THE IMPACT OF THE MENTALLY HANDICAPPED CHILD
UPON THE PARENTS: A COMPARATIVE STUDY

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ABSTRACT

The purpose of this study was to explore the impact of the mentally handicapped child upon the parents. A paucity of systematic and comprehensive work exists in this field in general, and particularly in South Africa. For this reason broad aims and exploratory research hypotheses were formulated, within the theoretical framework of stress, coping and social support.

Participants were the biological parents of mentally handicapped children (N = 72). All participants were classified as 'white' and an equal number of mothers and fathers was selected. Two groups (n = 36) of participants were chosen for comparison, i.e. parents who had placed the handicapped child in permanent residential care and parents whose handicapped child lived at home and attended a day-care centre. The number of parents with a male child equalled the number of parents with a female child in each group.

The study embraced both quantitative and qualitative methods. In terms of the quantitative design, participants completed two questionnaires. The Personal Details Questionnaire, drawn up by the researcher, served to elicit the demographic details of participants. The short-form of the Questionnaire on Resources and Stress (Friedrich, Greenberg & Crnic, 1983), a true-false questionnaire, was used to estimate the psychological costs to parents living with and caring for a mentally handicapped child. Parametric and non-parametric tests, where appropriate, were employed to analyse the data. Qualitative material was gathered during the course of depth interviews which were conducted with the parents. All parents were interviewed twice in their own home and the duration of each interview was between two and five hours. A semi-structured interview schedule was used to
guide the interview, during which the two questionnaires were also completed. All interviews were tape-recorded, transcribed and loosely content analysed.

Several variables were found to be significantly associated with parental stress. Mothers were shown to experience stress of a different nature to that experienced by fathers in relation to the handicapped child. A significant relationship between parental stress and gender of child and type of care, in interaction, was revealed. The variables of socio-economic status, religious conviction and the parents' medical and psychological history were related to parental stress. Interpersonal social support was shown to influence the manner in which parents coped with the mentally handicapped child. Findings were discussed in the light of relevant theory and an attempt was made to formulate a theoretical framework, utilizing the concepts of stress, coping and social support.
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CHAPTER ONE

CONCEPTUAL ISSUES

1.1. INTRODUCTION

The present study is concerned with the families, and in particular the parents, of mentally handicapped children. The broad purpose of this work is to provide empirical evidence on a range of issues pertaining to the stress parents experience in relation to their handicapped child. This includes the nature of that stress, to factors which ameliorate or exacerbate it, and the concomitant notions of coping and social support. In this first chapter the author will begin to raise and examine some of the conceptual issues surrounding the notions of stress, coping and social support in general, and the manner in which they relate to the field of mental handicap in particular. A brief historical review and a short discussion on the concept of mental retardation is also provided.

1.2. HISTORICAL REVIEW

During particular historical periods, changes in research direction occur (Rowitz, 1985). These changes may occur between disciplines, within disciplines, or there may be a change in emphasis within a specific area. Thus during specific historical periods little or no research may be executed in an area because another area is in its ascendancy at this time. This pattern has also occurred within the field of mental handicap. During the 1950's and 1960's, work on the families of mentally handicapped persons was paramount – Farber's (1959) seminal work in this area probably being a major force in the generation of research interest. The 1970's saw a decline in this area, and attention shifted to the ambit of social services.
In the 1980's, a resurgence of interest in the families of mentally handicapped persons is apparent, with an emphasis upon stress, social support and coping processes (Kessler, Price & Wortman, 1985).

As noted by Rowitz (1985) the reasons behind these shifts are many. Rowitz himself outlines several, including: government policy directions and associated funding, major methodological or theoretical breakthroughs in an area, the possibilities for research arising from interdisciplinary work, and the non-existence of a uniform data base, without which research priorities are unclear. A number of these are of particular pertinence to the field of mental handicap.

Firstly, the development of new methodological tools has affected research direction. The publication of the Maternal Malaise Inventory (Rutter, Graham & Yule, 1970) has, for instance, resulted in a number of studies investigating stress in families of mentally handicapped children - although not originally devised for this purpose. Examples of these are Tew and Laurence (1975), Bradshaw and Lawton (1978), Chetwynd (1985) and Quine and Pahl (1985).

Secondly, research of an interdisciplinary nature has precipitated further research in an area. A study by Jubber (1980), for example, on the impact of the handicapped child upon the family adopts a broader sociological perspective. This has revealed the value of this approach to the field and subsequently more research of this type has been forthcoming. Thirdly, in the arena of mental handicap in general, and in South Africa in particular, no sound theoretical or empirical base underpins much of the work executed. Research to date therefore remains largely undirected and is not undertaken as a result of a careful assessment of research priorities.
Prior to the 1950's, little research had been conducted in the field of mental handicap. Perhaps one of the most notable pieces of work in these years was that of Binet and Simon (1914), who attempted to differentiate between persons of 'normal' and 'subnormal' intelligence by designing an IQ test. A number of other studies were conducted but these appear to reflect sporadic interest. Witmer (1909), for example, examined the study and treatment of retardation, Doll (1924) focused on problems in mental diagnosis, Kephart (1939) noted the effect of a specialized programme on the IQ of retarded boys, whilst Burt (1944) addressed various problems associated with the subnormal mind.

The publication of Farber's monographs in 1959 and 1960 had a major impact upon the status of mental handicap. A comprehensive study examining many facets of the family led him to define different types of family organizations which affect marital integration and severity of family crisis for parents of children who are mentally deficient.

This work resulted in increasing interest amongst researchers, with respect to the adaptation of families to the crisis of a child who is severely mentally handicapped. Farber's original methodological tools, i.e. his indices of marital integration and sibling role tension, were used fairly extensively by researchers in the same area (e.g. Fowle, 1968). Thus throughout the 1960's work continued to focus upon the families of mentally handicapped persons, and many studies were forthcoming (e.g. Jordan, 1962; Cummings, Bayley & Rice, 1966; Matheny & Vernick, 1969). 

In the decade of the 1970's, research attended to the field of service utilization patterns in alternative treatment settings (Rowitz, 1985). Researchers investigated services in general (Beck, 1969), the institutionalization of the mentally handicapped child (Eyman, O'Connor, Tarjan & Justice, 1972), de-institutionalization effects...
(Willer, Intagliata & Atkinson, 1979), day-care facilities, clinics, attitudes toward the mentally handicapped (Vurdelja-Maglajlic & Jordan, 1974), and so forth. Research focus therefore shifted from examining the child and his or her nuclear family, to investigating the role of the community in mediating this crisis. This slightly broader perspective emphasized attitudinal studies and social service appraisal.

Although research in the above-mentioned areas continues, there has been a resurgence of interest in the families of mentally handicapped persons. In recent years, stress, and factors which may affect it, such as coping and social support, has begun to dominate mental health research (Kessler et al, 1985). So too have the notions of stress, coping and social support come to assume greater significance in the field of mental handicap. Indeed, Rowitz (1985) has written that social support in particular is the issue of the 1980's for those concerned with mental handicap.

The above description pertains largely to the historical path of research direction in the U.S.A. and Europe. In South Africa the 'history' of mental handicap is not as easily traced. One of the few South African researchers to have worked systematically in the field of mental handicap is Vera Grover. Her primary interest has been the development of suitable assessment devices for the handicapped (1979), but more recently she has adopted a broader perspective. An extensive survey of the facilities available to mentally handicapped individuals is at present being conducted on a national basis by Grover and her associates, in an attempt to assess the needs of this group. The early findings of this study have been documented (Grover, 1986). A number of other studies have been conducted. In 1968, Groenewald presented a paper in the special education of the Indian mentally
handicapped child at a national conference held in Durban. Jubber (1980) conducted a broad sociological survey on the families of mentally handicapped children, and in 1981 Steenkamp and Steenkamp published a manual for day-centres catering for the mentally handicapped child.

1.3. THE CONCEPT OF MENTAL RETARDATION

Much conceptual confusion surrounds the term 'mental retardation' (Braginsky & 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. All such persons are thought to suffer from an intellectual deficiency that significantly impairs their ability to become fully competent and independent members of society - regardless of aetiology, age of onset or severity of the impairment.

Thus the formulation of a broad definition of mental retardation allows for the inclusion of a wide range of disparate 'conditions'. The American Association on Mental Deficiency in 1973 has adopted the following formulation which is largely accepted in clinical arenas:

mental retardation refers to significant sub-average general intellectual functioning (two standard deviations below the normal) existing concurrently with deficits in adaptive behaviour and manifested during the developmental period.

(Kaplan & Sadock, 1981: 851).

Certain writers regard the diagnosis of people as mentally retarded in a critical light (e.g. Braginsky & Braginsky, 1971; Ryan, 1980).
They hold that mental retardation is a convenient category created under the guise of medical science for the purpose of controlling those people who do not conform to societal norms. From this radical perspective, no such entity should exist - not even for the severely or profoundly retarded.

In general, the greater the degree of mental deficiency, the less controversy exists surrounding classification. In cases where definite lesions or damage is apparent it is easier to view the problem of mental retardation as a medical one. It is in instances where no physical abnormality is discernible, and yet the individual is deemed as deficient, that the diagnosis of mental retardation is more hotly debated. The latter individuals are usually classified as mildly mentally retarded and aetiology is frequently unknown. Those diagnosing mental retardation in these instances, where individuals do not fall clearly within the domain of medicine, are open to being criticised for the medicalization of what Ryan (1980 : 14) views as a "social problem". That is, upholding society's intolerant attitude toward those who do not act in accordance with social norms, and are therefore regarded as deviant. In order to legitimise the control of deviant persons, the 'social problem' is transformed into a 'medical problem', and the person is labelled as 'sick'. Hence there are those who view mental retardation as a valid diagnostic category, there are those who view certain aspects of mental retardation with some uncertainty, and there are those who are of the opinion that mental retardation does not exist, except in the minds of those who wish to maintain the status quo.

For those who do view mental retardation as a valid category, there remains confusion relating to the great diversity of conditions which
fall hereunder. This confusion is still further compounded by the changing terminology used to describe people with limited intellectual capacities, and which constitutes the history of mentally handicapped people (Ryan, 1980). In the past, terms such as idiot, imbecile and moron were used to describe the 'feeble-minded'. These were later replaced by the terms mild, moderate, severe and profound retardation. The World Health Organization recommended the use of the term 'subnormal' rather than retarded, but this has not been widely accepted (Edgerton, 1979). More recently the term mental handicap has begun to replace mental retardation. This shift appears to be linked to an attempt to reduce the stigma attached to retarded people. Handicap has been proclaimed a 'nicer' term, and one which is less harshly condemning than retarded. Other more 'sensitive' terms include 'developmentally delayed' (e.g. Butler, 1979), 'developmentally disabled' (e.g. Bradley, 1978), and intellectually handicapped, now the official term used in Western Australia (Seed, 1980).

These changing terms are always conceived of by others. They are never, according to Ryan (1980), an expression of the mentally handicapped people themselves - "of a group of people finding their own identity, their own history" (p.13). Hence others provide a term - by implication on behalf of those who cannot express themselves. This term is essentially an assertion of differences between people, i.e. normal as opposed to mentally handicapped. Moreover, this assertion of differences is seldom neutral, usually implying some negative social distance.

Recently the cultural relativity of defining who is socially or intellectually competent, and best able to adapt to the demands of society, has been recognized. Thus an attribution of differences is made, but that attribution of difference is dependent upon the
culture in which it is made. Mittler (1979) comments on this as follows:

The criteria which any given society uses to decide whether someone is mentally handicapped will vary greatly from one time to another ... but it is probably true to say that most countries have used criteria based on social competence and ability to adapt to the demands of that society.

(1979 : 20)

It is evident from the above discussion that whatever the term used to describe those who are united by their assumed intellectual deficit, there is a need to critically re-examine present terminology and the implications that this has for the mentally handicapped. Seed (1980) suggests that it is desirable to actively promote the re-definition of mental handicap in order that those regarded as handicapped are either thought of as less handicapped or not handicapped at all. Thus Seed is proposing to apply the principle of normalization to the plight of the mentally handicapped; that is, enabling handicapped persons to live as normal lives as possible. In the author's opinion, the stigma associated with being mentally handicapped is not easily eradicated. Changing the terminology and by implication the definition of difference has not been successful in reducing prejudice. Essentially the name is immaterial. More important is the basic assumption which society makes about 'difference' which must be called into question if changes in attitude are to be effected.

The term mental handicap has been chosen as the preferred term for use in this study since it is widely accepted amongst researchers, and moves away from the more negatively connoted 'retardation'. Thus,
while not removing the stigma attached to those to whom the label is applied, it appears to be a term which is viewed by investigators and parents of mentally handicapped children alike (e.g. Hannam, 1980; McCormack, 1978) as being less condemning in its application.

1.4. THE CONCEPT OF STRESS

The concept of stress has been utilized in a broad range of settings; consequently a plethora of meanings abound. Until recently, research has tended to focus upon occupational stress, largely a perogative of industrial psychology. By implication the concept has evolved a greater depth of sophistication within the industrial arena. The past decade has, however, seen a growing interest in clinical aspects of stress; in particular, the role of stressors in the development of psychopathology (Kessler et al, 1985). Despite this, the concept of stress remains problematical - at conceptual and operational levels. It is the focus of the following discussion to briefly highlight some of the most salient of these difficulties, pertaining to stress in general, and to the use of this concept within the field of mental handicap in particular.

It must be noted at the outset that it is possible to make a distinction between purely conceptual and operational constructs. However, for the purposes of the present discussion this is not a particularly useful distinction. The primary reason for this is that within the research domain of mental handicap, stress has frequently been conceived of, in operational terms. That is, stress has been defined as that which the tools devised to measure stress, measure. Therefore, attempting to delimit conceptual and operational aspects of stress becomes difficult.
1.4.1. Conceptual and Operational Problems

Stress is a multi-faceted, and therefore elusive, concept (Cox, 1978). Colloquial application of the term is sufficiently vague and general for both the layman and the professional to understand. However, when a more precise account is required, the notion of stress is understood by few (Rutter, 1981). Thus, when used in the natural or social sciences, confusion regarding the exact meaning of stress, is characteristic. Indeed, Mason (1975) has commented upon this lack of conceptual clarity as follows:

> The single most remarkable historical fact concerning the term 'stress' is its persistent, widespread usage in biology and medicine in spite of almost chaotic disagreement over its definition. (p.7)

Some of this "chaotic disagreement" stems from the fact that there are three main approaches to the problem of defining stress: response-based approaches, stimulus-based approaches and interactional approaches (Forshaw, 1984). These approaches have been discussed in detail by several authors, including Lazarus (1966), Appley and Trumball (1967), Cox (1975, 1978), Levine and Scotch (1970), McGrath (1970) and Shirom (1982). Cox (1978) has noted that there is some common ground between these three approaches and that the most salient differences involves the emphasis of definition and associated methodology. In brief these approaches are as follows:

1. Stress is viewed as the dependent variable for study. It is therefore conceived as the individual's response to a negative life event.
2. Stress is viewed as the independent variable for study. It is therefore conceived as the stimulus or trigger which precipitates distress in the individual whom it affects.

3. Stress is viewed as a 'lack of fit' between person and environment (French, 1974; Van Harrison, 1978). Hence it is seen as an intervening variable between stimulus and response. The principle of interaction between individual and environment is therefore recognized.

Not only are there clear differences in the conceptualization of stress between these approaches, but within each approach differences of opinion are to be found. Rutter (1981) has therefore begged the question: "in view of this all too evident chaos, confusion and controversy, why has the concept of 'stress' proved to be so enduring?" (p.323) In recent years, in fact, research interest into stress and associated concepts such as coping and social support has grown considerably. It would thus seem that whilst both conceptually and operationally 'stress' is problematical, it is an important concept in that it draws attention to some interesting and notable phenomena (Rutter, 1981).

Some researchers hold a more optimistic outlook regarding the conceptual status of stress. House (1981) for example, has stated:

... an increasing number of researchers have converged on a similar conceptualization of the nature of stress as a phenomenon or process.

(p.35)

This growing consensus involves a comprehensive paradigm of stress, incorporating many of the complexities hitherto inadequately accounted for. In essence, this paradigm posits that people perceive stress
in relation to certain objective conditions. These conditions may be perceived as stressful when the demands they place on the individual, exceed that individual's abilities (McGrath, 1970). In other words, stress is defined as an imbalance between perceived demand and perceived capability to meet that demand; whilst the experience of stress is the perception by the individual of an appreciable, unwanted imbalance (Cox & Mackay, in Cox, 1978). It is evident from this description that this exposition is located within the basic 'person-environment fit' model (Kasl, 1978), but also involves feedback in the process of stress; hence incorporating cyclical rather than linear elements (Forshaw, 1984). That is, the individual may react back upon the environment and thereby modify the experience of stress in some way.

The above 'model' of stress forms a useful framework within which to view the phenomenon of the birth of a mentally handicapped child in a family. This comprehensive 'lack of fit' exposition, which incorporates the mechanism of feedback, goes some way to lending meaning to the complexity of this particular situation. Thus, the discovery of mental handicap in the child may be regarded as a stressor. The subsequent demands placed upon parents, in most cases, exceed their capability to meet those demands, at least for some period of time. Parents may therefore perceive their circumstances to be stressful. As noted by Cox (1978) this stress response may not be confined to 'feeling stressed' per se, but is frequently associated with other emotions, including, anger, grief, guilt, shame or anxiety. Indeed, an extensive literature reveals that these emotions are common to parents of handicapped children (Olansky, 1966; Kromberg, 1977; Schild, 1971). Further, the presence of a feedback mechanism in this model allows for consideration of the relationship between parents.
and child. Thereby the active role of both parties in generating or dissipating stress is acknowledged. Finally, other factors which may mediate stress, such as socio-economic status, religious conviction and so forth, may be accounted for in terms of the "Objective conditions" (McGrath, 1970) in relation to which people perceive stress.

To date the majority of researchers concerned with mental handicap have not attempted to locate their work within a framework such as the one just described. Studies examining stress in relation to the handicapped child are generally inadequate at the conceptual, and by implication therefore, at the operational level. This forms the basis of two major criticisms which may be levelled at existing research in this field. Firstly, investigators seldom provide an adequate conceptualization of stress. Many studies lack conceptual clarity, whilst others make absolutely no attempt to define stress. Where vague reference is made to the notion of stress, it becomes apparent that a greater proportion of studies are located within the oft criticised stimulus-based approach to stress; that is, the mentally handicapped child is regarded as the stimulus or stressor. Secondly, researchers neglect to adequately operationalize the concept of stress. Thus, certain studies employ instruments to measure stress without giving due consideration to the reliability and validity of these measures.

In order to clearly illustrate the inadequacies associated with much of the research to date pertaining to stress in families of mentally handicapped children, three examples will be cited.

1.4.1.1.

A study conducted by Fotheringham, Skelton and Hoddinott (1972) is
illustrative of a body of research which may be criticized on both conceptual and operational grounds. This study set out to examine "the impact of the retarded child upon his family" (p. 283) by means of observing changes in family functioning when the handicapped child was removed permanently from the nuclear family and institutionalized. The notion of stress is frequently encountered in this paper - indeed Potheringham and colleagues conclude by stating:

This study conceptualizes the presence of a retarded child within a family as constituting a stress which the family attempts to cope with by bringing its resources to bear on the problem. If the stress proves too great for the family's coping mechanism, institutionalization may be sought.

(p. 288)

From the above quotation it would appear that this study has adopted a predominantly stimulus-based approach to stress (i.e. mentally handicapped child = stressor). This position is however never clearly articulated or defended. Indeed, the manner in which stress is conceptualized in this study is in no way made explicit, the last statement being the only one to shed some light on the manner in which stress is understood.

Furthermore, stress appears to be directly inferred from the Family Functioning Scale (FFS) since no independent rating of stress per se is given. This is reflected in the second of the study's hypotheses:

That the stress caused by the presence for another year of the retarded child results in a reduction in the adequacy of family
functioning, and that this change is reflected in alteration in the FFS measures.

(p.285)

A direct relationship between the variables 'family functioning' and 'stress' appears to be unequivocally assumed - that is, adequate family functioning, low stress; inadequate family functioning, high stress. No evidence for this correlation is cited. Furthermore, no figures of reliability or validity for the FFS are given and the relationship of scale scores to stress is unclear. Finally, bold conclusions are drawn with regard to stress in families of mentally handicapped children, based entirely upon the use of a single instrument.

1.4.1.2.

A series of studies, utilizing the Malaise Inventory, reveals the general lack of consideration afforded to operationalizing stress within mental handicap research. This instrument was adapted from the Connel Medical Index by Rutter and Graham for their study in the Isle of Wight (Rutter, Graham & Yule, 1970). Several researchers have subsequently made use of the Malaise Inventory to investigate stress in families with handicapped children (e.g. Tew & Laurence, 1975; Bradshaw & Lawton, 1985; Quine & Pahl, 1985). Most assume the validity of this inventory and report their findings with confidence. However, some doubt has been cast upon the validity of the Malaise Inventory (Bradshaw, 1982; Hirst & Bradshaw, 1983). Indeed, Hirst (1983) has concluded that malaise scores are untrustworthy for testing empirical hypotheses about degrees of stress, arguing that there is no evidence to suggest a single dimension of emotional disturbance underlying the set of items. Recent work by Bebbington and Quine (1985) is in contradiction with Hirst's findings, and claims are made for the undimensionality of the scale. It is thus apparent that the
evidence relating to the validity of the Malaise Inventory is contradictory. This fact is however seldom reported by those employing the measure. Generally, researchers have neglected to discuss the uncertainty surrounding the validity of the Malaise Inventory. Little or no caution is exercised in generalising findings and these are, in most cases, reported with conviction.

