups i.e. those who have been developing normally but are born prior to full term and those who are delivered at or close to full term but whose growth has been deficient during gestation.

Studies (Robinson, Robinson 1976) have revealed a strong association between prematurity and low social class. In the low socio-economic class poor nutrition during pregnancy is common as well as the lack of means with which to compensate for the developmental disadvantage of an infant born with a low birth weight.

As early as 1862 Little reported a link between prematurity and cerebral palsy. Some low birthweight children showed perceptual motor disturbances; flaws in comprehension and reasoning, impaired IQ's, gross motor deficits and immature speech (Robinson, Robinson 1976).

2.5.8 Retardation following psychiatric disorder

This category includes those individuals with mental retardation following on psychiatric disorders. Brain or cerebral damage prior to the disorder should be excluded. The most common psychiatric disorder known to have been followed by mental retardation is schizophrenia.

Mercer and Payne (1975) are of the opinion that the relationship between retardation and psychiatric disorder is hazy when the disorder occurs during the developmental period.

Benton (1964) gives the following interpretations of the association of mental retardation and psychiatric disorder:

> ... the two may occur coincidentally; a single basic process may result in both the intellectual subnormality and the neurotic or psychotic behavior; the retardation is primary in appearance with the subsequent stressful environment causing the psychiatric disorder; and the psychological disturbance is primary and results in mental deficiency.

2.5.9 Environmental influences

Grossman's classification of mentally retarded persons places the majority in this category. He calls them the mentally retarded due to "psycho-social disadvantage". Heber in his classification which preceded Grossman's, gave the label 'cultural-familial'. His definition stated that:

> cultural-familial mental retardates invariably exhibit a mild degree of retardation in measured intelligence and adaptive behavior (Robinson, Robinson 1976:167).

In this category, a history of retardation coupled with a deprived environment is seen to be a cause of mental retardation. This diagnosis according to Robinson and Robinson (1976) is presumptive rather than positive.

Children from sub-standard homes who have parents and siblings who are retarded often exhibit symptoms of mild retardation. These children may be institutionalised as adolescents should they get into trouble with the law. As adults they often blend into the lower socio-economic groups in society. Retardation of this kind is often likely to show up when the child starts school, unless there is a deliberate case-finding effort.

Grossman outlines four criteria by which a child in this category is judged to be retarded (Robinson, Robinson 1976:166):

(i) He must function as a retarded person both at the intellectual and adaptive level;

(ii) there must be traceable evidence of retardation in his immediate family, and evidence of below intelligence functioning in his larger family circle:

(iii) there must be no clear indication of a cerebral pathological condition, although it is possible that such a child may have suffered brain damage, and

(iv) the child's background is usually an improverished one characterized by poor housing, poor health, malnourishment, illiteracy, et cetera.

The nature-nurture controversy in as far as etiology of mental retardation is concerned has dominated the field for more than a century. In 1877 Dugdale made a genealogical survey of the notorious family to which he gave the name Juke. He found that this family was characterized by immorality, criminality, poverty and mental retardation. Forty years later, Estabrook followed up this family and he located about 1 258 living members. Half of these were found to be feeble-minded. They were found to be:

> ... incapable of responding normally to the expectations of society; brought up under faulty environmental conditions which they consider normal, satisfied with the fulfillment of natural passions and desires, and with no ambition or ideals of life (Robinson, Robinson 1976:169).

Dugdale and Estabrook found that heredity and environment were implicated in their findings on the etiology of mental retardation (Robinson, Robinson 1976).

Payne and Mercer (1975) cite a study undertaken by Goddard in 1913. Goddard studied a family he named Kallikak. After studying two sets of offspring from Martin Kallikak's union with two women - one a barmaid and the other from a 'good family' - Goddard was convinced of the role played by heredity in mental retardation. His conclusions were, however, criticized on the basis that he was not sure whether the barmaid was mentally retarded or not and also because he ignored the influence of environmental factors on the respective families.

Reed and Reed (Robinson, Robinson 1976:169) undertook a modern-day study of 289 mentally retarded persons who had been institutionalised between 1911 and 1918. He traced all the 82 217 descendants of the persons and found that half the children, whose parents were both retarded themselves, and only 0,5 % of those with normal parents and siblings were retarded. Reed and Reed's position is heavily weighted on the side of hereditary influences. They also maintained that the general population is composed of one to two per cent retarded persons who will produce a third of the retarded population of the next generation.

When one looks at the above studies, one sees them as proponents of both the nature and nurture standpoints. The genetic lineage of the families is emphasized by the hereditarians while the environmentalists emphasize the role of poor conditions, ignorant and amoral parents who are unable to take care of themselves and give adequate support to their offspring.

Robinson and Robinson (1976:169) state the following in respect of the nature-nurture debate. that:

> ... it is clear that, no matter how sophisticated the investigation of retarded families in their natural setting, it cannot furnish proof for either environmentalists or hereditarians. It is wisest to assume that both factors are involved in an interactive relationship which has not been untangled.

They further state that factors responsible for cultural-familial mental retardation may include a large number of gene pairs whose cumulative effect may be expressed in the adequacy of the structure and function of one's central nervous system. In addition, factors such as poor housing and nutrition, lack of emotional stimulation, low economic status with accompanying poor hygiene, large family structure, parental disharmony and racial discrimination may be said to play a dominant role.

They go on to state that:

> ... the main point is that the number of influences is large, that they function almost independently of each other, and that they are genetically and environmentally determined (Robinson, Robinson 1976:170).

In their discussion on the difference between a retarded child and a normal child, Robinson and Robinson (1976) mention the home environment as a key point of difference. They point to the fact that the poor home harbours a variety of hazards for the developing child. This type of home is characterized by overcrowding, lack of hot water, poor temperature control, infestations of rodents, poor ventilation, lack of safe outdoor playing space, lack of academic stimuli and low morals.

Apart from the poor physical conditions, the patterns of child rearing do not offer the stimulation required for normal physical and intellectual development. In this type of home, the passive and conforming child is valued, there is a lot of disorganization and chaos, home is a place from which to escape and the children have very little exposure to the kinds of material that can supplement their daily school experience.

A family characterized by a series of nagging problems becomes depressed, discouraged and alienated. The parents show a sense of powerlessness and helplessness in their attitudes towards their childrens' development. The parents have very little time to spend with their children in their pre-occupation with earning an income. There is no time or inclination to train children to be independent.

Robinson and Robinson (1976) cite evidence that retarded children from lower socio-economic groups have untapped potential for success, possibly because they are known to retreat from situations which threaten failure.

2.6 PREVALENCE OF MENTAL RETARDATION

The question of the prevalence of mental retardation is as intricate as the one of classification. The determination of prevalence is influenced by whether one uses IQ scores or adaptive behaviour as the criterion for diagnosing mental retardation.

An IQ of 70 is often used as a cut-off score for determining whether an individual is retarded or not. According to this criterion, about three per cent of the population would be regarded as mentally retarded. Some surveys quoted by Robinson and Robinson (1976:36) tend to defend a lower figure; that of one per cent although rural areas are seen to yield a figure higher than three per cent. Tarjan (Robinson, Robinson 1976:36] has repeatedly emphasized that these assumptions are not supported by clinical evidence. Robinson and Robinson (1976) feel that whether one considers a three per cent estimate as being high or low depends on one's frame of reference.

Estimates depending on IQ only, fail to take adaptive behaviour into consideration. A major problem in this area is the non-existence of a well-standardised measure of adaptive behaviour suitable for the general population.

Since prevalence surveys are time consuming, difficult to conduct and expensive, the figure released by the U.S. Office of Education and the President's Committee on Mental Retardation are commonly accepted. The accepted figure is that of three per cent, although there is still a great deal of disagreement about it. One could ponder and question the applicability of this figure in the world community at large especially in areas with sparse populations such as Iceland and some desert areas; while thinking at the same time of some over-populated countries such as India and other Third World countries.

Prevalence is affected by a number of factors which one often has to take into consideration such as:

2.6.1 Standards and practices of the community

A handicapped adult in this highly technological and industrial era has a lot to contend with in trying to find his rightful place in the community and to live an independent life. The school child on the other hand has to compete with classmates according to relatively rigid standards of competence.

Farber (Robinson, Robinson 1976) states that one of the crucial problems which the retarded adult has to face is trying to grasp the complex network and the variety of integrated relationships which form part of his daily life. The modern nuclear family is made up of fewer individuals who in most cases are self-centred and who fail to lend support to the retarded individual, a practice which was common in the extended family.

There was a time when a handicapped person could adjust in a rural area. The rural areas no longer provide a safe and easy environment. Increased population mobility as well as mechanised farming equipment has complicated rural life.

On the issue of prevalence, one may find the data rather inaccurate because in rural areas retardation still appears to be suspected and confirmed at a later stage than in urban areas.

2.6.2 Age

Prevalence estimates of mental retardation show a high incidence during the school years which then increase gradually during adolescence but which show a low incidence during the pre-school period and adulthood.

The high estimate during school years is due to the situation in our schools where the child obviously has to compete for school entrance and promotion and generally has to maintain a certain level of performance in accordance with set standards.

Children from disadvantaged backgrounds immediately stand out during this period. School requires prompt mastery of certain skills and concepts which may be further handicapped by language, poor preparation and cultural conflicts. The prevalence estimates during this period tend to give an impression that there is a sudden influx of mildly retarded children, and yet the main issue is that during the pre-school period, parents are often not aware of their children's retardation until the child is exposed to competition with others. Some children may show signs of mental retardation during school hours while showing competency at home. Payne and Mercer (1975) refer to this child as the "Six hour retarded child".

The problem in this area is that adaptation during childhood is judged mostly by school achievement and intellectual and adaptive behaviour are often seen as synonymous during this period.

The increased rate of reported cases during adolescent years is due to the fact that the youngster is faced with a complex developmental period and also because society begins to put pressure on him which he may not be in a position to cope with. Parents sometimes aggravate the situation with their own inadequacies and fears of sexual molestation.

As adults most of these persons live a dull to normal existence and are often found in the lower socio-economic levels of society. In areas where there are no suitable services or diagnostic facilities, many mildly retarded persons remain undetected and unrecognized.

2.6.3 Racial and ethnic background

Payne and Mercer (1975:39) report that there is a high incidence of mental retardation amongst ethnic and racial minority groups.

While there is evidence of lower intelligence in certain racial groups, there is a possibility of environmental influences producing performance differences.

2.6.4 Geographic region

Geographic region has an influence on intellectual and scholastic attainment. Lee (Robinson, Robinson 1976) concludes that it is not so much the influence of the geographic region as the socio-economic status predominant in a given region. Children moved from the South-eastern states in the U.S. (predominantly rural) to Northern areas have shown an IQ increase over a period of years.

2.6.5 Sex

Almost all the studies dealing with children conclude that there is a higher incidence of mental retardation amongst boys than amongst girls.

Robinson and Robinson (1976:42) attribute the situation to the hereditary mechanisms involved which improve the chances of males manifesting recessive characteristics carried by the X-chromosomes and also to the fact that far more stringent demands are placed on males by society.

They went on to state that:

> Lest we leap to the conclusion that girls are simply smarter than boys, we should note the existence of highly complex interactions in the determination of intelligence based on biologically based potentials, differential parental relationships with boys and girls, educational practices and cultural reinforcement of sex-role patterns (Robinson, Robinson 1976:42).

2.7 CONCLUSION

The history of the care and treatment of the mentally retarded reflects societal concern about the plight of those born with a low intellect. Since the time of Itard up to the present period there has been an advancement in diagnosing and treating the mentally retarded. The current emphasis is on early diagnosis and community involvement in contrast to institutionalisation with the exception of those who are profoundly or acutely retarded.

Classification and determination of etiology will undergo changes with the advent of new information in this field.

The present classification and the identified etiological factors currently at our disposal help to facilitate identification and possible treatment of those diagnosed as mentally retarded. A lot of ground has still to be covered in the area of prevalence estimates expecially in those areas with dense or extremely sparse populations.

In those societies which uphold individual human rights, great strides have been made in improving the lot of the mentally retarded. In 1971 the UN General Assembly adopted the UN Declaration of the Rights of Mentally Retarded Persons which grants equal rights for normal living, education and legal protection to the mentally retarded. Those countries that have adopted the terms of this declaration take great care when dealing with issues of labelling, educating and caring for the mentally retarded.

While IQ scores are used as determinants of whether an individual can be regarded as mentally retarded or not these should be used in conjunction with other scales especially in areas where the tests need to be adjusted, i.e. when applied to children in Third World countries.

CHAPTER 3

AN OVERVIEW OF THE PRETORIA AND NORTHERN TRANSVAAL MENTAL HEALTH SOCIETY WITH SPECIFIC REFERENCE TO SERVICES IN MAMELODI AND ATTERIDGEVILLE

3.1 INTRODUCTION

As the sample for this study was drawn from the caseload of the Pretoria and Northern Transvaal Mental Health Society, an outline of the services rendered by this body is essential for a better understanding of certain aspects of the study.

This chapter will present background material on the society i.e. it's history, aims and objects, staff structure and staff development programme, it's utilization of volunteers and the services it renders. Specific mention will be made of the services in Atteridgeville and Mamelodi townships where the study took place.

3.2 BRIEF HISTORICAL BACKGROUND

The society was established in 1951 as a body functioning under the auspices of the South African National Council for Mental Health. The place of the society in relation to the national council and other government departments is as reflected in Annexure B.

Since it's establishment, and until 1979, the society was rendering it's services to the white population group only. The first services for blacks were started in 1979 and the first black social worker was employed in 1981 for Mamelodi and Atteridgeville. The black township of Soshanguve received it's first qualified social worker in 1984. Services in the coloured township of Eersterust were started in 1981.

3.3 THE AIMS OF THE SOCIETY

The aims of the Society are as reflected in the constitution (see Annexure C).

3.4 THE CATCHMENT AREA OF THE SOCIETY

The area served by the society is reflected in clause 2 of the constitution (see Annexure C). The Pretoria magisterial district includes the townships of Eersterust, Laudium, Soshanguve, Mamelodi and Atteridgeville.

3.5 STAFFING - QUALIFICATIONS AND EXPERIENCE

The responsibility of the society rests on the Director, who holds the position of head of the society. The Director is professionally trained and has a B.A.(SW) Honours degree of the University of South Africa. She has 33 years' experience as a social worker and for 8 years has been in the field of mental health as Director of this society.

As head of the services, the Director has the responsibility to see to it that the agency is well managed both in terms of administration and the effective rendering of services and she is answerable to the Executive Committee consisting of 11 members (see Constitution on Executive Committee).

3.5.1 Professional staff

The society has seven qualified social workers at present whose experience ranges from 6 months to 33 years. Their length of service at the society ranges from 6 months to 8 years. All the social workers' posts are subsidized (in terms of the National Welfare Act No. 100 of 1978) with the exception of one. Their qualifications are either a B.A. (SW) or a B.A. (SS) degree depending on the university at which they trained. All the social workers received special training in the field of mental retardation.

For the first in 1986 the agency qualified for a supervisor's post. A part-time supervisor with a B.A. (SW) and 9 years of experience has been appointed.

3.5.2 Administrative staff

The administrative staff is composed of a secretary and a bookkeeper. The agency also has a street collection convenor. There are four volunteer administrative assistants at the central office.

3.5.3 Centres functioning under the society

The society has training centres in the following areas functioning under its auspices: Eersterust, Mamelodi, Zodwa (Atteridgeville), Horizon and Soshanguve. The centre at Laudium is semi-independent. The Horizon centre is a special care centre while the Roger Stephen Centre is a protective workshop. All the training centres have special care units, except Mamelodi, and some are also in the process of developing protective workshops.

The staff at the centres varies in number and qualification from centre to centre. All the centres are run by paid staff (subsidized and non-subsidized). Some of the staff are qualified teachers (at Zodwa and Eersterust).

The Friends of Weskoppies is a sub-committee functioning under the auspices of the society. This sub-committee is concerned mainly with recreational facilities for patients at Weskoppies hospital.

3.6 SUPERVISION

In addition to the interpretation of agency objectives and goals, policies and procedures, standards of work, and expected levels of production, supervision is designed to stimulate development of social workers as professional persons (Williamson, Grossman 1976:148).

To elucidate what supervision entails, Kadushin (1976:21) describes a social work supervisor as:

> ... an agency administrative staff member to whom authority is delegated to direct, co-ordinate, enhance, and evaluate the on-the-job performance of the super-

> visees for whose work he is held accountable. In implementing this responsibility the supervisor performs administrative, educational and supportive functions ...

Since August 1985 the agency has been benefitting from supervision received from two supervisors delegated by the South African National Council for Mental Health. After a needs assessment was done, a supervisor's post was made available to the agency. This post was filled with effect from 1st May 1986.

a. Nature of supervision

Both group and individual supervision is conducted in this society. Group supervision is done on a monthly basis and through this method staff members are able to share and benefit from each other's experiences. This technique pre-supposes that the members of the group are concerned with similar problems and similar services. An advantage of group supervision is economy on administrative time and effort.

Individual supervision was carried out on a weekly basis by the Director and prior to that by the supervisor from National Council. Currently the newly appointed supervisor is taking this responsibility.

b. Purpose

The purpose of the supervision conducted by the society is education, support and control. Educational supervision is geared towards developing job-related self-awareness, to encourage self-examination and professional development. The supervisor does not teach the worker the specifics of practice in a given case, she teaches the various possibilities both theoretical and practical that might affect the nature of the service rendered.

The function of the two supervisors was to render support to the social workers in their daily functions and to assist them in interpreting the goals of the agency to the community.

The control aspect of the supervision focusses mainly on the case load and the interaction of the social workers with the various committees in the areas where they work. This aspect of supervision utilizes case records to assess the standard of performance and the number of interviews and home visits conducted over a given period.

3.7 STAFF DEVELOPMENT

The society boasts regular programmes of staff development which are geared to the expressed needs of the social workers as well as housemothers and teachers at the training centres.

3.7.1 In-service training

Like most social work agencies, the society arranges for the orientation of its new staff. In-service training programmes are run for all the professional staff by officers from the National Council for Mental Health for one year only. Prior to this the in-service training programme was the responsibility of the Director and technical committee members.

A fortnightly staff development programme is also run for the various training and special care centres. The programme is arranged in such a way that the professional staff at the agency, as well as the staff at the training centre, share expertise and experiences. The following are amongst some of the aspects dealt with: administration, policy, structure of the society, child development, causes of mental handicap, functional academics, social training, arts and crafts and behaviour modification. The staff at the centres are also trained in running a daily programme at the centre.

3.7.2 Conferences and workshops

The active participation of social workers at conferences and workshops contributes to their professional development. The agency makes it possible for all the social workers to attend and participate in workshops and conferences which address issues of relevance to their work such as for e.g. crisis, rape crisis, intervention techniques as well as issues relevant to the profession in general.

The social workers are encouraged to visit other services that are of a similar nature to theirs or those that may benefit their clients.

Papers read at conferences and workshops that the workers did not attend are sometimes made available to them.

3.8 PROFESSIONAL SERVICES

The clientele of the society is made up of mentally ill and mentally retarded persons and their families as well as individuals who are in life crisis situations.

The agency utilizes all the basic three methods of social work as well as administration. Each worker has on average a caseload of 68. The crisis intervention technique and supportive help are the most utilized techniques because of the nature of the cases.

Group work sessions are held with the mentally retarded and mentally ill. Growth orientated groups are held in the White section.

The social workers are all involved in community development programmes. Some of these programmes have culminated in the establishment of training centres and special care centres. Through this method a lot of positive conclusions are reached due to parental involvement. Through the utilization of this method the society established special educational facilities for mentally handicapped children on a prevention oriented level.

There are various youth groups that are run by the social workers in the different communities. The youth receive training in the development of communication and leadership skills, the development of self-assertiveness and an increase in community awareness.

The society does not have a post for a researcher.

3.9 UTILIZATION OF VOLUNTEERS

It seldom happens that professional staff are able to fulfill their professional responsibilities satisfactorily without the utilization of volunteers. Muller (1970:135) stongly supports the use of volunteers in agencies when she says that:

> By allying itself with the community and by involving citizens in social work, the profession is more likely to achieve sophisticated standards of practice, service and accompanying increase in status. Thus for the survival, growth and development of the profession, social workers need to encourage, welcome and accept volunteers in their work.

This society utilizes volunteers at two levels, i.e. those that serve on the management committee or on one of the committees functioning under the management committee and those that are practically involved in the daily activities of the society (administration) as for example those serving the Roger Stephen Centre.

The functions of the members of the committees in the different communities varies from place to place. In some areas the social worker and trained committee members are involved in public education while in other communities the committee members assist the social worker in identifying needs and seeing to it that these needs are met. The committees also act as management committees of individual centres in conjunction with salaried staff.

The services rendered by the volunteers also varies from centre to centre. In general the volunteers have been found to be innovative, flexible and creative depending on the needs of an individual area. Sieder (1965:830) cites as one of the functions of a volunteer the identification of human conditions or problems requiring social welfare services. In this society volunteer work does not include this aspect.

A successful volunteer programme depends on a carefully planned orientation and training programme. Through training, agencies ensure that volunteers render effective service and maintain agency standards.

This agency does not have a volunteer training programme. Only the paid staff members at the centres undergo training once a fortnight. Committee members i.e. those attached to the various centres do sometimes attend the training sessions but their attendance is irregular. The training is geared towards enabling the volunteers to understand what the agency is trying to achieve in the community, what mental health is and also to understand the genetic and physical aspects of mental handicap.

In the black community volunteer participation is limited to those serving on committees only. As far as the White community is concerned, volunteer services are rendered at the Roger Stephen Centre only.

3.10 SERVICES IN MAMELODI AND ATTERIDGEVILLE

Both Mamelodi and Atteridgeville are serviced by one social worker who works full-time and is fully subsidized.

3.10.1 The Zodwa Training Centre in Atteridgeville

This centre was established as a result of the initiative taken by the women of the local Methodist Church in the late 70s. These women identified a need for services for mentally retarded children. Some of the children were roaming the streets and others were kept at home under the care of their parents. These children needed basic services and their parents had no future plans for them.

The women from the Methodist Church then approached the social workers of the then Department of Co-operation and Development. The women were advised to conduct a survey in the area in order to assess the number of mentally retarded children and what their needs were. The Pretoria branch of the South African Black Social Workers Association met with the women after the survey was concluded.

The above association then reported the existence of this group of women to the Pretoria and Northern Transvaal Mental Health Society and also what the women had done up to that stage.

In 1979 services for blacks were then developed by this society. The Methodist women under the leadership of a Mrs Panelo worked hand-in-hand with a social worker who volunteered her services. In May 1981 a centre for the mentally retarded was established. A full-time social worker was then appointed in November of the same year.

A further survey was conducted in Mamelodi by the Nursing Administration students of Westfort Hospital.

When first established this centre had 30 children registered in the care of three staff members. At the time of writing there were 50 children registered. These children can be divided into three categories i.e. those requiring special care, the trainable and those qualifying for a protective workshop.

The centre is fully subsidized by the Department of Education and Training and this has led to the employment of more staff. The staff is now made up of: a principal, two qualified teachers, four house-mothers and a driver. The teachers do not hold any special qualifications for this kind of job, but they are now enrolled for a diploma in special education with the Department of Education and Training.

The role of the social worker

The social worker's role was a clearly and well defined one of enabler, educator and community worker prior to the subsidization of the centre. Since the subsidization and subsequent take-over of the centre by the above Department, the social worker has had to consult with a higher authority before rendering any services at the centre. This is consistent with the Department's policy concerning the role of the social worker in all it's schools.

Prior to this stage she was involved in mobilizing the community and making them aware of the centre, their responsibility towards it and the role that they could play. The social worker now has to see the centre as a community work task which is completed and has now moved on to the identification of needs pertaining to the psychiatric client. The social worker is mainly concerned with meeting the following identified needs:

a. more parent support groups

b. more community awareness in respect of the needs of the mentally retarded

c. development of special care facilities

d. establishment of a protective workshop

e. extension of existing services

f. establishment of a mental health committee to promote meeting the needs of the mentally ill and to undertake mental health promotion programmes.

3.10.2 Mamelodi Training Centre

A need for a centre of this nature was identified by the local offices of the then Child Welfare Society based on the data collected by the Westfort student nurses. This agency was inundated with requests for help from parents of mentally retarded children.

Most of these children were identified after staying for 5 years in the Sub-Standard A class without making any progress. The schools dismissed these children, who then roamed the streets and became problem children.

The Child Welfare Society then embarked on a community education programme to make the people of Mamelodi aware of this problem.

When the Pretoria and Northern Transvaal Mental Health Society appointed a social worker for Atteridgeville, one of her assignments was to extend her services to Mamelodi. Further work in this area was undertaken by a social work student of the University of South Africa as part of her practical work assignment.

In 1982 two social work students of the same university did a follow-up on the children who had already been identified as mentally retarded. The need for a training centre was realized and in 1983 a parents' committee was formed to get the project off the ground.

The local Dutch Reformed Church was acquired as a venue and in September 1983 the centre began functioning. At this stage the enrolment was 10 children. The society acquired the services of a retired private teacher to run the centre.

The centre has experienced rapid growth since its establishment. At the time of this report the enrolment was 76 with two staff members. The high enrolment figure has resulted in a crisis situation due to lack of suitable staff and accommodation.

Several schools in Mamelodi were running special classes where the slow children received tuition. These children usually stayed for up to 5 years in one class. At the beginning of 1986 all these children were refused re-admission. They were then admitted to the centre.

These children fall into two categories i.e. those that are trainable and those that qualify for the services of a protective workshop. There are no special care cases at this centre.

The role of the social worker

The role of the social worker consists mainly of:

a. Publicizing the centre;

b. promoting community education;

c. involving the parents and the wider community in the activities of the centre;

d. helping with the assessment of the children by making referrals for psychological diagnosis;

e. counselling parents;

f. evaluating applications for admission to the centre;

g. educating the community on mental health, and

h. developing life skills training programmes with the local youth.

The immediate identified need is for a protective workshop because the centre has a large number of children in the age group 14 years and older.

3.11 RESOURCES

The resources available to the social worker in both these areas are the centres themselves, other social work agencies such as the Child and Family Care Society, the Northern Transvaal Cripple Care Association, the local clinics, hospitals and general practitioners, local schools, women's clubs, churches and businesses.

3.12 DISCUSSION AND CONCLUSION

The catchment area of this society is a wide one, it includes a large city and several small towns. When one looks at the staff complement in relation to the geographic area covered, it becomes clear that either certain areas are not serviced or if they are serviced then the services are inadequate.

Voluntary services or some form of support groups may perhaps serve as a possible solution to the problem. No exact figures were available on the number of volunteers utilized by the agency. There is also no specific description of the services that they would render. In the black areas volunteers serve on the committees that are involved in the services of the centre.

One may also draw the conclusion that mentally ill clients seem to be neglected in this society. The Director pointed out that a lot of services seem to be directed to the mentally retarded because of parental involvement with these children.

There appears to be a serious shortage of facilities for those children catered for in the Mamelodi and Atteridgeville areas. All the children are grouped together regardless of their level of retardation. This may prove detrimental to those children with a higher level of functioning as they may deteriorate due to mixing with slower children.

From the above, one may also conclude that the agency does not only need more staff - professional as well as non-professional - but also needs to have the roles of the social workers clearly defined in terms of the area in which they function.

The agency can be evaluated in terms of its developmental cycle. In the White sections the training centres have become independent and autonomous. The social workers now focus mainly on crisis work and prevention programmes. A lot of developmental work is still being done in the other sections of the population.

When a training centre qualifies for a government subsidy it then falls under the Department of Education as a special educational facility. The social worker will have completed her community work task by handing the centre over to the education authorities.

CHAPTER 4

THE RETARDED CHILD AND HIS FAMILY

4.1 INTRODUCTION

When a child is born into a family, each parent has his/her own idea of what the child should be like. The birth of a normal child is coupled with certain demands on the parents. They love the child and make plans for him for the future. The parents are not at all worried about the child especially if he was planned and is born into a two-parent family of moderate means.

The normal child is perceived as a means of vicarious satisfaction to the parents; he is seen as an extension of 'self' and a personalised love object.

The birth of a mentally retarded child on the other hand is accompanied by different reactions from parents. Sometimes the retardation is observed or diagnosed quite soon after the birth of the child (3-10 months) or sometimes much later when the child shows slowness in comparison with his peers in attaining certain milestones. The rewards of parenting may be completely lost to the parents of the handicapped child. This situation may often be aggravated by the pressures which tend to disrupt family equilibrium.

The different reactions to such a birth are not only restricted to parents, even siblings and relatives tend to be affected. The parents' perception of themselves and of their handicapped child is heavily influenced by societal attitudes.

> Comparisons of their children's prominent characteristics with prevailing value systems, cultural and personal, yield data to parents which contribute to their evaluations of themselves and others (Cummings, Bayley, Rie 1966:596).

If the family as an agent of community care is to fulfil its role effectively towards the handicapped child, then certain aspects of its functioning in respect of this child should be focussed upon. Attention should be given to what the effect of the handicapped child is on the family in general and on the mother in particular.

This chapter discusses the reactions of parents, siblings and relatives to the birth of a mentally retarded child. The various reactions and the coping mechanisms are outlined as well as the problems surrounding the raising of such a child.

4.2 COMING TO TERMS WITH THE CHILD'S CONDITION

Society often treats the mentally retarded as a homogeneous group and professionals in particular have often generalized parental reactions to the birth of such a child. Schild (1971) mentions that there is a general agreement in the literature that these reactions are 'highly individualistic'.

Although each family is unique, parents have certain common reactions, and the intensity and duration of these reactions is determined by a number of factors such as: individual personality, nature of the marital relationship, social class, parental aspirations, feelings about deviancy, level of parental education, physical and mental make-up of the parents (Gallagher, Beckman, Cross 1983: Kazak, Marvin 1984; Farber 1970). The advice that is available after diagnosis and the supportive as well as sensitive nature of the dialogue will affect the reactions of the parents.

According to Robinson and Robinson (1976:414) there is no hard scientific data available concerning the families of mentally retarded children. According to them whatever studies have been conducted in this area are "impressionistic, poorly controlled and designed". They further state that the data available are fraught with superstition, impressionism and over-generalization because the literature is based on material collected in uncontrolled circumstances such as out-patient clinics where White middle-class mothers of young severely handicapped children were the subjects.

Some families do not take well to the presence of a mentally retarded child in the home, while others will even deny the existence of such a child and go as far as to 'hide' him/her (Levinson 1967; McCormack 1978; Parks 1977; Marks 1980). At one stage or another, especially when the child is approaching or has reached school-going age, the parents begin to come to terms with their child's condition.

Parents go through a variety of reactions when they realize that they have a mentally retarded child (Robinson, Robinson 1976; Parks 1977; Sieffert 1978). Their initial reaction - whatever it's nature - constitutes a normal coping process. Rosen cited by Robinson and Robinson (1976) outlines the following stages through which parents go: an awareness that a serious problem exists; recognition of the retardation as a basic problem; the search for a cause; the search for a solution and the acceptance of the problem - a goal which he says is seldom attained.

4.2.1 Awareness of the problem

Often when parents reach a diagnostic clinic or a psychologist's practice, they have probably been aware for some time that there is something amiss with their child. They will have observed a hearing defect, some slowness in attaining certain milestones. behavioural problems, certain physical disabilities, clumsiness or general immaturity. Many parents postpone seeking a professional opinion about the child's condition because of confusion and the fear of having to face reality.

By the time they see a psychologist, these parents will have already been to see a social worker, a paediatrician, an audiologist, a family physician or, in some cases, a faith healer. A referral to a diagnostic clinic or a psychologist is often made by one of the above professionals or by a teacher.

