AN INVESTIGATION INTO FACTORS AFFECTING THE INVOLVEMENT OF PARENTS WITH THEIR INSTITUTIONALISED MENTALLY HANDICAPPED CHILD

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ABSTRACT

This study explores the factors that affect the involvement of parents with their mentally handicapped children after the children have been admitted to Lentegeur Care and Rehabilitation Centre in Mitchells Plain, Cape Town.

The study was motivated by the concern of the researcher regarding the lack of parent-child contact and the failure of attempts by social work staff to increase parental involvement. For the purposes of the study involvement is defined as visits and telephone calls by parents to the institution and their subjective description of their emotional closeness to their children.

The literature review explores the effect the presence of a mentally handicapped child may have on family functioning and the circumstances that may cause the family to consider placing the child in an institution. Other studies concerned with parent-child involvement after institutionalization are reviewed.

An exploratory-descriptive research design was employed in this study. One hundred and sixty six residents of the Centre had families who lived within 20 km of the Centre and these families formed the study population. Of these residents, 44 were diagnosed as mild to moderately mentally handicapped and 122 were diagnosed as severe to profoundly mentally handicapped. A non-probability random purposeful sampling method was employed to ensure a range of mental handicap was represented in the

sample. Ten families of mild to moderately mentally handicapped children and 15 families of severe to profoundly handicapped children formed the sample. Twelve families of severe to profoundly handicapped children ultimately participated.

A semi-structured interview schedule was employed to gather quantitative and qualitative material. The interviews were all conducted by the researcher in the homes of the respondents.

The results of the study were largely supported by other studies in that the parents' lack of involvement was associated with socio-economic factors, the degree of mental handicap and the length of stay in the institution. It is suggested that the absence of professional help and counselling for the parents led to unresolved feelings regarding their children which could account for their lack of involvement. Parents responded positively to the individual interview, and 12 of the 22 parents have continued in individual or group counselling. Further research would be needed to establish whether this leads to increased involvement.

Recommendations include improved information be given to parents regarding diagnosis, the provision of counselling regarding emotional and practical issues, and improved community services.

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CHAPTER 1

INTRODUCTION AND GENERAL ORIENTATION

1.1 INTRODUCTION

Historically, the care of mentally handicapped people in certain societies has been characterized by their placement in institutions. Admission to an institution was frequently advised by professionals and other concerned people with the assumption that this course of action would be best for the family and the mentally handicapped child. The social stigma attached to having such a child also led many parents to institutionalise their child as soon as possible after diagnosis regardless of the degree of the handicap and with little understanding of alternative forms of care.

During the apartheid years in South Africa the lack of residential institutions precluded this course of action even being considered for the black population except in cases of extreme need. However, for the white, and, to some extent, coloured population, numbers of mentally handicapped children were admitted to institutions. As no alternative services were offered or considered, these admissions became permanent.

Recently, however, there has been a shift internationally from institutional care to community care for mentally handicapped persons. The present trend is towards encouraging and facilitating family involvement in the care of mentally handicapped people. It is becoming recognized that any child, irrespective of the degree of mental

handicap, will develop better living with his/her own family within the community, provided the family can care for him/her adequately. In South Africa, the current policy in health and welfare circles is to reduce residential services of all kinds, and to focus on community care.

The shift to community care requires that society becomes more understanding and tolerant of mental handicap. It also requires the provision of community facilities such as day centres and sheltered workshops. Where possible, those mentally handicapped people currently in institutions would need to be reintegrated with their families and communities. The first step in this process would be to encourage the involvement of families with their institutionalised mentally handicapped child.

1.2 STATEMENT OF THE PROBLEM

I am employed as a social worker at the Care and Rehabilitation Centre for mentally handicapped persons at Lentegeur Psychiatric Hospital, Mitchells Plain, Cape Town. It has concerned me and my colleagues that subsequent to placing their children in the Centre many families fail to maintain contact with them. This breakdown in the relationship between parents and their mentally handicapped children is highlighted by the emergence of the Centre's policy of reintegration of mentally handicapped residents back into the community. The aim of the policy is to place the mentally handicapped person back with his or her family and provide the necessary resources in the community to assist the parents. Where discharge is not possible, ongoing contact by families with the mentally handicapped person in the institution is

encouraged.

Most of the children who have been admitted to the Centre have been there for several years. Many have progressed through their developmental stages with minimal or no contact with their parents. The social workers at the Centre employ various methods of intervention such as family support groups, family sessions and "Family Days" in an attempt to encourage parent involvement. The failure of these attempts to increase the involvement of these parents with their children prompted me to study the reasons why parents are not involved or have minimal contact with their institutionalised children. For practical reasons the social workers' main outreach is to parents within reasonable travelling distance of the Centre, and therefore the study is focused on these parents.

1.3 DEFINITION OF MENTAL HANDICAP

Mental handicap is a condition of arrested or incomplete development of the mind, resulting in below average intellectual functioning (Gillis, 1986). However, mental retardation does not only include below average intelligence. Other functions are affected, such as emotional responses, social skills and the capacity to care for self and earning a living. Often there are associated biological or physical factors which result in a deformed body. The syndrome of mental retardation is thus complex.

Considerable conceptual confusion surrounds the term "mental retardation" (Braginsky and Braginsky, 1971). Edgerton (1979) attributes this to the fact that a great diversity

of "conditions" have come to be grouped together under the category of mental retardation.

The Mental Health Act, No 18 of 1973, regards mental handicap as a psychiatric illness and thus the same provisions apply in terms of admission to an instuitution and in relation to civil and criminal responsibility. The Mental Health Act defines mental illness as "any disorder or disability of the mind, and includes any mental disease, any arrested or incomplete development of the mind".

Within the South African context the term "mental handicap" has begun to replace the term "mental retardation". According to Lea and Foster (1990) this appears to be linked to an attempt to reduce the stigmatization attached to those being labelled. Various other terms are also used, for example, "developmentally delayed", "developmentally disabled" or "intellectually handicapped" in an attempt to sound less harsh and discriminating. Research has shown that modifying labels do not alter peoples' attitudes toward those whom they perceive to be different. Whatever the label, the label in itself connotates difference. Seed (1980) confirms that changing terminology does not reduce or eradicate the stigma attached to the label.

In the past mental handicap has been treated as a form of deviance. Lea and Foster (1990) note that in the early twentieth century the mentally handicapped in South Africa were associated with delinquency, prostitution, criminality, the 'poor white' and other associated phenomena. Although this perception of mentally handicapped people has changed they are often discriminated against because of their limited intellectual

ability and physical appearance.

In this study "mental handicap" has been chosen as the preferred term since it is widely accepted amongst the mental health professions. There seem to be no solutions to the dilemma of the stigma attached to a label. Therefore, I would ask the reader to carefully examine his or her own motives for rejecting or preferring any particular label and especially that of "mental handicap".

1.4 MENTAL HANDICAP IN SOUTH AFRICA

There seems to be little written about the history of mental handicap in South Africa. In the past mental handicap was treated as a form of insanity, thus forming a sub-category of mental illness. This largely reflects how the medical model has dominated in the treatment of mentally handicapped persons.

The historical development of the legal provisions for the mentally ill and handicapped in South Africa took place over three major periods according to Lea and Foster (1990):

(1) Between 1879 and 1895 all four regions of the future South Africa established both legal and institutional machinery to deal with lunatics.

(2) After union, between 1916 and the early 1930's, legislation applicable to the country as a whole was passed. More attention was given to the problem of mental health. Academic training in psychology, psychiatry, social work, psychiatric nursing, special education and other disciplines was established.

(3) Between 1965 and 1977, under the dominance of apartheid policy, numerous commissions of inquiry were instituted and a wave of modernising legislation regarding the broad field of mental health was promulgated. This period showed some shifts toward community based and day care approaches for the mentally handicapped, but mainly for whites.

(4) In the 1980's mental handicap was classed with the disabled, that is, the deaf, blind and crippled. Racial segregation and discrimination remained entrenched.

(5) In the 1990's there has been a shift in policy with the abolishment of apartheid. There has also been a move to more community orientated services.

One of the most striking characteristics in the field of mental handicap in South Africa has been racial discrimination within the mental health system. This has led to discriminatory services and limited community based services for the disadvantaged population groups. It is only recently that the process of integration of services started. However, we are still dealing with the consequences of apartheid. It will take some time before the disadvantaged sector of the community is on par with the previously advantaged sector of the community which has had access to all resources.

1.5 CHANGING NATURE OF INSTITUTIONS

The Concise Oxford Dictionary (1990) defines an 'institution' as an organisation for the promotion of some public object, or the building used for this. The Mental Health Act, No 18 of 1973, refers to an institution as "a state psychiatric hospital or a provincial hospital or halfway house at which provision has been made for the

detention or treatment of persons who are mentally ill".

However, the term "institution" has traditionally implied a strong, rigid, and structured environment in which the residents have minimal freedom of choice and action, and for whom life and the pursuit of happiness is planned according to the administrators of such institutions (Thorne, 1965). Goffman (1961) goes further and refers to a "total institution" as:

> "A place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together they lead an enclosed, formally administered life".

Goffman felt that in the past mentally handicapped people were treated as outcasts of society and were referred to colonies or placed in institutions where they were kept apart from the so-called "normal" society. Baroff (1974) agrees when he refers to these institutions as "human warehouses" bereft of training and humanity. Not all institutions can be described in such negative terms.

However, because mentally handicapped persons tended to be set apart from the rest of society, institutions for the mentally handicapped have traditionally had the aura of permanent placements. Mentally handicapped persons were seldom discharged into the care of their parents and their communities.

The term "rehabilitation centres" has been introduced in place of "institutions". The use of the term "rehabilitation centre" seems to shift the emphasis away from custodial care to rehabilitation. The aim is to increase the mentally handicapped person's

adaptive behaviour and social and life skills and where possible reintegrate the handicapped back into the community. To rehabilitate means "to restore to effectiveness or normal life by training" (Concise Oxford Dictionary, 1990). According to Anthony et al. (1981) rehabilitation is directed at increasing the strengths of the clients so that they can achieve optimum potential for independent living and meaningful careers.

In the field of mental handicap the aim would be to assist the mentally handicapped individual to develop personal, social and vocational skills as far as it is possible for that individual. Rehabilitation, therefore, encompasses a wide range of activities from the treatment of symptoms to the development of skills.

The multidisciplinary team should work together to provide the environment, instruction, and guidance which is necessary for the mentally handicapped person to acquire the above skills. Rehabilitation should involve the merging of institutional resources and community resources as well as assistance from state resources. Joint responsibility between the parents and the state are required. With increasing rationalisation of the health services the responsibility of parents will definitely increase.

1.6 THE STUDY

The proposed study investigates the factors affecting the degree of involvement of a sample of parents with their mentally handicapped children who are resident at

Lentegeur Care and Rehabilitation Centre, which is situated in Mitchells Plain, Cape. The Centre opened in September 1987 when staff and residents moved from Dr A.J. Stals Care and Rehabilitation Centre in West Lake. This institution previously only served the so-called coloured population group but since 1990 serves all population groups.

It is fully appreciated that the concept of "parental involvement" is a complex one. However for the purposes of this study "parental involvement" will be operationalised as consisting of:

(1) Physical involvement, which refers to visits by parents to their mentally handicapped child and attendance at conferences or family groups.

(2) Non-physical involvement, which refers to telephone contacts from parents.

(3) Emotional involvement, which refers to the parents' subjective description of their closeness to their son/daughter.

Although the study will only focus on these three types of involvement, it must be kept in mind that parents might be involved with their children at various other levels, for example, through religion i.e. praying for the child. This study will not deal with these other levels of involvement.

"The parents" in the study will refer to the biological parent(s) of the mentally handicapped child. The terms "child", "son/daughter" and "resident" will be used interchangeably to refer to the mentally handicapped person who is resident in the Centre. It must be noted that these terms are not altogether satisfactory as the

majority of the residents are adults in terms of chronological age.

The main research question is as follows:

What are the factors affecting the degree of parental involvement with their institutionalised mentally handicapped child?

This study will further attempt to address some specific concerns:

(1) To establish parents' views on the institution and whether this is linked to their degree of involvement.

(2) To establish whether there is a relationship between the quality of the parents' relationship with their child before institutionalisation and the frequency of visits after institutionalisation.

(3) To establish whether parents' degree of involvement is linked to the degree of mental handicap of the child.

(4) To establish whether the degree of involvement is related to transport issues.

(5) To establish whether the lack of counselling post diagnosis of mental handicap of the child is related to the degree of involvement of parents.

The outcome objective of the study is to establish the actual needs of parents and ways of increasing parents' involvement with their mentally handicapped son/daughter.

Currently social workers in the Centre are responsible for helping to develop and maintain relationships between the child and his or her family. Enormous frustration and disillusionment are experienced as efforts appear to have little effect. It is hoped

that this study will assist in helping social workers and other members of the multi-disciplinary team understand the nature of this relationship better and therefore plan more appropriate services. It is also hoped that the staff's improved understanding will lead to a changed attitude towards the parents of residents. Currently the staff display some anger and irritation towards the parents which has a negative effect on their relationship with the community and their work in general.

1.7 LIMITATIONS OF THE STUDY

The limitations of the study are that the results are limited to those families living in proximity to the Care and Rehabilitation Centre, Lentegeur Hospital and caution should be taken in generalizing beyond this population. The sensitivity of the subject may have led to difficulty in obtaining accurate information from parents. The researcher's dual role of social worker and researcher could also affect the parents' responses to questions.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

A number of factors which affect parents' involvement with their institutionalised mentally handicapped child must be understood. These include the circumstances surrounding the birth of the child, the impact of the child on family relationships and functioning, and events associated with admission.