Notably, other researchers (e.g. Gath, 1977) who have also made use of the Malaise Inventory to investigate the impact of the mentally handicapped child upon the family have been cautious in the interpretation of their findings. Gath (1977), for example, in her study, made use of a number of measures of which the Malaise Inventory was one. Furthermore, she does not refer to 'stress' when discussing the results of her work. Gath speaks of marital disharmony or breakdown but does not assume this to be indicative of stress - possibly thereby acknowledging the conceptual complexity of this term, and recognizing that she has measured areas of family functioning and not stress per se.

1.4.1.3.
A third area of research represents a group of researchers working in the field of mental handicap, who have attempted to develop a measure of stress in a systematic and vigorous manner. Holroyd (1974) has been concerned with the family as an increasingly important resource for handicapped persons. However, aware of the difficulties associated with rearing a handicapped child at home, Holroyd recognized the need to devise a means of assessing the pressures to which families with handicapped members are subject. Thus Holroyd describes how she reviewed an extensive literature on stress, finally defining the concept in accordance with Vickers (1968). Briefly, Holroyd
differentiated between degree of stress in the system — that is, the handicapped child and his or her associated characteristics — and breakdown in the system — that is, the inability of the family to cope. From this conceptual base Holroyd designed the Questionnaire on Resources and Stress (QRS) noting that "little has been done to develop a standardized instrument for evaluating the psychological costs to persons living with and caring for a handicapped or chronically ill relative" (1974: 92). Since this questionnaire yields data pertaining both to the child and to the parents, the framework within which it is couched may be described as interactional in perspective.

Validity studies have shown the QRS to be useful in discriminating between populations which differ in amount of stress, and in describing the particular nature of the stress. In an early study Holroyd (1974) reports how the various sub-scales differentiated between mothers and fathers, married and unmarried mothers, and mothers of retarded as opposed to mothers of emotionally disturbed children. The findings of a second study in which Holroyd (Holroyd, Brown, Wilker & Simmons, 1975) examined stress in families of institutionalized and non-institutionalized autistic children, using the QRS and an interviewer rater of familial stress, lent further support to the validity of the QRS as a measure of parental stress. A third study conducted by Holroyd and McArthur (1976), contrasted by Holroyd and McArthur (1976), contrasted parental stress in relation to Down's Syndrome and childhood autism. Results showed the QRS to differentiate between the two groups of participants and Holroyd and McArthur note

the multidimensional Questionnaire on Resources and Stress appears to be a useful instrument for research with families of
handicapped persons.

(1976 : 435-436)

A final study in the series conducted to establish the usefulness and limits of the QRS by application to successive clinical populations, compared parents of children with neuromuscular disease to parents of children with psychiatric diagnoses (Holroyd & Guthrie, 1979). This study corroborated the findings of earlier work in showing the QRS to make valid and meaningful discriminations among families of children with different handicaps. Holroyd and Guthrie conclude:

The present study demonstrated the usefulness of the QRS not just for differentiating stress patterns present with a chronic illness, but also for measuring the effect of the illness as it progresses.

(1979 : 739)

Further research into this instrument has resulted in the development of a short-form of the Questionnaire on Resources and Stress, the QRS-F (Friedrich, Greenberg & Crnic, 1983). This has been shown to be a "psychometrically stronger inventory" (p.41) than the original questionnaire, according to the authors. Research into the reliability and validity of both forms continues.

Undoubtedly there remain difficulties with the QRS and QRS-F at both the conceptual and operational level. However, the significance of these instruments is that they represent the sole attempt to date to systematically devise a valid means of assessing the stress experienced by families of handicapped children.

To summarise, the concept of stress represents an area of increasing research interest. However, much of the work to date remains conceptually and operationally flawed. This criticism is particularly
pertinent to the field of mental handicap, and the stress experienced by families with a mentally handicapped member. A re-examination of the concept of stress is therefore required. Unchallenged assumptions regarding the nature of stress, and loose definitions thereof are frequently encountered in the literature. Moreover, attempts to measure stress are often subject to question - particularly in terms of reliability and validity. It is the author's contention that many studies are, in fact, unscientific and that if research of value is to be produced in future, an approach founded on greater systematicity and rigour is essential. This constitutes one of the purposes of the present empirical research.

1.5. THE CONCEPT OF COPING

The concept of coping is at least as diffuse and unsatisfactory as that of stress (utter, 1981). Until recently little effort had been made to systematically define coping and only within the last decade have attempts been made to gain conceptual clarity.

In earlier periods, 'coping' was influenced by the psychoanalytic conceptions of Freud (1979) which viewed coping and defense as largely unconscious responses to internal conflicts. More recently a shift in conceptual emphasis has occurred and the process of coping is seen predominantly in terms of external stressors. This change in conceptualization may be largely attributable to the work of Lazarus (1966, 1976; Lazarus & Launier, 1978) which has been a major influence in the field of coping research. Contemporary approaches to stress therefore tend to emphasize the active role of the individual in constructing his or her psychological world and in utilizing resources to manage stress or to master problematic aspects of the environment (Kessler et al., 1985).
Despite current concern over the conceptual inadequacy of coping, little progress has been made with regard to coming to a consensus of definition. It is suggested that this may be due to the position of the concept of coping, relative to that of stress. These two concepts are, in most research, associated with one another. Thus, for example, McCubbin (1979) refers to how families cope with stress. It would appear that to date the concept of stress has received the greater amount of attention with respect to problems of conceptualization and operationalization. Thus stress may be seen to be primary, whilst the concept of coping may be regarded as associated with stress and therefore of secondary significance.

According to Haan (1982), there remains considerable disagreement as to the definition of coping. This may, in part, be attributable to three issues which appear central to the present controversy (Kessler et al., 1985). Firstly, the notion of cross-situational consistency serves to create differences in opinion with respect to its applicability to coping. Certain researchers view coping as a dispositional trait, and therefore assume that individuals will react to stressful experiences in similar preferred modes. Others challenge this notion of consistency of coping behaviour across situations, stating that individuals will not necessarily respond in similar ways to a range of stressful stimuli. To date, research has revealed contradictory findings - some studies reporting relative consistency of coping response (e.g. Pearlin & Schooler, 1978), and others reporting little evidence to suggest such consistency (e.g. Folkman & Lazarus, 1980).

Secondly, the role of factors referred to as resilience and resistance has been a source of disagreement between investigators concerned
with the concept of coping. These factors have been used to account for individual variation in response to stressful occurrences; for example, offering some explanation for why certain persons 'do well' in spite of having experienced a form of stress known to carry the risk of an adverse reaction (Rutter, 1981). At present, little empirical evidence is available regarding the development, structure or function of these factors. Consequently, much work surrounding resilience and resistance is speculative, creating further possibility for differing opinions.

Thirdly, there is lack of consensus between investigators regarding the extent to which individuals are aware of the coping strategies they employ, and their effectiveness. There is some evidence to suggest that coping strategies or styles are not always conscious and deliberate (Kessler et al., 1985). This contradicts much work which assumes that individuals are conscious of their coping behaviour, and raises questions regarding research whilst has relied upon the use of self-report inventories to assess coping (e.g. Folkman & Lazarus, 1980).

In short, the area of research pertaining to coping in general remains controversial, and is characterized by conceptual disagreement and empirical inconsistency. Within the domain of coping as it pertains specifically to families of mentally handicapped children, however, greater conceptual clarity appears to have been achieved. Indeed, the concept of coping has been a major focus of research with these families. This is probably attributable in part to mental health professionals concern with the impact of the mentally handicapped child upon the family and by implication, the amelioration stress and development of coping strategies. Two dominant conceptions of coping are identifiable from the extensive literature on coping in
parents of mentally deficient children. The first considers coping as a process, the second regards coping as an outcome, or response. Each of these will be examined in turn.

An abundance of literature describes the process by means of which parents come to terms with their mentally handicapped child; that is, how parents cope. Moreover, there is considerable agreement regarding this process amongst mental health professionals and researchers working in this field. Generally this adjustment parallels that described within the literature on death and dying (Refer for example Kubler-Ross, 1970), and various phases or stages are documented. Feelings of grief are paramount (Solnit & Stark, 1961; Olsansky, 1966; Kennedy, 1970; Wright, 1976; Kromberg, 1977) and this period is therefore often referred to as the grief or mourning process. By 'working through' their grief parents are seen to positively adjust to, or cope with, the trauma of discovering the child's deficit. On the other hand, parents who do not manage to 'work through' this period of mourning are regarded as not having adequately coped with the experience (Kromberg, 1977).

The nature of the emotions parents experience in response to their child, and the sequence in which these progress is consistently reported in most studies. However, differences in opinion are in evidence regarding the precise boundaries of each of the phases described in the grief process. Kromberg (1977), for instance, refers to three distinct phases - protest, despair and detachment - in accordance with Bowlby (1960). Wright (1976), on the other hand, documents "six distinct psychological stages; shock, denial, guilt and anger, shame and martyrdom, depression, and recovery" (p.161). Despite differences in the number of phases the nature and sequence of the emotional reactions of parents in these and other frameworks
is remarkably similar.

According to Kromberg (1977), the first phase of protest is characterized by feelings of shock, disbelief and anger. Parents may also embark upon a phase of 'searching for magic cures', in an attempt to refute the diagnosis of mental retardation (Mannoni, 1973; Fischer & Roberts, 1983). The end of this first phase of adjustment is regarded by some as the point at which parents begin to acknowledge the true nature of the child's problem (Fotheringham & Creal, 1974).

During the second phase, termed 'despair' by Kromberg (1977), parents are reported to experience feelings of disappointment, loss, sorrow, helplessness, hopelessness, and guilt. Having accepted the reality of the child's condition, the full implication thereof becomes apparent to parents. A familiar and bitter refrain of parents at this time is described by Cormack (1978) as 'why me?' Following the acknowledgement of, and despair associated with, the child's deficiency, Fischer and Roberts (1983) refer to a period during which parents' attempt to find help for their child.

Finally parents enter and pass through the phase of detachment, at which time they are regarded as having affected a "constructive adaptation to the situation" (Kromberg, 1977: 34). Kennedy (1970) whose work represents a psychoanalytic interpretation of the grief process views this phase as involving a decathexis from the lost object, i.e. the symbolic object of the normal and healthy infant the parents desired. Within this framework, parents are seen to remain cathected to the fantasy object of the healthy infant during the first two phases of the grief process. Decathexis frees parents to cathect the 'new' object, i.e. the real object of the handicapped child. Accordingly if parents do not manage to 'work through' the
entire grief process they may remain cathexed to the 'lost' object (the healthy child) and never come to terms with the presence of the real object (the handicapped child).

An alternative approach to understanding the manner in which parents of handicapped children cope is that which considers coping as an outcome or response. Coping mechanism (e.g. Fotheringham, Skelton & Hoddinott, 1972), coping patterns (e.g. Marcus, 1977), coping styles or strategies (e.g. Fotheringham & Creal, 1974), or styles of adaptation (e.g. McCubbin, 1979) are referred to. What precisely differentiates each of these terms from one another remains unclear, and it would appear that they are largely interchangeable.

One of the most sophisticated formulations of coping styles is that proposed by Hutt and Gibbey (1979). They outline three types of parental reaction to the mentally handicapped child: the accepting parent, the disguising parent, and the denying parent. The accepting parent is regarded as having coped most adequately with the trauma associated with the child's handicap, whilst the denying parent is described as having coped least adequately. Thus certain styles of coping are deemed to be effective whilst others are regarded as ineffective, a distinction Rutter (1981) supports.

Hutt and Gibbey (1979) outline the accepting parent as one who acknowledges and accepts the child's disability. They remark that the parent therefore "loves the child as the child is" (p.280). The disguising parent, however, is typified by his or her attempts to hide the child's condition from others — and from him- or herself. Thus although the parent may perceive that there is "something wrong" (p.282), there is an unwillingness to accept that the child's lack of progress is due to limited intellectual ability. Hutt and Gibbey
note that disguising parents may continue to search for other factors to which the child's condition may be attributed, and medical consultations may be frequent. The third style of coping, the denying parent, is described as a severe emotional reaction characterized by the parents' inability to accept that the child suffers any difficulty. Fierce denial results in the child being regarded as normal, despite medical diagnosis to the contrary.

It is possible, having considered these two approaches to coping in families of handicapped children, to draw parallels between them. For example, Hutt and Gibby (1979) describe disguising parents as frequently consulting medical professionals. This corresponds closely to what was described earlier in Kromberg's (1977) phase of despair as 'searching for magic cures'. Furthermore, denying parents characteristically refuse to acknowledge that their child has any deficit and feelings of anger and disbelief may be apparent. This 'style' corresponds to the emotions typically expressed by parents in the protest phase of Kromberg's (1977) typology. That is, parents exhibited shock, disbelief, anger, and denial.

It could therefore be argued that depending upon the degree of resolution of the grief process, different styles of coping will evolve. Thus, parents who remain fixated within the first phase of the grief process will continue to experience the emotions associated with that phase and may be termed denying parents. Similarly, parents who remain 'fixated' in the second phase of despair, will continue to search for alternative explanations for the child's lack of progress, and may be classified as disguising parents. Finally, parents who manage to work through the entire grief process, thereby managing to detach themselves from the handicap and love the child, may be regarded as accepting parents.
From the above it is evident that the possibility exists for an integration of process and outcome approaches to coping. Although, to date, it would appear that no attempt at such an integration has been considered, it is argued that this would be valuable. Coping, as mentioned earlier, is a complex and currently ill-defined concept. A comprehensive model of coping incorporating both process and outcome aspects may address some of the complexities associated with this concept that have not hitherto been accounted for.

Recently, Shapiro (1983) reviewed clinical and research material pertaining to family coping strategies in response to the mentally handicapped child. She presents several theories of coping, and, taking cognisance of the current trend in coping theory which emphasizes the role of external stressors, proposes a comprehensive formulation thereof. Shapiro distinguishes between the individual's coping resources and coping responses. The latter, according to Shapiro, refers to "an action, thought, verbalization or feeling elicited by the stressor of illness, thus having a direct and identifiable link to this particular stressor" (1983: 915).

The former, coping resources, are defined as "aspects of the individual's external and/or internal environment which are either not directly or completely under the individual's control; they exist in a quiescent state, ready to mediate in a positive or negative direction the individual's response to the advent of a stressor" (1983: 915).

Internal and external coping resources are differentiated. Aspects of the person's internal environment include personality attributes, such as self-concept, and what Shapiro (1983) terms "psychological hardiness". It would appear that this concept is synonymous with
what others have referred to as resilience (Rutter, 1981), or resistance (Kessler et al., 1985). Shapiro also notes the role of past experience with stressful situations in affecting the individual's subsequent coping abilities. This aspect of coping is largely neglected by other writers in this field. Aspects of the external environment which may mediate the individual's ability to cope embrace demographic and socio-economic variables (social class, educational level, religious affiliation, etc.), disease-or handicap-specific factors (diagnosis, etiology, prognosis), and formal and informal support systems. Again factors often overlooked in other theoretical formulations.

Finally, Shapiro introduces a new concept in coping: family coping. She cautions that little has been examined in the way of family coping per se, and that this concept needs further theoretical formulation. In essence, an effectively coping family is one judged able to attain a new adaptive equilibrium in relation to an individual member's handicap. A tentative definition is proffered:

At this point, however, it is unclear in what sense it is possible to talk about family coping as more than an aggregate of the coping strategies of individual family members.

(1983: 918)

The conceptual framework proposed by Shapiro has been considered in some depth since it represents one of the few attempts to formulate a comprehensive model of coping. Consideration of response and resource, and external and internal resources is a valuable means of assessing families with a handicapped child. Furthermore, although in its relative infancy, the concept of 'family coping' appears
potentially useful, particularly for professionals concerned with how the family copes with the impact of the handicapped child. At present, many questions regarding family coping remain unaddressed; for example, can family coping be understood in terms of an aggregate of the coping of individual family members? How are discrepancies between family members accounted for? How would family coping be operationalized? Nevertheless, it is the author's contention that with greater theoretical and empirical work, the concept of family coping may be of great utility in understanding how families adjust to the impact of a mentally handicapped child.

In short, the concept of coping has received greater attention within the field of mental handicap than almost any other concept to date. Hence coping has attained a relatively sophisticated level of conceptual development, in comparison to other concepts central to this area. Attempts to operationalize coping have, however, been few and are predominantly inadequate. Coping has evolved theoretically largely as a result of mental health professionals documenting their clinical experience with families of handicapped children. This is particularly the case with regard to the development of the 'process account' of coping; that is, the grief process. Much of the empirical research in this field, which systematically attempts to study coping in these families, lacks vigour. Conceptualization of coping is frequently inadequate, and therefore any attempt to operationalize the concept is difficult. Qualitative interviews are hence the dominant mode of gathering data on coping—based on loose and vague questions, and resulting in findings which should be, at best, speculative.

A study by Fairfield (1983) is typical of much of the research in this area. Fairfield investigated the use of early recollections
in eliciting how parents coped with their genetically handicapped children. Her opening statement reads:

Counselling parents of handicapped children presents a challenge to the counsellor to determine the attitudes, feelings, reactions, and concerns of the parents so that appropriate support can be given to maximize parental coping.

(1983 : 411)

Despite the salience of coping to her study, Fairfield offers no definition of that concept. No consideration is given to parental resources, external or internal, and brief mention is made of what could be assumed to refer to a coping response. Indeed, Fairfield concludes her study by differentiating between 'apparent coping' and 'real coping'. From her scant discussion it would appear that apparent coping describes parents who seem to cope but still encounter difficulties in accepting the child. Real coping, on the other hand, refers to situations in which parents also seem to cope and in fact are coping (in Fairfield's terms), that is, they no longer experience difficulties in accepting the child. No evidence, theoretical or empirical, is cited in support of this distinction, and the means by which a parent is judged to be really, as opposed to apparently coping, is not discussed. Due to these shortcomings in Fairfield's work, it is suggested that her findings should be interpreted with caution.

To summarize, the notion of coping appears to have received greater attention within the arena of mental handicap than in other areas of psychopathology. Furthermore, relative to other concepts of salience to research into families of mentally handicapped children,
Coping has evoked considerably more interest. Nevertheless, conceptually coping has been approached from different theoretical approaches, and researchers tend to fail to clarify their position in this regard. It is therefore proposed that researchers make explicit their definition of coping, rather than making assumptions regarding that concept. Greater conceptual sophistication, should create the potential for the operationalization of coping to become more adequate - thus allowing persons working in this field to systematically study coping, from a sound theoretical base and by means of valid and reliable instruments.

1.6. THE CONCEPT OF SOCIAL SUPPORT

Social support has been heralded by Rowitz (1985), writing in the journal *Mental Retardation*, as "the issue of the 1980s". Indeed, this concept appears to be receiving increasing attention in many areas of mental health (Kessler et al., 1985). Growing interest centres predominantly around the role of social support in mediating the deleterious effects of major life events upon the individual's psychological well-being (Thoits, 1982). Since significant correlations have been shown to exist between personal reactions to stressful life events and the nature of the individual's social support system, certain researchers have proposed that social support may buffer against the adverse effects of the stressful life event; and thereby play an inhibitive role in the development of psychopathology (Cobb, 1976; Henderson et al., 1978). This notion has been termed the buffering-hypothesis.

Despite increasing concern with social support Thoits (1982), after conducting a comprehensive review of current literature in this area, has concluded that the greater proportion of studies are theoretically,
conceptually and methodologically flawed. Her particular focus is the thesis that social support may buffer the impact of life events, and she notes with regard to this that "several serious problems with the empirical literature have yet to be resolved" (p.155) - an impression supported by the present author's appraisal of this field.

In short, these "serious problems" revolve around three central issues:

1. Conceptualization and operationalization of social support is often inadequate. Consequently, it is difficult to assess which properties of support are implicated in reducing the impact of life events.

2. The direct and interactive effects of life events and social support may have been inadvertently confounded in cross-sectional studies. Thus for example, life events may alter the support available in the individual. Alternatively support may decrease the likelihood of an event occurring.

3. The theoretical relationships between life events, social support and psychological disturbance have not been clearly articulated.

It is of salience to consider the direct and interactive effects of life events and social support in greater detail since a number of researchers have more recently become aware of the difficulties associated with this. House (1981) has noted that the interaction of life events and social support remains unclear, and that the issue of causality has been neglected in the majority of studies to date. Thus, much work is founded upon definitions of social support which make direct assumptions regarding the buffering effect thereof, as is reflected in the following statement:
social support, a term that is widely used to refer to the mechanisms by which interpersonal relationships presumably protect people from the deleterious effects of stress.

(Kessler et al., 1985 : 541)

Rutter (1981) too has cautioned against assuming the protective effect of personal relationships, stating that protective factors may not necessarily involve features which are beneficial. Moreover, as mentioned, Thoits (1982) draws attention to the possibility that life events may alter the support available to the individual—whether it be formal sources of support (Gallagher et al., 1983), or informal sources (Rutter, 1981). For example, certain life events may result in the individual seeking assistance from medical or mental health professionals and thereby increasing the number of potential sources of support available to him or her.

In short, a number of major criticisms may be levelled at much of the work conducted in the arena of social support. Particular weakness is evident in the manner in which social support has been conceptualized, and is assumed to function. One of the more adequate formulations of social support is that proposed by House (1981). His comprehensive conceptual account incorporates much of the complexity of social support, and offers clear guide-lines for operational definition. House notes that any notion of social support must address the issues expressed in the following question: Who gives what to whom regarding which problems? He states:

A thorough assessment of support will consider all possible sources, although some sources will be more important than
others depending on the nature of the person
and the problem needing support.