When parents go to a professional for a diagnosis, they already have their own hypothesis about the child's condition and often this hypothesis is correct. When these parents hear the doctor's diagnosis, they are greatly shocked, and yet the doctor might be merely confirming a suspicion which they have had for a long time. Misdiagnoses often occur especially in cases of children who suffer from peripheral hearing loss or particularly high frequency loss, which may interfere with language comprehension and thus produce inattentive or hyperactive behaviour, which often resembles mental retardation or emotional disturbance.

It is easier for parents to accept a diagnosis of physical disability than one of mental handicap. This is mainly due to confidence in the wonders performed by modern surgery. The parents may cling to their own diagnosis even if it is incorrect because of this reason. Some children have multiple handicaps which require a broad range of diagnostic work. On this note Robinson and Robinson (1976:417) advise that:

> ... a multidisciplinary approach, calibrated to the specific case, can be helpful in focusing on the problems which do exist enabling the parents to dismiss those which do not.

Waskowitz, in an exploratory study conducted at the Maryland Society for Mentally Retarded Children, found that out of a total of 40 parents studied, 30 suspected or were aware of retardation during the first year of life. The parents mentioned that the most frequently consulted practitioner was a paediatrician. The study further revealed that parents did not seem to obtain the help they needed early enough to prevent the development of the trauma of an endless pursuit of answers or solutions to their problems (Waskowitz 1970). Rapid access to professional support can help the parents to overcome the crisis and mobilize their coping mechanisms.

The initial awareness that one's child is retarded comes as a staggering blow to most parents because as Anderson (1982:63) puts it:

> ... nothing in our culture prepared young parents for the arrival of a damaged child; or perhaps it would be truer to say that our society works very hard to repress from consciousness the dark hints that it does give.

Concerning the timing of the diagnosis and parental reactions, Bicknell (1982:599) has the following to say:

> Whether the diagnosis is made at birth, slowly or suddenly in childhood, the reactions of the family are likely to follow the same broad pattern; that of mourning for the normal, perfect child who has not arrived or who has been transformed to abnormality, and the coming to terms with the real but imperfect child as he presents to them, both through direct contact with the child and through the information given to them by those who profess to know and care at the time.

4.2.2 Recognition of the basic problem

As soon as parents realize that their child is mentally retarded, they begin to see that their chances in life will be shattered and the realization of their dreams becomes remote. They begin to withdraw from the company of others because of a grief reaction which they are experiencing, and so they become pre-occupied with their own sorrow.

During this period parents need to be told the truth and long-range forecasts should be avoided as they may turn out to be incorrect and could cause additional problems. Avoidance of diagnostic labels is also unfair to the parents because there are other people who are going to refer to their child as 'mongoloid', 'retarded' or 'defective'. Parents need to be guided towards understanding terms like 'mental retardation' and the full implications of such a label.

Literature identifies a wide range of reactions to the birth of a mentally retarded child. The most prevalent reactions are guilt, ambivalence, disappointment, frustration, anger, shame and chronic sorrow (Cohen 1962; Olshansky 1970; Levinson 1967; Schild 1971; Parks 1977). Some parents refuse to accept the doctor's diagnosis and they try to convince him that he is mistaken, while at the same time acknowledging that there is something wrong with their child. Levinson (1967) states that he found such paradoxic reactions quite common in his practice.

Each parent of a retarded child reacts in a unique way to the realization that his child is defective. Referring to the reaction of parents of retarded children, Kanner (1953:100) states that:

> Their own life experiences which have helped to shape their personalities, have contributed to the manner in which they adjust to the pleasant and unpleasant realities in general and to the presence of a handicapped child in particular.

The manifestation of guilt is reported to be the most common response in parents of retarded children. The parents might feel they have done something or neglected to do something which could have caused the child's retardation. The question the parents often ask themselves is 'Why me?' They spend hours on end tormenting themselves in trying to think back about their actions prior to the birth of the child. Ryckman and Henderson (1970) state that parents cannot absolve themselves from the possibility that they may have somehow contributed towards their child's condition and this attitude is due to their lack of scientific knowledge of the cause of mental retardation. Sieffert (1978:36) says that the parent should repeatedly ask him/herself questions about what he could have done which contributed to the child's condition. He reasons that "this emotional working through is necesary if the parent is to escape a prison of self-doubt, anger, guilt (shame?) and a need to punish himself and/or others".

Parents with a religious background may perceive this retardation as a punishment from God. Some rural African parents see such a child as a symbol of the presence of their ancestors in the family. Such families often do not experience problems in accepting a mentally retarded child probably due to their own lack of sophistication.

It is not unusual for the manifestation of guilt to occur immediately after the pronouncement of the diagnosis. The main reason for this is the discomfort of the parents produced by them blaming themselves or each other for the condition of the child and because they feel helpless. If the mother takes the blame entirely upon herself, as is often the case, she may carry the full physical as well as emotional burden of caring for the child to the exclusion of the father. The father will then also begin to feel guilty because of this exclusion.

If the retarded child is the first or second in the family, some mothers may then decide not to have other children. Other mothers may decide on another child, who would then serve as a justification for her withdrawal from the defective child. The new infant would naturally demand a lot of attention from the mother, so instead of solving the problem, the situation would lead to a conflict of loyalties and add to the mother's guilt. Some couples decide on a second child in an attempt to prove to themselves that they are capable of producing normal offspring.

Some of the guilt expressed by parents is not based on reality although it appears to be a normal reaction to the situation and to dealing with unanswerable questions regarding the cause of the retardation. Wolfsenberger, as cited by Schild (1971), cautions that if guilt is reality-based, it belongs to the parents and should be used as a constructive force to stimulate them to care for the retarded child.

The role of the counsellor, in giving support to the family and providing factual data to enable them to 'work through their guilt'. cannot be over-emphasized.

Diagnosis arouses another reaction in parents; that of ambivalence. In any stressful situation both negative and positive feelings come into play. The parents of the mentally retarded child experience feelings that vaccilate between loving, nurturing and coping with their child to resenting the child and wishing for his death. Parents whose feelings vaccilate also vaccilate in their response to their child. Schild (1970:435) observed that:

> It is not surprising to see parents conflicted emotionally, resorting to a pattern of over-indulgence, overprotection, authoritarianism, and/or rigid child-rearing practices or swinging between these patterns.

The ambivalence experienced by parents is often sustained by the fact that no rational way can be found in which the parents can project blame onto their retarded child. It is stirred up every time the family experiences a crisis and it may not be entirely resolved.

Schild further states that these conflicting emotions are

> ... never completely resolved, as the long-term aspect of the problem and the repeated crises that stem directly from the child's handicap stir up the ambivalence from time to time (Schild 1970:356).

Sometimes ambivalence occurs in those cases where the child is mildly retarded, and where the level of intelligence between the normal and affected child is not clear-cut. This lack of a clear-cut distinction postpones the necessity for the parents to adjust to the retarded child.

In addition to guilt and ambivalence, most parents of retarded children suffer chronic sorrow throughout their lives irrespective of whether the child lives with them or has been institutionalised. Individual parents experience the sorrow in differing degrees. The feelings of one parent may be more intense than those of the other in the same family.

Olshansky (1970:328) states that all the parental reactions reported in the literature such as guilt, shame and anger may well be intertwined with chronic sorrow. The intensity of this sorrow as he sees it "... varies from time to time for the same person, from situation to situation, and from one family to another".

Factors that affect the intensity of this chronic sorrow are parents' personality, ethnic group, religion and social class.

There is a tendency amongst parents to try and deal with this sorrow by hiding their suffering from the public. Parents from low socio-economic groups tend to be less pre-occupied with hiding their feelings about the retarded child because of their pre-occupation with the daily struggle for economic survival.

This chronic sorrow is experienced by some parents of children with a minimal or mild retardation but is a universal reaction of parents with severely and profoundly retarded children.

Chronic sorrow is a normal and justifiable reaction in such a situation because of the realities which parents of a retarded child have to face. Robinson and Robinson (1976:417) have the following to say on the matter:

> Just as grieving for the death of a loved one serves a healthy function, this reaction probably affords an opportunity to face the problem and its implications profoundly and intimately and to emerge with thoughtfully considered attitudes.

Parents should be granted an opportunity to grieve for their lost imaginary child (Cunningham 1982).

Olshansky (1970) mentions that parents tend to deny this chronic sorrow because professionals often view chronic sorrow as a neurotic manifestation. This denial may, if not timeously dealt with, throw the parents into such a neurotic state that they may fail to mobilize their energy towards caring for the child.

In reporting on his dealings with parents in a children's developmental clinic, Olshansky (1970) states that some of the parents regressed to the point of denying the child's defectiveness while others became unduly optimistic about the child's potentialities. Both these reactions could hamper progress in adjusting to the child.

The parents of a mentally retarded child have little to look forward to compared with parents of a normal child. They may be faced with a life-time burden of caring for and worrying about their retarded child. They are faced with woes, trials and moments of despair throughout their lives and that of the child. They also have to try to cope with crises that occur from time to time.

Relief from this chronic sorrow is perceived by Olshansky (1970) to be obtainable only through death. It is unfortunate that many parents are not given the chance to complete the grieving process; they are expected to adjust to or accept the child prematurely.

Levinson (1967:28) states that shame is the most frequent reaction observed in parents of mentally retarded children. They are ashamed to face their family, relatives, friends and immediate neighbours. Such parents will hide their afflicted child and thus deprive the child of exposure to possible sources of help. This shame is often coupled with the self-blame that parents have about their having caused the child's condition (Gallagher, Beckman, Cross 1983).

In addition to the facts provided by the counsellor, the parent needs "... an opportunity to ventilate and clarify his feelings and to receive support for the legitimacy of the feelings he is expressing" (Olshansky 1970:331). The relationship between the retarded child and his parents is an intense and prolonged one and the counselling process should aim at making the parent comfortable in living with this child. It is for this reason that Parks (1977:59) says: "It is essential that parents are immediately aware that someone .... actively and genuinely cares about them and is willing to support them."

Robinson and Robinson (1976) as well as Mandelbaum and Wheeler (1960) agree that it is essential that both parents should be seen together by a counsellor. Lack of counselling may increase the parents' stress and compound the problem.

4.2.3 Search for a cause

After recognizing the extent of their problem, parents of a mentally retarded child begin to seek a cause for the retardation. Robinson and Robinson (1976:418) state that parents are motivated by two reasons in their search:

> The first and more rational is a hope that, in discovering the etiology of the disorder, they may find a way to cure it or to prevent its occurrence in any future children they may have. Additional motivation can stem from an ardent wish for

relief from a heavy burden of responsibility and guilt.

During this period, parents try to think back to possible negligence on their part towards the child when he was still an infant; such as when he was perhaps unattended to and fell off a bed or when they ignored a high fever or dehydration. Most women who have attempted an abortion attribute the child's condition directly to this act. Robinson and Robinson (1976) found that in certain clinic populations of mentally retarded children about 3 % of the mothers admitted that they had attempted to have an abortion.

Parents sometimes feel extreme anger because of their shattered hopes for a normal child. One of the most common responses to this anger is shopping around from doctor to doctor or professional to professional for promises of a possible cure. Much as this shopping around is a sign of acceptance of reality; if motivated by anger it is "... an effort at further self-protection by denying and avoiding unwanted and threatening reality" (Sieffert 1978:35). The parent is hoping for a less painful diagnosis and a quick cure.

Some parents feel that if they had had the means they would have obtained the best treatment and care for their child or they might possibly have avoided any damage to the child.

Such feelings increase the guilt felt by the parents.

Parents may experience some relief in knowing that they are not the only ones with such a child. The knowledge that the retardation was caused by a multiplicity of factors during gestation, and so was beyond the control of the parents, sometimes alleviates their pain.

Finding the cause of the retardation helps only in those cases where there is progressive deterioration which can be controlled or when the retardation is coupled with a significant emotional component. Very few parents find a cause for their child's retardation even with the most expert medical assistance. Mandelbaum and Wheeler (1960) see the search for a cause as a common defence utilised by the parent.

Robinson and Robinson (1976) advise that parents should be guided to utilize their resources for the future care of the child rather than for seeking a cause.

4.2.4 Search for a cure

Just as in the search for a cause, parents spend precious resources in the search for a cure. Some of them accumulate debts which will take a life-time to repay. Their motivation stems from the rapid advancement in technology which gives them the hope that mental retardation may be cured. They move from clinic to clinic, city to city and country to country in the most desperate search for a cure.

Helpful treatment has been utilized in cases of phenylketonuria and congenital hypothyroidism but even this treatment should be commenced early in life (Robinson, Robinson 1976).

Many specialized treatment programmes are now available for retarded children and where these are within reach, parents are advised to make use of them at an early stage. Many community clinics offer pre-school programmes, speech and physical therapy as well as help for the deaf and those with impaired vision. If retarded children are introduced to such programmes at an early stage they can be helped to make better use of the limited assets they possess. Some of these facilities deal only with the mildly retarded and those who have remediable handicaps but parents can be encouraged to shop around until they find a suitable institution for the treatment of their child's condition. In some centres psychotherapy is offered to the parents.

4.2.5 Acceptance of the child

After the initial stage of pain and the uncertainty surrounding the reality of having a retarded child has passed, the parents reach a point when they have to live and cope with this child. Once they are certain that their child does not fall within the parameters of 'normality' they are expected to start constructing realistic expectations of what the child's potential and capabilities are. This is often facilitated if they can be involved in an early and frank discussion of their child's condition.

Cunningham (1982:26) mentions 'functional acceptance' which he describes as getting to grips with the diagnosis; realizing that it will not change and then trying to function as well as one can. For most parents this takes up to two or three months and will vary from parent to parent. To some it may happen unconsciously; for others it requires willpower and conscious effort.

The term 'acceptance' is used extensively in the literature in respect of parental reaction to a handicapped child (Ryckman, Henderson 1970; Olshansky 1970; Robinson, Robinson 1976; Anderson 1982) but it is not clear what this 'acceptance' entails. Rosen, as cited by Robinson and Robinson (1976:420), sees this acceptance as the final stage of parental growth.

Robinson and Robinson (1976:420) themselves, however, see it as involving "... a warm respect for the child as he is, appreciation of his assets, tolerance for his shortcomings, and active pleasure in relating to him. The accepted child is viewed as having a smoothly functioning role in his household". Dybwad (1982:26) seems to be in agreement with the latter part of the above statement when he says that

> ... I have come to believe that one of the most crucial elements in the acceptance of the severely mentally handicapped child into the family unit rests in his having acquired eating skills and eating behaviors, so he can share in meals at the family table.

Surveys conducted by Glendinning (1983) and others have shown that most mothers will arrange a different meal-time for the retarded child because of the period of time required to complete the task of feeding him. According to Robinson and Robinson (1976) and Dybwad (1982), if this pattern is on-going in a family, then the retarded child has not yet been accepted. One may be inclined to disagree with these viewpoints because sometimes the child's physical deformities make it difficult for the family to have him at table with them and this is not necessarily a sign of non-acceptance of the child.

Wortis (Robinson, Robinson 1976:420) gives the following as indices of acceptance:

> ... the degree to which the mother functions in her usual manner, continuing her association with her friends, and the degree to which both parents meet the needs of their normal children as well as those of the retarded child.

Counsellors dealing with parents of retarded children often make earnest attempts to have the parents accept the diagnosis and their child's condition. Olshansky (1970:329) expressing the same concern as Mandelbaum and Wheeler (1960) on this issue states that:

> When the parent is asked to 'accept' mental deficiency, it is not clear just what he is being asked to do. The great stress professional workers tend to place on 'acceptance' may suggest to the parent that he is expected to perceive his child from the point of view of the professional helper.

The professionals who ask the parent to learn to accept the child are often not clear themselves as to what the acceptance entails. Does it mean that the parent should ignore the child's handicap and carry on as though the child is normal or does it mean that the parent should make adjustments in his life to accommodate the handicapped child? The parent finds himself being pressurized to a certain extent into accepting the child and this could lead to an increase in the guilt feelings which he already has regarding the child's condition.

The process of accepting a retarded child may be a very long one and parents will always have difficulty in accepting such a child. They do not only worry about the present situation when the child is still manageable; they also worry about his future when they might no longer be around to care for him.

Cunningham (1982:26) gives a report on an interview in which a parent talked about accepting the child but rejecting his condition. Kershaw (1966) on the other hand writes that parents ignore the child because they identify him with the impairment. Some parents show their rejection by insisting that the child be removed to an institution even though existing evidence makes it clear that they can cope with him at home.

Bayley, cited by Anderson (1982) suggests the following levels of acceptance: (1) a retreat into fantasy, while accepting the child physically; (2) behaving from a sense of duty - an externally imposed obligation; (3) resignation to a bleak fate; (4) acceptance of a personal obligation that one chooses; and (5) love for the child. Hall and Richmond (1984) seem to be in agreement with some of the points made by Bayley (Anderson 1982) in that they do not perceive acceptance as defined in terms of a resignation to a tragic situation but rather as a positive balanced attitude towards the needs of the child with a realistic place for him in his family.

Parents of the handicapped child may go through some or all of these phases at varying paces. Some may get stuck at certain stages while others go through all of them very quickly.

Parents vary in the rate at which they recover from the initial shock of realizing their child's condition. Some parents are immobilized for lengthy periods but do eventually recover enough to be able to mobilise their efforts on behalf of the child.

A study conducted by Saenger (Robinson, Robinson 1976:421) on adults with IQs of below 50 who as children attended classes in New York city revealed that there was a high correlation between parental acceptance, family cohesion and the absence of personality problems in the mentally retarded adult. Parental acceptance of their mentally retarded child is influenced by many factors amongst which their own nature and external circumstances play a predominant role. Educational and financial advantages may also play a role in the parent's acceptance of their child.

According to Parks (1977:63) parents cannot make an honest attachment to the actual handicapped child until they have withdrawn their affection from the normal wished-for child - "... protest and despair must occur before withdrawal". Farber (1970) on the other hand sees the family's adjustment to the retarded child as determined by the parents' marital integration and the family's interactional patterns.

4.3 THE EFFECT OF THE MENTALLY RETARDED CHILD ON THE FAMILY

Mentally handicapped people are defined by law as being individuals who are unable to care for or protect themselves and who are incapable of leading an independent existence. The extent to which they are dependent on others will differ according to the degree of disability and facilities available to them.

Since the advent of the new trend in community mental health in 1959, most of these persons now live at home with their families. It is for this reason that so much interest has been shown in the effects which living with a handicapped individual has on the entire family.

There are a number of problems, both emotional and practical, which may make living with a mentally retarded child a very stressful event for the parents. Family service agencies are concentrating their efforts on helping the family and defective child to live together with fewer crises and the minimum of stress.

Counsellors and other professionals working with these families have found that the ambivalence felt by the parents towards the mentally retarded child causes conflict which may result either in rejection or over-protectiveness towards the child. Schild (1970) contends that what aggravates this ambivalence is the fact that the parents cannot project any blame for their problems onto the retarded child. Instead, they blame themselves or each other.

Saenger on the other hand estimates that only two out of every ten mothers of severely handicapped children experienced significant ambivalent feelings (Robinson, Robinson 1976:422).

There are a number of common factors in the problems which parents of mentally retarded children experience although each family finds each situation unique. What most parents find demanding is the fact that they have to make a number of changes in their lives in order to adjust to the defective child. These changes may affect a number of areas in the life of the family - the marital relationship; the family finances; recreational activities; the daily routine; the family's interaction with the community and the parents' relationship with their other children (Farber 1960; Kazak, Marvin 1984).

Bicknell (1982), cites four dimensions which have to be considered when discussing the effects of living with a handicapped member of the family: age; the multiplicity of the handicap; the intrinsic skills for coping found in the family and the external support available. One may add a fifth dimension which is the birth order of the retarded child in relation to the other children, should there be any.

The period which the parents find to be the most trying is during the early years when the defective child (especially the severely retarded one) has grown physically but cannot walk or master certain skills for his age group. As the child grows older, the parents accept their changed life-style; and also the fact that he will never leave home like other children and be independent.

Most changes in the family have to be made during the early years. The changes may be too complex and difficult for individual family members to cope with and this may lead to insurmountable problems. It is at this point that families require extra help in order to cope with and manage the handicapped child.

4.3.1 Effects on the parents

Most women today find that they would like to pursue a career and have a family at the same time. Where this is the case, both parents share their responsibilities in the home and in the care of the children. When there is a handicapped child in the family, this changes the picture and the mother is more likely to stay at home and care for the child.

In families from the lower socio-economic ranks where the mothers are unlikely to be career-bound, there is no conflict when a situation of this nature arises. From the economic point of view, however, this mother should be the one who is more anxious to go out and seek employment in order to augment the family income and improve their life-style rather than the mother in the upper economic group. Farber (1970) says of these persons that, "... (they) are less motivated toward effective outward social mobility and therefore do not regard their retarded child as an impediment to their socioeconomic aspirations".

In those families where the mother has a career which she would like to continue pursuing or where the mother's income is required to enable the family to maintain a certain life-style, conflicts do occur with regard to the care of the handicapped child especially if this calls for the mother to leave her job.

Most mothers do eventually decide to stay at home and care for their handicapped child full-time. This often happens after she has come to terms with her grief, anger and guilt which according to Bicknell (1982:599), "... give way, in part at least, to the strong desire to nurture that child, however imperfect, and acceptance encompassing a strong sense of duty with the desire to nourish and protect ...". The father's active participation in the care of the child makes the mother's decision much easier.

At times a decision may be made to send the handicapped child to an institution and this is often prompted by various reasons such as the extent of the deformity, the unavailability of support and facilities in the family and the community and the psychological strain upon the family due to the presence of the handicapped child. In some cases the family makes such a decision only to regret it later because of guilt feelings. Yet other families will send the child away (possibly to a residential school) because they feel that it will be beneficial for the child (Hamilton, 1978).

Wilkin (1979:51-52) says that the birth order of the child has some effect on the decision to institutionalize him. He cites a number of British and American studies which reported that the child most likely to be institutionalised is the eldest child rather than the middle or youngest handicapped child.

Glendinning (1983) in her study of families with mentally retarded children found that while some mothers found the care of their handicapped child stressful, others described it as an emotionally rewarding experience and the older women actually mentioned that they were glad to be able to extend their maternal role by caring for an elder handicapped child. Farber and others as cited by McAllister, Butler and Tzien-Jen (1973) found that if the family has older normal children, it is easy for them to keep the handicapped child at home. Gallagher, Beckman and Cross (1983) mention that there are differing opinions regarding the actual effect of a handicapped child on the family. They found that some studies mention increased marital conflict while others found no change in the marital relationship.

Ayer and Alaszewski (1984) discussed two family models i.e. the pathological model and the normal family model in an attempt to explain the different types of family reactions and which factors play a role in these reactions.

Difficult or unmanageable behaviour of the child can also lead parents to consider institutional care especially if the behaviour is embarrassing to the family when strangers or visitors are present. As the parents grow older and their physical capacity to care for an older handicapped child wanes, they may consider residential care. On this note, Wilkin states that because boys tend to grow much bigger physically than girls, they are more likely to be institutionalised earlier (Wilkin 1979).

If the family belongs to a higher socio-economic group, the chance that they will almost certainly institutionalise their child is very good because they tend to be more concerned about the effect that such a child could have on their climb up the social ladder (Farber 1970). The handicapped child tends to fit in smoothly in the families belonging to the lower socio-economic ranks and he offers no major problems in as far as care is concerned. It is ironical that the latter family is financially unable to offer the child what he needs to improve his condition and to make preparation for his future and yet this family is the one which is more likely to shun institutional care than the former type of family (Wilkin 1979; Egnal, Daneel 1977).

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

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

Some of the adjustments that have to be made by the 'handicapped family' (Ayer, Alaszewski 1984) are due to the amount of time which the mother devotes to the care of the mentally retarded child. This will affect not only her physical energy to perform tasks for other persons in the family but it may also affect her mental and emotional ability to care for their other needs. This will obviously have an effect on her relationship with her family especially her husband.

Not only is the mother sometimes very tired at bedtime but - as we shall see in a later section - she also has to wake up at short intervals during the night if the mentally retarded child is restless. In some extreme cases the retarded child shares the parental bed and this puts a lot of strain on the parents. The marital sexual relationship may be adversely affected not only because of the lack of physical energy but also by the daily fear and anxiety relating to a possible pregnancy. Longo and Bond (1984) however, report that a number of investigators found that the quality of marriages in families that they studied remained stable regardless of the child's disability.

Anderson (1982) states that those marriages that break up because of the presence of a handicapped child do so because there have been difficulties all along that are not necessarily linked to the presence of the child. He further states that:

> In cases like these the mentally handicapped child merely fits into a drama that has been going on for some time. Obviously he or she may accentuate the drama, but does not hold the centre of the stage. Yet many forces conspire to put him or her in that position (Anderson 1982:72).

The mentally handicapped child then becomes an acceptable scapegoat. The family is able to escape from some of its problems by blaming the presence of the mentally handicapped child.

In some families the presence of a handicapped child brings about difficulties that have been suppressed for a long time. One parent may have more difficulty in accepting the child than the other and he may gradually stay away from home for longer hours or in the case of the mother she may over-identify with the handicapped child to the exclusion of the other children. "In cases like these the handicapped child plays an important part in the family drama, and the fulcrum around which much of the action takes place" (Anderson 1982:73).

With some couples the bone of contention is that the parents have different opinions concerning the child - the mother may be more tolerant of the child's clumsiness and inability to do certain things while the father may see him as hopeless and he may apply disciplinary measures to him which he applies to the normal children in the family. The parents may be less responsive to each other if one parent is grieving and is concerned with the financial burden of having such a child and the other is concerned about the daily demands of caring for him.

Some families perceive the presence of the handicapped child as having brought them closer together (Gallagher, Beckman, Cross 1983). They contend that since the birth of the disabled child they have found themselves to be more tolerant of each other's faults and weaknesses. McCormack (1978) states that in view of the guilt, shame, embarrassment and disappointment that accompanies the birth of a handicapped child, it is surprising that there are families that have stayed together. Robinson and Robinson (1976:428) on the other hand do not see the presence of a handicapped child as necessarily conducive to family integration.

There is a tendency amongst parents to overprotect the child with a handicap. This is not typical only of parents with a mentally retarded child it happens even with parents of children with physical handicaps (Robinson, Robinson 1976; Mandelbaum, Wheeler 1960). This tendency towards the over-protection of the handicapped child may be harmful towards the child in that it may prevent development and retard the child's limited ability to cope with the environment.

Robinson and Robinson (1976) see over-protection as stemming from three sources: (1) because the handicapped child is slow in his movements, it is easier for the busy mother to bathe, clothe and feed him and thus save much valuable time; (ii) extended infancy (childhood) sometimes is gratifying to both mother and child as the mother finds satisfaction in being needed for a longer time; and (iii) over-protection may also be a defensive manoeuvre to conceal irritation with the child. By being over-protective towards the handicapped child, the mother is able to conceal her actual feelings which are of resentment towards this child.

4.3.2 Effects on the siblings

It is not only the presence of a handicapped child in the family but also the size of the family and the position of that child in the family - whether he is the oldest, youngest or middle child - which will determine the effect which this child will have on the siblings.

The consequences of living with handicapped siblings have been discussed extensively in the literature (Farber 1960; Robinson, Robinson 1976; McCormack 1978; Wilkin 1979; Cunningham 1982, Glendinning 1983). The manner in which the other children will respond to the handicapped child is often determined by how the parents handle the situation. According to Ballard (1972:75) children are

> ... likely to take their lead from their mother and father, and the way in which they see them managing their relationship in dealing with the crisis. If the parents' attitude is a more or less optimistic and accepting one; it will probably be taken up by the children in a way which is sensible and essentially adaptive. If, on the other hand, their example is ambiguous and it seems to the children that what has happened poses an unmanageable threat to the marriage and expected life style of the family, then problems and unhappiness may arise.

Some parents who have not come to terms with their handicapped child themselves find that they do not know whether they should tell the other children that they have a handicapped brother or sister or whether the older children should just find out for themselves as time goes by. Some of these families will never ever discuss the child's handicap unless a significant incident related to the handicap occurs or until one of the children comes along with a complaint about being taunted by playmates.

In those cases where the parents have decided to discuss the handicap, they often do not know how to go about it and to what extent they should give explanations. Cunningham (1982) feels that the best way in this instance is to let the parent be guided by the child's questions which will reflect his level of understanding of the matter.

In those homes where parent-child relationships are based on mutual understanding and frankness, the handicap is discussed and the children often show their willingness to play a part towards caring for the handicapped child. McCormack (1978) found that some of the mothers she studied reported that they had found that their other children (older than the handicapped child) had become more patient, considerate and mature because of growing up with a handicapped sibling.

Much as a given family can strive to get the other children to accept and learn to live with their handicapped sibling, the outside world may not be making things easy for them. Children are noted for their unkindness and lack of discretion especially when they become aware of a difference in another child. Siblings of retarded children have been reported to have been involved in fights at school in order to defend their family honour or alternatively they have been found to be withdrawn because of the taunting they suffer daily (McCormack 1978; Cunningham 1982; Glendinning 1983).

The other side of the coin is when the siblings of the retarded child resent him and show extreme jealousy because of the attention which he is given by his parents. If the retarded child is hyperactive, he may cause disruption in the home. The older children may not be able to study or to find a place where they can have some peace because he would always want to be with them. He could also indulge in destructive activities such as breaking their belongings. The mother's involvement is constantly required and this could be very taxing on her. She understands that her other children need space and privacy but at the same time she is sympathetic towards the retarded child who needs both their company and hers.

In a family where there are only two children, the non-retarded child feels almost like an only child because of the lack of a playmate. The parents' attention is focussed mostly on the retarded child and the isolation and lack of attention can lead to a lot of resentment. Even in those cases where there is more than one non-retarded child, the retarded child will demand so much of the mother's attention that the others get little or nothing. This may cause them a lot of anguish especially if they are closer in age to the retarded child as they are then expected to assume a lot of responsibility much earlier. This situation often arises where the mother may be heard to express her single-minded devotion thus: "The handicapped child needs me, the others have no problems, they will manage whatever happens" (McCormack 1978:147).

Another problem area for the siblings of the retarded child is when they wish to bring friends home. In those homes where the retardation has been openly discussed, the young man or woman will be able to explain to the boyfriend or girlfriend that they have a retarded sibling and not let the visitor find out on his own. In such cases the friends have been prepared ahead of time and may even decline the invitation to visit if they feel uncomfortable in the presence of handicapped persons. In cases where they were not prepared ahead of time, they may react with shock, surprise or embarrassment and the brother/sister of the retarded child may not know how to handle the situation. This type of occurrence may spell an end to a promising friendship.

It is sometimes advisable to allow the children an opportunity to express their feelings about having a handicapped brother or sister. Some parents are under the misapprehension that their other children have accepted and are coping well with the presence of a handicapped sibling only to receive a rude awakening when their true feelings are revealed during a psychiatric consultation. The psychiatric consultation may have been necessitated by a referral from a school where behavioural problems were observed in the non-retarded children. In extreme cases some of these children run away from home.

Another source of resentment for the non-handicapped children may be when their parents expect them to help with the care of their retarded sibling. McCormack (1978) and Glendinning (1983) both report that most of the mothers they studied were not in favour of their other children assuming the great responsibility of helping to care for the handicapped child unless they volunteered to do so of their own accord. Even so some mothers ensure that this does not interfere with other aspects of their children's lives e.g. doing homework, visiting friends, etc.