2.2 THE IMPACT A MENTALLY HANDICAPPED CHILD HAS ON THE FAMILY

2.2.1 *THE BIRTH*

The birth of a mentally handicapped child has a profound effect on the family, the relationships of family members and their activities. Throughout the pregnancy parents expect and plan for a healthy baby. Therefore the birth of a mentally handicapped child is met with different reactions from parents. For the parents to accept this mentally handicapped child, they need to mourn the loss of the healthy child for which they had planned. In the literature, this process of mourning is identified as being similar to the bereavement process described by Kubler-Ross (1970). Waitman and Conboy-Hill (1992) summarize these stages as follows:

(1) Shock, disbelief, denial. Many parents cannot believe the news and may reject the baby.

(2) Anger at the hospital staff for any real or imagined difficulties with the birth, at God, or at themselves. Some parents blame themselves or their partners for some event during the pregnancy, however irrational this may be.

(3) Bargaining or searching. Parents may attempt to go back in time to recreate the pregnancy with a different outcome, or to search for a "cure".

(4) Depression and withdrawal. This may gradually give way to acceptance and resolution.

Working through these stages successfully will imply acceptance by parents of their mentally handicapped child. Normally, these stages do not follow neatly on one another.

Levinson (1967) found that parents go through many reactions in dealing with their misfortune. He found some common reactions among parents of mentally handicapped children, included:

(1) Shock - initially parents normally deny that there is something wrong with their child until they consult a doctor. Levinson states that parents are shocked on hearing the diagnosis. The doctor's diagnosis merely confirms their suspicion.

(2) Confusion - although parents suspect something is wrong with their child or have tangible proof, they tend to be afraid to face the truth. Levinson (1967) states that instead of parents addressing the situation they go through a lot of wishful thinking, "It can't be, I'm sure he'll outgrow it". Levinson described this state of parents as indecision, bewilderment and confusion.

(3) Shame - parents are ashamed to face their neighbours, their relatives, their friends and the public in general. It is this "shame complex" that makes parents hide their child behind closed doors.

(4) Bitterness and envy - the outstanding reaction according to Levinson (1967) on the part of the parents is one of bitterness, resentment, and envy. "Why did it have to happen to us?" "Why is everybody else's child normal?"

Studies highlight that parents seem to react in no set pattern to the birth of a mentally handicapped child but there seem to be some common reactions to this trauma. Kromberg (1977) in his study, investigated the responses of parents to the birth of a baby with Down's Syndrome. He found that parents invariably seem to exhibit grief reactions on hearing of their child's retardation.

Kennedy (1970) who also studied the maternal reactions to the birth of a defective child found that certain reactions characterised each phase of adjustment.

(1) Protest: includes shock, numbness, disbelief, not hearing, evasiveness, bewilderment, 'shopping', searching for magic cures and anger.

(2) Despair: includes disappointment, loss, hopelessness, helplessness, futility, sorrow, guilt, loss of warmth in relationships, and physical symptoms such as insomnia and loss of appetite.

(3) Withdrawal: includes recall of the pre-birth longings for the idealised infant and evidence of the cathexis of the live infant.

Thus the birth of a mentally handicapped child in the family creates a crisis. Most

parents need to know as much as possible about the diagnosis from the start, yet they need to discuss the same facts over and over before they can grasp their full significance. Therefore diagnosis needs to be explained as simply as possible without using jargon which may be meaningless to parents. During this stage of initial shock and denial as described in the literature, parents will also "shop" around and go to various professionals in the hope that they would find the child to be normal or provide a diagnosis with less stigma attached to it.

Some parents may even choose to ignore that there might be something wrong with their child until school going age when they are faced with the fact that the child is making no progress.

It becomes clear from the literature that parents experience intense emotions regarding the birth of their mentally handicapped child. It is not surprising therefore, that some parents totally reject their mentally handicapped child.

2.2.2 *FAMILY FUNCTIONING*

Parents also soon realise that having a mentally handicapped child will have a profound and long-lasting effect upon their lives. This tragedy may affect the parents much more than the mentally handicapped child, particularly if the child is severely handicapped. The more mentally handicapped the child, the less he or she realises the severity of his or her condition. The presence of a mentally handicapped child in the family affects various aspects of family life, for example, family relationships, siblings,

family size and associations. These aspects will be discussed briefly.

2.2.2.1 Family relationships

Family relationships can deteriorate due to the presence of the mentally handicapped child. The handicapped child affects the relationship between parents and the other brothers and sisters in the family. For some parents it may often mean that the worry and anxiety caused by the child can take away all the joy from the marriage and put strain on the relationship (Lonsdale, 1978). Mothers may have little emotional responsiveness left for their husbands at the end of an exhausting day. The marriage may break down completely because of the strain caused (Gath, 1977). Certain studies have found that the mentally handicapped child constitutes a negative influence on the parent's marital relationship (Farber, 1959; Tew, Lawrence, Payne and Rawnsley, 1977; Heaton-Ward, 1978; Chetwynd, 1985). Other studies have found the child to have strengthened the marital relationship (Kramm, 1963; Gath, 1977; Wright, Matlock and Matlock, 1985). Despite the awareness of the effects the mentally handicapped child has on the siblings very little research has been done on this aspect. The parents may be drawn closer together by the child, as they learn to share their troubles and become supportive of one another.

2.2.2.2 Siblings

The effect the mentally handicapped child has on the siblings must be considered briefly. Siblings commonly report feelings of shame and embarrassment at the looks

and behaviour of their mentally handicapped brother or sister (Cleveland and Miller, 1977). There might also be resentment at the additional responsibilities placed on them. They may also resent the amount of their mother's time being taken up by the handicapped child, leaving them with a disproportionate amount of attention (Fischer and Roberts, 1983).

2.2.2.3 Family size

Another effect on families with a handicapped child is that family size tends to be significantly smaller than would normally be expected. This is partly due to the practical problems of caring for a handicapped child. Much time and energy is demanded from the mother. The fear of having another mentally handicapped child possibly prevents families from having more children (Cleveland and Miller, 1977).

2.2.2.4 Social isolation

Another common effect is that families with a handicapped child are likely to be socially isolated. Parents tend to lead socially restricted lives for various reasons, for example, having problems with babysitting. This means that parents rarely go out as a couple, and this puts a strain on the marriage. Many mothers are forced to stay at home, because of a lack of day-care facilities, thus losing the financial and social benefits of working (Levinson, 1967). They may also find themselves in the position where they are virtually home-bound, unable to go to the shops or visit friends because of the difficult behaviour of the child.

Many parents thus disengage themselves from neighbours and the local community. The community may also be intolerant because of the stigma attached to mental handicap.

2.3 DECISION TO INSTITUTIONALISE

Caring for a mentally handicapped child is a difficult task and at some stage placement in an institution might be considered. The decision to institutionalise a handicapped child is both difficult and complex. It affects the handicapped child, his parents, siblings, close friends and the extended family.

The actual care of a handicapped child in the family is normally undertaken by the mother or another adult female who has been assigned the responsibility of caring for the child. Since caring for a mentally handicapped child can be a very demanding undertaking for any one person, the mother or caregiver needs to have adequate internal coping resources and normally also requires external support from some social network in order to cope with such a child. If this support network is lacking, institutionalisation may be needed. Morris (1969) and Black, Cohen, Smull and Crites (1985) confirm that the lack of community services is one of the precipitating factors leading to institutionalisation.

The disruptive nature of the mentally handicapped child's behaviour may be another reason for having the child admitted to an institution. According to Wolf and Whitehead (1975) the more the child is perceived to be disruptive, the more likely

he/she will be institutionalised. The degree of physical and mental disability is also regarded by Tausig (1985) as a predictor of placement in an institution.

As mentioned, the presence of a mentally handicapped child places strain on the family and has an impact on the relationships within the family. Farber (1959) said because of the impact the child has on the family, the family institutionalises the child as a means of "freezing out" a source of the family strain. Limited financial and social resources often precipitate the decision as well.

There seems to be an interplay of factors that leads to the decision to have a child institutionalised. The factors discussed above can be grouped in three categories namely:

(1) community factors;

(2) those concerning the handicapped child, and

(3) family factors.

Although research clearly identifies legitimate reasons for parents having their child admitted to an institution, other studies have also found that many mothers are not in favour of separating themselves from their children, even when the children are difficult to care for at home (Wilkin, 1979; Hallas, Fraser, Mac Gillivray, 1978).

2.4 ADMISSION PROCEDURE TO AN INSTITUTION - THE MENTAL HEALTH ACT NO 18 OF 1973

The Mental Health Act No 18 of 1973 makes provision for a mentally handicapped person to be admitted to an institution.

The Mental Health Act distinguishes between four categories of people who fall within the scope of the Act namely:

(1) Voluntary patients. These are persons who apply in writing and voluntarily submits themselves in terms of Section 3 of the Act, to treatment at the institution. If the person is a minor his or her guardian may make the application on his or her behalf.

(2) Patients by consent. This is a person who is admitted in terms of Section 4 of the Act. His or her admission is received and treated by the superintendent of the institution. The person will be admitted if he or she is not opposed to being treated and the application is made by suitable persons.

(3) Those detained in terms of a reception order issued by a magistrate and an order for further detention issued by a judge. This refers to Section 9 of the Act which refers to certified patients, where the magistrate may issue a reception order if he is satisfied that such a person is a danger to himself and others and found to be mentally ill.

(4) The President's patients and mentally ill prisoners. Persons are admitted to an institution as the President's patients and fall under Section 28 or as mentally ill prisoners admitted to an institution or hospital prison in terms of Section 30

to 32. A 'President's patient' is a person found to be guilty by a court of law for reasons of mental illness or mental defect and whom the court has then directed to be detained in a mental hospital pending the decision of the State President.

In practice most mentally handicapped persons get admitted by their parents in terms of Section 4 of the Mental Health Act. Where parents are found unfit to take care of their child, the child will be placed at the institution in terms of the Child Care Act (No 74 of 1983), or the child can be admitted in terms of Section 9 of the Act. The Act comes into operation when a mentally handicapped person is admitted to an institution be it for short term placement or permanent placement.

It seems, therefore, that because of various circumstances it may be advisable for the child to be admitted to an institution. Thus the process of placing a person in an institution is not negative in itself. However the lack of involvement after placement impacts negatively on the development of the child.

2.5 FAMILY INVOLVEMENT POST-INSTITUTIONALISATION

The family has always been seen as the most important institution in society. Craft, Bicknell and Hollins (1985) confirm this by stating, "The family has always been the foundation of our social structure".

Parents normally fulfil the role of attending to the varied needs of their children, be

they physical or emotional. When parenting a normal child, parents' practical responsibilities decrease as the child becomes older and more responsible. In contrast, the parents of a handicapped child have a lifelong responsibility which may vary in intensity depending on the degree of mental handicap. Caring implies nurturance, with the need for love and affection for the dependent person (Jennings, 1987).

There must also be continual guidance and socialisation of the dependent person, which will change at different phases of life as well as with the abilities of the dependent person. Jennings (1987) emphasises the provision of shelter is vital. Even if the person with a disability no longer lives at home, the parent still needs to provide the necessary caring where possible. Chinn, Drew and Logan (1975) sum it up when they state that irrespective of whether a mentally handicapped child is institutionalised or cared for at home, he or she is in no less need of the emotional support of his or her family than the child with normal intellectual potential. They go further to say that for these children to reach their potential they must have the same kinds and qualities of support as the normal child.

Family involvement of a child in an institution involves various aspects of the mentally handicapped child's life. For example the family could be involved in the planning of programmes while the child is in the institution and when considering discharge (Blacher and Baker, 1992). Family involvement in this aspect of the mentally handicapped child's life has resulted in successful community adjustment. The family could also become involved by taking the child out for weekends and by visiting them regularly. McConachie (1978) found that parental involvement was an essential catalyst

for maintaining the effects of educational programmes. Another aspect of family involvement is that family members can be important sources of physical and financial assistance and advocacy.

For those handicapped children who are in institutions, their families will be the only constant figures in their lives. The staff in the institution will rotate and change from time to time, therefore the constant involvement of parents is necessary.

Stoneman and Crapps (1990) found family involvement to be a contributing factor to successful community placement and of the resident's overall quality of life. Baker and Blacher (1993) in their study which investigated the dimensions of family involvement noted that parents and siblings can not only fulfil their usual roles but can also fill essential needs as friends, advocates and decision makers. The latter may be especially important to a mentally handicapped child.

There are only a few studies which investigate parents' relationship with their institutionalised mentally handicapped child. These studies, however, consistently show that families have limited involvement with their son or daughter when placed in an institution. There are various factors related to this limited involvement of parents.

The studies found that the factors that contribute to parents lack of involvement, include the degree of physical abnormalities, degree of mental handicap, distance from the institution, education level of parents, economic considerations and fear of having to take care of the child.

2.5.1 *PHYSICAL ABNORMALITIES AND DEGREE OF MENTAL HANDICAP*

Stoneman and Crapps (1990) and Anderson et al. (1975) found consistently that institutionalised children who are more able and competent were rated as having close ties with their parents, possibly because it is easier to maintain closeness when clients can contribute more to reciprocal social interaction.

Jubber's (1980) findings were similar, identifying that the greater the degree of the child's handicap the less frequent parental visits to the institution will become. The degree of the child's handicap is specifically related to the child's ability to relate meaningfully to parents.