(p.22)

He does not assume sources of support to be beneficial to the individual concerned.

House defines support in terms of four broad classes or types of supportive behaviour. He proposes that social support is an interpersonal transaction involving one or more of these classes.

1. Emotional support, i.e. the provision of empathy, caring, love and trust, and, according to House, seemingly the most important form of support.

2. Instrumental support, i.e. the provision of direct assistance such as goods and services.

3. Informational support, i.e. the provision of information which the person in need can use in coping with personal and environmental problems.

4. Appraisal support, i.e. the provision of information relevant to self-evaluation.

The above formulation is considered to be a potentially useful framework in terms of which to consider the role of social support in affecting the impact of the mentally handicapped child upon the family. As noted, this comprehensive account allows for the complexity of the concept, has clear implications for measurement, and does not assume support to be implicitly protective or buffering in nature.

To date, much of the work concerned with the social support of families with a mentally handicapped member has been characterized by at least
one of the three problems outlined by Thoits (1982). Primarily, however, almost no consideration has been given to the possibility that the relationship between life events and social support is complex and unclear. That is, firstly that the network of social support may itself affect or be affected by a significant life event, and secondly that social support is not necessarily beneficial to the individual who has been subjected to highly stressful circumstances. Each of these aspects as they pertain to the field of mental handicap will be examined in turn.

Recognition of mental handicap in a child signifies a major life; it severely disrupts the family concerned and demands their substantial readjustment following the diagnosis (Kobasa, 1979). Few studies have, however, considered that with the discovery of handicap shifts in social support networks are inevitable. For example, once the condition is diagnosed, parental contact with medical and mental health professionals usually increases. These "formal" sources of social support (Gallagher, Beckman & Cross, 1983) have been shown in a number of studies to play a significant role in influencing the adjustment of parents to the handicapped child (Zwerling, 1954; Matheny & Vernick, 1969). Hence the birth of a handicapped child may yield to sudden availability of a source of potential support hitherto not available to parents.

Similarly, it is suggested that changes in the informal sectors of the social support networks of these families may also take place. Autobiographical texts, written by the parents of mentally handicapped children frequently refer to a decline in their number of friends following the child's birth. Parents are reported as saying that they "find out who their friends are" (McCormack, 1979). Hannam (1980) refers to certain families as 'solids' - those who have lasting and
secure friendships to fall back on, and whose relationships with friends may become even more firmly cemented during the crisis. 'Brittles', on the other hand, are families who have few social supports and may suffer the further loss of friendships as a result of the arrival of the deficient child.

Research findings comparing matched families of handicapped and non-handicapped children have revealed significant differences with regard to social support. Friedrich and Friedrich (1981), for example, found that parents of handicapped children had significantly less social supports than parents of non-handicapped children. It would appear that Friedrich et al. wish to attribute this difference to the presence of the handicapped child. However, since no index of social support was available for these families prior to the child's birth, further research is required if such causality is to be inferred. It would nevertheless seem that the discovery of mental handicap in a child may be associated with changes in the social support network of the parents - at both a formal and informal level. However, this aspect of social support has been grossly neglected to date and few studies entertain the possibility of the birth of a defective child causing changes in the social support system of the parents.

Turning to the second aspect of social support - the adequacy of the buffering hypothesis in understanding the relationship between social support and the impact of life events - a similar lack of critical discussion is apparent in much mental handicap research. The greater majority of studies assume the protective effect of personal relationships and many studies document the role of social support in ameliorating stress in families of handicapped children (Gallagher et al., 1983). However, few studies have attempted to systematically examine the concept of social support as it pertains to those families.
Rather it would appear that the protective nature of social support is assumed, and evidence to support this assumption is cited where applicable. Thus researchers evoke a self-fulfilling prophesy—assuming something to exist. They naturally find evidence to suggest that it does so.

In short, on reviewing the literature, the notion of social support is often alluded to in studies examining the impact of the mentally handicapped child upon the family. However, no studies seek to specifically determine the nature and role of social support in these families. Few attempt to define the concept and little consideration is given to the theoretical relationships between support and associated concepts such as coping. Operational definition is poor and few studies report by what means they investigated the presence or absence of support, and determined the nature thereof. Thus, statements such as the following are common, but the material upon which they are based questionable:

... this group of parents not only appears to report more stress because of the handicapped child but also fewer psychosocial assets to help ameliorate the continual impact of this stress. An appropriate avenue of intervention might be to increase the availability of social support for these parents to help them cope with this additional stress.

(Friedrich & Friedrich, 1981 : 553)

In summary, as with the concepts of stress and coping, the concept of social support is problematic. Although increasing attention is being paid to the role of social support in mitigating the development
of psychopathology, many problems surround the use of this concept at present. Thoits (1982) has launched a sophisticated and critical attack on much of this work to date and her criticisms are appropriate to the use of the concept as it applies to families of handicapped children.

It is the author's contention that the notion of social support is potentially useful in understanding how families of handicapped children cope, and has practical implications for therapeutic intervention. However, due to the theoretical, conceptual and methodological inadequacy of the greater proportion of work in this arena, this potential has not as yet been realized. Hence, what is called for is a recognition of these inadequacies, and a serious questioning of the assumptions made with regard to the nature of social support.

With greater understanding of the relationship between social support and the diagnosis of mental handicap in a child, clearer guidelines for ameliorating parental stress may become apparent. This may prove of greater benefit to families than the blind prescription of increasing all forms of social support in order to ameliorate stress.

Finally, it is pertinent to note that other factors may prove to be 'supportive' to parents in that their influence serves to ameliorate or exacerbate stress. These include what are commonly termed 'demographic factors', such as socio-economic status and religious conviction. It is argued here, however, that demographic factors are also inherently social. Hence the author proposes a distinction between interpersonal social support and structural social support, the latter referring to demographic factors. Although a number of researchers recognize the possibility of structural factors influencing the stress experienced by parents of handicapped children, there is an absence of focus upon these specific factors. If an accurate under-
standing of the role of social support in ameliorating or exacerbating the stress experienced by "handicapped families" (Fotheringham & Creal, 1974) is to be attained, due consideration needs to be given to the positive and negative effects of interpersonal and structural social support.

1.7. CONCLUSION

The present chapter has attempted to review the current literature with respect to several conceptual issues of pertinence to this study. A number of conceptual and operational difficulties were identified with respect to the notions of stress, coping and social support. Such difficulties existed at the level of research in general, and applied specifically to work investigating the families of mentally handicapped children. Although the author has been critical of much of the literature in this regard, it is argued that the notions of stress, coping and social support may prove useful in understanding how families cope with the stress associated with bearing a mentally handicapped child. Indeed, an increasing number of researchers are recognizing the potential utility of this paradigm (Kessler et al., 1985). Hence, the present study employs the framework of stress, coping and social support and attempts to overcome at least some of the weaknesses identified earlier.
CHAPTER TWO

'HANDICAPPED FAMILIES'

2.1. INTRODUCTION

In the previous chapter critical consideration was given to concepts central to research investigating the impact of the mentally handicapped child upon the family. In this chapter an overview is provided of the literature specifically pertaining to the effect of the mentally handicapped child upon the family. The effect of the handicapped child upon the mother, the father, the parents' marital relationship, and siblings is examined. Consideration is also given to various factors which have been described as bearing influence upon these effects. Such factors include socio-economic status, religious conviction, the personal characteristics of the child, and the coping responses or resources of parents.

It is concluded that although such an overview uncovers the broad range of issues of salience to this field, much of the research in these areas lacks systematicity and rigour.

2.2. THE EFFECT ON THE NUCLEAR FAMILY

2.2.1. The effect on the mother and the father

In assessing the impact of the mentally handicapped child upon the family, extensive effort has been directed toward attempting to understand how a mother views such a child within the family (Gumz & Gumbrium, 1972). Studies of the relationship between fathers and the mentally handicapped child are scarce. However, as Cummings (1976) has noted there are compelling reasons, both practical and theoretical, for studying the fathers of handicapped children.
Greater understanding of fathers' adjustment may provide insight into mobilizing family strengths and minimizing parental stress. This is of particular salience when considering the provision of mental health services. The role of the father in the family cannot be underestimated, despite the fact that mothers are usually seen as more vulnerable and carrying the greater burden for the care of the child (Margalit & Raviv, 1983).

A study by Sandler and his colleagues (Sandler, Coren & Thurman, 1983) clearly illustrates the significance of the father in influencing the effectiveness of therapeutic intervention. In this investigation mothers and their mentally handicapped children attended a training programme. Both parents were, however, evaluated on a number of measures to ascertain the effect of the programme upon child's skill acquisition. Interestingly, it was found that as the children improved, mothers tended to express more positive attitudes, whereas fathers tended to express more negative attitudes. Sandler et al. (1983) suggest the following explanation for this result:

An intervention which strengthens the proximity of mother and child, while ignoring the father, might act to weaken the spouse subsystem .... this finding strongly suggests the need to involve fathers when a training program is provided for their wives.

(p.357)

Thus it would seem that the role of the father in maintaining family stability and influencing the child's progress is perhaps of greater significance than has been earlier presumed.
Cummings (1976) has suggested that recent changes in Western family structure and parental role allocation make the position of the father increasingly pertinent and therefore an increasingly important subject of study. He argues that the family unit is considerably smaller than it was a generation ago, and that mothers and fathers tend to share the care-taking responsibilities which were previously the domain of the mother, assisted by older siblings and/or other relatives. Mothers, he continues, are also more likely to wish to maintain a career outside the home, thereby implying that the father will have to assume a greater role in nurturing the young children.

Although Cummings' (1976) description of changing family structure is probably appropriate to families with 'normal' children, this does not appear to be the case in families with a handicapped family member. In general, traditional family roles appear to be upheld within the latter families, with the mother remaining at home and the father employed. This situation seems to arise out of necessity rather than choice. That is, mothers are forced to care for the handicapped child themselves because alternative forms of care are, in general, inadequate (Chetwynd, 1985). Despite the fact that role allocation has not been revolutionised with "handicapped families" (Fotheringham & Creal, 1974), the role of the father remains of salience. It is suggested that the discrepancy between the role of the mother and that of the father is highlighted in this situation, and may become a source of conflict (Refer Section 2.2.2.). Hence it is crucial that the role of the father be investigated regardless of whether, as Cummings has argued, changes in family structure have occurred.

The fairly extensive body of literature has documented the effect of the handicapped child upon the parents, but as mentioned this usually refers to mothers whilst fathers are somewhat neglected.
Marcus (1977) studied the impact of the psychotic child upon the parents and found that the perspectives and attitudes of mothers toward the child differed from those of fathers. He reports that the mother is typically closer to the situation in that she fulfills the household and nurturant tasks. Thus she is more aware of the child's disabilities and feels greater responsibility for him or her. Fathers, on the other hand, are reported to have less direct contact with the child, again a function of traditional role stereotypes. According to Marcus the nature of the father's relationship to the handicapped child allows fathers to be "confused and often analytical and quasi-objective in their judgements" (p. 392). The greater emotional distance of fathers described by Marcus has been reported in several other studies.

Gumz and Gumbrium (1972) compared the perceptions of mothers and fathers, and their behaviour toward the mentally handicapped child. The instrumental-expressive role framework of Parsons and Bales (1955) was used. Although not consistently statistically significant, their work does reveal a tendency for fathers to perceive their child more instrumentally than mothers - mothers' perceptions being more expressive. Thus mothers were more highly concerned about the emotional crisis involved in having a handicapped child, whilst fathers were more concerned about the child in roles outside the sphere of the family. Fathers were therefore reported as being concerned with wanting the child to be a "leader", a "winner" and to "stand up for himself or herself" in relation to other children, according to the authors (Gumz & Gumbrium, 1972:178).

Egnal and Daneel (1980) examined the personality strategies of parents of mentally handicapped children. Comparing mothers and fathers
following an interview and a TAT appraisal they conclude:

Feelings of depression and resentment were more significantly revealed by mothers than by fathers during the interview and this may suggest that mothers are more honest or closer to their true feelings towards their retarded children than are fathers.

(p. 4)

An alternative explanation for the greater expression of affect amongst mothers reported in Egnal and Daneel's study, and one which they neglect to consider, is that mothers experience greater depression and resentment than fathers. Given that the considerable burden of raising a handicapped child has been shown to fall primarily on the mother (Jordon, 1962), it is possible that mothers do experience feelings of greater resentment and depression than fathers.

Other studies have attempted to examine the direct implications the presence of a handicapped child has for the lives of the mother and the father. Parents' participation in social activities and their physical health amongst others have been identified as indicators of this. A study by Holroyd (1974) revealed that mothers described themselves as less able to experience personal development or freedom, and more limited in how they utilize their time than fathers. Furthermore, mothers were described as generally being poorer in health and mood than fathers, more sensitive to how the child fitted into the community, and more aware of disharmony within the family.

Cummings (1976) examined the impact of the child's handicap upon the mother and father in two separate studies. Parents were required to complete a battery of four self-administered tests assessing
prevailing mood, self-esteem, interpersonal satisfaction, and child-rearing attitudes. Cummings reports that a comparison between mothers and fathers was not possible due to sample compositions but he notes:

the data leave no doubt that fathers experience significant stress as parents of retarded children...

(p.252)

Cummings found that fathers, relative to mothers, are less involved in the child's rehabilitative or health-maintenance tasks, such as trips to the physiotherapist or doctor. Consequently the father has fewer opportunities to effect something directly helpful to the child, and remains somewhat excluded. Furthermore, Cummings remarks that organizations for parents of handicapped children seem to offer fewer services to fathers. Since fathers in this study were shown to suffer significantly lowered self-esteem, depressive feelings, little sense of themselves as competent fathers, and few satisfactions from family relationships; Cummings suggests that intervention with fathers of handicapped children is of salience.

The majority of studies to date have, however, neglected to examine the role of the father in considering the impact of the handicapped child upon the family. Tavormina, Henggeler & Gayton (1976), for example, attempted to delineate what he terms the "parent-reported problem behaviours" (p.38) of handicapped children. However, although Tavormina refers to "parents", only mothers participated in this study. It was concluded that many of the problems reported by mothers were similar to those faced by mothers of 'normal' children, but occurred at different ages. Tavormina hereby seems to imply that the stress experienced by these parents is perhaps not as intense as is commonly believed. What he fails to note is that these "problem
behaviours" are, in the mentally handicapped child, of prolonged duration and it is often this aspect which proves to be the most difficult to manage.

Several studies have focused specifically upon the emotional effect which the handicapped child has on the parents. Matheny and Vernick (1969) refer to the possibility of parents being "emotionally overwhelmed". Others view the nuclear family of the handicapped child as itself handicapped. This notion of the "handicapped family" (Fotheringham & Creal, 1974) arises from the view that diagnosis of mental handicap is an emotionally crippling experience. The term was first coined by Hartman who actually spoke of the "handicapped parents syndrome" (in Polansky, Boone, De Saix, & Sharlin, 1971). Hartman was referring to the process by which the mother, in particular, infantilizes the child and thereby unwittingly compounds the difficulties faced by the family.

The emotional impact of the handicapped child upon the parents and the process whereby parents cope with this has been documented elsewhere (Refer Chapter 1, Section 1.5.; Chapter 2, Section 2.3.4.) and will not be repeated here. It is sufficient to note that most parents experience a period of severe grief, in association with a host of other emotions such as ambivalence, anger, guilt and frustration. The abundant literature which describes the grief process is, however, almost solely based upon maternal reactions to the handicapped child. Thus it remains unclear as to whether the paternal reaction follows the same course and is of similar intensity. Research in this area is crucial if intervention with both parents is to be effective.

Finally, some researchers have conducted attitudinal studies with
mothers of mentally handicapped children. Watson and Midlarsky (1979) compared the attitudes of mothers with retarded children to those with non-retarded children. Using a Likert-type scale they attempted to establish if the two groups of mothers differed in their attitude toward mentally handicapped persons. They established that mothers of retarded children were more likely to express positive attitudes toward mentally handicapped persons than mothers of non-retarded children. An earlier study by Vurdalja-Maglajlic and Jordan (1974) had revealed similar trends in maternal attitude.

Watson and Midlarsky's (1979) study also showed that 79% of mothers of mentally retarded children expected the 'average' person in the community to have a negative opinion of mentally handicapped persons. This finding has implications for a mother's willingness to participate freely in the community with her handicapped child. If mothers perceive the community as essentially negative or hostile toward the handicapped child they may be unlikely to take the child on outings. Moreover, many mothers experience difficulty in finding a suitable child-minder. This may in part explain why many mothers of handicapped children describe themselves as socially isolated and rarely able to leave the house (Chetwynd, 1985).

In summary, parents of the mentally handicapped, both mothers and fathers, are deeply affected by the psychologically stressful experience of rearing a handicapped child (Cummings, 1976). To date, research has focused almost exclusively upon the mother, since she is regarded as assuming the primary child care role (Jordan, 1962). The role of the father within the "handicapped family" (Fotheringham & Creal, 1974), and the impact of the mentally handicapped child upon him, has been seriously neglected. Several studies have shown that fathers too are adversely affected by the trauma of raising a
handicapped child (Cummings, 1976) and if parent-oriented intervention is to be effective the role of the father must be considered. Moreover, it has been shown that fathers may exert influence upon the mother, and the child (e.g. Sandler et al., 1983) and therefore to intervene at the level of mother and child may not prove beneficial to overall family functioning. Future research must take into account the role of husband and father if the 'handicapped family' is to attain a restored balance and a situation approximating normality.

2.2.2. The effect on the marital relationship

Many studies have analysed marital disharmony as a result of the pressures of raising a mentally handicapped child. Farber's (1959) seminal work in this field revealed that the presence of a severely handicapped child negatively affected marital integration. The Farber Index of Marital Integration was designed to measure the extent to which a husband and wife were in agreement on domestic values. Considerable agreement between spouses was seen as indicative of marital integration, and vice versa. It was found that mentally handicapped boys, particularly over the age of nine years, had a greater disruptive effect than girls, on the parents' relationship. Farber also found that the placement of the handicapped boy in an institution tended to have a beneficial effect upon the relationship between parents. Gath (1978) has asserted that the Farber studies are exceptional because they represent an attempt to study the marital relationship by objective measures rather than by reliance on subjective impressions, usually obtained from the mother alone.

Fowle (1968) used the Farber Index to determine whether parents who had kept their severely mentally handicapped child at home exhibited lower marital integration than parents who had placed the child in
an institution. She was unable to detect any significant difference between the two groups of parents; possibly because the children in her study who remained at home were also enrolled in a community day-centre while those in Farber's study were not.

Several recent studies have supported Farber's (1959) work, finding the presence of a mentally handicapped child to have adverse effects upon the parents' marital relationship (Chetwynd, 1985; Wright et al., 1985). Heaton-Ward (1978) has commented that marriages may 'break-up' as a consequence of the constant pressure associated with caring for a handicapped child. Wright (Wright et al., 1985) states that the parents of handicapped children are six times more likely to indicate that their children contributed to marital difficulties, than parents of non-handicapped children. Furthermore, McCormack (1978) has reported that a survey conducted by the Welsh National School of Medicine showed the divorce rate amongst couples with severely mentally handicapped children to be ten times greater than the national average. Tew, Laurence, Payne and Ravnsløy (1977) investigated marital stability following the birth of an infant with spina bifida. They found that a handicapped child added significantly to the strain on a marriage. It was noted that where unresolved problems were already present in the marital relationship, the birth of a defective child exacerbated these difficulties. High divorce rates were shown to be associated with pre-nuptial conception. Tew et al., conclude, as have others (e.g. Todd, 1967) that a fragile and uncertain union may be irrevocably damaged by the birth of a handicapped child.

The study by Tew et al., (1977) yielded further findings of interest. In every case of divorce which occurred in the families with a spina
bifida child, the father was found to be the 'guilty party'. Desertion was the most common ground for divorce. Moreover, once the couple had separated, the father appeared to resume a 'normal life-style'. All of the divorced fathers had remarried or were shortly to do so, whereas only one mother whose child suffered a very mild condition had remarried. Similarly, Chetwynd (1985) found that 24% of the mothers in her sample of parents of handicapped children, were living without a spouse. Hence it would seem that where divorce occurs, fathers revert to living a 'normal' life, whilst mothers are faced with the additional burden - emotional, social and financial - of rearing a handicapped child alone. Fathers appear to seldom receive custody of the child.

McCormack (1978) believes that because the strain of the handicapped child is not evenly distributed between parents, this constitutes the first and most common "marital stumbling-block" (p.129). Inevitably the primary responsibility for caring for the child lies with the mother (Jordan, 1962). Thus whilst mothers remain confined by the child's presence, fathers can at least go to work and by immersing themselves can daily forget the difficulties at home (Hannam, 1980). This uneven distribution of responsibility may be a cause of marital tension, unless an alternative system is devised. Sarah Boston, the mother of a child with Down's Syndrome, wrote of her experience as follows:

The aspect of being at home all the time, that I didn't enjoy, and from time to time resented the fact that the main burden of domestic labour fell on me.

(1981: 47)

Thus it would seem that marital tension associated with a mentally
handicapped child may be consequent upon a number of factors including existing difficulties in the marriage and sex-role division within the household. Further, due to the mother's greater responsibility for the child it is inevitably she who continues to care for the child if the marriage should be terminated.