Some of the adult children who have often worried about what would happen to their retarded brother or sister when their parents died have often offered to live with them although the parents were not always in favour of this idea (McCormack 1978; Glendinning 1983).

Some parents who felt the need to institutionalize their handicapped child often used the other children as an excuse when they in fact unconsciously wished to rid themselves of the handicapped child. Where this was the case, the other children tended to feel extremely guilty and uncomfortable and this eventually proved to have been an unwise move on the part of the parents.

Farber and others, cited by Robinson and Robinson (1976) collected evidence which shows that boys and girls react differently to the institutionalisation of their handicapped sibling. They found that to the boy the handicapped child claimed so much of the parent's attention that he (the non-retarded child) was free to be more outgoing and to indulge in various activities outside the home. When the handicapped child leaves home the brother then deteriorates because he finds that all the family's tension and attention is now centered around him. To the sister who sometimes had to be a surrogate mother, the institutionalisation of the handicapped child comes as a long awaited relief. She is now able to pursue relationships outside the home.

Where the handicapped child is hyperactive and it becomes necessary to lock him up to control his excessive energy and to protect other children against possible harm, then institutionalisation is sometimes mutually agreed upon. If such a child is not institutionalised, the fact that he has to be locked up daily may have more harmful psychological effects on the family than would the fact of institutionalisation.

Rivalry amongst siblings is a normal phenomenon in any family. If the rival is a handicapped child then it is difficult for the other child not to feel guilty and blame himself for the handicap (Anderson 1982). Children will try to deal with these feelings by over-exerting themselves and by attempting to be the perfect child in order to compensate for the shortcomings of the handicapped child. This can be overcome by an open discussion with the child concerned.

The effects of a handicapped child on the siblings in general is not necessarily an adverse one (Cunningham 1982). Some children report that growing up with a retarded sibling has been a rewarding experience for them. Schreiber and Feely (1970), after studying 10 siblings of retarded children in a group situation concluded that in those families where the parents dealt with the handicap constructively, the siblings

"... developed greater maturity, tolerance, patience and responsibility than is common among children of their age". Farber (1970) states that children who interact on a daily basis with their retarded siblings tend to have a more serious outlook on life. When discussing their life goals they emphasized "devotion to a worthwhile cause" or "making a contribution to mankind". These children become welfare-oriented in one way or another.

4.3.3 Effects on the relatives

Both Cunningham (1982) and Glendinning (1983) report that they have had a number of contrasting reports on parents' experiences with regard to their friends' and relatives' reactions toward their handicapped child. Some relatives were found to be understanding and willing to help with the care of their child while others made it difficult for the family to cope with the child by showing total rejection.

The relatives that both the authors refer to are the grandparents on both sides. Normally grandparents have a very special role to play at the birth of a grandchild. When the news of the grandchild's condition is broken to them, they sometimes show immediate bewilderment and shock especially if this is coupled with little or no understanding of the condition.

They may blame their daughter - or son-in-law's forbears for such a condition stating that their side of the family is 'clean' throughout.

This may cause a lot of harm in the relationship between the child's own parents and also the one parent and his/her in-laws. This tension is not easily resolved especially if the harmful utterances are made continually (Cunningham 1982:49-50). Cunningham (1982) further says that these utterances are sometimes a reflection of how the grandparents are trying to deal with the discomfort of having a handicapped grandchild. Such grandparents need knowledge and guidance as do the parents. The grandparents might make the unpleasant utterances quite innocently and may not actually mean any harm.

Some grandparents may assume an optimistic view and state that the child's condition is not serious and that is is only temporary. Others will suggest residential care even before the parents have had time to think about the various options open to them or before they have had time to try to understand and cope with the child's condition.

On the one hand one may also find grandparents who have problems in accepting that they have a handicapped grandchild and so they cut themselves off completely from their children (Anderson 1982). On the other hand grandparents can be very helpful and will show the parents that they can cope with the situation and will offer to provide their home where the mother can leave the handicapped child whenever she needs a break.

4.4 THE PRACTICAL PROBLEMS OF CARING FOR A MENTALLY RETARDED CHILD AT HOME

The practical problems experienced by a 'handicapped family' will be discussed under minor and major problems. The minor problems include the daily routine of caring for a handicapped child while the major ones include aspects such as finances, leisure time activities, health and education of the handicapped child.

The families of handicapped children are not to be seen as a homogeneous group. Each family is unique in terms of its structure and interaction as well as in the type of problems which they experience concerning the handicapped child.

Families may sometimes encounter similar problems, but because their children are normal, their experience of these problems will be different. There are a number of contributing factors: the extent to which the tasks are shared; the facilities available in the home and in the community; the extent of the disability of the handicapped child and the attitude of the family towards him.

4.4.1 The daily routine

The care of a handicapped child is perceived as strenuous by the one person who is faced with the task on a daily basis - the mother.

The care of a normal child is a short-term process although in some cases the mother may find it a demanding though enjoyable task. Her patience and perseverance are not overly taxed because she knows that soon the child will be independent of her. The care of a handicapped child on the other hand "... in many respects represents a prolonging of the dependencies of early childhood long past the ages at which they would otherwise cease" (Glendinning 1983:41). This long-term series of tasks to which the mother of the handicapped child is subjected emerges into what Bayley (1973) terms 'the daily grind'.

The performance of the daily household chores and the care of minor children have different facets because household chores can be performed repeatedly on a routine basis over a number of years, while caring for a child each day may have variations and the parent is often rewarded by the milestones reached by the child and his move towards independence. Caring for a handicapped child is different:

> In contrast to the rearing of most children, a disabled child's prolonged dependency gives rise to an essentially repetitive set of servicing functions, which can be physically taxing, mentally exhausting and dispiritingly monotonous (Glendinning 1983:41).

Over a period of time parents make adaptations to this daily routine of caring for the handicapped child to such an extent that to some of them it ceases to be a taxing undertaking especially if the family shares the chores.

Following is a brief discussion of the various tasks which the mother has to contend with on a daily basis:

<u>Feeding</u>

Because of their mental state and often due to poor eye-muscle co-ordination, some of these children cannot feed themselves. Those who try often make such a mess of themselves that the family decides to have their meals at a different time. Some mentally retarded children can feed themselves and are not messy but their mothers often have to guard against over-eating or the development of a passion for certain types of food to the detriment of the child's health.

If the child is not severely physically handicapped, counsellors and psychiatrists often encourage the mother to teach the child to feed himself. This sometimes takes up a great deal of the mother's time and time is what she needs most in order to cope with the child and her other chores.

The mess that the handicapped child makes during meal times creates extra work for the mother in terms of cleaning up and she ends up having extra laundry to do. This makes most mothers decide to feed the child themselves and thus they do not give him an opportunity to learn to develop some degree of independence.

Toiletting

Unlike a normal toddler where the mother can accomplish positive results - though sometimes after a trying period - the task of toilet-training a handicapped child can be a lengthy process which may sometimes end up with the desired goal still not having been reached. In addition to having a toddler who is not toilet-trained the handicapped child may present an additional problem, that of incontinence.

The mother has to watch out for and cope with 'accidents' that occur both at night and during the day. Families will spend days, months and even years trying all methods at their disposal to toilet-train the handicapped child but these attempts are often made difficult by the child's inability to communicate.

Because of this problem, the mother has the additional burden of laundry and bathing the child, sometimes many times a day, depending on how often the child requires attention. If the child is heavy then the mother's physical energy is taxed even more. A difficulty related to incontinence or the lack of toilet-training is that a child with this problem will be refused admission to a school or training centre.

Certain welfare services such as the Family Fund in the United Kingdom are sensitive to this problem and they provide mothers with disposable nappies and towels and sometimes even washing machines if the budget allows (McCormack 1978; Glendinning 1983).

Lack of sleep

Most handicapped children are characterised by poor sleeping habits. Some will not go to bed before midnight and even then they do not sleep throughout the night. Some children will go to bed early but will be up most of the night and create such a disturbance that the mother will go to them for fear that they will rouse other family members and the neighbourhood or possibly even hurt themselves.

McCormack (1978) reports cases where sleeping drugs were tried but most of the time they proved to be ineffectual and did not have the desired effect on the children. After a full day of being active, one would expect the child to be tired, but some mothers reported that in the case of their children, the drugs had the opposite effect. The child would be wide awake or he would be extremely depressed and cry continuously.

At the end of a full day of carrying the retarded child from point A to B, the mother is often in desperate need of a good night's sleep. In some families the members will take turns in checking on the restless child during the night. The mother may sometimes find it necessary to put the child into the parental bed or may even decide to sleep with the handicapped child in his bed. This often places a great deal of strain on the marital relationship. Decisions to send the child into residential care are sometimes as a result of repeated episodes of this kind.

It is not unusual to find such mothers on the verge of a nervous breakdown and their marriages may also be under extreme pressure.

In addition to the above problems relating to physical care, some mothers have the difficulty of having to contend with the constant supervision required by the handicapped child. This supervision is change of scene and that he also received extra stimulation which made him less restless at night. Most parents further welcomed the opportunity of going out to the school, meeting the teachers and the parents of other handicapped children.

The biggest problem arises when the child is old enough to leave school which is round about the onset of adolescence. In certain areas some services for the mentally handicapped have made provision for this period by making tertiary education and sheltered employment training facilities available. Not many handicapped school leavers are fortunate enough to receive this benefit. Some end up staying at home with no training and no means of income. In those centres where training is provided, it has been noted that if local businesses and employing bodies do not support these programmes by later employing the trained handicapped person, valuable manpower is laid to waste.

(e) Adolescence

Adolescence is a period of social, emotional and biological change and the handicapped child does not have the same experiences as a non-handicapped child during this time because of his intellectual and sometimes physical limitations. The emotional changes can lead to depression while the biological ones can lead to autism (Bicknell 1982).

While a non-handicapped adolescent can be exposed to sex education which he/she may find difficult to understand at the beginning, the handicapped adolescent presents a complex problem to an ordinary family. While the young handicapped person may become aware of his sexuality, he may not be aware of the normal inhibitions that go with it. It does not help to solve the problem if the parents deny the sexuality of the handicapped youth.

Some parents cannot deal with the sexuality of their normal children. Bicknell (1982:603) says that many parents will exhibit signs of mental illness during this period because of the stress involved.

McCormack (1978) describes cases of mothers who did not know how to handle their children when they masturbated. Because of his limited understanding of societal norms, the handicapped adolescent will masturbate even in public. Hysterical reactions on the part of the parents will not help solve the problem. The parents should seek professional guidance if they feel at a loss as to how to handle this situation.

(f) Concerns about the future

Most if not all parents of handicapped children worry about what is going to happen to their child when they are old and unable to care for him any longer, or when they die. This concern is often used as a reason for requesting residential care for the adult handicapped person. When thinking of the future, parents know that their child has to grow up and that they are going to grow older and will not be as physically capable of caring for him and this does cause a lot of concern.

Some parents handle this by denying their child's development. They continue to treat him like a small child regardless of his growth. The parents often express a fear that when the handicapped child is older, he will become more aware that he is different and they cannot bear the pain of this awareness (Anderson 1982; Bicknell 1982).

In those cases where there was a death wish when the handicap was discovered, the parent's inability to help their child could trigger off these unresolved sentiments.

Very few family members are able or are keen to take charge of the handicapped child (adult) when parents express their concern regarding the future. Limited financial resources, unresolved conflicts concerning such a child in the family and general problems relating to care are often reasons for this reluctance to help.

4.5 CONCLUSION

The family cannot pretend that the mentally handicapped child has no effect on it. The extent to which the family is affected will differ from household to household according to certain basic characteristics. The extent to which the family is prepared and able to make adjustments will determine how they will experience their handicapped child.

There should be an adjustment of roles to accommodate the handicapped child because without this adjustment, the presence of such a child will produce an arrest in the developmental cycle of the family.

Normally there will be role tensions at the beginning as each family member is struggling to grapple with his own reaction to the situation but these should be resolved gradually and the family should go on with it's business of developing.

It is known that most parents immediately lapse into lethargy and helplessness when they realize that they have a handicapped child. The reason for this is seen by Wilkin (1979:56) as follows:

> Many professionals (doctors, social workers, psychologists, etc.) and researchers have viewed the family with a handicapped member within the framework of a pathological model, resulting in an overemphasis on the psychologically damaging effects on family members ....

The studies mentioned in this chapter have illustrated that raising a handicapped child does not always have an adverse effect on the family. Some families reported specific positive outcomes such as that the experience brought them closer together and changed the outlook of their children towards life.

The family that experiences major adjustment problems is the one where the child was born normal but became mentally handicapped later due to illness or an accident. "The clear memory of the perfect child with all his attributes and idealized future becomes caught in a moment of time and he remains the perfect child who would have reached all the goals in academic, sport, musical attainment or whatever was to be important for him" (Bicknell 1982:600).

CHAPTER 5

SOCIAL NETWORKS AND SOCIAL SUPPORT SYSTEMS: AN OVERVIEW

5.1 INTRODUCTION

Crotty and Kulys (1985) cite numerous surveys showing that people will turn to family, friends, neighbours and other trusted parties in time of need rather than wait until their problems require professional intervention. A client will first turn to family and friends before going to more organized sources of help such as the church or union and then perhaps much later s/he will go to formal institutions such as welfare organizations, mental health clinics and financial houses.

The help provided by the natural network is often easily accessible and it enables one to cope when hopes for mastery are still very high. The network sometimes serves a supportive function and can also buffer the effects of life stresses and help maintain the physical and psychological integrity of the individual (Caplan 1974; Killilea 1976; Thoits 1982; Ell 1984).

The sources and effects of stress are varied. An individual will first attempt to utilize his own in-built mechanisms to deal with stress and if these fail or prove inadequate, he will then turn to his environment where he may or may not get the required help.

If during the early stages of his help-seeking efforts the client finds assistance within his immediate social network, then it means that his network is both supportive and functional (Tolsdorf 1976). The opposite position may prevail for some clients. The importance of a supportive network is reaffirmed by those professionals involved in crisis work in that their attempts at helping the client resolve the crisis are based on the assumption that significant others can have a positive effect on the person in crisis.

In this chapter the author will concern herself with the concepts of social networks, social support and support systems. Social networks will then be discussed as sources of support and the different types of support systems as well as the nature of support that they provide will also be discussed.

5.2 SOCIAL NETWORKS

The concept of social networks was first introduced by Barnes, an anthropologist, after studying the organization of a rural Norwegian fishing community (Bott 1957; Timms 1983; Crotty, Kulys 1985). Later Bott (1957) and Mitchell (1973) did pioneer work in analysing the structure of networks and the interaction and interconnectedness of network members.

After studying working-class English families, Bott made the observation that:

> ... the research families did not live in groups. They 'lived in' networks, if one can use the term 'lived in' to describe the situation of being in contact with a set of people and organizations some of whom are in contact with each other and some not (Swensen 1979).

Sociologists carried the idea of network a little further by concentrating on how the structural form of networks affected individual behaviour. They developed different formulae for studying the individual in relation to his network and how the density and structure of the network affects him (Tolsdorf 1976; Wilcox 1981). The focus was on the personal network, i.e. those ties in which a given individual is the focal point.

Such studies went further to observe how the individual's personal ties link him with the wider community and how these ties enable him to acquire needed resources.

Some sociologists like Davis studied whole networks while others concentrated on defining what social networks are: what are their dimensions, their characteristics and their effects on the individual (Wellman 1981).

Ell (1984:134) defines a social network as all of an individual's contacts. She further states that these networks are sources of help to which an individual turns for support. In his original 1950s definition Barnes as quoted by Collins and Pancoast (1976:17-18) saw networks as:

> ... a set of points which are joined by lines; the points of the image are people or sometimes groups and the lines indicate which people interact with each other.

According to Garbarino (1983:4) networks are:

> ... inter-connected relationships, durable patterns of interaction, and relational structure(s) through which people request support and make demands.

He goes on to say that a social support network is

> ... a set of inter-connected relationships among a group of people that provides enduring patterns of nurturence (in any or all forms) and provides contingent reinforcement for efforts to cope with life on a day-to-day basis.

The above definitions imply that networks are made up of people who are not only connected to a focal individual but are interconnected in themselves. Unger and Powell (1980) are of the opinion that every member of a network does not necessarily interact with every other member. Network analysts do not concern themselves with the links between the various units of the network but rather with the nature of the units themselves.

The contacts or interpersonal connections that an individual has may be of a primary as well as a secondary nature. Primary networks consist of an individual's personalized contacts such as his immediate family and kin. Networks can therefore be perceived as close-knit intimate relationships or loose-knit casual acquaintances (Ell 1984; Bott 1957).

A person may also have personal networks (described from the perspective of an individual member) or general networks (described from the perspective of an outside observer). Since networks do not have boundaries, they are often delimited in terms of geographical areas such as a village where most people are in interaction with each other for specified periods. Networks can therefore be based on kinship, friendship, employment, education, politics, recreation or religion.

Several authors have identified different variables in studying social networks (Collins, Pancoast 1976; Thoits 1982; Tolsdorf 1976; Swenson 1979; Crotty, Kulys 1985). These authors have generated lists of variables to suit the research problem they are interested in. According to Tolsdorf (1976), these variables can be divided into three major types i.e. structural, content and functional variables.

5.2.1 Structural variables

Structural variables describe the basic morphological characteristics of the network (Tolsdorf 1976). The concern here is mostly with the density and size of the network.

Density

This concept was first described by Bott (Wellman 1981). Collins and Pancoast (1976:20) perceive density as the ratio of actual links to potential ones while Gallo (1984:14) makes reference to the extent to which links that exist do actually exist. According to Kazak and Marvin (1984:69) density refers to the extent to which members of a given network know each other irrespective of whether they know the focal person or not. One can thus speak of a high density network where there are many members linked together and low density network where there are fewer members linked together. A high density network may foster very close links between members as compared to a low density network. This type of situation has advantages as well as disadvantages.

A network with close links provides for a lot of support and thus less stress; while on the other hand the closeness of the network may be restrictive and perhaps harmful. Wilcox (1981) in his work with widows found that a widow may not be able to move around, seek new ties and be able to deal with her bereavement because of family restrictions. A drug addict may find himself unable to shed the habit because of the close-knit network of addicts to which he belongs.

On the other hand, a close-knit network can be an advantage for a divorcee who wishes to maintain her existing identity while it can be a disadvantage to another who wishes to establish a new identity and break away from her ex-husband's network.

One's network can also determine the extent to which a member may interact with formal organizations (Unger, Powell 1980:569). The network can hamper an individual from using formal sources of aid on the one hand, while on the other it can serve as a source of referral to formal organizations.

<u>Size</u> refers to the number of actual contacts within a network, while the range of a network refers to the number of persons within it.

5.2.2 Content variables

Content variables refer to the day-to-day quality of each of the linkages in the network (Tolsdorf 1976:409). Crotty and Kulys (1985:302) refer to the interactional dimension which describes the nature of the linkages among the units or the persons.

Network characteristics provide answers to questions about frequency of contact, the direction of the interaction, i.e. is it one way or two way (reciprocity) and is the support provided by the contact a single type of support or various types of support? Gluckman as cited by Tolsdorf (1976) refers to linkages that provide a singular support as uniplex and those providing more than one as multiplex linkages. It is important in any study of networks to know the uniplex and multiplex linkages that an individual enjoys. Multiplex relationships are more important and powerful to the focal person, for obvious reasons. The wider the linkages the greater the chances of receiving support.

5.2.3 Functional variables

Functional variables are those variables that describe the nature of linkages in which one individual serves a function for another individual (Tolsdorf 1976:410). Thoits (1982:148) sees this dimension of a network as:

> ... the perceived amount and adequacy of socio-emotional and instrumental aid received from various support system members.

In addition to the above three variables, networks can also be analyzed in terms of time and space. For an example a growing child's network increases in size in contrast to that of an ageing person. The size of one's network can also be determined by the area in which he finds himself at a given time.

5.3 FORMAL AND INFORMAL NETWORKS

Networks can be formal as well as informal. Formal networks are those that are made up of professionals and personnel at certain service agencies while informal ones are made up of family, kin, neighbours/ friends, local merchants, physician, bartender, to name but a few.

Collins and Pancoast (1976) differentiate between various types of 'natural' networks and artificial networks that have been developed to meet certain needs. The natural network is made up of family, friends and neighbours who are readily accessible to the individual. Artificial networks are developed from the theory of crisis intervention which holds that the resolution of a crisis depends on the immediate help available to a person.

Many crises occur when the natural network is not available and clergy, nurses or policemen often take their place. People with similar histories of problem situations can also create networks which could be supportive when the need arises.

5.4 SOCIAL SUPPORT SYSTEMS

In his discussion on network analysis, Wellman (1981:173) sees a support system as a social network. He further goes on to say that a support system is a constricted social network which only takes into account supportive ties.

When one looks at the content of ties or connections, one will find supportive as well as non-supportive ones. This means that support is a variable that may occur in certain social networks and not in others; it is not a given for any network. Gottlieb (1981:206) has the following to say on the issue:

> The fact of the matter is that people must have connections with other people in order to receive social support, but social connectedness is not equivalent to, nor is it a guarantee of access to, social support.

Crotty and Kulys (1985:303) confirm this point by stating that social networks are not necessarily supportive. Social networks, according to them, can be non-supportive and in some cases they can be hostile and cause stress.

In discussing the non-supportive nature of some social networks, Wellman (1981) mentions that the structure of certain networks affect the quality and quantity of the support that an individual can get. The availability of social supports could also be constrained by the social and personal characteristics of the receipient, his mental health and the characteristics of his environment. The more likeable the person, the more the likelihood of getting support from his network (Shinn; Lehman, Wong 1985). Characteristics such as sex, age, ethnicity and personality variables can also influence support (Vaux as cited by Shinn, Lehman, Wong 1985).

Pillisuk and Parks as cited by Garbarino (1983:4) refer to social support networks as

> ... a range of interpersonal exchanges that provide an individual with information, emotional reassurance, physical or material assistance and a sense of self as an object of concern.

According to Shumaker and Brownell (1984:12) social support is an exchange of resources between at least two individuals perceived by the provider or the receipient to be intended to enhance the well-being of the receipient. These definitions imply that social support is a two-way process, i.e., there is reciprocity between two parties.

This reciprocity is highly associated with stability and effective functioning (Unger, Powell 1980:571). The reciprocal nature of informal networks makes them effective while this could also prove to be a source of strain because the supported party will feel obligated to return the kindness. Norms of reciprocity and equity suggest that receipients of support should repay the support received (Shumaker, Brownell 1984).

Receiving aid may also threaten the receipient's self-esteeem if it implies a superiority-inferiority relationship (Shinn, Lehman, Wong 1985). When situations of this nature arise, people are known to refuse offers of help even when they continue to need it.

Shumaker and Brownell (1984:14) discuss a reciprocity model which they see as having the following implications: that if people cannot return a benefit, they may be less likely to seek assistance; that if reciprocity is prevented the relationship between receipient and donor may diminish and that receipients will move their burden from an informal network to a formal support system because not all formal support systems require reciprocity.

Another source of strain in social support occurs when a donor intends his actions to be supportive and these are misinterpreted by the receipient and are not seen as supportive. A donor may give unwanted advice or he may attempt to offer emotional support, which may be perceived by the receipient as an invasion of privacy. Too much support on the one hand may lead to dependency and may also be perceived as infringing on one's autonomy, while too little support on the other hand can also cause dissatisfaction and ill feelings (Shinn, Lehman, Wong 1985; Crotty, Kulys 1985).

Receipients may be open to offers of aid but occasionally the timing of the support can cause problems between the parties. Some bereaved persons appreciate emotional support immediately after experiencing the loss of a loved one or loss of a limb, while others prefer to "be left alone" and try to work through their grief on their own.

Most individuals maintain a sense of well-being by involving themselves in or being part of various networks which provide for the free expression of feeling; support for handling emotions; satisfaction of dependency needs and the need for love and affection. These networks may also provide certain services. In this way the individual may have a wide variety of sources of support (Crotty and Kulys 1985; Gottlieb 1985). Shumaker and Brownell (1984) claim however, that some providers will withdraw their support when they find that they share their responsibility with others. In this instance a large network may work against the receipients. This assertion is supported by Crotty and Kulys (1985).

Caplan (1974:7) in line with Wellman (1981:173) refers to networks as support systems which he further says implies

> ... an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of the individual over time.

Lin, Dean and Ensel quoted by Thoits (1982:146) suggest that social support is "... support accessible to an individual through social ties to other individuals, groups and the larger community."

From the above, one is made aware that social ties or social networks serve a certain purpose in the life of the focal individual although not all of them are supportive. A functional social network could provide support during times of need or crisis and this support as hypothesized by several investigators can buffer or moderate the impact of stress or certain life events (Caplan 1974; Cobb 1976; Gallo 1984; Gottlieb 1985). Thoits (1982:145) however, sounds the following warning as regards the buffering effect of social support:

> ... although there is suggestive evidence that social support can buffer the psychological and physical impacts of life events, the evidence must be interpreted with extreme caution.

The above definitions of social support indicate that the source of support is one's social networks. The question at this point is what then constitutes support? Several conceptual statements have been developed about what social support is, and a brief discussion of these follows.

Cobb (1976) suggests that social support can be seen as information that leads a person to believe that (s)he is cared for, loved, esteemed, valued and that (s)he belongs to a network of communication and mutual obligation. Weiss, as cited by Intagliata and Doyle (1984) gives an example of six provisions that support networks can offer. These provisions include (i) a sense of attachment, (ii) a feeling of social integration, (iii) the opportunity for nurturance, (iv) the reassurance of self-worth, (v) a sense of on-going reliable alliance, and (vi) the opportunity to receive guidance or advice.

Both Cobb (1976) and Weiss (Intagliata, Doyle 1984) have concentrated on the emotional aspect of support. House, as cited by Thoits (1982:147) identified other aspects in his definition in which he suggests that support is:

> ... an interpersonal transaction involving one or more of the following: (1) emotional concern (liking, love, empathy), (2) instrumental aid (goods and services), (3) information (about the environment), or (4) appraisal (information relevant to self-evaluation).

According to Unger and Powell (1980:569) social networks are seen as providing essentially three types of aid: instrumental support, emotional or social support and referral and information. In addition to the above dimensions, Hirsch (1981:164) mentions recognition and support for identities. Identities can be supported through verbal acknowledgement such as saying to a person 'you are a good mother'. Feedback can also act as a form of support.

The instrumental support provided by a network consists of goods (giving and lending) and the performance of certain services to alleviate financial, economic and physical strain. Support systems can also help an individual locate certain services and resources in the community (Unger, Powell 1980; Wellman 1981).

Craven and Wellman, as cited by Tolsdorf (1976) divide support into three major clusters, i.e. support which is tangible - money or other material assistance; and support which is intangible which can be in the form of encouragement, warmth et cetera. Secondly, it may be in the form of advice and lastly it can be feedback whereby an individual is provided with evaluative statements regarding his behaviour and his attempts at meeting certain goals.

From this discussion of the types of support, questions can be raised about whether specific situations require specific forms of support and whether certain forms of support can be obtained from certain sources only and not others. Further, one may ask whether some sources of support are more helpful than others and whether coping styles influence one's ability to make use of the support that is offered.

5.5 FORMAL AND INFORMAL SUPPORT SYSTEMS

Froland, Pancoast, Chapman and Kimboko (1981), citing Abrams, see the distinction between formal and informal networks as a distinction between the world of the bureaucrat and the private world of mothers.

Formal support systems are, as stated in the Wolfenden Report: "governmentally mandated or sponsored professional services, whether state-administered or provided through chartered intermediaries, such as nonprofit organizations" (Lentjies, Jonker 1985). They include in this group those private welfare organizations that are state subsidized. Rein (1970:47) on the other hand defines formal support as:

> collective interventions which are outside the marketplace to meet the needs of individuals as well as to serve the corporate interests of the community.

Formal service agencies operate under certain set rules such as for example requirements for eligibility or needs assessment, formal rules of procedure. specialization in service delivery and co-ordination among helping roles and prescribed standards for handling problem situations irrespective of the unique nature of circumstances.

These formal support systems can be in the education, health, welfare or other area of service in a given community.

Informal helpers usually comprise people who have experienced problems themselves, those who are generally concerned about the well-being of their fellowmen, people whose time is under-utilized and who have the ability and willingness to help others. In this group, help is provided to those who need it and it takes the form of mutual exchanges, rights and obligations within a primary group.

What follows is a discussion of the various informal support systems:

(a) Spontaneous or natural support systems

This group is made up of the immediate family and extended kin. Sociologists have long observed how the family group can serve several purposes in the life of a given individual.

Caplan (1974) perceives the family as performing an essential support function by having attitudes of sensitivity and a respect for all its members as well as being an effective communication system. He reports that in his clinical practice the common types of families found were those with disorders of communication like those that had scape-goats.

In some families the form of support is prescribed by the larger group, e.g. certain individuals have to provide certain services as prescribed by the culture. In other families the support is spontaneous and one receives it by virtue of being a member of that family. The significance of the family as a support system is demonstrated by the continuous placement of orphans with adoptive families and also the encouragement given to certain individuals to become surrogate families of long-term patients and institutionalised aged persons.

The urban family is experiencing a whittling down of the kinship obligations of the marital family and this leads the family to seek more outside help than is the case with some rural families. Outside help or support is then provided by other informal networks such as friends, neighbours or by formal networks.

Caplan (1974), cites a study by Young and Willmot, who found that in certain urban areas there are extended kinship networks especially amongst the low socio-economic groups, which are held together by powerful bonds of mutual obligations. Germain and Gitterman (1980:146), as well as Collins and Pancoast (1976:22), are of the contention that strong social networks exist in slum areas irrespective of their physically deteriorated nature.

The support provided by family, friends and neighbours is often augmented by the support from other informal helpers such as the local merchant, bartender, hairdresser, policeman, priest, pharmacist or family physician.

The latter group can be further divided into 'generalists' and 'specialists' (Caplan 1974; Froland, Pancoast, Chapman, Kimboko 1981). The common factor in these groups is that they are informal and localized. The generalists, as seen by Caplan (1974:12), are in contact with a wide circle of individuals in the community because of a social or economic role that they play and they are known to have some expertise on certain types of problems. They may have gained this expertise through being involved in certain situations or in helping their families who may have had problems. They make contact quite easily and like to involve themselves with people. Some of these individuals may also be grappling with problem situations in their own lives and be busy trying to master them.

Natural helpers differ in individual personalities, their sex and the settings in which they operate. However, when it comes to helping people and to responding to calls for help they are alike in their spontaneous responses and their willingness to listen and to act on behalf of others.

The 'specialists' are those who are generally known as having previously suffered some misfortune or who have gone through some trying experiences from which they have emerged with a certain expertise in handling similar situations. They have made a successful adjustment and adaptation and are willing to share their knowledge and experience with those who encounter similar problems.

Such people are often sought out by others who need their advice and they develop a reputation locally as very helpful people. Parents with handicapped children have been known to seek out other parents with handicapped children for advice and to benefit from their expertise.

These informal caregivers are perceived by those who seek them out for support as being more effective than professionals who have to use given techniques and have to assume a certain objective, non-involved and professional stance. This objectivity sometimes gives the client/patient an impression that the professionals do not understand their (clients) problems. Because they are uninhibited by a code of practice, the informal non-professional caregivers/support system involve themselves personally with the receipients and they offer both emotional and material support not dictated by requirements for eligibility.

The contact between the informal caregiver and the people that they help is characterized by mutual benefit. Both the supporter and the supported benefit but differently.