Anderson, Schlottman and Weiner (1975) in their study used two measures to establish parental interest namely, frequency of visits to the institution and attendance at parent conferences. They found that children who were functioning at a higher level of intelligence and social maturity were more likely to be visited often, a finding which supports Klaber's (1968) observation that self-sufficient children are visited more often. All the studies found that the degree of the child's handicap had a direct influence on parental visits.

2.5.2 *EDUCATIONAL LEVEL OF PARENTS*

A further factor affecting the parents' involvement is the educational level of the parents. Downey (1963) in his study on parental interest in the institutionalised,

severely mentally handicapped child in America, found that the more educated parents, who place younger children in institutions, demonstrate less interest in their children than less educated parents. These parents had less contact with their children possibly because they viewed their children in terms of their ability to be educated.

2.5.3 *OCCUPATIONAL LEVEL OF FATHERS*

A less common predictor of parental visits to their child as found by Anderson, Schlottman and Weiner (1975) was the fathers' occupational level which had an influence on attendance at parent conferences rather than on visits. Fathers in lower occupational positions attended parent meetings less frequently. This finding may be related to the fact that most visits occurred on weekends while parent conferences at the institution were scheduled on week days, when parents in lower occupational positions would have more difficulty getting off from work.

2.5.4 *ECONOMIC CONSIDERATION*

Economic factors also seem to influence parents' involvement with their mentally handicapped child. Anderson, Schlottman and Weiner (1975) in their study found family income was related to the frequency of institutional visits. Jubber's (1980) study confirmed this finding.

2.5.5 *DISTANCE*

Distance may have an effect on the frequency of parental visits to their child in an institution. Anderson, Schlottman and Weiner (1975) found that the further parents lived from the institution the fewer the visits their child would receive. Klaber (1968) in his study on parental visits to institutionalised children in America found no such relationship. He found that the parents used distance as the most socially accepted rationalisation. He rather found that the frequency of visits are enhanced in those institutions where residents' development is accelerated and they appear happier and more self-reliant. Jubber (1980) who studied the after-admission relationship between parents and their institutionalised mentally handicapped child at Dr Stals Centre, found that the frequency of visits were influenced by a combination of factors which included cost, distance, and transport problems of getting to the Centre.

2.5.6 *FEARS OF HAVING TO TAKE CARE OF THE MENTALLY HANDICAPPED CHILD*

Another factor related to parents' lack of involvement is identified by Stoneman and Crapps (1990). They found low family involvement across the lifespan of the mentally handicapped person. Their findings suggested that family members seemed to be reluctant to get involved or show an interest in their mentally handicapped child for fear of being forced to take over the care of their relative.

2.6 UNRESOLVED FEELINGS OF PARENTS

In the literature there is no clear theoretical perspective that explains parental lack of involvement per se. Studies tend to focus on specific factors leading to parents lack of involvement that have already been mentioned. There seem to be many factors playing a role, but in the researcher's opinion the following factor may be important.

Through the experience of working with mentally handicapped children and their families, I have questioned parental lack of involvement in terms of the loss paradigm of Kubler Ross (1970) in which the stages are shock, denial, anger, sadness and acceptance. It could be hypothesised that if parents are unable to work through each stage successfully, they will be "stuck". This will mean they may have unresolved feelings about their mentally handicapped child which will influence their relationship with their child, and more specifically their degree of involvement. Although the last stage is acceptance, the bereavement process may be repeated at the arrival of another developmental stage of the mentally handicapped child. It is the researcher's opinion that in order for the above to take place successfully, parents need counselling after the child has been diagnosed as being mentally handicapped. It is thus suggested that if parents can successfully work through the loss of the healthy child they wanted by means of counselling, they will become and remain involved with their mentally handicapped child.

Olshansky (1962) says that "parents who have a mentally handicapped child suffer chronic sorrow throughout their lives regardless of whether the child is kept at home

or is put away". All the other reactions reported in the literature may well form part of this "chronic sorrow". Parents will thus experience this intense grieving from time to time.

2.7 DETACHMENT OVER TIME

Baker and Blacher (1993) sought to understand parents' limited involvement with their mentally handicapped children in terms of "detachment". Bowlby's (1980) work refers to the child separating from the mother and individuating to form his or her own identity. Baker and Blacher (1993) refer to detachment as the process of the "loosening" of the parents from their child over time and this is reflected in thoughts and feelings as well as behaviour towards the child.

Detachment is thus seen as a progressive disengaging from the placed child, which is a natural process. Intagliata, Willer and Wicks (1981) also found that family contacts diminish over time. They felt this process of disengagement of parents from their institutionalised child accounts for their lack of involvement.

2.8 CONCLUSION

This chapter has examined the enormous impact a mentally handicapped child has on the family and has identified some of the factors that could lead to the decision to institutionalise the child. The researcher has also discussed factors which affect the family maintaining contact with their mentally handicapped child once institutionalised.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

The present chapter describes the aims and methods of this study. The manner in which the sample was selected is explained and the design of the study discussed.

3.2 RESEARCH DESIGN AND AIMS OF THE STUDY

Due to the fact that very little previous research has been done regarding this topic, an exploratory-descriptive design was employed. The survey method was used to collect a combination of qualitative and quantitative data through the use of a semi-structured interview schedule.

The main research question is as follows:
What are the factors influencing the involvement of parents with their institutionalised mentally handicapped sons/daughters? Specific questions were asked of the parents in the following areas, although there was opportunity for respondents to discuss other factors that might have influenced their involvement with their mentally handicapped sons/daughters:

- the parents' experience of the institution
- the quality of the parents' relationship with their sons/daughters before

admission to the institution and whether this relationship changed after admission to the institution

- the degree of mental handicap of the resident
- transport difficulties
- the degree/quality of counselling parents received post diagnosis of the mental handicap of their sons/daughters.

The outcome objective of the study was to establish the actual needs of the parents in order to find ways of increasing parents' involvement with their mentally handicapped sons/daughters.

3.3 DESCRIPTION OF THE POPULATION AND SAMPLE

The study was conducted at Lentegeur Care and Rehabilitation Centre. The Centre is situated in a suburb of Cape Town called Mitchells Plain. In the previous political structure of apartheid the health care system was divided along racial grounds and Lentegeur Hospital served mainly the local coloured population. Presently all population groups are admitted to the Centre.

All referrals to the Centre are processed via a committee which meets on a weekly basis to assess applications for suitability, after which patients will be admitted, or placed on a waiting list, or referred to an appropriate agency.

The Centre accommodates 880 mentally handicapped residents with diagnosis of mild,

moderate, severe and profound mental handicap. In some cases residents suffer from physical disabilities as well, for example, spasticity, blindness or deafness. The majority of the residents of the Centre have been institutionalised for many years. Holistic management principles are employed by the Centre to achieve optimum functioning of each resident.The multi disciplinary team works together to establish the needs of each resident. Tasks are identified and allocated to the most appropriate or available professional who is then empowered to perform the tasks.

The parents of many of the residents of the Centre are deceased. Others live considerable distances away from the Centre, and therefore cannot be expected to visit regularly. It was established that one hundred and sixty-six residents had a biological parent or parents who were still alive and lived within a radius of 20km of the Centre, and these families formed the study population.

Of these 166 residents, 44 had been diagnosed as suffering from mild-moderate mental handicap and 122 were diagnosed as having severe-profound mental handicap. In order to ensure that parents of residents suffering from the full range of mental handicap would be represented in the sample, a non-probability random purposeful sampling method was employed to select 10 families of residents in the mild-moderate range of mental handicap and 15 families of residents in the severe-profound range of mental handicap. Purposeful random sampling was employed. As Patton (1990:179) states:

> "The fact that small size will be chosen for indepth qualitative study does not automatically mean that the sampling strategy should not be random ... random sampling, even of small samples, will substantially increase the credibility of the results."

Twelve families of residents in the severe-profound range of mental handicap ultimately participated in the study, as two families refused to contribute and one mother was mentally handicapped and unable to participate.

3.4 MEASURING INSTRUMENT

The study was initiated by attempts to run a single session focus group with six parents of mentally handicapped residents who lived in the Mitchells Plain area to identify common concerns and issues that could generate questions for the interview schedule (Morgen and Spanish, 1984). Although the potential participants were approached individually, and invited to meet as a group, they failed to do so. A possible reason for this could be that the topic was experienced as too threatening to be discussed on a group level before trust had been built up with the researcher.

A semi-structured interview schedule was therefore developed, based on the literature review and the researchers' experience and tested by a pilot study of five interviews with parents of residents of the Centre. There were no major problems with the questionnaire but minor adjustments were made. The semi-structured questions in the interview schedule gathered demographic information; birth and developmental history of the mentally handicapped children and how these were experienced by their parent(s); the parents' relationships with their mentally handicapped sons/daughters before and after admission; and the nature and frequency of current contacts between the parents and their children. The counselling histories were also explored, including how they learned of the diagnosis. The interview schedule allowed for parents to

respond freely to all areas of investigation, particularly in the area of their relationship with their sons/daughters and the process by which they learned about their mental handicap.

3.5 DATA COLLECTION

Information was gathered by the researcher at the homes of residents' families by means of the semi-structured interview schedule. The researcher visited the parents in the evening or over weekends as most parents worked and this was judged to be the most convenient time for them. It was considered that an initial personal contact was preferable to a written request for their participation in the study which could be misconstrued as a complaint from the Centre regarding their failure to visit. The parent(s) were told what the research entailed and the reason for the study and were invited to participate. They were informed of the researchers' profession and that the research formed part of a Masters degree course at the University of Cape Town. At the outset of the interview parents were reassured of confidentiality, and that no information would be given to the staff of the Centre unless the parents so requested. It took the researcher approximately one and a half to two hours to interview parents, as they used this opportunity to talk about their experiences. Parents talked openly about very sensitive matters and appeared to have a need to ventilate their feelings about past experiences. The researcher, therefore, had a dual role to play in gathering information from, and providing support to these parents. The data obtained from the interviews was transcribed manually as tape recorders would not have been acceptable because of the sensitive nature of the study.

3.6 ETHICAL CONSIDERATIONS

Although an initial personal contact could be experienced as putting pressure on parents to agree to participate in the study, it was considered preferable to the receipt of a letter requesting their participation that could arouse anxiety and guilt. The sensitive nature of the field of study was acknowledged and given consideration in the interview. Respondents were given adequate time to communicate their concerns during the interview and care was taken during the interview to contain feelings. Patton (1990:355) says "while interviews may be intrusive in re-opening old wounds, they can also be healing". Three of the parents needed immediate counselling and are currently being seen by the researcher. Two parents were referred with their permission to relevant ward social workers. Another seven of the respondents indicated their wish to join a support group to be run by the researcher and attend monthly meetings regularly.

3.7 LIMITATIONS OF THE STUDY

The study was not intended to be generalised beyond this institution. Within this institution the focus of the study is on families within visiting distance of the Centre, where the major concerns of the social workers lie. While efforts were made to increase reliability and validity, the findings must be interpreted with the understanding that the sensitivity of the subject could lead to distortions by the respondents. The researcher's dual role of researcher and social worker at the institution may also have affected some of the responses.

CHAPTER 4

FINDINGS

4.1 FINDINGS

The findings will be presented in the following sections: demographic details, details of pregnancy and birth, post-natal development, counselling post-diagnosis, relationships with the mentally handicapped son/daughter before and after admission, admission to Lentegeur Hospital, parent-child contact and the parent's view of the institution. The results are presented in tables, supplemented by qualitative material including selected statements made by the respondents. Only when there are substantive differences between the responses of the parents of children in the severe-profound range and mild-moderate range will a distinction be made between the two groups.

Of the 22 families interviewed, the mother of the mentally handicapped resident was the primary respondent in all but one case. Thirteen of the families consisted of couples, the husband being the biological father, but in only three cases were the fathers present during the interview. In the one case where the father was the respondent the mother had not yet returned from work. The remaining 9 respondents were mothers who were single through divorce, separation or death of their spouse. Consequently, the information gathered reflected the mothers' perspectives and this needs to be taken into account in interpreting the findings. The findings will be

discussed fully in the following chapter.

4.1.1 *DEMOGRAPHIC DATA*

Table 1: ***Age distribution of residents at Care and Rehabilitation Centre***

Age Range	Number of Residents (%)		Total number of residents
	Severe - Profound	Mild-Moderate	
0 - 10	1 (8,3)	1 (10)	2 (9,1)
11 - 20	0 (0)	3 (30)	3 (13,6)
21 - 30	3 (25)	2 (20)	5 (22,7)
31 - 40	8 (66,7)	2 (20)	10 (45,5)
41 - 50	0 (0)	2 (20)	2 (9,1)
TOTAL	12 (100)	10 (100)	22 (100)

Most of the residents (45,5%) were between 31 and 40 years of age. Only 5 (22,7%) of the residents were below the age of 20 years.

Table 2: ***Length of stay of parents at present address***

LENGTH OF STAY	N (%)
More than 10 years	15 (68,2)
Less than 10 years	7 (31,8)
TOTAL	22 (100)

The majority 15 (68,2%) of the respondents have lived longer than ten years at their present address. Seven (31,8%) of the respondents have stayed at their present address

less than ten years and those that moved have changed suburbs.

Table 3: ***Religious denomination of parents***

DENOMINATION	N (%)
Protestant	14 (63,6)
Roman Catholic	0 (0)
Moslem	3 (13,6)
Other	5 (22,7)
TOTAL	22 (100)

Most of the respondents (63,6%) were Protestant. Three (13,6%) were Moslem. The "other" 5 (22,7%) were members of Charismatic Christian Churches.