It has been reported that the instability of the parents' marital relationship may precipitate the institutionalization of the handicapped child (Wolf & Whitehead, 1975). However, research to date does not generally support the expectation that family life would improve once the child is removed from the home. Fotheringham, Skelton and Hoddinott (1972) examined 'general family functioning', preceding the child's institutionalization, and one year following placement. Contrary to expectation the institutional sample did not demonstrate any statistically significant change in their functional adequacy over this period. This finding is in part contradiction with Farber's (1959) earlier work which revealed that the parents' marital relationships benefited from institutionalization of the male handicapped child. Colledge (1980) has commented that regardless of whether the handicapped child remains at home or is admitted to permanent residential care, emotional problems within the family tend to be lessened only if the child's handicap is totally accepted.

Not all studies report a decline in the quality of the marital relationship following the birth of a handicapped infant. Kramm (1963) for instance, reported that 21 of the 50 mothers of children with Down's Syndrome she studied felt that the child had drawn them closer to their husbands. Further support for this thesis comes from the work of Wright (Wright et al., 1985) and Gath (1977). Wright notes that 33.3% of the parents in the sample (N = 48) claimed that the handicapped child had actually served to strengthen their marital
relationship. Similarly, Gath comments regarding her research findings:

Many parents who had written letters to accompany their survey forms described their relationship as strengthened by the presence of the handicapped child.

(1977: 58-59)

The above findings require a number of comments. Various methodological approaches have been adopted to investigate the marital relationship of parents. Certain researchers (e.g. Fowle, 1968) have relied solely upon the use of a measuring instrument such as the Farber Index. As Fowle herself has noted there are problems with its usage:

A very real difficulty in the present study was the quantitative appraisal of the multiplicity of variables existing in family relations ... marital integration was defined by one particular instrument .... theoretical propositions cannot be subjected to empirical appraisal without measuring operations; however, one can never be certain that the yielded instruments are the equivalent of the definition of the proposed characteristics.

(1968: 472-473)

Other investigators have used a qualitative approach to assessing the marital relationship of parents of a handicapped child. Both Tew et al., (1977), and Gath (1977), relied upon the use of semi-structured interviews, a number being carried out with each family. The benefits of using qualitative methods are recognized - the delicate nature of the subject under investigation warrants qualitative rather
than an impersonal and quantitative approach. However, by employing both qualitative and quantitative methods a range of complementary data is gathered. Hence, studies such as that of Wright et al., (1985) which use interviews and scales, are regarded highly since they achieve a breadth and depth of data upon the marital relationship within a sound methodological framework.

In conclusion, research into the marital relationship of parents with a mentally handicapped child remains contradictory. Certain studies document the child's negative influence upon the parents' marriage, whilst others report the child to be of positive benefit to the marital relationship. At present it remains unclear as to what factors cause a marital relationship to deteriorate rather than improve. Research into this area is implicated since knowledge of such factors may alert medical and mental health professionals to parents who are possibly 'at risk'. Appropriate intervention may facilitate the impact of the handicapped child and reduce the adverse effects this has upon the parents' marital relationship.

2.2.3. The effect on the siblings

Research has shown the influence of the mentally handicapped child upon the family to be considerable (Gath, 1977; Quine & Pahl, 1985). Little interest has, however, been directed toward investigating the effect of the handicapped child upon his or her siblings (Fischer & Roberts, 1983), despite the fact that a number of researchers have documented this to be of significance (Cleveland & Miller, 1977; Fischer & Roberts, 1983). Indeed, San Martino and Newman (1974) report siblings of mentally handicapped children to be an important identifiable group amongst children seen in child psychiatric clinics.

It has been proposed that the attitude of siblings toward the mentally
handicapped child is, in part, determined by the attitude of the parent. Thus, if parents manage to adjust positively to the handicapped child - that is, work through the various phases of the grief process - it is postulated that the siblings will similarly adjust in a positive manner to their handicapped brother or sister. By contrast, where parents are unable to come to terms with the child's deficit, family stability may be disrupted and adverse repercussions upon the other children may result.

A number of studies have documented the active role assumed by older female siblings, in particular, in caring for their handicapped brother or sister (Farber, 1959; Cleveland & Miller, 1977, Gallagher et al., 1983). Hereby, parents are to some extent relieved of constantly supervising and caring for the child (Fischer & Roberts, 1983). Certain authors have interpreted the sibling's surrogate-parenting activities as an indication of the child's positive adjustment to the handicapped child (Cleveland & Miller, 1977). Fischer and Roberts (1983) have even suggested that such "involvement with the handicapped child frequently results in the female sibling adopting a 'helping' career later in life" (p.400). No evidence is cited in support of this statement, however.

Male siblings, on the other hand, have been shown to be less involved with their handicapped mother or sister (Farber, 1959), and to have less knowledge about mental retardation (Fischer & Roberts, 1983). A part explanation for this differential involvement may be found in the arena of gender stereotypes. Traditionally, in Western capitalist society, women are expected to fulfil domestic and maternal functions, therefore older female siblings could be expected to assist with the care-taking responsibilities of their handicapped brother or sister. Males, however, are not generally required to fulfil
these functions and it is therefore probable that boys would not be expected to assist in these nurturing responsibilities.

The birth of the handicapped child demands changes within the family structure, as does the birth of a normal infant. The specific needs of the handicapped child, however, places additional stress upon family members. Many siblings are reported to feel neglected because of the amount of attention that parents give to the handicapped child (Fischer & Roberts, 1983). Marcus (1977), for example, studied patterns of coping in families of children with "severely chronically disabling cognitive and behavioural conditions" (p.388) and has noted:

Sibling's are obviously affected as well. The disproportionate amount of time given to the psychotic youngster exacerbates the rivalrous feelings normally experienced by children. Unprepared siblings are sometimes burdened with caretaking responsibility and have to develop a level of tolerance that may be unfair and unrealistic to expect of them. (p.392)

Cleveland and Miller (1977) found that female siblings were more likely to feel neglected than their male counterparts, and attribute this to the additional parent-surrogate responsibilities placed upon them. Thus not only does the female sibling receive less attention from her parents because of the handicapped child, but in addition she is expected to give greater attention to that child. This may explain, in part, findings such as Farber's (1959), in which older female siblings were described as exhibiting greater "sibling role tension" than other siblings.
All siblings, regardless of gender have, however, been shown to exhibit some stress in relation to the handicapped child. Indeed, Thaman and Barclay (1967) found that the adverse effects of the handicapped child upon the siblings was a primary concern of parents. Thaman and Barclay investigated factors determining the residential placement of handicapped children. Parents most frequently cited "severe family disruption" (p. 158) as a primary factor to institutionalize the child — with particular emphasis upon the adverse effects of the handicapped child on the other children in the family.

Clearly, parents hope that by removing the handicapped child from the home, stability will return and any adverse effects reversed. However, Robinson and Robinson (1965 in Fischer & Roberts, 1983) report that institutionalization of the handicapped child may have differential effects upon siblings. Very young siblings may, according to Dittman (1962), become concerned that they too will be sent away from home or that something they did was responsible for the handicapped child's being sent away. San Martino and Newman (1974) have also noted high levels of anxiety and guilt among young siblings of mentally handicapped children related to their fantasies about the meaning of retardation, its causes and so forth. It is possible that these feelings may be exacerbated if the handicapped child is removed from the home; that is, the young sibling may feel guilty for his part in the child's placement or anxious that he or she will be next.

It has been argued that older female siblings may benefit the most from the handicapped child's placement, due to their greater involvement with the child than other siblings (Fischer & Roberts, 1983). Furthermore, placement may also result in the other children receiving greater parental attention, and may thereby serve to dispel the rivalry
often described between siblings and the handicapped child (Marcus, 1977). However, alternatively, older female siblings may experience greater distress following the handicapped child's placement precisely because of their greater involvement with the child.

Where parents themselves have experienced difficulty in adjusting to the handicapped child, siblings may be adversely affected (Fischer & Roberts, 1983). Parental tension may disrupt family stability and generate stress in and between other family members. It is at this point, when siblings are experiencing difficulties in relation to the handicapped child and parents are unable to provide the children with support and reassurance that intervention is implicated.

In summary, siblings of mentally handicapped children may be described as a "population at risk" (San Martino & Newman, 1974 : 168). Their vulnerability arises out of their particular position within family structure. That is, siblings are directly affected by the handicapped child, but parents are often unable to assist them in adjusting to that child because parents themselves are struggling with emotional reactions. For this reason, this much neglected group must be catered for in the provision of services. The needs of siblings, and the particular factors which induce greater stress in these children (e.g. age and number of siblings) must be assessed, and programmes of early intervention introduced if the development of psychological difficulties is to be prevented (San Martino & Newman, 1974).

2.3. FACTORS INFLUENCING FAMILY REACTION

2.3.1. Socio-economic status

It has been stated that the socio-economic status of the family is a critical demographic characteristic (Gallagher et al., 1983). Much
literature exists which associates patterns of family interaction with socio-economic status (e.g. Ramey, Mills, Campbell & O'Brien, 1975). Few studies have, however, attempted to focus upon the role of socio-economic status in mediating the stress families of handicapped children experience; and where this has been the subject of study, results have not been consistent (Weller, Costeff, Cohen & Rahman, 1974).

Research in this area to date may be broadly distinguished into two forms. Firstly, researchers have examined the influence of socio-economic status upon the families' ability to cope with the impact of the Handicapped child (e.g. Chetwynd, 1985; Quine & Pahl, 1985). The general contention is that families with greater financial and material resources will cope better, and experience less stress than families with few financial and material resources. Secondly, researchers have investigated what Willer, Intagliata and Atkinson (1979) refers to as the acceptance/rejection of the handicapped child (e.g. Donnay, 1963, Wadsworth & Wadsworth, 1971). The issue under scrutiny is whether parents of different socio-economic status experience greater or lesser difficulty in coming to accept their mentally handicapped child. Each perspective will be examined in turn.

In families with a mentally handicapped member, Quine and Pahl (1985) found a significant correlation between income and parental stress, as measured by the Malaise Inventory (Rutter, Graham & Yule, 1970). Mothers in families with higher incomes had significantly lower Malaise scores, indicating that they experienced lower stress than mothers in families with low incomes. It has been proposed by Chetwynd (1985) that parents in low income families have the double burden of a handicapped child and limited resources and therefore greater parental
stress could be expected.

Further support for this hypothesis is derived from studies which have included mothers of handicapped children who are no longer residing with their spouse. Single mothers have been shown to experience high levels of stress since they are faced with additional financial difficulties - it being problematic for a single mother with a handicapped child to be employed on a full-time basis (Holroyd, 1974). Increased stress in these mothers may also be attributable to the 'loss' of spouse and the related difficulties of adjusting to being a single parent. However, single mothers have articulated "money worries" (Quine & Pahl, 1985) as being a particular source of concern, and a factor contributing to their general feeling of tension.

Culver (1967, reported in Willer et al., 1979) found that families who kept the handicapped child within the home were more likely to show what he terms "downward social mobility", than those who did not. Culver appears not to have defined "downward social mobility". It would seem that he is suggesting that the handicapped child causes the families increased expenditure, and that this may result in a lowering of the families' standard of living. It is questionable whether a decrease in living standards, in material wealth, may be equated with social mobility, which implies change at the level of consciousness.

Final evidence in support of the "economic burden" of raising a handicapped child is reported by Willer et al., (1979). It was found that families of "lower social class" were more likely to place their child in an institution, than families classified as "middle class" (Eyman, Dingman & Sabagh, 1966). Willer proposes that this phenomenon may
be the result of the greater economic burden experienced by the "lower classes".

Bradshaw and Lawton (1978) have, however, found no significant difference in maternal stress between families of different socio-economic standing. Similarly, Chetwynd (1985) reports little evidence to suggest that low-income families experience greater stress than those with high incomes. Thus, the latter two studies do not lend support to the hypothesis that socio-economic status is related to parental stress.

The second area of interest with respect to socio-economic status is that of the parents' acceptance or rejection of the handicapped child. However, few studies have specifically sought to determine the association between socio-economic status and "acceptance/rejection" (Weller et al., 1979). Rather, the majority of researchers have speculated about this association following an investigation with a different emphasis.

Farber (1968) states the higher the socio-economic status of the family, the greater the impact on the family of labelling a child "mentally retarded". He argues that the stigma of mental handicap is less in the lower socio-economic group since it suffers a multiplicity of stigmata. Weller et al., (1974) have commented on Farber's work that amongst the "middle class" the mentally handicapped child is regarded as a failure and is thereby a reflection on the parents. This is seen to cause "middle class" parents greater distress. Weller does not distinguish between socio-economic status and social class, but uses the two terms interchangeably.

Wolfenberger (1967) has argued that amongst families of low socio-economic status "aspirations are low". Therefore, he suggests, the
handicapped child is not considered to be a disruptive influence in the family. Wolfenberger states that families of higher socio-economic status have greater expectations for their children to succeed, and thus experience the child's handicap as particularly painful. This analysis would seem to be somewhat value-laden in its approach. Persons of different socio-economic status are seen as embodying general characteristics for which there is little empirical evidence.

One of the few studies to examine the role of "social class" in the acceptance/rejection of the handicapped child is that of Weller et al., (1974). They classify "social class" as a "social variable" along with country of origin. Their findings are in contradiction with those of Farber (1968) and Wolfenberger (1967). Interviews were conducted with mothers from an Israeli population. Weller et al., found no significant difference to exist between mothers of different "social classes" with regard to the acceptance/rejection of the handicapped child. "Social class" in this study was ascertained by the occupation of the father; broad categories such as 'white-collar workers' and 'manual worker' were utilized. However, differences were found to exist between mothers of different "classes" in terms of their perception of the handicapped child. By this Weller is referring to the "degree of realism with which the parent views the child's ability" (p.275). "Middle class" parents were found to be more realistic in their appraisal of the child's abilities than parents of the "lower class". Weller explains this finding in terms of the greater "intellectual alertness" of "middle class" mothers. However, in this study, as Weller himself notes, the majority of severely handicapped children occurred in the "middle class" families, whilst the majority of moderately handicapped children occurred in the "lower-class" families. Since the limited abilities
of the severely handicapped child are more easily apparent than those of the moderately handicapped child, it is suggested that Weller has overlooked the possibility of an alternative explanation. In other words, "middle class" mothers may be better able to judge their child's abilities because of the severity of that child's deficiency and not because of greater "intellectual alertness".

A number of studies have proposed that the decision to institutionalize the handicapped child may be associated with socio-economic factors (Eyman, O'Conner, Tarjan and Justice, 1972; Wolf & Whitehead, 1979). Institutionalization has been viewed as a sign of parental rejection of the handicapped child. The rate of institutionalization, as mentioned earlier, has been found to be higher for "lower class" families (Eyman et al., 1966). Nevertheless, "lower class" families have been shown to maintain greater contact with their handicapped family member in an institution, and to look forward to their relatives' release more than "middle class" families (Willer et al., 1979). This would seem to imply that "lower class" families seek institutionalization as an alternative for their child, not out of lack of concern for her welfare, but due to the great social and economic burden of caring for such a child at home.

An earlier study by Downey (1963) found similar trends amongst parents of mentally handicapped children placed in institutional care. He explains differences in acceptance/rejection in terms of the educational level of the parents. "Because we did not find income or occupation to be related to parental interest" (p.192). Downey asserts that he views parental attitude toward the handicapped child as a "function of education as an experience rather than a style of life" (p.192). However, this view is not adequately substantiated. Nevertheless, Downey's study revealed that more educated parents who
placed their children in institutional care, demonstrated less interest in their children than did less educated parents. In terms of Downey's framework he attributes this finding to the fact that parents view their children in terms of their ability to be educated. Since handicapped children are not amenable to public education, their parents experience difficulty in accepting the child.

The work of Wadsworth and Wadsworth (1971) is in partial contradiction with the above. They sent questionnaires to parents who were members of a club for those with mentally handicapped children. The aim of this was to encourage greater parental involvement in the children's programme. Only 50% of families responded to the questionnaire. Consequently comparisons between respondents and non-respondents were drawn. A tendency was revealed for those with high "occupational status" to respond, whereas those of middle "occupational status" did not. Wadsworth and Wadsworth note that there were no parents considered to be "lower class" in their sample. It would seem that they infer "social class" from "occupational status", but this is not made explicit, and no justification for doing so is cited. Nevertheless, Wadsworth and Wadsworth postulate that those parents deemed of high occupational status responded because they were less threatened by the fact of having an intellectually limited child. They comment:

middle class parents tend to be less accepting of their retarded children while those in the lower class seem to exhibit an ability eventually to accept and deal with the problem.

(1971 : 144)

There is some evidence to suggest that parents of "lower class origin" do not uniformly accept their mentally handicapped child. Vasquez
found significant differences between mothers of different "ethnic groups", all of low "social class", in their acceptance/rejection of the handicapped child. Mexican-American and Black mothers were reported to be more accepting whilst white mothers were the least accepting. This finding suggests that "cultural" differences may be operating in interaction with "class" differences.

In summary, little work has systematically examined the association between socio-economic status and family stress on the one hand, and acceptance/rejection of the child on the other. Ramey et al., (1975) suggests that future research needs to attend to this area since the role of socio-economic status in affecting the family is being increasingly recognized. However, there are no major problems with much of the current work.

Firstly, different researchers have made use of different indicators of socio-economic status. Some have utilized level of education (e.g. Downey, 1962), others, occupational category (e.g. Wadsworth & Wadsworth, 1971) and others still income (e.g. Quine & Pahl, 1985). Moreover, within these indicators it is often not clear on what basis differentiations were made between levels of socio-economic status. Thus, for example, one researcher may decide that an income below R10 000 designates low-socio-economic status, whilst another may choose R15 000 as a cut-off point.

Secondly, many researchers do not adequately distinguish between "socio-economic status" and "social class". These terms are used interchangeably in a number of studies (e.g. Wadsworth & Wadsworth, 1971), and few researchers provide a definition of either "socio-economic status" or "social class". Furthermore, no regard appears to have been taken of the criticisms which have been levelled at the concept of "social class". That is, the categorization of people
on these grounds is subject to value judgements. This applies equally to whether the researcher adopts the paradigm of upper-middle-lower/working class, or uses a materialist definition through the relation to the means of production, i.e. bourgeoisie-working class.

Nevertheless, the notion of socio-economic status in the broadest sense does have implications for familial stress and the acceptance/rejection of the handicapped child. It is therefore argued that the concept be retained for use, but caution should be adopted in its application. Moreover, it is suggested that researchers attempt to use commonly accepted indicators of socio-economic status in order that comparisons between pieces of research may be meaningful.

2.3.2. Religious Conviction

Religious conviction has been related to parental acceptance of the mentally handicapped child (Zwerling, 1954; Stokes, 1976; Schmitt, 1978). However, the specific role played by religion in mediating parental adjustment to the child has received little attention to date.

A number of researchers have referred to the positive influence of religious conviction upon parents' ability to come to terms with the handicapping conditions from which their child suffers (Zwerling, 1954; Holroyd, 1974). This appears to be largely attributable to the framework of understanding that religion provides parents. In response to the almost universal question 'why me', parents with faith may reply 'because it was God's will'. Parents with deep religious conviction have thus been reported to view the handicapped child as a 'gift from God'. Stokes, for example, comments:

Many of our parents accept that these children as 'Duine le Dia', which is 'children of God'
in Irish, or accept that the child is the result of the will of God.

(1976 : 30)

Many of the Catholic parents Zuk (1959) interviewed regard their child as a "special gift from God" (p.141). In this way parents imbue what is seen by many as a negative experience, with positive meaning. In the extreme form parents may attribute the presence of the handicapped child in their family to the fact that they have been selected by God, especially, to care for a handicapped child.

Comparisons between parents of different religious denominations with respect to their adjustment to the handicapped child have revealed differences. Catholic parents have been found to be more accepting of the child than non-Catholics in a number of instances (Zuk, 1961; Jordan, 1962). This has been attributed to the doctrine of Catholicism by both Zuk and Jordan. In terms of the Catholic faith, suffering is seen as a "salvific process" (Jordan, 1962 : 249). The handicapped child is equated with other tolerable, but painful issues. A positive adjustment to this source of suffering is seen as analogous to the sufferings of martyrs and saints (Jordan, 1962).

Not all parents whose religious conviction has played a role in their adjustment to the handicapped child, view the child as a 'blessing in disguise', however. Parents may merely derive "strength and hope" from their faith (Michaels & Schucman, 1962: 570). Schmitt (1978) interviewed many parents of handicapped children and found a number who felt that their faith had been "a source of comfort" (p.83) to them. He describes these parents as not expecting God to relieve them of their suffering but as affording them hope in the spiritual realm. This knowledge of salvation 'allowed' parents to adopt an attitude of 'quiet acceptance' regarding the handicapped child.
Schmitt reports that few of these parents experienced inappropriate guilt or denial.

Evidence contradicting the view of religious conviction as beneficial has more recently been presented. Schild (1971) and others (Steenkamp & Steenkamp, 1981) have reported that faith may not serve to facilitate parental adjustment to the handicapped child. Schild notes that parents may view the child's condition as a punishment from God for their past sins. This may compound parental feelings of guilt and self-recrimination, which may in turn influence the quality of the parent-child relationship. For instance, parents may become over-protective of the child in order to 'make up' for the deficiency from which he suffers. Hoffman (1965) has stated that "elements of fundamentalist Protestantism seem at times to promote feelings of guilt", relating this to the dictum "the sins of the fathers are visited on the children" (p.886).