(b) <u>Organized supports not directed by caregiving professionals</u>

This category comprises support that is organized through formal groups and organizations but is under the main direction of lay individuals/ people, and not professionals. At times the group may call upon professionals to act as administrators but they (informal caregivers) are in control of the groups. Examples of these are the various women's organizations found all over South Africa and the burial societies which are a typical feature in black residential areas.

Basically, there are two types of these groups operating, i.e. the voluntary service groups who have come together to render aid or service to persons other than members and the mutual aid groups who are made up of members who help each other. The latter type of organization or group is made up of people, who through fate, have been exposed to similar circumstances such as war, death, resettlement or migration. These persons recognize common needs and help each other by offering financial loans or mutual counselling. The Alcoholics Anonymous is one group of this nature although it is characterized by a strict code of conduct centering on abstinence.

Caplan (1974) identified another group which places its emphasis on building a new community, where members who have suffered a certain loss in their lives or those who have a permanent stigmatized condition, can emerse themselves. Examples of such groups are paraplegics, single parents, parents with handicapped children, to name a few.

He sees as one of the characteristic features of this group their second-phase provision of long-term contacts and their various joint activities which serve as a psycho-social replacement for the losses they have suffered. In his opinion the provision made by the group never works completely as such because no amount of friendliness or support can make up for the loss that a widow or paraplegic has suffered. These groups do, however, provide opportunities for association with others who are in similar circumstances and this helps combat the depression and isolation that often is their lot. One needs to point out that there is sometimes a disadvantage in this type of association because it may reinforce the members' isolation from the wider 'normal' world.

Because of the benefits derived from membership of these groups, the members develop cohesion and may campaign in given communities for the improvement of services for people like themselves. In addition to providing emotional and social support, these groups also provide information and specific guidance for members to help them get out of their predicament.

(c) Religious denominations as organized support systems

In addition to their theological function, religious denominations have over the years served as support systems for their members because they are often organized in congregations of neighbours who already identify with each other and have a shared life-style.

According to Dyer (1981:97) Christian communities are based on a dogma which provides for a certain set of beliefs and the perception of the community as a support system. Based on their religious commitment, the members of these denominations are enjoined together to help each other, lend support (instrumental and emotional) and their religious life is designed to encourage such support through prayer. These supports are reinforced regularly through daily or weekly prayer meetings or religious services. A person who is affiliated to a religious organization and is actively involved in it enjoys a lot of support from such affiliation.

(d) Support groups under the guidance of a professional caregiver

Recognition of the role played by informal support systems has led professionals to utilize these groups to benefit certain of their client groups. Where such support systems do not exist, professionals have taken it upon themselves to have them developed. Professionals have also learned through experience that crises often occur when family, friends, relatives or sometimes neighbours are not immediately available and it then becomes necessary to create artifical systems that will go on to function as natural systems (Collins. Pancoast 1976). Some professionals are reluctant to utilize informal support systems. They question the quality of assistance provided by informal caregivers.

5.6 CONCLUSION

The study of social networks and support systems is based on the assumption that man does not exist in isolation; he is surrounded by and is in interaction with other individuals. This interaction or interconnectedness serves the purpose of providing him with sources of aid when in need, although it may also engender tension and stress for him.

In order to derive benefits of support from one's social network, one should have the competence to utilize them and be willing to reciprocate where possible. A person may be surrounded by a network which may prove functional to others and not to him. Network members will offer support to others in some cases when they are assured that their efforts will be appreciated and their goodwill reciprocated.

To the professional, the existence of informal support systems serves as a reservoir or supplementary service for his client group, although Gottlieb (1981) has pointed out the conflicts that exist amongst professionals with regards to accepting and utilizing informal social networks as sources of support for their clients. While this may be the case, professionals do give due recognition to the family as a primary source of support. The supportive functions of the family depend on a certain level of inactness, stability and integration of the family.

The co-operation that can exist between professionals and the informal support system can benefit the client in that he will have wider choice of resources and it can enable the professional to perform those duties for which he was professionally trained. Formal and informal support systems should be seen as complementing one another.

CHAPTER 6

SOCIAL NETWORKS AND SUPPORT SYSTEMS FOR MOTHERS OF MENTALLY RETARDED CHILDREN

6.1 INTRODUCTION

Having a mentally handicapped child can be a stressful event for a mother and for members of her family. There are many factors that play a role on the influence which a mentally retarded child has on his family. The mother is often singled out in discussions on this topic because of her socially prescribed role as primary caregiver to her child. A study of the mother only, however incomplete, does enable one to understand what the family goes through.

In order to cope with the demands of raising a mentally disabled child and to be able to see to the needs of the other family members, the mother needs a support system - formal as well as informal. The supportive network (system) may be made up of her own family, kin, friends and neighbours as well as other people in the community. It may also be composed of formal institutions providing health, welfare and educational services.

The family as a whole may perceive the presence of a mentally retarded child as a stressful event and this may have an effect on their normal development process as a unit. If the burden on those who live with, care for and work with mentally retarded persons becomes too heavy and is not eased periodically, then a lot of stress develops. This is where social networks can make a meaningful contribution before the caregiver burns out or the family disintegrates due to the strain and the lack of a much needed break.

While the focal point of the discussion is the mother of the mentally retarded child, attention in this chapter will be given to the family as a unit, the pressures placed up on it and the type of support systems available to the mother.

6.2 FAMILY STRESS AND THE MENTALLY RETARDED CHILD

Families are structural units designed to perform the functions of nurturing, controlling and enabling children to survive as well as avoiding environmental hazards. The presence of stress of any kind in the family is accepted as part of the developmental process of the family if the stress is not of unduly long duration and if it does not lead to the disintegration of the family (Gallagher, Beckman, Cross 1983).

As a unit, the family experiences predictable as well as unpredictable life-events such as the birth of the first child, death of a member, an adolescent leaving home, et cetera, which may cause stress. These stressful events may lead the family to a higher order of functioning and effectiveness or alternatively may tear the family unit apart (McCubbin, Boss 1980). Stress within limits is a necessary or natural condition which can lead to the creation of change. If the stress is intense however, it can lead to a breakdown (Bubolz, Whiren 1984).

According to Hill (1965) there are two factors that interact to establish the stressfulness of an event and the magnitude of stress. The first factor is the objective hardship for a particular family which accompanies the event. The second is how the family defines the event. This definition is in part the family's response to the event.

Not all families will perceive the birth of a handicapped child as a stressful occurrence. Families also differ in their reaction to stress. They differ in the way in which they are able to remain integrated or split in the face of pressures placed upon them (Oliveri, Reiss 1981; Schilling, Gilchrist, Schinke 1984). These differences are attribut- able to the developmental history of the family and to the social net- works with which the family interacts (Oliveri, Reiss 1981).

The family of a handicapped child can be considered to be at risk in as far as evidence of the presence of stress is concerned (Bubolz, Whiren 1984). Research has shown that the presence of a handicapped child challenges the most dedicated and able parents and presents them with a unique set of problems which they have to cope with (Farber 1974; Davidson, Dosser 1982; Intagliata, Doyle 1984). The parents may face stress that sometimes continues throughout the life-time of the child because of his prolonged dependency. Because the lifespan of handicapped people has now increased, the demands on the phychic and material resources of the family are very high (Bubolz, Whiren 1984).

Various authors have identified several factors which may lead to the presence of stress and also those which may raise the level of stress of parents of handicapped children (Wikler 1981; Gallagher, Beckman, Cross 1983: Chetwynd 1984).

Gallagher, Beckman, Cross (1983) make mention of studies in which significant differences were found in family stress based on the child's diagnostic category. The more severe the child's handicap the wider the variety of problems experienced by the family.

After conducting a study amongst a group of New Zealand mothers of mentally retarded children. Chetwynd (1985:301) found no significant results when exploring the relationship between stress levels and the degree of disability of the child. She goes on further to mention that her study suggests that the disability does affect stress in the mother but this only applies to the aspect which relates to over or under activity.

It is, however, reported by Glendinning (1983) and Cummings, Bailey and Rie (1966) that mothers that they have studied appear to have had more problems with severely retarded children than those who had mildly retarded children. This is to be expected because the mildly retarded child is more independent than the severely retarded one.

A dimension that seems to be related to stress is the age of the handicapped child. The older the child the more difficult he/she is to manage. Also the differences between the handicapped child and other children becomes more noticeable as he grows older. He may also become more aware of these differences and this may result in problems of management.

Even where the handicapped child shows no secondary problems, stress appears in the mother due to his prolonged dependency which results in physical exhaustion caused by carrying him from one point to another and by the restrictions placed on the parents' movements. While mothers of non-handicapped children look forward to engaging in certain activities when the children begin school, the mother of the mentally retarded child finds that at this stage her task of caring for her handicapped child is becoming increasingly demanding.

The level of the handicap, the manifestation of behaviour problems and the age of the child also influence the amount of supervision required by the child. If the mother has to be attentive to the child at all times in order to protect him from harming himself or others, and after seeing to all her family's needs for the day, she hardly has time to herself. She functions under stress in contrast to the mother whose child spends time alone without constant supervision.

With such a burden of constant care and the problem of restricted mobility, most mothers find it difficult to have a regular break. This curtails their movements and subsequently their social life (Chetwynd 1985). The prolonged burden of care is continuous and there is no respite from the burden except where special arrangements have been made (Wikler 1981; Ayer, Alaszewski 1984). Most baby-sitters would prefer to care for the other children rather than for the handicapped child unless they are volunteers organized specifically to care for mentally retarded children.

In some cases where offers to baby-sit the handicapped child are made, the mothers often show reluctance to accept because they become very anxious when away from the child for a prolonged period (Glendinning 1983). Parental reaction will also range from punishing to ignoring the child as long as he is not causing harm to himself or others or perhaps damaging furniture.

Beckman-Bell cited by Gallagher, Beckman and Cross (1983:12) studied the relationship between the number of problems reported by mothers and the specific characteristics of their handicapped children. He found that "... high levels of parental stress were significantly associated with a slower rate of progress, more difficult temperament, less social responsiveness, more stereotypic behavior patterns, and the presence of additional or unusual care-giving demands".

Certain parental characteristics may also influence the parents' ability to cope with the stress of caring for a handicapped child. Factors such as parental age, socio-economic class, personality characteristics, verbal skills, and intelligence all affect the perception of stress by the parents.

Chetwynd (1985) found no significant relationship between maternal stress and socio-economic background although she found a relationship between stress level and expenditure on solid fuel heating supplies. The families in which she found this relationship were those who lived in poor conditions and couldn't afford to move to more modern houses. She concluded that these findings may therefore point to a relationship between maternal stress levels and the financial standing of the family although the relationship is not a direct one.

Each family has it's own peculiar characteristics and it's own way of reacting when faced with a stressful situation (Oliveri, Reiss 1981). The reaction will be determined by crucial aspects of the family's history and development - how the family handled past stresses, whether these were perceived as threats or challenges.

One of the ways in which a family deals with the stress which accompanies the birth of a handicapped child is that of role re-definition (Ayer, Alaszewski 1984; Glendinning 1983). Parents may not be able to cope with the demands of a re-defined role which is in contrast to their normal role as a parent of a particular sex. If the family members collectively regard the mentally retarded child as someone who interferes with the successful attainment of their goals in life, they may be reluctant to modify their way of living (Farber 1974). Instead of re-defining her role, the mother completely overhauls her schedule with regard to her usual chores and the care of the handicapped child. Closely related to these internal coping mechanisms are social supports which play an important role.

6.3 SOCIAL SUPPORT AND THE MOTHER OF THE MENTALLY HANDICAPPED CHILD

In her way of responding to her handicapped child's deviation from normality, the mother as the agent responsible for the daily care of the child needs to affirm her place in the community as a member of a conventional social order. She is expected to accept and cope with her child's disability in the best possible way. She sees her role as 'mother' changed to that of 'mother of a handicapped child'.

Although the birth of a 'normal' child may also be experienced as a crisis to the extent that it involves readjustments in the family (Hill 1965), the birth of a handicapped child can be more stressful (Suezle, Keenan 1981).

In order to continue to regard herself as a member of the conventional social order, the mother of the handicapped child must receive support from her social network. She needs recognition, backing and help from others who are interested in helping her to affirm her role in the wider community.

6.3.1 Informal support system

The informal social network of the mother should be considered in terms of (i) those with whom she is in direct contact; (ii) those in her immediate environmental/residential milieux who might be mobilized; and (iii) those outside the immediate locality/setting who share a common problem, disability, interest, et cetera with the client (Allan 1983:419).

The informal support system of the mother of a handicapped child comprises her family (husband and children), kin (parents, in-laws, sisters, et cetera), friends, neighbours and other mothers of mentally retarded children and role-related helpers such as the local pharmacist or a priest.

Bristol cited by Gallagher, Beckman and Cross (1983), found that mothers who reported the least stress were receiving more help from all sources including spouses, friends, relatives and other parents of handicapped children. A person with a wider social network will receive a variety of support from different sources although the person may not require all the types of support at a given time.

(a) The family as a support system

The constant care necessary for many severely handicapped children frequently has damaging effects on the health of the mother (Wilkin 1979). In order to care for the handicapped child at home as most parents would prefer to do, the mother needs support from those around her.

The extent to which each mother of a handicapped child meets the demands of caring for her child varies greatly and may be determined by the composition of the family, the re-definition of family roles, the material conditions, the attitudes and expectations of the mothers and their families.

Generally the father is the one single person from whom the mother of the child receives a great deal of support. This support varies vastly from family to family. In some families the father contributes little or nothing towards the care of the child while in extreme cases he participates in all aspects involving the care of the child.

In the latter cases the father will not only give emotional support to the mother but he will make adequate material provision for his family and for the special needs of the child while being actively involved in the daily routine of the actual care of the child. Some fathers will share the general household chores but will not participate in the physical care of the handicapped child.

Ayer and Alaszewski (1984:141) report a study in which they found that the majority of fathers never helped with the tasks of child care which included feeding and toiletting although they would help with child-minding tasks such as taking the child out to play or keeping him occupied. They further reported that the mothers generally accepted a very low level of participation on the part of the fathers.

Ayer and Alaszewski (1984) also found a correlation between father's participation in domestic activities and the child's age. They further report that younger fathers tend to participate more in domestic activities and in child care. They mention a study by Oakley in support of their findings in which a correlation between father's participation and social class was found to exist. Middle class fathers tend to be more involved in child care and household activities.

While it is expected that fathers would only participate on a low level in household chores or child care activities due to being employed outside the home, Gallagher, Cross and Scharfman (1981) found that groups of mothers and fathers agreed that fathers should have a more important role to play in the care of their handicapped child.

The low level of participation of the father in the actual care of the child can be attributed to the fact that the limits placed on the father's role are socially prescribed. In many cases the handicapped child does not develop sufficiently to enable the father to be involved in his care. The more severe the handicap, the less the involvement of the father.

Tallman cited by Gallagher, Beckman and Cross (1983) reports a study in which he found that fathers had more trouble coping with a handicapped child and that they were more vulnerable to social stigma than were the mothers.

siblings

(b) Children as a support system

Just as in the case of the fathers, the level of support provided by children varies from family to family, and also from child to child within the same family.

In some families the children provide no support at all while in others they provide support from as early as the age of 6 when they play with and amuse their mentally retarded siblings.

Children can be both a source of support and stress for parents. If the children have difficulty in adjusting to a handicapped sibling, their attempts at adapting may be stressful not only to themselves but also to their parents (Gallagher, Beckman, Cross 1983). Younger children can also constitute a drain on the physical, emotional and material resources of the family. This can continue until they leave home.

As the children grow older their demands on other family members decline and in many families they begin to offer help. The presence of grown-up children is, however, not a guarantee of support. Glendinning (1983) found that older daughters were generally considered to be important sources of practical and emotional support to their mothers. The family's financial burden could be eased if the working child continued to live with his parents or if he made a contribution to the family income while living on his own.

Where older children assist with child care and domestic chores this can represent an important source of support for the mother. The changes in the life-cycle of the family will affect the amount and type of support which the mother receives. When daughters are between the ages of 12 and 16 the mother receives more support both with domestic chores and child care than either before or after the daughters have attained these ages (Wilkin 1979).

In some families with severely handicapped children problems with the non-handicapped children often lead to a decision to seek long-term care.

(c) Relatives

The extent to which relatives can serve as a source of support depends on the genealogical connection that exists between them as well as the geographical distance that separates them (Wilkin 1979; Allan 1983; Ayer, Alaszewski 1984). According to Allan (1983) rules of primary kinship involve a long commitment to each other's welfare. This commitment has two consequences: such relationships are inalienable - they endure regardless of external pressure - and they are not affected by the pressure of reciprocating services or favours rendered.

In a study he conducted on the participation of relatives, friends and neighbours in child care, Wilkin (1979) found that large numbers of relatives were neither involved in the domestic chores nor the care of the child. These relatives were ideally situated to lend a hand with various tasks but they were assisting with baby-sitting only; and even then they would offer to baby-sit the non-handicapped children. Glendinning (1983) also reports that the parents that she studied received no regular help from their relatives. She, however, found a few exceptional cases where relatives provided regular support. The relatives who gave more support were often the ones who lived within the same household as the family of the handicapped child.

Just as in the case of children, relatives can also be a source of stress as well as a source of support. The family of the handicapped child may find that they are burdened with an elderly relative who may tax their resources. This relative may require the mother to do shopping for her or request to use the family car when it is most needed.

(d) Friends and neighbours as support

Friendships can be long-term or short-term and they can be based on a wide variety of reasons. While part of the reason for the existence of friendship is caring about one another very few friendships have this as an inherent element.

Allan (1983) says the following about friendships in relation to their supportive nature: "Many are largely a forum for enjoyment rather than asssitance and, as such, they too cannot that easily be turned into the kind of relationship in which caring is defined as paramount." A key characteristic of friendship is choice.

Mothers of mentally retarded children have repeatedly mentioned their social isolation (Wilkin 1979; Glendinning 1983). Having a handicapped child often restricts the opportunity to make friends or to maintain friendships that existed before the birth of the child. The child's behaviour and the discomfort felt by certain persons in the presence of a person different from themselves precludes the parents from forming friendships or else practical difficulties exist in visiting others. If one's movements are restricted it is not unusual to find that one has very few friends or no friends at all.

Wilkin (1979) points out that sometimes the lack of friendship for this mother is not so much due to having a handicapped child as being socially isolated because of her other domestic responsibilities.

Friends can assist the mother by baby-sitting the handicapped child or the other non-handicapped children. The restraining aspect of obtaining help from a friend is that there is often an element of reciprocation involved with such help and this may have a stressful effect on the mother of a handicapped child because she may not be able to reciprocate.

Another type of relationship which is included amongst non-kin relationships is that of neighbouring. There are times when one's friends and kin can also be one's neighbours.

For many people neighbours are those who live within the same block as themselves. The concept of a neighbourhood can, however, embrace a much wider area comprising several blocks. While families can choose their friends, they cannot select their neighbours. Families may elect to live in certain neighbourhoods but have little control over who lives in the same block.

The support that one gets from neighbours may have certain kinds of clearly defined limits because people are often wary of neighbours who know every aspect of their family life. The length of residence in the neighbourhood and the element of sharing certain facilities with the same people may make it possible for the mother of a handicapped child to develop a network of supportive neighbours to help in the care of her child (Ayer, Alaszewsky 1984).

While neighbours can be supportive, they can also be a source of stress. One's neighbours may only turn out to be helpful for short-term immediate emergencies such as calling an ambulance, offering shelter, et cetera. Immediate neighbours can be a source of stress if they isolate the family because of the disabled child.

Consistent caring is not a characteristic of neighbourliness. Neighbours prefer to help only at given times or during crises.

(e) Role-related helpers

Identified in this group are those people who have influential roles to fulfill in the community. These include bartenders, hairdressers, the local pharmacist, store-keeper etc. They usually provide help both directly and indirectly to the community and they are often centrally situated because of their occupation or trade.

(f) Other mothers of mentally retarded children

According to Gallagher, Beckman and Cross (1983) there is conflicting evidence in the literature concerning the need for people with similar problems to be together.

Some mothers of mentally handicapped children need to relate to other mothers with similar problems while still others feel that such contacts are not serving any purpose. This type of group presents a unique opportunity for the mother to relate to others who have gone through more or less the same experience. Such a group, although it does not assist with the care of the child, provides an opportunity to reduce the social isolation which parents often feel (Intagliata, Doyle 1984).

Davidson and Dosser (1982) describe a parent helpers programme which proved successful with parents of newly born developmentally disabled infants. The programme was based on the assumption that the helpers could give empathic understanding because they had already experienced similar crises. The helpers received training in basic counselling skills in order to be effective and they also served as role models.

According to Caplan (1974) one of the characteristics of such groups is that they do not only offer emotional and social support and opportunities but they usually provide detailed information and offer specific guidance in increasing their members' understanding of their situation.

Intagliata and Doyle (1984) advise that for parents to have a more comprehensive base of support, they should relate to other people who are different from themselves such as the parents of non-handicapped children.

Mothers of mentally retarded children, especially those with severely retarded children are the ones who require such groups as a source of support, but they often lack the time to attend meetings because of the condition of their children.

6.3.2 Formal support system

The formal networks which are available to provide mothers of handicapped children with support are welfare, health and educational agencies and in some cases voluntary organizations which render a variety of services. The availability of institutions which render formal support to the mother of a mentally handicapped child will differ from community to community. Some communities will have specialized welfare, health and educational facilities for mentally retarded children; others will group mentally and physically handicapped children together while a third type will render services that are generic in nature.

(a) Educational services

Until recently all mentally retarded children were perceived as ineducable. The education and training of the mentally retarded child is focussed on enabling him to live as independently as his disability will allow. The focus is not only on cognitive aspects but also on social competence so that he can co-exist with others.

There are now diagnostic and preventative services that reach downwards to the pre-school years.

Whereas in the past mentally retarded children were placed in special classrooms, they are now incorporated or mainstreamed into normal classes. Special classrooms are still being used particularly for those who are severely or profoundly retarded. This situation is not ideal either.

Sometimes parents do not understand or accept their child's limitations and this makes them cherish unrealistic expectations for his education and achievements. If a child who is not educable is placed in a 'normal' classroom, he will not benefit at all regardless of the teachers' well-meaning efforts.

In addition to educating the child and developing his social skills, the teachers also act as child-minders. For some mothers, especially those who have come to terms with their child's disability, this function of the teacher is perceived as the most important. The mothers manage to have a few hours to themselves each school day. Some special schools have an arrangement by which these children can continue going to school for part of the normal school holidays.

Teachers who are trained to deal with handicapped children are better able to lend support to parents than those who are not trained. The parents welcome an opportunity to discuss their child with an understanding professional even though the type of support may only be the giving of information. Ayer and Alaszewski (1984), in their study, found that most mothers had a positive attitude towards teachers at the special schools; they found them to be supportive and understanding.

(b) Health services

Over the years the focus on health services for the mentally retarded has undergone changes. There has been a movement away from concern with diagnosis and custodial care to assessment, treatment and community care.

Community care which Wilkin (1979) defines as care by the mother can only be effective if she receives support. Depending on the sophistication of the area in which she lives the mother of the mentally retarded child can obtain support from the general practitioner, district nurses, community health nurses, paediatricians, mental handicap specialists, physio-therapists, occupational therapists, et cetera.

Some communities do not have all these specialists but parents can easily contact them when needed.

The reactions of families range from satisfaction to extreme dissatisfaction regarding their contact with health professionals (Glendinning 1983; Wilkin 1979). The family doctor is the one to whom the family will go first when they notice that there is something slightly amiss with their child. The general practioner, in most cases, knows the family well and may play a very supportive role. Wilkin (1979) reports that parents will go to a GP to get advice and also to enquire about the future prospects of the child and whether there is any cure for his condition. If the GP is non-supportive this can be a stressful experience for the parents because underlying their request is a plea for reassurance and for hope for the future.

Ayer and Alaszewski (1984) state that mothers in their study did not expect much from their family doctor. Some felt the same about the health visitor. These mothers often mentioned the ignorance of the health professionals with regard to mental handicap. They perceived health professionals as being too busy to make time to discuss their problems.

(c) The social worker

The supportive function of the social worker to the mother of a handicapped child entails amongst others the provision of information on what services are available; knowing the family well enough to be able to respond to their special needs and working out strategies for making new services available. The social worker may perform these functions alone or with any one who is willing to be of assistance.

The above is the ideal situation. The question is whether there is any contact between the social worker and the family of the handicapped child. Ayer and Alaszewski (1984) found that only 16 % of the mothers they studied had seen a social worker during the previous year. Of those mothers that were in contact with the social worker all reported that she was not helpful.

Social workers have a special role to play in the family of the handicapped child. They also face special difficulties because sometimes cases are referred to them only when a crisis has developed. They often carry a heavy case-load and as they try to prioritize their time they meet with a great deal of opposition from those clients who may feel neglected (Glendinning 1983).

Like all other professionals dealing with the mentally handicapped, social workers have to equip themselves with specialized knowledge in order to be effective and to meet the challenge presented by this special group of clients.

(d) Voluntary services

Voluntary services can be seen as a supplement to both formal and informal networks. The term voluntary agency refers to "... a wide variety of organizations ranging from organizations set up by service providers ... to self-help or mutual aid groups" (Ayer, Alaszewski 1984:184).

The history of social work is characterized by the mention of various charitable organizations that were doing voluntary work before the state took over the provision and administration of social services. Voluntary organizations still play an important role alongside the state in providing social services.

When clients feel stifled or overwhelmed by the bureaucracy that usually typifies state assistance, they often resort to voluntary agencies. Some voluntary agencies are state subsidized and others are not and are therefore more autonomous. This gives the voluntary organization a measure of independence which enables it to offer it's services to a wider variety of clients.

Mothers of mentally retarded children often receive support from voluntary agencies. This may come in the form of practical help in the home, caring for the handicapped child for some hours or even days in some cases, as well as material assistance. Some voluntary organizations provide services such as outings for the children or for whole families.

In some cases mothers of handicapped children become members of a voluntary association, mutual aid or self-help group. Such an organization or body provides the mothers with an outlet where they can share their feelings and experiences even if they did not receive practical help. The mother receives psychological support which reinforces her abilities to care for her handicapped child.

Social workers have the responsibility of introducing these mothers to existing voluntary organisations.

6.4 CONCLUSION

The stress that the parents of a handicapped child experience manifests itself in various ways and has various causes. There is no conclusive evidence which shows that the stress is directly related to the presence of a handicapped child. Some families with a handicapped child do not suffer any stressful effects while others with normal children might experience a lot of stress because of various events in their life-cycle.

Regardless of whether the stress is caused or aggravated by the presence of a handicapped child, a family that is functioning under stress needs to have a supportive network. The mother in particular needs to be supported in all areas as she is the person who has the major responsibility of caring for such a child in addition to having to meet other family needs.

The wider the supportive network the wider the variety of support that the mother of the retarded child wil receive. The utilization of the support network by the mother will vary over the life-cycle of the child. When the child is under school-going age she will use a different set of supportive networks from the one she will use when the child reaches school-going age or becomes a teenager. Some of her supports, however, remain stable throughout the life of the child.

CHAPTER 7

FINDINGS AND CONCLUSIONS

7.1 INTRODUCTION

This study was basically an exploratory study which aimed at discovering significant variables in a situation.

The findings and conclusions will be discussed under the following major headings: demographic variables; childrens' disabilities; level of independence; problems experienced in raising the child, formal and informal networks; formal and informal support systems, orientation towards using networks, awareness of formal services and serious problems experienced by the mothers.

7.2 DEMOGRAPHIC VARIABLES

This study was made up of two samples i.e. the mothers/caregivers of the mentally retarded children and the mentally retarded children themselves. The demographic variables will be presented in two tables, one for the mothers (Table 7.1), and one for the mentally retarded children (Table 7.2).

TABLE 7.1

DEMOGRAPHIC VARIABLES OF THE MOTHERS

Residential area	Number	%
Atteridgeville	33	41,3
Mamelodi	47	58,8
TOTAL	80	100,0

(Table continues)

TABLE 7.1 (continued)

Age	Number	%
21-30	9	11,3
31-40	21	26,2
41-50	21	26,2
51-60	16	20,0
61-70	12	15,0
71-80	1	1,3
TOTAL	80	100,0

Marital status	Number	%
Married	43	53,8
Living together as husband and wife	3	1,3
Never married	16	20,0
Divorced/deserted/separated	8	10,0
Widow	12	15,0
TOTAL	80	100,0

Educational qualification	Number	%
None - never attended school/did not finish a class	15	18,8
Std 3 or lower	13	16,2
Std 3 to Std 5	16	20,0
Std 6 to Std 8	27	33,8
Std 9 to Std 10	5	6,2
Std 10 plus 1 or 2 years further training	3	3,8
Std 10 plus 3 or more years further training	1	1,3
TOTAL	80	100,0

Types of employment	Number	%
Full time	32	40,0
Part time	3	3,8
Other (e.g. own business)	8	10,0
Unemployed	37	46,2
TOTAL	80	100,0

Relationship of the mentally retarded to the respondent	Number	%
Biological child	67	83,8
Grandchild	8	10,0
*Other	5	6,3
TOTAL	80	100,0

* Other specified as aunt, sister etc.

TABLE 7.1 (continued)

Income	Number	%
Less than R100 (including no income)	7	8,8
R100-R299	23	28,8
R300-R499	13	16,2
R500-R699	5	6,2
R700-R899	1	1,3
More than R900	7	8,8
Don't know	24	30,0
TOTAL	80	100,0

Number of biological children	Number	%
One child	6	7,5
Two children	9	11,3
Three children	15	18,8
Four children	11	13,8
Five or more children	37	46,3
None	2	2,5
TOTAL	80	100,0

The data in this table indicates that there were more mentally retarded children in Mamelodi than there were in Atteridgeville. This is not necessarily so because the population from which the sample was drawn was obtained from the social worker's records (see Chapter 1). It is not known whether all the mentally retarded children in the two areas were part of the social worker's case load. Again it is generally assumed that most mentally retarded children come to the attention of helping agencies when they begin to go to school and are found to be lagging behind their peers in class (Robinson, Robinson 1976). This is probably why Table 7.2 shows that there were no mentally retarded children below the age of four in the social worker's records.

More than half of the mothers (52,4 %) were in the 31 to 50 age group with 16,3 % who could have been referred to as aged. Slightly less than 10,0 % of the respondents families had a very low income or no income at all. Only 8,8 % had the highest income of R900 or more.

Quite a large percentage (30,0 %) did not know their families' income and, due to the lack of information in this respect, no conclusion could be reached concerning the general socio-economic status of the sample.

Slightly less than half of the respondents had five or more children of their own. The number of these children who still lived at home and their ages could not be ascertained from the data. It was also established that 56.2 % of the respondents had children in their care who were not their own. Five was the largest number of such children and 10,0 % of the respondents had this many. Only 1,3 % of the respondents had 16 children in their care altogether.

Only 46,3 % of the respondents mentioned that the men they lived with were the fathers of their mentally retarded children.

TABLE 7.2

DEMOGRAPHIC VARIABLES OF THE MENTALLY RETARDED CHILDREN

Sex	Number	%
Male	50	62,5
Female	30	37,5
TOTAL	80	100,0

Age	Number	%
4-6 years	2	2,5
7-10 years	13	16,2
11-15 years	23	28,8
16-18 years	18	22,5
19 years and older	24	30,0
TOTAL	80	100,0

Medical diagnosis	Number	%
Mental retardation	73	91,2
Down's syndrome	6	7,5
Spina Bifida	1	1,3
TOTAL	80	100,0

(Table continues)

TABLE 7.2 (continued)

Position of the child in his/her family	Number	%
First	24	30,0
Second	13	16,3
Third	7	8,8
Fourth	10	12,5
Fifth	6	7,5
Sixth child or subsequent children	16	20,1
Only child	4	5,0
TOTAL	80	100,0

Most of the children (30,0 %) were eldest children. It is interesting to note that with the exception of those children born third in line the number of children decreases proportionately as their position in the birth line decreased. Kershaw (1966:21-22) wrote as follows on this issue:

> If the handicapped child is the first born, then it is the obvious reaction of the parents to want to have a normal child as soon as possible. The reaction is a healthy one and to be encouraged, but it is hard to expect a mother to embark on the adventure of having and bringing up another baby if the first one is going to be a continuing and increasing burden to her, as may happen if the first child is very grossly mentally defective.

