

**THE IMPACT OF THE MENTALLY
RETARDED CHILD ON THE FAMILY
LIVING IN THE RURAL AREAS OF
TRANSKEI**

BY

SINDISWA SIPAMBO

*A THESIS SUBMITTED TO THE FACULTY OF SOCIAL SCIENCE, DEPARTMENT OF
SOCIAL WORK, RHODES UNIVERSITY, GRAHAMSTOWN, FOR THE DEGREE OF
MASTERS OF SOCIAL SCIENCE*

GRAHAMSTOWN 1994

*The impact of the mentally
retarded child on the family
living in the rural areas
of Transkei*

Sindiswa Sipambo

ACKNOWLEDGEMENTS

My sincere and heartfelt thanks go to my supervisor, Professor W.A. Mitchell, for his guidance and unfailing support and encouragement.

Many thanks are also due to my respondents for the invaluable information given and their stimulating questions and answers.

I also thank the social workers of the Sterkspruit district, not only for making it possible for me to obtain the sample but also for welcoming me to their office at all times.

Many thanks are also due to Michael Lepheana whose valuable efforts and support to the success of this study will not be forgotten.

I also acknowledge with thanks the financial assistance received from my sponsors, namely: Sales House Club Bursary and DAAD Bursary.

I owe much to Helen Bradfield for typing the dissertation from start to finish and also to Thirish Cunningham and Angela Wessels for proof-reading this research report.

Finally many thanks to my immediate family, friends, relatives and colleagues, who in one way or the other have contributed to the success of this study.

(ii)

DECLARATION BY CANDIDATE

I hereby declare that this dissertation is my own unaided work and that any assistance obtained in its preparation was received from my supervisor, Professor W.A. Mitchell. No part of this dissertation has been previously submitted to any other university.

SINDISWA SIPAMBO
JANUARY 1994

TABLE OF CONTENTS	PAGE
CHAPTER 1	
STATEMENT OF THE PROBLEM	
1.1 INTRODUCTION	1
1.2 Statement of the problem	3
1.3 Motivation for the study	4
1.4 Goals of the study	5
1.5 Assumptions for the study	5
1.6 Research design and methodology	6
1.7 Definition of concepts	7
1.8 Presentation of data	9
CHAPTER TWO	
RESEARCH DESIGN AND METHODOLOGY	
2.1 Research design	11
2.2 Sampling	11
2.2.1 Choice of area and subjects	11
2.2.2 Type of sample	12
2.3 Data collection	12
2.3.1 Pilot study	13
2.4 Data analysis and presentation	13
2.5 Limitations of the study	13
CHAPTER 3	
THE CONCEPT OF MENTAL RETARDATION	
3.1 Introduction	16
3.2 The nature of mental handicap	16
3.2.1 Description in developmental terms	17
3.2.2 Description in social terms	18
3.2.3 Description in medical terms	18
3.3 The AAMD definition of mental retardation	20
3.3.1 Significantly subaverage general intellectual functioning	20
3.3.2 Existing concurrently with deficits in adaptive behaviour	20
3.4 Manifested during the developmental period	22
3.5 Behavioural characteristics of the mentally retarded	22
3.5.1 Mild mental retardation	23
3.5.2 Moderate mental retardation	24
3.5.3 Severe mental retardation	25
3.5.4 Profound mental retardation	25
3.5.5 Borderline intelligence	26

3.6	Conclusion	26
-----	------------	----

CHAPTER FOUR

THE FAMILY OF THE MENTALLY RETARDED CHILD

4.1	Introduction	27
4.2	Parental reactions to mental retardation	27
4.3	Strains placed on roles of family members and the impact of retardation on the family relationships	29
4.4	Problems confronting families having a mentally retarded child	31
4.5	Conclusion	33

CHAPTER FIVE

SOCIAL WORK AND MENTAL RETARDATION

5.1	Introduction	34
5.2	Social Casework	35
5.3	Groupwork	39
5.4	Community work	40
5.5	Social work theory in working with mentally retarded children and their families	40
5.6	Conclusion	42

CHAPTER SIX

TRANSKEI'S SOCIAL WELFARE POLICY WITH REGARD TO THE MENTALLY RETARDED CHILD AND HIS FAMILY

6.1	Introduction	43
6.2	Legislation to meet the needs of the mentally handicapped	43
6.3	Other facilities available for the mentally handicapped	47

CHAPTER SEVEN

THE SURVEY GROUP

7.1	Introduction	49
7.2	Age of the parent or guardian	49
7.3	Marital status of the parent	50
7.4	Duration of marriage	51
7.5	Educational qualifications	52
7.6	Religious denomination	52
7.7	Relationship to the retarded child	54
7.8	Sex of the child	54
7.9	Age of the child	55
7.10	Conclusion	56

CHAPTER EIGHT

THE IMPACT OF THE RETARDED CHILD ON THE FAMILY

8.1	Introduction	57
8.2	Discovery that the child is handicapped	57
8.3	Partner's reaction	59
8.4	The effects of looking after the handicapped child	59
8.5	Limitation of the capacity to carry out domestic tasks	61
8.6	The attitude of the other children in the family towards the handicapped child	62
8.7	Time spent with the retarded child	63
8.8	Feelings of other children with regard to the time spent with the retarded child	64
8.9	The effect of the presence of the retarded child on the lives of the normal siblings	65
8.10	Whereabouts of the partner	66
8.11	The relationship of parents prior to the birth of the retarded child	67
8.12	The effect of the birth of the retarded child on the marriage or relationship	68
8.13	Custody of the child	69
8.14	Going out with the partner without children	70
8.15	Care received from the father of the handicapped child	71
8.16	Help received with household chores	72
8.17	Number of other children	73
8.18	Children's ages	74
8.19	Whereabouts of other children	75
8.20	Assistance received from other children with the caring of the retarded child	76
8.21	Role changes in the family resulting from the birth of the handicapped child.	77
8.22	Interaction between the family and other people in the community in relation to the handicapped child	78
8.23	Labels used to describe the family of the child	79
8.24	Reactions of the people in public places	80
8.25	Causes of the people's reactions to the retarded child	81
8.26	Suggestions to improve the community's attitude towards the mentally retarded	82
8.27	Feelings of isolation resulting from having a retarded child	83
8.28	Respondent's time to themselves without the retarded child	84
8.29	Development as a result of the child's age	85
8.30	Support when experiencing problems with the child	86
8.31	Future care of the child	86
8.32	Material conditions	88
8.33	Source(s) of income in the case of unemployment	89
8.34	Additional expenditure incurred by the handicapped child	89
8.35	Reduction of the earning capacity of the family	90
8.36	Conclusion	91

CHAPTER NINE

THE DAILY ROUTINE IN CARING FOR MENTALLY HANDICAPPED CHILDREN

9.1	Introduction	92
9.2	Mother's description of the physical health of the children	92
9.3	Epileptic seizures	93
9.4	Washing and bathing	94

9.5	Dressing and feeding	95
9.6	Contenance or incontinence of the children	96
9.7	Method of communication	97
9.8	Level of speech development	98
9.9	Child's response to affection	98
9.10	Spontaneous approaches to other people	99
9.11	Self-amusement	100
9.12	Understanding of everyday dangers	101
9.13	Extent to which the children were educable and trainable	102
9.14	Behavioural problems	103
9.15	Conclusion	104

CHAPTER TEN

SUPPORT SYSTEMS AVAILABLE TO FAMILIES WITH MENTALLY RETARDED CHILDREN

10.1	Introduction	105
10.2	Informal support	105
10.3	Availability of training centres or special schools	106
10.4	Wish to send the children to a training centre	107
10.5	Improvement as a result of attending a special school	108
10.6	Satisfaction with the activities of the centre	108
10.7	Satisfaction with the services available in the area	108
10.8	Voluntary groups	109
10.9	Health services	109
10.10	Physical health of the child	110
10.11	Satisfaction with the services received from the nurses and doctors	111
10.12	Visitation by community health nurses	111
10.13	Social work services	112
10.14	Length of time known to the social worker	112
10.15	Satisfaction with the services received from social workers	113
10.16	Suggestions for improving social work services	114
10.17	Nature of services received	115
10.18	Social policy with regard to the mentally handicapped	116
10.19	Conclusion	117

CHAPTER ELEVEN

FINDINGS AND CONCLUSIONS

11.1	Main findings	118
11.1.1	The handicapped children	118
11.1.2	The families	122
11.1.3	Informal support	125
11.1.4	The services	126

11.1.4.1	Education	127
11.1.4.2	Health	128
11.1.4.3	Welfare	128
11.2	Conclusion	129
11.3	Recommendations	131
	Appendix	134
	The Fieldworkers	135
	Schedule	136
	Bibliography	157

LIST OF TABLES

1.	Age of the parent or guardian	49
2.	Marital status of the parent	50
3.	Duration of marriage	51
4.	Educational qualification	52
5.	Religious denomination	53
6.	Relationship to the retarded child	54
7.	Sex of the child	55
8.	Age of the child	55
9.	Discovery that the child is handicapped	58
10.	Partner's reaction	59
11.	The effects of looking after the handicapped child	60
12.	Limitation of the capacity to carry out domestic tasks	61
13.	The attitude of the other children in the family towards the handicapped child	62
14.	Time spent with the retarded child	63
15.	Feelings of other children with regard to the time spent with the retarded child	64
16.	The effect of the presence of the retarded child on the lives of the normal siblings	65
17.	Whereabouts of the partner	66
18.	The relationship of parents prior to the birth of the retarded child	67
19.	The effect of the birth of the retarded child on the marriage or relationship	68
20.	Custody of the child	69
21.	Going out with the partner without the children	70
22.	Care received from the father of the handicapped child	71
23.	Help received with household chores	72
24.	Number of other children	73
25.	Children's ages	74
26.	Whereabouts of other children	75
27.	Assistance received from other children with the caring of the retarded child	76
28.	Role changes in the family resulting from the birth of the handicapped child	77
29.	Interaction between the family and other people in the community in relation to the handicapped child	78
30.	Labels used to describe the family or child	79
31.	Reactions of the people in public places	80
32.	Causes of the people's reactions to the retarded child.	81
33.	Suggestions to improve the community's attitude towards the retardates	82
34.	Feelings of isolation resulting from having a retarded child	83
35.	Respondent's time to themselves without the retarded child	84
36.	Development as a result of the child's age	85
37.	Support when experiencing problems with the child	86
38.	Future care of the child	87
39.	Material conditions	88
40.	Source(s) of income in the case of unemployment	89
41.	Additional expenditure incurred by the handicapped child	90
42.	Reduction of the earning capacity of the family	91
43.	Mother's description of the physical health of the children	93
44.	Epileptic seizures	93
45.	Washing and bathing	94
46.	Dressing and feeding	95

47.	Continence or incontinence of the children	96
48.	Method of communication	97
49.	Level of speech development	98
50.	Child's response to affection	99
51.	Spontaneous approaches to other people	99
52.	Self-amusement	101
53.	Understanding of everyday dangers	101
54.	Extent to which the children were educable and trainable	102
55.	Behavioural problems	103
56.	Informal support	105
57.	Wish to send the children to a training centre	107
58.	Health services	109
59.	Physical health of the child	110
60.	Satisfaction with the services received from the nurses and doctors	111
61.	Visitation by community health nurses	112
62.	Length of time known to the social worker	113
63.	Satisfaction with the services received from social workers	114
64.	Social policy with regard to the mentally handicapped	116

ABSTRACT

This research was designed to do four things: first to discover what problems face caregivers who bring up handicapped children in their own homes; second, what community resources are available or which should be available to assist the mentally retarded and his family to cope with the problem; third, social policy measures available through the Transkei government, e.g. single care grant and disability grant and under what conditions are they available and whether other resources/services are available, and fourth, to find out from caregivers themselves how well the social services, although limited which are intended to help them and their children work in practice, more specifically in rural areas especially when community and public sector measures are highly circumscribed.

The lack of resources for mentally retarded children and their families in Transkei and particularly the Sterkspruit district raised some questions in the researcher's mind on how to rear a mentally retarded child in this area.

Data was gathered from a sample of all mentally retarded children who are single care grant recipients. The subjects were the mothers of these children or the present custodian about the time of the study. Information was also gathered from the social workers in the district mainly from their case files in the office.

The sample was sufficient for the study to be meaningful and well represented and to eliminate guesses and assumptions about the lives of mentally handicapped children and their families.

Findings reveal that caring for a mentally retarded child is a demanding task with varying levels of stress. Families of the retarded, in general, tend to have more problems in individual and marital adjustment, child-rearing practices, and sibling relationship. They are significantly affected - socially, economically and emotionally - by mental retardation. Support systems both formal and informal, were a great single source of help for these families for them to cope with these children.

Recommendations for better quality of life for both the handicapped child and his family are given in the last chapter, and they are most suitable for undertaking by the Welfare and Education Departments. It is not the purpose of this study to give advice to parents on how to bring up their handicapped children. Often using the mothers' own words, the researcher only presents the picture given by the parents themselves of how they actually learn to live with a handicapped child.

CHAPTER ONE

STATEMENT OF THE PROBLEM

1. INTRODUCTION

This study will focus mainly on mental retardation and family life in the Sterkspruit district which is part of the Republic of Transkei. Recent years have brought about a shift in public attitudes towards the problem of mental retardation, resulting in a more enlightened concern and understanding for the retarded and their families. The retardate is recognized as having the same needs and rights as any other member of society. The young child, retarded or not, requires the loving care, protection, and guidance from his parents to foster his growth and development in a positive direction. The child needs a stimulus of social interaction and the presence of environmental opportunities for learning how to cope with life problems and for developing his innate potentials to the fullest extent. Each retardate, whenever possible, is deserving of the chance to find his place in society where he can become a useful, productive member of his community. Just as the normal child, the retardate's major arena of socialization in the early years of life is his family.

Adams (1960: 2) has stated that the rationale for providing adequate social services to the retarded is based not only on the retardate's needs; but, of more importance, on the needs of the total family unit containing retarded members. Services, while focused on the needs of the retarded child, should primarily be family-centred and community-concerned.

Generally, mental retardation presents a problem of life-long disability for the affected individual. Families with retarded children face very complex problems which are often complicated by still

prevalent negative and stigmatic societal attitudes towards mental retardation. This occurs in spite of the fact that the problem of mental retardation is shared by a broad cross-section of the population. (Koch and Dobson: 1971: 432). For example, families in the middle and upper strata of our society are being increasingly afflicted as medical advances help babies with congenital defects to survive. The condition of mental retardation cannot be solely, and conveniently, ascribed to being the particular evil of the less fortunate socio-economic group of the lower level of the societal scale. In effect, many families who have been functioning independently find themselves suddenly confronted with unusual difficulties related to their retarded child with which they cannot cope by themselves. The established equilibrium is often upset and families, who under normal circumstances would not be clients of social agencies, find they are in need of helping services from community resources.

On the other hand, because they are less articulate and less powerful, the disadvantaged poor often neglect to seek help in respect of their retarded members. Also, these families are plagued with more urgent problems of survival and have little energy to devote to dealing singularly with intellectual deficits of their retarded members. The problems stemming from poverty are hostile to growth. Intellectual impairment due to economic and social deprivation needs to be dealt with concomitantly with the global attack on the eradication of poverty.

The lack of resources for mentally retarded children and their families in Transkei and particularly the Sterkspruit district raised some questions in the writer's mind on how to rear a mentally retarded child in this area. This study will, therefore, focus on:

1 The problems faced by the family members of a mentally retarded child;

- 2 Community resources available or which should be available to assist the mentally retarded child and his family cope with the problem;
- 3 Social policy measures available through the Transkei government e.g. single care grant and disability grant; under what conditions they are available and whether other resources/services are available; and
- 4 The roles and services that the social worker can provide to the child who is mentally retarded and his family; more specifically in rural areas especially when community and public sector measures are highly circumscribed.

1.2 STATEMENT OF THE PROBLEM

For centuries the history of the care of the mentally retarded was typified by institutionalization. Recently, however, there has been a shift from institutional care to community care for two important reasons. (Payne and Mercer 1975: 20). As knowledge about mental retardation increased, it appeared that society became more understanding and tolerant of those suffering from such a handicap, which made their care within the community a possibility. On the other hand, the number of mentally retarded people has increased proportionately with the increase in the world population, and their lifespan has also increased. This has made institutional care an expensive undertaking, both in terms of quality and quantity for any government. (Chinkanda: 1987: 1).

The care of the mentally retarded in the community appears in most cases to be undertaken by the family. Community care as perceived by Wilkin (1979: 80) refers to the care of the handicapped person within his family with minimum support from the state. Whereas the mildly and moderately

retarded will benefit in most cases from community care, it appears desirable to care for the profoundly and severely retarded in institutions. The actual care of a retarded individual in the family is normally undertaken by the mother or another adult female who has been assigned the responsibility of caring for him. Since caring for a mentally retarded child can be a very demanding undertaking for any one person, the mother or caregiver needs to have adequate internal coping resources, but normally also requires external support from her social network in order to cope with such a child. Families of the retarded, in general, tend to have more problems in individual and marital adjustment, child-rearing practices and sibling relationships. They are affected, i.e. socially, economically and emotionally, - by mental retardation. (Koch and Dobson: 1971: 436).

1.3 MOTIVATION FOR THE STUDY

The motivation for this study came from the writer's experience as a social worker from January 1990 to February 1991 in the Sterkspruit district, Transkei. During this period she dealt with more than twenty new cases of mentally retarded children. The degree of retardation differed from those who were mildly retarded and moderately retarded to those who were severely and profoundly retarded. In addition to the number stated above, between 1985 and 1989 there were more than forty mentally retarded children who were single care grant recipients. Among these numbers there was a family clan named Mqungqutho in the Kromspruit Administrative Area which appeared to have a mental incapacity problem. Five of the single care grant recipients were from this family and they also had family members who were psychiatric patients.

Among the mentally retarded children brought to the writer's attention whilst still a social worker were illegitimate children whose mothers abandoned them, and whose biological fathers were not interested in their upbringing resulting in them being cared for by their maternal grandmothers or relatives. They

only received a single care grant from the government for the retarded child for which they qualify at the age of four and at the age of eighteen the grant will be transferred to a disability grant. In most families the income from such grants are shared among family members with the result that the retarded child does not derive the maximum benefit from the grant. Poor housing and living conditions in these families are a common phenomenon.

1.4 GOALS OF THE STUDY

1.4.1 To investigate the particular needs, problems and coping mechanisms used by the family that raises a mentally retarded child.

1.4.2 To study Transkei's social welfare policy with regard to the mentally retarded child and his family.

1.4.3 To evaluate the effectiveness of existing resources provided by the Transkei Government for the mentally retarded children.

1.4.4 To assess the contribution which the social worker can make in helping these children and their families to meet their needs and solve problems which confront them.

1.5 ASSUMPTIONS FOR THE STUDY

The basic assumption in this study is that families of the retarded, in general, tend to have more problems in individual and marital adjustment, child-rearing practices, and sibling relationships. They are significantly affected - socially, economically and emotionally - by mental retardation.

Arising from this basic assumption this study proposes to test the following assumptions:

- 1.5.1 The nature of family adjustment to retardation is related to the nature of the marital integration of the parents, sex of the retarded child, social class status, family interactional patterns as well as services and support available in the community. (Koch and Dobson: 1971: 436).
- 1.5.2 Emotional stress is unavoidable due to the constant physical care, financial demands, restrictions placed on their normal lifestyle, the disappointments of having a handicapped child, the guilt feelings arising from their anger and rejection of the child and concerns about his future and life-long care.
- 1.5.3 Marital problems can be caused by parents blaming one another for producing a child with a handicap and disagreements concerning the care and placement of the child. The father often feels neglected if the mother remains constantly busy with the child. Another attitude which is quite common is the pathological over-attachment to the child which can be described as hyperpaedophilia. Here the parent's love for the handicapped child develops into a grossly exaggerated devotion and over-protectiveness which negatively affects the life and needs of the other members of the family. (Ntombela: 1991: 15).

1.6 RESEARCH DESIGN AND METHODOLOGY

The research design, methods and techniques are described in Chapter 2. The design contains both qualitative and quantitative descriptions. The record method is used for data from the social workers office, Sterkspruit district. An exploratory descriptive design was used. Research methods included

the evaluation of services rendered by the government and private sector where applicable.

1.7 DEFINITION OF CONCEPTS

MENTAL RETARDATION

For the purpose of this study the terms mentally retarded/handicapped/disabled (child/person) /retardate and retarded (child/person) will be used interchangeably to refer to a person whose mental development is deficient or retarded, who shows a marked lack of intelligence either temporarily or permanently and who therefore fails to adapt to his environment.

More specifically, the use of the term mental retardation adopted in this study will be based on the definition of the American Association on Mental Deficiency (AAMD), namely that "mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour, manifested during the developmental period." (Robinson and Robinson: 1976: 30).

The various classes of the mentally retarded are reflected as follows in the AAMD manual:

<u>TERMINOLOGY</u>	<u>IQ SCORE</u>
mildly retarded	55 - 69
moderately retarded	40 - 54
severely retarded	25 - 39
profoundly retarded	24 and below

FAMILY

Family can be defined as people related by blood or marriage. It is the centre of all relationships in tribal life (Ndabandaba: 1987: 20).

For the purposes of this study the term mother will be used to refer to the adult female who cares for the mentally retarded child. This includes the biological mother, the foster or adoptive mother, the older sister or grandmother and other adult female relatives or non-relatives who have been assigned the responsibility of caring for the mentally retarded child. This person will also be referred to as a caregiver throughout the study. The presence of a caregiver does not necessarily imply the absence of the mother. Rather, because in some cases mothers have to work full time, the responsibility of caring for the child is assigned to someone else.

CHILD

Child means any person below 18 years (Child Care Act No 74 of 1983 Section 1 {v}).

RURAL

A typical rural setting is characterized by intimate relationships and a prescribed status, and where the population is relatively low. (Phillips and Williams: 1984: 11).

Lastly, it must be remembered that all villages in the Transkei are proclaimed rural and therefore privately or tribal owned and controlled.

1.8 PRESENTATION OF DATA

The data in this study will be presented as follows: The first chapter states the problem to be investigated and the significance of the study as well as the assumptions of the study.

Chapter 2 is the exposition of the research design and methodology. The research design and methods or investigation used are given as well as the research sample, methods of gathering data and the methods of analyzing data.

Chapter 3 gives a brief look at the concept of mental retardation. The nature of mental handicap; the AAMD definition of mental retardation; and the behavioral characteristics of the mentally retarded are discussed in-depth.

Chapter 4 deals with an overview of the family of the mentally retarded child and the way they are affected, i.e. socially, emotionally and economically, by the presence of a retarded child.