Schmitt (1978) also found evidence to suggest that not all parents found their religion to be a source of hope and comfort. He too encountered the theme of punishment for past sins. Interestingly, a significant number of parents in this sample believed that they were punished because their children had been conceived out of wedlock. A number of parents reported feeling bitter or angry with their God for having burdened them with a deficient child, and some informed Schmitt that their belief in a beneficent God had been shaken. This may account in part for the finding that parents of handicapped children are in general less religious than parents of non-handicapped children (Holroyd, 1974). Thus it is suggested that parents may lose faith if, despite their attempts to be good believers, they are severely punished - by being 'given' an abnormal child.
In summary, religious conviction does appear to play a role in parental adjustment to the mentally handicapped child. This appears to be associated predominantly with the manner in which the event (the birth of a handicapped child, or the recognition of mental deficiency later in the child's life is interpreted. Parents may make positive or negative attributions to the handicapped child. Thus parents are either 'blessed' or 'punished' by their God, depending on their frame of reference. What remains unclear is why some parents attach positive meaning to the handicapped child's presence in the family, whilst others view the same phenomena in a negative light.

2.3.3. The Personal Characteristics of the Handicapped Child

The personal characteristics of the mentally handicapped child may influence the degree of stress perceived by the parents (Fotheringham & Creal, 1974; Gallagher, et al., 1983). These characteristics include the child's age, diagnosed condition, severity of handicap and possession of social skills. Little empirical work has been undertaken to investigate the precise nature of the relationship between the child's characteristics and parental stress; but many researchers nevertheless comment upon the existence of this relationship in their studies.

The degree of retardation, as indicated by IQ level, is the most frequently cited characteristic which affects the parents of handicapped children. This is perhaps the case because diagnosis of mental handicap is dependent upon the intelligence quotient - hence IQ is central to the notion of mental deficiency. Generally research to date has indicated that the greater the severity of the handicap, the greater the stress experienced by the parents (Sexton, 1980). Wishart, Bidder and Gray (1980), for example, examined parental
responses to their "developmentally delayed children" and noted in conclusion:

It would seem that this group of low functioning children are the most difficult for parents to understand and cope with.

(p.374)

Furthermore, it has been reported in a number of studies that low IQ or severity of retardation is a major determinant of the residential placement of handicapped children. Eyman and co-workers (Eyman et al., 1972) found that children with an IQ of less than 53 had a higher probability of being institutionalized than those with an IQ of above 53. Thaman and Barclay (1967) have noted that severity of retardation was one of the most frequently cited responses given by parents in response to the question, "could you briefly discuss the main factors which might influence your decision to institutionalize a retarded child?".

Institutionalization is often viewed as a decision taken when parents are unable to endure intolerably high stress levels associated with the handicapped child. An attempt is made to restore family stability by removing the child, which is seen as the source of the families' difficulty. From the above it would appear, in general, that more severely handicapped children are perceived by their parents as more stressful - and hence institutionalization may be sought. Thus, in general, it would seem that the greater the child's intellectual deficit, the more likely he or she will be institutionalized.

Further research has revealed that parents of children with lower IQ's tend to be less involved with these children. Wadsworth and
Wadsworth (1971) report that even amongst parents of mildly retarded children in special education classes, those parents who displayed less involvement in the programme had children with lower IQ's. This phenomenon appears not only to be a function of parental preference. Professionals may actively discourage parents from becoming too involved with a child of limited potential. Winterbourn, in 1958, for example, writes in his guidebook for parents of 'intellectually handicapped children':

The point to bear in mind at this stage is that there are degrees of trainability or handicap, so the guiding rule would seem to be, the more serious the handicap the greater the desirability of institutionalization, the less severe the handicap the more the child's own home has to offer.

(p.14-15)

Kershner (1970) introduced the concept of social quotient in his work and compared the latter to the intellectual quotient of handicapped institutionalized and 'community' children. He noted that the social quotients, as measured by the Vinelands Maturity Scale (Doll, 1924), of the 'community' children were almost without exception higher than the IQs. By contrast, the institutionalized children were shown to have IQs higher than their social quotient. Both groups had been matched for chronological age (CA) and mental age (MA). This research raises crucial questions with regard to social competence as compared to intellectual capability. These findings seem to suggest that, within Kershner's sample at least, parents placed greater emphasis upon the child's ability to integrate socially, than on mental capacity.
Further evidence for the thesis that social competence, rather than intelligence, is important to parents comes from various studies which have noted the role of behavioural problems in parental stress. Clearly, behavioural difficulties reflect the child's poor social adjustment. Tavormina, Henggeler and Gayton (1976) state that mothers of mentally handicapped children felt the most pressing behavioural problems to be the child's disobedience, stubbornness and non-compliance. This was particularly so for mothers with handicapped adolescents. Indeed, as age increases the handicapped child may become more difficult to manage, and the differences between the child and his or her peers become more noticeable (Farber, 1959). As Tavormina has also noted, society is generally not sympathetic to grown-up girls and boys behaving like young children. Other studies support the fact that parents experience stress in response to the social pressure for their child to behave in a socially-appropriate manner. Quine and Pahl (1985) report "behaviour problems in the child" to be the major factor to which parents attributed their feelings of stress. Furthermore, it has been shown that the child's "adoptive behaviour failures" is one of the primary determinants of his or her institutionalization (Eymen et al., 1972).

It has been found that not only is it the desire of the parents that the child behaves in as 'near-normal' a manner as possible, but also that 'normal appearance' is preferred. Unusual appearance resulting from congenital abnormalities for example, may cause parents additional stress (Potheringham & Creal, 1974). A child with an 'abnormal' appearance may arouse comments by others. For parents who themselves have to contend with the shock of an unusual looking child, this may well prove a further source of undue stress. Indeed, Quine and Pahl (1985) report that 'problems with the child's appearance' was one
of the significant factors contributing to parental stress in their study. Further, Colledge (1980) who examined visiting of the mentally handicapped child in residential care, found that the most frequently visited subjects had a more normal appearance as a baby; whereas the unvisited subjects were more likely to have been born with an abnormal appearance. Colledge suggests the latter may have produced an adverse reaction in the parents, possibly triggering institutionalization and infrequent visiting.

The presence of additional physical handicaps may contribute to the exceptional appearance of a mentally handicapped child. Not only does this compound the difficulties associated with his or her physical appearance, but usually places even greater restrictions on the child's capabilities. This in turn places greater demands upon the parents in terms of what Tizard and Grad (1961) call 'the burden of care'. Not surprisingly, research has indicated that those children suffering more physical disabilities on a multiplicity of impairments induce greater stress in their parents (Quine & Pahl, 1985), and are more likely to be placed in permanent care (Thaman & Barclay, 1967; Eyman et al., 1972).

A number of researchers have noted significant differences in parental stress on the basis of the diagnostic category in which the child is placed (Holroyd & McArthur, 1976; Gallagher et al., 1983). In a study contrasting Down's Syndrome and autism (Holroyd & McArthur, 1976) it was found that the families of autistic children reported the greater general degree of stress. This was ascribed to the fact that the mothers of autistic children reported greater interference with normal personal and family functioning than the mothers of Down's Syndrome children. However, the hypothesis that levels of stress in the parent might vary with the diagnostic category of the child's
handicap has not always been supported. Quine and Pahl (1985) found no significant difference in mean malaise scores of parents when main diagnostic categories were compared. Similarly Bradshaw & Lawton (1978) concluded from their study, also using the Maternal Malaise Inventory:

The mean malaise scores of mothers with children with different diseases were compared. In no case was the difference in scores observed larger than could be expected to occur by chance. This finding suggests that there is nothing specific to a particular disease that causes a mother to experience more or less stress.

(p.184)

A further study by Chetwynd (1985) which made use of the same instrument, reports similar non-significant findings to those of Quine and Pahl, and Bradshaw and Lawton. This raises the possibility that the Malaise Inventory is insensitive to differences relating to the handicapped child's diagnosis; consequently no differences are detected. This possibility should be considered in the light of other studies which have shown the particular condition from which the child suffers to be of significance to parental stress (e.g. Holroyd & McArthur, 1976). Alternatively, it could be argued that, in Holroyd's study for instance, autism is not comparable to other types of mental handicap in that it represents a somewhat controversial category. Hence, had Holroyd and McArthur compared Down's syndrome to cerebral palsy, for example, no differences in parental stress may have been apparent. In short, the evidence pertaining to the child's diagnosis and parental stress lacks clarity.
It is proposed that part of the reason for this confusion lies in the consideration of 'diagnosis' as an entity in itself. Diagnosis as used in the above studies implies a uniformity within each diagnostic category. However, in reality there is the potential for large discrepancies to exist between members of the same diagnostic category with regard to the factors mentioned earlier. For example, even within the category of Down's syndrome which is generally considered to be relatively homogeneous, significant variation between members occurs. Thus, one person with Down's syndrome may be mildly retarded, display appropriate social behaviour, be fairly normal in appearance and suffer few associated handicaps. Another person within the same diagnostic category may be severely retarded, aggressive, unusual in appearance and suffer additional handicaps. For this reason it is suggested that examining the effect of diagnosis per se upon parental stress may prove of little value.

Other factors which have been noted to influence stress are the degree of activity of the child (Chetwynd, 1985) and the child's general health (Quine & Pahl, 1985). The latter has not been systematically researched as the former, and the nature of their relationship to stress remains unclear. It is assumed that too little or too much activity increases parental stress, as does the child's poor health.

In summary, it would appear that the child's unique characteristics are associated with the level of stress and type of difficulties parents experience in attempting to cope with their handicapped child (Gallagher et al., 1983). According to the literature the characteristics of greatest influence in affecting parental stress include: severity of retardation, social adjustment, physical appearance, associated physical handicaps and diagnosis. It is suggested that
future research be directed at examining the influence of these 'child variables' on parental stress more closely, since clarity with regard to these may assist counsellors in foreseeing possible areas of difficulty in families with a handicapped child.

2.3.4. Coping Resources of the Parents

Coping with the outer reality of a child with a congenital defect and the inner reality of feeling the loss of a desired, normal child, demands a great deal of the parent (Solnit & Stark, 1961). Various methodologies have been employed to report on the effect of mental handicap on the parent. Studies have examined the process of coping, or have attempted to distinguish between 'successful' and 'unsuccessful' coping, whilst others have investigated various coping patterns or styles of adaptation. Since the concept of coping has been discussed in depth earlier (Refer Chapter 1, Section 1.5.) the problems associated with the concept per se will not be repeated here. The purpose of this brief discussion is to examine the literature on the coping of parents of mentally handicapped children.

Several studies refer to identifiable emotional phases which families exhibit in response to the child's handicap. These phases are similar to those reported in the literature on death and dying (Shapiro, 1983). Thus, Solnit and Stark (1961), in studying parents' reactions to the birth of a defective child, refer to the "process of mourning" in which grief is a central emotion. Wright (1976) refers to the presence of "chronic grief" in parents whose children suffer a handicapping condition, whilst Olshansky (1966) prefers to use the term "chronic sorrow".

Most research documents a progression of emotion which includes:
initial shock and disbelief, followed by denial, guilt or anger, and finally an adjustment to or an acceptance of the handicapped child. Certain authors propose processes that deviate slightly from this. Wright (1976), for example, reports six distinct psychological stages: shock, denial, guilt and anger, shame and martyrdom, depression, and recovery.

A number of authors working within the phases approach, are informed by a psychoanalytic base. Kennedy (1970) finds the typology of grief put forward by Bowlby (1960) of greatest utility in describing how parents cope with the handicapped child. He delineates three phases, in accordance with Bowlby: protest, despair and detachment. These three phases are characterized by emotions similar to those described by others. For example, the protest phase incorporates feelings of shock and disbelief. Kennedy interprets this process from a psychoanalytic perspective, drawing on the work of Anna Freud (1979). He therefore describes the resolution of the grief process as the final decathexis of the lost object (the dead, normal infant), which then frees the individual for cathexing new objects (the handicapped child). A new cathexis of the live infant then occurs.

Kromberg (1977), using Bowlby's typology, stresses the need for parents to 'work through' the natural process of grief and mourning if they are to assume a healthy adjustment to the handicapped child. She refers to this as a "constructive adaptation to the situation" (p.34). Wright (1976), however, observed that not every parent progresses through the stages sequentially. Some stages may be omitted, some reversed, and parents may not necessarily achieve the final stage - remaining 'fixated' in an earlier one. In the latter instance parents would not be regarded as having made a positive adjustment with respect to the handicapped child.
Under the rubric of coping response, both positive and negative adjustments to the handicapped child are considered. Thus coping responses may be categorized as adaptive or maladaptive. Various studies have described the coping response of parents who are unable to come to terms with the handicapped child, and are therefore seen as not having successfully worked through the process of mourning. These maladaptive coping responses have been identified by some (e.g. Sharlin & Polansky, 1972) from a psychoanalytic perspective, as rigid systems of defence. One of the most common reactions is what Sharlin and Polansky (1972) refer to as "infantilization" (p.92). This extreme form of over-protection of the handicapped child is usually manifested by the mother. Slaughter (1960) notes a similar phenomena in parents she studied but termed it "overindulgence" (p.6). She explains this overly solicitous and sacrificial behaviour as the parents' attempt to "make up" to the child for his deficiency - also a predominantly maternal reaction. Other less common defences have also been described, such as "pseudostoicism", a form of primitive denial identified by Polansky, Boone, De Saix and Sharlin (1971).

Researchers, who are not informed by a psychoanalytic perspective, have documented styles of adaptation to the handicapped child, alternatively referred to as coping strategies or coping patterns. Hutt and Gioby (1979) outline three styles of parental adaptation to their mentally deficient child. They term these: the accepting, the disguising, and the denying parent. The accepting parent is one who would be regarded as having made a positive adjustment to the child; the equivalent to having "worked through" the process of mourning. Thus, the mother or father is described as acknowledging and accepting the reality of the child's disability - thereby loving the child for what he or she is.
Both the disguising and denying parent are regarded as not having come to terms with the child's handicapping condition, and could be seen as not having successfully negotiated the process of mourning. The disguising parent is typified by an attempt to conceal the child's defect from others, but also from him- or herself. Although often acknowledging that 'there is something wrong', disguising parents attempt to attribute this to 'something else' and do not admit to reality of the child's limited intellectual capabilities. Medical consultations may be frequent as parents continually struggle to prove the diagnosis of mental handicap incorrect. In the denying parent this reaction is present in a more severe form. The denying parent refuses to accept that the child suffers any condition and regards the child as normal in spite of evidence to the contrary. Clearly, the latter represents a very severe emotional reaction and is not commonly encountered.

Some researchers have not attempted to formulate a typology, such as that of Hutt and Gibby (1979). By contrast, they have documented specific strategies of coping - emphasizing the role of cognition, rather than that of emotion. Thus the parent is seen as consciously planning and eventually adopting certain strategies and not others. Fotheringham and Creal note:

> In order to cope with the stress of having a handicapped child the parents develop various strategies

(1974 : 358)

Examples of such strategies are: the parents' decision to live one day at a time, or to go out one night per week, (Marcus, 1977), or to alter the allocation of roles within the household (Fotheringham & Creal, 1974). According to Fotheringham et al., (1972), if stress
becomes too great for the parents' coping mechanism, institutionalization may be sought.

The greater proportion of writers in the field of mental handicap have a generally pessimistic view of parents' ability to cope with handicapping conditions. Parents are described as experiencing intense and chronic grief, as well as associated emotions of anger, guilt, and anxiety. The findings of a recent study by Wright, Matlock and Matlock (1985) however, suggest that parents of handicapped children are better able to cope than has previously been believed. They conclude their comprehensive study, based on interview and questionnaire data, with the following statement:

These findings suggest that the majority of exceptional parents substantially recover from the shock of having a handicapped child and that the greatest continuing impact on their lives is directly related to problems associated with child-rearing.

(p.39)

Coping with emotionally demanding situations requires what Marcus (1977) terms "resourcefulness and resilience" (p.393) of parents. Marcus is hereby referring to intrinsic personality factors which may affect how parents cope under stress. He describes, in his study of parents with a psychotic child, how some parents reported growing in strength and becoming increasingly adjusted to the child - evidence of resilience and resourcefulness. Other parents, however, continually battled to cope with stressors in general, and with the handicapped child. He also takes cognisance of personality factors in mediating stress, noting in accordance with Rabkin and Streuning (1976), that persons with "more versatile defenses" (p.12) cope better with
stressors than others with limited defenses.

Other factors may also influence the parents' ability to adjust to the handicapped child. These include, amongst others, parental age at the time of the child's birth, number of other siblings, and parents' knowledge of mental handicap prior to the diagnosis of their own child. The role of these factors has been neglected in the past, and few studies have specifically sought to investigate the nature of the relationship between them and parents' ability to cope. It is unfortunately beyond the scope of this work to examine the many factors which may influence the parents' response to the handicapped child; however, those factors considered to be of particular salience have been highlighted (Refer Section 2.3).

In summary, coping would appear to be a multi-faceted concept and for this reason it is difficult to assess the nature of coping per se. For example, the distinction between 'successful' and 'unsuccessful' coping remains unclear. Furthermore, research in this field has relied almost exclusively upon clinical judgement whilst psychometric techniques are seldom employed. Although the value of qualitative methods, such as clinical judgement, is recognized, quantitative methods are necessary to complement these earlier research findings. Shapiro (1983) has therefore proposed that "developing the tools and skills to assess family coping resources and responses" (p.926) should be a priority for those investigating the notion of coping.

2.4. CONCLUSION

This chapter has extensively examined the calibre and scope of work pertaining to the impact of the mentally handicapped child upon the family, and the factors which may influence the nature of that impact.
A broad range of problems has been identified and since Farber's seminal work in 1959, research in this area has been undertaken with increasing frequency. Despite this, the majority of studies conducted to date are conceptually or methodologically weak, hence findings remain suggestive, rather than informative.

The identification of mental handicap in a child impacts upon all members of the nuclear family. Nevertheless, research findings as to precisely how this event affects each member (mothers are compared to fathers, for example) remains largely inconclusive. There is certain agreement that the primary burden of care for the child falls upon the mother (Jordan, 1962), and a concomitant expectation that she experiences the impact of the child most profoundly. However, since little research has investigated the effects of the handicapped child upon the father and siblings, it is the author's contention that to make assumption regarding maternal stress in relation to that of other family members is unwise. Controversy also surrounds the impact of the handicapped child upon the parents' marital relationship and upon the siblings' psychological well-being. In both cases, the handicapped child has been shown in some studies to have a deleterious effect, whilst in others to be of positive influence.

Various factors have been associated with ameliorating or exacerbating the impact of the mentally handicapped child upon the family. Factors of particular significance are: socio-economic status, religious conviction, the personal characteristics of the child, and the coping resources of parents. Research findings regarding the role of these factors remain largely inconsistent. Moreover, neither the relationships between each of these factors nor the relative contribution of each to parental stress have been explored. In short, future research needs to systematically address the impact of the mentally
handicapped child upon the nuclear family, examine the nature of factors which may influence this impact, and attempt to determine the inter-relations between factors. In this way a clear understanding of the impact of the handicapped child upon the family may be gained.
CHAPTER THREE

SOCIAL SUPPORT ISSUES

1.1. INTRODUCTION

In the previous chapter an overview of the literature documenting the impact of the mentally handicapped child upon the family, and the factors which may determine the nature of that impact, was presented. The present chapter aims to address the issue of social support, and particularly the role it plays in ameliorating or exacerbating the impact of the mentally handicapped child upon the family. The various sources of support potentially available to the family are considered, and the nature and effects thereof discussed. In turn, this chapter examines the supportive role of family and friends, of medical professionals, and of social services in meeting the needs of both parents and the mentally handicapped child. It is concluded that researchers have, in general, made assumptions regarding the nature of social support and the role it plays in influencing the family's reaction to the handicapped child. This has undermined to some extent the validity of findings causing them to be interpreted with caution.

3.2. SOCIAL SUPPORT OF THE FAMILIES

It has been suggested that social support can moderate the impact of life events (Thoits, 1982) such as the impact of the mentally handicapped child upon the parents. Consequently, Rowitz (1985) has stated that social support is a crucial concept in examining the families of mentally handicapped persons, and believes it to be "the issue of the 1980's" (p.165). (The general concept of social support per se has been extensively considered in Chapter 1, Section 1.6.).
It is, therefore, the purpose of this brief discussion to examine specifically the role of social support in 'buffering' the parents of a mentally handicapped child against stress.

As noted earlier, social support will be defined in accordance with House (1981), who identifies four broad classes of supportive behaviour. To reiterate, social support is regarded as an interpersonal transaction involving one or more of these classes: emotional, instrumental, informational, and appraisal support. This discussion will focus upon the influence of intimate sources of social support; that is, family and close friends of the parents of the handicapped child. The influence of professional support has been considered elsewhere (Refer Sections 3.3. and 3.4.).

Fotheringham and Creal (1974) have noted the importance of extended family and friends in affecting the nuclear family adjustment to the mentally handicapped child. They comment that it is within the parents' relationship with friends, relatives and neighbours that parents perceive acceptance or rejection of their child, and by implication, of themselves. Furthermore, within these relationships, parents receive assistance, encouragement and/or criticism for the manner in which they are dealing with the situation.

Willer et al. (1979) have suggested that, not only do sources of intimate support assist parents in their adjustment to the child, but also affect the relationship between parent and mentally handicapped child. In accordance with Bryant and Hirschberg (1961, in Willer et al., 1979) they propose that if friends and relatives reject the child, the family may become isolated and this may evoke negative feelings in the parents which are then directed towards the child. Generally, evidence suggests that parents who lack social
support, experience greater stress than those involved in a network of supportive relationships. The work of Quine and Pahl (1985), for instance, has revealed that 'social isolation' is a factor of major significance in contributing to stress in parents with a mentally handicapped child. Gath (1978), in a study of families with a Down's Syndrome child, found that the most distressed mothers were those who had "little or no support from relatives, no compensatory social life and had no regular contact with a social worker, health visitor or doctor". (p.104).