Table 4: ***Education level of parents interviewed***

EDUCATION LEVEL	N (%)
No formal education	0 (0)
Primary	17 (77,3)
Secondary	5 (22,7)
Tertiary	0 (0)
TOTAL	22 (100)

Seventeen (77,3%) respondents have had only a primary school education and five (22,7%) had a secondary education.

Table 5: ***Employment status of parents interviewed***

EMPLOYMENT STATUS	N (%)
Full-time employed	11 (50)
Part-time	1 (4,5)
Shifts	0 (0)
Contract	0 (0)
Unemployed	0 (0)
Retrenched	0 (0)
Other	10 (45,5)
TOTAL	22 (100)

Eleven (50%) of the respondents are full-time employed. Ten (45,5%) respondents fall into the group 'other'. Of these ten respondents, five are housewives, four pensioners and one was in receipt of a disability grant.

Table 6: ***Employment status of the partners or spouses of those interviewed***

EMPLOYMENT STATUS	N (%)
Full-time employed	10 (55,6)
Part-time	3 (16,7)
Shifts	0 (0)
Contract	0 (0)
Unemployed	1 (5,6)
Retrenched	0 (0)
Other	4 (22,2)
TOTAL	18 (100)

Of the twenty two respondents interviewed only eighteen respondents had partners or spouses. the remaining four respondents were single, due to divorce or death of their spouse. Of the respondents interviewed it seemed that in every household one parent held a job. Thirteen (72,3%) of the partners or spouses had some form of employment, 10 (55,6%) of the spouses or partners had full-time employment and 3 (16,7%) had part-time employment. One (5,6%) partner or spouse was unemployed. The remaining 4 (22,2%) fell into the group 'other', three of which were pensioners and one in receipt of a disability grant.

Table 7: ***Total household income per month***

TOTAL HOUSEHOLD INCOME PER MONTH	N (%)
R200 - 300	1 (4,5)
R301 - 400	0 (0)
R401 - 500	1 (4,5)
R501 - 600	2 (9,1)
R601 - 700	8 (36,4)
R701 - 800	2 (9,1)
R801 - 900	2 (9,1)
R901+	6 (27,3)
TOTAL	22 (100)

Fifteen (68,2%) respondents earned between R500 - R900 per month. Six (27,3%) respondents earned R901 and more per month. One (4,5%) respondent earned between R200 - 400 per month.

Table 8: ***Marital status of mothers***

MARITAL STATUS	N (%)
Married and living with father of child	12 (54,5)
Married and living with man, other than child's father	3 (13,6)
Divorced/separated and living alone	2 (9,1)
Divorced/separated and living with man, not father	1 (4,5)
Widowed and living alone	1 (4,5)
Widowed and living with man, not father	1 (4,5)
Never married and living alone	0 (0)
Never married and living with man, not father	0 (0)
Common-law marriage (Moslem)	1 (4,5)
Widowed and living with daughter	1 (4,5)
TOTAL	22 (100)

The majority 13 (59%) of the respondents were still married to or living with the father of their mentally handicapped son/daughter. One marriage was a common-law marriage. Three (13,6%) of the respondents were divorced or, separated and three (13,5%) were widowed.

Table 9: *Number of children*

NUMBER OF CHILDREN PER FAMILY	N (%)
2	2 (9,1)
3	2 (9,1)
4	2 (9,1)
5	6 (27,3)
6	4 (18,2)
7	1 (4,5)
8	1 (4,5)
9	2 (9,1)
10 and more	2 (9,1)
TOTAL	22 (100)

This table represents the number of children per family. Sixteen (72,7%) had five and more children. The families who participated in the study were quite large.

Table 10: *Type of dwelling*

TYPE OF DWELLING	N (%)
Free standing	7 (31,8)
Semi-detached	15 (68,2)
TOTAL	22 (100)

Fifteen (68,2%) respondents lived in semi-detached houses and seven (31,8%) respondents lived in free standing houses. These dwellings are characteristic of the socio-economic class of the respondents.

Table 11: *Type of home ownership*

TYPE OF OWNERSHIP	N (%)
Rented	10 (45,5)
Owned	12 (54,5)
TOTAL	22 (100)

Ten (45,5%) respondents rented the houses in which they lived and 12 (54,5%) respondents owned their homes. The pattern of home ownership was consistent with the rest of the community in terms of ownership style and duration of stay. These are relatively settled communities.

4.1.2 *DETAILS OF PREGNANCY AND BIRTH*

Table 12: *Age of mother at time of pregnancy*

AGE RANGE	N (%)
15 - 20	9 (40,9)
21 - 30	7 (31,8)
31 - 40	6 (27,3)
TOTAL	22 (100)

A large proportion, 9 (40,9%) of the mothers fell pregnant before the age of 20 years. Sixteen (72,7%) of the mothers had fallen pregnant before the age of 30 years.

Table 13: ***Birth order of the mentally handicapped child***

BIRTH ORDER	N (%)
1	9 (40,9)
2	2 (9,1)
3	2 (9,1)
4	5 (22,7)
5	2 (9,1)
6	1 (4,5)
10	1 (4,5)
TOTAL	22 (100)

For 9 (40,9%) of the mothers their first child was mentally handicapped.

Physical problems experienced during pregnancy and birth:

Data obtained indicated that 19 (86,4%) of the respondents experienced no problems during their pregnancy while 3 (13,6%) of the respondents experienced problems. Of these three mothers, one had German measles during pregnancy, one had a complicated birth due to prolonged pregnancy and one had fibroids and believed that she was bewitched. Of these pregnancies, 15 (68,2%) of the respondents had a normal birth and 7 (31,8%) experienced problems.

4.1.3 *POST-NATAL DEVELOPMENT*

Achievement of early milestones within the normal range of development, 0-2 years

The term "milestones" refers to the age at which the child started walking, talking, crawling, playing and so forth. The majority 17 (77,3%) of the respondents reported that their child's milestones were not achieved within the normal range of development. Five (22,7%) of the children achieved their milestones within the normal range and problems were only noticed when they went to school.

Table 14: ***Age at which a problem was noticed in the child***

PERIOD OF TIME	N (%)
1st few weeks	6 (27,3)
1st few months	7 (31,8)
at two years	6 (27,3)
after two years	3 (13,6)
TOTAL	22 (100)

Data indicates that the majority 19 (86,4%) of the respondents knew by two years that their child had some delay in their developmental milestones. By this age most parents had became aware that their child was unable to perform tasks that other children could manage. The extent of the developmental delay was not known at this stage. Only 3 (13,6%) respondents found out after their child was two years that there was a developmental delay in their child's milestones.

4.1.4 *COUNSELLING POST-DIAGNOSIS*

Table 15: ***Person who informed parents of their childrens' handicap***

PERSON WHO INFORMED PARENT(S)	N (%)
Doctor	16 (72,7)
Social Worker	2 (9,1)
Nursing sister	1 (4,5)
Mothers knew their children were handicapped	3 (13,6)
TOTAL	22 (100)

Sixteen (72,7%) of the respondents were told by a doctor of their child's handicap. Two (9,1%) respondents were told by a social worker and one (4,5%) respondent was told by a nursing sister. Three (13,6%) mothers "knew" that their child was mentally handicapped.

Those parents who were informed by a doctor of their child's mental handicap received different and very limited explanations. Fourteen respondents were only told that their child's progress would be slower than other children. Many of these respondents did not understand at the time what the doctor meant or the implications of what the doctor said. This is illustrated by the following examples. A mother recalled that the doctor only said,

> "Your child will be backward and will have difficulty learning".

The mother at that stage did not realise that the condition was permanent. She only realised the permanency of the condition after a few years. This mother said,

> "If the doctor only spent more time explaining to me that my son will have this condition for the rest of his life, I would have been prepared, but here I

> thought he would initially have difficulty learning but with our support this would be corrected, but no, later we were shocked to realize that his condition was permanent. I was angry towards the doctor for not telling us, but maybe I should have asked questions. Up until today I feel that the doctor could have spent more time. I am feeling angry all over again, lets stop talking about this."

Another explanation, as a mother recalls is:

> "Jou kind kry epileptiese aanvalle en sal gesond wees as hy gereeld sy medikasie gebruik. Dit is eers later toe ek my kind skool toe stuur en hy maak geen vordering het ek besef dat daar iets verkeerd is met hom. Ek het geredeneer maar hoe kon daar iets fout wees wanneer die dokter vir my gesê het hy sal gesond wees as hy sy medikasie gereeld gebruik en ek het dan gesorg dat hy sy medikasie gereeld neem."

One mother recalls the following explanation by the doctor,

> "The doctor told me your child is retarded and needs to go to an institution because you will not be able to look after her. I was outraged by this doctor who told me that I would not be able to look after my child. No explanation was given what retarded meant, but me and my husband was determined to look after our own child. It was only after a few years that we realised that we were unable to cope with our daughter's behaviour. But the doctor did not give us reasons why placement in an institution will become necessary and what he meant by retarded."

Three respondents were given a detailed account by the doctor of their child's diagnosis of mental handicap and how their child would develop and what could be expected from their children.

One respondent was told by the doctor that her child had a speech defect and was referred to a speech therapist, only to find out after a few years of therapy that her child was mentally handicapped. This mother's response was:

> "Om the hoor dat jou kind nie kan praat nie is moeilik om the aanvaar en uiteindelik het ek dit aanvaar. Om na dit the hoor jou kind is vertraag, is hart-

verskeurend. Die dokters het ek vertrou, maar van daardie tyd vertrou ek hulle nie meer nie."

Table 16: ***Emotional reactions of respondents and their families on learning of their child's mental handicap***

Main reaction of Respondents	Number of respondents	Reaction of Rest of Family as reported by respondents	Number of respondents
Anger	8	not sure	5
Sadness	22	cannot remember	4
Disbelief	12	sad	22
Hopeless	6	rejected	1
Self-pity	4	showed no emotion	5
Disappointed	5	shocked	11
Felt bad/ill	10	-	-

All respondents felt that the diagnosis had a negative effect on them and some members of their families. The range of words that respondents used to describe their feelings were anger (towards the person who they thought had caused the condition), felt "bad", shocked, sadness and so forth. A mother's response to the diagnosis of her child was:

> "I asked myself why me? Why did God allow this to happen to me. I tried to think what I did wrong to deserve this. My only son and now I was told he was mentally handicapped. The sadness, the anger and disappointment I experienced during that period was overwhelming. Then to be told by your mother to accept your child's condition as God's will was enough to drive me into a state of depression."

The respondents also reported on how their families reacted on hearing the diagnosis. The reactions ranged from family members being sad and shocked to telling the

mothers to accept their mentally handicapped child. Some respondents reported that they were unaware how their families reacted because they were more concerned with their own feelings.

Table 17: ***Counselling after diagnosis***

COUNSELLED	N (%)
Yes	1 (4,5)
No	21 (95,5)
TOTAL	22 (100)

Counselling in this question means the opportunity parents had to talk through issues related to their mentally handicapped child within a professional relationship. Twenty one (95,5%) of the respondents were not counselled. Only 1 (4,5%) respondent was counselled on an ongoing basis for nine years by a social worker who visited the family regularly. The one mother who was counselled said,

> "As ek met ander ouers praat wie dieselfde probleem het, dink ek, ek was in 'n gelukkige posisie, want 'n maatskaplike werker het gereeld vir my kom besoek vir nege jaar. Ek het vir daardie tydperk die geleentheid gehad om probleme wat ek met my kind ervaar het met haar te bespreek. Soms het dit nie oor probleme gegaan nie, maar oor my gevoelens. 'n Mens kan nie altyd met jou man gesels nie."

Parents' opinion on whether on-going counselling, had it been available, would have helped them to cope better.

All but one of the respondents said that they felt that ongoing support and counselling

would have helped. One mother said:

> "I often felt that I needed to speak to someone because I had so many unanswered questions. There was simply nobody to speak to. My family who tried to be supportive somehow never understood what I was going through."

Another respondent sadly recalled:

> "Die pyn destyds was so intens, maar ek moes voorgee dat alles goed gegaan het. Ek het niemand gehad om mee te gesels nie. Ek moes alles alleen dra. Van tyd tot tyd raak ek steeds hartseer, veral as ek na my kind kyk. As ek iemand gehad het om mee the gesels, sou die seer dalk minder gewees het of dit sou net beter gevoel het om iemand the hê met wie ek my pyn kon deel."

Another mother said that if she only had someone to speak to, she would have spent more time with her daughter and would have brought her home more often. The mothers in this sample generally verbalised their regrets for not having somebody to speak to and thought of how it might have been different for them.

Only one mother said that she felt that counselling would have made no difference. She said that nobody would have been able to help her because she struggled too much. It seemed as if this mother was still very angry.

4.1.5 *FAMILY AND NEIGHBOURHOOD RELATIONSHIPS WITH THEIR MENTALLY HANDICAPPED CHILDREN BEFORE AND AFTER ADMISSION*

Relationship before and after admission between the severe to profoundly mentally handicapped children and their mothers

In most cases the mother was the respondent in the interviews. All those mothers (12)

who had children in the severe to profound range of mental handicap reported a good relationship with their child before admission. They reported a good relationship after admission as well. Their criteria for considering the relationship to be good was that they had cared well physically for the children. They had difficulty in describing this relationship on an emotional level. As one mother explained,

> "I gave birth to my child. How can you question my relationship with her. I looked after her before she was admitted. Struggled to feed and wash her, which her father did not help me with. If I was by the means I will still take care of her."

Relationships before and after admission between the mild to moderately mentally handicapped children and their mothers.