Chapter 5 discusses social work and mental retardation. Different social work methods, i.e. casework, groupwork and community work, are discussed.

Chapter 6 describes the Transkei's social welfare policy with regard to the mentally retarded child and his family.

Chapter 7 outlines the personal characteristics of the respondents. These include the age of the parent or guardian; marital status; the educational qualifications; religious denomination; relationship to the retarded child; the sex of the child and the age of the child.

Chapter 8 focuses on the psychological and social effects of having a retarded child; the social life of parents/guardians of the retarded child; the anxiety about the future care of the child; and; the family's material conditions.

Chapter 9 describes how caring for a handicapped child dominated the mother's life. The problems of day-to-day burden of care experienced by the mothers are revealed in the mother's own descriptions.

Chapter 10 focuses on the formal and informal support systems received by the mother for the care of the handicapped child.

Chapter 11 gives the findings, conclusion and recommendations.

A final section contains appendices consisting of the interview schedule and information on the respondents involved in the study. A list of selected references is also tabulated at the end in the bibliography.

CHAPTER TWO

RESEARCH DESIGN AND METHODOLOGY

2.1 RESEARCH DESIGN

An exploratory descriptive design was used in this study. As Arkava and Lane (1983: 190) state, this sort of investigation becomes necessary when a poorly defined problem confronts the researcher. Often the researcher possesses little objective information about the nature of a problem and the possible factors influencing it. In such cases, therefore, the research worker first must objectively describe the problem before studying its causation and designing intervention strategies to deal with it.

This design stresses representativeness of all elements for the units under study. This cross-sectional survey was selected for this study to provide data which can be generalised to some delineated population.

2.2 SAMPLING

2.2.1 CHOICE OF AREA AND SUBJECTS

This study was conducted in the Sterkspruit district, Republic of Transkei. Sterkspruit comprises twenty three Administrative areas. Only retardates who were single care grant recipients in the social worker's office in this district at the time of the study were included.

The subjects were mothers of the mentally retarded children or the custodian of the child at the time of the study.

2.2.2 TYPE OF SAMPLE

The caseload of the social worker at Sterkspruit district consisted of sixty three mentally retarded children who were single care grant recipients. As the number of respondents was not high and would be accessible enough to the researcher, the latter intended to include all of them in the investigation. This intention could not succeed as some respondents were not at home at the time of the study; or the children were no longer in their care without the social worker's knowledge; or the respondents could not be found at their house-holds when the researcher called. This resulted in the number of forty six respondents interviewed in this study.

2.3 DATA COLLECTION

Social workers rely more heavily on the interview for data collection than any other method because it can be used flexibly to obtain the complex data that they need (Reid and Smith: 1981: 207).

This was an in-depth investigation. The researcher used a social survey method using an interview schedule to collect the data. The interview was chosen in this study as a data collection method because of the following advantages: naturalness and spontaneity, flexibility, control of the environment, high response rate and it yielded more detailed information. The interviewer, besides asking standard questions, can note such things as the respondent's manner of speaking, home and neighbourhood, dress and general reactions to the subject matter. By astute observation, the interviewer may even find that no more personal or delicate questions need be asked. (Arkane and Lane: 1983:

171) Direct observation to supplement data collected through interviews was used.

2.3.1 PILOT STUDY

A pilot study was undertaken in this investigation. Five respondents were involved for this purpose as the number of research subjects for this study was not high. Some changes had to be made to the questionnaire, mainly it had to be shortened as it was too long. Some respondents had difficulty in understanding some of the questions and as such those questions had to be simplified. Grinell Jr (1981: 253) found that a review of completed questionnaires, along with a group discussion with respondents about their difficulties in answering them, is one of the most valuable ingredients of the pilot study.

2.4 DATA ANALYSIS AND PRESENTATION OF FINDINGS

Data was presented and analyzed. Variables which were presented were those most central to the goals of the study and were presented in the form of tables. The contents of which were frequencies (raw scores) and percentages and measures of central tendency (averages) such as the mean.

In the presentation of findings, objectives are restated and the findings of the investigation are related to them to conclude whether they have been reached or not. On the basis of the conclusions, recommendations for social intervention based on these conclusions and suggestions for further research have been made.

2.5 LIMITATIONS OF THE STUDY

While every effort was made to achieve the aims of the study, difficulties arose in the course of planning and of field work which limited the degree of success achieved.

- 2.5.1 The questionnaire was long and each interview took between 45 mins to an hour or more depending on that particular interviewee.
- 2.5.2 As the interviews were conducted at the interviewee's households, the children concerned sometimes disturbed the interview which cost more time. The mothers had to attend to the children as some of them were attention-seeking.
- 2.5.3 Some of the subjects could not be located easily or could not be located at all. This whole exercise was time-consuming with negative results. Sterkspruit district is a predominantly rural area with no streets or numbers.
- 2.5.4 The researcher intended to include all single care grant recipients at the time of the study. This intention could not be fulfilled as some respondents were unavailable at the time of the study.
- 2.5.5 Some of the questions were rather sensitive or personal. For example, matters related to the question of the marriage relationship as a result of the birth of the handicapped child and the support received from the father with the care of the child. The researcher could detect during the course of the interview that the information elicited by the respondent was not a true reflection of the situation. In some instances the father of the child was present during the interview and this was another cause of this limitation.

2.5.6 Thirteen percent of the respondents were not the biological mothers of the children and the questionnaire was more suitable to the biological mothers and for this reason some of the questions were not well answered.

CHAPTER THREE

THE CONCEPT OF MENTAL RETARDATION

3.1 INTRODUCTION

This chapter addresses the question, "what is mental retardation ?" Although there is a generally accepted definition (that is, the American Association on Mental Deficiency definition, discussed later in the chapter), there is no simple, adequate answer to this question. Maloney and Ward (1979: 112) noted that the concept of mental retardation has been primarily legal and social administrative. The courts needed a concrete set of criteria on which to base critical decisions on issues like competency to stand trial, culpability for criminal acts, and when institutionalization could be ordered. School systems needed to set eligibility requirements for admission to their special classes. The legislators, social planners, and bureaucrats charged with providing services for this population needed a practical set of guidelines so that laws could be formulated and funds made available.

This chapter, therefore, is divided into the following sections: the nature of mental handicap; the AAMD definition of mental retardation; and the behavioural characteristics of the mentally retarded.

3.2 THE NATURE OF MENTAL HANDICAP

The term "mental handicap" refers to impaired mental ability. It is both a symptom of an underlying developmental disorder and an assessment of potential ability to learn. The retarded individual learns slowly, and at physical maturity his capacity to understand will be, to varying degrees, less than

average. (Menolascino: 1977: 11).

The discussion on the nature of mental handicap will be based on three main areas noted by Eden (1976: 11) namely: {1} developmental {2} social; {3} medical;

3.2.1 DESCRIPTION IN DEVELOPMENTAL TERMS

There is wide agreement among the disciplines concerned that a child whose mental age is half, or less than half, his chronological age may be considered mentally handicapped. It is not only the intellect which develops slowly, the stages of physical maturation are usually delayed also, the mentally handicapped child will often learn to sit, stand and walk later than his normal brother or sister. For this reason, mentally handicapped children are sometimes assessed in terms of their DQ (Development Quotient), which compares developmental age with chronological age. The pattern of development of the mentally handicapped child is fundamentally normal, however, and differs in degree, not in kind, for that followed by the normal child. The mental handicapped person does not, in practice, progress much beyond a mental age of seven, however long he lives. Moreover, his attainments within his mental age, say four, do not in all respects match those of a normal four year old. He is unlikely to show anything like the normal fluency of speech, may be clumsy, unable to dress himself, and will almost certainly not show the normal constructive curiosity about anything and everything. His thoughts will be extremely concrete, and confined to his immediate environment.

Patchy development of this kind may be due to a variety of external circumstances which have simply not offered the child the opportunity to learn. However, the progress of a mentally handicapped child is often additionally hindered by the presence of sensory handicaps such as partial sight or partial hearing loss, which prevent him from making full use of his potential.

3.2.2 DESCRIPTION IN SOCIAL TERMS

The main act in America concerned with mental handicap is the Mental Health Act of 1959. (Eden: 1976: 14). The Act includes under the term "mental disorder" both mental handicap and mental illness. While it is true that a mentally handicapped person may also suffer from a mental illness, mental handicap is not a mental illness but a condition in which the mind though limited, is perfectly sane. The mentally handicapped have incomplete development of mind which includes subnormality of intelligence and as such he is incapable of living an independent life of guarding against exploitation. or will be so incapable when of an age to do so. Social incapacity is of course the direct consequence of retarded development. There is nothing in law which prevents a retarded individual from marrying, voting or owning property. The law is concerned with the social consequences of poor intellectual capacity, not with the mere existence of it. (Bicknell: 1982: 597)

3.2.3 DESCRIPTION IN MEDICAL TERMS

Mental handicap implies disability of some sort associated with the mind, which is often thought of as a non physical entity somehow associated with the body. Severe subnormality is a phenomenon which manifests itself among the rich and the poor, the high and the low, the just and the unjust. It is not a disease of affluence or a punishment for sin, but one of the "thousand natural shocks that flesh is heir to" (Eden: 1976: 18). For medical science, however, the mind is the physical brain. The person "who is so severely handicapped in his mind that his IQ is below 50, invariably has something wrong with his brain."

The brain of a mentally handicapped person may be small and underdeveloped; sometimes whole sections are missing or imperfectly formed; sometimes essential cells are lost and have been replaced

by a tissue of functionless cells; sometimes there is nothing overtly wrong; but the brain nevertheless fails to function properly. The greater the area of brain which does not work properly the greater the degree of mental handicap. Damage in the part of the brain which controls vision will produce blindness or partial sight; similarly with the areas of hearing, speech, memory, movement and so on. Brain function may be considered to have three broad aspects, thus:

Input ----- Processing ----- Output

If damage occurs in any of the three aspects the result is the same, namely an impaired ability on the part of the individual concerned to function in the whole area to which the single aspect relates. Using speech as an example we may illustrate the effects of damage in the following manner. In order to be able to answer a question the individual must:

- (1) be able to hear (input);
- (2) be able to understand (processing);
- (3) be able to form speech (output).

If the defect is found in any of the three areas he is unable to answer.

Any mentally handicapped child will possess an individual pattern of damages which together make up the organic basis of the haphazard development. Often, however, brain damage is global, so that input, processing and output are all affected. Once it has occurred brain damage does not usually get worse, but so far as contemporary science is concerned it is incurable. The concern of doctors and all others who work with the mentally handicapped is not therefore with cure but with assisting him to overcome the disabilities which a natural shock has laid upon him. (Eden: 1976: 18 - 19).

3.3 THE AAMD DEFINITION OF MENTAL RETARDATION

According to the American Association on Mental Deficiency (AAMD) "mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour, manifested during the development period" (Robinson and Robinson: 1976: 30). We shall now discuss each of these criteria in the order stated in the definition.

3.3.1 SIGNIFICANTLY SUBAVERAGE GENERAL INTELLECTUAL FUNCTIONING

This first requirement relates to the person's level of general intelligence. The word "significantly" refers to the fact that the IQ cutoff for mental retardation is two or more standard deviation below the average IQ of 100. Thus, all persons with IQs below this cutoff point satisfy the first requirement for a diagnosis of mental retardation, namely, significantly subaverage general intellectual functioning.

3.3.2 EXISTING CONCURRENTLY WITH DEFICITS IN ADAPTIVE BEHAVIOUR

This second essential ingredient for a diagnosis of mental retardation represents a major historical shift in the diagnostic process. There must be a manifest impairment in adaptive behaviour as well unlike in the past where IQ alone was considered the sole and sufficient criterion for mental retardation.

Adaptive behaviour is defined as the degree to which the individual meets the standards of personal independence and social responsibility expected for his age and cultural group. (Maloney and Ward: 1979: 139). While the criteria vary with age level, there is a general expectation for increasing independence, self-mastery, and conformity to societal demands and conventions as the person progresses from one developmental level to the next.

3.3.2.1 INFANCY AND EARLY CHILDHOOD

During this period, the focus is on the development of sensory-motor (e.g. crawling, walking, gross and fine motor co-ordination), communication (receptive and expressive language), self-help (eating, dressing, personal grooming, and hygiene), and socialization (ability to deal and interact with peers and adults) skills. Deficits in the maturational process or lags in the appearance of developmental milestones are evidence of adaptive impairment.

3.3.2.2 LATER CHILDHOOD AND EARLY ADOLESCENCE

The primary focus during this period is school performance in general and learning in particular. Difficulty in school, low achievement, and being two or more grade levels behind are signs of potential adaptive impairments. In addition to academic pursuits, the person in this age group should be developing more social skills, such as forming interpersonal relationships and participating in group activities.

3.3.2.3. LATE ADOLESCENCE AND ADULT LIFE

During this period, the primary focus is on vocational and social responsibilities. The ability to obtain and maintain employment, to handle financial matters with judgement and foresight, to meet the practical requirements of daily living and to develop close interpersonal relationships. In short, the ability to conform to community standards and to maintain an independent existence is assessed. The mere presence of deficits at any of these age levels does not, by itself, imply mental retardation. Such deficits can occur for a variety of reasons e.g. situational or emotional problems. It is only when these deficits are manifested by a person with an IQ below 70 that they constitute criteria for mental

retardation. At that point, the adaptive impairment is considered to be related to the intellectual deficit. (Maloney and Ward: 1979: 140).

3.4 MANIFESTED DURING THE DEVELOPMENT PERIOD

This third requirement is included primarily to distinguish mental retardation from a variety of other disorders where low IQ and adaptive impairments are present. For example, a person suffering from brain damage secondary to an automobile accident may score well below 70 on an IQ test and manifest all sorts of adaptive impairments. Likewise, people with acute emotional disturbances are often quite impaired behaviourally and unable to perform well on the IQ test. However, although both of these examples satisfy the first two requirements of the definition, such people cannot be called mentally retarded. The best way of eliminating such cases is to ensure that the low IQ and behavioural deficits be initially manifested during the developmental period. Thus, the people in the above examples are not mentally retarded because their condition did not originate or exist in the developmental period. The developmental period refers to the time during which the growth of intelligence is presumed to occur. Practically, this is considered to be from the time of birth until 18 years of age. (Maloney and Ward: 1979: 140 - 141).

3.5 BEHAVIOURAL CHARACTERISTICS OF THE MENTALLY RETARDED

In this section, we will consider the behavioural characteristics of the mentally retarded at the four classification levels. The borderline intelligence category will also be described. Menolascino (1977: 19) noted that the degrees of mental retardation are usually discussed according to severity and potential to grow, learn and develop. They are usually classified as follows: (1) mild; (2) moderate; (3) severely; (4) profoundly (5) borderline.

The various levels of mental retardation areas follows using the two different standardized intelligence tests.

LEVEL OF RETARDATION STANDARDIZED INTELLIGENCE TEST

	<u>STANFORD-BINET</u>	<u>WELHSLER</u>
Mild	52 - 67	55 - 69
Moderate	36 - 51	40 - 54
Severe	20 - 35	25 - 39
Profound	Below 20	Below 25
Borderline	68 - 83	70 - 84

It is felt, however, that persons falling within the borderline level of retardation should not be considered mentally retarded. Rather they are individuals whose measured intelligence falls between the mentally retarded and the normal ranges.

3.5.1 MILD MENTAL RETARDATION

Adults functioning in the mild range of mental retardation have a mental age which ranges from about eight years and six months to ten years old and ten months. These persons usually look and act normal, there is nothing obvious about their retardation. In fact, many are not even suspected of any retardation until the age of six, when they encounter the intellectual demands of school. As adults, they are frequently able to find and keep a job, but often need supervision in social and financial affairs. Intellectually they are at the level of a fourth or fifth grade child. However, their academic achievement is usually below this level. Vocational training is the major educational emphasis rather

than proficiency in academic skills. In addition, the training focuses on the personal social skills necessary for job success rather than on job tasks. Mildly retarded are vary vulnerable to occupational displacement by adverse economic conditions or automation. Motor slowness and lack of reading skills make competitive employment difficult for them. Mildly retarded women are more capable than men of succesful marriage, since homemaking and the social skills required of them are less demanding than the public work skills required of men. Although women in this group are capable of adequate married life, they may not be able to provide an optimal environment for their children. One of the most common problems with mildly retarded adults is their inability to handle leisure time (Maloney and Ward: 1979: 174 - 175).

3.5.2 MODERATE MENTAL RETARDATION

The moderately retarded person has an approximate mental age of from six years and one month to eight years and five months. These individuals often have some observable physical features which indicate abnormality. They frequently look as though something is wrong with them. Some of them do maintain full-time jobs, and many others have part-time or odd jobs. The chief focus of training is on self-care and other practical skills, and the majority become fairly proficient in such skills as dressing, toileting, eating, and grooming. The moderately retarded adult is roughly equivalent intellectually to normal second or third grade children. However, although the moderately retarded may be able to recognize some written words or even read some simple sentences, they are essentially functionally illiterate. Very few of these persons marry or become independent. They have few friends outside the immediate family, and any employment they obtain is usually of a repetitive, unskilled nature, perhaps in a sheltered setting where income is not dependent on production. (Maloney and Ward: 1979: 173 - 174).

3.5.3 SEVERE MENTAL RETARDATION

Severely retarded persons have a mental age roughly from three years and nine months to sixty years. This group of retardates respond to teaching in an environment similar to that of a nursery school, but that has a more structured approach. They are capable of communicating orally and are also able to respond to verbal instructions. These persons are likely to have sustained neurological damage that further restricts their social behaviour. Most are mobile and are able to clothe and feed themselves and are also able to attend to or indicate their toilet needs. They can acquire self-help skills through prolonged, careful and supervised practice. Although very little independent behaviour can be observed, most are able to find their way around the neighbourhood. Their verbal skills are extremely limited and verbal communication consists of two or three word sentences. Although the majority in this group are incapable of leading full independent adult lives, they can benefit from sheltered work or from attending an adult day care centre. (Chinkanda: 1987: 4).

3.5.4 PROFOUND MENTAL RETARDATION

Profoundly retarded persons have an estimated adult mental age of three years and eight months or less. The probability of concomitant neurological damage is high, and many are nonambulatory. They are often multiply handicapped. They differ from the other three groups in respect of their level of awareness. They are apparently unaware of their surroundings and require various kinds of constant sensory stimulation, that is, in terms of sight, sound and touch. They may respond to such stimulation and these responses may eventually become spontaneous. This particular group requires a considerable amount of supervision, and because many of them are not mobile they require help with feeding and toileting. They are considered incapable of benefitting from any type of training. Because of the neurological damage suffered most of them remain at home and are bedridden or wheelchair bound.

The mortality rate in this group tends to be high. (Chinkanda: 1987: 4).

3.5.5 BORDERLINE INTELLIGENCE

Persons in the borderline range of intelligence have a mental age from about ten years and eleven months to about thirteen years and three months. Their level of intellectual development can be compared to that of a normal child of similar age. Adults in this group are frequently able to achieve adequate vocational and social adjustment if they have the proper training and reasonable employment opportunities. As a rule, they are employed in unskilled and labouring positions, although they are capable of attaining some skilled and semi-skilled levels. Many of these individuals blend into the normal population and have never been identified or labelled as having difficulty related to intelligence. They are most often of low socio-economic status, which possibly causes more difficulty than intellectual level. However, low intelligence clearly compounds the problems of low socio-economic level, preventing the individual from rising above the poverty line. Based on mental age, adults of borderline intelligence would perform academically like normal sixth to eighth grade students. (Maloney and Ward: 1979: 176).

3.6 CONCLUSION

The sample in this study consisted of different levels of retardation as outlined in this chapter. The category which was largely present was the mildly and moderately retarded. The conditions under which the researcher found the profoundly retarded were sometimes not satisfactory, they were neglected and some malnourished which was an indication that the caregivers were not coping with their care.

CHAPTER FOUR

THE FAMILY OF THE MENTALLY RETARDED CHILD

4.1 INTRODUCTION

It is no exaggeration to say that in the background of every individual handicapped child there is always a handicapped family. (Sheridan (1965) from Hewett with John and Elizabeth Newson: 1970: 76). Parenting any child is a difficult and challenging task, one that brings, along with its rewards, varying levels of stress. Stress stems from both demands on the parents' time and energy and challenges to the parents' feeling that they are competent to deal with their child's needs. The demands and challenges of parenting are often intensified for parents of children with handicapping conditions. (Gowen, Johnson-Martin, Goldman and Appelboum: 1989: 239).

In its focus on the family this chapter will be divided into the following sections: the first will examine the reactions of parents to the identification of mental retardation in their families. The second will discuss some strains placed on roles of family members and the impact of retardation on the family relationships. The third part will deal with a brief overview of problems confronting families having a retarded member.

4.2 PARENTAL REACTIONS TO MENTAL RETARDATION

There is general agreement in the literature that parental reactions to the diagnosis of retardation in their child are highly individualistic. These reactions depend upon a variety of dynamic factors:

individual personality, nature of the marital interactions, parental aspirations, feelings about deviancy, social class, etc. (Koch and Dobson: 1971: 433 - 434). The reactions that are going to be noted here are: guilt, ambivalence, disappointment, frustration, anger, shame, sorrow and isolation. In addition to this list a recent research finding indicates that if such families do not break down there is a strong possibility that they will be too cohesive and include the danger that the handicapped children will be overdependent because their mothers are overprotective. (Hewett with John and Elizabeth Newson: 1970: 77).

4.2.1 GUILT

Guilt is perhaps the most common response to the impact of diagnosis. Parents feel rejecting, hostile, and destructive towards the defective child; unable to tolerate their negative feelings, they become guilt-stricken. (Koch and Dobson: 1971: 434). Marital problems may be caused by parents blaming one another for producing a handicapped child. For some religious parents, the child may be viewed as a punishment for past sins. (Ntombela: 1991: 15).

4.2.2 AMBIVALENCE

In such a stressful situation, both positive and negative feelings come into play. Parents show mixed emotions about their adequacies to cope with a problem regarding the affected child and about their contacts with professional personnel. Anger, disappointment, grief and frustration are often evoked. On the positive side, parents have normal impulses to love and nurture their child and to cope independently with their life problems. (Robinson and Robinson: 1976: 100).

4.3 STRAINS PLACED ON ROLES OF FAMILY MEMBERS AND THE IMPACT OF RETARDATION ON THE FAMILY RELATIONSHIPS

The impact of mental retardation is never restricted to retarded individuals; members of the immediate and extended families are affected to varying degrees. The relationships and influences between retarded children and their families would also seem to be reciprocal and circular; i.e., although families are affected by the presence of retarded children, so too are the children affected by their families' responses. Satisfactory emotional development of retarded children may be dependent more upon the families' responses to them than to the extent of the handicap itself. (Crnic, Friedrich and Greenberg: 1983: 125).