Certainly a number of writers and researchers have referred to the beneficial influence of positive social support on parents with a handicapped child. Sarah Boston (1981), herself the mother of a child with Down's Syndrome, has written of her experience:

"Most of our friends and relatives appeared to accept Will unhesitatingly. Many were keen too to show their support of us .... It helped us that people accepted Will. It was a good start ...."

(p.35/36)

She also speaks of the "strengthening effect" every "gesture of solidarity" on the part of their friends had upon her partner and herself.

Certain studies have identified the maternal grandmother as a key figure in providing social support to the family of a handicapped child (Davis, 1967; Gath, 1978; Gallagher et al., 1983). Indeed, Gath (1978) has focused almost exclusively upon the role of "the grandmothers" in her study. She notes that the maternal grandmother, in particular, fulfills what House (1981) refers to as emotional and
instrumental functions. Thus the maternal grandmother will, in general, babysit, shop, and help with household duties whilst also providing her daughter with 'moral support'.

Almost no work has, however, systematically examined the potential mediative effects of the extended family and friends in facilitating the adjustment of parents to a handicapped child. The greater preponderance of research interest has examined the nature of the marital relationship, and made assumptions regarding the influence of broader social networks. Thus, although a positive correlation has been established between social isolation and greater parental stress in some studies, the relationship between social support and parental stress remains unclear. The issues raised earlier (Refer Chapter 1, Section 1.6.) with respect to social support, such as whether social support is inherently positive, are equally pertinent to research examining the social support of families with mentally handicapped children. Similarly then, future research needs to critically address the concept of social support at theoretical, conceptual and operational levels.

3.3. THE INFLUENCE OF MEDICAL PROFESSIONALS

It is usually the task of the medical practitioner to inform the parents of their child's mental handicap. The time at which this information is imparted varies, depending upon the nature of the handicap (Wolraich, 1982). Thus, it may be detected at birth, as with Down's Syndrome, or may only be recognized later, as with socio-cultural retardation. In all cases, informing the parents of the diagnosis of mental handicap, is an important and difficult responsibility.
Much criticism has been levelled at medical professionals for the manner in which they have informed parents of their child's deficit. As early as 1954 papers pertaining to the psychological aspects of paediatrics were forthcoming, and the crucial nature of initial counselling with parents of handicapped children acknowledged. Zwerling (1954) analysed 85 letters from parents of 'retarded' children in which they described their initial experience on being informed by the physician of their children's deficit. It was found that parents stressed the importance of the physician's attitude, the thoroughness of the examination which preceded the announcement of the diagnosis, and the clarity and directness of the physician's communication. Parents condemned the physician's tendency to emphasize the limitations and not the assets of the child, and the failure of medical professionals to discuss the prognosis of the child in "both general and specific, day-to-day terms" (p.479). Physicians who recommended institutionalization were regarded as insensitive to parents' feelings, and were strongly reproved.

Zwerling's study was qualitative in nature and no statistical analyses were performed. Moreover, no independent data was available as to physicians' actual communications. Letters were received several years following initial diagnosis and, as Zwerling himself notes, this may have led to distortions or misconceptions regarding the original contact between parent and physician. Finally, the adequacy of the means of collecting data must be questioned. Although Zwerling draws attention to the weakness of the 'letter' method he does not adequately account for the rationale behind its use. As one of the respondents wrote: "I think you would get more information through interviews than letters" (p.470). Yet, despite these limitations, the results of this work have generally been supported by subsequent
investigations (e.g. Matheny & Vernick, 1969; Wolraich, 1982; Quine & Pahl, 1986).

The issue of "clarity and directness" of communication is one which has been repeatedly raised amongst parents of the mentally handicapped. Matheny and Vernick (1969) have proposed that the severe emotional crisis parents experience has been over-emphasized at the expense of the importance of providing clear, direct and honest information. They note:

What the 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)

Only if this is provided can parents make realistic judgements about their child's future developments.

Essentially the majority of professionals assume that parents are 'emotionally overwhelmed' and that this is the basis for any unrealistic expectations they have of their handicapped children. Indeed, the literature is replete with accounts of chronic sorrow, grief processes and so forth. Hence it is not difficult to assume that the reasons behind many parents inaccurate perception of their child is their emotional morbidity. However, as Wolfensberger and Kurtz (1971) note, many of these beliefs about parental reaction to, and knowledge regarding handicap are not based upon sound empirical research. Rather, the source of these presuppositions is a stereotype of a parent who is guilt-ridden, overprotective and unable to face
up to the child's intellectual deficiency. This prompted Matheny and Vernick (1969) to question whether parents unrealistic expectations arose, not out of their emotional state, but from the fact that parents were 'informationally deprived'.

Matheny and Vernick's (1969) findings suggest that many parents' lack of acceptance of their child's limitations might indeed result from non-emotional constraints, including the communication of inadequate information by professionals. This substantiates the findings of earlier work. Cruikshank (1955), for example, reported that parents very rarely receive the kind of advice and guidance they need, thus not knowing what to expect from their child. Others have put their case forward with even greater assertion - Slaughter (1960) has written with almost journalistic appeal:

Fortunate indeed is the parent if his search takes him to someone qualified and able to tell him the truth about his child, and to suggest suitable measures for his care and training, rather than into the hands of some pseudo-authority who fills the parent with false hope ...

(p.3)

Clearly, without adequate guidance, realistic expectations of an unfamiliar phenomenon such as a mentally handicapped child are difficult to attain.

Although raising crucial questions regarding the perception of the family of the mentally handicapped in relation to the medical professional, many of these earlier studies are methodologically flawed. Sample sizes are small and generalizability questionable.
Methods of attaining the information reported are not always clearly discernible, and means of analysis where reported appear unclear in certain cases.

Nevertheless, recent research findings of greater empirical validity appear to lend support to these earlier findings; many reporting that parents felt deprived of adequate information. Murphy and her co-workers (Murphy, Pueschel & Schneider; 1973) conducted a comprehensive, longitudinal study of families including a child with Down's Syndrome. They found that the majority of parents complained about a general lack of information from professional staff in maternity hospitals. Moreover, these parents felt that hospital personnel avoided them, and their child, and served to hinder their contact with the child.

Quine & Pahl (1986) found similar themes recurring in their work when investigating parental satisfaction with the first information concerning their handicapped child. Parents were largely dissatisfied with the way in which the news of the child's disorder had first been given to them. Primary complaints were that parents had not received adequate information and that the medical staff had been unsympathetic in attitude, and that medical staff had been evasive and secretive regarding the examination preceding diagnosis.

Interestingly, parents in this sample who were satisfied with the way in which the first information was communicated to them were more likely to have a child suffering from Down's Syndrome and were almost all informed at birth or within the first week. By contrast, Gath (1977), who studied the parents of children with Down's Syndrome exclusively, reports that only 27% of her sample were satisfied with the manner in which the diagnosis had been imparted.
Wolraich (1982) has outlined three major factors influencing physicians - parent communication: the physician's knowledge of developmental problems, the physician's attitude toward handicapped children, and the physician's skill in communicating with parents. These factors are seen to influence the physician's ability to communicate with parents, which in turn will affect the way in which parents' experience their contact with the physician.

Wolraich makes a number of salient points with regard to physician-parent communication. Firstly, he notes that medical professionals receive little training in the area of mental handicap, which has clear implications for communicating with parents. If medical professionals are unfamiliar with and uncertain about mental handicap they will be unable to clearly and directly communicate knowledge regarding the child's condition to the parents. Secondly, Wolraich draws attention to the fact that medical personnel may themselves hold negative attitudes about the mentally handicapped - a reflection of societal attitudes, and due to the lack of instruction they receive regarding the condition. Thirdly, physicians may be ineffective in dealing with parents if they lack communication skills, or "bedside manner".

Wolraich, however, fails to consider the trauma that the birth of a handicapped infant may precipitate in the medical professional him- or herself. Lipton and Svarstad (1977) found that 80% of clinicians experienced difficulties in conveying the diagnosis of mental handicap and that this significantly affected the amount of information the clinician imparted. Where difficulties were reported, only 27% of parents reported a high amount of information compared to 100% of parents reporting a high amount of information where no difficulties
were expressed by the clinician. The difficulty of breaking news of such an unpleasant nature appears to have been largely underestimated, and remains unexplored. The clinician's dilemma is further compounded by the fact that the parents may respond negatively toward the persons imparting the news (Nurse, 1972). Since most medical professionals receive inadequate training to cope with their own and others emotional responses, this situation may well be harrowing for the medical professional. The personal testimony of Sarah Boston (1981) seems to bear witness to this. She writes of her experience of being informed that her son, Will, had Down's Syndrome:

The consultant was obviously finding the task of telling me about Will a difficult one, although he must have had considerable experience. The junior registrar was even more uncomfortable. I could see him sitting there hardly daring to look at me and evading my eyes whenever I looked at him. In fact he was a kind, gentle man but both he and his consultant were obviously unschooled in handling such situations.

(p.15)

The implications are clear: medical professionals require greater training in the area of developmental handicaps, and in the psychology of medicine. Physicians need to be instructed in imparting distressing news in a sensitive and sympathetic manner, and in being able to understand the psychological strain such an encounter places upon the physician him- or herself. In this way the needs of parents at the moment of diagnosis will be met with greater regularity. Quine and Pahl (1986) have identified the needs of parents at this time as follows:
1. To be informed as early as possible that there is cause for concern even though doctors may be unsure of the exact nature of the impairment.

2. To be approached with sympathy and caring by doctors and other medical personnel.

3. To be given full information regarding the child's condition. It is not the clinician's perogative to pass judgement upon the parents' emotional state and base their communication on that judgement. It has been shown that vague communication, based on the clinician's genuine concern about the inability of parents to cope with the diagnosis serves only to heighten parents' fears and emotionality (Lipton & Svarstad, 1977).

Finally, much research to date has focused solely upon the parent's point of view. This approach may be defended on the grounds that where people define situations as real, those situations have real consequences (Quine & Pahl, 1986). However, if the relationship between physician and parent is to be improved, a thorough examination of the experiences of both parties in that situation is fundamental. This brief literature review therefore reveals the need for future research into the parent-physician dyad, and for a re-evaluation of existing medical training facilities. This is regarded as salient in that the physician's role has been shown to be linked to parental stress. The provision of inadequate information communicated in an insensitive manner does nothing to alleviate the distress parents experience on discovering their child to be handicapped. On the other hand, accurate, timely and informative communication could be important and beneficial to parents.
3.4. THE AVAILABILITY OF SOCIAL SERVICES

3.4.1. Appropriate to Parents

The provision of social services should be aimed at meeting the needs of the mother, father and siblings of the handicapped person, in addition to providing for his or her specific needs. Parents of mentally handicapped children have special needs and difficulties (Mittler, 1979), and in the course of earlier discussion (Refer. Sections 3.2. and 3.3.) some of these needs have been made apparent. To date, however, much 'family counselling' and group activities have been mother-oriented, and the needs of the father and siblings are seldom acknowledged (Gallagher et al., 1983).

Clearly, the needs of the family of a mentally handicapped person are numerous. Moreover, each family has its own specific needs and difficulties, hence one should be cautious about prescribing a specific set of services as appropriate to all situations. Gallagher has made the following statement in this regard:

"The diversity of family needs and support would veto the unthinking application of one particular pattern of service to each family."

(1983 : 17)

Although there is a growing body of literature documenting parental responses to the handicapped child, and the problems associated with rearing such a child, the actual needs of parents still tend to be neglected. Mittler (1979) attributes this to the fact that "it is no one's clear responsibility to provide a sense of direction" (p.65). He further points out that doctors, social workers and others may be concerned with the parents, but that none of them will get very
far "working in isolation" (p.65). This limits each medical professional's ability to attend with sensitivity to parental needs. This is particularly pertinent to South Africa, where the network of social services is comparatively less developed by first world standards. Some authors (e.g. Milligan, 1971) have even gone so far as to refer to the parents of handicapped children as 'forgotten'. Indeed, professionals recognise that they have, in general, failed to meet parental needs (Ayer, 1984), and that there is much parental dissatisfaction with the current availability of social services (Quine & Pahl, 1986).

Yet, what are the needs of parents of a handicapped child? It is possible to differentiate between two primary needs of parents with a handicapped member - the need for information and the need for emotional support. Both needs should be considered of equal importance; yet many working in the field of mental handicap over-emphasize the latter. Matheny and Vernick (1969) suggest that the stereotypic image of parents of the handicapped child as neurotic, overwrought, and 'emotionally overwhelmed' is inaccurate. In agreement with this Wolfensberger and Kurtz (1974) propose further, that parents are informationally deprived, and that were this need met, parents would cope better emotionally.

The type of information parents require will now be examined. Although at first this issue may seem simply addressed, there is much that the parent needs to know. Obviously the parent must be told the diagnosis of the child, and where diagnosis is unknown, this must be carefully explained. The full implications of the diagnosis should be made explicit. Parents will require the ongoing provision of information. With time new fears often arise, so parents should feel at ease to contact the professional and seek advice (Sarason, 1955).
Some writers (Hannam, 1980; McCormack, 1978) have documented an early phase in parental adjustment to the child during which parents actively seek information; such as going to the public library, or approaching professionals and other parents. McCormack (1978), for example, speaks of encountering parents with 'a continual thirst for knowledge' - regarding the child's condition.

Parents have been shown, in a number of studies, to be discontent with professionals who conceal the truth from them, or who are vague as to how the child will develop (Quine & Pahl, 1986). Wadsworth and Wadsworth (1971) believe that the extent to which the professional is clear and honest has serious implications for the parents of a handicapped child. They note, following the completion of their study of parental involvement with mildly retarded children:

"...the findings illustrate is that misconceptions still abound regarding mental retardation. A primary reason for this, despite earnest efforts in recent years to correct it, is that the professionals inadvertently perpetuate the problem. They do this through ill-conceived practice concerning classifying mild retardation and counselling parents."

(1971: 145)

Parents have also been shown to react strongly to certain kinds of advice proffered by professionals, particularly regarding the placement of the child (Zwerling, 1954). Zwerling (1954) reports that parents in his study expressed 'strong condemnation' toward the professionals who advised them to institutionalize the child without knowing about
institutions and with little regard for the parents' own wishes to care for the child.

Finally, parents need to know what other general services are available for their children, and for themselves. Parents need to be informed about whom they can turn to for material assistance (Ayer, 1984). As Stokes (1976) notes, this information should include guidelines for obtaining services such as "full monetary support" and special medical supplies often required if the child is to remain within the family. Unfortunately, it is the minority of medical professionals who are knowledgeable as to the availability of community resources. Hence, as Sarason (1955) notes, parents rarely receive the kind of information they seek.

Essentially, the parents need to be fully informed about the ramifications of the child's disorder, and the nature of the impact he or she may have upon the family. Moreover, this information should be communicated to the parents in a neutral and unbiased manner by the professional. The parents should also be made aware of the range of services available to them, and their child, and given details of how to utilize these facilities.

The needs of parents in terms of emotional support will now be investigated. Fotheringham and Creal (1974) have stated that a range of services is required to assist the parents in meeting the challenge of a handicapped child. Thus, counselling of the parents may take different forms. For example, counselling may centre around the decision to place the child, take the form of genetic counselling, or provide the parents with emotional support. Those who obtain general emotional support from family and friends may require counselling directed toward the resolution of a particular problem.
Different means of intervention with parents have been investigated with a view to ascertaining their effectiveness. Murphy and co-workers (Murphy, Pueschel & Schneider, 1973) report the success of their group-work with parents of children with Down's Syndrome. Nurse (1972) too, obtained positive results in running a group for parents in which they could explore feelings and work through common issues. Others (e.g. Milligan, 1971) have reported the value of task-oriented counselling of parents. Tavormina and colleagues (1976), for instance, advocate the utility of assisting parents with the behavioural problems of their handicapped children. In a second study they found that behavioural group counselling was 'superior' to reflective counselling in assisting parents to deal with the problems they faced in raising their mentally deficient children. Tavormina et al., do not, however, appear to have taken into account that the nature of the problem determines the type of counselling required. Thus certain problems may be effectively dealt with using behavioural counselling, whereas others may be more appropriately handled within the context of a reflective group.

In summary, the availability of appropriate services which serve the diverse needs of parents of handicapped children is crucial. Sarason, as early as 1955, noted that it was the mental and medical health professionals' goal to assume the "responsibility", wherever possible, of assisting those parents to lead "happy and effective lives" (p.468). Furthermore, it has been widely acknowledged that the manner in which professionals approach parents of handicapped children may influence the parents' adjustment to the child. The comparative failure of professionals and the services they render, to meet the needs of
parents of handicapped children has been recognized (Ayer, 1984),
and the need for improvement acknowledged.

Dickerson (1982) has proposed a team approach in order to ameliorate
the above problems. This would involve the active participation of
parents themselves in the handicapped child's therapeutic programme.
In this way parents are provided with a supportive context within
which to deal with their own difficulties - and those of their mentally
handicapped child.

3.4.2. Appropriate to the Handicapped Child

Most mentally handicapped children are placed in some form of care.
This placement may occur almost immediately after birth or at a later
point in the child's development. Moreover, 'care' may refer to a
diverse range of services, from a play-group or day-centre, to
permanent institutionalization. Few attempts have, however, been
made to systematically examine the effects of placement upon the
parents. Indeed, as Sandler, Coren and Thurman (1982) note, little
research has investigated even the effects of simple training
programmes upon the child's parents.

Parents have two basic options with regard to placing their mentally
handicapped child in care. They may choose to keep the child within
the nuclear family and enrol him or her in a day-care centre.
Alternatively, the parents may decide to place the child in residential
care. The latter may take the form of a hostel or community centre;
or be an institution to which the child may be committed, thereby
becoming a ward of the State (Mental Health Act; Act No. 18 of 1973).
As mentioned earlier, decisions as to the child's future are often
perceived as stressful by parents and they may seek counsel regarding
the best placement for their child.
Two of the few authors to have evaluated the effects of day-care on parents are Steenkamp and Steenkamp (1981). In their manual for parents of handicapped children, they provide information as to the benefit of day-centres and outline four specific 'values' of these therapeutic settings.

1. Day-centre staff may assist parents by listening to their fears and anxieties. Thus, they provide the parent with someone with whom they can share their feelings.

2. Day-centres provide the mother, in particular, with some relief from the constant 'burden of care' (Tizard & Grad, 1961).

3. Parents and the centre can cooperate with regard to working toward maximizing the child's full potential. Both parent and teachers possess special knowledge relating to the handicapped child which can complement that of the other.

4. Day-centres provide parents with the opportunity to meet other parents who share similar problems. In this way parents may share experiences with others who understand fully the difficulties associated with rearing a mentally handicapped child.

Others (e.g. Chetwynd, 1985; Quine & Pahl, 1985), through studying the causes of stress as families with a mentally handicapped child in the home, have made strong recommendations for the development of flexible child-care schemes. Chetwynd proposes that social services also be made available which may care for the child whilst the family takes a holiday. Thus she comments:

Essentially, the findings suggest that to ease the stress on mothers greater relief is needed.
from the on-going burden of child care for both short periods of time on a regular basis, and for longer stretches on an annual basis (1985 : 302)

Since parental stress is directly associated with caring for the mentally handicapped child, relief from that 'burden' may serve to alleviate parental stress. Moreover, there are secondary gains from day-centres for parents, as Steenkamp and Steenkamp (1981) outline.

It has been shown that merely introducing training programs to families of handicapped children may be of benefit. Sandler et al., (1983) observed changes in parental attitudes toward the child, following the implementation of a training program for mothers and their children. This study, discussed earlier, showed mothers to develop more positive attitudes toward their children. Fathers, however, tended to express some negative attitudes, a finding attributed to their non-participation in the programme. Thus, involving parents with the handicapped child seems to influence the nature of the parent-child relationship (Fotheringham & Creal, 1974). The day-care centre therefore may not only prove a respite to parents but may, through including the parents in the child's activities, have the added benefit of improving the parent-child relationship.

However, for a handicapped child to remain at home rather than in residential care requires that a wide range of educational, recreational and occupational facilities be available in the community (Fotheringham & Creal, 1974). Unfortunately, such facilities are not in abundance in any country, and certainly not in South Africa. Thaman and Barclay (1967) found that one factor of major significance in the decision to institutionalize the child was the lack of
appropriate community resources to meet the needs of the handicapped child who remains in the home. They note:

The implication is that many parents decide on institutional placement when there are no community facilities to aid the family in managing the child's educational, emotional, and medical problems. This finding reflects the tragic result of the community's failure to meet its responsibility (1967: 159).

Although community services could obviate the need for institutional care, Tizard (1964) has stated that not even the best community services would do away with the need for hospitals and other types of residential provision for the handicapped, "if life is to be worth living for many families" (p. 55).

Various factors, other than the lack of community facilities, have been found to be determinants of the residential placement of mentally handicapped children. These include: the child's IQ, age and physical appearance (Eyman et al., 1972), the size of family, "social class" (Willer et al., 1979), and the degree to which the child is perceived to have disrupted family functioning (Wolf & Whitehead, 1975). According to Wolf and Whitehead (1975), there is some evidence to suggest that the gender of the child influences the likelihood of parents defining the handicapped child as problematical. Although, in general, it may be considered better for the child to live with the family, there are many circumstances in which residential care becomes necessary (Colledge, 1980).