Of the 10 mothers who had mentally handicapped children in the mild to moderate range of mental handicap, nine reported a good relationship before admission and one reported a poor relationship. The reason given for the poor relationship was that the mother had too many children to take care of including another mentally handicapped child. This mother said,

> "I had too many children, plus another mentally handicapped child. There was just not enough time to spend with each child. My husband and I worked. The children had to look after each other. And then my husband had extra marital relationships. There was so many stressful things happening to me, that I did not have the time or the energy to build up a relationship with any of my children. I regret this today, but what can I do."

After admission, seven of the nine mothers reported having a good relationship. One mother reported that the relationship had deteriorated and one reported no relationship with their child.

Relationships before and after admission between the severe to profoundly and mild to moderately mentally handicapped children and their fathers.

Generally it was reported by the respondents that fathers had poor relationships with their mentally handicapped children. They spent very little time with them, because of their work, or had difficulty in accepting their child's condition which resulted in the poor relationship perceived by the respondents. In most cases, after admission, this poor relationship deteriorated and fathers seldom kept contact. Only three fathers kept regular contact with their children after admission.

Relationships before admission between the severe to profoundly handicapped children and their siblings as observed by respondents

The data was obtained from the respondents who commented on the siblings' relationships. The following data about the siblings relates to those twelve residents who fell into severe to profound range of mental handicap. Ten (83,3%) of the respondents reported that the siblings had poor relationships with their mentally handicapped sister or brother. Eight of these ten respondents reported further that the siblings felt shy and embarrassed on account of their brother or sister's physical appearance and as a result never brought friends home. A father's account of the siblings relationship with his brother:

> "Ek en my vrou was aanvanklik so behep met ons eie gevoelens en met hom wie al ons aandag vereis het dat ons half vergeet het van ons ander seun. Ons het bewus geraak dat hy baie eensaam is en geen vriende huistoe bring nie. Toe ons hom vra waarom hy nie sy maats huistoe bring nie het hy gesê dat hy skaam is en dat sy maats nie weet dat hy 'n vertraagde broer by die huis het nie. Ek en my vrou het onmiddellik besef hoe moeilik dit vir hom moet wees

as kind om sy vertraagde broer the aanvaar."

One respondent said that her daughter would bring friends home on occasions but would ask her mother to lock her sister in her room.

Two (16,7%) respondents said that siblings were scared of their brothers because of their behaviour (head banging). Two (16,7%) of the respondents said that their siblings had a good relationship with their mentally handicapped sister or brother.

Relationships before admission between the mild to moderately handicapped children and their siblings as observed by respondents.

A positive relationship between their siblings and their mentally handicapped brother or sister was reported for those ten children who fell into the mild to moderate range of mental handicap. Eight (80%) respondents said that siblings had a good relationship with their mentally handicapped brother or sister. The mentally handicapped siblings were treated as 'normal' and did most things with their siblings. Two (20%) respondents said that siblings had a poor relationship with their mentally handicapped brother or sister, the reason being the aggressive behaviour of the mentally handicapped child. Another mother commented about the siblings' relationship with their mentally handicapped sister.

> "It was more sad for me to see how the children reacted to their sister. They would ignore her. Become angry at me and say she is an embarrassment to the family. They never brought friends home and would constantly remind me that it was because of M."

Relationships after admission between the severe to profoundly mentally handicapped children and their siblings as observed by respondents

Data indicated that the siblings' relationship with those mentally handicapped children who fell into the severe to profound range of handicap did not change significantly after admission. Ten (83,3%) respondents reported that the siblings continued having a poor relationship with their brother or sister after admission to the extent that they stopped having contact with their brother or sister. The other two respondents (16,7%) reported that the siblings' relationship deteriorated because they had other responsibilities to attend to, and seldom made contact with their institutionalised brother or sister.

Relationships after admission between the mild to moderately mentally handicapped children and their siblings as observed by respondents.

Data indicated that the relationships between siblings and their mentally handicapped brother or sister who fell into the mild to moderate range changed significantly after admission. It was reported that five (50%) of the sibling relationships deteriorated after admission because they spent less time with their mentally handicapped brother/sister. The reasons given were mainly because of other responsibilities and having families of their own. Four (40%) of the respondents reported that the siblings' relationship remained unchanged. They continued to maintain contact after admission, by visiting regularly and fetching their brother or sister for weekends. Only one (10%) respondent reported that the sibling's relationship improved with the mentally

handicapped sister after admission. The reason given was that the sibling was encouraged by family members to make contact with his/her sister.

Relationship before admission between the severe to profoundly mentally handicapped children and neighbours, children and other adults

Ten (83,3%) of the twelve respondents whose mentally handicapped children fell into the severe to profound range reported that their child had very little relationship with other children, neighbours and adults because the child was kept indoors while being at home. This was because parents felt protective towards their child and also embarrassed in some measure about their mentally handicapped child. Most respondents reported teasing by the neighbours' children which further led to the mentally handicapped child being secluded in the home. Two (16,7%) of the respondents reported that neighbours' children and other adults had a good relationship with the mentally handicapped child and at times helped to take care of him/her.

Relationships after admission between the severe to profoundly mentally handicapped children and neighbours, children and other adults.

After the mentally handicapped child was admitted to an institution the neighbours' relationship remained unchanged. Those neighbours who had a good relationship with the mentally handicapped child continued to enquire about his/her condition.

Relationships before and after admission between the mild to moderately handicapped children and neighbours, children and other adults.

Six (60%) respondents with children in the mild to moderate range of mental handicap reported a good relationship between neighbours, children and other adults before admission. After admission, this positive attitude was maintained when the child came home for holidays/weekends. Neighbours and others helped with the care-giving and took the mentally handicapped child on outings. Two (20%) respondents reported a poor relationship with neighbours which was characterised by teasing before admission. This relationship continued after admission. A further two (20%) respondents reported to very little relationship between the child and neighbours because their mentally handicapped child was kept indoors. This lack of any relationship was maintained after admission as well.

Summary

In summary, mothers claimed their relationships with their children were good before admission and remained so after admission. Fathers' relationships were reported to be poor before and after admission. The respondents reported that the relationships between the severe to profoundly mentally handicapped children and their siblings, their neighbours, other children and adults were poor before admission and remained so after admission.

Relationships between the mild to moderately mentally handicapped children and their

siblings were reportedly good prior to admission but deteriorated slightly after admission. Relationships with neighbours, other children and adults were fair. Sixty percent of the mothers reported a good relationship before admission and this was largely maintained after admission.

It must be noted particularly in relation to the findings regarding the fathers' relationships, that most relationships were reported from the mothers' perspective.

4.1.6 *ADMISSION TO THE CARE AND REHABILITATION CENTRE, LENTEGEUR HOSPITAL*

Table 18: *Age of child on admission to Care and Rehabilitation Centre, Lentegeur Hospital*

AGE ON ADMISSION (Years)	NUMBER ADMITTED
2	1
4	1
5	1
7	2
8	4
10	6
12	1
13	1
14	1
18	1
19	1
24	1
35	1
TOTAL	22

Data indicated that 77,3% of children were admitted to the institution before adolescence (up to the age thirteen).

Table 19: ***Reason(s) given by parents for having child admitted***

REASONS	Number of times mentioned
Behavioral problems	12
Inability to cope	10
Sexually inappropriate behaviour	7
Relationship difficulties	5
Financial reasons	3
Death of parent/care-giver	2
Epileptic seizure (severe)	2
Mother pregnant	1
Mother admitted to a psychiatric hospital	1

Parents gave more than one reason for having their child admitted. The problems listed above provides an idea of the difficulties parents, especially mothers, had to encounter. The behavioral problems respondents mentioned included feeding problems, hyperactivity and the child wandering away from home and eating faeces. All of these problems discussed affected the parents' social life. The sexually inappropriate behaviour of the child caused the parents much distress. One mother explained,

> "Ek kon alles hanteer, maar wat vir my die moeilikste was om te aanskou, was wanneer my seun hom in die straat ontbloot het en mense met hom die spot gedryf het. Dit het my baie ontstel."

Table 20: ***Were parents advised to have their child admitted to an institution***

ADVISED	N (%)
Yes	15 (68,2)
No	7 (31,8)
TOTAL	22 (100)

Fifteen (68,2%) of the respondents were advised to have their child admitted to the Care and Rehabilitation Centre while seven (31,8%) of the respondents made the decision on their own.

Table 21: ***Knowing what they know now, would respondents take the same decision to have their child admitted to an institution***

RESPONSE	N (%)
Yes	15 (68,2)
No	7 (31,8)
TOTAL	22 (100)

Fifteen (68,2%) of the respondents felt that if they were faced with the decision to have their child admitted again, they would do so. Seven (31,8%) of the respondents said that they would not make the same decision again. They gave various reasons. Two mothers said that if they could afford it, they would give up their jobs and take care of their children. Two felt that it was too sad and they would not be able to re-live the experience. Three mothers felt that their children would have made better

progress at home.

Table 22: ***Have respondents considered discharging their children from the Centre?***

CONSIDERED DISCHARGE	N (%)
Yes	6 (27,3)
No	16 (72,7)
TOTAL	22 (100)

Sixteen (72,7%) of the respondents have not considered bringing their child home while six (27,3%) of the respondents thought of the possibility of bringing their child home.

4.1.7 CONTACT BETWEEN PARENTS AND THEIR MENTALLY HANDICAPPED RESIDENT IN THE CENTRE

Table 23: ***Number of visits per annum by respondents to severe to profoundly mentally handicapped children compared to mild to moderately mentally handicapped children***

FREQUENCY OF VISITS P.A.	DEGREE OF MENTAL HANDICAP	
	Severe to profound	Mild to moderate
Never	8	3
3 - 6 times	3	1
12 times	1	5
52 weekends home	0	1
TOTAL	12	10

Eight (66,7%) of the respondents who had children in the severe to profound range of mental handicap never visited their son/daughter. Three (25%) respondents visited their son/daughter 3-6 times a year. In comparison 5 (50%) of the respondents who had children in the mild to moderate range of handicap visited their children once per month, and one took their child home every weekend.

All factors were examined to see if any patterns could be established between the factors and the frequency of visits of parents to their mentally handicapped children. The only factors that appeared to have some correlation were the degree of mental handicap, the length of stay in the institution in relation to severe to profoundly mentally handicapped residents and whether counselling was given. These findings, however need to be interpreted with caution.

Frequency of visits per annum to severe to profoundly mentally handicapped residents in relation to their length of stay in hospital.

The length of stay in the Centre for the severe to profoundly handicapped residents varied from 4 to 26 years. The eight (66,7%) residents who had spent 11 years and longer in the Centre were never visited. Of the four (33,3%) residents who had spent less than 11 years. Three were visited 3-6 times per annum and one was visited 12 times per annum. It appears therefore that the longer the resident is institutionalised, the fewer the visits.

Frequency of visits per annum to mild to moderately mentally handicapped residents in relation to their length of stay in hospital.

The length of stay in the Centre for the mild to moderately handicapped residents varied from 3 to 29 years. There seemed to be no direct relation between the number of visits by parents and the length of stay of the residents. Parents of residents who fell into this range of mental handicap visited their son/daughter more often then parents of severe to profoundly handicapped children.

Table 24: ***Feelings of parents of severe to profoundly mentally handicapped children when visiting their child***

MAJOR FEELINGS	N (%)
Sad and distressed	10 (83,3)
Happy	2 (16,7)
TOTAL	12 (100)

Those who reported feeling happy were satisfied with the care their son/daughter was receiving. Those who reported feeling sad said they were distressed to see their child in that condition. A mother comments:

> "It is so painful for me to go and visit my child and see him there. It is so upsetting that I spent days crying. It seems with every visit I am reliving the past. that is why I decided not to visit him any longer. I know the staff are looking after him well."

Others commented on how the appearance of their son/daughter also made them sad and distressed when visiting.

Table 25: ***Feelings of parents of mild to moderately mentally handicapped children on visiting their child***

MAJOR FEELINGS	N (%)
Sad and distressed	7 (70)
Ambivalent (sad and happy)	1 (10)
Happy and satisfied	2 (20)
TOTAL	10 (100)

Seven (70%) of the respondents felt sad and distressed to see their son/daughter. One mother said:

> "I felt sad to see my child in a place like that amongst all the other children, but what can I do I could not look after him all by myself".

Another mother sadly comments:

> "Dis nie lekker vir my om my kind in die hospitaal the sien nie. Dit sal enige ma se hart breek om jou kind daar tussen al die ander vertraagde kinders the sien. As jy jou kind tussen die ander kinders sien lyk jou kind soveel erger. Maar wat kan ek doen destyds het ek geen hulp gehad nie en was genoodsaak om my kind the laat opneem by Dr A.J. Stals."

Table 26: ***Parents' impressions of staff members when visiting their mentally handicapped child***

RESPONSE	N (%)
Helpful	21 (95,5)
Uncooperative	0 (0)
Aloof	1 (4,5)
TOTAL	22 (100)

Twenty one (95,5%) of the respondents reported staff members to be helpful, and one reported that staff members was aloof. The staff members referred to are the nursing staff, who are on duty when parents visit their mentally handicapped child.

Table 27: ***Type of transport used to get to the Centre***

TYPE OF TRANSPORT	N (%)
Car (own)	10 (45,5)
Taxi	3 (13,6)
Train	1 (4,5)
Bus	0 (0)
Car (hire)	5 (22,7)
Combination of above	2 (9,1)
Walked	1 (4,5)
TOTAL	22 (100)

Ten (45,5%) respondents indicated that they had their own car, in which they travelled to the Centre. Six (27,2%) used public transport, 5 (22,7%) hired a car and one lived within walking distance of the institution.