The birth and continuing care of mentally retarded children are often stressful experiences for family members. The effects on the family unit can be far-reaching, restrictive, and disruptive, and they may be economic, social or emotional. Consequently, parents of retarded children have generally been viewed as being at risk for a variety of family life problems and emotional difficulties. Paramount among their family life problems are unusual caregiving demands and restrictive time demands. For many family members, especially mothers, management of the daily needs of a retarded child may constitute an all-consuming task. (Harris and McHale: 1989: 231). Crnic and Greenberg (1985: 76) found that the cumulative impact of daily parenting hassles and difficulties in dealing with children represent significant stressors that may subsequently affect parent and family functioning.

Caring for a mentally retarded child at home can result in major changes in the family finances, leisure activities and general life-style. For example the family budget may be strained by the inclusion of special food types, special equipment or clothing, a higher medical, electricity or fuel bill and the cost of special transport of its own. (Robinson and Robinson: 1976: 105). Depending on the extent of

the child's handicap or on whether he has behavioural problems that call for constant supervision in order to prevent him from hurting himself and or others, the family may also need hired help. Family income may be reduced because caregiving responsibilities make it difficult for two parents to work outside the home.

An added area of concern for some families is difficulty managing family relationships. Roles within the family may need to be restructured and the resulting strain may manifest itself in family problems, including high rates of desertion, divorce, family quarrelling, and marital breakdown. Outside the nuclear family, parents may have difficulty establishing and maintaining satisfying social networks. Social support networks of relatives, friends, and professionals, however, can be important mediators of stress in these families. (Gallagher, Beckman and Cross: 1983: 15).

The problem for the parents of the retarded child is further complicated by the need to learn a new role which they have to integrate within an existing and defined parental role. He has to behave one way to normal children and another way to the retarded offspring. The uniqueness which exists is that so often the goal aspirations and role demands which are relevant for the normal siblings are not applicable to the retarded one.

Normal siblings of the retardate often experience problems. They often become targets for excessive high parental aspirations in order to compensate for parental disappointments and frustrations about the retarded child. Their needs are often unmet by parents who are overwhelmed or over-involved with the care of the handicapped child. At an early age, normal siblings need to deal with peer reactions to their retarded sibling - sometimes at an age when they are unusually vulnerable to teasing and taunting and when they lack the life experience and intellectual maturity to fully comprehend the nature of the sibling's problem. Sometimes guilt feelings develop about being the normal child and positive

feelings about not being the afflicted one. (Koch and Dobson: 1971: 437).

Not only are sibling relationships affected by the presence of a retarded child, but there also appear to be detrimental effects on the nonretarded sibling's (primarily female) individual functioning, involving high degrees of anxiety and conflicts with parents, lower sociability or emphasis on interpersonal relationships, and the adoption of life goals involving dedication and sacrifice. (Crnic, Friedrich and Greenberg: 1983: 130). Grossman (1972) also noted that sibling reactions were related to parental reactions and ability to cope.

The retardate's role as a member of the total family system is important. He has similar needs to establish satisfying interactions and relationships with his family members. Retardates generally need assistance in forming interpersonal relationships and in learning appropriate role behaviour. They frequently suffer from limited social experiences and are further handicapped by the social rejection or negative attitudes expressed to them by other people. Given a warm, accepting family, the retardate can learn to fill a useful and compatible role. If respected and perceived as an individual with emotional capacity and some ability for learning, the retardate can be given his own responsibilities which contribute to family functioning. (Koch and Dobson: 1971: 439).

4.4 PROBLEMS CONFRONTING FAMILIES WITH A MENTALLY RETARDED CHILD

The family, as a core unit in society, forms the foundation for individuals who are emotionally well-balanced and well-functioning. It can also, however, be the breeding ground for emotional and functional problems. Mental retardation poses a problem for the family of a long-time burden of care and management of the retarded individual. This means that families may be, and usually are, confronted with many crises in the areas of their psychological and emotional lives as well in their

daily living experiences. (Mdaka: 1991: 1).

4.4.1 STIGMATIZED SOCIAL INTERACTIONS

The community stereotype all mentally retarded people as completely lacking in basic competence. People generally feel uncomfortable with the mentally retarded and tend to avoid interacting with them. Families may be faced with the unique and cruel torment of social isolation as they frequently feel ostracized and indeed in reality are often shunned by the community in which they reside. This is partly a reflection of the lack of understanding of retardation as well as the stigma attached to it; partly due to the realistic living problems stemming from mental limitations; and, in part, a result of the lack of adequate resources available to serve the needs of retardates and their families. Parents of the retardates face hostile stares, judgemental comments, murmurs of pity and intrusive requests for personal information whenever they are with their retarded children in public. (Wilker: 1981: 282).

4.4.2 PROLONGED BURDEN OF CARE

Caring for a child under normal circumstances can be a demanding undertaking, especially when coupled with other domestic chores. Mothers often bear this responsibility, sustained by the knowledge that the child will gradually become independent and their responsibility will become less and less and they will eventually have more time to themselves.

This is not so with the mother of a mentally handicapped child, especially a severely or profoundly handicapped child, who may or may not have physical disabilities as well. For her, caring for her disabled child may be a lifetime undertaking because of the prolonged dependence of some of these children. Some major caring problems that are experienced by the families of the mentally

handicapped are as follows: feeding, bathing, toileting, laundry, dressing, night-time care and supervision.

4.5 CONCLUSION

Parenthood is not an easy undertaking even under normal conditions. When the child to be raised is a mentally handicapped child, more demands are made on the parents and on whatever resources are available to them. The burden that the mother of a mentally retarded child carries, calls for her to receive support not only from her family but also from the informal as well as the formal network in the community.

CHAPTER 5

SOCIAL WORK AND MENTAL RETARDATION

5.1 INTRODUCTION

The mentally retarded child is different from the normal, in intellectual endowment and often in physical appearance; he may never achieve physical maturity, he may always be dependent to a greater or lesser extent on his parents and frequently he is not accepted by society. By his very existence he can become, to his parents, a symbol of guilt. (Turner: 1983: 516) The concern of social work with the family of a retarded child is not with the mental retardation per se but with the tasks that having a mentally retarded child present to the family and their ability to cope with these tasks. Do the parents have the knowledge and time to deal with any special problems the child might present ? Are there resources in the community such as special day care centres and schools ? Are the parents aware of and able to use such resources ? Is there an organized group of parents of mentally retarded children which could provide the parents with information and advice, help link them to needed resources as the child grows up, provide an outlet for sharing problems and concerns, and act as an advocate for their interests ? (Specht and Vickery: 1979: 79).

Meeting needs of clients is every social worker's responsibility. Working with people who have a mental handicap is not easy, it can often be stressful, difficult, unpleasant, dirty and mentally and physically demanding. People who have a mental handicap have a range of special needs in many different areas, e.g. physical function, learning and understanding social skills, communication and independent living skills. They may also have additional needs that are not directly caused by their

mental handicap, e.g. cerebral palsy, epilepsy, sensory deficits or mental illness. This makes every client unique in their training needs, and requires those involved in meeting those needs to have sufficient skill and flexibility to adopt whichever approach (or combination of approaches) brings most benefit to the client (Peck and Hong: 1988: 1-2). Social work skills required for working with retarded children and their families are generic social work skills. The social worker's role will be assessing the need for services, providing skilled emotional support, ensuring continuity of informal help and co-ordination of care and support services. The special task of the social worker of maintaining a continuing relationship with the handicapped and his family is of utmost importance. He acts as facilitator, liaison officer and a key resource, giving the individual or his family access to the whole spectrum of health and welfare services. This role is necessary but largely unfilled where services for mentally handicapped people usually assume low priority. Social work in its dual role as provider of practical assistance and a source of emotional support is uniquely situated to emphasize the positive aspects of having a handicapped family member (Hanvey: 1981: 34-35).

In the field of mental retardation, the social worker must understand the individual's relation to society, its institutions and the forces for social change. His tasks include providing direct and indirect social services to the clients with this problem. Depending upon the setting, he may have added responsibilities for research, teaching and community activities. (Koch and Dobson: 1971: 198-201). The three social work methods, namely: casework, groupwork and community work, will be discussed.

5.2 SOCIAL CASEWORK

As a caseworker the role of the social worker can generally be seen in terms of three periods.

5.2.1 BEFORE BIRTH

At this point the function of the social worker should be seen as a preventative one. The ideal situation is that couples who wish to marry and married couples who wish to start a family should receive genetic counselling. Sometimes skilled genetic counselling may be required to allay fears or provide information on the risks of other handicapped children. Genetic counselling will involve a medical diagnosis, together with an investigation into the family of the handicapped child. Advice on the hereditary or non-hereditary nature of the disorder can then be given. Risk figures may also be provided, leaving parents with the responsibility of making up their own minds. (Hanvey: 1981: 36). A technique known as amniocentesis makes it possible through laboratory tests to ascertain whether a pregnant woman is carrying a foetus with a Down's syndrome. If the laboratory analysis indicates Down's syndrome, the ideal step would be to advise the mother to terminate the pregnancy. This is rather a sensitive issue and the social worker should base her actions on her knowledge of the circumstances of the family and possible outcomes of any step she might take. (Chinkanda: 3.86: 8).

5.2.2. PRE-SCHOOL OR EARLY YEARS

It is common for parents to initially react with shock and disbelief when presented with tragic information about their child. (Bicknell: 1982: 605). The challenge to the skill of the social worker is to distinguish between the reasonable and the unrealistic in parental attitudes, and to identify material need in a situation which may be dominated by emotion (Eden: 1976: 45). Social work has a difficult and sensitive role to play, interpreting medical conditions in lay terms and, where possible, answering some of the inevitable questions which crowd a parent's mind during the initial period of shock: What does mental handicap mean? What effect will it have on my child's development? What school will

he go to ? What help will I get ? What is going to happen to us ? And what is the future likelihood of our producing other handicapped children ? There may be very fundamental philosophical and religious needs experienced by the parents, requiring the spiritual help of a local minister before they are able to accept this new, painful experience into their personal philosophy. As noted by Hanvey (1981: 37) many parents have initial problems in their sexual relationship, following the birth of a handicapped child. Some decide to have no more children, in order to give themselves more time for the particular needs of their handicapped offspring. Yet this can provide additional problems if, as Alice Candy asserts, the parents have no other child with which to compare and the feelings of failure and inadequacy must be unrelieved (Candy: 1976: 87). Social work has a positive role to play in encouraging both optimism and a belief that dreams are not necessarily destroyed by the birth of a handicapped child.

Some of the challenges result not only from physical or mental problems, but also from behavioral problems. Irrational fears, phobias, hyperactivity, incontinence and sleeplessness are some of the behaviours which confront many parents. Help is needed with those poor behaviour patterns which are being established during this period and to establish more normal ones. The community social worker can play a valuable role in helping to understand individual behavioral problems, seek further professional guidance, where appropriate, and find ways of alleviating pressures on the family when necessary. (Hanvey: 1981: 37-39).

5.2.3 SCHOOL AGE

In most cases mental retardation, especially mild retardation, is detected only when the child begins school. It is at this stage, when these children are expected to cope with the outside world and to compete with their peers, that they begin to drop back and cause concern. Some teachers who are

rather sensitive quickly identify these children while others identify them only after they have been in one class for more than two years. When the parents are notified, the school often advises them to contact the social worker. The social worker then arranges for tests with a psychologist. If the tests confirm mental handicap the social worker begins counselling the parents, who had perhaps been unaware of the child's problem or had perhaps been aware of but refused to accept its existence. There may be a lot of denial because the parents had convinced themselves that their child is normal. This denial may also lead to a refusal to send the child to the place the social worker may have referred him to. The social worker should empathise and help the parents to deal with new information about their child and help them to plan for the future. (Chinkanda: 86: 8). Depending on the availability of resources and the level of the child's retardation, the child will either be living with his parents and attending a day care or special centre or he will be in an institution. In the former case the child will be living with its parents and will be away from home at certain hours. In other cases lack of facilities leads to these children being at home all day with their mothers.

5.2.4 CASEWORK WITH THE RETARDED CHILD

It is sometimes assumed that the mental retardate has no feelings, or at most a limited range of fleeting, highly-held emotions since he is a person for whom both learning and communication are difficult. A retarded individual can feel very deeply and he can participate in a casework relationship.

In order to help the mentally retarded person, the caseworker must believe that he is capable of emotion. He can respond to help when it is offered with sensitivity and understanding. If the social worker applies the basic principles of generic casework with understanding of the client's particular need, the client can be helped. It is important to go slowly, to speak simply, to give him time to turn the thought over in his mind and make his own thought connections, not to try to cover too much in

one interview, and to be sure that the choice of plan is left to the client. A mental retardate is capable of utilizing the help available to him in a casework relationship in order to change and to grow, to move from fear and dependence on another person to self-confidence and independence (Turner: 1983: 520).

5.3 SOCIAL GROUPWORK

The social worker can arrange to do groupwork with mothers or parents of retarded children or with the retarded children themselves, depending on their level of functioning.

5.3.1 GROUPWORK WITH MOTHERS/PARENTS

The aim of the group process is to assist members to bring forth concerns, angers and thoughts so that gradually the strengths of each individual should come to the fore and be more creatively utilised by other members.

The group should allow for the sharing of both positive and negative experiences to enable members to learn from one another. It should serve as a source of support. The types of support provided should be informal, emotional and advisory. The social worker should use the group to make mothers/parents aware that they are not alone in their situation. Where both parents are in the group this may provide an opportunity for the one to learn about feelings in the other that they did not know existed. Involvement of parents in groups can also lead to their involvement in community projects for their children. (Chinkanda: 86.9)

5.3.2 GROUPWORK WITH RETARDED CHILDREN

The social worker has to be selective about whom to involve in these groups. She should know something about the social functioning of prospective members, their level of retardation and their age, especially as far as sexual maturity is concerned. The group serves as a source of socialisation and a learning medium. Sex education should be handled carefully by the social worker, as it is an important aspect of group work with these children. It should promote the learning of certain skills such as the handling of money and how to behave on certain occasions in the community. (Urbani: 1982: 100-101).

5.4 COMMUNITY WORK

Community work in the field of mental retardation will focus on the following:

- * Community education as regards the causes and extent of mental retardation as well as regarding services and facilities for the care and treatment of the mentally retarded.
- * Development of services through community development.
- * Dissemination of information on genetic services and how they can provide prevention of retardation.
- * The development of support systems for mothers of mentally retarded children, especially respite care services. (Urbani: 1982: 105: 107).

5.5 SOCIAL WORK THEORY IN WORKING WITH MENTALLY RETARDED CHILDREN AND THEIR FAMILIES

5.5.1 BEHAVIOUR MODIFICATION

Application of Behaviour Modification by Parents for Treatment of a Mentally Retarded Child.

Parental assistance has frequently been employed by social workers to help eliminate problem behaviour in their children. However, in the field of retardation, perhaps uniquely, parents can help their children to acquire adaptive behaviour, particularly self-help and social skills. Tasks which parents may help teach in day-to-day activities include language acquisition, play behaviour, toilet training, dressing skills, feeding skills, attention focusing and imitation. In day-to-day tasks, parents can help maximize their children's self-sufficiency and social workers can help prepare to do so. Parents assume a role of teacher to their children, and social workers assume a role of consultant or trainer to parents. These roles present several advantages. Parents are usually the first to encounter and have to deal with problematic behaviour, and they can facilitate the transfer of learning from school or treatment at home. In addition, parents of retarded children can gain a great deal of satisfaction from contributing to their child's achievement.

Familiarity with learning processes may be required for social workers to guide parents in developing these behaviours in their children. Social workers may then fulfil their unique and most important role: translating the processes of child education to parents and helping them to generalize these processes within new contexts. In addition to specific adaptive skills, social workers working with parents may also focus on more general problems of behaviour management, such as discipline issues or parent-

child communication. Skills imparted in counselling may then be individualized and applied in a variety of situations which may later arise in the home. (Turner: 1983: 520-525).

CONCLUSION

Literature on mental retardation repeatedly mentions that more and more mothers are choosing to care for their children at home. This type of situation calls for the development of certain services and the improvement of others to make it possible for these mothers to care for their children at home and to enable the community to participate in the care of these children where possible. Social workers should encourage the community not only to give material and emotional support to these mothers but also to give them one of the things that they need most, time.

Community networks should be mobilised and linked to formal services to assist these mothers and their families. Potential support systems such as church groups, women's clubs and youth clubs should be utilised and developed. Once developed, these networks can complement the existing welfare services and thus enable the social worker to do only the professional aspect of her work. Research should be undertaken into the attitude of different community groups towards serving as sources of support towards making certain resources such as church halls or garages available to be used as workshops or centres for handicapped people. Community education can form a sound basis for work amongst the mentally retarded.

CHAPTER SIX

TRANSKEI'S SOCIAL WELFARE POLICY WITH REGARD TO THE MENTALLY RETARDED CHILD AND HIS FAMILY

6.1 INTRODUCTION

Transkei recognises the needs of the mentally handicapped and, in so doing, offers services to patients who are mentally handicapped. The different services offered to these children are mainly from the health, welfare and education departments.

6.2 LEGISLATION TO MEET THE NEEDS OF THE MENTALLY HANDICAPPED

In terms of The Mental Health Act, 1973 (Act 18 of 1973), a patient qualifies for committal into single care if he or she is a child:

1. who is ineducable and untrainable;
2. whose mental ability is so low that constant care is necessary;
3. who cannot benefit by an educational programme as offered by schools or special classes in schools;
4. who is three years or older, but not older than 18 years;
5. whom it is deemed safe and convenient to be cared for a single household, instead of in an institution.

The procedure is as follows:

1. Application for certification of patients in terms of Section 9 of Act 18 of 1973, committal into care of parents/guardians (Section 10) and payment of a single care grant to the caregiver, are processed by the magistrate's office. It is important that the actual caregiver receives the grant, regardless of whether the person is the parent/guardian or not. This does not apply in cases where the caregiver is hired, but the applicant still makes provision for the total care of the child. The magistrate may request a social work report or a psychiatric report in terms of Section 9 (2) (a) of Act 18 of 1973.
2. Correspondence takes place between the social worker's office, the magistrate's office and the Department of Health. Files are opened in each case and these are kept at the social worker's office. The Department of Health authorises payment and a maximum amount of R278,00 per month is payable to all successful applicants.
3. Application for a disability grant is made when the patient reaches the age of 18 years.
4. Documents which have to be completed and of which copies are attached are:
 - 4.1 Application for a reception order (Section 8 (1) and (2) and form 62/1). The application has to be made at the magistrate's office within seven days of its issue and may be accompanied by a medical certificate, form G2/2, i.e. Section 8 (3) of the Act. The applicant, i.e. the caregiver, must be 18 years old, and must be related to the child concerned. Reasons for application must be submitted if the applicant is not related to the child. All questions must be completed. Words such as unknown or not applicable are not permitted. The applicant has to sign the application form and hand it in at the magistrate's office within seven days of

signing.

- 4.2 The magistrate shall consider the application and may examine the patient (Section 9 (1) of the Act). After submission of the application, the child must then be examined by two medical practitioners; one of which must be a district surgeon. In the event of only one medical practitioner being available, one certificate will be accepted, provided that it is clearly stated that that is the case. As a first requirement, it is compulsory that the child is physically examined to ensure that he/she does not suffer from any physical condition which should be treated. Should the child require medical treatment, issue of the reception order should be withheld until medical attention has been given. The medical practitioner has to state whether the child can be certified. Certification is a condition for committal into single care. Every medical practitioner should make an individual assessment of the child's condition. Medical information should not be copied from one form to the other. The magistrate may call other witnesses to obtain clarity, if the two medical practitioners differ about the child's condition. The medical certificates must be dated within 14 days prior to the issue of the reception order. Section 10 (2) states that a reception order shall not be issued for a single care patient unless the certifying medical practitioner(s) certifies that it would be safe and convenient for the patient to be received and detained as a single patient in the care and custody of the applicant instead of in an institution.
- 4.3 Section 9 of the Act states that the magistrate may issue the reception order when he has satisfied himself on the grounds of the medical certificates and sufficient background information, that the child qualifies for placement into single care. All questions not applicable to the child, must be cancelled and endorsed. The order can only be issued after receipt of the medical certificates (62/2). It may bear the same date as the medical certificates.

- 4.4 Notice of issue of reception order, i.e. Section 55 of the Act - the magistrate completes this notice after issuing the reception order. The form has to be sent to the Master of the Supreme Court within 24 hours after issuing the reception order.
- 4.5 Notice of admission may be issued on or after the date of the reception order.
- 4.6 Section 18 (1) of the Act states that a medical practitioner has to examine the child again within a period of 2 - 8 days after issue of the reception order, complete form G2/28, and submit it to the magistrate. This medical report, plus copies of the original medical certificates must be sent to the office of the Attorney General of Transkei within 10 days of application. Any question not applicable to the child, must be cancelled. The office of the Attorney General submits medical certificates to the Registrar or the Supreme Court who will, after studying the application, submit this to a judge in chambers for the issuing of the order for further detention of a patient in terms of Section 18 (3) and 19 of the Act. The office of the Attorney General may ask for more information if required. The order must be issued within 42 days after issue of the reception order, if not, the application expires (Section 11 {1}). The order is sent back to the magistrate's office. The complete application is forwarded by the magistrate's office to the Department of Health for consideration. All enquiries are directed to the social worker's office for further attention. The social worker is informed of the approval or refusal of the single care grant and in turn informs the applicant.
- 5 A review is done annually in the same month that the patient was certified. Form G2/8 is completed and Section 25 of 35 of the Act Section 44(1) and (2) requires that social workers visit patients in their private dwellings to ascertain whether the person in charge of such patient is still a fit and proper person to take care of the patient. A report should be submitted every

six months.

The grant is cancelled when the patient reaches the age of 16. In exceptional cases where it is deemed to be in the interest of the patient to remain under protection and control of the Act, application may be made for the single care grant to be continued. However, when the child reaches the age of 18, the caregiver has to submit a statement to the social work office confirming that the child is unable to work in sheltered employment as provided by the Department of Manpower. Social workers have to inform the parent or caregiver six months before the patient turns 16, that application for identity documents has to be made, in order to make application for a disability grant.

Regulations 16 and 17 which are contained in R.S.A. Regulation Gazette No 2127 dated 27 March 1975 states that the caregiver has to inform the social worker's office of the death of a patient. The death certificate must be submitted to the social worker's office who will in turn inform the Department of Health.