The different levels of mental retardation were all represented in the group under study as follows: mild (36,3 %); moderate (24,0 %); severe (18,0 %); acute (5,0 %), multiply handicapped (5,0 %). There was also a group (12,5 %) of those whose level of retardation was not known or was undisclosed.

Table 7.3 reflects the centres attended by the children of different levels of retardation.

TABLE 7.3

PERCENTAGE DISTRIBUTION OF LEVEL OF RETARDATION ACCORDING TO CENTRE/SCHOOL

Level of retardation	Centre/School attended						
	N	Day care centre	School	Training centre	Other*	None	Total %
Mild	29	6 (20,7 %)	5 (17,2 %)	4 (13,8 %)	3 (10,3 %)	11 (37,9 %)	100,0
Moderate	19	8 (42,1 %)	1 (5,3 %)	3 (15,8 %)	1 (5,3 %)	6 (31,6 %)	100,0
Severe	14	1 (7,1 %)	1 (7,1 %)	8 (57,1 %)	0 (0,0 %)	4 (28,6 %)	100,0
Acute	4	1 (25,0 %)	0 0,0 %)	0 (0,0 %)	0 (0,0 %)	3 (75,0 %)	100,0
Multiple handicapped	4	0 (0,0 %)	0 (0,0 %)	0 (0,0 %)	0 (0,0 %)	4 (100,0 %)	100,0
Unsure	10	0 (0,0 %)	1 (10,0 %)	2 (20,0 %)	1 (10,0 %)	6 (60,0 %)	100,0

* 'Other' refers to a special class in an ordinary school.

According to the above table, 37,5 % of the children were receiving some form of education or training (total percentage of those in a training centre or school) while 20,0 % were in a day-care centre. It is not clear, however, from this study what the position was with regard to the remaining 42,5 % children who were not enrolled in a school or a centre. Some of these children (11,5 %) were multiple handicapped at the time of the study.

The mothers gave various reasons why some of their children were not attending school, a day care centre or a training centre. Some of the reasons given were health related, others centred around alleged inefficiency of the staff at the centres and yet other mothers mentioned that their children were refused admission because they were not toilet-trained or were incontinent. One grandmother expressed her dissatisfaction with one of the centres as follows: "... the children should be separated according to disability so that those like my grandson should be taught certain skills".

From the data obtained from the mothers and also from the agency (see Chapter 3), it is difficult to ascertain whether admission to the centres for the mentally handicapped was preceded by psychological assessment and whether the educational or training programmes carried out were designed to meet the needs of the children according to their level of functioning.

Thatcher as cited by Lombaard (1982:5) has the following to say in this regard:

> It is necessary to study the severely mentally handicapped child's problems in their totality with a view to the implications of these problems for the nature and content of the training programme with regard to inter alia reading matter, methodology and aids.

7.3 DISCOVERING THE CHILD'S DISABILITY

Glendinning (1983) mentioned that discussions with parents concerning the period when they discovered their child's mental handicap shows that this discovery was a gradual process. The word 'discovery' suggests a sudden recognition and this could be misleading (Ayer, Alaszewski 1984). The word is however used throughout the literature on mental retardation (Glendinning 1983; Ayer, Alaszewski 1984; Robinson, Robinson 1976).

The discovery of mental retardation is actually a time of confirmation and perhaps consensus on a label for a condition the existence of which the parent(s) has suspected for some time. This discovery can be made at different times during the early stages of the child's life and also by people both inside and outside the family.

TABLE 7.4

PERCENTAGE DISTRIBUTION OF PERSON(S) WHO DISCOVERED THE MENTAL HANDICAP

Person	Number	%
Mother	46	57,5
Family	8	10,0
Doctor	14	17,5
Nurse	4	5,0
Teacher	7	8,8
Unknown/child was known to be mentally retarded when placed with respondent	1	1,3
TOTAL	80	100,0

Approximately two fifths of the people who discovered the child's impairment were outsiders or professionals. In most cases (57,5 %) the mothers discovered the impairment themselves. Some times the disability is obvious from birth but confirmation may come later.

Only 38,8 % of the mothers mentioned that their children had a psychological assessment.

In cases where the discovery was made by someone else other than the mother (N = 33), about four fifths of the respondents mentioned that they were given an explanation of the condition by the person who made the discovery. Forty five per cent mentioned that the explanation given was clear.

The mothers who were given an explanation concerning the child's condition had different perceptions regarding the attitude shown by the people who made the explanations. These reactions were as follows: 41,9 % were very sympathetic; 22,5 % were sympathetic; 6,4 % were unsympathetic; 12,9 % were indifferent and 16,1 % showed no reaction, were guarded or neutral.

The mothers reported a variety of reactions, most of which emanated from professionals. When a mother approaches a professional, especially a medical practitioner for a diagnosis, or confirmation of her suspicions or for an explanation, she is already under tremendous stress. Delcampo, Chase and Delcampo (1984) mention that the mothers they studied reported a lack of sensitivity on the part of physicians. These findings are also confirmed by Glendinning (1983) as well as Ayer and Alaszewski (1984).

Regarding this study it should be borne in mind that some of the children were born more than nineteen years ago and consequently the mothers' recollections have been coloured by time and other experiences both related and unrelated to the child.

The mother's experiences in her dealings with professionals at this sensitive time may lead to a certain amount of bitterness especially if the physician refuses to acknowledge the mother's anxiety and to give her honest answers (Glendinning 1983). These early experiences with professionals may set the pattern for the mother's future relationship with them. A large number of the mothers in this study who were given an explanation reported positively concerning their experiences.

It is not clear from the study what the explanation entailed. Whether or not it included referral to other sources of assistance such as welfare agencies or funding sources for the care of the child cannot be ascertained.

After discovering the condition of the children the mothers than discussed the matter with other people. These persons again included professionals and non-professionals and here too there were wide-ranging reactions. Table 7.6 details the attitudes of these people as experienced by the caregivers.

The respondents' partners/spouses and families were being mentioned as sympathetic by over two thirds of the respondents (63,8 % and 71,3 % respecitively). Relatives were mentioned as sympathetic by approximately half the respondents (48,8 %). Friends and neighbours were mentioned by 27,5 % while among the professionals a doctor was mentioned by the largest group (38,3 %).

TABLE 7.5

ATTITUDE OF PERSON WITH WHOM THE CHILD WAS DISCUSSED

Person	Attitude						
	Sympathetic	Unsympathetic	Cold/Aloof	Guarded/neutral no reaction	Other reaction**	Did not discuss/ had no need to discuss/no contact	Total %*
Partner/spouse	51 (63,8 %)	0 (0,0 %)	5 (6,3 %)	2 (2,5 %)	2 (2,5 %)	20 (25,0 %)	100,0
Family (e.g. sisters, brothers)	57 (71,3 %)	1 (1,3 %)	1 (1,3 %)	1 (1,3 %)	0 (0,0 %)	20 (25,0 %)	100,0
Relatives	39 (48,8 %)	0 (0,0 %)	3 (3,8 %)	4 (5,0 %)	1 (1,3 %)	33 (41,3 %)	100,0
Friends, neighbours	22 (27,5 %)	1 (1,3 %)	1 (1,3 %)	4 (5,0 %)	1 (1,3 %)	51 (63,8 %)	100,0
Social worker	24 (30,0 %)	2 (2,5 %)	0 (0,0 %)	5 (6,3 %)	1 (1,3 %)	48 (60,0 %)	100,0

* N = 80.
** Other reactions mentioned were concern, pity and understanding.

It would appear that more of those persons who were regarded as family members were the ones who were sympathetic towards the respondents when compared to those who could be regarded as outsiders. The study however does not distinguish between those relatives who are linked to the respondent by blood and those who are linked by marriage.

In addition to the persons provided for in the question, one respondent mentioned the family medicine man who was said to have been sympathetic.

Learning that one's child is mentally retarded can be a shattering experience for parents (Farber 1970; Olshansky 1970; Schild 1971; Robinson, Robinson 1976). These parents are in a crisis situation and their experiences are summed up by Farber (1968:266) as follows:

> Some parents are filled with overwhelming guilt feelings, anxiety, anger, denial, rejection, optimism, self-pity, aggressive, excessive self-condemnation or extreme overprotection. However some parents have an excellent acceptance of an unhappy situation which results in almost a blessing in disguise.

All the mothers in this study did discuss their children's condition with more than one person in and outside the family.

In response to a question concerning their reactions to the birth of a disabled child, 32,5 % of the respondents mentioned that they were sad and disappointed when they discovered that they had a mentally retarded child. Eighteen comma eight per cent accepted the child while 16,3 % felt anger and frustration and 15,0 % were extremely depressed. Only one mother (1,3 %) experienced relief after a lengthy period of uncertainty and 2,5 % mentioned that they were confused. Seven comma two denied the problem and 6,3 % were overcome with helplessness.

According to Gallagher, Beckman and Cross (1983), the circumstances under which parents learn about their child's condition often determines their reaction to the child. This reaction can also affect their future perception of the child and his handicap.

The reactions of the mothers mentioned above were, according to them, based on experiences which occurred at different periods after the child's birth and some of these reactions were probably experienced more than ten years ago. Because of this, one may be correct to state that certain events surrounding the child may have changed the mother's initial reaction and that it is possible that some may be having lapses of memory which may lead to their statements being relevant to current reactions than to reactions at the time of the discovery. Glendinning (1983) warns about the possibility of the mothers recounting their current or recent reactions and not what they experienced when the disability was discovered or confirmed.

Forty per cent of the mothers did not know what the cause of their child's condition was. Twelve comma five per cent said that their child was born handicapped. It would appear that this group also did not know the cause of their child's condition. Some of the causes mentioned were: accident or trauma 2,5 %; effect of treatment by physician or medicine man 3,8 %; mishap during pregnancy/delivery or a premature birth 12,5 %; witchcraft 5,0 %; "fault in mother's/father's blood" 5,0 %; arrested development 5,0 % and prolonged illness or attacks of fits 12,0 %.

Less than half of the mothers did mention the causes of their mentally retarded children's condition. However, it could not be ascertained from the study whether they themselves understood the causes and how they came to know about them. Specific examples here are those who mentioned 'fault in mother's/father's blood'. This 'fault' could be infection or some congenital blood abnormality.

When asked to describe their handicapped child's condition, close to two thirds (63,8 %) of the caregivers described the condition by referring to the children's intellect. The remaining 26,1 % described the children more according to physical deformities than according to mental or behavioural problems.

A mother's views of the cause of her handicapped child's condition may fundamentally affect her behaviour towards the child (Gallagher, Beckman, Cross 1983:12). These authors go on to emphasize their point by citing studies done by Lavelle and Keogh who point out that:

> The nature and intensity of some parent affective reactions may be linked to their belief that somehow they 'caused' the child's handicap. Other parents, however, might believe that something else caused the child's handicap or that it was an accident or an act of God.

It is not only the mother of the mentally retarded child who reacts to the discovery of her child's condition. Other people such as relatives, friends and neighbours also react to the discovery in a variety of ways and these reactions are known to have an influence on whether these people will be supportive to the mother or not (Anderson 1982).

Urbani (1982) in his study on problems surrounding children with genetic impairments found that 87,5 % of the parents stated that their families reacted with sympathy to the news that they had a handicapped child. In this study 77,5 % of the mothers stated that their families were sympathetic. Seven comma five per cent stated that only some family members were sympathetic and others were not and only 2,5 % said that family members showed no reaction. The percentage of unsure ones were 3,8 %. In the remaining cases the child was not the respondent's biological child so the question was not applicable.

7.4 THE HANDICAPPED CHILD'S LEVEL OF INDEPENDENCE

As in the case of parents of normal children, parents of mentally retarded children also concern themselves with their children's functional capacity for independence. This concern may be more pronounced in the latter case.

Sixty five per cent of the children in the study had no physical disabilities. The remaining 35,0 % had disabilities such as: the inability to use an arm or a leg (11,3 %); hemiplegia (7,5 %); paraplegia (5,0 %); speech defect (5,0 %); microcephallus or hydrocephallus with spinal defect (1,3 %); deafness (1,3 %); total or partial blindness (1,3 %) and quadruplegia (1,3 %).

One cannot take it for granted that those children who did not have physical deformities would automatically be considered as independent. The extent to which a mentally disabled child can perform certain tasks with or without assistance depends on a number of factors such as: level of retardation, availability of certain types of aids, age of the child and whether or not he/she has been trained.

Only 6,3 % of the children in the study can be considered to be completely dependent upon others because of their physical condition.

TABLE 7.6

PERCENTAGE DISTRIBUTION OF THE TASKS WHICH THE MENTALLY RETARDED CHILDREN CAN OR CANNOT PERFORM

Activity	Child too young for this activity	Can perform without difficulty	Can perform with difficulty or with help	Cannot perform at all	* % Total
Wash himself/herself	1 (1,3 %)	44 (55,0 %)	17 (21,3 %)	18 (22,5 %)	100,0
Dress himself/herself	0 (0,0 %)	44 (55,0 %)	18 (22.5 %)	18 (22,5 %)	100,0
Reach and use toilet	0 (0,0 %)	62 (77,5 %)	8 (10,0 %)	10 (12,5 %)	100,0
Walk	0 (0,0 %)	69 (82,5 %)	7 (8,7 %)	4 (8,8 %)	100,0
Climb stairs or steps	0 (0,0 %)	58 (72,5 %)	11 (13,7 %)	11 (13,7 %)	100,0
Catch a bus/train	3 (3,8 %)	42 (52,5 %)	15 (18,7 %)	20 (25,0 %)	100,0
Do shopping	3 (3,8 %)	35 (43,7 %)	14 (17,5 %)	28 (35,0 %)	100,0
Cook a hot meal	11 (13,7 %)	14 (17,5 %)	10 (12,5 %)	45 (56,3 %)	100,0
Clean the house	10 (12,5 %)	26 (32,5 %)	9 (11,3 %)	35 (43,7 %)	100,0
Do laundry	9 (11,3 %)	21 (26,3 %)	13 (16,2 %)	37 (46,2 %)	100,0

* N = 80.

More than half - and in some cases more than three quarters - of the children could perform basic self-care tasks on their own without assistance. It would appear therefore that the majority of the children could be considered as capable of functioning mostly on their own and with minimal assistance if necessary.

The extent to which these children could function independently would not only make it easier for them to be integrated into the community but would also lessen the tasks of the mothers in respect of the actual caring activities involved in raising the children.

7.5 PROBLEMS EXPERIENCED IN RAISING A MENTALLY RETARDED CHILD

Glendinning (1983) as well as Robinson and Robinson (1976) have classified the problems experienced by the mother of the mentally retarded child in raising her child into major and minor problems (see Chapter 4). For the purpose of this study the areas of concern for the mothers/caregivers were grouped as follows: the daily tasks of caring for the child; requirements for raising the child and those problems which they considered to be serious problems.

7.5.1 Daily tasks

Some mothers will require more help than others depending upon the level of the child's independence. Some may require aid with only one task while others will require assistance with more than one. In this study, only 13,7 % of the mothers required help with one task. The tasks were as follows: bathing (2,5 %); carrying the child (1.3 %); dressing (2,5 %); toiletting (1,3 %) laundry (2,5 %), and supervision (3,6 %).

More than half of the mothers (56,3 %) did not require any assistance and the remaining 30,0 % either required aid with more than one task or with all the tasks mentioned above. The tasks with which the latter group required assistance were categorised as follows: bathing (25,0 %); dressing (23,7 %); laundry (20,0 %); feeding (10,0 %); toiletting (8,7 %), and supervision (5,0 %).

When one looks at the extent to which most of the children could perform certain tasks without help, it is not surprising to find that a large number of the mothers either did not need assistance or those who did, required help with only one task. Table 7.6 shows that very few of the children could not perform certain tasks entirely on their own while those who could manage with aid were receiving that help from the mothers themselves. Perhaps the mothers felt the need for help for those tasks which the children could not perform satisfactorily even though the mother helped them. The mothers of children who could dress themselves with some help from them would find the task less taxing than the mothers of children who could not perform the tasks completely.

Table 7.3 reflects that 36,3 % of these children were mildly retarded and it is expected that most if not all of them could perform basic self-care tasks without help (Robinson, Robinson 1976). The moderately retarded (23,8 %) are expected to master basic skills such as feeding themselves and dressing and they can be toilet-trained (see Chapter 2). If the mildly and moderately retarded children in this study could perform the tasks they are expected to perform then the mothers' burden of caring could be lighter.

Bathing appears to be the task with which most mothers (30,0 %) required assistance. Bathing a heavy child or a child with a disability or one who perhaps has behaviour problems can present a major problem. It is also a time-consuming activity because of the other activities associated with it such as dressing, lifting and carrying.

Concern with laundry does not only focus upon the amount of work involved but also upon how often it has to be done. Mothers of incontinent children may have to do large quantities of laundry twice a day if they do not watch the child closely in order to be able to prevent 'accidents'.

Not all mothers/caregivers in this study received the help that they required with the daily tasks of caring for the child. Table 7.7 shows those tasks with which the mothers either did not receive help and also whether they needed more help or not.

TABLE 7.7

TASKS FOR WHICH HELP WAS REQUIRED

	N	Does get enough help	Needs help but does nog get it	Does get help but would like more	Does require help but for crisis only		Total
					and does get it	Does not get it	
Feeding	12	7 (58,1 %)	1 (8,3 %)	2 (16,6 %)	2 (16,3 %)	0 (0,0 %)	100,0
Bathing	24	15 (62,5 %)	3 (12,5 %)	2 (8,3 %)	3 (12,5 %)	1 (4,2 %)	100,0
Laundry	21	13 (61,9 %)	4 (19.0 %)	2 (9,5 %)	1 (4,7 %)	1 (4,7 %)	100.0
Carrying	11	4 (36,3 %)	2 (18,1 %)	3 (27,2 %)	2 (18,1 %)	0 (0,0 %)	100,0
Dressing	22	15 (68,1 %)	3 (13,6 %)	1 (4,5 %)	2 (9,0 %)	1 (4,5 %)	100,0
Toiletting	13	6 (46,1 %)	2 (15,3 %)	2 (15,3 %)	2 (15,3 %)	1 (7,6 %)	100,0

Close to two thirds - and in some cases more than two thirds - of those mothers who required help stated that they received enough help with feeding (66,6 %), bathing (62,5 %), laundry (61,9 %) and dressing (68,1 %). Slightly more than a third received enough help with carrying (36,3 %), while almost half mentioned receiving enough help with toiletting (46,1 %).

When one takes into consideration those mothers who stated that they got sufficient help as well as those who received some assistance but would have liked more; it appears that on the whole the mothers received a considerable amount of help with the daily tasks of caring for their children.

According to Wilkin (1979), the tasks of bathing, feeding, dressing and laundry generally require a high level of competence and greater motivation and if a mother receives help with these, she is likely to receive help also in other areas.

7.5.2 The mothers'/caregivers' needs or requirements in raising the child

The mother of a mentally retarded child does not only need help with the daily tasks of caring for the child. She has other requirements of a material nature such as money, transport, medication and perhaps hired help, to name a few.

In this study about a third (33,7 %) of the mothers expressed a need for more than one form of material aid while 40,0 % mentioned only one form of material aid.

TABLE 7.8

ASSISTANCE AND/OR FACILITIES REQUIRED IN RAISING THE CHILD

Type of assistance	Number	%
Financial	37	46,2
Medication	12	15,0
Special transport	12	15,0
Ordinary transport but convenient	10	12,5
Hired help	9	11,2
Training centre or equipment*	6	7,5
Handicraft centre*	1	1,3

* Specified as 'other' forms of aid required.

The impression gained from the above table is that less than half (46,2 %) of the mothers required financial help in raising their handicapped children. When one considers other requirements bearing in mind that there are costs involved in acquiring some of them, it can be correctly concluded that the figure of those requiring financial help may be higher than 46,2 %. It is however not clear from the above table what the financial assistance was specifically required for. This higher percentage requiring financial aid is to be expected considering the number of children in some of the households, the income levels of the families and the fact that 46,2 % of the respondents are unemployed (cf. Table 7.1).

According to Glendinning (1983) families will spend money on extras such as special types of toys or in altering their house to make certain areas accessible to the handicapped child and an outsider may consider this expenditure unnecessary. When one has to care for a disabled child it is sometimes difficult to establish criteria for 'necessity'. In justifying this type of spending, Glendinning (1983:69) says that "in view of the very many practical restrictions, anxieties and stresses involved in the 'daily grind' of care, such expenditure can be important for the social psychological and emotional well-being of the whole family".

7.6 RESPONDENTS' FORMAL AND INFORMAL NETWORK

Effective community care of mentally handicapped children depends on the support which the mothers of such children receive from their social network - both formal and informal (Wilkin 1979; Ayer, Alaszewski 1984).

Table 7.9 shows the value of the professionals according to the period when their expertise was required by the respondent in relation to the birth of the handicapped child.

TABLE 7.9

RESPONDENTS' FORMAL NETWORK

Professional person	Before birth but not now	Since birth and still important	Only since birth i.e. not before	Only recently	Never important	No contact or do not know such person	*Total %
Social worker	0 (0,0 %)	7 (8,8 %)	7 (8,8 %)	47 (58,7 %)	9 (11,3 %)	10 (12,5 %)	100,0
Doctor	2 (2,5 %)	28 (35,0 %)	15 (18,8 %)	7 (8,8 %)	19 (23,8 %)	9 (11,3 %)	100,0
Nurse	1 (1,3 %)	19 (23,8 %)	11 (13,8 %)	6 (7,5 %)	25 (31,3 %)	18 (22,5 %)	100,0
Teacher	0 (0,0 %)	8 (10,0 %)	9 (11,3 %)	25 (31,3 %)	15 (18,8 %)	23 (28,8 %)	100,0
Priest	3 (3,8 %)	16 (20,0 %)	3 (3,8 %)	9 (11,3 %)	27 (33,8 %)	22 (27,5 %)	100,0
Créche or nursery school teacher	0 (0,0 %)	0 (0,0 %)	1 (1,3 %)	4 (5,0 %)	21 (26,3 %)	54 (67,5 %)	100,0

* N = 80.

The social worker is considered important by more than three quarters of the respondents. In order of their importance to the respondents other professionals were mentioned as follows: doctor 62,6 %, nurse 45,1 %, teacher 52,6 %, priest 35,1 %, and a crèche or nursery school teacher 6,3 %.

A large percentage of those who mentioned the social worker as well as a teacher stated that these professionals only became valuable to them recently.

This type of situation is to be expected considering the condition of these children. Teachers become aware of the disability of these children when they start school while a social worker may know about their handicap from a very early state of their lives, for example from shortly after their birth when they are referred by the medical personnel or at a later stage when they show lack of progress in attaining certain milestones. In some cases the first contact with the social worker may be made when the child is not making the expected progress at school and (s)he is referred to the social worker.

If the priest does not know the family intimately it may be a few years before he finds out that they have a mentally retarded child, but if he knows the family well he will be told at the birth of the child.

Mentally retarded children, especially those who are severely handicapped are often considered as permanent patients (Glendinning 1983). Perhaps this might explain why more than half of the respondents appreciated the importance of a doctor, nurse and perhaps a priest in their lives right from the birth of the child.

These persons considered as important by the mothers/caregivers form part of their formal social support system. They are considered by the respondents as playing a significant part in relation to the care of the handicapped child.

Some of the respondents mentioned that they sometimes had contact with professionals for the following reasons: "when the child is ill";

"when there is a problem" or "when there is a parents' meeting".

TABLE 7.10

TYPE OF CONTACT WITH FORMAL NETWORK

	N	Regularly at least once a month	Irregularly: only when the need arises	Other basis	Total
Social worker	60	3 (6,6 %)	46 (76,6 %)	11 (16,6 %)	100,0
Doctor	51	18 (18,2 %)	30 (30,8 %)	3 (5,8 %)	100,0
Nurse	36	12 (33,3 %)	20 (55,5 %)	4 (11,1 %)	100.0
Teacher	39	7 (17,9 %)	18 (46.1 %)	14 (35,8 %)	100.0
Priest	28	19 (67,8 %)	6 (21,4 %)	3 (10,7 %)	100,0
Créche or nursery school teacher	5	1 (20,0 %)	3 (60,0 %)	1 (20,0 %)	100,0

More mothers cited the value of the health and religious professions than any other due to the fact that there is regular contact between these professionals and them.

According to Crotty and Kulys (1985) several studies have revealed that people with problems will go to their immediate kin, friends and neighbours before going to organized institutions in the community.

As in the case of the formal network, the respondents considered different people as important to them at various times during and after the birth of the disabled child.

Those persons who were considered important were mentioned by the respondents in the following order: own siblings (55.0 %); relatives (55,0 %); friends and neighbours (51.3 %); father of the child (47.5 %), and siblings of father of the child (30.1 %). It is not surprising to find that the fathers of the children and their siblings

TABLE 7.11

RESPONDENTS INFORMAL NETWORK

	Period of importance to respondent						
Person(s)	Before birth only not at present	Before birth and still important	Since birth but not before	Only recently	Never important	No such person/ no contact	*Total %
Father of the child	25 (31,3 %)	38 (47,5 %)	0 (0,0 %)	0 (0,0 %)	5 (7,5 %)	11 (13,8 %)	100,0
Siblings of father of the child	8 (10,0 %)	19 (23,8 %)	3 (3,8 %)	2 (2,5 %)	25 (31,3 %)	23 (28,8 %)	100,0
Own siblings	10 (12,5 %)	48 (60,0 %)	4 (5,0 %)	0 (0,0 %)	10 (23,5 %)	8 (10,0 %)	100,0
Relatives	12 (15,0 %)	40 (50,0 %)	4 (5,0 %)	0 (0,0 %)	10 (23,5 %)	14 (17,5 %)	100,0
Friends/neighbours	0 (0,0 %)	26 (32,5 %)	5 (6,3 %)	10 12,5 %)	29 (36,3 %)	10 (12,5 %)	100,0

* N = 80

TABLE 7.12

CONTACT WITH THE INFORMAL NETWORK

Person(s)	N	Regularly: at least once a month	Irregularly: only when the need arises	Other basis	Total %
Father of the child	48	38 (79,1 %)	4 (8,3 %)	6 (12,5 %)	100,0
Siblings of father of the child	27	16 (59,2 %)	7 (25,7 %)	4 (14,8 %)	100,0
Own siblings	61	39 (63,9 %)	17 (27,8 %)	5 (8,1 %)	100,0
Relatives	47	26 (55,3 %)	13 (27,6 %)	8 (17,0 %)	100,0
Friends and neighbours	39	17 (43,5 %)	11 (30,7 %)	9 (25,0 %)	100,0

were mentioned by a small percentage. This is to be expected since only 53,8 % of the caregivers were married and not all of them were the biological parents of the children in question.

Some of the respondents mentioned that they only contacted their informal network during school holidays when they could visit without the child and leave him in the care of his school-going siblings. Others mentioned that they only had contact with their informal network when there is a major crisis. One mother said that "the father of the child only comes when he has transport because he is also handicapped".

The general impression gained is that there is a reasonable amount of contact between the respondents and their informal social network considering that with the exception of friends and neighbours, more than half of the respondents have regular contact - at least once a month - with their network.

Other persons mentioned by the respondents as playing an important role in their lives at the time of the study and with whom they had regular contact were: boyfriends (2,5 %); church members (2,5 %); brothers' grown-up children (1,3 %); own grown-up children (6,3 %); medicine man/witchdoctor (1,3 %) and the staff at the training centre (1,3 %).

7.7 FORMAL AND INFORMAL SUPPORT SYSTEMS

Spontaneous help may be forthcoming from the networks, especially the informal network although sometimes one has to make a request for assistance. The policies of some formal networks allows them to seek out consumers for their services while others render service only to those who approach them for assistance.

Although almost two fifths of the respondents mentioned the fathers' siblings as part of their informal network, a very small percentage regarded them as a source of spontaneous help. It is interesting to note the percentage of the respondents' husbands who are not the fathers of the handicapped children who will help spontaneously.

A person in need of help goes to various people for different types of assistance. When asked whom they would go to when worried about the children the mothers in this study gave the following responses: father of the child 51,3 %; siblings of father of the child 25,0 %; present husband who is not the father of the child 6,3 %; own siblings 58,8 %; relatives 48.8 %; friends and neighbours 10,0 %; employers 2,5 %; church people 2,5 %, and boyfriends 2,5 %.

TABLE 7.13

PERCENTAGE DISTRIBUTION OF PERSONS WHO WILL HELP WITHOUT BEING ASKED

	N	Yes	No	Uncertain	Total %
Father of the child	54	35 (64,8 %)	14 (25,9 %)	5 (9,2 %)	100,0
Siblings of father of the child	49	3 (6,1 %)	29 (50,1 %)	17 (34,6 %)	100,0
Present husband (not father of the child)	7	6 (85,7 %)	0 (0,0 %)	1 (14,2 %)	100,0
Grown-up children	57	39 (68,4 %)	8 (14,0 %)	10 (16,9 %)	100,0
Relatives	58	33 (56,9 %)	14 (24,1 %)	11 (18,9 %)	100,0

Although it is not clear if 'worried about the child' refers to concern regarding the care of the child or whether it is concern for the child's general health or perhaps refers to aspects pertaining to the future care of the child; it would appear that the mothers did, generally speaking, have someone they could contact when they worried about the handicapped child. These persons included both professional and non-professional people. With regard to those mothers who stated that they would not approach anyone, it was not established whether they had nobody they could contact or whether they did not wish to contact anyone. One mother, however, volunteered her reason as follows: "I do not contact anyone because I do not want to burden people especially because I myself am physically handicapped".

When asked who they would contact when they were worried about things other than the child, the responses were as follows: father of the child 43,8 %; siblings of father of the child 15,0 %; own siblings 58,8 %; grown-up children 55,0 %; husband who is not father of the child 8,8 %; relatives 48,8 %, and professional people 36,3 %. Once again 6,3 % of the respondents mentioned that they would not contact anyone.

It would appear that approximately an equal percentage of mothers who would contact their own siblings and grown-up children concerning the child would also approach them about other problems. These may not necessarily be the same individuals. Fewer mothers would contact professionals regarding matters which do not concern the child.

Not only did the mothers receive different types of assistance from a variety of sources, but the assistance received in some cases was provided on a regular basis while in other instances it was on an occasional basis. In order to operationalise community care it is necessary to consider the contributions made by various individuals.

7.7.1 Support from the father of the child

Forty eight comma seven per cent of the mothers stated that they received material aid from the fathers of their mentally retarded children and 28,7 % received advice.

TABLE 7.14

TYPE OF SUPPORT RECEIVED FROM THE FATHER

	N	Emotional	Informational	Instrumental	Feedback on behaviour	Referral to a service	Total
Regularly	36	14 (38,9 %)	1 (2,8 %)	20 (55,6 %)	1 (2,8 %)	0 (0,0 %)	100,0
Occasionally	38	10 (26,3 %)	6 (15,8 %)	16 (42,1 %)	5 (13,2 %)	1 (2,6 %)	100,0

Less than half of the mothers received different types of support on a different basis from the fathers of the mentally retarded children. Compared to other forms of support, more instrumental and emotional support was received from both categories of fathers who proffer support.