Taking the decision to place the handicapped child in permanent care
is frequently traumatic for parents. Carver and Carver (1972, in Willer et al., 1979) report that parents typically feel a tremendous sense of guilt and failure following institutionalization. Whatever the initial reaction to institutionalization, family members are likely to expect that the family will then return to relatively normal patterns of family functioning (Tizard & Grad, 1961). However, Fotheringham, Skelton and Hoddinott (1972) found that families showed no improvement in family functioning based on measures taken one to three months prior to, and one year following, institutionalization. Similarly, Fowle (1968) found no significant difference in "marital integration" or "sibling role tension" between families in which the handicapped child had been retained in the home and those who had placed the child in an institution. Certain authors (e.g. Willer et al., 1979) have therefore concluded that the decision to institutionalize a handicapped child may be based on an "erroneous assumption" - that family functioning will be restored once the child is removed from the home.

However, other research has revealed findings contradictory to those described above. Kershner (1970) conducted an investigation similar in design to that of Fotheringham et al., (1972). The interviewed families just prior to, and one year following, the institutionalization of the handicapped child, and compared these findings to a second group of families who did not institutionalize their child during this period. He refers to these groups as the "institution" and "community samples" respectively. Kershner comments:

As predicted, the institution sample exhibited a significant pre-postadmission gain in family functioning and the community sample showed
a significant pre-postadmission loss in family functioning

(1970 : 280)

This study therefore not only supports the contention that family functioning does benefit from placing the child in residential care; but moreover suggests that by retaining the child within the home, family functioning may be detrimentally affected. However, Kershner acknowledges that caution needs to be exercised with regard to the latter finding. All members of the community-based sample had approached an outpatient clinic for the handicapped to seek professional help. Families with handicapped children at home who did not approach the clinic may not have displayed decrements in family functioning.

In conclusion, it would appear that service provision for the care of mentally handicapped children is at present inadequate, particularly in South Africa. This may cause parents of handicapped children further undue stress. Although there are clear advantages to retaining the child at home and sending him or her to a day-centre, the lack of a comprehensive service system, means parents rarely experience the benefits of the alternative of residential care, remain unclear. Future research needs to be directed toward examining types of care and the implications each has for the family. In this way, clear recommendations regarding the nature of services can be made, rather than broadly observing the need for an increased quantity and improved quality of services for the mentally handicapped and their families.

3.5. CONCLUSION

This chapter has sought to review the literature pertaining to social support, with particular reference to the families of mentally
handicapped children. Various sources of support were considered, and a number of areas of controversy revealed.

A major criticism to be levelled at much of the work reviewed is that it operates from the basic premise that social support is intrinsically positive. That is, that it will inevitably benefit the individual to whom support is offered. Hence, the perspective of social support as a buffer against stress is unequivocally adopted. Evidence does however exist which is in contradiction with that supporting the buffering hypothesis (e.g. Thoits, 1982). Clearly, the benefits of positive social support should not be underestimated - the literature does reveal significant associations between positive social support and the stress levels of parents of handicapped children. Nevertheless, there is an almost complete absence of awareness that social support may not have positive effects.

Despite the above criticism, it would appear that social support, from both intimate and public sources, is regarded as desirable by parents of handicapped children. Lack of support is expressed with dissatisfaction and may induce greater parental stress. This is particularly pertinent with regard to medical professionals, and the availability of social services. The supportive role of friends and family appears in general to be significant to many parents in ameliorating stress; parents with few social supports experience greater distress. Finally, however, future research should take into account the potentially negative aspects of social support if a full understanding of its role is to be gained.
CHAPTER FOUR

METHODOLOGY

4.1. INTRODUCTION

In the previous three chapters, literature pertaining to the impact of the mentally handicapped child upon the family has been reviewed. The present chapter sets out to elucidate the aims and methods of this study. Drawing from the literature, the aims and objectives are posed, and the research questions and hypotheses formulated. The manner in which the sample was selected is explained and the design of the study discussed. The analysis of results is considered in the following two chapters.

4.2. AIMS AND OBJECTIVES

Reviewing the literature to date regarding the various facets of 'handicapped families' certain areas of consensus, and others of controversy, are apparent. A major source of difficulty for many researchers has been the distinct lack of conceptual clarity with respect to several key notions in the field - these include the notions of stress, coping and social support discussed earlier (Refer Chapter 1). Furthermore, the greater proportion of studies are conducted in the absence of a broader conceptual framework. That is, for example, albeit that issues of stress, coping and social support are being heralded as central to current debate, few investigators have attempted to place their work within this paradigm. It is therefore, the broad aim of the present work to begin to address this problem - by considering the more specific questions posed in this study within the context of a general framework of stress, coping and social support.

The notion of stress is central to the present study. Since there is strong consensus within the literature to date that a mentally
handicapped child does represent a major source of stress to his or her parents, the question of whether or not such a child is a stressor will not be reconsidered here. Rather, the focus of interest in this work is to establish if stress is a variable process; that is, whether or not parents of handicapped children experience stress differentially. Further, if stress is a variable process, to ascertain which factors are implicated in the resultant individual variation.

Past literature has shown stress in parents of handicapped children to be linked to a number of factors, including religious conviction, socio-economic status and various personal characteristics associated with the parents and the handicapped child. However, a thorough investigation, taking into account the complex interrelations between factors has seldom been attempted. Variables of potential significance have been neglected, and others have been inadequately approached, both conceptually and methodologically. Hence, it is an objective of this study to acknowledge the complexity arising from the possible interrelatedness of variables associated with stress, and to attempt systematically to investigate the contribution of each factor, as well as noting its association with others.

Arising from the literature survey, four loose categories of variables associated with stress have been identified. Clearly, these are not definitive and merely provide parameters within which to systematise thought. These are:

1. **Parent variables** - including gender, country of origin, previous personal physical or psychological history, personal coping resources and responses, and parents' age at the time of the handicapped child's birth.

2. **Child variables** - including gender, age, medical diagnosis, age at which mental handicap was first recognized, and the type of
care in which he or she is placed.

3. **Family variables** - including the total number of children in the nuclear family, previous history of mental handicap, and whether the family recognized that there was something 'different' about the handicapped child prior to medical diagnosis.

4. **Demographic variables** - including religious conviction and socio-economic status, as indicated by paternal income per annum, parental level of education and paternal occupation.

Within these categories several variables are regarded as being of particular interest. Although receiving scant attention to date they are considered to be of possible significance to parental stress. They are: gender of parent, gender of child, and the type of care in which the child is placed, i.e. permanent residential care or day-care.

The concept of stress implicitly raises other questions, such as those of coping and social support. The latter are therefore, by implication, also concerns of the present study. The concept of coping has been addressed in a number of other studies; indeed, as mentioned earlier (Refer Chapter 1) it is one of the few areas to have been relatively systematically examined within the broader research arena of families of mentally handicapped children. Thus, coping per se will not be addressed here, but rather factors which contribute negatively or positively to the process of coping will be a source of investigation. The concept of social support has, by comparison, received scant attention to date and shall therefore be a focus of this research. In particular, different types of social support (Refer House, 1981; Chapter 1), and different sources of support (intimate or public) will be considered. Hence, in addition to the variables outlined in points 1 - 4 above, the following will also be addressed:
5. **Coping** - factors such as socio-economic status and religious conviction which may influence parents' ability to cope with a handicapped child will be investigated.

6. **Social support** - the role of social support in ameliorating or exacerbating parental stress in relation to the mentally handicapped child will be addressed. Different sources of support will be considered, i.e. intimate (e.g. spouse, close family and friends) and public (e.g. medical professionals). Different types of social support will be taking into account; that is, in accordance with House (1981) support may be described as emotional, instrumental, informational or appraisal in nature.

Finally, it is an objective of this study to examine the above within a sound methodological framework. There is increasing recognition of the value of employing a methodology incorporating both qualitative and quantitative elements (Stainbeck & Stainbeck, 1984). In this way a greater breadth and depth of understanding the problems may be achieved. This is particularly useful where the subject of investigation has not been systematically studied, and therefore does not yield clear and direct research questions. For this reason the methodology employed in this study will include qualitative and quantitative aspects. Qualitative methods have been the dominant means of data collection in the arena of 'handicapped families' and therefore the present researcher's use thereof does not represent a departure from the current research climate.

Little attempt has, however, been made to approach the problem using sound objective techniques, and it is thus an aim of this study to employ such techniques in an attempt to obtain findings of more substantial reliability. Clearly, one could expand upon the method-
ological issue of the use of combinatory styles; however, this is simply beyond the scope of the present thesis.

4.3. RESEARCH QUESTIONS AND HYPOTHESES

From the above, a number of research questions and hypotheses are formulated. The variable of particular interest in this research is that of parental stress. At the outset it is important to clarify what is meant by stress as used in the context of this research.

For the purposes of this study stress is measured in two ways. Firstly, stress is operationally defined in terms of the short-form of the Questionnaire on Resources and Stress, or QRS-F (Friedrich et al., 1983). This questionnaire is based upon a thorough and systematic examination of the concept of stress, and its reliability and validity have been ascertained (Refer Chapters 1 and 4, sections 1.4 and 4.8.2 respectively). The aim of the QRS-F is to produce a score which indicates the family member's stress and coping resources (Holroyd, 1982). In short, the higher the score, the greater the stress and the lower the coping resources; and similarly, the lower the score, the lower the stress, and the greater the coping resources. Hence this questionnaire measures both stress and coping - the two variables being inextricably interwoven.

This tendency to view stress and coping as intricately interrelated is characteristic of much of the literature in this field. The majority of studies focus upon one of these variables for study, and then draw inferences regarding the other. No clear distinction between them has yet been formulated (Refer Chapter 1, Section 1.7). For this reason the present study, by implication, is also concerned with coping. Thus, although the focus of this work is stress, and the factors which serve to influence stress, by implication, coping and the factors
which serve to influence coping are also of salience.

The second means of measuring stress is qualitative in nature. Depth interviews in which parents of handicapped children were invited to speak of their experiences with their children were conducted. In the course of these, particular note was taken of that which parents felt to be stressful, and how they reported coping in these circumstances.

In setting out hypotheses, some will be directional in nature whilst others will not. These differences are largely a reflection of the current status of the literature. In certain areas it is possible to formulate clear hypotheses, whereas in others hypothesis setting is, of necessity, exploratory.

4.3.1. Gender of Parent

Previous lines of evidence have not systematically shown differences between mothers and fathers with respect to the stress they experience in relation to the handicapped child; indeed, the role of the father has been greatly neglected (Refer Chapter 2, section 2.1.3). Despite this, underpinning the literature in the field is the widespread assumption that mothers of mentally handicapped children do experience greater stress than fathers. Further, given the contribution of sex-role research, it is at least reasonable to expect that differences exist with respect to parental stress in relation to the handicapped child. The following hypothesis is therefore postulated on the basis of this widespread assumption and within the context of sex-role research:

Mothers of mentally handicapped children manifest greater stress in relation to the handicapped.
4.3.2. Gender of child

Little empirical work has set out to systematically examine the role of the gender of the child in influencing parental stress. A few studies (Refer Chapter 2, section 2.2) have, however, reported that mentally handicapped boys have a greater disruptive effect upon the family than mentally handicapped girls. In the light of this finding, and in view of the contribution of sex-role studies, the following hypothesis is postulated:

The gender of the handicapped child will have differential influence upon the stress experienced by the parents of that child.

4.3.3. Type of Care

No studies comparing parental stress on the basis of the type of care in which the child is placed appear to have been conducted. Focus has been directed at the reasons for placement of the child in residential care and at the effects of such a placement upon general family functioning (Refer Chapter 2, section 2.4.2). Underpinning much of the literature to date, however, is the assumption that parents who place their child in residential care are less accepting of the child, and therefore experience greater stress in relation to that child. It is therefore, at least, possible to hypothesize that parental stress may be associated with the type of care in which the child is placed. Furthermore, given the widespread assumptions made with regard to parental stress and the child's place of care it is not unreasonable to postulate the following:
Parents of mentally handicapped children placed in residential care are more likely to report greater stress in relation to that child than parents of mentally handicapped children who attend a day-care centre.

4.3.4. Secondary Stress Variables

A number of other variables were identified from a careful reading of the literature as being of possible salience to parental stress. These variables, in general, were given mention in studies, but were not systematically examined. Hence no clear trends with respect to these variables and their relationship to parental stress were apparent. This necessitated their role being explored in the present work, in the absence of clear guide-lines for hypotheses. In short, exploratory and non-directive statements of expectation were made with regard to the remaining variables cited in the categories specified above (Refer section 4.2); that is, the categories of parent, child, family and demographic variables.

Three variables were, in the light of past literature, regarded as being of particular interest: socio-economic status, religiosity, and social support. Studies to date examining the former two variables have yielded inconsistent results (Refer Chapter 2, sections 2.2.1 and 2.2.2 respectively). Without clear direction it is only therefore possible to hypothesize that these two factors will at least have influence upon parental stress - and by implication, upon resources to cope.

The issue of social support is addressed by qualitative means. In the course of depth interviews parents were questioned regarding their
relationships with other intimate and public figures. Intimate figures included spouse, offspring, extended family and friends; whereas public figures include members of the general public, medical professionals and others engaged in offering social services. To date, literature has tended to assume that social support is beneficial, in that it ameliorates stress and facilitates coping. More recently, this notion has been challenged and the possibility that social support may have negative effects raised (Refer Chapter 1, section 1.6). Consequently it is reasonable to postulate that social support may be positive or negative in its influence, thereby increasing or decreasing stress, and personal coping resources. The following hypothesis is therefore formulated:

Social support, as provided by intimate or public sources, may serve to positively or negatively influence the stress experienced by parents of mentally handicapped children, or their ability to cope.

4.4. SAMPLING

The major comparative variable in this study was the type of care in which the family had placed the mentally handicapped member. In particular, the researcher was interested in the differences between families with a child placed in custodial care and families whose child was permanently domiciled at home, and attended a day-care centre. For this reason two places of care were chosen from which the sample was then to be drawn.

The first was a large government institution for 'white' mentally handicapped children, serving the catchment area of the entire Cape Province. Hereafter parents whose children were placed in the
institution will be referred to as the residential sample, or the residential parents. The second place of care selected was a government-subsidised day-care centre, providing education for mentally handicapped children deemed 'educable' or 'trainable' (Mentally Retarded Childrens Training Act, No. 63 of 1974). Hereafter parents whose children attended the day-care centre will be referred to as the day-care sample, or the day-care parents.

This primary comparative variable yielded a potential sample of 88 residential parents and 30 day-care parents. Two secondary comparative variables further restricted the available sample. These were: the gender of the parent and the gender of the mentally handicapped child. An attempt was made to ensure an equal number of married biological mothers and fathers in the residential and day-care samples. Further, in order to control for gender of child an equal number of males and females from the residential and day-care samples was required.

These criterion variables yielded a final sample of 72 parents. The residential and day-care samples each included 36 mothers and fathers. Any attempt to match the mentally handicapped children would have resulted in a very small sample, and therefore was not feasible.

In short, given the criteria specified above and the directives of the experimental design, the present sample is exhaustive.

4.5. DESIGN AND ANALYSIS OF STUDY

The design of this study aimed at allowing for three types of formal comparison which, in terms of the sampling procedure, lent itself to the possibility of a 2x2x2 factorial design, i.e. gender of parent x gender of child x type of care. Comparison of the following levels of these factors was therefore possible:
1. mothers x fathers
2. handicapped girls x handicapped boys
3. residential care x day-care

A chief advantage of such a formal design procedure is that it lends itself to the examination of interaction effects.

The collection of data in this study was approached in two ways, yielding two smaller studies - one quantitative and the other qualitative in nature.

4.5.1. Quantitative Study

The basis for the quantitative study was the short-form of the Questionnaire on Resources and Stress, or QRS-F (Friedrich et al., 1983). The use of a scale score allows for quantitative analysis and thereby the examination of interaction effects. The three independent variables were gender of parent, gender of child, and type of care. As outlined above there are two levels of each of these variables. The dependent variable was interval level data derived from the QRS-F. The QRS-F yields a global score and four subscale scores, allowing for the possibility of five separate three-way analyses of variance as the main design.

This did not, however, exhaust the forms of analysis since further information of a quantitative nature was collected. The additional quantifiable data was obtained from the Personal Details Questionnaire (PDQ), which was designed for the purpose of collecting demographic details of participants. This questionnaire yielded data of an ordinal nature and therefore non-parametric statistics were utilized for the purpose of further exploration of the data. Variables under investigation included demographic characteristics of the family, the parents and the handicapped child, listed earlier (Refer Section 4.2 for details).
4.5.2. Qualitative Study

Depth interviews were employed to supplement the data gathered by means of the questionnaires. The amount of material collected in this section of the study exceeded the scope of the quantitative factorial design. Since depth interviews are not easily subjected to quantitative methods, further analysis of a qualitative nature was conducted. This involved the transcription of taped interviews, the careful reading of protocols, working from tapes and partially transcribed protocols in order to explore further trends and themes within the data.

Although the above design appears complex there are, nevertheless, advantages to this form of data collection. The value of collecting both quantitative and qualitative data is being increasingly recognised (Stainbeck and Stainbeck, 1984). Eisner (1977) has noted that using qualitative and quantitative methods together provides a depth of perception that neither one can provide alone, whilst Filstead (1979) has commented on the complementary use of these methods, 'the middle ground of blending the assets of both approaches appears optimal' (p.43).

4.6. PARTICIPANTS

The parents (n=72) of 36 mentally handicapped girls (n=18) and boys (N=18) participated in this study. Their children, predominantly diagnosed as 'severely mentally retarded' were aged between three and 17 years (mean = 11.2), and were either enrolled in a day-care centre or were placed in residential care. The diagnosis of the children's handicap was diverse and the age at which the presence of handicap was first recognised varied. Any efforts to achieve a
homogeneous sample with regard to these two variables would have yielded a very small sample size since diagnosis and age of recognition varies considerably amongst the mentally handicapped population. Furthermore, other research to date has not considered this a limitation in the generalisability of findings since the impact of having a mentally handicapped child appears to affect most parents in similar ways (Chetwynd, 1985; Quine and Paul, 1986). Thus although the cause of impairment may differ from child to child, the reaction of the parent to the handicap per se tends to be fairly uniform. Age of recognition and diagnosis were nevertheless carefully monitored and any trends which have become apparent are documented. Table 4.1 illustrates the diversity of diagnosis in this sample.

### TABLE 4.1

Children's Diagnoses - Percentage in the sample

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Percentage of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cause Unknown (5 cases)</td>
<td>13.8</td>
</tr>
<tr>
<td>Down's Syndrome (17 cases)</td>
<td>47.2</td>
</tr>
<tr>
<td>Environmental Deprivation (4 cases)</td>
<td>11.1</td>
</tr>
<tr>
<td>Congenital Abnormalities (3 cases)</td>
<td>8.3</td>
</tr>
<tr>
<td>Brain Damage (5 cases)</td>
<td>13.8</td>
</tr>
<tr>
<td>Hydrocephalus (2 cases)</td>
<td>5.5</td>
</tr>
<tr>
<td>Base for Percentages</td>
<td>36</td>
</tr>
</tbody>
</table>

All parents were classified so-called 'white' and lived in the metropolitan area of greater Cape Town. The rationale behind examining
only so-called 'white' families in this study is as follows. Firstly, the political climate within which this study was conducted was tense, data collection due to begin shortly after the declaration of a State of Emergency. It would therefore have been difficult for the researcher to gain access to other 'population groups', in particular the so-called 'black' group. Concomitant heightened feelings of mistrust and suspicion toward 'whites' in general may have further complicated the process of gathering data.

Secondly, the prevalence and incidence of mental handicap amongst other 'population groups' is difficult to estimate (Eichorn, 1985) since there are few adequate facilities for these sectors of the population; thus, systematic recording of all cases is not undertaken. Obtaining a representative sample would for this reason have been unlikely. Furthermore, facilities for the mentally handicapped, as with all mental health facilities in South Africa, are segregated along racial lines. This too would have created problems of access for the researcher. Thirdly, to include persons of another 'race' in this study would be to introduce another variable of major significance. This was beyond the scope of this particular study. A final and most pertinent reason for the choice of 'white' participants was that the researcher has an historical connection, in her capacity as a lay-worker, with a large institution in the Cape. Hence, factors of trust and accessibility, mentioned earlier, were easily overcome.

Both Afrikaans and English-speaking parents were interviewed. The greater majority of parents were the biological mothers and fathers of the mentally handicapped child. In two cases the biological mother had remarried, and her new husband had adopted her children. In one
family the father had recently left the home and his whereabouts were unknown. Mothers had a mean age of 40.61 years, whilst fathers had a mean age of 44.37 years.

The average number of children in the family was 3.08. Eight percent of the sample had only one child in the family. In 47% of the sample the handicapped child was the youngest in the family, while in 22% of families he or she was the eldest. One sixth (16.6%) of families included more than one mentally handicapped child. Ten (14%) of the sample had no formal school qualifications, 35% had a junior certificate, 21% had matriculated, and 30% had a tertiary qualification.

4.7. PILOT STUDY - 1984

A pilot study, with the primary purpose of testing the efficacy of the depth interview as a means of data collection, was conducted. Ten families with a mentally handicapped child in residential care were interviewed. Each interview was of one to three hours duration, and was conducted in the participant's home. Results of the pilot study proved the semi-structured interview to be an effective and valuable means of information-gathering.

4.8. APPARATUS

Three methods of data collection were employed: two interview schedules and a depth interview. Each will be comprehensively discussed below.