The Department of Health closes its file whenever a single care grant is discontinued. In all such cases official notice of closure will be given to the relevant social worker's office as well as the caregivers concerned.

6.3 OTHER FACILITIES AVAILABLE FOR THE MENTALLY HANDICAPPED

As mentioned earlier in the introduction, the facilities discussed already were mainly from the health and welfare departments. The Education department does have a few special schools for these children. There are only four of these for the whole of the Transkei, which does not meet the need. Only two

of these special schools have boarding facilities. These special schools cater only for the mildly and moderately retarded. They are not well equipped to care for the interests of these children and as a result most parents in Sterkspruit prefer to take care of their children at home. There is no provision made for the severely and profoundly retarded, i.e. no institutions for them. Parents have the burden of caring for them 24 hours of the day, seven days per week.

CHAPTER SEVEN

THE SURVEY GROUP

7.1 INTRODUCTION

This chapter outlines the personal characteristics of the respondents. These will include the age of the parent or guardian; marital status; the educational qualification; religious denomination; relationship to the retarded child; the sex of the child and the age of the child. This information gives a background of some factors that may influence the way each family is affected with the presence of a handicapped child.

7.2 AGE OF THE PARENT OR GUARDIAN

The age of the parent has a bearing on whether or not they are able to cope with their handicapped child. Mothers of these children are often older than the average and the physical effort of controlling a difficult strong child or caring for a heavy paralysed child may tax their vitality (Ntombela: 1991: 15).

TABLE 1: AGE OF THE PARENT OR GUARDIAN

AGE IN YEARS	NUMBER	PERCENTAGE
21 - 30	6	13
31 - 40	12	26
41 - 50	18	39
61 - 60	4	9
61 - 70	6	13
TOTAL	46	100

Age of the parent as at the time of the study was as it is indicated above. Thirty nine percent of the respondents were between the age of 41 - 50; twenty six percent were between 31 - 40; thirteen percent were between 21 - 30 and 61 - 70 respectively; and nine percent were between 51 - 60 years. Other groups in the sample may not be well represented as they were not biological parents of the children and as such did not know the age of the parent. In this study the majority of the respondents, i.e. thirty nine percent, were in their middle adulthood, i.e. 41 - 50 years, and as such does not confirm the finding already mentioned (Ntombela; 1991: 15).

7.3 MARITAL STATUS OF THE PARENT

This question was asked so as to determine whether there was any relationship between the marital status of the parent and mental retardation together with the support received from the biological fathers of the children. Distinction was not made on whether the respondents were married under civil rites or customary union.

TABLE 2: MARITAL STATUS OF THE PARENT

RESPONSE	NUMBER	PERCENTAGE
Married	30	65
Single	5	11
Divorced/Separated	1	2
Widowed	10	22
TOTAL	46	100

As it is reflected in table 2 above sixty five percent of the respondents were married. From this group three respondents were not married to the biological father of their children. The children were then cared for by their maternal relatives. All the mothers who were single were no longer on good terms with the fathers of their children (11%). The reasons for this differed. There were those who were

now married to other women and others just rejected the children because they were handicapped. Out of 10 respondents who were widowed (22%) one mother was reported to be deceased and the child was looked after by the maternal aunt.

7.4 DURATION OF MARRIAGE

Respondents who were married were asked the duration of their marriage so as to determine whether the support received from the husband with the retarded child had an effect on the marriage duration or not. This finding will be analyzed and interpreted further on the table below.

TABLE 3: DURATION OF MARRIAGE

RESPONSE	NUMBER	PERCENTAGE
0 - 5 years	2	4
6 - 10	6	13
11 - 15	5	11
16 - 20	4	9
20 and above	13	28
Other	16	35
TOTAL	46	100

Table 3 above indicates that the majority of the respondents (35%) fell under the group of other which meant that they were either single, divorced/separated or widowed. Twenty eight percent were married for a period of 20 years and more; thirteen percent were married between six and ten years; eleven percent were married between eleven and fifteen years; nine percent were married between sixteen and twenty years; and four percent were married between zero and five years. No determination could be made from the findings on whether the support received from the husband had an effect on the marriage duration or not.

7.5 EDUCATIONAL QUALIFICATIONS

This question on the educational qualification of the respondent was asked mainly to determine whether the incidence of mental retardation was more prone to the working class families or middle class families and how the two social classes coped with the situation.

TABLE 4: EDUCATIONAL QUALIFICATIONS

RESPONSE	NUMBER	PERCENTAGES
Never attended school	15	33
Std 3 or lower	10	22
Std 4 to Std 6	12	26
Std 7 to Std 10	6	13
Std 10 to further training	2	4
Other	1	2
TOTAL	46	100

Table 4 above reflects the educational qualification of the mothers of the handicapped children. All families in this study could be regarded as working class families who have either never attended school or did not proceed any further with formal education which limited their chances of prosperity in life especially in the light that they were staying in rural areas where there are no open labour markets for employment.

7.6 RELIGIOUS DENOMINATION

Respondents were asked their religious denomination; whether they were regular attenders or not; and to support their answers. They were also asked what services or support systems were available at churches. Table 5 below reflects their answers.

TABLE 5: RELIGIOUS DENOMINATION

RESPONSE	NUMBER	PERCENTAGE
Roman Catholic	4	9
Methodist	10	22
Anglican	13	28
Zionist Christian	9	20
Apostolic Faith	7	15
Presbyterian	1	2
Other	2	4
TOTAL	46	100

Nearly all the respondents (96%) were affiliated to some religious denomination. Only four percent of the respondents were not affiliated to any religious denomination because their husbands refused to allow them to go to church. Two respondents who were affiliated to the Anglican Church said they no longer attend church services. Their reason for this differed. One respondent said that she does not attend church because she is looking after the handicapped child and the other respondent said that she does not have money for the offering and the tithes. Laziness was another reason the respondents mentioned for not going to church. Eighteen respondents were occasional attenders because they were looking after the children and as such would not like to burden the school-going children with the care of the handicapped child. Four respondents reported that they were occasional attenders because the handicapped child was creating problems in church as they are restless and attention seeking. Regular attenders (20 respondents) reported that they went to church regularly because they were spiritually revived and loved going to church.

Amongst the services and support systems available in church for these children and their families were praying, drinking holy water which was believed to heal, and home visits by the pastors and the manyano women. Some of the churches offered no services at all.

7.7 RELATIONSHIP TO THE RETARDED CHILD**TABLE 6: RELATIONSHIP TO THE RETARDED CHILD**

RESPONSE	NUMBER	PERCENTAGE
Biological mother	34	74
Grandmother	8	17
Other e.g. aunt, sister, etc	4	9
TOTAL	46	100

As Wilkin (1979: 93) puts it: the basic unit social structure in our society is the nuclear family and it is therefore within the family that the mentally handicapped child receives community care. Mothers are principal agents of care in the community, so community care usually means care by the mother. Seventy four percent of the respondents were biological mothers of the children; seventeen percent of the respondents were the maternal grandmothers of the children. In this group the biological mothers were either married to someone else other than the child's biological father or had gone to seek employment in Johannesburg or Cape Town. Some biological mothers were reported to have deserted their children and their whereabouts were unknown to the custodians. This finding was also confirmed by Ntombela (1991: 15): the young inexperienced mother feels totally inadequate to care for the handicapped child and often chooses to rather abandon the child. Many of these children are consequently cared for by their grandparents. Nine percent of the respondents were either the sister or the sister-in-law of the retarded child.

7.8 SEX OF THE CHILD

Studies of mentally handicapped children in institutional care are consistent in reporting that boys are more likely than girls to be admitted (Wilkin: 1979: 80). In this study there was no marked

preponderance of boys over girls as is indicated in the table below.

TABLE 7: SEX OF THE CHILD

RESPONSE	NUMBER	PERCENTAGE
Male	22	48
Female	24	52
TOTAL	46	100

Fifty two percent of the children were females and forty eight percent were males. Two children from the female group were twins but the other twin was normal. One child from the male group was also a twin but the other twin had died during early childhood.

7.9 AGE OF THE CHILD

According to the Transkei policy for single care the mentally retarded child qualifies for the single care grant when he is 4 years old and when he turns 18 he is transferred to the disability grant.

TABLE 8: AGE OF THE CHILD

RESPONSE	NUMBER	PERCENTAGE
4 - 6	6	13
7 - 10	11	24
11 - 15	21	46
16 - 18	8	17
TOTAL	46	100

Table 8 above indicates that the majority of the children (46%) were between 11 and 15 years old;

twenty four percent were between 7 and 10 years old, seventeen percent were between 16 and 18 years old; and thirteen percent were between 4 and 6 years old.

CONCLUSION

This chapter introduced the reader to the survey group of this study. It should be noted that some respondents were not biological mothers of the child and as such some of the questions were not well answered, e.g. the age of the parent, marital status of the parent together with the duration of marriage.

CHAPTER EIGHT

THE IMPACT OF THE RETARDED CHILD ON THE FAMILY

8.1 INTRODUCTION

This chapter will focus on the psychological and social effects of having a retarded child; the social life of parents/guardians of the retarded child; the anxiety about the future care of the child and; the family's material conditions.

8.2 DISCOVERY THAT THE CHILD IS HANDICAPPED

Parental reactions to the diagnosis of retardation in their child are highly individualistic. The intensity of responses and manifestations of reactions varies widely among and between parents, depending upon a variety of dynamic factors: individual personality, nature of the marital interactions, parental aspirations, feelings about deviancy, and social class (Koch and Dobson: 1971: 434).

Respondents were asked how did they feel when they discovered that the child was handicapped and table 9 gives their responses to the question.

Please see Table 9 overleaf.

TABLE 9: DISCOVERY THAT THE CHILD IS HANDICAPPED

RESPONSES	NUMBER	PERCENTAGES
No feelings	30	65
Helpless	6	13
No comments	5	11
Depressed	3	7
Guilty	2	4
Ashamed	0	0
Self-pity	0	0
TOTAL	46	100

As is reflected in the table above sixty five percent of the respondents reported that they had no specified feelings because their children were more normal than retarded, thirteen percent said they felt helpless but they accepted the child as it was a gift from God; eleven percent could not comment as they were not biological mothers of the children; seven percent said they were depressed and four percent said they felt guilty. Eppersen (1977: 265 - 274) and Kohurt (1966: 160 - 167) describe parent reactions in terms of phase theory: parents pass through phases in which different emotions predominate before they reach a state of emotional equilibrium and fully accept the situation. Emotional reactions may manifest in specific behaviour. One such manifestation is to constantly seek opinions and help in cases where parents deny the handicap or refuse to accept it. Another manifestation is overprotection of the child. Overprotectiveness could be a manifestation of covert rejection of the child: through overconscientious nurture without any real warmth the parent allays his guilt feelings and feels that he is meeting his parental responsibility.

8.3 PARTNER'S REACTION

Respondents were asked what were their partner's reaction on the discovery that the child was handicapped. Table 10 gives their responses to the question.

TABLE 10: PARTNER'S REACTION

RESPONSES	NUMBER	PERCENTAGES
Supportive	29	63
Rejected the child	7	15
Deserted the family	4	9
Other	6	13
TOTAL	46	100

Sixty three percent of the respondents said their partners were supportive on the discovery that the child was handicapped; fifteen percent rejected the child; nine percent deserted the family; and thirteen percent fell under the group of other. In this group three respondents said the father of the children died before the children were born; two said they never saw the child, and one said she did not know the father of the child.

8.4 THE EFFECTS OF LOOKING AFTER THE HANDICAPPED CHILD

Respondents were asked whether they thought that looking after the handicapped child had any effect on their health. In support Table 11 analyses their responses to the question.

Table 11: The effects of looking after the handicapped child, appears on page 60.

TABLE 11: THE EFFECTS OF LOOKING AFTER THE HANDICAPPED CHILD

RESPONSES	NUMBER	PERCENTAGES
Emotionally affected	16	35
Psychologically affected	8	17
Emotionally and psychologically	3	7
Physically affected	2	4
Physically and emotionally	2	4
Physically and psychologically	0	0
Not affected	15	33
TOTAL	46	100

The constant care necessary for many severely handicapped children frequently has damaging effects on the health of the mother (Wilkin: 1979: 94). Thirty five percent of the respondents said they were emotionally affected with the care of their handicapped child. The effect was said to be severe when the child was sick. Crying was reported to give some relief from this pain. One mother who had a 12 year old, profoundly handicapped described the strain and its effects on her own health: "I can't like I should and the anxiety of seeing him in these fits is terrible. You feel helpless because you cannot help the child. Sometimes you are up in the night with him. If I have lost sleep I am grumpy the next day. I am always getting colds and flu because I am so run down." Some respondents did visit the doctors for treatment and they were diagnosed as having high blood pressure or heart problem. Seventeen percent of the respondents said they were psychologically affected. Consistent headaches, confusion and dizziness were the main symptoms which were reported. Some of the respondents in this group were diagnosed as having nervous breakdown because they think a lot. Four percent said they were physically affected because the children could not walk and were too heavy for them to carry. These were mainly the grandmothers who were caregivers.

Mental retardation poses a problem for the family of long-time burden of care and management of the retarded individual. This means that families may be, and usually are, confronted with many crises in the areas of their psychological and emotional lives as well as in their daily living experiences (Mdaka: 191: 10). Seven percent of the respondents reported that they were emotionally and psychologically affected; while four percent reported that they were physically and emotionally affected. Hard praying gave some form of relief. Thirty three percent of the respondents reported that they were not affected.

8.5 LIMITATION OF THE CAPACITY TO CARRY OUT DOMESTIC TASKS

Respondents were asked whether the effect on them from caring for a handicapped child limited their capacity to carry out routine domestic tasks.

TABLE 12: LIMITATION OF THE CAPACITY TO CARRY OUT DOMESTIC TASKS

RESPONSES	NUMBER	PERCENTAGES
Yes	17	37
No	29	63
TOTAL	46	100

The majority of the respondents (63 %) reported that they had no limitation in their capacity to carry out routine domestic tasks. To support their responses the respondents said their children were not giving problems and those who were having problematic behaviour they were not much. Thirty seven percent reported that they do experience some limitations in their capacity to carry out routine domestic tasks. Depression, tiredness and a feeling for rest, waking up late were reasons cited by this group. According to Wilkin (1979: 94) most physical health problems fell into two broad categories, general debility and chronic conditions which limited performance. The former included being generally

rundown, suffering from frequent colds or lacking energy, whilst the latter included chronic bronchitis, rheumatism and back problems.

8.6 THE ATTITUDE OF THE OTHER CHILDREN IN THE FAMILY TOWARDS THE HANDICAPPED CHILD

Respondents were asked whether they experience any problems with their other children in relation to the handicapped child.

TABLE 13: THE ATTITUDE OF THE OTHER CHILDREN TO THE HANDICAPPED CHILD

RESPONSES	NUMBER	PERCENTAGES
Positive	40	87
Negative	5	11
Other	1	2
TOTAL	46	100

The majority of the respondents (87%) reported that their children had positive attitudes towards the handicapped child. Positive was shown in many ways such as aiding the handicapped child; playing with her even though they are sometimes short tempered; and looking after him generally when the caregiver is not around. Grossman (1972: b 100 - 105) indicates that the life-style of the handicapped child does not necessarily affect siblings. The handicapped child may have a positive effect on a brother's or sister's personality development. Normal siblings can do a great deal to help the social and emotional development of the retarded child if they have a realistic and positive attitude about the handicap.

Joubert (1986: 170) found that the attitude of normal siblings towards a handicapped child is largely determined by the parents' acceptance of and manner towards the latter, which are reflected in their

own attitudes and manner. Kew (1975: 70). On the other hand, refers to various forms of negative behaviour that siblings may develop as a result of the presence of a handicapped child. Eleven percent of the respondents reported that they had problems with their other children in relation to the handicapped child. Three from this group said they had problems with their daughters-in-law who showed feelings of dislike towards the retarded child. Two respondents from this group again reported that their other children were scolding the handicapped child and sometimes became impatient with him. One respondent could not respond to this question as the sibling was still young.

8.7 TIME SPENT WITH THE RETARDED CHILD

Respondents were asked whether they thought they spent more time with the retarded child than with other children. Table 14 shows their responses to the question.

TABLE 14: TIME SPENT WITH THE RETARDED CHILD

RESPONSES	NUMBER	PERCENTAGES
Yes	38	83
No	6	13
Other	2	4
TOTAL	46	100

The majority of the respondents (83%) reported that they spent more time with the retarded child than with other children. Koch & Dobson: 1971: 437) noted that some of the problems experienced by normal siblings are that of having needs unmet by parents overwhelmed or overinvolved with the care of the handicapped child. Thirteen percent reported that they did not spend more time with the retarded child because the child did not give any problems. Four percent could not respond to the question as the other children were not staying at home and the other one was staying with the retarded child only.

8.8 FEELINGS OF OTHER CHILDREN WITH REGARD TO THE TIME SPENT WITH THE RETARDED CHILD

Respondents were asked how their children felt about the time spent with the retarded child. Table 15 gives their responses to the question.

TABLE 15: FEELINGS OF OTHER CHILDREN WITH REGARD TO THE TIME SPENT WITH RETARDED CHILDREN

RESPONSES	NUMBER	PERCENTAGES
Supportive	28	61
Jealous	9	20
Frustrated	2	4
Guilty	0	0
Other	7	15
TOTAL	46	100

The majority of the respondents (61%) reported that their children were supportive. The development of healthy children and gratifying child-rearing can neutralize parental disappointment about having a retarded offspring. (Joubert: 1987: 10). Twenty percent reported that the children were jealous and felt neglected. Ntombela (1991: 15) noted that the brothers and sisters of the handicapped child are affected in the following ways: jealousy, even rejection due to the parental attention demanded by the child with a mental handicap as well as the material deprivation as a result of increased financial responsibilities towards the disabled child. Frustration resulting from parents' restrictions concerning the kind of games and outings in which their handicapped child and his/her siblings may be involved. Four percent reported that their children were frustrated. This was the feeling of those mothers who had younger children who would like to communicate or play with the retarded child, but they could not. Fifteen of the respondents reported that their children were not showing any feelings such as those

described above.

8.9 THE EFFECT OF THE PRESENCE OF THE RETARDED CHILD ON THE LIVES OF THE NORMAL SIBLINGS

Respondents were asked whether they thought that the presence of a retarded child had any effect on their other children's lives, e.g. poor school performance, and to explain further on their responses Table 16 below gives their responses to the question.

TABLE 16: THE EFFECT OF THE PRESENCE OF THE RETARDED CHILD ON THE LIVES OF THE NORMAL SIBLINGS

RESPONSES	NUMBER	PERCENTAGES
Yes	15	33
No	23	50
Other	8	17
TOTAL	46	100

The majority of the respondents (50 %) reported that the presence of the retarded child had no effect on the normal children's lives. Thirty-three percent reported that their children were affected in one way or the other by the presence of the retarded child. The effect was manifested in different ways. Some of the children would not go to school when the mother would be attending to urgent family matters and especially when it is grant pay-out every month. As the majority of the children are epileptic and this illness mostly attacks them at night the normal children would not be in a position to read on that evening when the child is sick and this would result in poor school performance. Some of the retarded children were reported to be rowdy resulting in the school-going children being unable to read until the sibling fell asleep. Some of the normal children were reported to be overprotective towards their retarded sibling. They would become upset when other children in the area teased or

shunned their sibling. This finding was also reported by the following different writers:

- 1 Koch and Dobson (1971: 437) noted that at an early age, normal siblings need to deal with peer reactions to their retarded sibling - sometimes at an age when they are unusually vulnerable to teasing and taunting and when they lack the life experience and intellectual maturity to fully comprehend the nature of the siblings problem.
- 2 Ntombela: (1991: 15) noted that a feeling of shame resulting in social isolation as normal siblings feel that they cannot invite their friends home, as they are often teased by other children.
- 3 Collins (1982: 100) also noted that a severely handicapped child can also impair the sibling's social life and their status among their peers.

8.10 WHEREABOUTS OF THE PARTNER

The respondents were asked where were their partners so as to find out how did their absence affect their ability to cope with the situation.

TABLE 17: WHEREABOUTS OF THE PARTNER

RESPONSES	NUMBER	PERCENTAGES
At home	11	24
At work	19	41
Other	16	35
TOTAL	46	100

Forty one percent of the respondents reported that their partners were at work. Out of the nineteen

respondents from this group, one said her partner was working locally and the remaining eighteen said their partners were working in Johannesburg, Cape Town, Welkom and other places afar. Respondents reported that they were not affected by their absence as they were used to being alone. Other respondents reported that with the presence of older children who assist with the care of the retarded child they are able to cope with the situation.

Twenty four percent of the respondents said their partners were at home. Thirty five percent of the respondent fell under the group of other. In this group respondents reported that their partners were either deceased, no longer on good terms or were not biological parents of the child.

8.11 THE RELATIONSHIP OF PARENTS PRIOR TO THE BIRTH OF THE RETARDED CHILD

Respondents were asked about their relationship with their partners prior to the birth of the retarded child.

TABLE 18: THE RELATIONSHIP OF PARENTS PRIOR TO THE BIRTH OF THE RETARDED CHILD

RESPONSES	NUMBER	PERCENTAGES
Good	27	58
Poor	6	13
Other	13	28
TOTAL	46	100

A sound relationship would probably stand up better than a poor one with the birth of a retarded child. Fifty eight percent of the respondents reported that they had a good relationship with their partners prior to the birth of a retarded child. Thirteen per cent reported that they had a bad relationship prior

to the birth of the retarded child. Twenty eight percent of the respondents could not respond as they were not the biological parents of the child.

8.12 THE EFFECT OF THE BIRTH OF THE RETARDED CHILD ON THE MARRIAGE OR RELATIONSHIP

Respondents were asked whether they thought the birth of a retarded child had any effect, either positively or negatively on their marriage or relationship. They were encouraged to support their answers.

TABLE 19: THE EFFECT OF THE BIRTH OF THE RETARDED CHILD ON THE MARRIAGE OR RELATIONSHIP

RESPONSES	NUMBER	PERCENTAGES
Positively	2	4
Negatively	5	11
No Change	26	57
Other	13	28
TOTAL	46	100

Fifty seven percent of the respondents reported that the birth of a handicapped child had no effect on their marriage or relationship. M. Fowle, in Wilkin (1979: 38) reports the findings of his study show there was no difference in marital integration between families with male and female retardates and between those whose child lived at home and those whose child was institutionalized. Eleven percent reported that their relationship was negatively affected by the birth of a handicapped child. Tizard and Grad (1972: 150), Kew (1975: 175) and Gath (1978:95) indicate that a handicapped child may have a negative effect on the parents' sex life and could inhibit further additions to the family. Marital problems can be caused by parents blaming one another for producing a child with a handicap.