However, it should be borne in mind that the fathers in the study do not necessarily live with the mothers of the children.

Black fathers would participate to a much lower degree in the care of children because of the strict tradition regarding the role played by husband and wife in the family. Because 47,8 % of the mothers mentioned receiving material aid from the fathers, one could safely say that instrumental support was understood to refer to doing practical things with and for the mother.

However, some of the mothers felt that their husbands did not care about the child and Ayer and Alaszewski (1984) also observed the same sentiment in their study. Typical comments in this respect were:

"My husband will only help when I force him to do so"

"My husband does not care about me and the children. He had a tendency to punish Andrew until his relatives reprimanded him"

Ayer and Alaszewski (1984) found that while many mothers resented the fact that fathers accepted far less responsibility both emotionally and practically for the child, "... increased involvement of fathers with children can in some cases have a detrimental effect on the woman's work load as the father's involvement is often confined to the more enjoyable tasks such as play and outings and the women are usually left with the bulk of the hard, time-consuming tedious domestic jobs". They (Ayer and Alaszewski 1984), also found that some fathers did assist with bathing and carrying the children.

In this study, some fathers were found to be involved with the care of their children as shown by the following statements:

"The father of the child tries by all means to help wherever he can. In most cases, emotional, instrumental and informational support is received from him."

"Father of the child also offers emotional help."

"My husband is very supportive and he provides for all our material needs, I value his emotional support more than the material things although they also help."

"The father of the child supplies (sic) emotional and instrumental help. He takes the child for treatment and makes all enquiries regarding a suitable institution."

7.7.2 Support from the husbands who are not the fathers of the children

The total percentage of mothers who live with husbands who are not the fathers of their mentally retarded children is 8,8 %. As mentioned in an earlier section, not all the children are the biological offspring of the respondents. Furthermore, the respondent - although being the biological mother of the said child, may be married to someone other than the father of the child.

An equal number of respondents (13,7 %) who live with husbands who are not the fathers of their mentally retarded children, receive material aid as well as advice from them. With regard to other forms of support, the situation is demonstrated as shown in Table 7.15.

TABLE 7.15

TYPE OF SUPPORT RECEIVED FROM THE RESPONDENTS' HUSBANDS WHO ARE NOT THE FATHERS OF THE CHILDREN

	N	Emotional	Informational	Instrumental	Feedback on behaviour	Referral to a service	Total
Regularly	7	2 (22,6 %)	0 (0,0 %)	4 (57,1 %)	1 (14,3 %)	0 (0,0 %)	100,0
Occasionally	6	3 (50,0 %)	1 (16,7 %)	1 (16,7 %)	1 (16,7 %)	0 (0,0 %)	100,0

None of the above-mentioned persons referred the respondents to services they could utilise and no regular information was received from them. Considering that these men could be step-fathers, grandfathers or uncles by marriage, the amount of instrumental help rendered on a regular basis by them to help in the care of the child is significant.

7.7.3 Support received from the siblings of the father of the child

Ten per cent of the mothers receive material aid from the father's siblings and 10,0 % also mentioned that they received advice. This percentage could reflect one group of mothers or perhaps apply to two separate groups. Possibly there could be an overlapping with some mothers receiving both material aid and advice from the fathers' siblings. Thirty three comma seven per cent received material aid from their own siblings and 26,2 % received advice from the same source.

TABLE 7.16

TYPE OF SUPPORT RECEIVED FROM THE FATHERS' AND MOTHERS' SIBLINGS

	N	Emotional	Informational	Instrumental	Feedback on behaviour	Referral to a service	Total
Fathers' siblings							
Regularly	17	9 (52,9 %)	2 (11,8 %)	3 (17,6 %)	0 (0,0 %)	3 (17,6 %)	100,0
Occasionally	22	5 (22,7 %)	8 (36,4 %)	6 (27,3 %)	1 (4,5 %)	2 (9,1 %)	100,0
Mothers' siblings							
Regularly	46	27 (58,7 %)	7 (15,2 %)	12 (26,1 %)	0 (0,0 %)	0 (0,0 %)	100,0
Occasionally	53	14 (25,4 %)	9 (17,0 %)	25 (47,2 %)	3 (5,7 %)	2 (3,8 %)	100,0

In general more support seems to be forthcoming from the mothers' siblings than from the fathers' (a percentage of 21,2 respondents mentioned that the fathers' siblings helped on a regular basis compared to 57,5 % of the mothers' siblings; 27,5 % of the respondents mentioned that the fathers' siblings helped on an occasional basis compared to 66,2 % of the mothers' siblings).

While Glendinning (1983), Ayer and Alaszewski (1984) and Wilkin (1979) in their studies found that most support came from the mother's side of the family, it is of particular interest to note that this study yields similar findings. The position with black families in Africa is that the fathers' side of the family is the one that has the final say about the upbringing of the child (Tshabalala 1986).

In his discussion on kinship networks among the Nguni, Tshabalala (1986) explains what pertains to these families as follows: "The father was undoubtedly head of his family and had complete authority over his children as long as they remained in his household ... The behaviour to a father's sister was controlled by her membership of the same family as the father. She knew the peculiar ways and traditions of the paternal home far better than the mother". He further goes on to state that this patriarchal family granted the father's relatives a greater responsibility in the bringing-up and control of the children.

Taking the findings of this study into consideration a question that comes to the fore is whether the involvement of the maternal siblings is influenced by the children's condition or whether these families have undergone changes due to their urbanised life-style.

7.7.4 Support from grown-up children

According to 45,0 % of the respondents, grown-up children provided instrumental support and 47,5 % gave advice. Compared to other members of the support system the mothers mentioned also that most of the instrumental aid and advice received was provided by grown up children.

TABLE 7.17

TYPE OF SUPPORT GIVEN BY GROWN-UP CHILDREN

	N	Emotional	Informational	Instrumental	Feedback on behaviour	Referral to a service	Total
Regularly	44	14 (31,8 %)	4 (9,1 %)	23 (52,3 %)	3 (6,8 %)	0 (0,0 %)	100,0
Occasionally	45	9 (20,0 %)	13 (28,9 %)	18 (40,0 %)	3 (6,7 %)	2 (4,4 %)	100,0

Wilkin (1979) found that other than the father, the siblings of the mentally retarded child were a major source of support. The findings of this study show that the largest group of mothers (56,0 % regularly, 55,2 % occasionally) mentioned their own siblings as being the greatest providers of support followed by the handicapped child's siblings who were mentioned by the second largest group (55,0 % regularly, 56,2 % occasionally) of mothers. Later we shall see that the fathers and relatives rank third.

The handicapped children's fathers and grown-up siblings can render instrumental support in the form of doing practical things as well as giving material aid while the younger siblings can probably only assist with doing practical things (Wilkin 1979).

Some of the mothers in the study described the assistance received from their children in the following terms:

"The siblings are always willing to help with instrumental service (sic) i.e., helping the grandmother to take the child for treatment, give him food when she is not home and also do his laundry".

"My children help with household chores and make me aware of existing services".

One respondent mentioned that her children were professionals and so she relied entirely on them for everything. Another mentioned having a daughter who was a social worker and she therefore did not need outside assistance.

As Gallagher, Beckman and Cross (1983) have stated, children, however, can also be a source of stress. They can drain the parent's material, emotional and physical resources. The position in this study was that all the siblings proved to be supportive as was the experience of one respondent whose husband was unemployed and her grown-up children refused to contribute to the family income.

If the siblings of the handicapped child experienced difficulty in adapting to him, this may result in a great deal of stress in the family. In a case where there are younger non-handicapped children, the stress experienced by the parents may be increased because the younger children would require a great deal of care and attention. Siblings can therefore be supportive or they can cause stress (Gallagher, Beckman, Cross 1983).

7.7.5 Support received from relatives, friends and neighbours

As far as material aid is concerned, 37,5 % of the respondents mentioned relatives as a source and 12,5 % mentioned that friends and neighbours gave material aid. Twenty six comma two per cent stated that they received advice from relatives and 22,5 % mentioned that they were advised by friends and neighbours.

While friends, neighbours and relatives would to some extent give support to the mother, the basic type of assistance they would give would be moral support and help with baby-sitting. Some would specifically state their willingness to baby-sit the non-handicapped children only. The instrumental help rendered by them seldom if ever included actual child-care activities or assistance with household chores (Ayer, Alaszewski 1984).

When mothers receive help from friends or neighbours they often felt that they should reciprocate especially if the aid is forthcoming from people who have children of more or less the same age as their own.

In this study approximately half of the mothers received occasional help from relatives, friends and neighbours and less than half received regular help from the same sources. Friends and neighbours seemed to make more referrals to various services than all the others who gave support.

While friends and neighbours would sometimes shun the family because of the handicapped child's behaviour, it has been observed that relatives were more tolerant (Wilkin 1979). This type of situation could account for the fact that mothers received more help from relatives than from friends and neighbours.

TABLE 7.18

TYPE OF SUPPORT RECEIVED FROM RELATIVES, FRIENDS AND NEIGHBOURS

	N	Emotional	Informational	Instrumental	Feedback on behaviour	Referral to a service	Total
Relatives							
Regularly	35	15 (42,9 %)	5 (14,3 %)	14 (40,0 %)	1 (2,9 %)	0 (0,0 %)	100,0
Occasionally	39	13 (33,3 %)	10 (25,6 %)	13 (33,3 %)	1 (2,6 %)	2 (5,1 %)	100,0
Friends and neighbours							
Regularly	27	12 (44,4 %)	5 (18,5 %)	6 (22,2 %)	1 (3,7 %)	3 (11,1 %)	100,0
Occasionally	40	12 (30,0 %)	10 (25,0 %)	9 (22,5 %)	1 (2,5 %)	8 (20,0 %)	100,0

One respondent who found her neighbours supportive said: "the neighbours are very informative and they usually help with the child when I go to town or to pay the rent".

Mothers seemed to accept the fact that some relatives only made minimal contributions to the care of the child. Some mentioned that they felt that their relatives had their own families to care for and others stated that relatives lived far away to be involved with the care of the child.

As mentioned earlier community care involves care by the family and actually rests on the support that the mothers of handicapped children receive from inside and outside the family. The situation as perceived in this study and in the studies by Wilkin (1979), Glendinning (1983) as well as Ayer and Alaszewski (1984), is that the support received by a large number of the mothers came from within the family.

Hanvey (1981) recommends that for kin network to function as a viable support system, kin has to learn to communicate and exchange help in ways other than the traditional face-to-face exchange and especially in the case of loans and gifts.

In addition to the sources provided for in the question, the respondents mentioned other sources from which they received support. These sources also provided regular and occasional support to 6,3 % of the respondents. The sources are as follows: priest, church members, employer, woman's club, co-workers, boyfriend, nephews/nieces and professional person.

One respondent mentioned that her employer understood that her child was crippled and he usually advised her on the type of medication she could use to remedy minor illnesses. Another respondent mentioned a traditional medicine man as a source of emotional support. The mention of this source of support was not surprising considering that 5,0 % of the mothers mentioned witchcraft as a cause of their children's condition.

The respondents who did receive help from church members and the priest seemed to be satisfied. Typical descriptions of help received were:

"My church regularly sends me foodstuff and clothing".

"The church people give emotional help which I greatly appreciate because I get a chance to speak to someone outside the family".

"Our priest occasionally helps with transport, money and food".

One is, however, surprised by the fact that the respondents did not seem to mention a large number of professionals from whom they received assistance. This might create the impression that only minimal help was received from professionals and yet observation of the findings on material aid and advice shows that 25.0 % of the respondents received material aid and 70.0 % received advice from professionals. It may be assumed that contact with professionals such as doctors, nurses and social workers is usually based on some form of therapy, the dispensation of information or advice or referral to a social service. Table 7.10 reflects that large numbers of the respondents had both regular and irregular contact with these professionals.

Perhaps the low response is due to the fact that the role of the professional was not handled as a direct question as for instance in the case of the father of the child, the mother's siblings or relatives et cetera. It may be that although respondents received help from professionals, the fact that their assistance was mentioned by so few reflects how they felt about that help, especially in view of the fact that the professionals did not participate directly in the caring activities of raising the child.

The fact that clients or patients who need help are expected to contact people or service agencies themselves often causes a great deal of stress (Glendinning 1986). As a result, contact with service agencies is irregular, infrequent and lacks continuity. In addition, parents are often reluctant to be seen to need help especially from sources outside their families or informal network (Glendinning 1986).

It is to be expected that the mothers of mentally disabled children should spend much more time interacting with professionals than the mothers of normal children. Their accounts of these interactions often lead to the conclusion that in most cases the parent-professional interaction is a source of stress rather than one of support (Gallagher, Beckman, Cross 1983; Ayer, Alaszewski 1984; Wilkin 1979). Glendinning (1983) found that mothers sometimes displayed mixed feelings with regard to their experiences with professionals.

Some of the mothers in this study had the following to say about professionals (social workers):

"The social worker is not always there when I need her but when she is available I discuss the child with her".

"My (handicapped) son has started drinking and I am very worried because I do not see the social worker often so that I can ask her advice".

"I have always trusted professional people especially social workers".

It is not uncommon to find social workers in the field of the mentally handicapped often having large case loads. The social worker covering the area where this study was conducted had a case load of 148 mentally retarded children plus some cases of mentally ill persons (see Chapter 2). Therefore, it is not surprising that only 6,6 % of 60 mothers (Table 7.11) stated that they saw the social worker at least once a month on a regular basis.

Wilkin (1979) and Glendinning (1983) found that criticism of social workers were very common even amongst those mothers who benefited by their services.

Over a certain period of requesting and receiving help from different sources, the mothers in the study developed a support system to which they would refer other mothers in a similar position to theirs (Table 7.19 below).

Professionals had the highest percentoge in contrast to the siblings of the father of the child.

TABLE 7.19

PERCENTAGE DISTRIBUTION OF THOSE PERSONS TO WHOM OTHER MOTHERS OF MENTALLY RETARDED CHILDREN WILL BE REFERRED

	Will refer	Will refer to some not others	Have no such person/contact Will not refer	*Total %
Father of the child	35 (43,8 %)	3 (3,8 %)	42 (53,0 %)	100,0
Siblings of father of the child	11 (13,8 %)	11 (13,8 %)	58 (73,0 %)	100,0
Own siblings	35 (43,8 %)	15 (18,0 %)	30 (38,0 %)	100,0
Relatives	23 (29,0 %)	22 (28,0 %)	35 (44,0 %)	100,0
Grown-up children	31 (39,0 %)	15 (19,0 %)	34 (43,0 %)	100,0
Professionals	50 (63,0 %)	16 (20,0 %)	14 (18,0 %)	100,0

*N = 80.

7.8 ORIENTATION TOWARDS USING NETWORKS

Networks are characterized by reciprocity whereby one favour is exchanged in return for another (Unger, Powell 1980; Shumaker, Brownell 1984). Recipients of support are sometimes obliged to return the kindness shown to them. One often finds that those who are prepared to help others receive help from the network themselves. Table 7.20 shows the mothers' responses to requests for help.

Approximately three quarters of the respondents stated that they had comforted a bereaved person or one who had a crisis while slightly more than a third provided information or material assistance.

When one looks at the responses in cases where respondents were approached for assistance, the impression gained is that the respondents can be generally perceived to be helpful people.

TABLE 7.20

PERCENTAGE DISTRIBUTION OF REACTIONS OF RESPONDENTS TO REQUESTS FOR ASSISTANCE

	I was not asked for help during this time	I tried to help in all cases	I sometimes tried to help	I did not help		I helped but did not really feel like it	Total*
				because I was unable to	because I did not want to/did not really feel like it		
Financial aid	35 (43,8 %)	18 (22,5 %)	7 (8.8 %)	20 (25.0 %)	0 (0,0 %)	0 (0,0 %)	100,0
Material things but not money (e.g. clothing, food, etc.)	33 (41,2 %)	28 (35,0 %)	12 (15,0 %)	7 (8,8 %)	0 (0,0 %)	0 (0,0 %)	100,0
To perform a task (e.g. care for a child, do laundry, cook, etc.)	43 (53,8 %)	21 (26,3 %)	6 (7,5 %)	9 (11,3 %)	0 (0,0 %)	1 (1,3 %)	100,0
Information (directions to a place, advise about available service, etc.)	41 (51,3 %)	29 (36,3 %)	6 (7,5 %)	4 (5,0 %)	0 (0,0 %)	0 (0,0 %)	100,0
Comfort (during bereavement or crisis)	14 (17,5 %)	58 (72,5 %)	7 (8,8 %)	1 (1,3 %)	0 (0,0 %)	0 (0,0 %)	100,0

*N = 80.

The capacity of parents to help is often restricted by their heavy domestic responsibilities and their social isolation. Glendinning (1983:106) says of the situation that:

> "The relatively little practical help given to families with disabled children may reflect a desire by parents to avoid a situation of serious, chronic 'indebtedness' and an abrogation of the responsibilities and obligations attached to the receipt of informal help".

Tshabalala (1986) emphasizes the element of reciprocity in the extended African family where members who do not make a contribution but expect to receive help are strongly reprimanded. Citing Martin, he further went on to explain that one of the functions of the Nguni family was to promote the welfare of members, deal with crisis situations, provide family members with the basic necessities of life and to give them some feeling of economic security. To sum up the situation, a member of such a family should rightfully expect help but he should realise that he also has an obligation to render assistance whenever possible.

The respondents cited a variety of ways in which they had requested assistance from others. Approximately three quarters asked for help directly either by phoning or visiting the person or organization concerned. Three comma eight per cent requested aid indirectly by the sending of messages while 16,3 % used a combination of the above methods. Only 5 % stated that they had never required help and 2,5 % never had no one to ask.

The success of community initiated programmes often depend not only on the participation of benevolent persons in the community but also on the involvement of the consumers of services. In this study 82,5 % of the mothers stated that they would be willing to assist if approached to start a service for mentally retarded children. Ninety per cent stated that if they were approached to become involved in an existing service for mentally retarded children, they would consent to do so.

It would appear that respondents were to a very large extent willing to become involved and participate in services that will benefit their children. The question, however, was whether they would have time to be involved especially those mothers who had severely handicapped children.

7.9 AWARENESS OF EXISTING RESOURCES

The extent to which formal resources are utilised depends on how many respondents are aware of the existence of these services, the nature of services being offered and to some extent what experience the respondents have had of them, if any. The experiences of friends, relatives and neighbours with regard to formal services might also influence the respondents (Unger, Powell 1982). While all prospective consumers of a service experience a certain amount of anxiety before approaching that service, the anxiety of the mothers (parents) of mentally retarded children is often magnified by their children's condition.

The lack of knowledge concerning existing services can handicap the mother who is trying to care for her mentally retarded child at home.

With the exception of services which related to mentally retarded children, between half to three quarters of the respondents stated that they did not know of other services available in the community.

Thirteen comma eight per cent of the respondents stated that they did not know of any welfare services for mentally retarded children while 11,3 % knew of the existence of such services but have never used them. This is not surprising in view of the fact that only 75,0 % of the respondents mentioned that the social worker was a member of their formal network (cf. Table 7.11). One would imagine that considering the problem facing them, the mothers of mentally retarded children would enquire about the existence in their community of welfare services available to help their children. Ayer and Alaszewsky (1984) report that in their study all the mothers had come into contact with one or other welfare organization because of the condition of their children.

The services that the mother of the mentally retarded child will require will vary according to the child's developmental stages. The social worker, however, remains a central figure in the provision of service because of her role as a referral agent and as a link between the mother and other services in the community.

Sometimes the parents do not use available services because they are unfamiliar with the structures and operations of the various health and welfare services, and of the concepts and terminology used by officials and professionals who provide the services; they are also unsure of the procedures involved in applying for help and the criteria for eligibility (Glendinning 1986). In as far as the present study is con-

TABLE 7.21

PERCENTAGE DISTRIBUTION OF RESPONDENTS' AWARENESS OF COMMUNITY RESOURCES

		There are no such facilities	I do not know of such facilities	I know of such facilities			Total* %
				but have never needed them/didn't get round to using them	and have tried to use them but found them to be unsatisfactory	and have used them and found them to be satisfactory	
Welfare services	for children (child welfare)	1 (1,3 %)	35 (43,8 %)	39 (48,8 %)	1 (1,3 %)	4 (5,0 %)	100,0
	for mentally retarded children	0 (0,0 %)	11 (13,8 %)	9 (11,3 %)	10 (12,5 %)	50 (62,5 %)	100,0
	for crippled children	1 (1,3 %)	40 (50,0 %)	33 (41,3 %)	1 (1,3 %)	5 (6,3 %)	100,0
Special clinic	for cripples	10 (12,5 %)	61 (76,3 %)	5 (6,3 %)	1 (1,3 %)	3 (3,8 %)	100,0
	for mentally retarded children	13 (16,3 %)	57 (71,3 %)	3 (3,8 %)	1 (1,3 %)	6 (7,5 %)	100,0
Protective workshop		14 (17,5 %)	55 (68,8 %)	5 (6,3 %)	2 (2,5 %)	4 (5,0 %)	100,0
Day care centre		1 (1,3 %)	39 (48,8 %)	11 (13,8 %)	10 (12,5 %)	19 (23,8 %)	100,0
Genetic clinic or clinic with genetic counselling services		15 (18,8 %)	62 (77,5 %)	1 (1,3 %)	0 (0,0 %)	2 (2,5 %)	100,0
Training centre		16 (20,0 %)	35 (43,8 %)	10 (12,5 %)	4 (5,0 %)	15 (18,0 %)	100,0

*N = 80

cerned, the problems may be magnified slightly due to the fact that the literacy of the average black mother is of a low standard.

Another reason for the high percentage of respondents who stated that they did not know of the existence of facilities could perhaps be due to the fact that they felt no need for assistance as their handicapped children were relatively independent and therefore did not require help (cf. Tables 7.6 and 7.7).

7.10 SERIOUS PROBLEMS EXPERIENCED IN RAISING A MENTALLY RETARDED CHILD

In addition to problems involving the daily tasks of caring for the child as well as the need for special equipment or facilities, the mothers of mentally retarded children experience other problems which they consider as important. These problems can have their origin both inside and outside the home and some of these problems can result in a great deal of stress for the mother. In this study the mothers mentioned the problems they considered serious as follows:

TABLE 7.22

PERCENTAGE DISTRIBUTION OF MOTHERS WITH SPECIFIC PROBLEMS

Problem	Number	%
Social stigma	30	37,5
Adjustment/attitude of siblings	10	12,5
Adjustment/attitude of relatives	10	12,5
Adjustment/attitude of friends/neighbours	20	25,0
Physical demands of caring for the child	23	28,8
Discipline problems	29	36,3
Money problems	48	60,0
Lack of service	27	33,8
Lack of a suitable institution	31	38,8
Restriction of movement	30	37,5

Approximately two thirds of the mothers mentioned finance as their most serious problem. This is not surprising in view of the nature of the children's condition and consequently the additional costs incurred due to the need for special types of food, clothing, medication or other equipment.

Less than a third of the mothers mentioned the physical demands of caring for their children as a serious problem. When one studies the tasks mentioned by the mothers - for which they required and received help or those tasks that they did not receive help with (cf. Table 7.7) in addition to the percentage of children who required help with certain tasks and/or those that could not perform some tasks at all (cf Table 7.6) - it is to be expected that only a third of the mothers mentioned physical demands upon them as a serious problem.

The presence of a handicapped child can affect the relationship between the family, relatives and neighbours and also relationships within the family itself. Farber (1966) found that the degree of dependence of the handicapped child did have an adverse effect on the siblings. In this study only 12.5 % of the mothers considered the attitude and adjustments of their other children in respect of the handicapped children as a problem.

If the mothers' natural network i.e. family and relatives have difficulty adjusting to the presence of the handicapped child, they may create a social distance between themselves and the family of the handicapped child and such a situation can have an adverse effect on the potential for support from these persons. In this study the findings reveal that this was not a major problem for most mothers although more than a third had difficulty with social stigma.

Of those mothers who mentioned that discipline was a problem, it transpired that their greatest difficulty was trying to confine the handicapped child to the family yard or immediate neighbourhood.

Thirty eight comma eight per cent of the respondents found the lack of a suitable institution a serious problem, however, a little less than that figure (33,8 %) thought that their handicapped children should be in an institution.

Although 37,5 % of the respondents stated that restriction of parents' movements was a serious problem, it is not clear from the study to what extent the parents' movements were restricted. Glendinning (1983) found that even where the handicapped child is relatively independent i.e. can walk, feed, dress himself and use the toilet, some parents still found their movements restricted by their own reluctance to leave the child in the care of other people. The position in this study could be the same in view of the fact that more than three quarters of the children can be considered to be independent in terms of the above functions nevertheless close to forty per cent of the mothers stated that restriction of movement was a serious problem.

7.11 DISCUSSION

The following emerged from the study:

- Almost half of the mentally retarded children are neither enrolled in a school, a day care or training centre
- A large majority of the children in the study could perform basic self-care tasks
- Bathing, dressing the child and doing laundry are the main tasks with which the mothers in the study needed help and a large majority of those who required help received it
- A substantial proportion of the mothers/caregivers were in need of financial assistance
- The mothers received mostly emotional and instrumental support from their informal support system
- The mothers'/caregivers' informal support system consisted mainly of the fathers of the children, the mothers' own siblings, grown-up children, relatives, friends and neighbours. The siblings of the fathers were mentioned by a very small proportion as actual sources of support

- The major sources of support were grown-up children as well as the mothers'/caregivers' siblings

- Other sources of informal support mentioned by respondents were: employers, women's clubs, co-workers, boyfriends, nephews/nieces, church members and traditional medicine man (witchdoctor)

- More than half of the respondents considered a doctor and a social worker as major sources of formal support, although a priest appeared to have regular contact with a majority of the respondents who mentioned him as a source of support

- Generally speaking, there appeared to be more regular contact between respondents and their informal support system than with their formal support system

- There appeared to be very little contact amongst mothers of mentally retarded children

- Sources of spontaneous help were identified by the respondents within their formal and informal support systems

- Respondents generally felt that they could approach both their formal and informal systems when worried about the child

- On a large scale it would appear that respondents were not aware of formal services in their communities

- Services known to a majority of the respondents were general child welfare services and services for disabled children (mentally and physically disabled)

- Although only a small proportion of caregivers had regular contact with the formal social network, a considerably high percentage would refer other mothers of mentally retarded children to professionals

- Almost all the mothers/caregivers expressed a willingness to be involved in the establishment of a new service if approached for the purpose

- Respondents appeared to receive few requests for help from others

- A majority of the respondents did not wish to have their children institutionalised.

7.12 CONCLUSION

The findings of this study seem to point to the fact that the mothers/caregivers of mentally retarded children in the sample do require some assistance in caring for their mentally retarded children at home. The help required is material (financial) as well as instrumental support (practical help). The tasks for which help is required are those tasks which according to Wilkin (1979) require a great deal of competence and motivation i.e. bathing, dressing the child and doing laundry.

The help which the mothers/caregivers receive is mostly from the mothers' own family and from grown-up children. The mothers have people they can approach for help about the child. The mothers themselves are generally willing to be involved in services in the community if they could be approached to participate.

Although some mothers/caregivers require material and practical support in raising their children, a large proportion would prefer to care for their afflicted children at home than have them sent to an institution.

The mothers generally appear to be uninformed about services in their communities especially services other than the ones intended for mentally retarded children. This situation can be attributed either to the lack of time to seek out services on the part of mothers or to the fact that the service agencies themselves do not adequately publicize their services in the community.

CHAPTER 8

SUMMARY AND RECOMMENDATIONS

8.1 INTRODUCTION

The main aim of this study has been to determine whether the mothers of mentally retarded children have people helping to care for their disabled children, to identify the activities with which the mothers require help. and to ascertain whether they receive such help or not.

The family, particularly the black family, has been portrayed as a source of various types of support on which members can call for help at any time. The experiences of some of the respondents in this study have shown that not all of them can consider their families as a natural network of support, especially in respect of the daily caring tasks.

Because each family is unique and as families are at various stages of development at different times, the nature and amount of help which will be required at a specific time, differs from family to family.

Families of mentally retarded children require consistent support while potential sources of this support continue to dwindle. This type of situation raises questions regarding the extent to which community care can be based upon care available within the family should the family be without the basic support structures required to enable them to keep the handicapped child at home for as long as possible.

From this study it appears that the mother's side of the family seems to be more involved with her situation concerning her handicapped child. Relatives also appear to be involved to a considerable extent, and it would be interesting to ascertain whether these relatives are members of the maternal or paternal side of the family. Grown-up children seem to play a major role in rendering support. The role of the father of the child, who is the respondent's husband, requires further exploration generally, and in particular the part he plays in the life of the handicapped child.

If and when the mother receives assistance from service providers, this support is likely to focus on the major problematical areas, such as those which relate to health, finance, education, acquisition of aids and matters pertaining to long-term or residential care. The mother has to make a formal request for this type of aid and often the difficulties experienced by her with bureaucracy help to bring home the fact that she has a 'problem' child. This may cause mothers to become increasingly reluctant to approach formal organizations for help.

The study did not focus on specific tasks which were attended to by the respondents' support system. The aspects which were considered to be related to the proffering of support were touched upon very broadly; for example instrumental support. Strictly speaking, this type of support can be broken down into the giving of material aid or doing things for and with the respondent. This can be further broken down into the types of things given or done for the respondent, when and by whom.

8.2 PRACTICE IMPLICATIONS

Although the evidence is inconclusive regarding the stress-buffering effect of social support, the fact of the matter is that people must have connections with others in order to receive support.

The organisation of family life in terms of the roles of the different family members and the aspirations of individual members is an area that needs to be focussed on by the social worker, especially in view of the changes which the urban black family is experiencing. The extent to which the father is involved in the ordinary domestic routine and participation by all the children can help to ease the burden of caring for the mother.

In addition to focussing on role re-definition within the family, the social worker should also link the family, especially the mother, with potential support systems in the wider community, such as for example other mothers of mentally retarded children or role-related helpers.

This is possible if the professional is convinced of the potential of the informal social network as a source of support and does not perceive it as a threat. Professionals in human services can strengthen the role of existing informal networks as support systems, work towards their development and link them with existing formal services. Because the informal network is highly pluralistic and differentiated in terms of the type of person involved; what they do and why, its potential as a source of support is high. This support can be co-ordinated to prevent a concentration in one area and a lack of support in another area.

While professionals can help to develop the primary network as a source of support, care should be taken not to render these informal networks vulnerable because of possible stress resulting from the expectation on the part of the formal services that they (the informal networks) 'carry' the entire responsibility of caring and supporting.

The relationship between formal and informal support systems should be perceived as complementary and one system need not displace another or overwhelm it with responsibility. "It is the role of public authorities to sustain and, where necessary, to develop - but never to displace - such support and care" (Glendinning 1986:4). The role of social workers should therefore be to enable, empower, support and encourage social networks.

Mothers of mentally retarded children need to have a source of information which is easily accessible. In this study most mothers did not know of existing services in the community. Certain members of the informal support system such as the role-related helpers could become sources of information in conjunction with the formal service providers. Because they comprise a small section of the community and are centrally placed, regular information sessions could be held in order to bring them up to date on what is available and what the procedures are for applying for certain services. The service agency could supply the role-related helpers with leaflets and booklets which could be distributed to those with whom they come into contact, and also to the entire community.