Table 28: ***Frequency of visits by those parents who owned cars***

NUMBER OF VISITS P.A.	N (%)
Never	9 (90)
12 times	1 (10)
TOTAL	10 (100)

Nine (90%) of parents who owned a car never visited their child. Only one parent visited once per month and the other parent visited 3 - 6 times a year.

Table 29: ***Respondents' response as to whether they would like to visit their child more often***

RESPONSE	N (%)
Yes	19 (86,4)
No	3 (13,6)
TOTAL	22 (100)

Nineteen (86,4%) respondents felt that they would like to visit their child more often. Of the three (13,5%) respondents who said they would not like to visit, two were advised by staff members not to visit too often because of the children's demanding and aggresive behaviour after visits. The other respondent felt that the child became too demanding if she visited too often.

Table 30: ***Reasons for not visiting***

REASONS GIVEN FOR NOT VISITING	Number of Respondents
Scared of travelling with public transport	12
Financial difficulties	16
Buying luxuries for child and extra expense	14
Sadness evoked by visiting	12
Working over weekends	8
Inability of residents to communicate	10

Parents gave various reasons for not visiting, the most common reason being experiencing financial problems. Buying luxuries when visiting their child added to the financial burden and prevented them from visiting. Many parents also mentioned that the sadness which a visit provoked incapacitated them. The residents' inability to communicate added to the reasons parents gave for not visiting. For those parents where children fell into the severe to profound range the most common reason was the intense sadness a visit evoked in them. For those in the mild to moderate range transport difficulties and working over weekends were the main reasons.

Table 31: *Number of telephone calls by parents to the Centre per annum*

FREQUENCY OF TELEPHONE CALLS P.A.	DEGREE OF MENTAL HANDICAP	
	Severe to profound	Mild to moderate
Never	10	6
3 - 6 times	1	1
12 times	1	2
52 weeks	0	1
TOTAL	12	10

Ten respondents with children in the severe to profound range never made contact. Only one respondent made weekly contact with the Centre. It is uncertain, how many respondents had telephones in their homes, so these findings should be interpreted with caution.

4.1.8 *PARENTS INVOLVEMENT WITH CENTRE ACTIVITIES*

Table 32: *Parents' awareness of regular family or parents' groups*

RESPONSE	N (%)
Aware	20 (90,9)
Not aware	2 (9,1)
TOTAL	22 (100)

Twenty (90,9%) of the respondents knew of regular parent groups held. Two (9,1%) respondents had never heard of these groups being held.

Table 33: *Frequency of attendance at family or parents' support groups*

FREQUENCY OF ATTENDANCE	Parents of severe to profound mentally handicapped	Parents of mild to moderate mentally handicapped
Attend every meeting	0	4
Attend infrequently	2	3
Never attend	10	3
TOTAL	12	10

Awareness of meetings in relation to attendance.

Severe to profound range of mental handicap.

Of the twelve respondents whose sons/daughters fell into the severe-profound range of mental handicap, eleven were aware of regular parent support groups being held and one said she was unaware of these meetings. A typical response as to why they did not visit was given by a mother who said,

> "I have no specific reason. I just don't attend. Maybe I don't want to go to the place that brings back so much sadness".

Mild to moderate range of mental handicap

Of the 10 respondents whose sons/daughters fell into the mild-moderate range of mental handicap, 9 respondents knew of regular parents support groups being held and one said that she was unaware and as a result never attended these meetings. Of the nine respondents who knew about the meetings, four attending every meeting, two never attended and three attended infrequently. Respondents were asked the reasons for not attending. The three who attended infrequently gave the following explanations.

One mother said:

> "I am so pre-occupied with my problems at home that I just don't have the energy to attend these meetings or visit my child".

Another mother responded by saying:

> "Om u die waarheid the sê ek het geen verskoning nie".

The other mother said:

> "My husband works every alternate weekends and unfortunately it often falls on the weekend when the ward has this meeting".

Two parents never attended any meetings. The reasons given for not attending, was that the one mother was blind and the other mother responded as follows:

> "I have been involved in the past and feel that I have done enough I am just tired of going to that place".

4.1.9 *PARENTS VIEWS ON THE CENTRE*

Positive comments:

Three respondents commented that the Care and Rehabilitation Centre was a great improvement on Dr. A.J. Stals. They commented that the hospital was cleaner and neater and the buildings gave a more positive impression to outsiders. The remaining respondents all made general comments about how the hospital looked and that the hospital was rendering a good service to the community.

Negative comments:

Seven respondents had negative comments regarding the care given by the Centre. One respondent complained that the staff/patient ratio was too small and this led to poor nursing care. Four respondents complained of the distance they had to walk from the main entrance to the wards when visiting. Two respondents mentioned the inconsistency of the security at the gate, at times checking the cars and taking down names, and at other times letting them through without checking.

Generally speaking, despite encouragement by the interviewer, the respondents had few comments to make about the Centre.

Parents view of the care their child was getting in the Centre

Two respondents had no comments to make in this regard. Twenty (90,9%) of the respondents commented on the good care their child was receiving, namely regular meals, medication on time and the cleanliness of the residents.

Five respondents had negative comments to make regarding the care by the Centre. Two respondents complained that there were not enough nursing staff, and one mentioned that their child was being locked up because of this shortage. One respondent felt that their daughter should be amongst residents with a lesser degree of handicap. Two respondents felt that their child's progress was too slow.

Suggestions from the parents regarding improvements

Seventeen respondents had no suggestions to make. Four respondents felt that the hospital should employ more nursing staff, the reason being that the respondents felt that caring for the mentally handicapped was emotionally draining job and many felt sorry for the nurses. One respondent felt that the hospital should provide transport from the main entrance to the various wards. It seems as if parents had very few suggestions to make because of their lack of contact.

CHAPTER 5

DISCUSSION OF FINDINGS

5.1 INTRODUCTION

This study has attempted to look at the factors that influence the degree of parents' involvement with their institutionalised mentally handicapped son/daughter. The factors that influence the degree of the parents' involvement seem to be interrelated. To understand how the family currently thinks, feels and behaves toward the mentally handicapped resident in an institution, it is necessary to understand the impact on the family of historical as well as current events.

5.2 NEED FOR INDIVIDUAL COUNSELLING

A very significant finding of the study was that the parents who were interviewed not only freely answered questions asked but demonstrated a need to share their experiences and feelings related to their mentally handicapped sons/daughters. Much of the data was produced spontaneously by the respondents and the strength of their feelings could be observed directly by the investigator. It seemed that for many parents, this was their first opportunity to express these feelings and discuss past painful events (see Table 17). It was clear that experiences from many years ago had not been resolved.

The reluctance of parents to meet together as a focus group also constituted an important finding. Despite visiting parents in their homes to invite them to attend a group to share their experiences regarding their mentally handicapped children, they chose to avoid this experience. When parents were interviewed individually they were eager to discuss their feelings and experiences regarding their mentally handicapped children. It can be postulated that the prospect of doing so in a group proved unattractive and possibly threatening. This finding is particularly important in that it could help to explain the reasons behind parents' reluctance to attend groups offered by the Centre. It is possible that individual counselling focusing on unresolved past issues of parents is necessary before they are ready to deal with these and more current issues in a group. This hypothesis is supported by the fact that twelve of the twenty two parents who participated in the study are currently attending individual or group counselling.

The aim of the study was to elicit the responses of both parents regarding their involvement with their mentally handicapped child. To this end, visits were made to the homes in the evenings when both parents could be expected to be home. However, in all but one instance the mothers assumed the role of respondent. In nine cases fathers were not at home, and in three cases when fathers were present they indicated that the mother should speak. The findings of the study, therefore, are not only from the perspective of the mothers, but it also seemed clear that it was the mothers who had been expected to shoulder the major responsibility of care of the mentally handicapped child, both in the past and in the present.

5.3 FACTORS AFFECTING PARENTS' INVOLVEMENT WITH THEIR INSTITUTIONALISED MENTALLY HANDICAPPED CHILD

5.3.1 *SOCIO-ECONOMIC FACTORS AND PARENTS' NEED TO INSTITUTIONALISE THEIR MENTALLY HANDICAPPED CHILD*

The majority of parents, whose sons/daughters were placed in an institution and who participated in this study, came from poor socio-economic conditions (see Table 7). The majority of the respondents only had a primary school education (see Table 4), which meant that their ability to obtain a job with a reasonable salary was very limited. Most parents in the study performed unskilled or semi-skilled labour, which resulted in a low income.

The Human Sciences Research Council's statistics for 1995 found that the minimum wage for a family of five (father, mother and three children) should be R871.00 per month. This study found that the majority of families had three or more children and the average wage was R842.00 per month, which is below the breadline. Many of these parents also live in sub-economic areas which are characterised by gangsterism, alcoholism and unemployment.

The presence of these social and economic factors and the lack of community resources places an additional stress on parent's ability to care for the mentally handicapped child. Normally it is community factors such as overcrowding, lack of proper housing, poverty and so forth, which contribute to the institutionalisation of the mentally handicapped child. Black, Cohen, Smull and Crites (1985) found that lack of

community resources often necessitates institutionalisation. Eyman, O'Connor, Tarjan and Justice (1972) and Wolf and Whitehead (1975) also suggest that the decision to institutionalise the handicapped child may be associated with socio-economic factors. Willer, Intagliata and Atkinson (1979) confirmed that coming from a low socio-economic status and having a mentally handicapped child constitute a double burden which is extremely stressful.

This study also suggests that poor socio-economic factors and lack of resources seem to have forced parents to have their mentally handicapped sons/daughters institutionalised. Many parents experienced difficulty in handling their sons/daughters' behaviour. They described how they did not have the physical resources to care for a child who required constant attention and supervision. For many parents therefore, to institutionalise their handicapped child was a financial relief, and thus reluctance of many parents to discharge their children is understandable (see Table 19 & 21). The poor socio-economic conditions from which these parents come from place them in a vulnerable position to take care of a mentally handicapped child. Mothers expressed how difficult it was caring for a mentally handicapped child and the lack of resources in the community. One mother said:

> "Ek wou so graag self my kind versorg, maar daar was niemand om my te help of te wys hoe nie. Ek was jonk, dit was my eerste kind en skielik moes ek 'n vertraagde kind versorg. Dit was nie maklik nie, totdat ek gesê was om my kind in 'n inrigting te sit. Daai tyd was ek verlig en bly dat daar 'n plek was waarheen ek my kind kon stuur, want ek het gesukkel. Maar vandag is ek spyt. As hulle my daai tyd kon help om hom te hanteer en versorg, kon ek self na hom gekyk het. Die ander ding is dat ek ook nie geld gehad het om iemand te betaal om my te help nie."

5.3.2 *COMMUNICATION OF THE DIAGNOSIS OF MENTAL HANDICAP AND PARENTS INVOLVEMENT WITH THEIR MENTALLY HANDICAPPED CHILD*

For most mothers the birth of a child is a stressful event. But for the mothers who participated in the study there were a combination of factors which contributed to making the event extremely stressful. For a large proportion of the respondents it was their first child (Table 13) and the majority of mothers were very young at the time they gave birth (Table 12) and the majority had only a primary school education (Table 4). The mothers reported being ignorant. They did not know what was wrong with their child or what to expect. As one mother described her experience:

> "Ek was jonk en baie dom. Ek het nie geweet my kind gaan vir altyd so wees nie, ek het gedink hy gaan beter word. Juffrou ek was dom en daar was niemand om my te help of vir my te verduidelik wat om te doen nie."

All parents hope for a healthy baby and one of sound mind. They said that the realisation that they had given birth to an unhealthy baby had a negative effect on everyone. Parents' immediate response to this traumatic event was shock. Levinson (1967) confirms this shock which normally goes together with the initial denial that the parents experience on hearing the news that their child is mentally handicapped.

In this study the majority of the mothers were told of their child's diagnosis by a doctor (see Table 15) who according to parents, gave them very vague explanations. Some of the explanations that were given to parents were that their child was "backward", that he/she would progress slowly and would remain a "child". Some mothers expressed that they never fully understood what was said to them and the extent of the diagnosis. One

mother explained how she felt at that time, "Ek het weggegaan en gedink my kind sal beter raak sodra hy skool toe gaan en tussen ander kinders is". Another mother said, "When I got home I forgot everything the doctor said, only 'backward' lingered in my mind".

Other studies for example (Quine and Pahl, 1985) have also found that parents complained that they had not received adequate information and that medical staff had been evasive and secretive regarding the examination preceding diagnosis.

The difficulty parents and especially mothers had in understanding and accepting their child's mental handicap seem to be related to various factors. Firstly it could be directly related to how the doctor conveyed the message, which might have been vague and unclear. Wolraich (1982) found that one of the factors that influenced the physician - parent communications was the physician's ability to communicate with the parents and this would in turn affect the way parents experienced the contact. Another factor he mentioned is the physician's attitude toward mental handicap and his knowledge about development problems.

Secondly, parents' poor educational level might have been a factor related to the parents difficulty to understand the diagnosis and grasp the consequences of such a condition. Thirdly, this inability to understand may also be related to Kennedy's (1970) first stage of working through the feelings and emotions of having mentally handicapped child, namely shock, denial, disbelief and not hearing. The parents could have been using the defence of denial, which could have resulted in them not "hearing"

the diagnosis.

It is suggested that the lack of opportunities to talk through issues pertaining to their mentally handicapped child led parents to feel inadequate, to blame others and to utilize the defence of denial which may have led to some rejection of the mentally handicapped child. These unresolved feelings could have led to their current lack of involvement with their mentally handicapped child but the study was unable to demonstrate this.