Nevertheless, although it is generally agreed that the birth of a handicapped child is a crisis in the life of the parents and may impose severe stress on the marital relationship, it will not in itself cause the marriage to disintegrate. From this group one respondent said her separation from her husband had nothing to do with the birth of a handicapped child. Four percent of the respondents reported that their marriage/relationship was positively affected by the birth of a handicapped child. Cohen (1962: 139 - 140) mentions that a handicapped child is often blamed for marital strife which was latently or covertly present long before its birth. This has led to the conclusion that the birth of a handicapped child may affect an unstable marriage negatively, but it will reinforce a stable one. Twenty eight percent of the respondents could not respond to the question as they were not biological parents of the children.

8.13 CUSTODY OF THE CHILD

Respondents were asked with whom was the child staying presently.

TABLE 20: CUSTODY OF THE CHILD

RESPONSES	NUMBER	PERCENTAGES
Parents	32	70
Grandmothers	8	17
Relative	4	9
Institutionalized	2	4
TOTAL	46	100

As reflected in the table above, seventy percent of the children were staying with their parents, mainly their mothers. The findings of Wilkin (1979: 38 - 4-), Collins (1982:102) and Joubert (1986: 90) indicate that the mother carries the primary responsibility for the nurture of a handicapped child, often with little support from the rest of the family. Seventeen percent were staying with their grandmothers.

In this category the biological mothers were either married to someone else other than the father of the child; have gone to seek employment in Johannesburg or Cape Town; or have deserted their children and their whereabouts were unknown to the caregivers. Nine percent were staying with a relative, either the sister or the sister-in-law. Four percent of the children were reported to be in institutions.

8.14 GOING OUT WITH THE PARTNER WITHOUT CHILDREN

Respondents were asked how often they went out (together for those who had partners at home) without taking the children as it is assumed that the retarded child confines a parent/caregiver at home at all times.

TABLE 21: GOING OUT WITH THE PARTNER WITHOUT CHILDREN

RESPONSES	NUMBER	PERCENTAGES
Often	16	35
Not often	8	17
Not at all	22	48
TOTAL	46	100

Forty eight percent of the respondents reported that they could not get out at all due to caring for the handicapped child. These respondents who were staying with their partners at home reported that one of them had to stay behind in order to look after the child while the partner would go out. Even though this was the case the mothers felt restricted as they were no longer in a position to attend to funeral eves, funerals or feasts in the area. Chinkanda (1986: 6-9) found that for many mothers evenings out were so rare they constituted an event which had to be planned well ahead and which was often traumatic due to the fear that something might go wrong. The following comment was characteristic of many mothers' feelings about leaving their handicapped child: "I could not leave him

with anyone. There's no one who really knows him well enough. If we went out I would never stop worrying till I got back." Other respondents reported that they do attend funerals as these are mostly during weekends when school-going children are around.

Seventeen percent of the respondents reported that they did not go out except to nearby places. They mainly take the child with them on long journeys. They also reported that they felt restricted as it was difficult to attend funerals except for those of close family members. Going to church was also not possible as the child becomes restless and causes a disturbance in the church.

Thirty five percent of the respondents reported that they had no problem going out without the child as the latter did not present problems. These respondents had older children who were able to attend to the retarded child while the mother was away.

8.15 CARE RECEIVED FROM THE FATHER OF THE HANDICAPPED CHILD

Respondents were asked whether the father of the child helped them with caring for the child.

TABLE 22: CARE RECEIVED FROM THE FATHER OF THE HANDICAPPED CHILD

RESPONSES	NUMBER	PERCENTAGES
Yes	26	57
No	12	26
Other	8	17
TOTAL	46	100

Fifty seven percent of the respondents reported that the father of the child did help with the caring of the child. The help they gave was that of looking after the child when the mother was not available, and to feed and bath the child. Jaehnig as quoted by Wilkin (1979: 44 - 54) found that parents of retarded children were more likely to adopt a joint pattern of conjugal roles rather than having carefully

defined responsibilities for husband and wife, which usually meant that the husband played little or no part in child care and housework. Respondents whose partners were working out of town reported that they received financial and emotional support from their partners and they would even help with the physical needs of the child when they were on holiday.

Twenty six percent of the respondents reported that they received no help from the biological fathers of the children. Children were born out of wedlock and no help was received either in the form of money, i.e. maintenance, nor the visitation of the child. Seventeen percent reported that the fathers were either deceased or they knew nothing about the biological father of the child.

8.16 HELP RECEIVED WITH HOUSEHOLD CHORES

Respondents were asked whether the father of the child helped with household chores and how often did he offer such help.

TABLE 23: HELP RECEIVED WITH HOUSEHOLD CHORES

RESPONSES	NUMBER	PERCENTAGES
Yes	17	37
No	8	17
Other	21	46
TOTAL	46	100

Thirty seven percent of the respondents reported that they were assisted by the fathers of their children with household chores while attending to the retarded child. They would dish for themselves or fetch water from the river. One father was reported to even cook for the child. Fifteen respondents reported that the father offered such help regularly and only two from this group did offer the help on an irregular basis. There is general agreement from the literature that it may well be time that fathers of

disabled children provide as much support for their wives as do fathers of non-handicapped children, but to describe this as considerable without reference to the overall amount of work which has to be done is misleading.

Seventeen percent of the respondents reported that they received no help from the fathers of their children with other household chores. The latter maintained that they refused to help as it was seen as womens work. Forty six percent of the respondents fell under the group of other. In this group one respondent who received help with the caring of the retarded child reported that the father did not help her with other household chores; twelve respondents did not receive any help whatsoever from the biological fathers as children were born out of wedlock; eight respondents reported that the fathers were either deceased or knew nothing about him.

8.17 NUMBER OF OTHER CHILDREN

Respondents were asked the number of their other children, whether they were intending to have more children and to support their answers.

TABLE 24: NUMBER OF OTHER CHILDREN

NUMBER OF CHILDREN	RESPONDENTS	PERCENTAGES
1 - 2	13	28
3 - 4	16	35
5 - 6	11	24
7 or more	6	13
TOTAL	46	100

Thirty five percent of the respondents had children between 3 and 4; twenty eight percent had children between 1 and 2; twenty four percent had children between 5 and 6; thirteen percent had children

between 7 or more. It should be remembered that not all respondents were biological mothers of the children and responses reflected above were given in respect of the actual number of children the biological mothers had. Twelve respondents could not respond to the question of whether or not they were intending to have more children. The biological mothers reported that they were not intending to have any more children. They cited various reasons. Fifteen of them reported that they could not afford to have more children as they were having difficulty in providing for those that they had at that moment; ten reported they could not have more children as they were looking after the disabled child. The latter was a baby himself as they put it. Five reported that they were too old to have more children; and four reported that they were no longer feeling strong and healthy enough to have more children.

8.18 CHILDREN'S AGES

TABLE 25: CHILDREN'S AGES

AGE GROUP	NUMBER	PERCENTAGE
0 - 5	5	11
6 - 10	7	15
11 - 15	16	35
16 - 20	8	17
20 and above	10	22
TOTAL	46	100

Thirty five percent of the respondents reported that their children were between the age of 11 and 15; twenty two percent reported that their children were twenty years and above; fifteen percent were between six and ten years; and eleven percent were between zero and five years. The majority of the respondents reported that they coped well with the children as the latter were old enough to look after themselves. Others were even working and no longer staying at home. Seven respondents got help

from their husbands with the upbringing of their children; five respondents got help from relatives and other older children; and fifteen respondents were on their own with the upbringing of the children. They described the job as strenuous both physically and emotionally. This finding was also noted by Gowen, Johnson-Martin and Goldman (1988, Vol. 94, No. 3: 259 - 271) - parenting any child is a difficult and challenging task, one that brings along with its rewards, varying levels of stress. Stress stems from both demands on the parents' time and energy and challenges to the parents' feeling that they are competent to deal with their child's demands. The demands and challenges of parenting are often intensified for parents of children with disabling problems. Available evidence suggests that the additional demands on the parent's time, energy, finances, and emotions result in increased feelings of distress.

8.19 WHEREABOUTS OF OTHER CHILDREN

Respondents were asked whether all their children stayed with them and if not to state with whom they stayed so as to ascertain the coping skills used to deal with the situation of bringing up the normal children as well as the disabled child.

TABLE 26: WHEREABOUTS OF OTHER CHILDREN

RESPONSES	NUMBER	PERCENTAGE
At Home	34	74
Not at home	12	26
Other	0	0
TOTAL	46	100

Seventy four percent of the respondents reported that they were staying with all their children; and twenty six percent reported that they were not the biological mothers of the children. (Table 6 in

Chapter 6 gives the position of these respondents).

8.20 ASSISTANCE RECEIVED FROM OTHER CHILDREN WITH THE CARING OF THE RETARDED CHILD

Respondents were asked whether their other children assisted them with the caring of the handicapped child . The following table indicates their responses.

TABLE 27: ASSISTANCE RECEIVED FROM OTHER CHILDREN WITH THE CARING OF THE RETARDED CHILD

RESPONSES	NUMBER	PERCENTAGES
Yes	39	85
No	5	11
Other	2	4
TOTAL	46	100

The majority of the respondents (85 %) reported that they were assisted by their other children with the caring of the child. The assistance received was one of looking after the child when the mother or caregiver was not at home; bathing and dressing the child; feeding the child and administering the prescribed medication. Some children were reported to assist with the changing of nappies for those children who were incontinent. The majority of the children who gave assistance were even helping around the house while the caregiver was attending to the retarded child. The assistance received related strongly to the sex and age of the children. Girls proved to be more helpful than boys and older children were more helpful. Respondents who were staying with young children reported that although the latter were young they were able to help with such things as bringing the wash basin and the baby lotions during bathing time. The provision of practical and material support by children was dependent upon their age, sex and whether or not they lived in the family home, although the presence of older

children was no guarantee of any support. Where an older child did help with child care and housework this could be an important source of support for the mother. (Wilkin 1979: 102 - 136).

Eleven percent of the respondents reported that they received no help from other children as they were still young. Four percent reported they had no children staying with them.

8.21 ROLE CHANGES IN THE FAMILY RESULTING FROM THE BIRTH OF THE MENTALLY HANDICAPPED CHILD.

Respondents were asked to describe any role change in the family as a result of the birth of the handicapped child.

TABLE 28: ROLE CHANGES IN THE FAMILY RESULTING FROM THE BIRTH OF THE HANDICAPPED CHILD

RESPONSES	NUMBER	PERCENTAGES
Yes	12	26
No	21	46
Other	13	28
TOTAL	46	100

Twenty six percent of the respondents reported that there were role changes within the family as a result of the birth of a handicapped child. The widows and those who had the children out of wedlock reported that they had to assume the role of a mother and a father and it proved to be a difficult task. Others complained that they had problems in adjusting to the role of being the mother of a handicapped child. There were times when they did not know what to do. They had normal children and it was their first experience having to deal with a handicapped child. Koch and Dobson: (1971: 439) found that the problem for the parents of the retarded is further complicated by the need to learn a new role

which they have to integrate as a piece within an existing and defined parental role. An almost schizoid-like character attaches itself to a parent who is to behave one way to normal children and another way to the retarded offspring.

Forty six percent of the respondents reported that there was no change whatsoever in the family roles as a result of the birth of a handicapped child. Twenty eight percent of the respondents fell within the group of other. These were not the biological mothers of the children and could not comment on this question.

8.22 INTERACTION BETWEEN THE FAMILY AND OTHER PEOPLE IN THE COMMUNITY IN RELATION TO THE HANDICAPPED CHILD

Respondents were asked how the family interacted with other people in the community in relation to the handicapped child. The community is not always supportive towards the family. To confirm this statement, Table 29 states the respondents' responses.

TABLE 29: INTERACTION BETWEEN THE FAMILY AND OTHER PEOPLE IN THE COMMUNITY IN RELATION TO THE HANDICAPPED CHILD

RESPONSES	NUMBER	PERCENTAGE
Positive	15	33
Negative	14	30
Have not noticed anything	17	37
TOTAL	46	100

Thirty seven percent of the respondent reported that they were unaware of community's attitudes towards the retarded child as the latter was always at home due to his condition. Two respondents from this group reported that they have not noticed anything as their children were still young.

Thirty three percent of the respondents reported that the community members did like the retarded child. One respondent reported that some people are scared of him expecting him to be aggressive while others responded positively. Two respondents reported that people in the area would even go to the extent of looking for him when he is missing or bringing him home when they find him roaming around the area.

Thirty percent of the respondents reported that people in the area disliked their children. Three respondents reported that some people showed negative attitudes, but some did not. Four respondents reported that other people did not like their children due to the dripping saliva from their open mouths. In this group some respondents reported that some parents in the area did not want the retarded child to play with their children as they would contract the 'disease' of retardation or the aggression of the child. One respondent reported that she is not on good terms with her neighbours as the latter scolds and beats the child. They maintained she is naughty and destroys their property resulting in the mother sometimes having to pay damages.

8.23 LABELS USED TO DESCRIBE THE FAMILY OR THE CHILD

Respondents were asked whether they felt labelled by the community due to having a disabled child.

Responses were as follows:

TABLE 30: LABELS USED TO DESCRIBE THE FAMILY OR THE CHILD		
RESPONSES	NUMBER	PERCENTAGES
Yes	10	22
No	36	78
TOTAL	46	100

The majority of the respondents (78%) reported that they did not feel labeled by others. Twenty two percent reported that there was a label that their child was labeled. Six respondents from this group

reported that their children were labelled as fools; two reported they were labelled as mental patients; and the other two were labelled as abnormal children. Joubert (1987: 15) states that some parents also find that they are discriminated against or stigmatised because of their child, thus forfeiting social acceptability.

8.24 REACTIONS OF THE PEOPLE IN PUBLIC AREAS

Respondents were asked how others reacted to the children especially in public places and how they felt about those reactions.

TABLE 31: REACTIONS OF THE PEOPLE IN PUBLIC PLACES

RESPONSES	NUMBER	PERCENTAGES
Shunned	10	22
Pitied	29	63
None	7	15
TOTAL	46	100

The majority of the respondents (63%) reported that people felt pity for both the child and the mother. They would ask why the child was in that condition. Some would even give advice and offer suggestions as to where the respondents could take the children for healing. From this group thirteen respondents reported that they did not like the people's reactions, but that they could not help it and as a result they avoided public places. Five respondents reported that they felt hurt and did not like to talk about the child's condition to other people. In this group one respondent mentioned that she felt hurt as some people did not mean what they said. Five respondents reported that they were not worried about other people's reaction towards their handicapped children. Three respondents reported that they felt worried, but could not help it. Two respondents reported that they were happy with the

advices and suggestions made by other people. One respondent reported that she felt some people were making a joke of her handicapped child.

Twenty two percent of the respondents reported that people shunned the retarded child. Eight of the respondents reported that they were very hurt as they did not choose to have retarded children. One respondent in this group even wished that the people concerned would also have a retarded child. Two respondents reported that they were not bothered as they loved their children very much.

Fifteen percent of the respondents reported that no reactions were shown by people in public places as they were always at home with their children.

8.25 CAUSES OF THE PEOPLE'S REACTIONS TO THE RETARDED CHILD

Respondents were asked what they thought could be the cause of others reactions as this could be significant with regard to coping with the retarded child.

TABLE 32: CAUSES OF THE PEOPLE'S REACTIONS TO THE RETARDED CHILD

RESPONSES	NUMBER	PERCENTAGES
Lack of understanding of the retardation	20	43
Ignorance	4	9
Concern	3	7
Curiosity	5	11
Other	14	30
TOTAL	46	100

Forty three percent of the respondents reported that they thought the cause of people's reactions were the lack of understanding of the retardation. Eleven percent reported that they thought people were

curious; seven percent reported that they thought people were concerned; nine percent reported that people were ignorant; and thirty percent fell under the group of other. In this group six respondents stated that as they did not have retarded children they did not know what it means to have a retarded child. One respondent said that people were puzzled; and one respondent said that people were sympathetic. Six respondents had no comment.

8.26 SUGGESTIONS TO IMPROVE THE COMMUNITY'S ATTITUDE TOWARDS THE MENTALLY RETARDED

Respondents were asked what they thought could be done to improve the community's attitude towards the mentally retarded.

TABLE 33: SUGGESTIONS TO IMPROVE THE COMMUNITY'S ATTITUDE TOWARDS THE RETARDATEES

RESPONSES	NUMBER	PERCENTAGES
Educational workshops	40	87
Community awareness campaigns	0	0
Pamphlets	6	13
Other	0	0
TOTAL	46	100

As is reflected in the table above the majority of the respondents (87%) reported that educational workshops could be held to improve the community's attitudes towards the retardates; and thirteen percent were in favour of issuing of pamphlets to the community.

8.27 FEELINGS OF ISOLATION RESULTING FROM HAVING A RETARDED CHILD

Respondents were asked whether they experienced feelings of isolation as a result of having a retarded child. The results are listed hereunder:

TABLE 34: FEELINGS OF ISOLATION RESULTING FROM HAVING A RETARDED CHILD

RESPONSES	NUMBER	PERCENTAGES
Isolated	8	17
Sometimes isolated	9	20
Not isolated	28	61
Other	1	2
TOTAL	46	100

Families frequently feel ostracized and shunned by the community. This is partly a reflection of the lack of the understanding of retardation as well as the stigma attached to it; partly due to the realistic living problems stemming from mental limitations; and in part, a result of the lack of adequate resources available to serve the needs of retardates and their families. (Koch and Dobson: 1971: 440).

Seventeen percent of the respondents reported that they frequently experience feelings of isolation as a result of having a retarded child. They had different statements to support their answer. Five respondents said they were unable to go anywhere because of the child. One respondent from this group said she would lock the child in and go and visit friends. One respondent said she sometimes would feel like crying; one said she was asking why her Lord; and one said she was isolated but was not worried as she enjoyed being with her child all the time.

Twenty percent of the respondents reported that they sometimes feel isolated as a result of having a

retarded child. From this group four respondents said they have adjusted to the child's condition; and five had no comments.

Sixty one percent of the respondents reported that they did not feel isolated as a result of having a retarded child. Twenty two respondents from this group stated that they did not feel isolated as they were able to take the children with them wherever they went. Three respondents said they did not feel isolated as they left the child with relatives; two said the children were now older and more independent and did not present problems; and one said she did not blame God for giving her such a child.

8.28 RESPONDENTS' TIME TO THEMSELVES WITHOUT THE RETARDED CHILD

Respondents were asked whether they would like to have more time to themselves without the retarded child and to support their answers.

TABLE 35: RESPONDENTS' TIME TO THEMSELVES WITHOUT THE RETARDED CHILD

RESPONSES	NUMBER	PERCENTAGES
Yes	6	13
No	39	85
Other	1	2
TOTAL	46	100

The majority of the respondents (85%) said they would not like to have more time to themselves. Their reasons differed. Twenty eight respondents from this group said they would like to be with their children all the time as there was no one who could look after the child the way they wanted. Seven respondents said they had accepted the child's condition; two said the children did not present

problems as they were unable to walk; and two said they could not blame God for giving them such children. Thirteen percent of the respondents reported that they would like to have more time to themselves. Their reasons differed. Five respondents from this group said it was tiring to look after such children and they would be glad if some relatives could offer such relief or even taking the child to a special school if there was one existing in the area; and one said the child sometimes made her angry.

8.29 DEVELOPMENT AS A RESULT OF THE CHILD'S AGE

Respondents were asked whether they thought there was an effect or improvement in their lifestyle as a result of the children's age.

TABLE 36: DEVELOPMENT AS A RESULT OF THE CHILD'S AGE

RESPONSES	NUMBER	PERCENTAGES
Yes	30	65
No	15	33
Other	1	2
TOTAL	46	100

The majority of the respondents (65%) reported that there was an improvement in their lifestyle as a result of their children's age as the children were sickly and crying a lot while young. Thirty three percent reported that the children's present age had an effect in their lifestyle. Six respondents from this group said the children were wandering away from home and thus needed more supervision; three respondents reported that the children liked to play with water and mud especially when it rained and more supervision was needed; two reported that the children were destructive; one reported that it was difficult now as the mother had to wash her even when she was on her periods; and one the child was

now sickly.

8.30 SUPPORT WHEN EXPERIENCING PROBLEMS WITH THE CHILD

Respondents were asked with whom did they talk to when they had problems with the child.

TABLE 37: SUPPORT WHEN EXPERIENCING PROBLEMS WITH THE CHILD

RESPONSES	NUMBER	PERCENTAGES
Partner	24	52
Mother	8	17
Relative	6	13
Professionals	3	7
Other	5	11
TOTAL	46	100

As reflected in the table above fifty two percent of the respondents reported that they talked to their partners when they had problems with the children. One respondent from this group reported that she did not get any co-operation from her husband. Seventeen percent of the respondents reported that they talked to their mothers; thirteen percent reported that they talked to their relatives; eleven percent reported that they talked to the professionals, viz the social worker, the nurse and the doctor, and eleven percent of the respondent fell under the group of other.

8.31 FUTURE CARE OF THE CHILD

Respondents were asked who they thought would take care of the child when they were no longer able to do so and how they felt about it.

TABLE 38: FUTURE CARE OF THE CHILD

RESPONSES	NUMBER	PERCENTAGES
Partner	7	15
Siblings	5	11
Relative	17	37
Other	17	37
TOTAL	46	100

As reflected in the table above thirty seven percent of the respondents reported that they thought it would be the relative who would take care of the child when they would be no longer able to do so. Seven respondents from this group said they thought the maternal aunt of the child would take care of the child. Four respondents said the in laws would take care of the child at that time. Five respondents said their son or daughter would take care of the child. One respondent said the grandfather would take care of the child. Respondents had different feelings on this issue. Six felt worried and one respondent from this group said she always prays that they should die together with the child; five said they felt very hurt but believed that God would make a plan, four said they did not feel worried as they had confidence in the people they thought of would take care of their children; two said they did not like to think about it.

Thirty seven percent of the respondents fell under the group of other. From this group nine respondents said they did not know anyone who could take care of the child at that time, five said they hoped that the child would be better if he would be in an institution if only there was one existing in the area. Two said they had not thought about it and were always dismissing the thought; one said there was no one except for the biological mother if only she could come to an understanding with her husband and decide to take the child to their custody. Respondents had different feelings on this issue. Seven of them said they did not feel worried as they trusted that God would make a plan; three said

they felt hurt and helpless; four said they felt worried and always prayed that they should die with the child; two said they quickly dismissed the thought as it was not nice to think about it; and one said she has not thought about it.