Consideration could be given to small residential units for the handicapped in the midst of the community as an alternative to large institutions outside the community. This could promote community awareness and possible involvement in the care of the mentally retarded and it could also promote the integration of the mentally retarded into the community.

8.3 RECOMMENDATIONS FOR FUTURE RESEARCH

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

- the incidence of mental retardation in Black urban areas;
- support systems for adult mentally retarded persons;
- longitudinal studies of families with a retarded child. The aim here would be to study the families' needs at different developmental stages of the mentally retarded child;
- the attitude of social workers regarding the involvement of the informal social network in the rendering of service;
- the attitude of the community towards involvement in the care of the mentally handicapped;
- ascertaining the acceptability of small residential care units within the community, and
- demonstration projects on self-help for the mothers of mentally retarded children.

REFERENCES

ALLAN, G. Informal networks of care: Issues raised by Barclay. British Journal of Social Work 13, 1983:417-433.

ANDERSON, D. Social work and mental handicap. London: The MacMillan Press, 1982.

ARKAVA, M.L., LANE, T.A. Beginning social work research. Boston: Allyn & Bacon Inc; 1983.

AYER, S., ALASZEWSKI, A. Community care and the mentally handicapped: Services for mothers and their mentally handicapped children. London: Croom Helm, 1984.

AUSTIN, J.M., CROWELL, J. Survey research. In: GRINELL, R.M. (ed.). Social work research. Itasca: F.E. Peacock Publishers, 1981.

BABBIE, E. The practice of social research. New York: The Free Press, 1983.

BALLARD, R. Taking the family into account. Mental Handicap 10(3), 1982:75-76.

BAUMEISTER. A.A. Mental Retardation. London: University of London Press Ltd., 1968.

BAYLEY, M. Mental handicap and community care : A study of mentally handicapped people in Sheffield. London: Routledge, Kegan Paul, 1973.

BELL, W., BOAT, M.D. Urban neighbourhoods and informal social relations. American Journal of Sociology 63, 1957:391-398.

BENTON, A.L. Psychological evaluation and differential diagnosis. In: STEVENS, H.A., HEBER, R. (eds). Mental retardation. Chicago: University of Chicago Press, 1964.

BICKNELL, D.J. Living with a handicapped member of the family. Postgraduate Medical Journal Oct. Vol. 58, 1982:597-605.

BIERENBAUM, A. The mentally retarded child in the home and family cycle. *Journal of Heath and Social Behaviour* 12, 1971:55-65.

BOSS, P.G. Normative family stress : Family boundary changes across the life-span. *Family Relations* 29, 1980:445-450.

BOTT, E. *Family and social networks*. London: Tavistock Publ., 1957.

BUBOLZ, M.M., WHIREN, A.P. The family of the handicapped: An ecological model for policy and practice. *Family Relations* 33, 1984:5-12.

BUDOFF, M., SIPERSTEIN, G.N. Judgments of EMR students toward their peers : Effects of label and academic competence. *American Journal of Mental Deficiency* 86(4), 1982:367-371.

CAPLAN, G. *Support systems and community mental health*. New York: Behavioral Publ., 1974.

CAPLAN, G. The family as support system. In: CAPLAN, G., KILLILEA, M. (eds). *Support systems and mutual help: Multidisciplinary explorations*. New York: Grune & Stratton, 1976.

CAPLOVITZ, D. *The stages of social research*. New York: John Wiley & Sons, 1983.

CHETWYND, J. Factors contributing to stress on mothers caring for an intellectually handicapped child. *British Journal of Social Work* 15, 1985:295-304.

CHINKANDA, E.N. Pre-tests and pilot studies. An unpublished paper presented at a seminar on social work research at the Human Sciences Research Council, Pretoria Oct. 1985.

CHINKANDA, E.N. Caring for a mentally handicapped child at home. *Maatskaplikewerk Praktyk/Social Work Practice* 3, 1986:6-9.

CLEVELAND, D.M., MILLER, N. Attitudes and life commitment of older siblings of mentally retarded adults: An exploratory study. *Mental Retardation* June 1977.

COBB, S. Social support as a moderator of life-stress. Psychosomatic Medicine 35(5), 1976:300-314.

COHEN, P. The impact of the handicapped child on the family. Social Casework 42, 1962:137-142.

COLLINS, A.H., PANCOAST, D.L. Natural helping networks : A strategy for prevention. Washington, D.C.: NASW, 1976.

CUMMINGS, S.T., BAILEY, H.C., RIE, H.E. Effects of the child's deficiency on the mother : A study of mothers of mentally retarded, chronically ill and neurotic children. American Journal of Orthopsychiatry 36, 1966:595-608.

CUNNINGHAM, C. Down's syndrome: An introduction for parents. London: Souvenir Press (E & A) Ltd., 1982.

CROTTY, P.. KULYS, R. Social support networks : The views of schizophrenic clients and their significant others. Social Work 30(4), 1985:301:309.

DAVIDSON, B., DOSSER, D.A. A support system for families with developmentally disabled infants. Family Relations 31, 1982:295-299.

DELCAMPO, R.L., CHASE, T., DELCAMPO, D.S. Growth disorders in children : The impact on the family system. Family Relations 33, 1984:79-84.

DIMACHAEL, S.G. Social and economic effects of mental retardation. In: ROTHSTEIN, J.H. (ed.). Mental retardation. New York: Holt, Rhinehart, Winston Inc., 1961.

DUNN, L.M. (ed.). Exceptional children in the schools : Special education in transition. New York: Holt, Rhinehart, Winston Inc., 1973.

DYBWAD, G. The role of community services. In: ROTHSTEIN, J.H. (ed.). Mental retardation. New York. Holt, Rhinehart. Winston Inc. 1961.

DYBWAD, G. The re-discovery of the family. Mental Retardation 32(1) Winter, 1982.

DYER, M. Some religious aspect of support systems : Neo-Pentecostal groups. In: GOTTLIEB, B.H. (ed.) Social networks and social support. Beverly Hills: Sage Publ., 1981.

EGNAL, N.S., DANEEL, A.B. Counselling parents of the mentally retarded. Rehabilitation in South Africa 21(2), 1977.

ELL, K. Social networks, social support and health status: A review. Social Service Review 5 8 March, 1984:133-148.

FARBER, B. Mental retardation : Its social context and social consequences. Boston: Houghton Mifflin, 1968.

FARBER, B. Notes on Sociological knowledge about families with mentally retarded children. In: SCHREIBER, M. (ed.). Social work and mental retardation. New York: The John Day Co., 1970.

FARBER, B. Family adaptations to severely mentally retarded children. In: BEGAB, M.J., RICHARDSON, S.A. (eds). The mentally retarded and society : A social science perspective. Baltimore: Park Press, 1974.

FOTHERINGHAM, J.B. at al. The effects on the family of the presence of a mentally retarded child. Canadian Psychiatric Association Journal 17(4), 1972.

FOWLE, C. The effect of the severely mentally retarded child on his family. American Journal of Mental Deficiency 73(3), 1968:468-475.

FROLAND, C., PANCOAST, D.L., CHAPMAN, N.J., KIMBOKO, P.J. Helping networks and human services. Beverly Hills: Sage Publ., 1981.

FROLAND, C., PANCOAST, D.L., CHAPMAN, N.J., KIMBOKO, P.J. Linking formal and informal support systems. In: GOTTLIEB, B.H. (ed.). Social networks and social support. Beverly Hills: Sage Publ., 1981(b).

GALLAGHER, J.J., BECKMAN, P., CROSS, A.H. Families of handicapped children: Sources of stress and its amelioration. Exceptional Children 50, 1983:10-19.

GALLAGHER, J.J., CROSS, A.H., SCHARFMAN, W. Parental adaptation to a young handicapped child : The father's role. *Journal of the Division of Early Childhood* 3, 1981:3-14.

GALLO, F. Social support networks and the health of elderly persons. *Social Work Research and Abstracts* 20(4). Winter 1984:13-19.

GAMBRILL, E. *Casework : A competency-based approach*. Englewood Cliffs: Prentice-Hall Inc., 1983.

GARBARINO, J. Social support networks: R for the helping professionals. In: WHITTAKER, J.K., GARBARINO, J. (eds). *Social support networks : Informal helping in the human services*. New York: Aldine Publ. Co., 1983.

GEARHEART, B.R., LITTON, F.W. *The trainable retarded : A foundation's approach*. St. Louis : The C.V. Mosby Co., 1979.

GERMAIN, C.B., GITTERMAN, A. *The life model of social work practice*. New York: Columbia Univ. Press, 1980.

GIELE, J.Z. A delicate balance : The family's role in the care of the handicapped. *Family Relations* 33, 1984:85-94.

GLENDINNING, C. *Unshared care : Parents and their disabled children*. London: Routledge, Kegan Paul, 1983.

GLENDINNING, C. *A single door : Social work with families of disabled children*. London: Allen, Unwin, 1986.

GOTTLIEB, B.H. Social networks and social support in community mental health. In: GOTTLIEB, B.H. (ed.). *Social networks and social support*. Beverly Hills: Sage Pub., 1981.

GOTTLIEB, B.H. Preventive interventions involving social networks and social support. In: GOTTLIEB, B.H. (ed.). *Social networks and social support*. Beverly Hills: Sage Publ., 1981.

GOTTLIEB, B.H. Social support strategies : Guidelines for mental health practice. Beverly Hills : Sage Publ., 1983.

GOTTLIEB, B.H. Assessing and strengthening the impact of social support on mental health. Social Work 30(4), 1985:293-300.

GRUENBERG, E.M. Epidemiology. In: STEVENS, H.A., HEBER, R. (eds). Mental Retardation. Chicago: University of Chicago Press, 1964.

HALL, C.N., RICHMOND, B.O. Consultation with parents of handicapped children. The Exceptional Child 31(3), 1984:185-191.

HALLAS, C.H., FRASER, W.M., MacGILLIVRAY, R.C. The care and training of the mentally handicapped. Towbridge : John Wright & Sons Ltd., 1978.

HANVEY, C.P. Social work with mentally handicapped people. London: Heinemann, 1981.

HAMILTON, J. Caring enough to let go. Parents Voice 28(3), Sept. 1978:10-12.

HAYWOOD, H.C. Reducing social vulnerability is the challenge of the eighties (Presidential address) Mental Retardation 19, 1981:190-195.

HEBER, R. (ed.) A manual on terminology and classification in mental retardation. Monogrammed Suppl. American Journal of Mental Deficiency 64(2), 1959.

HILL, R. Genetic features of families under stress. In: PARAD, H.S. (ed.). Crisis Intervention. New York: FSAA, 1965.

HIRSCH, B.J. Social networks and the coping process. Creating personal communities. In: GOTTLIEB, B.H. (ed.). Social networks and social support. Beverly Hills: Sage Publ. 1981.

HYMOVICH, D.P., BAKER, C.D. The needs, concerns and coping of parents of children with cystic fibrosis. Family Relations 34, 1985:91-97.

INTAGLIATA, J., DOYLE, N. Enhancing social support for parents of developmentally disabled children: Training in interpersonal problem-solving skills. Mental Retardation 22(1), 1984:4-11.

KADUSHIN, A. Supervision in social work. New York: Columbia University Press, 1976.

KANNER, L. Parents' feelings about retarded children. American Journal of Mental Deficiency 57, 1953:375-383.

KANNER, L. History of the care and study of the mentally retarded. Springfield: Charles C. Thomas, 1964.

KAPLAN, S. A model of person-environment compatibility. Environment and Behavior 15(3), 1983:311-332.

KAPLAN, B.H., CASSEL, J.D., GORE, S. Social support and health. Medical Care 15(5). Suppl., 1977:47-58.

KAZAK, A.E., MARVIN, R.S. Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. Family Relations 33, 1984:67-77.

KERSHAW, J.D. Handicapped children. London: Heinemann, 1966.

KILLILEA, M. Mutual help organizations: Interpretations in the literature. In: CAPLAN, G., KILLILEA, M. (eds). Support systems and mutual help : Multidisciplinary explorations. New York: Grune, Stratton, 1976.

LENTJIES, S., JONKER, J.M.L. Social support networks: A literature study. In: YODER, J.A., JONKER, J.M.L., LEAPER, R.A.B. (eds). Support networks in a caring community. Dodrecht: Martinus Nijhoff Publ., 1985.

LEVINSON, A. The mentally retarded child. London: Allen, Unwin, 1967.

LONGO, D.C., BOND, L. Families of the handicapped child: Research and practice. Family Relations 33, 1984:57-65.

McALLISTER, R.J., BUTLER, E.W., TZIEN-JEN, L. Patterns of social interaction among families of behaviorally retarded children. *Journal of Marriage and the Family* 35(1), 1973:93-100.

McCORMACK, M. *A mentally handicapped child in the family : A guide for parents*. London: Constable & Co., 1978.

McCUBBIN, H.I., BOSS, P.G. (Guest editors). Family stress and coping : Targets for theory, research, counselling, and education. *Family Relations* Oct., 1980:429-430.

McMILLAN, D.L., JONES, R.L., ALOIA, G.F. The mentally retarded label : A theoretical analysis and review of research. *American Journal of Mental Deficiency* 79, 1974:241-261.

MANDELBAUM, A.W.WHEELER, M.E. The meaning of the defective child to parents. *Social Casework* 41(7), 1960:360-67.

MARKS, L. Parents' needs and how to meet them. In: SIMON, G.B. (ed.). *The modern management of mental handicap*. MTP Press Ltd., 1980.

MAQASHALALA, T.N.V. An analysis of support systems among African widows in the Tyhume Basin, Ciskei, South Africa. Unpublished doctoral thesis. University of Alabama, 1984.

MERCER, J.R. *Labelling the mentally retarded : Clinical and social perspectives on mental retardation*. Berkeley : Univ. of California Press, 1973.

MITCHELL, J.C. The concept and use of social networks. In: MITCHELL, J.C. (ed.). *Social networks in urban situations*. Manchester: Manchester Univ. Press, 1969.

MULLER, C. The dynamics of volunteer participation in social work. An exploration of the role and functions of service volunteers in community, child and welfare organizations. Unpublished MA (SS) thesis. University of South Africa, 1970.

NARAN, R.V. The effectiveness of social work intervention in voluntary agencies in the Durban area. Unpublished MA (SW) dissertation. University of Durban-Westville, 1982.

O'CONNOR, G. Social support of retarded persons. Mental Retardation 21, 1983:187-196.

OLIVERI, M.E., REISS, D. The structure of families' ties to their kin : The shaping role of social constructions. Journal of Marriage and the Family May, 1981:391-407.

OLSHANSKY, S. Chronic sorrow : A response to having a mentally defective child. In: SCHREIBER, M. (ed.). Social work and mental retardation. New York : The John Day Co., 1970.

PARKS, R.M. Parental reactions to the birth of a handicapped child. Health and Social Work 2(3), 1977:51-65.

PAYNE, J.S., MERCER, C.D. A sketch of the past, present and future. In: KAUFFMAN, J.M., PAYNE, J.S. (eds). Mental retardation : Introduction and perspectives. Charles E. Merrill Publ. Co., 1975

POMEROY, D.FEWTRELL, J., ADAMS, N.B., GILL, R. Improving the quality of life for families with a mentally handicapped child. Parents Voice 28(4), 1978:4-5.

POWELL, D.R. Relations and early childrearing : The role of social networks and neighbourhoods. Journal of Research and Development in Education 13(1), Fall 1979:1-11.

POWELL, D.R. Social network and demographic predictions of length of participation in a parent education program. Journal of Community Psychiatry 12 January, 1984:13-20.

QUIENE, L., PAHL, J. Examining the causes of stress in families with severely handicapped children. British Journal of Social Work 15, 1985:467-477.

RAPOPORT, L. Working with families in crisis : An exploration in preventive intervention. Social Work 7(3), 1962:48-56.

RAPOPORT, R. Normal crisis, family structure and mental health. <u>Family Process</u> 2(1), 1963:68-80.

REIN, M. <u>Social policy : Issues of choice and change</u>. New York: Random House, 1970.

REISS, D., OLIVERI, M.E. Family paradigm and family coping : A proposal for linking the family's intrinsic adaptive capacities to its responses to stress. <u>Family Relations</u> Oct., 1980:431-444.

Report to the President from the Presidents Commission on Mental Health Vol. 1, 1978.

RIVERS, A. The problems, needs, and concerns of families of mentally retarded children as perceived by their parents. Unpublished doctoral thesis. Kent State Univ. 1983.

ROBINSON, N.M., ROBINSON, H.B. <u>The mentally retarded child</u>. New York: McGraw-Hill, 1976.

ROOS, P. Psychological counselling with parents of retarded children. <u>Mental Retardation</u> December, 1963:343-350.

ROWLANDS, O. Down's syndrome and the family. <u>Mental Handicap Bulletin</u> 47 Dec., 1982:21-23.

RYCKMAN, D.B., HENDERSON, R.A. The meaning of a retarded child for his parents : A focus for counsellors. In: SCHREIBER, M. (ed.). <u>Social work and mental retardation</u>. New York: The John Day Co., 1970.

SCHILD, S. Counselling with parents of retarded children living at home. In: SCHREIBER, M. (ed.). <u>Social work and mental retardation</u>. New York: The John Day Co., 1970.

SCHILD, S. The family of the retarded child. In: KOCH, R., DOBSON, J.C. (eds). <u>The mentally retarded child and his family : A multidisciplinary handbook</u>. New York : Brunner/Mazel Inc., 1971.

SCHILLING, R.F., GILCHRIST, L.D., SCHINKE, S.P. Coping and social support in families of developmentally disabled children. Family Relations 33, 1984:47-54.

SCHILLING, R.F., SCHINKE, S.P. Social support networks in developmental disabilities. In: WHITTAKER, J.K., GARBARINO, J. (eds.) Social support networks. Informal helping in the human services. New York: Aldine Publ. Co., 1983.

SCHILLING, R.F., SCHINKE, S.P. Personal coping and social support for parents of handicapped children. Children and Youth Services Review 6, 1984:195-206.

SCHREIBER, M., FEELY, M. Group processes with parents of retarded children. In: SCHREIBER, M. (ed.). Social work and mental retardation. New York: The John Day Co., 1970.

SEABERG, J.R. Sampling procedures and techniques. In: GRINELL, R.M. (ed.). Social work research. Itasca: F.E. Peacock Publ., 1981.

SHINN, M., LEHMANN, S., WONG, N.W. Social interaction and social support. Journal of Social Issues 40(4), 1985:55-76.

SHUMAKER, S.A., BROWNELL, A. Toward a theory of social support : Closing conceptual gaps. Journal of Social Issues 40(4), 1984:11-36.

SIEDER, V.M. Volunteers. In: LURIE, H.A. (ed.). Encyclopaedia of social work. 15th Issue. New York: NASW, 1965.

SIEFFERT, A. Parents' initial reactions to having a mentally retarded child: A concept and model for social workers. Clinical Social Work Journal Vol. 6(1), 1978:33-43.

SNYMAN, S.A. Affordable social security. Newsletter No. 169, Pretoria: Human Sciences Research Council.

SOLARSH, B. The family of the mentally retarded child. Unpublished lecture notes. Sunshine Centre for the stimulation of mentally handicapped preschoolers.

STARK, C.B. All our kin : Strategies for survival in a black community. New York: Harper & Row, 1974.

SUEZLE, M., KEENAN, V. Changes in family support networks over the life cycle of mentally retarded persons. American Journal of Mental Deficiency 86(3), 1981:267-274.

SWENSON, C. Social networks, mutual aid and the life model of practice. In: GERMAIN, C. (ed.). Social work practice : People and environments an ecological perspective. New York: Columbia Univ. Press, 1979.

TARJEIN, G., WRIGHT, S.W., EYMAN, R.K., KEEVAN, C.V. Natural history of mental retardation : Some aspects of epidemiology. American Journal of Mental Deficiency 77, 1973:369-379.

THOITS, P.A. Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress. Journal of Health and Social Behavior 23 June, 1982:149-159.

TIMMS, E. On the relevance of informal social networks to social work intervention. British Journal of Social Work 13, 1983:405-415.

TOLSDORF, C.C. Social networks, social support and coping : An exploratory study. Family Process 15, 1976:407-417.

TSHABALALA, M. Kinship networks : An analysis on the use of kinship systems for the promotion of mental health among the Nguni. Social Work/Maatskaplike Werk 32(2), 1986:72-79.

UNGER, D.G., POWELL, D.R. Supporting families under stress : The role of social networks. Family Relations 29 Oct., 1980:506-514.

URBANI, G. The problems surrounding children with genetic impairments. Pretoria. Human Sciences Research Council. 1982.

VAUX, A. Variation in social support associated with gender, age, and ethnicity. Journal of Social Issues 41, 1985:89-110.

WARD, R.A. Informal networks and well-being in later life : A research agenda. The Gerontologist 25(1), 1985:55-61.

WASKOWITZ, C.H. The parents of retarded children speak for themselves. In: SCHREIBER, M. (ed.) Social work and mental retardation. New York: The John Day Co., 1970.

WEINGOLD, J., HORMOUTH, R. Group guidance of parents of mentally retarded children. Journal of Clinical Psychology 9, 1953:118-124.

WELLMAN, B. Applying network analysis to the study of support. In: GOTTLIEB, B.H. (ed.). Social networks and social support. Beverly Hills: Sage Publ., 1981.

WELLS, L.M., SINGER, C. A model for linking networks in social work practice with the institutionalized elderly. Social Work 30(4), 1985:318-322.

WILCOX, B.L. Social support in adjusting to marital disruption : A network analysis. In: GOTTLIEB, B.H. (ed.). Social networks and social support. Beverly Hills: Sage Publ., 1981.

WIKLER, L. Chronic stresses of families of mentally retarded children. Family Relations 30, 1981:281-288.

WILKIN, D. Caring for the mentally handicapped Child. London: Croom Helm. 1979.

34th Annual Report of the Pretoria and N. Transvaal Mental Health Society.

INTERVIEWS:

1. Mrs S. von Staden, Director Pretoria and N. Transvaal Mental Health Society.

2. Mrs A. Dube, Social Worker Pretoria and N. Transvaal Mental Health Society.

ANNEXURE A

HUMAN SCIENCES RESEARCH COUNCIL
INSTITUTE FOR SOCIOLOGICAL AND DEMOGRAPHIC RESEARCH

SUPPORT SYSTEMS OF MOTHERS/CAREGIVERS OF MENTALLY RETARDED CHILDREN

The task of raising a mentally retarded child can be very demanding particularly on the person who bears the greatest responsibility. The daily task of caring for such a child sometimes results in a lot of stress and strain especially if the task is undertaken without the help of certain networks (both formal and informal) in the community.

This study has the following aims:

(i) to identify and describe any support systems that are utilized by Black mothers/caregivers of mentally retarded children in the Mamelodi and Atteridgeville areas

(ii) to identify and describe latent systems which could be supportive

(iii) to ascertain the level of awareness of existing systems, and the extent to which they are utilised

(iv) to identify and describe systems having some negative effects on such families and

(v) to identify the circumstances under which institutionalization is the only answer.

Your participation in this study is important as it will help those who offer services to mentally retarded persons to understand how you manage to raise your retarded child, what sources of help are available to you and what services you still require.

The information which you provide to the fieldworker, who is a qualified social worker, will be kept confidential.

	1

PROJECT NUMBER	S	D	A	B	6	3	1-6
CARD NUMBER						1	7
RECORD NUMBER							8

PROFILE OF THE RESPONDENT

1. Family name ....

2. Residential address	Atteridgeville	1	
	Mamelodi	2	10

3. How old are you at present?		11-12

FIELDWORKER: If respondent doesn't know, make an estimate and mention that it is an estimate.

4. Which of the following best describes your situation?

Married	Living together	Never married	Divorced/ Deserted/ Separated	Widow		
1	2	3	4	5		13

Describe status where necessary

....

....

5. If 'married' or 'living together', is the man in question the father of your mentally retarded child?

Yes	1		
No	2		
N.a.	9		14

6. If the answer to Question 5 is NO, are you in contact with the father of your mentally retarded child?

Yes	1		
No	2		
N.a.	9		15

	1

7. If the answer to Question 4 is 'never married' or 'divorced/deserted/separated', are you in contact with the father of your mentally retarded child?

Yes	1		
No	2		
N.a.	9		16

8. How many children do you have? (Own biological children; to whom you gave birth)

One child	1		
Two children	2		
Three children	3		
Four children	4		
Five or more children	5		17

9. How many children are living in your household who are being cared for by you, <u>but are not your own children</u>?

One child	1		
Two children	2		
Three children	3		
Four children	4		
Five or more children	5		
None	6		18

10. How many children do you have in your care (i.e. biological children as well as other children)?

Altogether			19-20
Still living with you			21-22

1

11. How many mentally retarded children do you have (i.e. biological children as well as others in your care? ....

.... 23-24

12. What is your highest educational qualification?

None - never attended school/did not finish a class	1	
Std 3 or lower	2	
Std 4 to Std 5	3	
Std 6 to Std 8	4	
Std 9 to Std 10	5	
Std 10 plus 1 or 2 years further training	6	
Std 10 plus 3 or more years further training	7	25

13. Are you gainfully employed (including own business)?

Yes	1	
No	2	26

14. If YES are you:

In a full-time job	1	
Doing odd jobs	2	
Seasonally employed	3	
Other (e.g. runs a business)	4	
N.a.	9	27

15. If YES at Question 13: What is your present occupation? (Give precise description of your job e.g. factory worker, clerk, etc. or your role in the business e.g. handling phone calls, manages everything, etc.) 28

....

....

1

16. What is the total monthly income of your family?

Less than R100 (including no income)	1		
Between R100 and R299	2		
Between R300 and R499	3		
Between 500 and R699	4		
Between R700 and R899	5		
More than R900	6		
Don't know	7		29

(IF PAID WEEKLY, FIELDWORKER CONVERTS TO MONTHLY)

PROFILE OF THE MENTALLY RETARDED CHILD

(IF MORE THAN ONE MENTALLY RETARDED CHILD, COMPLETE THIS SECTION ON THE OLDEST CHILD)

SEX

17. What sex is the mentally retarded child or the eldest mentally retarded child?

Male	1		
Female	2		30

AGE

18. How old is the child in question now?

Under one year	1		
1 to 3 years	2		
4 to 6 years	3		
7 to 10 years	4		
11 to 15 years	5		
16 to 18 years	6		
19 years and older	7		31

1

19. Indicate the relationship of this child to you

Biological child	1	
Adopted child	2	
Stepchild	3	
Foster child	4	
Grandchild	5	
None of the above (specify)	6	32

20. How old were you/was the mother when the child was born? (IF DON'T KNOW answer - 00) 33-34

21. What is the position of the handicapped child in the (his/her) family? (If only child use Code 00; if 1st child use Code 01; if 2nd child use Code 02, etc.) .....

.... 35-36

22. Which one of the following does this child attend?

Crèche	1	
Day care centre	2	
Ordinary school	3	
Training centre/protective workshop	4	
Other (specify)	5	
None of the above/no centre whatsoever	6	37

Comments: ....

....

23. Medical diagnosis (from social worker's file) 38

1

24. Level of retardation of the child (from social worker's file)
Is the child classified as:
(CHOOSE CATEGORY WHICH BEST DESCRIBES THE CHILD)

Mild	1	
Moderate	2	
Severe	3	
Acute/Profound	4	
Multiple handicapped	5	
Unsure/information not available	9	39

25. What physical impairments (if any) does the child have (e.g. inability to walk or use one or both arms, etc.)? 1

.... 0 40

26. Which of the following can this child do with or without help?

	N.a.-e.g. child too young for this activity	Easily without difficulty	Only with difficulty or with help	Not at all	
Wash himself/herself	9	1	2	3	41
Dress himself/herself	9	1	2	3	42
Reach and use the toilet	9	1	2	3	43
Eat meal by himself/herself	9	1	2	3	44
Walk	9	1	2	3	45
Climb stairs or steps	9	1	2	3	46
Catch a bus or train	9	1	2	3	47
Do shopping	9	1	2	3	48
Cook a hot meal	9	1	2	3	49
Clean the house	9	1	2	3	50
Do laundry	9	1	2	3	51

1

MOTHER'S KNOWLEDGE OF THE CHILD'S IMPAIRMENT

27. What, in your own words, is the matter with the child?

....

.... 52

28. What in your opinion is the cause of the child's condition?

.... 53

29. Was the child assessed by a psychologist/by someone else?

Yes	1	
No	2	54

FIELDWORKER: PROBE ALL RESPONSES AND WRITE EXPLANATORY COMMENTS BELOW.

COMMENTS ....

....

30. At which of the following does the child receive treatment? Choose <u>one only</u>.

Clinic only	1	
Hospital only	2	
Elsewhere (specify)	3	
At more than one of the above	4	
Nowhere	5	55

1

MOTHER'S EXPERIENCES

31. Where was the child born?

In a clinic	1	
At home	2	
In a nursing home	3	
In a hospital	4	
Elsewhere (specify)	5	
Do not know (e.g. not own child, etc.)	6	56

32. When did you discover that there was something the matter with the child?

Shortly after birth	1	
A few months after birth but within the child's first year	2	
After some years but before the child went to school	3	
When child started school	4	
Any other time (specify)	5	
The child was known to be retarded when placed with respondent	6	57

33. By whom was the child's impairment first discovered?

Yourself	1	
Family (specify)	2	
Doctor	3	
Nurse	4	
Teacher	5	
Other (specify)	6	
Do not know (e.g. not own child or the child was known to be retarded when placed with respondent)	7	58

1

34. If the discovery was made by someone other than yourself, did the other person explain what was wrong with the child?

Yes	1
No	2
N.a. - answered 'do not know' at Question 33	3
N.a. - discovery by self	4

59

35. If the answer to Question 34 is YES, was the explanation: clear, not clear, etc.

Clear	Not clear	Uncertain	N.a. - self-discovery or answered 'do not know' at Question 33
1	2	3	9

60

36. Would you say the person who made the explanation was:

Very sympathetic	1
Sympathetic	2
Unsympathetic	3
Indifferent	4
Guarded/no reaction/neutral	5
N.a. - self-discovery or answered 'do not know' at Question 33	9

COMMENTS: ....

....

....

61

37. Describe the circumstances under which the explanation was made

....

....

....

N.a. - self-discovery or answered 'Do not know' at Question 33 - 9

62

1

38. After you became aware of the child's condition or when the child was placed with you did you discuss it with any of the following persons?

(a) Partner/Spouse

Yes	1	
No	2	
No need - he was included in discussion when child was placed with you	3	
N.a. - have no partner/spouse/no contact	9	63

(b) Family (e.g. sisters, brothers, etc.)

Yes	1	
No	2	
No need - he was included in discussion when child was placed with you	3	
N.a. - have no family/no contact	9	64

(c) Relatives (e.g. aunts, cousins, etc.)

Yes	1	
No	2	
No need - he was included in discussion when child was placed with you	3	
N.a. - have no relatives/no contact	9	65

(d) Teacher

Yes	1	
No	2	
No need - he was included in discussion when child was placed with you	3	
N.a. - child not in school	9	66

	1

(e) Doctor

Yes	1	
No	2	
No need - he was included in discussion when child was placed with you	3	
N.a. - no contact	9	67

(f) Nurse

Yes	1	
No	2	
No need - he was included in discussion when child was placed with you	3	
N.a. - no contact	9	68

(g) Social worker

Yes	1	
No	2	
No need - he was included in discussion when child was placed with you	3	
N.a. - no social worker or not in contact	9	69

(h) Friend/neighbour

Yes	1	
No	2	
No need - he was included in discussion when child was placed with you	3	
N.a. - no friends/neighbours or not in contact	9	70

(i) Other (specify) ....