What becomes clear from the above is the need that parents have to get clear and direct explanations from professionals as soon as possible regarding their child's diagnosis. Metheny and Vernick (1969) emphasize the importance of giving parents clear, direct and honest information regarding the diagnosis of their child. They state:

> "What parents require most from diagnostic or informative counselling is specific, clearly transmitted, honest information about the child, implications for his future, and knowledge of what concrete steps they can take to deal with the problem (p.954)."

With this information about their child's diagnosis parents will be able to make informed decisions regarding their child.

5.3.3 *COUNSELLING AND PARENTS INVOLVEMENT WITH THEIR MENTALLY HANDICAPPED CHILD*

The researcher had not anticipated that so few respondents would have received counselling regarding their mentally handicapped child. As only one of the parents had

received counselling it was not possible to compare the degree of involvement with their mentally handicapped child between those who had received counselling and those who had not received counselling.

Nevertheless, the one respondent who did receive counselling demonstrated the highest degree of involvement of all the respondents. She reported that the opportunity she had to talk through her feelings had resulted in a better relationship with her child and she visited regularly and takes him out for weekends and holidays. The majority of the respondents expressed that they would have benefitted if they had been given the opportunity to talk to a professional on an ongoing basis. This is expressed by one mother saying "I had nobody to talk to. My family never seem to understand what I was going through." Others said that they would have felt better if they were able to speak to someone. A mother sadly recalled, "Irrespective of the feelings I was experiencing at the time I had to continue as if nothing happened". The above-mentioned comments indicate the great need the parents had in the past to share their feelings with someone. This need to talk has been confirmed during the interviews where parents made use of the opportunity to open up and speak about past events and share some of their feelings. Intense feelings were shared and the interview itself was a means of working through some of these feelings.

5.3.4 *RELATIONSHIPS OF THE FAMILY AND PARENTS INVOLVEMENT WITH THE MENTALLY HANDICAPPED CHILD*

The study highlighted the effect a mentally handicapped child had on family

relationships and how these relationships were affected after admission. In all the families who formed part of the study the presence of a mentally handicapped child affected all its members, the mother, father and siblings.

In this study, the mothers generally reported a good relationship with their child before admission. The impression that this was a "good" relationship was based on what they did physically for their mentally handicapped child, namely, the caregiving role they fulfilled and may not truly reflect the relationship in emotional terms. However, for the severe to profoundly handicapped child, physical care is possibly a major component of the interaction between parents and child.

All mothers except for one reported a positive relationship and related no negative feelings regarding this role. However they found the child's behaviour difficult to manage. For most of the mothers after the admission of their handicapped child their relationship with the child seems to have deteriorated.

A study done by Hill, Rotegard and Bruiniks (1984) found that the best predictor of the frequency of parents' visits was the quality of the parents' relationship with their child before institutionalisation. This study, however, found that a good relationship as reported by the mothers before institutionalisation did not guarantee regular visits by parents after admission. A finding that the study yielded was that the longer a severely to profoundly handicapped child's length of stay in the institution, the less the parents had contact. This was not found in the case of the mild to moderately handicapped children. The finding in relation to the severe-profoundly mentally handicapped

children seem to be in keeping with Baker and Blacher's (1993) theory about detachment which states that this is a natural process of disengaging from the child which will have a direct influence on the frequency of the visits to the child. In the case of the mild to moderately handicapped children, possibly the child's ability to relate better to the parents reduces to some extent the detachment process.

Although the siblings were not asked directly about their relationship with their mentally handicapped brother or sister, it was reported by the mothers how they perceived this relationship. The majority of siblings whose brother or sister fell into the severe to profound range experienced the presence of their handicapped brother or sister as extremely stressful and this influenced their relationships negatively. They felt embarrassed at the mentally handicapped child's behaviour and his or her physical abnormalities. This embarrassment prevented siblings from bringing friends home. Cleveland and Miller (1977) report that siblings commonly report feelings of shame and embarrassment at the looks and behaviour of their mentally handicapped brother or sister. Fischer and Roberts (1983) found that children may be resentful of their mother's time being taken up by the handicapped child.

The mothers' perceived the fathers' relationship with their mentally handicapped children as poor. Fathers were experienced as doing little for their children, and this was interpreted by the mothers as having a poor relationship. This should only be seen as the mothers' opinion.

5.2.5 *PHYSICAL ABNORMALITIES AND DEGREE OF MENTAL HANDICAP AND PARENTS INVOLVEMENT WITH THEIR MENTALLY HANDICAPPED CHILD*

The study also found that the frequency of visits by parents is strongly linked to the mentally handicapped child's physical abnormalities and the child's ability to converse with the parents. The study found that where there were physical abnormalities present, parents were overwhelmed by feelings of sadness and intense grief during a visit. This together with the child's inability to communicate may have led to the breakdown in visits to the mentally handicapped child. One mother said:

> "She does not know that I am her mother and is unable to communicate with me. It is also very difficult to see my child in that condition amongst the other residents."

Stoneman and Crapps (1990) found that with institutionalised children who were more able and competent, parents found it easier to maintain contact because reciprocal interaction could take place. A significant finding of this study is that most parents whose children fell into the severe to profound range of mental handicap never contacted their child. The severity of the child's handicap was associated with the frequency of parental visits to their institutionalised child.

5.2.6 *REASONS FOR NOT VISITING AS GIVEN BY PARENTS*

The parents were also asked directly their reasons for not visiting their mentally handicapped child. The honesty of the respondents when stating how often they visited or made a telephone call was interesting. The majority of parents freely admitted that they never visited or telephoned their son/daughter at the Centre. The researcher

anticipated that the respondents would exaggerate the frequency of their visits to create a better impression but this was not the case. It is possible that the parents' truthfulness could be related to the fact that the respondents knew that the researcher is directly connected to the Centre and thus might know their visiting pattern to the Centre. However the impression was gained that they gave this information freely and openly.

Parents gave as reasons for not visiting that they were scared of travelling with public transport, or that financial difficulties prevented them from visiting (too expensive to hire a car). A large number also said that they needed money to buy their son/daughter luxuries when visiting which added to the expense of the visit. Often food was mentioned, which could be interpreted as a substitute for the care the parents felt they were not able to provide. This concern with bringing material gifts seemed to cause distress to many parents. Most parents whose children fell into the range severe-profound mentally handicapped said that they did not visit their child because it was difficult for them to see their child in that condition. It also evoked feelings of sadness. A parent described her feelings:

> "It becomes unbearable for me to see my child in that condition. After a visit to her I am so upset that it influences my relationship with my other family members. I just decided not to visit her because it is too painful."

Parents whose children fell into the range mild-moderate mental handicap, gave as reasons for not visiting, financial difficulties, transport difficulties and that they were working.

Many parents mentioned transport difficulties as a reason for not visiting. Parents

expressed their fears of travelling on public transport. The fear of being robbed on trains and the reckless driving of taxi drivers were the most common reasons for not using public transport. The Centre also seems to be inconveniently situated. The respondents in this study mostly mentioned the difficulties associated with public transport and the cost involved when visiting, but seldom mentioned distance as a reason for not visiting as they lived within close proximity of the Centre. Anderson, Schlottman and Weiner (1975) found that distance was associated with the frequency of visits. Klaber (1968) rejected this and said parents used distance as the most socially accepted rationalization. This study found however that many respondents had cars but did not visit (see Table 28). The degree of the child's handicap seems to be a stronger predictor of how often parents visited.

The questions regarding the frequency of telephone calls to the Centre were badly handled by the researcher, as it was assumed that everybody had a telephone. Not having a telephone could have influenced the number of respondents who said they never telephoned to the Centre.

The study found that the majority of parents felt that their child was well looked after at the institution and most would have their child institutionalised should they be faced with a similar decision. Negative feelings about the institution do not seem therefore to be associated with visiting patterns. Very few negative comments were made about the institution and the care their children was receiving. There seems to be a feeling of relief experienced by the parents that someone was there to take care of their child.

5.2.7 *CONCLUSION*

The factors affecting parents' involvement with their mentally handicapped child seem to be complex and interrelated. It seems however socio-economic factors may influence parents' involvement with their institutionalised mentally handicapped child and that ongoing stressors experienced further exacerbate this relationship. The degree of handicap and the length of the child's stay in the institution are prominent factors. The parents seem to sever ties with their mentally handicapped son/daughter as time goes by especially those parents who have a severely handicapped son/daughter. Generally the birth of the mentally handicapped child and the subsequent counselling was poorly managed by professionals, and the parents are still left with many unresolved feelings regarding the birth, admission and current relationship with their mentally handicapped child. There seems to be no relationship between the parents' involvement with their child and their views on the institution.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

It is generally accepted that being cared for in the community is preferable for mentally handicapped people rather than being institutionalised. If they have to be institutionalised, maximum involvement of their families is essential. Recommendations will, therefore, be made with these two goals in mind. It is accepted that increased involvement with the mild to moderately handicapped child is more easily promoted because of the child's ability to relate in some meaningful way with parents.

Although the study was unable to identify a correlation between the way parents were told of their child's mental handicap and their involvement with their child in later years, the process of breaking the news of mental handicap clearly needs much improvement. It is recommended that doctors and social workers be educated as to how to inform parents with concern and empathy, and yet with honesty and clarity regarding expectations families might have of their child's development. Similarly, the study clearly showed the need these parents had for counselling in order to initially help them to grieve the loss of the perfect child they had hoped for, and later to help them handle the many practical and emotional problems having such a child entails. Many admissions to institutions occurred because parents could not cope with the behaviourial problems of their mentally handicapped children. This difficulty in coping is still one of the reasons residents are not discharged home. It is strongly recommended that parents be taught practical skills regarding the care of the mentally

handicapped person and the management of difficult behaviour.

The findings of the study suggest that once the child is admitted to the institution parents will initially require individual counselling, and only later will they be able to form support groups. The majority of the respondents who participated in the study, have elected to continue to seek individual or group counselling, thereby demonstrating their need to seek counselling. Whether this will result in long term increased involvement with their mentally handicapped child is not yet known. It is recommended that this be the focus of further study.

It is recommended that the social workers of the Centre reach out into the community, for both individual and group counselling, and venues in the community be utilised particularly in the initial stages of contact with parents. Community education projects are also required to sensitize communities to the needs of mentally handicapped people in order for them to be more supportive and accepting of handicapped persons and their families. Lobbying groups could be initiated, for example, with the taxi associations, to help provide transport. Other community facilities, for example, day centres and sheltered workshops would make it more possible for the mentally handicapped to remain in the community. It is very sad that with the current rationalisation process taking place in both Health and Welfare sections, the number of community facilities are decreasing in the Cape at the same time as residential institutions are discharging residents into the community.

As the involvement of parents with their institutionalised mentally handicapped child

tend to deteriorate over time, efforts should be made soon after admission to encourage interaction, and where possible for parents to consider relief or short term admissions, in order to maintain the bond with their mentally handicapped child. Institutionalisation, however, will always have to be an option for some parents who have mentally handicapped children.

The research has been extremely valuable for the researcher in terms of expanding her understanding of the parents needs regarding their institutionalised mentally handicapped children. It has also been valuable for the other social workers in helping them to plan services more appropriately for the Centre.

BIBLIOGRAPHY

Allen, R.E.
(1990)
The Concise Oxford Dictionary of Current English Press. Oxford University Press. Oxford.

Anderson V.H., Schlottmann R.S., & Weiner B.J.
(1975)
Predictors of parent involvement with institutionalised retarded children. American Journal of Mental Deficiency. 79, 705-710.

Anthony W.A., Pierce R.M., Cohen M.R. & Cannon J.R.
(1981)
The Skills of Diagnostic Planning: Psychiatric Rehabilitation Practice Series. University Park Press. Baltimore.

Baker B.L. & Blacher J.B.
(1993)
Out of home placement for children with mental retardation: Dimensions of family involvement. American Journal on Mental Retardation. 98(3) 368-377.

Baroff G.S. (1974) Mental retardation nature cause and management.Hemisphere Publishing Corporation. Washington. D.C.

Blacher J.B. & Baker B.L. (1992) Toward meaningful family involvement in out-of-home placements. Mental Retardation. 30, 35-43.

Black M.W., Cohen J.F., Smull M.W. & Crites L.S. (1985) Individual and Family factors associated with risk of institutionalisation of mentally retarded adults. American Journal of Mental Deficiency. 90, 271-275.

Bowlby J. (1980) London. Attachment and Loss. Loss, Sadness and Depression. Volume 3. Hogarth Press.

Braginsky D. & Braginsky B. (1971) Hansel and Gretel's studies of children in institutions for the mentally retarded. Holt, Rinehart and Winston Inc. New York.

Chetwynd J. (1985) Factors contributing to stress on mother caring for an intellectually handicapped child. British Journal of Social Work 15(3) 295-304.

Chinn P.C., Drew C.J. & Logan D.R. (1975) Mental Retardation: A Life Cycle Approach. University of Caroline Press. Berkley.

Clarke D.F. (1984) Help, hospitals and the handicapped. Aberdeen University Press. U.S.A.

Cleveland D.W. & Miller N. (1977) Attitudes and life commitments of older siblings of mentally retarded adults: an exploratory study. Mental Retardation. 15, 38-41.

Craft M., Bicknell J. & Hollins D. (1985) Mental Handicap. Bailliere Tindall. Philadelphia.

Cruikshank W.M. (1995) Psychology of exceptional children and youth. Staple Press. London.

Dittman L.T. (1962) The family of the child in an institution. American Journal of Mental Deficiency. 66, 759-765.