Fifteen percent of the respondents reported that their partners took care of the child. Four of them from this group said they felt sad as the husbands were not co-operative in caring for a child, according to them, it is a woman's job; three said they did not feel bad or worried as they trusted that the partners would do the job satisfactorily; and one respondent said she felt scared as there was no one who could cope with the child. Eleven percent of the respondents reported that the retardate's siblings would take care of him. Different feelings were expressed by the respondents. Two said they dismissed the thought immediately; they did not feel bad or worried as they had confidence in the siblings; and one said she felt bad as there was no one who could cope with the child.

8.32 MATERIAL CONDITIONS

Respondents were asked whether they were employed and if "yes" were requested to disclose their occupational status and if not to explain why not.

TABLE 39: MATERIAL CONDITIONS

RESPONSES	NUMBER	PERCENTAGE
Yes	3	7
No	43	93
TOTAL	46	100

Nearly all respondents (93%) were not working. Thirty respondents from this group could not work as there was no one who could look after the child; seven said they had never worked before; four

said they were old and thus could not work and two said they were sickly themselves and so could not work. Seven percent of the respondents reported that they were working - a nursing sister; a domestic helper; and one was doing odd jobs.

8.33 SOURCE(S) OF INCOME IN THE CASE OF UNEMPLOYMENT

Those respondents who were unemployed were asked to disclose their source(s) of income.

TABLE 40: SOURCE(S) OF INCOME IN THE CASE OF UNEMPLOYMENT

RESPONSES	NUMBER	PERCENTAGES
Single care grant only	21	46
Single care grant and other sources	19	41
Other	6	13
TOTAL	46	100

As reflected in table 40 above forty six percent of the respondents reported that their only source of income was the single care grant. Forty one percent reported that their source of income was the single care grant plus other sources. The other sources mentioned by respondents were from their partners and relatives. Three respondents from this group received single care grants while being employed. Thirteen percent of the respondents were still awaiting for their grant applications to be processed.

8.34 ADDITIONAL EXPENDITURE INCURRED BY THE HANDICAPPED CHILD

Respondents were asked whether there was any additional expenditure incurred by the handicapped child other than caring for him/her and to support their answers.

TABLE 41: ADDITIONAL EXPENDITURE INCURRED BY THE HANDICAPPED CHILD

RESPONSES	NUMBER	PERCENTAGES
Yes	31	67
No	15	33
TOTAL	46	100

As is reflected in the above the majority of the respondents (67%) reported that the handicapped child incurred additional expenditure other than caring for him. The expenditure was as follows: medical expenses; transport costs to and from the doctor; additional candles for the nights when the child was sick, washing powder due to incontinence; special food like milk and meat or soft foods which the family sometimes did not have; shoes as they soon were out due to the child wandering away from home; clothes which are often torn when jumping over fences and wear through continual movement while seated.

Thirty three percent of the respondents said the handicapped child did not incur any additional expenditure but some children were said to be particular when it comes to food.

8.35 REDUCTION OF THE EARNING CAPACITY OF THE FAMILY

Respondents were asked whether they thought the birth of a handicapped child reduced the earning capacity of the family and to support their answers.

TABLE 42: REDUCTION OF THE EARNING CAPACITY OF THE FAMILY

RESPONSES	NUMBER	PERCENTAGE
Yes	16	35
No	30	65
TOTAL	46	100

The table above reflects that the birth of a handicapped child did not reduce the earning capacity of the family. To support their answers twenty five of the respondents said they never worked before; and five discontinued due to ill-health. Only thirty five percent of the respondents reported that the birth of a handicapped child did reduce the earning capacity of the family. To support their answers the respondents said that after the birth of the child they had to leave their jobs in order to look after the child as there was no one else to do so. One respondent said she had to leave her job as the biological mother of the child deserted the child; another respondent said the biological mother got married.

CONCLUSION

From the data obtained from the respondents it would appear that the retarded child did not create undue hardship or stress. The reason for this could be due to the fact that many of the children were seen to be more normal than retarded and therefore were not as problematic for the family. The siblings of the retarded children together with the parents have a great responsibility in reconciling normal role performance with the new tasks required of them in order to cope and meet the needs of their retarded family member.

CHAPTER NINE

THE DAILY ROUTINE

9.1 INTRODUCTION

This chapter describes how caring for a handicapped child affected the mother's life. Other family members were affected but no one else experienced the same involvement felt by the mothers. This was community care in practice, and the effects it had on the lives of the people who did the caring are revealed in the mother's own descriptions of their day-to-day experiences. Information was obtained on a wide range of behaviour in order to obtain an overall assessment of the children's social maturity, which will be discussed later.

9.2 MOTHER'S DESCRIPTION OF THE PHYSICAL HEALTH OF THE CHILDREN

Forty percent of all persons with an extreme mental handicap are also subject to other disabilities and illnesses. The most common of these are cerebral palsy and epilepsy. (Ntombela: 1991: 14)

Table 43: Mothers' description of the physical health of the children, appears overleaf on page 93.

TABLE 43: MOTHERS' DESCRIPTION OF THE PHYSICAL HEALTH OF THE CHILDREN

RESPONSES	NUMBER	PERCENTAGE
Can Walk	12	26
Cannot do anything (profoundly retarded)	10	22
Partially paralysed	7	15
Can crawl	5	11
Can hear but has a hearing defect	4	9
Can walk but not properly	3	7
Can sit but moves while seated	2	4
Can see but has a sight defect	2	4
Can stand only	1	2
TOTAL	46	100

Physical mobility was one criterion used to measure the children's physical health. Some children had multiple-handicaps like sight and hearing defects.

9.3 EPILEPTIC SEIZURES

Epileptic seizures have been observed among the children and the table below reflects the respondents' responses to this effect.

TABLE 44: EPILEPTIC SEIZURES

RESPONSES	NUMBER	PERCENTAGE
Yes	20	43
No	26	57
TOTAL	46	100

As reflected in the table above the majority of the respondents (57%) reported that the children did not suffer from epileptic seizures. From this group two respondents stated that their children used to have epileptic seizures, but stopped because of the traditional medication they used for treatment. The type of medication was not mentioned.

Forty three percent of the respondents reported that their children suffered from epileptic seizures. From this group seven of the respondents said the children got the attack frequently. One respondent even said sometimes her child has the epileptic seizures for the whole week. Other respondents reported that their children rarely received attacks. It ranged from once per month to once per year. All children from this group were on treatment using both the traditional and the prescribed medication. From the group whose children were the victims of frequent attacks the respondents reported that constant care and supervision were needed. The children usually got sick at night which would leave them feeling tired and drowsy the next day and less able to perform normal domestic routines.

9.4 WASHING AND BATHING

Washing and bathing themselves was one of the tasks the mentally handicapped children could not perform on their own and those who could, could not do that properly. Table 45 below reflects the respondents' responses to this effect.

TABLE 45: WASHING AND BATHING

RESPONSES	NUMBER	PERCENTAGE
Yes	11	24
No	35	76
TOTAL	46	100

Seventy six percent of the children could not wash or bathe themselves. Some of the children did not like bathing and as such presented problems during bath time. Respondents who had teenage handicapped daughters were finding the problems of dealing with menstruation a great strain. One respondent explained these problems: "Her periods are the biggest problem. She is forever going to the toilet and I have got to stand with her all the time. She still expects me to go with her and change her." In some instances the child becomes pregnant and it would not be possible to know who the father of the child is. Sterilization of these women is one best option to deal with the situation but the choice lies with the family.

The children who could wash themselves, could not do that properly. Supervision was needed as they could not wipe themselves and would spill the water while bathing.

9.5 DRESSING AND FEEDING

Dressing and feeding themselves were also the tasks the mentally handicapped children could not perform on their own. These tasks were amongst the daily routines which the mother/caregiver had to perform and took much of her time.

TABLE 46: DRESSING AND FEEDING

RESPONSES	NUMBER	PERCENTAGE
Dress and feed	13	28
Feed but not dress	9	20
Neither	24	52
TOTAL	46	100

Severely handicapped children differ from normal children, not in that they are dependent, but in the

degree to which they are dependent. Large proportions of the handicapped children require help in both feeding and dressing. These children included some who could only manage a liquid diet using a special feeding cup. Sometimes feeding was further complicated by the child's refusal to eat certain foods or even to eat at all.

From the group whose children could feed and dress themselves the respondents reported that supervision was needed and some assistance was also needed especially with dressing as the children would not fasten buttons and only laceless shoes were suitable for them.

9.6 CONTINENCE OR INCONTINENCE OF THE CHILDREN

One of the most difficult problems faced by mothers of the mentally handicapped children is that of incontinence. The practical and social problems of coping with incontinence were largely dependent upon the age of the child. Mothers of the younger children tended not to identify it as a major problem, but for families of older children life inside and outside the home often revolved around the problems of changing nappies, washing, getting rid of smells and finding toilets. Apart from the practical difficulties which increase as the child grows older, incontinence becomes less and less socially acceptable with age.

Respondents's responses to qualify the description made above are given hereunder.

TABLE 47: CONTINENCE OR INCONTINENCE OF THE CHILDREN

RESPONSES	NUMBER	PERCENTAGE
Continent	18	39
Incontinent	28	61
TOTAL	46	100

Sixty one percent of the respondents indicated that their children were incontinent and would not indicate when they wanted to relieve themselves. They stayed on a nappy day and night. From the group whose children were continent they reported that some of the children needed help with wiping after toileting.

9.7 METHOD OF COMMUNICATION

The ability to understand and to be understood is a necessary precondition of the development of many other skills and for the development of relationships - table 48 reflects whether the children could speak and their usual method of communication.

TABLE 48: METHOD OF COMMUNICATION

RESPONSES	NUMBER	PERCENTAGE
Yes	16	35
No	30	65
TOTAL	46	100

A high proportion of children (65%) could not speak and a small number from this group were able to understand verbal communication and do respond to "NO" and understood instructions. Lip-reading and pointing were mostly used as the non-verbal communication skills. In contrast, only thirty five percent of the children could speak but the majority of those who could speak (12) were reported to have a speech defect, even though parents could understand them. The usual method of communication was verbal.

TABLE 50: CHILD'S RESPONSE TO AFFECTION

RESPONSES	NUMBER	PERCENTAGES
Smiling	5	11
Coughing	22	48
Hugging and kissing	1	2
Shaking the head	1	2
Crying	1	2
Anger and aggression by hitting	13	28
Child does not understand	3	7
TOTAL	46	100

The ability to give and respond to affection is very important for the development of satisfactory relationships. Many mothers found caring for their handicapped children a rewarding experience, but this was only so when the children responded to their parents and other people in a socially acceptable way. Even children with little or no speech were in some cases able to give and respond to affection and to communicate through other means. The table above indicates that the children were able to respond to affection in one way or the other. Two mothers whose children were profoundly retarded said the children would laugh as if they were going to say something.

9.10 SPONTANEOUS APPROACHES TO OTHER PEOPLE

Respondents were asked whether the children made spontaneous approaches to other people so as to determine the social responsiveness of children and how did they feel about it. The table below reflect their answers to the question.

TABLE 51: SPONTANEOUS APPROACHES TO OTHER PEOPLE

RESPONSES	NUMBER	PERCENTAGE
Yes	15	33
No	31	67
TOTAL	46	100

The spontaneous approaches the children made were those of pestering for attention; talking to a stranger at a close range; touching the stranger; sitting on the stranger; hitting the person; not scared of people refusing to talk; and angry with the people. From this group seven respondents said they felt ashamed when the children were making these approaches; one respondent said she would take the child from that person as people would ask what type of a child is this who would dirty them; four respondents said they got cross with the child and would sometimes smack them; and three said they did not feel worried, but would explain the child's condition to the person.

From the group who said no, some children were described as shy. Some parents said they were pleased that their children were not making spontaneous approaches to other people as the latter do not like such children.

9.1 SELF-AMUSEMENT

Another criteria used to measure the social responsiveness of the children was self-amusement. Table 52 overleaf shows the respondents' responses to this effect.

TABLE 52: SELF-AMUSEMENT

RESPONSES	NUMBER	RESPONSES
Yes	29	63
No	17	37
TOTAL	46	100

The children who were socially responsive were also able to amuse themselves. They would laugh alone, either when playing alone, when asleep or in the dark or laughing at the fowls. Two children were said to make a lot of noise. With the children from this group it meant they would be left alone without stimulating or close supervision for periods of time. In contrast, thirty seven percent of the children were reported not to amuse themselves. They never initiated any activities themselves and could not be left without close supervision.

9.12 UNDERSTANDING OF EVERYDAY DANGERS

An attempt was made to determine whether the children understood everyday dangers e.g. touching a hot stove, playing with a sharp knife or falling from a height. The table below is a presentation of the respondents' responses to the question.

TABLE 53: UNDERSTANDING OF EVERYDAY DANGERS

RESPONSES	NUMBER	PERCENTAGES
Yes	28	61
No	18	39
TOTAL	46	100

One of the most important preconditions for some degree of independence is a basic understanding of

everyday dangers. Thirty nine percent of the children had no such understanding. They had no comprehension of the danger involved in touching a hot stove, playing with a sharp knife or falling from a height. From the group whose children understood everyday dangers they were reported to be scared of fire or hot food or anything hot. Some of the children were reported to have been burnt with boiling water at least once.

9.13 EXTENT TO WHICH THE CHILDREN WERE EDUCABLE AND TRAINABLE

Respondents were asked whether the children were educable and trainable so as to determine the children's level of mental development and to further explain their responses.

TABLE 54: EXTENT TO WHICH THE CHILDREN WERE EDUCABLE AND TRAINABLE

RESPONSES	NUMBER	PERCENTAGES
Yes	22	48
No	19	41
To a lesser extent	5	11
TOTAL	46	100

The children's level of mental development could be more clearly understood from the way they responded to the education and training given at home by their caregivers. The responses are reflected in the table above. From the group of children who were trainable and educable it was reported that they could obey instructions and would do as instructed even though they were sometimes stubborn. Some children were reported to obey simple instructions only, e.g. putting the dish on top of the table after eating. One child was reported to respond to toilet-training only, i.e. urinating.

From the group who said that their children responded very little to training, respondents expressed that

the children were stubborn and very slow in thinking which made the whole exercise difficult.

9.14 BEHAVIOURAL PROBLEMS

Respondents were asked whether the children presented the behavioural problems outlined in the table below and how they coped with these problems.

TABLE 55: BEHAVIOURAL PROBLEMS

RESPONSES	NUMBER	PERCENTAGES
Self-inflicted injury	10	22
Difficulties with other children	6	13
Aggressive behaviour	5	11
Screaming	4	9
Hyperactivity	3	7
Temper tantrums	2	4
Pestering for attention	1	2
Destructive	1	2
None	13	28
TOTAL	46	100

To a certain extent, behaviour such as destructiveness, temper tantrums, hyperactivity and others, is inversely related to the degree of disability, i.e. the more disabled the child the less he or she would manifest behavioural problems. The most severe problems tend to be presented by more able children, since many of the profoundly handicapped are incapable of such behaviour, simply because they are immobile. Nevertheless, the table above shows that a consistently higher level of behaviour disorders were found among the majority of the children. The latter were said to show these behaviour problems for different reasons. Screaming - when they want something that the mother did not give him, temper

tantrums - when angry or hungry; unacceptable behaviour - undressing and one child was reported to prefer to dress without underwear; aggressive behaviour - hitting other children when playing and children were said to be short tempered; self-inflicted injury - biting himself, bleeding in the teeth and the child injured himself especially when attacked by epilepsy; and hyperactivity - chewing nothing.

From the group whose children were not giving any problems, nine were cerebral palsied and four were moderately retarded.

The way parents coped with these behaviours differed. In cases of destructiveness, parents kept everything out of reach of the children. The majority of the parents said they would talk to the children softly and tenderly to stop such behaviour. With screaming the children would not stop until they fell asleep or stop when they liked. Some parents said that because of anger they would hit the children.

CONCLUSION

Parenting a mentally handicapped child is a demanding task that presents numerous problems. The time it takes, the lack of communication between the mother and the child, the behavioural problems that the child presents, all have a demanding role for the mother. The burden that the mother of a mentally handicapped child carries, calls for her to receive support not only from her family but also from the informal as well as the formal network in the community which is sometimes lacking.

CHAPTER TEN

SUPPORT SYSTEMS AVAILABLE TO FAMILIES WITH MENTALLY RETARDED CHILDREN10.1 INTRODUCTION

Literature on mental retardation repeatedly mentions that more and more mothers are choosing to care for their children at home (Wilkin: 1979: 90). This type of a situation calls for the development of certain services and the improvement to make it possible for these mothers to care for their children at home and to enable the community to participate in the care of these children where possible. This chapter will discuss the support systems received by the caregivers of the mentally handicapped children, both formal and informal support systems.

10.2 INFORMAL SUPPORT

Respondents were asked whether they received any informal support with the care of the children, from whom did they receive the support, the exact tasks these people helped with, and how often.

TABLE 56: INFORMAL SUPPORT

RESPONSES	NUMBER	PERCENTAGE
Yes	40	87
No	6	13
TOTAL	46	100

The informal support of the mother of a mentally retarded child is usually made up of several persons

who may be categorised according to whether she has direct or indirect contact with them, their geographical distance from the mother, and whether they share a common problem with her or not. The different sources of informal support include the immediate family, relatives, friends and neighbours (Allan: 1983: 417 - 433). In this study the respondents identified the following persons as members of their informal support system: their relatives, friends, and neighbours.

The type of support received from the informal support system differed from one source to the other and also on the basis of whether it was regular or occasional support. The type of support received by most caregivers was what may be termed instrumental and emotional. Instrumental support refers to, among other things, help with family work or responsibilities and financial aid. In as far as the tasks involving the day to day care of the child are concerned, respondents again differed on the tasks for which they required and received help and whether the help received was adequate or not. The help received was that of bathing and feeding the child and fetching water from the river to wash nappies. The majority of the respondents (59%) reported that they received the support in times of crisis only; and twenty eight percent received the support very often.

10.3 AVAILABILITY OF TRAINING CENTRES OR SPECIAL SCHOOLS

Concerning the need for the training centres/special schools in their areas and the role they played in their children's lives, the respondents reported as follows:

The formal support systems of mothers of mentally retarded children are usually made up of professionals from educational, welfare and health institutions within the community. No special schools/training centres were available in the areas where the respondents lived. Only two respondents had children in an institution - one child was attending a normal school, doing STD 2 and he was reported to be making progress even though he was a slow learner; the other child was attending a

special school outside of the area where the study was conducted. At the time of the study the child was reported to be able to learn crioning and numbering.

10.4 WISH TO SEND THE CHILDREN TO A TRAINING CENTRE

Respondents were asked whether they would like to send their children to a centre if it was located in their area. Their responses are reflected in table 57 below.

TABLE 57: WISH TO SEND THE CHILDREN TO A TRAINING CENTRE

RESPONSES	NUMBER	PERCENTAGE
Would support a centre	38	83
Would not support a centre	6	13
Other	2	4
TOTAL	46	100

The respondents had different views with regard to sending their children to a centre. A large number of respondents reported that their children would be able to learn basic self-help skills like bathing and feeding themselves; would be able to learn to read and write so that communication could be facilitated; would be able to learn skills like sewing, knitting and gardening so that they could earn a living and gain independence. Some respondents felt that the centre would relieve them of the burden of caring for the handicapped child, twenty four hours a day, seven days a week. One respondent stated that the centre would keep the child in one place as he wanders away from home.

Other respondents (13%) felt they would not send their children to a centre as the child would not be able to learn anything. Four percent of the respondents, as mention earlier, had children in an institution.

10.5 IMPROVEMENT AS A RESULT OF ATTENDING A SPECIAL SCHOOL

Respondents were asked whether there was any improvement in the child's ability to learn social skills now that he was attending a special school. It should be remembered that only two respondents had their children in an institution and as such this question was only applicable to them. In response to this question, one respondent reported that there was an improvement in the child's ability to learn social skills. This child was attending a normal school and was able to read and write. Another respondent, who also had a child in a special school, said it was too early for her to determine any improvement as the child had only been at the centre for a month at the time of the study.

10.6 SATISFACTION WITH THE ACTIVITIES OF THE CENTRE

Respondents were asked whether they were satisfied with the activities of the centre and whether there was an opportunity for parents or guardians to discuss with teachers any problems that the child was experiencing. Two percent of the respondents were satisfied with the activities of the centre and meetings with parents were held annually to discuss the problems experienced with children. One respondent could not comment as the child had been at the centre for only a month and thus was not well conversant with the activities of the centre and moreover the centre was far from where she lived.

10.7 SATISFACTION WITH THE SERVICES AVAILABLE IN THE AREA

Respondents were asked whether they were satisfied with the services available in the area. Suggestions of what could be included in the school's activities were included. Services in the area were not what the respondent who had a child in a special school outside the area wanted. She would have preferred a special school for children with learning disabilities nearby. Both respondents could

not make any suggestions with regard to the school's activities they wish to be included.

10.8 VOLUNTARY GROUPS

Respondents were asked whether there were voluntary groups in their areas and what services did they offer. Wilkin (1979: 162) noted that voluntary groups continue to play an important role in increasing public awareness of the problem of mental handicap, campaigning for better services, providing information on services available and sometimes actually giving practical help to families. In this study there was a voluntary group. This group consisted of mothers and custodians of the mentally handicapped children and social workers as the group leaders. The group met monthly on the grant pay out day. The activities of the group were the giving of talks and guidance on how to care for the handicapped children. This group was contributing a sizeable proportion of the emotional support available to the families. The problems of day to day care of these children were discussed by the caregivers. It was fulfilling to the caregivers to share their experiences and coping mechanisms for dealing with these children. All the respondents made use of these group services.

10.9 HEALTH SERVICES

Respondents were asked whether there was a clinic in their areas. The table below gives their responses to the question.

TABLE 58: HEALTH SERVICES

RESPONSES	NUMBER	PERCENTAGE
Clinic available	31	67
Clinic not available	15	33
TOTAL	46	100

The role of health services in the care of the mentally handicapped children is important with regard to assessment, treatment and community care. General practitioners; nurses; community health doctors and community health nurses were involved in varying degrees. From table 58 above sixty seven percent of the respondents had clinics in their areas. Some were mobile clinics which visited the areas on Tuesdays only. Some respondents were not making use of the clinic services, but preferred to visit the doctors or hospital for treatment of their children. Some used the service often as it was more convenient and less expensive.

10.10 PHYSICAL HEALTH OF CHILD

Respondents were asked whether the child was sickly.