Yes	1	
No	2	
No need - he was included in discussion when the child was placed with you	3	71

(j) None of the above/no one whatsoever 1+2

Yes (discussed with no one)	1	
No (did discuss with someone see above)	2	72

PROJECT NUMBER	S D A B 6 3	1-6
CARD NUMBER	2	7
RECORD NUMBER		8-9

39. (FIELDWORKER: IF NO YES(1) WAS MARKED AT QUESTION 38 ASK ONLY 39(j))

Would you describe the reaction of the person you spoke to as sympathetic/unsympathetic/cold or aloof or was there no reaction?

	Sympathetic	Unsympathetic	Cold/aloof	Guarded/no reaction/ neutral	Other reaction (specify under comment)	N.a. - e.g. if answered 'n.a.' and 'no' at:		
(a) Partner/spouse	1	2	3	4	5	38(a) 9		10
(b) Family (e.g. brothers, sisters, etc.)	1	2	3	4	5	38(b) 9		11
(c) Relatives (e.g. aunts, cousins, etc.)	1	2	3	4	5	38(c) 9		12
(d) Teacher	1	2	3	4	5	38(d) 9		13
(e) Doctor	1	2	3	4	5	38(e) 9		14
(f) Nurse	1	2	3	4	5	38(f) 9		15
(g) Social worker	1	2	3	4	5	38(g) 9		16
(h) Friends/neighbours	1	2	3	4	5	38(h) 9		17
(i) Other (specify)	1	2	3	4	5	38(i) 9		18
(j) None (spoke to no one)	1	(True) spoke to no one				0		19

Comments: ....

....

2

40. **Have you ever had to change/leave your job because of the child's condition?**

Yes	1	
No	2	
N.a. - e.g. never worked	3	20

41. **Have you ever had to change your residence for reasons related to the child's condition?**

Yes	1	
No	2	21

42. **Have any of the following people been an important part of your life before and/or since the birth of the child in question?**

	Before birth only, i.e. not now	Since before birth and still important	Since birth only, i.e. not before	Only recently	Never important	N.a. - e.g. no such person	
Own siblings	1	2	3	4	5	9	22
Father of the child	1	2	3	4	5	9	23
Siblings of father of the child	1	2	3	4	5	9	24
Relatives (e.g. in-laws, own parents, etc.	1	2	3	4	5	9	25
Friends/neighbours	1	2	3	4	5	9	26
Other (specify)	1	2	3	4	5	9	27

Comments ....

....

2

43. How would you describe your contact with this/these persons?

	Regular: at least once a month	Irregular: only when the need arises	Any other basis	N.a. - not important part of my life/ no contact		
Own siblings	1	2	3	9		28
Father of the child	1	2	3	9		29
Siblings of father of the child	1	2	3	9		30
Relatives (e.g. in-laws, own parents, etc.)	1	2	3	9		31
Friends/neighbours	1	2	3	9		32
Other (specify)	1	2	3	9		33

Comments: ....

44. Do you know any other mothers/caregivers of mentally retarded children?

Yes	1		
No	2		34

45. Are you in contact with any of these mothers/caregivers?

Yes	1		
No	2		
N.a. - answered NO at Question 44	9		35

2

MOTHER'S FORMAL SOCIAL NETWORK

46. Have any of the following (professional) persons been an important part of your life before and/or since the birth of the child in question?

	Before birth, but not now	Since birth and still important	Only since birth, i.e. not before	Only recently	Never important	N.a.-e.g. do not know such person/no contact	
Social worker	1	2	3	4	5	9	36
Doctor	1	2	3	4	5	9	37
Nurse	1	2	3	4	5	9	38
Teacher	1	2	3	4	5	9	39
Priest	1	2	3	4	5	9	40
Crèche or nursery school teacher	1	2	3	4	5	9	41
Other (specify)	1	2	3	4	5	9	42

47. How often do you have contact with this\these person(s)?

	Regularly: at least once a month	Irregularly: only when the need arises	Other basis, specify under comments	N.a.-e.g. not important part of my life/no contact	
Social worker	1	2	3	9	43
Doctor	1	2	3	9	44
Nurse	1	2	3	9	45
Teacher	1	2	3	9	46
Priest	1	2	3	9	47
Crèche or nursery school teacher	1	2	3	9	48
Other (specify)	1	2	3	9	49

Comments: ....

....

2

48. How would you describe the attitude of your family towards you when it was discovered that you had a mentally retarded child?

Family was:

On the whole very sympathetic	1		
On the whole very unsympathetic	2		
Some sympathetic - some unsympathetic	3		
Guarded, very careful, showed nothing	4		
Do not know, am not sure	5		
Is not the respondent's biological child	6		50

Comments ....

....

SUPPORT SYSTEMS

49. How would you rate the following persons in terms of their emotional closeness to you (e.g. are they very close, not close, etc.)? Mark only one category. (If no such person or no such contact, answer N.a. = 9.)

	Very close	Close	In between/ neutral	Not close	Not close at all	N.a.		
Father of the child	1	2	3	4	5	9		51
Sibling of father of the child	1	2	3	4	5	9		52
Present husband (if not father of the child)	1	2	3	4	5	9		53
Own siblings	1	2	3	4	5	9		54
Grown-up children	1	2	3	4	5	9		55
Relatives (e.g. in-laws, parents, etc.)	1	2	3	4	5	9		56
Professional person (e.g. social worker, doctor, etc.)	1	2	3	4	5	9		57
Other (specify)	1	2	3	4	5	9		58

2

50. Which of the following persons do you contact/go to when you are worried about the child? (If no such person or no contact answer N.A. = 9).

	Yes	No	N.a.	
Father of the child	1	2	9	59
Siblings of the father of the child	1	2	9	60
Present husband (if not father of the child)	1	2	9	61
Own siblings	1	2	9	62
Grown-up children	1	2	9	63
Relatives (e.g. in-laws, parents)	1	2	9	64
Professional person (e.g. social worker, doctor, etc.)	1	2	9	65
Other (specify)	1	2	9	66
No one at all Yes (contact/go to no one) No (contact/go to someone as above)	1	2	9	67

51. Which of the following persons do you contact/go to when you are worried about anything other than the child? (If no such person or no contact answer N.A. = 9)

	Yes	No	N.a.	
Father of the child	1	2	9	68
Siblings of the father of the child	1	2	9	69
Present husband (if not father of the child)	1	2	9	70
Own siblings	1	2	9	71
Grown-up children	1	2	9	72
Relatives (e.g. in-laws, parents, etc.)	1	2	9	73
Professional person (e.g. social worker, doctor, etc.)	1	2	9	74
Other (specify)	1	2	9	75
No one at all Yes (contact/go to no one) No (contact/go to someone as above)	1	2	9	76

2+3

52. How often to you feel the need to discuss the child with at least one of the persons identified above?

Very often (at least once a day)	1	
Often (at least once a week)	2	
Sometimes (at least once a month)	3	
Very seldom (once in a period of 6 months)	4	
Never	5	
I feel the need but	6	77

Comments: ....

PROJECT NUMBER S D A B 6	3	1-6
CARD NUMBER	3	7
RECORD NUMBER		8-9

53. Which of the following persons will help you without your asking for help? (E.g. give money, take the child to the clinic, do shopping, offer transport etc.) (If no such person or no contact answer N.a. = 9)

	Yes	No	Uncertain	N.a.		
Father of the child	1	2	3	9		10
Siblings of father of the child	1	2	3	9		11
Present husband (if not father of the child)	1	2	3	9		12
Own siblings	1	2	3	9		13
Grown-up children	1	2	3	9		14

Question (continued)

3

Question (continued)

	Yes	No	Uncertain	N.a.		
Relatives (e.g. in-laws, parents, etc.)	1	2	3	9		15
Other (specify)	1	2	3	9		16
No one at all Yes (no one will help)	1					
No (someone will help as above)		2				
Not certain if they will help			3			
Do not have any of these persons/no contact				9		17

Comments: ....

....

54. Indicate type of help you get from the following persons:

FIELDWORKER: If more than one choice per row, select one provisionally, and write full comments below:

		Emotional	Informational	Instrumental (e.g. give money, discipline children, do laundry, etc.)	Feedback on own behaviour	Referral to a service	Nothing, no help	No such person	Other (specify)		
Father of child	Regularly	1	2	3	4	5	6	7	8		18
	At some stage/ occasionally	1	2	3	4	5	6	7	8		19
Present husband (If not father of the child)	Regularly	1	2	3	4	5	6	7	8		20
	At some stage/ occasionally	1	2	3	4	5	6	7	8		21
Siblings of father of the child	Regularly	1	2	3	4	5	6	7	8		22
	At some stage/ occasionally	1	2	3	4	5	6	7	8		23

Question (continued)

3

Question (continued)

		Emotional	Informational	Instrumental (e.g. give money, discipline children, do laundry, etc.)	Feedback on own behaviour	Referral to a service	Nothing, no help	No such person	Other (specify)		
Own siblings	Regularly	1	2	3	4	5	6	7	8		24
	At some stage/ occasionally	1	2	3	4	5	6	7	8		25
Grown-up children	Regularly	1	2	3	4	5	6	7	8		26
	At some stage/ occasionally	1	2	3	4	5	6	7	8		27
Relatives (e.g. in-laws own parents)	Regularly	1	2	3	4	5	6	7	8		28
	At some stage/ occasionally	1	2	3	4	5	6	7	8		29
Friends/ neighbours	Regularly	1	2	3	4	5	6	7	8		30
	At some stage/ occasionally	1	2	3	4	5	6	7	8		31
Other (specify)	Regularly	1	2	3	4	5	6	7	8		32
....	At some stage/ occasionally	1	2	3	4	5	6	7	8		33

Comments: ....

....

....

55. Do you require help (e.g. someone to help feed, dress the child, give financial aid, discipline child) with the raising of the child?

Does not require help

N.a. - does not require help and doesn't get it	9
Does not require but gets it anyway	1

3

Question (continued)

Requires help from time to time

Requires but gets nothing	2
Requires and receives but helpers take over completely	3
Requires and receives but it is given reluctantly	4
Requires and receives: helpers supportive but do not take over	5

Requires help always

Requires but gets nothing	6
Requires and receives but helpers take over completely	7
Requires and receives but it is given reluctantly	8
Requires and receives; helpers supportive but do not take over	10

34-35

Comments: ....

....

56. Whom of the following would you ask if you required material aid (e.g. money, food, transport, etc.) for the child? (Tick one or more.)

Father of the child	1
Present husband if not father of the child	2
Siblings of father of the child	4
Own siblings	8
Grown-up children	16
Relatives (e.g. in-laws, own parents, etc.)	32
Friends/neighbours	64
Professional person (e.g. social worker, priest, etc.)	128
Other (specify)	256
No one	0

36-38

Comments: ....

3

57. Whom of the following would you ask if you required <u>advice</u> (e.g. how to do certain things, where to go for certain things) concerning the care of the child? (Tick one or more.)

Father of the child	1
Present husband if not father of the child	2
Siblings of father of the child	4
Own siblings	8
Grown-up children	16
Relatives (e.g. in-laws, own parents, etc.)	32
Friends/neighbours	64
Professional person (e.g. social worker, priest, etc.)	128
Other (specify)	256
No one	0

39-41

Comments: ....

3

AWARENESS OF FORMAL ORGANIZATIONS IN THE COMMUNITY

58. Do you know about, and have you made use of the following facilities for mentally retarded persons in your community?

		A	B	C			
		There are no such facilities	I do not know of such facilities	I know of such facilities			
				but have never needed them/ didn't get round to using them	and have tried to use them but found them unsatisfactory	and have used them and found them satisfactory	
01 Welfare services	for children (child welfare)	1	2	3	4	5	42
	for mentally retarded children	1	2	3	4	5	43
	for crippled children	1	2	3	4	5	44
	other (specify)	1	2	3	4	5	45
02 Special clinic	for cripples		2	3	4	5	46
	for mentally retarded children	1	2	3	4	5	47
	other (specify)	1	2	3	4	5	48
03 Protective workshop		1	2	3	4	5	49
04 Day care centre		1	2	3	4	5	50
05 Genetic clinic or clinic with genetic counselling services		1	2	3	4	5	51
06 Training centre		1	2	3	4	5	52
07 Other (specify)		1	2	3	4	5	53

Comments: ....

3

DAILY CARE

59. Do you need help with any of the following tasks in the daily care of the child? (Tick one or more.)

Feeding	1
Bathing	2
Carrying from place to place	4
Dressing	8
Toiletting	16
Laundry	32
Other (specify)	64
None (I do not need help)	0

54-56

60. Indicate at which time of the day you would normally be <u>most in need</u> of help with the following tasks?

	Between 5h30 and 8h30	Between 9h00 and 12h30	Between 13h00 and 14h30	Between 15h00 and 15h30	Between 16h00 and 18h30	Between 19h00 and 20h30	Between 21h00 and later	Do not require help		
Bathing	1	2	3	4	5	6	7	9		57
Dressing or changing soiled clothing/ linen	1	2	3	4	5	6	7	9		58
Feeding	1	2	3	4	5	6	7	9		59
Toiletting	1	2	3	4	5	6	7	9		60
Laundry	1	2	3	4	5	6	7	9		61
Supervision of child when busy with other tasks e.g. ironing, cooking	1	2	3	4	5	6	7	9		62
Other (specify)	1	2	3	4	5	6	7	9		63

Comments: ....

....

3+4

61. What types of crises have you experienced in connection with this child?

FIELDWORKER: IF NO CRISIS ANSWER = 0

....

....

....

62. If you do need help with any of the tasks in Question 59, in respect of which tasks do you receive help or not, and if you do get help, would you like to receive more?

	Do get enough help	Need help but do not get it	Do get help but would like more	Do require help for crisis only		Do not require help		
				And get it	Do not get it			
Feeding	1	2	3	4	5	9		65
Bathing	1	2	3	4	5	9		66
Carrying from place to place	1	2	3	4	5	9		67
Dressing	1	2	3	4	5	9		68
Toiletting	1	2	3	4	5	9		69
Laundry	1	2	3	4	5	9		70
Other (specify)	1	2	3	4	5	9		71

Comments: ....

....

PROJECT NUMBER	S	D	A	B	6	3	1-6
CARD NUMBER						4	7
RECORD NUMBER							8

4

63. Do you at times consider the following to be serious problems in raising your child? Answer all categories.

	Yes	No		
Social stigma	1	2		10
Adjustment/attitudes of siblings	1	2		11
Adjustment/attitudes of relatives	1	2		12
Physical demands of caring for the child	1	2		13
Discipline problems	1	2		14
Money problems	1	2		15
Lack of services (transport, medical care, etc.)	1	2		16
Lack of suitable institution (i.e. place where handicapped children live away from their parents and are cared for by other people)	1	2		17
Restriction of parents' movements	1	2		18
Other (specify)	1	2		19

Comments (e.g. constantly, occasionally but very taxing):

....

....

....

....

FIELDWORKER: NOTE STRESS factors and write down

64. Do you think that this child needs to be in an institution?

Yes	1		
No	2		
Not sure	3		21

Comments: ....

....

4

65. Which of the following do you need as a form of help in caring for the child?

Special equipment	1	
Special transport	2	
Ordinary transport but close by	4	
Finance	8	
Medication	16	
Hired help or a volunteer	32	
Other (specify)	64	
Nothing at all (none of the above)	0	22-24

ORIENTATION TOWARDS USING NETWORKS

66. If you need assistance of any kind regarding the child, how do you ask for it? (Choose one of the following.)

Directly (phoning or visiting person or organization)	1	
Indirectly (messages)	2	
On the whole a combination of both	3	
I never need assistance	4	
There are no persons/organizations I can approach although I do need assistance	5	25

4

67. What, during the past six months was your reaction if someone asked you for the following assistance?

	I have not been askedfor help during this time	I tried to help every time	I sometimes tried to help	I did not help because I was unable to	I did not help because I did not want to/did not feel like it	I helped but did not really feel like it	
Financial aid	1	2	3	4	5	6	26
Something but not money (e.g. clothing, food, etc.)	1	2	3	4	5	6	27
To perform a task (e.g. care for a child, do laundry, cook, etc.)	1	2	3	4	5	6	28
Information (directions to a place, tell of available service, etc.)	1	2	3	4	5	6	29
Comfort (during bereavement or crisis)	1	2	3	4	5	6	30
Other (specify)	1	2	3	4	5	6	31

68. Based on your own experience, to whom would you refer another mother with the problems of a mentally retarded child? (If never had such person or contact with such person answer N.a. = 9)

	Yes	No	To some not other	N.a.	
Father of the child	1	2	3	9	32
Siblings of father of the child	1	2	3	9	33
Own siblings	1	2	3	9	34
Relatives (e.g. in-laws, own parent, etc.)	1	2	3	9	35
Grown-up children	1	2	3	9	36
Professional person (e.g. social worker, doctor, etc.)	1	2	3	9	37
Other (specify)	1	2	3	9	38
No one Yes (will refer to no one)	1				
No (will refer to someone as stated above)		2			39

4

69. If you were approached by someone (professional or non-professional) to <u>start a service</u> for mentally retarded children would you be willing or unwilling to assist or would you rather ask someone else then assist them?

I would be willing to assist	1		
I would not be willing to assist	2		
I would rather ask someone else then assist them	3		
Not sure	4		40

70. If you were approached by someone (professional) or non-professional) to <u>be involved in an existing service</u> for mentally retarded children would you agree or disagree?

I would agree	1		
I would disagree	2		
Not sure	3		41

71. Has any provision been made for the child's future?

Yes	1		
No	2		
Unsure	3		
Don't know	4		42

Comments (e.g. type of provision made): ....

....

....

72. Describe how you felt/reacted when you discovered/were told of the child's impairment ....

....

.... 43

4

73. Comments by respondent on questions: ....

....

.... 44

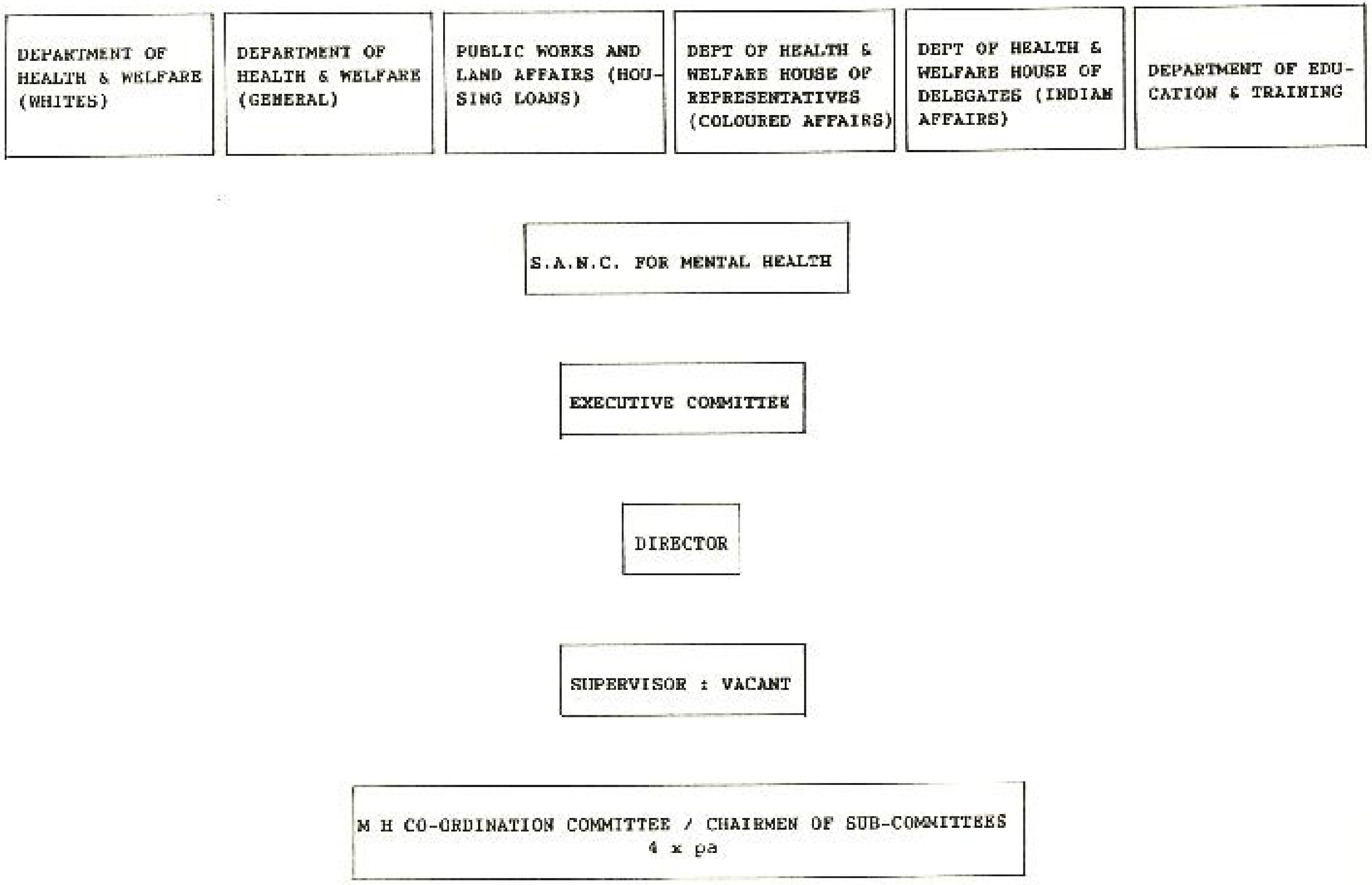
74. Comments by respondent on questionnaire: ....

.... 45

75. Comments by fieldworker on all aspects of the interview: ....

.... 46

The place of the Pretoria and Northern Transvaal Mental Health Society in relation to government departments and the SANC
for Mental Health



ANNEXURE C.

PRETORIA AND NORTHERN TRANSVAAL SOCIETY FOR MENTAL HEALTH

Fundraising number: 02 200155 000 1

CONSTITUTION

1. NAME AND INCORPORATION

The Society is known as the PRETORIA AND NORTHERN TRANSVAAL SOCIETY FOR MENTAL HEALTH. It is a juristic person which can act independently as plaintiff or defendant in lawsuits, can obtain or alienate property, acquire loans, incur debts and liabilities, pay fees and honoraria, appoint and/or dismiss staff, provide securities and indemnities and perform all such other legal rights as authorised by its aims and as its constitution permits;

2. AREA DEFINITION

The area where the Society operates and contributions are raised, includes the following magisterial districts: Pretoria, Cullinan, Brits, Bronkhorstspruit, Groblersdal and Warmbaths.

3. LIAISON

The Society is affiliated to the South African National Council for Mental Health.

The constitution of the Society and the boundaries wherein it operates will be subject to the approval of the South African National Council mentioned. After its Annual General Meeting, the Society sends its Annual Report and Audited Financial reports to the South African National Council for inspection. All matters pertaining to National Policy are settled by the SA National Council and all State Departments and other National Organisations are approached in this way by the SA National Council. To ensure uniformity, all the literature, except for local convening for funds, is referred to the SA National Council for information before it is circulated. Subject to the above, the Society operates entirely autonomously.

4. AIMS

The aims of the society are to undertake any work which promotes the following:

4.1 The preservation of mental health in the community;

4.2 The prevention and alleviation of mental disabilities and disturbances;

4.3 The investigation, treatment and care of those who are suffering from psycho-pathological conditions and supervision of people suffering from mental afflictions;

4.4 The care, training and supervision of mentally disabled people;

4.5 Provision of services in aid of children, juveniles and adults who display symptoms of behavioural problems;

4.6 Establishing group-houses, workshops and service centres where necessary;

4.7 Provision of food, meals, accommodation, clothing and other necessities and facilities to mentally disabled persons;

4.8 Obtaining and distribution of realiable information relating to mental health;

4.9 Stimulation of interest of the community in mental health by means of suitable communication and public relations;

4.10 Co-operation and affiliation with organisations and bodies with similar aims, should it be deemed necessary;

4.11 The establishment of autonomous Mental Health Societies and Branch Organisations among all population groups;

4.12 The undertaking of any task or action which promotes the aims of the Society.

5. MEMBERSHIP

The Society consists of members, life-long members, honorary members and representative members subject to the approval of the Executive Committee.

5.1 Members

Any person who applies in writing for membership is deemed a member as long as membership fees are paid. Membership fees to be determined from time to time by the Executive Committee. Members are entitled to participate in and to vote at Annual General Meetings.

5.2 Life-long Members

A person or an organisation becomes a life-long member on payment of such life-long membership fees as determined by the Executive Committee. A life-long member has the same rights and privileges as an ordinary member.

5.3 The Executive Committee can name members who have done valuable work or render services to the Society, as honorary president, honorary vice-president, honorary psychiatrist, honorary psychologist or honorary member. Honorary members of the Society enjoy the same rights and privileges as members.

5.4 Representative Members

Any centre, organisation or business wishing to work together with the Society may apply for membership subject to the approval of the Executive Committee and choose a representative (with an alternative representative) who enjoys the same rights and privileges of a member as long as the centre, organisation or business pays the membership fees.

6. ORGANISATION

The activities of the Society are controlled by the following:

6.1 An Executive Committee

which is chosen by members at the Annual General Meeting;

6.2 Sub-Committees

which are nominated by the Executive Committee and fall under direct control of the Executive Committee;

7. COMPOSITION AND DUTIES OF COMMITTEES

7.1 The Executive Committee consists of:

- Chairman
- Vice-Chairman
- Honorary Treasurer
- A maximum of eleven (11) members of the Society
- Six (6) to form a quorum

7.2 The Executive Committee

The work of the organisation shall be carried out by the Executive Committee as it may consider necessary and proper subject to the provision of its constitution.

7.3 The Executive Committee has the right to fill vacancies on the Executive Committee by co-opting members of the Society.

7.4 Sub-Committees

The Executive Committee can appoint members of its own or members of the Society as sub-committee members.

Sub-Committees shall minute all meetings and submit such minutes to the Executive Committee.

8. TERM OF OFFICE

Members of the Executive Committee and its sub-committees serve from the date of their appointment to the next election.

9. FORFEITURE OF MEMBERSHIP

Membership of the Executive and sub-committees will be forfeited if the member neglects to attend three consecutive meetings without leave of absence.

10. VOTES

All attending members have one vote. In case of equal voting, the preciding chairman will have a deciding as well as an ordinary vote.

11. MEETINGS

11.1 The Annual General Meeting of the Society takes place as soon as possible after the 31 March, <u>but not later than 30 September</u>. The quorum for the Annual General Meeting is fifteen (15) members present. The Chairman occupies the chair and in his absence, the Vice-Chairman. In the absence of both the meeting elects a chairman. The following matters are dealt with at the Annual General Meeting.

11.1.1 Submission of the Annual Report and Audited financial report;

11.1.2 Appointment of honorary auditor and honorary legal advisor;

11.1.3 Election of an Executive Committee with the usual majority of votes from a list of nominated members. The written nominations must reach the Director three (3) days before the Annual General Meeting. Any person who is nominated for a specific task and who is not elected can indicate verbally, personally or through an authorised member whether he/she is willing or not to be eligible for another task or as a member of the Executive Committee;

11.1.4 Appointment of representatives to the South African National Council for Mental Health.

11.2 A Special General Meeting of the Society will be arranged by the director on instruction of the Executive Committee or on request signed by at least seven (7) members of the Society in which the nature of the business to be discussed will be explained. The chairman of the Society occupies the chair and in his absence the vice-chairman. Such meetings shall not be able to discuss matters of which notice was not received beforehand.

11.3 Meetings of the Executive Committee take place at least eight (8) times a year. The chairman of the Society will hold the chair or in his absence the vice-chairman. If both are absent the meeting elects a chairman from those members present.

11.4 Repeal, amendment or addition to the Constitution may take place by two thirds (2/3) majority of votes of members present at any Annual General Meeting or a Special General Meeting of the society, provided that written notice of proposals to repeal, amend, alter or add to the Constitution, be given to the Director three (3) weeks before the date of the meeting at which such proposals are to be dealt with and that the proposed changes be included with the notice of such a meeting and the Agenda circulated, provided that such repeal, amendment or additions shall not be proposed before the South African National Council for Mental Health has been consulted and <u>such repeal, amendment or additions shall be forwarded to the Commissioner of Inland Revenue</u>.

11.5 The Society can be dissolved when two thirds (2/3) of the members present at an Annual General Meeting or Special General Meeting called with the aim to dissolve it, vote in favour of the dissolution. At least twenty-one (21) days notice should be given of such a meeting and the notice shall state clearly that the dissolution of the Society and the disposal of assets will be dealt with. If a quorum is not present at such a meeting, the meeting is adjourned for at least one week and the members attending such an adjourned meeting form a quorum.

When the Society is dissolved any assets that remain after debts and liabilities have been settled become the property of the South African National Council for Mental Health.

If the demands of the dissolution clause are not complied with then the director of Fund Raising receives power from the Executive Committee to decide on the assets in agreement with the aims of the Constitution.

11.6 Notices of all meetings must be posted to each member's registered address as follows:

At least 21 days before the date of the Annual General Meeting;

At least 21 days before the date of the meeting for the purpose of dissolving the Society;

At least 14 days before the date of a Special General Meeting;

At least 7 days before the date of a meeting of the Executive Committee;

At least 7 days before a date of a meeting of a sub-committee;

12. FINANCE

12.1 The financial year of the Society extends from 1 April to 31 March.

12.2 After issuing of receipts for monies received, the Executive Committee must deposit all such monies in a bank account or any registered financial institution chosen by the Executive Committee.

12.3 Account books shall show the exact financial state of affairs of the Society with regard to all particulars concerning property acquired or sold;

12.4 Nominate at least two (2) officials who sign all cheques, bills of exchange of any nature of the Society.

12.5 See to it that all accounts, books, registers and minutes of meetings are open to inspection at any time.

12.6 Ensure that the Annual Report, Audited balance sheets, statements of income and expenditure, not audited by a member of the Executive Committee, are submitted not later than six (6) months after the end of the financial year of the organisation, to the director of Fund Raising.

12.7 Income and assets of the Society are to be utilized for the aims of the Society and no member shall be enriched provided that reasonable remuneration of any employee or member will not constitute such enrichment.

12.8 The Society will endeavour to utilise at least 75% of its nett income in the furtherance of its aims in the twelve (12) months following the financial year within which such income was received.

13. BRANCH ASSOCIATIONS AND AFFILIATIONS

13.1 The Society may establish branch associations within the area of its activities or accept existing organisations as affiliated organisations of the society provided that:

13.1.1 The aims and functions of such a branch association or affiliated organisation conforms to the aims of the Society;

13.1.2 The constitution of such branch associations or affiliated organisations are accepted by the Executive Committee;

13.1.3 Prior consultation with the South African National Council for Mental Health has taken place;

13.2 Subject to the provisions of clause 13.3 such branch association and affiliated organisations will act autonomously and will be responsible for its organisation management and finances. The Society is entitled to receive reports of activities, functions and finances of such Branch Associations and Affiliated Societies:

13.3 Subject to the aims of the Society as well as existing statutory provisions, the Society may conclude written agreements with branch associations and affiliated organisations with regard to:

13.3. Fundraising and the necessary control exercised by the Society;

13.3.2 Representation on the Executive Committee of the Society;

13.3.3 Financial relations between Organisation, branches and affiliated organisations;

13.3.4 Dissociation by the Society from branch associations and affiliated organisations;

13.3.5 Any other matter with regard to the co-operation between the Society, branch associations and affiliated organisations.

NOVEMBER 1986
SvS/mw/30116