Downey K.J. (1963) Parental interest in the institutionalised severely mentally retarded child. Social problems. 11, 186-193.

Dyson S. (1986) Professionals, mentally handicapped children and confidential files. Disability, Handicap and Society. 1(1) 73-87.

Edgerton R. (1979) Mental Retardation: The developing child. Fontana/Open Books. London.

Eyman R.K., O'Connor G., Tarjan G. & Justice R.S. (1972) Factors determining residential placement of mental retarded children. American Journal of Mental Deficiency. 76, 692-698.

Farber B. (1959) Effects of a severely mentally retarded child on family integration. Monographs of the Society of Research in Child Development. 24(2) 39-41.

Fischer J. & Roberts S.C. (1983) The effect of the mentally retarded child on his siblings. Education. 103(4) 399-401.

Folch-Lyon E. & Frost J. (1981) Conducting focus group sessions: Studies in family planning. 12(2) 443-449.

Freeman A. (1988) Parents: Dilemmas for professionals Disability, Handicap and Society. 3(1) 79-85.

Gath A. (1977) The impact of an abnormal child upon the parents. British Journal of Psychiatry 130, 405-410.

Gillis L.S. (1986) Guidelines in Psychiatry. Creda Press, Cape Town.

Goffman E. (1961) Asylums - Essay on the social situation of mental patients and other inmates. Penguin Books Ltd. Middlesex.

Grinnell R.M. (1988) Social Work Research and Evaluation Peacock Publishers. London.

Hallas C.H., Fraser W.M. & Mac Gillivray R.C. (1978) The care and training of the mentally handicapped. John Wright & Sons. Towbridge.

Heaton-Ward W.A. (1978) Left Behind: A study of mental handicap. Woburn Press. London.

Hill. B.K., Rotegard L.L., & Bruiniks R.H. (1984) The quality of life of mentally retarded people in residential care. Social Work. 29, 275-280.

Intagliata J., Willer B. & Wicks N. (1981) Factors related to the quality of community adjustment in family care homes. American Journal on Mental Deficiency. 4, 217-230.

Jennings J. (1987) Elderly parents as caregivers for adult dependent children. Social Work 32, 430-433.

Jubber K. (1980) The relationship between parents/guardians and their institutionalised mentally retarded child. Journal of Social Work. 16(2) 81-90.

Kennedy J.F. (1970) Maternal reactions to the birth of a defective baby. Social Casework. 51(7) 410-416.

Klaber M.M. (1968) Parental visits to institutionalised children. Mental Retardation 6, 39-41.

Kramm E.R. (1963) Families of mongoloid children. U.S. Government Printing Office. Washing D.C.

Kromberg J.G.R. (1977) Responses of parents to the birth of a baby with Down's Syndrome. South African Nursing Journal. 44(11) 33-35.

Kubler-Ross E. (1970) On Death and Dying. Tavistock Publications. London.

Lea S. & Foster D. (1990) Perspective on mental handicap in South Africa. Butterworth. Durban.

Levinson A. (1967) The Mentally Retarded Child. George Allen and Unwin Ltd. London.

Lonsdale G. (1978) Family life with a handicapped child: The parents speak. Child, Care Health and Development. 4(2) 99-120.

Matheny A.P. & Vernick J. (1969) Parents of the mentally retarded child: Emotionally overwhelmed or informationally deprived? The Journal of Paediatrics. 74(6) 953-959.

Mc Conachie H. (1978) Parents and Young Mentally Handicapped Children. Academic Press. London.

Morgan D.L. & Spanish M.T. (1984) Focus Groups: A new tool for qualitative research. Qualitative Sociology. 7(3), 252-269.

Morris P. (1969) Put Away - A sociological study of institutions for the mentally retarded. Routledge and Kegan Paul Limited. London.

Olshansky S. (1962) Chronic Sorrow: a response to having a mentally defective child. Social Casework. 43, 190-193.

Patton M.Q. (1990) Qualitative evaluation and research methods. Sage Publications. London.

Payne J.S. & Mercer C.B. (1975) A sketch of the past, present and future. In: Kauffman J.M., Payne J.S. (eds). Mental retardation: Introduction and perspectives. Charles E. Merill Publishing Co. London.

Quine L. & Pahl J. (1985) Examining the causes of stress in families with severely mentally handicapped children. British Journal of Social Work. 15(5) 501-517.

Quine L. & Pahl J. (1986) First diagnosis of severe mental handicap: Characteristics of unsatisfactory encounters between doctors and parents. Social Science and Medicine. 22(1) 53-62.

Roos P. & Mc Caan B. (1980) Shaping the future - community based residential facilities for mentally retarded people. University Park Press. Baltimore.

Ryan J. (1980) The Politics of mental handicap. Pelican Books. London.

Seed P. (1980) Mental Handicap: Who helps in rural and remote communities? Turnbridge Wells: Costello Educational.

Stoneman Z. & Crapps J.M. (1990) Mentally retarded individuals in family care homes: Relationships with the family-of origin. American Journal on Mental Retardation. 94, 420-430.

Tausig M. (1985) Factors in family decision-making about placement for developmentally disabled individuals. American Journal of Mental Deficiency. 89, 352-361.

Tew B.J., Lawrence K.M., Payne H. & Rawnsley K. (1977) Marital stability following the birth of a child with spina bifida. British Journal of Psychiatry. 131, 79-82.

Thorne G.D. (1965) Understanding the Mentally Retarded. Mc Graw-Hill Book Company. London.

Waitman A. & Conboy-Hill S. (1992) Psychotherapy and Mental Handicap. Sage Publications. London.

Wilkin D. (1979) Caring for the mentally handicapped child. Croom Holm: London.

Willer B., Intagliata J. & Atkinson A.C. (1979) Crises for families of mentally retarded persons including he crises of deinstitutio-nilisation. British Journal of Mental Subnormality. 25(1), 38-49.

Wolf L.C. & Whitehead P.C. (1975) The decision to institutionalise retarded children: Comparison of individually matched groups. Mentally Retardation 13, 3-7.

Wolraich M.L. (1982) Communication between physician and parents of handicapped children. Exceptional Children. 48(4) 324-329.

Wright L.S. Matlock K.S. & Matlock D.T. (1985) Parents of handicapped children: their self-ratings, life satisfaction and parental adequacy. The Exceptional Child. 32(1) 37-40.

LEGISLATION

Mental Health Act No. 18 of 1973.

ANNEXURE A: INTERVIEW SCHEDULE

SECTION A: IDENTIFYING INFORMATION

(To be completed by interviewer before commencement of interview)

Name of Child: .....

Gender: .....

Date of Birth: .....

Date of Admission: .....

Hospital No.: ..... Ward No.: .....

Name of Parent: .....

Parent's Suburb of Residence: .....

Child's degree of mental retardation:

	Mild - Moderate		Severe - Profound

Nature of child's handicap(s) *(if any abnormalities)*: .....

Date and Time of Interview: .....

SECTION B: DEMOGRAPHICAL DATA

1. **How long have you lived at your present address?**

<10 Years	>10 Years

2. **Did you live in a different suburb before this?**

Yes	No

3. **To what church or religion do you belong?**

Protestant	Roman Catholic	Moslem	Other

4. **What form of education did you have?**

No formal education	Primary	Secondary	Tertiary

5. **What is your current employment status?**

	Yourself	Partner/Spouse
Full-time employment		
Part-time		
Shifts		
Contract		
Unemployed		
Retrenched		
Other		

6. **What is your total household income?**

Per Week	Per Month . . . . .

7. **Marital Status:**
For mother: which of the following apply to you?

Married and living with (F) of the child	
Married and living with man other than child's father	
Divorced/Separated and living alone	
Divorced/Separated and living man, not father	
Widowed and living alone	
Widowed and living with man, not father	
Never married and living alone	
Never married and living with man, not father	
Common law marriage (Moslem)	
Other	

8. **How many living children do you have?**

1	2	3	4	5	6	7	8	9	10

9. **What type of dwelling do you occupy?**

Flat	
Cottage	
Semi-detached	
Freestanding	
Living with other people (renting room)	
Wendy house (backyard)	
Other	

10. Do you rent or own the above dwelling?

	Own
	Rent

SECTION C: DETAILS OF PREGNANCY AND BIRTH

11. How old were you when you fell pregnant with the child?

.....years

12. Is your mentally handicapped child your first born, second born etc.?

1	2	3	4	5	6	7	8	9	10	10 +

13. Did you experience any problems during your pregnancy?

	Yes
	No

If yes, please specify: .....
.....
.....

14. The birth of your child, was it normal?

	Yes
	No

If no, please specify: .....
.....
.....

SECTION D: POST-NATAL DEVELOPMENT PERIOD

15. Did your baby achieve his/her milestones within the normal range of development?

	Yes
	No
	Unsure/Don't know

If not, specify how was milestone achieved:
.....
.....
.....

16. **At what age did you first think that there may be something different about your child?**

First few weeks	
First few months	
At first two years	
After two years	

SECTION E: COUNSELLING POST DIAGNOSIS

17. **Who first told you of your child's handicap?**

Doctor	
Family	
Friends	
Other	

18. **What was told to you by the above person?**

.....
.....

19. **What effect did this have on you at the time?**

.....
.....

20. **How did the other members of your family react?**

.....
.....

21. **Were you counselled after being told of the diagnosis?**

	Yes
	No

If yes, specify what did it entail and for how long? .....
.....

22. **Looking back now do you think that ongoing counselling from a professional would have helped you to cope better with your child?**

.....
.....

SECTION F: RELATIONSHIP WITH MENTALLY HANDICAPPED CHILD BEFORE AND AFTER ADMISSION

23. Can you describe the relationship between your child and his/her siblings when he/she was at home (probe)?

.....

.....

24. Can you describe the relationship between your child and other children, neighbours and adults when he/she was at home (probe)?

.....

.....

25. Can you describe the relationship between your child and his father and mother, when your child was at home (probe)?

.....

.....

26. Can you describe the relationship between your child and his/her siblings after his/her admission to hospital (probe)?

.....

.....

27. Can you describe the relationship between your child and other children, neighbours and adults after his/her admission to hospital (probe)?

.....

.....

28. Can you describe the relationship between your child and his father and mother after your child's admission to hospital (probe)?

.....

.....

SECTION G: ADMISSION TO LENTEGEUR

29. At what age was your child admitted to Lentegeur C & R Centre?

.....

30. What were the reasons for having him/her admitted/which most apply to you?

(a) Behavioural problems	
(b) Inability to cope	
(c) Financial reasons	
(d) Relationship difficulties	
(e) All of above	

If other, please specify:

.....

.....

31. Of these reasons, what do you regard as the main one? Why?

.....

.....

32. Did anyone advise you to have your child admitted?

	Yes
	No

If yes, who advised you? .....

33. What reasons did they give?

.....

.....

34. As regards your child going to Lentegeur/Dr Stals, how did you feel, which most apply to you? Were you:

Totally against	
Moderately against	
Neutral	
Moderately in favour	
Totally in favour	

35. Why did you feel this way?

.....

.....

36. What were your husband/wife's reactions to your child being admitted? Which most apply:

Totally against	
Moderately against	
Neutral	
Moderately in favour	
Totally in favour	

37. What were the reactions of the siblings? (probe)

Totally against	
Moderately against	
Neutral	
Moderately in favour	
Totally in favour	

38. Knowing what you know now, if you were to make the decision again to have your child admitted, would you do it again?

	Yes
	No

SECTION H: PARENT-CHILD CONTACT

39. How often do you visit your child?

Never	
Birthdays, special holidays	
3-6 times per year (incl. birthdays and holidays)	
1 per month	
Weekly	
Daily	
Other	

40. **How often do you make a phone call to the centre?**

Never	
Birthdays, special holidays	
3-6 times per year (incl. birthdays and holidays)	
1 per month	
Weekly	
Daily	
Other	

41. **Do you know about regular Parent Group Meetings held at Lentegeur Hospital?**

	Yes
	No

42. **If yes, how regularly do you attend these meetings?**

1. Attend every meeting	
2. Attend frequently	
3. Attend infrequently	
4. Never attend	

43. **If no, why don't you attend?**

.....

.....

44. **Would you like to visit your child more often?**

	Yes
	No

45. **If yes, what prevents you from doing this (probe)?**

.....

.....

46. **If no, why don't you want to visit your child more often (probe)?**

.....

.....

47. **Do you feel close to your child (attached) now?**

No, not at all	
A little	
Somewhat	
Much	
A great deal	

48. **Has there been any changes in the closeness (attachment) to your child since placement?**

Weaker since placement	
Same as before placement	
Stronger since placement	

49. **Is your closeness (attachment) to your child lessening?**

Yes	
No, attachment is the same	
No, attachment is stronger	

50. **What type of transport do you use to get to the centre?**

Car (own)	
Taxi	
Train	
Bus	
Car (hire)	
Combination of the above	
Other	

51. **How much does it cost you in fare to make a visit to your child?**

.....

52. **How long does the journey to the centre take from your home?**

.....

53. Do you think about bring your child home?

	Yes
	No

SECTION I: PARENTS' VIEWS ON THE INSTITUTION

54. What do you think of Lentegeur C & R Centre and the care you child is getting (probe)?

What do you see as positive? .....

.....

What don't you like? .....

.....

55. Have you any suggestions for improvements?

.....

.....

56. How do you find the staff members when visiting your child?

Helpful	
Uncooperative	
Aloof	

57. Are you satisfied with the treatment your child is getting at the centre?

Dissatisfied	
Moderately satisfied	
Satisfied	
Perfectly	

Specify why:

.....

.....