TABLE 59: PHYSICAL HEALTH OF CHILD

RESPONSES	NUMBER	PERCENTAGE
Sickly child	22	48
Healthy child	24	52
TOTAL	46	100

Of the children who were reported to be sickly, various illnesses were reported. The children had sore throats, toothaches which resulted in the child not being able to swallow and losing their appetite; flu and coughing; diarrhea; eye and ear problems. Treatment was received for these ailments. Some children were not sickly, but had epileptic seizures for which they received treatment. From the group whose children were reported to be healthy, two respondents stated that their children were hyperactive. They had to take tablets before they could sleep. Malnourishment of some of the children was observed by the researcher at the time of the study. Underweight was one of the symptoms visible and the general physical appearance of the children were not satisfactory.

10.11 SATISFACTION WITH THE SERVICES RECEIVED FROM THE NURSES AND DOCTORS

Respondents were asked whether they were satisfied with the services they received from the nurses in the clinics and doctors in the hospitals. The table below reflects their responses to the question.

TABLE 60: SATISFACTION WITH THE SERVICES RECEIVED FROM THE NURSE AND DOCTORS

RESPONSES	NUMBER	PERCENTAGE
Satisfied with services	28	61
Dissatisfied with services	7	15
Other	11	24
TOTAL	46	100

Although the majority of respondents (61%) reported that they were satisfied with the services they received from the nurses and doctors, one respondent reported that at one stage the nurses did not provide the correct service. The respondents who reported that they were not satisfied with services, stated the some nurses were not patient. They harrass them and did not show concern. Sometimes tablets were not available even though they had paid for them. One respondent said nurses reported that the child was malnourished and thus he could not grow well. The mother promised to improve the child's condition by feeding him adequately.

10.12 VISITATION BY COMMUNITY HEALTH NURSES

Community health nurses sometimes do visit the households with mentally handicapped children to render health services and referring the child to relevant resources. The table below gives the respondents' responses to this effect.

TABLE 61: VISITATION BY COMMUNITY HEALTH NURSES

RESPONSES	NUMBER	PERCENTAGE
Community health nurses visited	15	33
Community health nurses did not visit	31	67
TOTAL	46	100

Contact with community nursing services was low. Only thirty-three percent of families were visited. Of this group nine respondents said the nurses used to visit, but that was three years ago; three respondents were visited often and these contacts were the continuation of contacts which had started shortly after birth; and three respondents were visited occasionally.

10.13 SOCIAL WORK SERVICES

The Sterkspruit district had four social workers at the time of this study. Two social workers had offices at the magistrate's office and the other two were located at the two different hospitals. All respondents had a social worker in their area. Contact with social workers differed. Some respondents were seeing the social workers monthly. These were the respondents whose children were already in receipt of a single care grant. While other respondents had met the social worker once or twice and these were those whose single care grant applications were still being processed.

10.14 LENGTH OF TIME KNOWN TO THE SOCIAL WORKER

Respondents were asked how long they had known the social worker and their responses to the question are reflected on the table overleaf:

TABLE 62: LENGTH OF TIME KNOWN TO THE SOCIAL WORKER

LENGTH OF TIME	NUMBER	PERCENTAGE
0 - 2 years	12	26
3 - 4 years	10	22
5 and over	24	52
TOTAL	46	100

As indicated in the table above, fifty two percent of the respondents had known the social worker for five years and more; twenty six percent for two years or less; and twenty two from three to four years. The length of time that the respondents were known to the social worker together with the number of single care grant recipients determined that the services rendered by the social worker were known to the community.

Different services were rendered by social workers. Thirty three percent of the respondents were assisted with single care grant applications; thirty three percent again were assisted with counselling and guidance on caring for the retardates; thirteen percent were assisted with the applications for a single care grant, but their applications were still being processed; four percent were assisted by rail warrants to attend a hospital outside Sterkspruit; two percent were assisted with the application for admission to a special school; thirteen percent were referred to the relevant resources in the community and two percent were assisted with food parcels.

10.15 SATISFACTION WITH THE SERVICES RECEIVED FROM SOCIAL WORKERS

Respondents were asked whether they were satisfied with the services they received from social workers and to support their answers.

Table 63: Satisfaction with the services received from social workers, appears overleaf on page 114.

TABLE 63: SATISFACTION WITH THE SERVICES RECEIVED FROM SOCIAL WORKERS

RESPONSES	NUMBER	PERCENTAGE
Satisfied with services	40	87
Dissatisfied with services	0	0
Other	6	13
TOTAL	46	100

Many respondents (87%) benefited from the services rendered by social workers. They cited different reasons: they were able to feed and clothe the handicapped child, and in some instances the whole family as the single care grant was the only stable source of income. In these families the breadwinner might be working outside the district and did not send the money timeously. Some respondents stated that they were able to pay the child's medical expenses, some were able to save money and the social workers were also giving more insight on the subject of mental retardation.

Thirteen percent of the respondents could not comment as their single care grant application were still being processed. The help seems largely practical and material, rather limited.

10.16 SUGGESTIONS FOR IMPROVING SOCIAL WORK SERVICES.

Respondents were asked whether they could think of anything else the social worker could do in order to help them, their families and the community.

Social workers should possess a knowledge of the general problems of mental handicap, the services available and the specific circumstances of individual families. Only in this way it is possible to

anticipate needs and meet them with practical support which corresponds to the family's day-to-day domestic routine. More than half of the respondents (52%) said the social workers were doing all they could to help them and their families. Thirty-five percent of the respondents reported that the social workers needed to do more to be of help to them and their families. Nine respondents from this group stated that they would like the children to be sent to a special school; three respondents said they wanted a wheelchair for the child as the latter was too heavy and the wheelchair would relieve him from sleeping all the time; two said they would like the social workers to make application for a disability grant for them as they were physically weak due to the burden of caring for the handicapped child; one said she would like the child to receive orthopaedic shoes for easy mobility; and one reported that she was not satisfied with the treatment she once received from the social worker. The latter had an argument which ended up in the senior social worker's office in trying to resolve it.

10.17 NATURE OF SERVICES RECEIVED

Respondents were asked whether the services received were what they needed.

The majority of the respondents (65%) received the services they needed. Some of the respondents had managed to develop a relationship with social workers which provided necessary services and someone to talk to who could understand their problems. Twenty-two percent of the respondents reported that they would like to receive more money for the grant as it was inadequate; and thirteen percent could not comment as their grant applications were still being processed and did not know much about social work services.

10.18 SOCIAL POLICY WITH REGARD TO THE MENTALLY HANDICAPPED

Respondents were requested to make suggestions what the government could do to alleviate the burden of caring for the handicapped child.

TABLE 64: SOCIAL POLICY WITH REGARD TO THE MENTALLY HANDICAPPED

RESPONSES	NUMBER	PERCENTAGE
Build a special school	22	48
Appoint more social workers	14	30
Increase the single care grant	10	22
TOTAL	46	100

The majority of the respondents were in favour of building a special school nearby so that they could visit the children regularly. The special schools had much to offer the mentally handicapped child which was not possible in normal schools. Another factor which the respondents put forward was that the special schools would relieve them from the burden of caring for the handicapped child 24 hours a day, seven days per week.

Thirty percent of the respondents stated that they would appreciate it if more social workers could be appointed as they appeared to be overworked. High caseloads made it impossible for them to pay sufficient attention to their clients.

Twenty two percent of the respondents said they would like the money for the grant to be increased, as it was inadequate and caring for the handicapped child incurred additional expenses.

No further suggestions regarding the services/assistance were made.

10.19 CONCLUSION

The support systems received by the caregivers of the mentally retarded children were not enough especially the formal support systems. The education service, i.e. the initiating of a special school for these children, needed to be developed and improved. This would make a marked improvement in the lives of these children and their families.

CHAPTER ELEVEN

FINDINGS AND CONCLUSIONS

The major findings of the study are summarised in this chapter. Some general conclusions are drawn and recommendations made. They all relate directly to the stated goals of the research topic.

11.1 MAIN FINDINGS

11.1.1 THE HANDICAPPED CHILDREN

The children in this study ranged from the profoundly handicapped who were unable to sit up, to those who were on the border line of mild mental handicap. The degrees of mental retardation are usually discussed according to severity and potential to grow, learn and develop (Menolascino: 1977: 19). The various levels of mental retardation using standardized intelligence tests were observed, i.e.

Stanford-Binet test:	Mild	52 - 67
	Moderate	36 - 51
	Severe	20 - 35
	Profound	below 20
	Borderline	68 - 83

The researcher did not conduct any intelligence test with mentally retarded children. Eighty seven percent of the children were in receipt of the single care grant while thirteen percent had their applications on process. In terms of the Mental Health Act No. 18 of 1973 a patient qualifies for committal into single care if he or she is a child:

1. who is ineducable and untrainable;
2. whose mental ability is so low that constant care is necessary;
3. who cannot benefit by an educational programme as offered by schools or special classes in schools;
4. who is three years old, but not older than 18 years;
5. whom it is not deemed safe and convenient to be cared for in a single household, instead of in an institution.

Due to the lack of services for the mentally handicapped children in Transkei, the qualification for committal into single care were sometimes not observed, especially point 1, 3, and 5. It should be remembered that one child from the sample was attending a normal school, doing STD 2, but was in receipt of the single care grant. This was in contravention with point 1 and 3 as discussed above. Another child was reported to wander away from home and would sometimes disappear. He was also in receipt of the single care grant and this contravened point 5 of the qualification for committal into single care. Income from the single-care grant was sometimes shared among the family members with the result that the handicapped child did not derive the maximum benefit from the grant. The families' financial position were very poor and the grant was often the only stable source of income. Malnourishment and neglect of the handicapped children, especially the profoundly handicapped, were observed at the time of the study. The researcher found at least two children left alone at the different households on arriving for visits for the interviews. This was a clear indication that the caregivers were not coping with the burden of caring for the handicapped child and as such the establishment of an institution is a requirement.

The sex and age of the children varied. Fifty two percent of the children were females while forty eight percent were males. From this finding one cannot conclude that mental retardation was more

prominent among the female than male children. Studies of handicapped children in institutional care are consistent in reporting that boys are more likely than girls to be admitted. (Wilkin: 1979: 80). The children's ages was the most important factor in determining the behavioural problems presented by the child and whether the family was coping with the child or not. Up to a certain point, problematic behaviour such as destructiveness, temper tantrums, hyperactivity, self-injury and others, are inversely related to the degree of disability, i.e. the more disabled the child the less likely he or she is to manifest such behavioural problems. The most severe problems tend to be presented by more able children, since many of the profoundly handicapped are incapable of such behaviour, simply because they are immobile. (Wilkin: 1979: 89). Sixty-five percent of the children were reported to have demonstrated an improvement in the lifestyle of the mothers/caregivers as a result of their age because they were sickly and crying a lot when younger. Most of the children did not suffer from epileptic seizures. From this group two respondents reported that the children used to have epileptic seizures but stopped because of the traditional medication they used for treatment. Forty three percent of the children were reported to have epileptic seizures. Although some children were reported to be attacked rarely there were those who were attacked more frequently. Constant care and supervision was needed and as the children usually got sick at night, respondents would be feeling tired and drowsy the next day and thus could not perform normal domestic routines. Hewett (1979: 28) noted that children with mental handicap were twice as often reported as having fits or convulsions than were the children rated as normal 49 or 63 % of the children with confirmed mental handicap, as opposed to 13 or 29 % of the children with unimpaired intelligence.

Catering for the handicapped child's basic physical needs sometimes presented enormous problems. Most of the children appeared to be unable to perform personal care tasks and as such help was required. Seventy-six percent of the children could not wash or bathe themselves and some children were giving problems during bathing time. The children who could wash themselves could not do that

properly. Supervision was needed as they could not wipe themselves and would spill the water while bathing. A large proportion of the children, i.e. fifty two percent, required help in both feeding and dressing. These children included some who could only manage a liquid diet using a special feeding cup. Sometimes feeding was further complicated by the child's refusal to eat certain foods or even to eat at all. The majority of the children, i.e. 61 % were reported to be incontinent and would not even indicate when they wanted to relieve themselves. They stayed on a nappy day and night. Cohen (1962: 137) and Collins (1982: 75) noted that one of the most difficult problems faced by mothers of severely handicapped children is that of incontinence. The practical and social problems of coping with incontinence are largely dependent upon the age of the child. Mothers of younger children tend not to identify it as a major problem, but for the families of older children life inside and outside the home often revolves around the problems of changing nappies, washing, getting rid of smells and finding toilets. Apart from the practical problems which increase as the child grows older, incontinence becomes less and less socially acceptable with age. In this study respondents complained about the issue of doing washing much of the time. Fetching water from the river was a major problem especially for the grandmothers who no longer have that much strength for the job. The mothers received no help at all with nappy changing as this task is traditionally regarded as part of the maternal role. Attempts to toilet-train some of these children had met with little success. However, a number of mothers dismissed these problems. For example, one mother who had a ten year old, non-ambulant, doubly incontinent child said "It is the incontinence and the feeding that are most difficult but I have had her so long that I have just got used to it." Some respondents referred specifically to a problem which was not dealt with directly in the investigation, that of menstruation. They were finding the problems of dealing with menstruation in their teenage handicapped daughters a great strain. A high proportion of children (65%) could not speak and a small number from this group were able to understand verbal communication and did respond to "NO" and understood simple instructions. In some cases problems of communication overshadowed the difficulties of physical care. One mother

identified communication as one major problem. She expressed the question of her not understanding the child and the child not understanding her as the worst thing. She does not understand what the child wants and what he was trying to tell her. Studies of handicapped children agree with this finding. The ability to understand and to be understood is a necessary precondition for the development of many other skills and for the development of relationships. (Grossman: 1972: 101).

Generally, the majority of the children required close supervision during their waking hours and in some cases even when they were asleep. The mothers/caregivers were largely responsible for this task.

11.1.2 THE FAMILIES

It is no exaggeration to say that in the background of every individual handicapped child there is always a handicapped family (Sheridan: 1965: 175). One of the main concerns in this study was to attempt to discover the extent to which the lives of the families of handicapped children differ from the lives of families which include only normal children. The sample included only families with handicapped children. It was found that there was no relationship between the age of a parent and having a mentally handicapped child, nor the social class of the family. The mentally retarded children came from a wide variety of backgrounds. The families in this sample could be regarded as working class families which lived below the poverty line. Respondents in this study did not continue far with formal education, some never went to school, and as such had limited chances of employment. This study was conducted in a typical rural area where poverty and unemployment were the order of the day. Poor housing conditions under which these children were cared for and overcrowding were major problems. The general standard of living in these families was very low.

The mother's feeling on discovery that the child was a handicapped child together with their partner's

reactions were studied. When a couple is expecting a baby they have certain hopes and expectations, all centring on the image of a healthy, normal child. If this child turns out to be abnormal at birth or is left abnormal through some incident, the parents all at once face a situation in which their dreams are shattered and they have to adjust their expectations to the child's anticipated potential. While still in this emotional crisis, they are confronted with the heavy demands of caring for the child. Parents therefore find the birth of a handicapped child a highly emotional event and react with intense feelings of shock, guilt, depression, disillusionment and the like. They may experience a combination of such feelings of varying intensity, depending on the nature and degree of the handicap. For those respondents who were married their partners were reported to be supportive.

Information was collected concerning the relationship between the mentally retarded child and his siblings. Generally the retarded child was well liked and well accepted by his siblings even though smaller children were reported to have been jealous about the time spent with the retarded child. Hewett (1970: 76) noted that the children in a family with a spastic child are in danger emotionally because the handicapped member of the family is not unique to these mothers. In any family with more than one child, the mother has to learn to divide her favours equally and as needed this can be difficult and rivalry and jealousy inevitably occur in some circumstances in spite of the mother's best efforts to prevent them.

As quoted by Hewett (1970: 77) "without adequate help, the birth of a handicapped child can be the final straw that breaks a marriage apart". In this study the birth of the retarded child had no discernible effect on the marital relationship of most of the respondents. The only respondents who were negatively affected were those whose children were born out of wedlock. Not only do the physical problems of caring for the severely mentally handicapped person in the family increase as the child grows older, but the ability of ageing parents to cope with these problems may decline, and siblings

of the handicapped member, who may have provided support in the past, tend to leave home and have families of their own to care for. The mothers/caregivers state of health and feelings about the restrictions they experienced as a result of caring for their handicapped children were also studied. Slight problems were experienced with the physical and mental health and respondents expressed resentment at being unable to go to work or to enjoy satisfactory social lives. The retarded child incurred additional expenditure while with other families he reduced the earning capacity of the family as the mother/caregiver could not go and work because she was looking after the handicapped child. The majority of the respondents never worked and as such a small number of respondents were affected with reduction of the earning capacity of the family.

Respondents, i.e. those who were biological mothers of the handicapped children, were not keen to have more children as they were already burdened with the handicapped child. The findings of Tizard and Grad (1962: 100), Kew (1975: 170) and Gath (1978: 80) indicated that a handicapped child may have a negative effect on the parents' sex life and could inhibit further additions to the family.

Research findings indicate that a handicapped child has a negative effect on the entire family's social life. Especially in the case of severe handicaps the family has to learn to adapt to the child's demands from an early stage. Events like holidays and family outings become a luxury in which the family can seldom indulge as a unit. Families find that their pattern of social life changes radically after the birth of a severely handicapped child. Sometimes parents also find that they are discriminated against or stigmatised because of their child, thus forfeiting social acceptability. Mothers in rural areas often experience practical obstacles to making the contact they would like and having a child who is not easily transportable naturally adds to the difficulties. The interaction between the family and other people in the community in relation to the handicapped seemed to have no negative effect or respondents did not notice anything as the handicapped children were always at home. Some

respondents expressed that some people in their area disliked their children.

The question of 'looking ahead' for the handicapped child, i.e. who will look after him if/when anything happens to me was also addressed. Mothers of the severely handicapped children expressed the deep concern and misgivings about the problem, but they were realistic in answering the question. The majority of them stated that the child's maternal aunt would look after her. This finding clearly indicates that the families relied in one way or the other on their relatives for support. Other researchers, i.e. Hewett (1970) and Wilkin (1979) found that most mothers hoped for the permanent residential care for their children. Mothers' comment on this topic were that they could not bear to face the future, one mother said she has many troubles which had eventually exhausted her capacity for worrying.

11.1.3 INFORMAL SUPPORT

Informal support refers to that provided by other family members, relatives, friends and neighbours. The findings of Wilkin (1979), Collins (1982) and Joubert (1986) indicate that the mother carries the primary responsibility for the nurture of the handicapped child, often with little support from the rest of the family. All these researchers are critical of the father's lack of involvement in the educational task. In the 1971 White Paper, London, Better Services for the Mentally Handicapped, stated that "understanding and help from friends and neighbours and from the community at large are needed to help the family maintain a normal social life and to give the handicapped member as nearly a normal life as his handicap or handicaps permit". There was no further mention in the paper of what help might be provided by these people or how common it was in practice for families to receive this sort of help. In this study, the help that the mothers/caregivers received was little in relation to the amount of work necessary. The mothers/caregivers' informal support systems rendered mostly instrumental

help. Fathers, to those who were married, were the greatest single source of support but their contribution reflected a very traditional division of labour in the home, the mothers being responsible for the children and the home whilst their husbands went out to work. The fact that all these families had a highly dependent child appeared to make no difference to the involvement of most fathers in routine child care and household tasks. Respondents whose children were born out of wedlock received no help whatsoever from the biological fathers of their children.

Siblings of the handicapped child made a valuable contribution to the domestic routine and the general caring of the handicapped child even though they could only help during weekends as they were schooling. The overall level of support provided by siblings was not related to the severity of their siblings' handicap. It was similar in those families with a profoundly handicapped child and in those with a child approaching the educationally subnormal level. This may reflect a desire, on the part of the mothers, not to impose the burden of their handicapped child on the other children. Some said they made every effort to ensure that the lives of their other children were not adversely affected. Relatives, friends and neighbours provided direct support with the aspects of domestic routines and emotional support especially when the child was sick. The support was mostly provided in times of crisis. The findings of Joubert (1986) indicate that the mothers may have received support in crises or emotional and psychological support from these people, but they certainly did not receive much help with the day-to-day practical burdens of providing care. The level of support provided by relatives, friends and neighbours was low in comparison with the contribution made by fathers and siblings of the handicapped child.

11.1.4 THE SERVICES

A handicapped child places the family, particularly the parents, in contact with a whole range of

helping professions such as the medical and paramedical professions, psychologists, educationist, social workers and the like. If the child is placed in an institution, the parents also have contact with institution or school staff.

11.1.4.1 EDUCATION

Transkei has got twenty eight districts, Sterkspruit, where the study was conducted, being one of those districts. Services for the retarded in this area are limited. Only four special schools, for the whole of Transkei, are available. From these special schools only one special school has boarding facilities for these children as a result some parents preferred to keep their children at home rather than send them to the school. In Sterkspruit there is no special school, or training centre for retarded children. There is no residential care for children whose parents are not able to look after them at home, no day care facilities for the handicapped child which would develop motor, sensory, communication and selfhelp skills as well as elementary health habits, depending on the degree of the child's handicap. The only service available is the single care grant which was R278 per month at the time of the study. The lack of special care centres, mentioned above, in general is another factor which has a negative effect on the family of a handicapped.

Respondents expressed their willingness to send their children to a special school/training centre if there was one located in their area. This would help the handicapped child with self-help skills like feeding and bathing himself; to learn to read and write so that communication could be easy; and the child would also learn some technical skills like sewing, knitting or gardening so that he could earn a living and gain independence. Another need which could be fulfilled by a special school, i.e. a secondary need, is to relieve the respondents from the burden of caring for the handicapped child.

11.1.4.2 HEALTH

Investigation was made as to the availability of clinics in the areas where the respondents lived. The majority of the respondents (67%) had clinics in their areas even though some clinics were mobile clinics. Respondents' experiences with doctors and nurses varied, tablets were sometimes not available at the clinics, but some respondents were satisfied with their doctors and nurses. Community health nurses were rarely seen by the respondents at their households and some respondents were not visited at all.

11.1.4.3 WELFARE

Social services provided the most important support needed by the families, that of money through the single care grant. Most respondents spoke appreciatively of the social workers, but there were some needs the respondents expressed which they needed the social workers to fulfil. They needed their children to be sent to special schools; needed wheelchair for the child as the latter was too heavy to carry and to relieve him from sleeping. Obtaining a wheelchair was rather difficult in Transkei as one has to look at the cost effectiveness of the use of the aid. The practicality of the use of the aid was also considered as Transkei is predominantly a rural area. Some respondents wanted the social workers to make the applications for a disability grant for them as they were physically weak because of the burden of caring for the handicapped child. A voluntary group consisting of the mothers and guardians of the retarded child was available and the main service rendered was advice and guidance on how to care for the retardates. Finally, respondents expressed their wish to have a special school in the Sterkspruit district where it would be possible for them to visit their children more easily anytime. There was no planning to that effect in the department.

Services for the mentally handicapped and their families available in Transkei, i.e. Sterkspruit district in particular, cannot compare with those of developed countries.

11.2 CONCLUSION

There is evidence from other reports and studies that no specific kind of handicap brings unique problems to the family. Far more difficulties are shared by all families with a handicapped child than are specific to the medical category of the handicap. Some mothers - often, but not exclusively, those where the child was slightly handicapped - gave the impression that they have had little difficulty in maintaining a matter of fact attitude towards the child and the total situation. In this study the majority of the children were born as normal children and they were attacked by epileptic seizures in their early childhood years which resulted in the present mental condition. These children, thus, could be categorised as mildly retarded and they did not give as much stress to the family which was expected by the researcher. The children could benefit a great deal from the special school if one was allocated to the area. The respondents were worried about the future care of their handicapped children and they expressed their wish to have a special school in their area.

The families in this study could be regarded as low-income families which lived below the poverty line. The main problematic areas that these families were experiencing were poor housing conditions and unemployment which resulted in poverty. The fact that this study was conducted in a rural area was one of the main concerns of the researcher. The respondents had few resources at their disposal to cope with the situation. There were no counselling services available to the families of the retardate nor any practical assistance with the care and stimulation of the child. There were no special care centres like day care centres for the handicapped child which would give the mother some relief from her emotional and physical stress; no residential care for children whose parents were not able to look

after the retarded child at home; nor any stimulation programme for the handicapped child which would help to develop motor, sensory, communication and self-help skills as well as elementary health habits, depending on the degree of the child's handicap. A disconcerting feature about Transkei is that it has no mental health societies. The family, therefore, has to look after its retarded child with a single care grant from the state from the age of 4 and at age 18 the grant will be replaced by a disability grant. In most families income from such grants is shared among family members with the result that the retarded child does not derive the maximum benefit from the grant.

There are only four special schools for training of the mildly and moderately retarded in the whole of Transkei. Even these schools are not well equipped to cater for the interests of the retarded as a result most parents in Sterkspruit preferred to take care of their children at home. The impact of the mentally retarded child on the family was made easier by the availability of informal support systems to the family of the retardate. It was unexpected to hear from the respondents, especially those who were married, the compliments of their partners with the support they gave with the caring of the child. Culturally it is very uncommon for a husband to help with the caring of the children and doing the household tasks.

Social work intervention on behalf of the handicapped child and his family is most effective when the social worker is part of a multiprofessional team composed of members of the medical and paramedical professions, psychologists, educationists and remedial teachers. The social worker's role in such a team is that of therapist and supporter to the parent, as well as spokesperson and mediator acting on behalf of the parents.

The structure of social services in Transkei and Sterkspruit in particular, because of lack of resources in their area are not in a position to play the role as described above. Social workers compile a

background report on the social circumstances of the retardate and his family, thereafter refer the retarded child to the district surgeon for medical examination, i.e. to ascertain the child's level of mental handicap. All this information is handed over to the magistrate for the certification of the child under Section 9 of Act 18 of 1973; for committal into care of parents/guardians under Section 10 of the same Act; and the recommendation for the payment of a single care grant to the caregiver. After all this has been done these documents are submitted to the Department of Health, Umtata, for approval. This procedure is followed with all single care grant applications. Payments are made monthly at the magistrate's office. These grants are renewed annually with the same procedure followed.

The age of a parent; the age, sex and number of other siblings; the family's standard of living; and the availability of both the formal and informal support systems all had a bearing on whether or not the family felt able to cope with their handicapped child. At the same time the age of the handicapped child, his sex, handicaps, skills and the behaviour problems he presented had an effect on the family's ability to cope with him.

11.3 RECOMMENDATIONS

1. The preceding discussion about the burden of care for the family indicates that services must play an increasingly important part in the future in providing the support necessary to facilitate the mentally handicapped child remaining at home especially those severely afflicted. The establishment of mental health societies in Transkei could result in a marked improvement in the quality of life for large numbers of families with the mentally retarded child. These societies could result in a number of projects being established in the communities for caring of these children. Special care centres which could provide day care facilities for the

handicapped child and give the mother some relief from her emotional and physical stress while the child is away; residential care for the children whose parents are not able to look after them at home or who have no access to day care centres, these care centres should have the treatment facilities necessary especially for the profoundly handicapped child; a stimulation programme for the handicapped child in order to develop motor, sensory, communication and selfhelp skills as well as elementary health habits, depending on the degree of the child's handicap; all these could make a vast difference in the improvement of the quality of life for the families and the mentally handicapped child. The communities themselves should take an initiative in trying to establish the special care centres described above, but they could only do this with guidance from professionals like social workers, community doctors and nurses. The availability of these professionals could bring light especially in matters of fundraising both from the government and some private sources and even from the community itself; and how to start a self-help project.

2. Community education can form a sound basis for work amongst the mentally retarded. Community networks need to be mobilised and linked to existing formal services to the caregivers and their families. Potential support systems such as church groups, women's clubs and youth clubs need to be initiated, developed and utilised. The present women's church groups could take this initiative to form the groups just described. Once developed, these networks can complement the existing welfare services and thus enable the social worker to do only the professional aspect of her work. Research should be undertaken into the attitude of different community groups towards serving as sources of support or towards making certain resources such as church halls to be used as workshops and centres for handicapped children or adults.

3. The improvement of the existing services for the mentally retarded children and their families like appointing more social workers in each district so that adequate attention could be given to each family for effective social work service; the establishment of clinics in all areas for easy access to the family especially in times of crisis; and the provision of special schools with all the necessary equipment and the general improvement of the standard of the school, all could have a considerable positive effect on the quality of life of the family and the handicapped child.

APPENDIX

PROJECT DESIGN

1. SAMPLE

This study was conducted in the Sterkspruit district, Republic of Transkei. The subjects were mothers of the mentally retarded children or the custodian at the time of the study. These included only retarded children who were single care grant recipients in the social worker's office in this district. The caseload of the social worker in the district consisted of sixty three mentally retarded children who were single care grant recipients. The researcher intended to include all of them in the investigation. This intention could not succeed as some respondents were not at home when the social worker called; or the children were no longer in their care without the social worker's knowledge. This resulted in the number of forty six respondents in this study.

The interviewing process took a period of one month, i.e. March 1993. Interviewees, i.e. the subjects, were visited at their households. No appointments were made for the interviews as the area where the study was conducted is a rural area with no telephones. The researcher knew most of the respondents as she once worked with them in 1990 while she was a social worker in the district. On the grant pay out day in March 1993 the researcher met all the subjects as a group and a brief talk was given to them concerning the study. Each interview took at least 45 to 60 minutes. There were some few limitations met during the study time but in general the study was a success.

2. THE FIELDWORKERS

Interviews were conducted by four fieldworkers on the first day of the interviews. They composed of the researcher and three social workers from the district. They understood the language of the interviewees, their background culture and beliefs as well as their childhood experiences. They were part of the community. The positive approach to respondents was emphasized and the art of communication and the importance of confidentiality, respect and appropriate approach to interviewees was discussed. Nine interviews were conducted on this day and the researcher conducted all other interviews on her own.

SCHEDULE

Please answer all questions to the best of your ability. All information will be kept strictly confidential.

SECTION A - PERSONAL DATA

1. Age of the parent

- 21 - 30
- 31 - 40
- 41 - 50
- 51 - 60
- 61 - 70

2. Educational qualification

- Never attended school
- Std 3 or lower
- Std 4 to std 6
- Std 7 to std 10
- Std 10 plus further training

3. Which religious denomination do you belong to ?

If belonging to some religious denomination, state attendance:

- Regular
- Occasional
- Do not attend at all

State reason for your answer

Are there any services/support systems available from your church ? Please explain

4. Relationship to the retarded child

- Biological mother
- Grandmother
- Other e.g. aunt, sister, etc.

SECTION B

5. Did you have a difficult pregnancy ? or delivery ?

6. What do you think might have been the cause of the retardation ?

7. How many children are you still expecting to have ? State reason for your answer

8. What was your age at first birth

9. If you have more than one child, please state parity (period between births)

10. Sex of the child

- Male
- Female

11. Place of the child in the family

- 1st born
- 2nd born
- 3rd born
- 4th born and so on

12. Age of the child

- 4 - 6
- 7 - 10
- 11 - 15
- 16 - 18

SECTION C - PSYCHOLOGICAL EFFECTS

13. How did you feel when you discovered that your child is handicapped ?

- Guilty
- Ashamed
- Angry
- Self-pity
- Depressed
- Helpless
- Other

14. What was your partner's reaction ?

- Supportive
- Rejected the child
- Deserted the family

15. Do you think looking after the handicapped child has had any effect on your health ? (either physically, emotionally or psychologically)
Support your answer

16. Are you taking any treatment presently for that ?

Yes

No

Support your answer

17. Does this perhaps limit your capacity to carry out routine domestic tasks ?

Yes

No

Support your answer

18. Do you have any problems with your other children in relation to their attitude to the handicapped child ?

Yes

No

Describe their attitude (both positive and negative)

19. Do you think you spend more time with the retarded child than with other children ?

Yes

No

20. How do they feel about this ?

Supportive
Jealous
Frustrated
Guilty

21. Do you think the presence of a handicapped child had any effect on their lives ? e.g. poor school performance. Please explain.

SECTION D - SOCIAL EFFECTS

D - (1) RELATIONSHIPS WITHIN THE FAMILY

22. Are you married ?

Yes

No

23. If no, how is the relationship between you and the father of the child ? Support your answer.

24. If yes, how long have you been married ?

25. Where is your partner ?

26. How does his absence affect your ability to cope with the situation ? Support your answer.

27. How was the relationship between you and your partner prior to the birth of this child ?

28. Do you think the birth of this child had an effect on your marriage/relationship ? (either positively or negatively)
Support your answer

29. What is the age of your partner ?

30. With whom is the child presently staying ?

- Parents
- Grandmother
- Relative
- Institutionalized
- Other

31. How often do you go out together with your partner without children ?

32. To what extent do you feel restricted in going out on your own without children ?

33. Does the father help you with the caring of the child ?

Yes

No

Support your answer

34. Does he help you with other household chores ?

35. How often does he provide such help ?

36. Number of other children

Younger

Older

37. Are you intending to have more children ?

Yes

No

Support your answer

38. What are your children's ages ?

39. How do you cope with these children ?

40. Do all your children stay with you ?

Yes
No

If no, with whom do they stay ?

41. Do your children assist you with the care of the child ?

Yes
No

Support your answer

42. Do they perhaps help around the house while you attend to the handicapped child ?

Yes
No

43. Whether the assistance you received from your other children was related to their sex and age ?

44. Describe any role change in the family as a result of the birth of the handicapped child.

D - (2) RELATIONSHIP BETWEEN THE FAMILY AND THE OUTSIDE WORLD

45. How does your family interact with other people in the community in relation to the handicapped child ?

46. Is there any label that your family or child has ? Please explain.

47. Do people shun or feel pity for you and the child especially in public areas ? Please explain

48. How do you feel about this ?

49. Do you think people's reactions are a lack of understanding of the retardation or ignorance ?

50. What do you think can be done to improve the community's attitude towards the retardates ? e.g. educational workshops

SECTION E - SOCIAL LIFE OF PARENTS OF THE RETARDED CHILD

51. How frequently do you experience feelings of isolation as a result of having a retarded child ?

52. Would you like to have more time to yourself ?

Yes
No

Support your answer

53. Do you think the child's age presently had had an effect or improvement in your life style ?

Yes
No

Please explain

54. Who do you talk to when you have problems with the child ?

- Partner
- Mother
- Sister
- Relative
- Friend
- Other parents of the retardates
- Professionals
- Other

SECTION F - ANXIETY ABOUT THE FUTURE CARE OF THE CHILD

55. Who do you think will take care of the child should you no longer be able to do so ?

56. How do you feel about it ?

SECTION G - MATERIAL CONDITIONS

57. Are you presently employed ?

- Yes
- No

If yes, what is your present occupational status ?

If not employed, explain why not ?

If unemployed, what is (are) your source(s) of income ?

- Parents
- Friends
- Welfare grant
- Relative
- Partner
- Other

58. Does the handicapped child incur additional expenditure other than caring for him/her ?

- Yes
- No

Support your answer

59. Do you think the birth of a handicapped child reduced the earning capacity of the family ?

- Yes
- No

Support your answer

60. Describe the child's physical health

61. Does he suffer from seizures ?

Yes
No

If yes, how frequently ?

62. To what extent does this disturb normal domestic routines ?

63. Can the child wash and bathe himself ?

Yes
No

Support your answer

64. Can the child dress and feed himself ?

Yes
No

If yes, does he do this satisfactorily without supervision ?

If no who helps him ?

65. Is the child continent or incontinent ? Please explain

66. Can the child speak ?

67. What is your usual method of communication with him ?

68. What is his level of speech development ?

Does he not say any words

Single words only

Talks in sentences

69. How does the child respond to affection ?

70. Does he make spontaneous approaches to other people ?

How do you feel about this ?

71. How does he amuse himself ?

72. Does he understand everyday dangers ? e.g. touching hot stove, playing with sharp knife or falling from a height

73. Is the child educable and trainable ? Please explain

74. Does he show any behavioural problems mentioned below ?

- 74.1 Destructiveness
- 74.2 Screaming
- 74.3 Temper tantrums
- 74.4 Hyperactivity
- 74.5 Unacceptable behaviour in public places
- 74.6 Difficulties with other children
- 74.7 Aggressive behaviour
- 74.8 Rebellious behaviour
- 74.9 Pestering for attention
- 74.10 Injures himself

75. How do you cope with these types of behaviours ?

SECTION I - SUPPORT SYSTEMS

76. **INFORMAL SUPPORT**

76.1 Do you get informal support with the care of the child ?

- Yes
- No

If yes, may be from -
Relatives
Friends
Neighbours
Other

76.2 Exactly what tasks do these people help with ?

76.3 How often ?

76.4 How did the support provided compare with the total needs of the family ?

77. FORMAL SUPPORT

77.1 Are there any training centres/special school in your area ?

Yes
No

77.2 If yes, what role do they play in your child's life ?

77.3 If no, would you like to send your child to a centre if it was located in your area ? Support your answer

(The following questions are to be completed in the event of the child attending a centre)

77.4 Is there any improvement in your child's ability to learn social skills that now he is attending the training centre ?

77.5 Are you happy with the activities of the centre ?

Yes
No

Support your answer

77.6 Do you have an opportunity as a parent/guardian to discuss any problems with teachers that your child is experiencing ? e.g. parents day/meeting

77.7 Do you the services available in your area are what you want and need ?

Yes
No

Support your answer

77.8 Give suggestions of what you would like to be included in the school's activities.

77.9 Are there any voluntary agencies in your head area ? (Those organisations which provide help without remuneration) e.g. group of parents for the retardates

77.10 If yes what are their activities ?

77.11 Is use made of these services ?

SECTION J - THE SERVICES

78. **HEALTH SERVICES**

78.1 Is there any clinic in your area ?

Yes

No

78.2 How often do you visit the clinic ?

78.3 Is your child a sickly child ?

78.4 What is he suffering from ?

78.5 Are you satisfied with the service you are receiving from the nurses and doctors ? e.g. quality of services, support and advice

78.6 Do the community health nurses visit you ?

Yes

No

If yes how often ?

79. SOCIAL SERVICES

79.1 Is there a social worker in your area ?

Yes

No

79.2 If yes, how often do you see her ?

79.3 How long have you known the social worker ?

79.4 What type of help do you get from her ?

79.5 Is this help of any assistance to you ?

Yes
No

Support your answer

79.6 What do you think the social worker can do to be more helpful to you, your family and the community ? Support your answer

79.7 Do you think the services you receive is what you want and need ? Support your answer

79.8 What do you think the government can offer so as to alleviate the burden of caring for the handicapped child ?

80. Any further suggestions regarding services/assistance wich should be available in the community ?

BIBLIOGRAPHY

- Adams, M. (1960) The Mentally Subnormal - The Social Casework Approach. London: Heineman Medical Books Ltd.
- Allan, G. (1983) Informal Networks of Care: Issues raised by Barclay, British Journal of Social Work 13: 417 - 433.
- Anderson, D. (1979) Social Work and Mental Handicap. London: MacMillan.
- Arkava, M.I. & Lane, T.A. (1983) Beginning Social Work Research. London: Allyn & Becon.
- Bicknell, D.J. (1982) Living With a Mentally Handicapped Member of the Family; Postgraduate Medical Journal Volume 58. No. 684: 597 - 605.
- Child Care Act No. 74 of 1983.
- Chinkanda, E.N. (1986) Caring for a Mentally Retarded Child at Home. Social Work Practice 3: 6 - 9.
- Chinkanda, E.N. (1987) Support System of Mothers of Mentally Retarded Children. Pretoria: Human Research Council.
- Collins, K.J. (1982) Children with Learning Difficulties and their Parents. Johannesburg: University of Witwatersrand. D. Phil Thesis.
- Cohen, P.C. (1962) The Impact of the Handicapped Child on the Family. Social Casework 43: 137-142.
- Crnic, K.A. & Greenberg, M.T. (1985) Parenting Hassles: Relationship among minor stresses, family functioning and child development. Paper presented at the biennial meeting of the Society for Research in Child Development, Toronto, Canada.
- Crnic, K.A., Friedrich, W.A. and Greenberg, M.T. (1983) Adaptation of Families with Mentally Retarded Children: A model of stress, coping and family ecology. American Journal of Mental Deficiency Volume 88. No. 1002: 125 - 138.
- Darling, R.B. (1979) Family Against Society: A study of reactions to children with birth defects: London: Sage.
- Eden, D.J. (1976) Mental Handicap: An introduction. London: George Allen and Unwin Ltd.
- Epperson, M.M. (1977) Families in Sudden Crisis: process and intervention in a critical care centre. Social Work in Health Care (Spray) 265 - 274.

- Fowle, C.M. (1968) The Effect of the Severely Mentally Retarded Child on His Family. American Journal of Mental Deficiency 73: 468 - 473.
- Gallagher, J.J., Beckman, P. and Cross, A.H. (1983) Families of Handicapped Children: Sources of stress and its amelioration. New York: Oxford University.
- Gath, A. (1978) Down's Syndrome and the Family. London: Academic Press.
- Gowen, J.W., Johnson-Martin, N., Goldman, B.D. & Appelbaum (1989) Feelings of Depressional and Parenting Competence of Mothers of Handicapped and Non-handicapped Infants: A longitudinal study All American Journal of Mental retardation Vol. 94 No. 3 259-271.
- Grinnell, R.M. (1988) Social Work Research and Evaluation. U.S.A.: F.E. Peacock Publishing. Third Edition.
- Grossman, F.K. (1972) Brothers and Sister of Retarded Children: An exploratory study. New York: Syracuse University Press.
- Hanna, C. (1975) Parents and Mentally Handicapped Children. Middlesex: Penguin Books.
- Hanvey, C.P. (1981) Social Work With Handicapped People. Gordon: Heinemann Educational Books Ltd.
- Harris, V.S. & McHale, S.M. (1989) Family Life Problems, Daily Caregiving Activities and the Psychological Wellbeing of Mothers of Mentally Retarded Children. American Journal on Mental retardation. Vol. 94 No. 3: 231-239.
- Hewett, S. with Johan and Elizabeth Newson (1970) The Family and the Handicapped Child. London: George Allen and Urwin Ltd.
- Ingalls, R.P. (1978) Mental Retardation: The changing outlook. New Jersey: John Wiley.
- Joubert, Z.H.D. (1987) Social Work and Mental Handicap. Relating to parents. Social Work Practice 2: 10 - 12.
- Kew, S. (1975) Handicap and Family Crisis: A study of the siblings of handicapped children. Concon: Pitman.
- Koch, R.M.D. and Dobson, C.J. (1971) The Mentally Handicapped Child and His Family. New York: Bruner/Mazel Inc.
- Kohurt, S.A. (1966) The Abnormal Child: His impact on the family. Physical Therapy (46) 120 - 125.
- Maloney, M.P. and Ward, M.P. (1979) Mental Retardation and Modern Society. New York: Oxford University Press.

McKendrick, B. (Ed) (1987) Introduction to Social Work in South Africa. Pinetown: Owen Burgess.

Mdaka, B. (1991) Self-Help in Caring for the Mentally Handicapped. Social Work Practice 1: 10 - 11.

Miller, M.D. (1968) Toward a Greater Understanding of the Parents of the Mentally Retarded Child. The Journal of Pediatrics. Seattle, Wash. Vol. 73 No. 5: 699 - 705.

Menolascina, F.J. (1977) Challenges in Mental Retardation: Progressive ideology and services. New York: Human Sciences Press.

Mental Health Act No. 18 of 1973.

Ndabandaba, G.L. (1987) Crimes of Violence in Black Townships. Durban: Butterworths.

Ntombela, T. (1991) The Family of the Retarded Child. Social Work Practice 1: 15 - 17.

Office of the Attorney General: Republic of Transkei (General Minute 24/8/1/5 1980).

Payne, J.S. & Mercer, C.B. (1975) A Sketch of the Past, Present and Future. In: Kauffrian, J.M.; Payne, J.S. (eds) Mental Retardation: Introduction and perspectives. Charles E. Merrill Publishing Co.

Peck, C. and Hong, C.S. (1988) Living Skills for Mentally Handicapped People. Sydney: Croom Helm.

Phillips, D. and Williams, A. (1984) Rural Britain: A Social Geography. Great Britain: Basil Blackwell Publisher Ltd.

Robinson, N.M. and Robinson, H.B. (1976) The Mentally Retarded Child. New York: McGraw Hill.

Reid, W.J. and Smith, A.D. (1981) Research in Social Work. New York: Columbia Press University.

Schreiber, M. (1970) Social Work and Mental Retardation. New York: The John Day Company.

Specht, H and Vickery, A. (1979) Integrating Social Work Methods. Boston: George Allen and Urwin.

Tizard, J. and Grad, J. (1962) The Mentally Handicapped and Their Families: A social survey. London: Oxford University Press.

Turner, F.J. (1983) Differential Diagnosis and Treatment in Social Work. New York: The Free Press. Third Edition.

Transkei Govt. Circular No. 1 of 1989 Dept. of Welfare and Pensions.

Urbani, G. (1982) The Problems Surrounding Children with Genetic Impairments. Pretoria: Human Sciences Research Council.

Wilker, L. (1981) Chronic Stresses of Families with Mentally Retarded Children. Family Relations Vol. 30 No. 2: 281-288.

Wilken, D. (1979) Caring for the Mentally Regarded Child. London: Croom Helm.