4.8.1. Personal Details Questionnaire (PDQ)

This brief self-administered questionnaire was drawn up by the
researcher for reasons of efficiency. The pilot study revealed that an excess of interview time was spent inquiring about the basic demographic details of participants. This information had then to be transcribed from the tape recording of each interview and categorised and coded for the purpose of analysis. The aim of the PDQ is therefore to attain this demographic data in an efficient manner and in a manageable form. As yet this questionnaire has not been standardised.

The PDQ covers the following categories of standard demographic information: gender, age, physical and psychological history, family composition, educational and occupational history, and socio-economic data. Also included are various child-related items pertaining to the aetiology of the handicap, the circumstances under which the impairment was recognised, and the number and type of centres the child has attended. (Refer Appendix A for a full copy of the PDQ.)

This material was used for comparative purposes between the two groups of parents, that is, residential and day-care. Both mothers and fathers completed the PDQ in the presence of the interviewer during the first part of the interview. The PDQ takes approximately 20 minutes to complete and each spouse completed a separate questionnaire. In this way information could be cross-checked for inconsistencies between spouses. If any two questionnaires conflicted, the interviewer clarified this with the couple during the process of the interview.

Verbal collection of personal data is often seen, from a clinical perspective, as a useful period during which initial barriers are broken down and rapport fostered. The procedural use of the PDQ within the battery of methods used in this research seemed, however, not to affect the establishment of rapport.
4.8.2. Short-Form of the Questionnaire on Resources and Stress (QRS-F)

The QRS-F (Friedrich et al., 1983) is a 52-item true-false questionnaire designed to measure four dimensions pertaining to families caring for handicapped family members. Each of the four dimensions yields a score. A global score is also derived. The latter gives an indication of stress and family members' coping abilities (Holroyd, 1982) - thus, the higher the global score, the greater the stress experienced by the family and the lower their ability to cope with the handicapped child. Each of the four sub-scales yield scores which give an indication of the degree to which that dimension is present in the family. Thus, the higher the score, the greater the presence of that dimension within the family.

The QRS-F was derived from a previous version of this questionnaire, the Questionnaire on Resources and Stress, devised by Holroyd (1974). The rationale behind the development of the original questionnaire was that "little has been done to develop a standardised instrument for evaluating the psychological costs to persons living with and caring for a handicapped or chronically ill relative" (Holroyd, 1974: 92). Indeed the majority of studies examining the impact of the mentally handicapped child upon the family have relied solely on clinical judgement and very little attempt has been made to supplement this with more objective techniques.

The Questionnaire on Resources and Stress (Holroyd, 1974) is a 285-item true-false questionnaire designed to measure 15 dimensions pertaining to families caring for chronically ill or handicapped family members. The 15 face-valid subscales measure three broad categories: parent problems, problems in family functioning, and problems the
parents foresee for the child (Friedrich et al., 1983).

Although research to date supports the utility of the QRS as a measure applicable to parents of a handicapped child, the scale is somewhat lengthy. No reports are available on its internal reliability and it is questionable whether the 15 rationally determined scales are, in fact, distinct and valid (Friedrich et al, 1983). For this reason Friedrich et al., (1983) have developed a shorter and psychometrically stronger inventory, known as the short-form of the Questionnaire on Resources and Stress (QRS-F). Their investigation involved an item analysis of the 285-item QRS (which reduced the length of the QRS to 52 items, forming the QRS-F), an initial factor analysis of these 52 items with a heterogeneous group of parents of handicapped and non-handicapped children, and a determination of the validity of these factors with an independent sample. The principle components factor analysis yielded four factors, namely the four sub-scales of the present scale (Refer Appendix B).

4.8.3. Depth Interview
The depth interview was selected as an appropriate tool for obtaining the highly emotionally charged material to be tapped in this research. The pilot study, conducted in 1984, showed the interview schedule to be effective in revealing parental feelings about their mentally handicapped child. Almost all parents built up good rapport with the interviewer, and within the flexible boundaries of the semi-structured interview, parents seemed generally to express themselves freely and openly.

The interview schedule took the form of a clinical history and covered the following broad areas: pregnancy and birth, the child's post-
natal development, the circumstances surrounding recognition of the impairment, contact with medical professionals and social services, intimate and public social support, coping mechanisms, and parental difficulties experienced since diagnosis. This framework guided the course of the interview, but within each of the above categories, flexibility was exercised. Due to the sensitive nature of the data tapped, great care had to be taken in eliciting data. The interviewer was aware that some parents may experience considerable difficulty in speaking about the mentally handicapped child. For this reason, parents were informed that if they felt disturbed following the researcher's visits, professionals at the respective residential and day-care centres could be contacted.

Both parents were interviewed together. The interviewer sought, however, to ensure that each parent participated equally in the interview process. It was felt that due to the sensitive nature of the material under investigation, parents would prefer to be interviewed together. Moreover, by observing parents' interaction and communication during the course of the interview, valuable insight into the marital relationship was gained. Conflicting accounts of events could also be immediately clarified.

All interviews were conducted by the researcher herself. She is experienced in the field of mental handicap and therefore is sensitive to the plight of parents with handicapped children. For this reason it was felt that she would be the most appropriate person to conduct the interview.

4.9. PROCEDURE

Each family with a mentally handicapped child enrolled in the day-
care centre received a letter, from the director of that organisation, explaining that the researcher would be contacting them. The letter contained a broad statement of the research aims and the director's approval thereof.

Families with children in custodial care were contacted by the researcher direct, since she is affiliated with that organisation. No covering letter was therefore required. None of the parents in this study had had previous contact with the researcher, however, and she had no prior knowledge of these families.

All families were contacted by telephone. They were informed that a psychologist was conducting research into mental handicap, and were requested to participate in this study. The broad aims of the study were clearly explained to parents, and any questions answered. All agreed to participate.

Two interviews, each of which included both parents, were conducted. The time between the two interviews was stipulated as no longer than one week. All interviews were held in the participants' homes. It was felt the parents would feel more secure and at ease in familiar surroundings, and thereby the process of rapport would be facilitated. Additional qualitative information was gleaned by observing the family in their own home environment. The duration of each interview varied between two to five hours. In all cases, bar three where situations become procedurally impossible, two interviews were conducted with each family. Each interview was, with the parents' permission, audiotaped and later transcribed.

Parents were reassured that confidentiality would be observed. They were also informed that the findings of this research would be made
available to them upon completion. Letters of appreciation were sent to all participants (Refer Appendix C for correspondence).

The analysis of data is considered in the following two chapters. Chapter 5 provides a detailed analysis of the quantitative results, whilst in Chapter 6 the qualitative findings are reported.
5.1. INTRODUCTION

The data collected by means of the two questionnaires, i.e. the Personal Details Questionnaire (PDQ) and the short form of the Questionnaire on Resources and Stress (QRS-F), was subjected to various forms of quantitative analysis. Both parametric and non-parametric methods, where appropriate, were employed. In this chapter the results of this analysis are reported. Parametric methods were used to analyse the data obtained from the QRS-F global and sub-scale scores, that is, the data pertaining to parental stress. Non-parametric methods were then employed to examine the role of various demographic variables of interest to this study. The results of the non-parametric analysis yielded the necessity for further analysis. To this end, parametric tests were conducted. Several central variables were shown to be consistently of significance in contributing to parental stress with regard to the mentally handicapped child.

5.2. PARAMETRIC ANALYSIS: STRESS FACTORS

Each of the dependent variables was analysed by means of a simple 3-way ANOVA. Thus five separate analyses of variance were computed - one for the QRS-F global score and one for each of the four QRS-F subscales. The independent variables were in each case: gender of parent (A), type of care in which the mentally handicapped child is placed (B), and gender of the mentally handicapped child (C).
5.2.1. ANOVA 1

QRS-F Global Score (Score range: 52-104)

Table 5.2.1.1. Means and Standard Deviations

<table>
<thead>
<tr>
<th></th>
<th>B₁ Residential</th>
<th>B₂ Day-Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>C₁</td>
<td>C₂ Female</td>
<td>C₁ Male</td>
</tr>
<tr>
<td></td>
<td>77.88</td>
<td>66.22</td>
</tr>
<tr>
<td></td>
<td>(6.11)</td>
<td>(7.93)</td>
</tr>
<tr>
<td>A₁</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>A₂</td>
<td>77.33</td>
<td>69.11</td>
</tr>
<tr>
<td></td>
<td>(12.16)</td>
<td>(6.58)</td>
</tr>
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<td></td>
<td>9</td>
<td>9</td>
</tr>
</tbody>
</table>

Table 5.2.1.2. Anova Summary Table

<table>
<thead>
<tr>
<th>Source</th>
<th>Ss</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (parent gen.)</td>
<td>19.2307</td>
<td>1</td>
<td>19.2307</td>
<td>0.21</td>
<td></td>
</tr>
<tr>
<td>B (type of car)</td>
<td>114.4923</td>
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<td>114.4923</td>
<td>1.25</td>
<td></td>
</tr>
<tr>
<td>C (child gender)</td>
<td>170.0136</td>
<td>1</td>
<td>170.0136</td>
<td>1.85</td>
<td></td>
</tr>
<tr>
<td>AB</td>
<td>62.3076</td>
<td>1</td>
<td>62.3076</td>
<td>0.68</td>
<td></td>
</tr>
<tr>
<td>AC</td>
<td>0.2769</td>
<td>1</td>
<td>0.2769</td>
<td>0.00</td>
<td></td>
</tr>
<tr>
<td>BC</td>
<td>971.2444</td>
<td>1</td>
<td>971.2444</td>
<td>10.59</td>
<td>p&lt;0.1</td>
</tr>
<tr>
<td>ABC</td>
<td>0.4136</td>
<td>1</td>
<td>0.4136</td>
<td>0.00</td>
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<tr>
<td>ERROR</td>
<td>5779.7777</td>
<td>63</td>
<td>91.7425</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The F ratio for the interaction between type of care in which the mentally handicapped child is placed and gender of the mentally handicapped child (DC) is significant at the 1% level. No effect due to gender of parent (A) was apparent. The interaction was investigated using an analysis of simple main effects.

Table 5.2.1.3. Type of Care and Gender of Child Means

<table>
<thead>
<tr>
<th></th>
<th>B₁ Residential</th>
<th>B₂ Day-Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>C₁ Male</td>
<td>77.605</td>
<td>67.665</td>
</tr>
<tr>
<td>C₁ Female</td>
<td>67.105</td>
<td>71.970</td>
</tr>
</tbody>
</table>

Figure 5.2.1.1. Graph of Type of Care and Child Gender

Cell Mean Profiles
Table 5.2.1.4. Analysis of Simple Main Effects

<table>
<thead>
<tr>
<th>Source</th>
<th>Ss</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>B at C1</td>
<td>876.2581</td>
<td>1</td>
<td>876.2581</td>
<td>9.5513</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>B at C2</td>
<td>209.4339</td>
<td>1</td>
<td>209.4339</td>
<td>2.2828</td>
<td>N/S</td>
</tr>
<tr>
<td>Error</td>
<td>5779.7460</td>
<td>63</td>
<td>91.742</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C at B1</td>
<td>976.9846</td>
<td>1</td>
<td>976.9846</td>
<td>10.6492</td>
<td>p&lt;0.01</td>
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<tr>
<td>C at B2</td>
<td>164.2673</td>
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<td>164.2673</td>
<td>1.7905</td>
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<tr>
<td>Error</td>
<td>5779.7460</td>
<td>63</td>
<td>91.742</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The analysis of simple main effects indicates a significant difference (F = 9.5513; p<0.01) between the parents of male mentally handicapped children depending upon the type of care in which the child is placed, i.e. day-care or residential. Parents with a male child in residential care show greater stress, as measured by the QRS-F global score; whereas parents with a male child in day-care show less stress. No such trend was indicated for parents of female mentally handicapped children.

The analysis of simple main effects also indicates a significant difference (F = 10.6492; p<0.01) between parents of children in residential care, depending upon the gender of that child. Parents with a male child in residential care show greater stress, as measured by the QRS-F global score; whereas parents with a female child in residential care show less stress. No such trend was indicated for parents of mentally handicapped children placed in day-care.
5.2.2. ANOVA 2

QRS-F Sub-Scale 1: Parent and Family Problems (Score range: 20-40)

Table 5.2.2.1. Means and Standard Deviations

<table>
<thead>
<tr>
<th>Source</th>
<th>B₁ Residential</th>
<th>B₂ Day-Care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>C₁ Male</td>
<td>C₂ Female</td>
</tr>
<tr>
<td>A₁ Fathers</td>
<td>28.00</td>
<td>24.33</td>
</tr>
<tr>
<td></td>
<td>(4.24)</td>
<td>(3.64)</td>
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<td></td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>A₂ Mothers</td>
<td>29.22</td>
<td>23.98</td>
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<tr>
<td></td>
<td>(5.95)</td>
<td>(3.33)</td>
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<td></td>
<td>9</td>
<td>9</td>
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</table>

Table 5.2.2.2. Anova Summary Table

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<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (parent gender)</td>
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<td>19.7470</td>
<td>0.97</td>
<td></td>
</tr>
<tr>
<td>B (type of care)</td>
<td>83.2000</td>
<td>1</td>
<td>83.2000</td>
<td>4.10</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>C (child gender)</td>
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<td>34.1880</td>
<td>1.68</td>
<td></td>
</tr>
<tr>
<td>AB</td>
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<td>1</td>
<td>7.8769</td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>AC</td>
<td>0.8752</td>
<td>1</td>
<td>0.8752</td>
<td>0.04</td>
<td></td>
</tr>
<tr>
<td>BC</td>
<td>171.5418</td>
<td>1</td>
<td>171.5418</td>
<td>8.45</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>A/B/C</td>
<td>6.6188</td>
<td>1</td>
<td>6.6188</td>
<td>0.33</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>1279.3333</td>
<td>63</td>
<td>20.3068</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The F ratio for the interaction between type of care in which the mentally handicapped child is placed and gender of the mentally handicapped child (BC) is significant at the 1% level. No effect
due to gender of parent (A) was apparent. A main effect for type of care was noted as significant at the 5% level, but since this variable is significantly involved in interaction with gender of the mentally handicapped child it is not meaningful to examine this variable in isolation. The interaction (BC) was investigated using an analysis of simple main effects.

Table 5.2.2.3. The Type of Care and Gender of Child Means

<table>
<thead>
<tr>
<th></th>
<th>B₁ Residential</th>
<th>B₂ Day-Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>C₁ Male</td>
<td>28.61</td>
<td>23.33</td>
</tr>
<tr>
<td>C₂ Female</td>
<td>24.10</td>
<td>25.05</td>
</tr>
</tbody>
</table>

Figure 5.2.2.1. Graph of Type of Care and Child Gender Cell Mean Profiles
Table 5.2.2.4. Analysis of Simple Main Effects

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>B at C₁</td>
<td>246.8582</td>
<td>1</td>
<td>246.8582</td>
<td>12.1569</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>B at C₂</td>
<td>7.9134</td>
<td>1</td>
<td>7.9134</td>
<td>0.3897</td>
<td>N/S</td>
</tr>
<tr>
<td>Error</td>
<td>1279.278</td>
<td>63</td>
<td>20.306</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C at B₁</td>
<td>179.4861</td>
<td>1</td>
<td>179.4861</td>
<td>8.8390</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>C at B₂</td>
<td>26.2922</td>
<td>2</td>
<td>26.2922</td>
<td>1.2948</td>
<td>N/S</td>
</tr>
<tr>
<td>Error</td>
<td>1279.278</td>
<td>63</td>
<td>20.306</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The analysis of simple main effects indicates a significant difference (F = 12.1569; p<0.01) between the parents of male mentally handicapped children depending upon the type of care in which the child is placed, i.e. day-care or residential. Parents with a male child in residential care show greater stress as measured by the QRS-F sub-scale on Parent and Family problems; whereas parents with a male child in day-care show less stress. No such trend was indicated for parents of female mentally handicapped children.

The analysis of simple main effects also indicates a significant difference (F = 8.8390; p<0.01) between parents of children placed in residential care, depending upon the gender of that child. Parents with a male child in residential care show greater stress, as measured by the QRS-F sub-scale on Parent and Family Problems; whereas parents with a female child in residential care show less stress. No such trend was indicated for parents of mentally handicapped children placed in day-care.
5.2.3. **ANOVA 3**

QRS-P Sub-Scale 2: Pessimism (Score range: 11-22)

Table 5.2.3.1. Means and Standard Deviations

<table>
<thead>
<tr>
<th></th>
<th>B₁ Residential</th>
<th>B₂ Day-Care</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>C₁ Male</td>
<td>C₂ Female</td>
<td>C₁ Male</td>
<td>C₂ Female</td>
</tr>
<tr>
<td>A₁ Fathers</td>
<td>18.44 (1.66)</td>
<td>15.55 (2.50)</td>
<td>16.66 (3.27)</td>
<td>17.25 (3.28)</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>9</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>A₂ Mothers</td>
<td>17.11 (3.48)</td>
<td>15.77 (2.68)</td>
<td>17.44 (2.24)</td>
<td>17.88 (3.29)</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>9</td>
<td>9</td>
<td>9</td>
</tr>
</tbody>
</table>

Table 5.2.3.2. Anova Summary Table

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (Parent gender)</td>
<td>0.1034</td>
<td>1</td>
<td>0.1034</td>
<td>0.01</td>
<td>N/S</td>
</tr>
<tr>
<td>B (type of care)</td>
<td>6.1752</td>
<td>1</td>
<td>6.1752</td>
<td>0.75</td>
<td>N/S</td>
</tr>
<tr>
<td>C (child gender)</td>
<td>11.3034</td>
<td>1</td>
<td>11.3034</td>
<td>1.38</td>
<td>N/S</td>
</tr>
<tr>
<td>AB</td>
<td>7.0777</td>
<td>1</td>
<td>7.0777</td>
<td>0.86</td>
<td>N/S</td>
</tr>
<tr>
<td>AC</td>
<td>2.2230</td>
<td>1</td>
<td>2.2230</td>
<td>0.27</td>
<td>N/S</td>
</tr>
<tr>
<td>BC</td>
<td>30.5307</td>
<td>1</td>
<td>30.5307</td>
<td>3.73</td>
<td>N/S</td>
</tr>
<tr>
<td>ABC</td>
<td>3.1803</td>
<td>1</td>
<td>3.1803</td>
<td>0.39</td>
<td>N/S</td>
</tr>
<tr>
<td>Error</td>
<td>515.5000</td>
<td>63</td>
<td>8.1825</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

No significant 3-factor, or 2-factor interaction effects, or main effects are apparent. Hence, no further analysis is required.
5.2.4. ANOVA 4

QRS-F Sub-Scale 3: Child characteristics (Score range: 15-30)

Table 5.2.4.1. Means and Standard Deviations

<table>
<thead>
<tr>
<th>Source</th>
<th>B1 Residential (Mean, Std Dev)</th>
<th>B2 Day-Care (Mean, Std Dev)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1 Fathers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C1 Male</td>
<td>23.66 (3.42)</td>
<td>20.11 (4.62)</td>
</tr>
<tr>
<td>C2 Female</td>
<td>19.55 (2.96)</td>
<td>21.25 (4.65)</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>A2 Mothers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C1 Male</td>
<td>23.00 (2.39)</td>
<td>17.22 (3.83)</td>
</tr>
<tr>
<td>C2 Female</td>
<td>20.55 (2.60)</td>
<td>21.44 (4.03)</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>9</td>
</tr>
</tbody>
</table>

Table 5.2.4.2. Anova Summary Table

<table>
<thead>
<tr>
<th>Source</th>
<th>Ss</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (parent gender)</td>
<td>0.1444</td>
<td>1</td>
<td>0.1444</td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td>B (type of care)</td>
<td>11.3034</td>
<td>1</td>
<td>11.3034</td>
<td>0.85</td>
<td></td>
</tr>
<tr>
<td>C (child gender)</td>
<td>24.9923</td>
<td>1</td>
<td>24.9923</td>
<td>1.89</td>
<td></td>
</tr>
<tr>
<td>AB</td>
<td>8.3769</td>
<td>1</td>
<td>8.3769</td>
<td>0.63</td>
<td></td>
</tr>
<tr>
<td>AC</td>
<td>1.1700</td>
<td>1</td>
<td>1.1700</td>
<td>0.09</td>
<td></td>
</tr>
<tr>
<td>BC</td>
<td>108.9307</td>
<td>1</td>
<td>108.9307</td>
<td>8.22</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>ABC</td>
<td>0.3769</td>
<td>1</td>
<td>0.3769</td>
<td>0.03</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>13.2478</td>
<td>63</td>
<td>13.2478</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The F-ratio for the interaction between type of care in which the mentally handicapped child is placed and gender of the mentally
handicapped child (BC) is significant at the 1% level. No effect due to gender of parent (A) was apparent. The interaction was investigated using an analysis of simple main effects.

Table 5.2.4.3. Type of Care and Gender of Child Means

<table>
<thead>
<tr>
<th></th>
<th>$B_1$ Residential</th>
<th>$B_2$ Day-Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>$C_1$ Male</td>
<td>23.33</td>
<td>20.05</td>
</tr>
<tr>
<td>$C_2$ Female</td>
<td>18.66</td>
<td>21.34</td>
</tr>
</tbody>
</table>

Figure 5.2.4.1. Graph of Type of Care and Gender of Child cell means Profiles
Table 5.2.4.4. Analysis of Simple Main Effects

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>B at C₁</td>
<td>95.2201</td>
<td>1</td>
<td>95.2201</td>
<td>7.1880</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>B at C₂</td>
<td>63.6708</td>
<td>1</td>
<td>63.6708</td>
<td>4.8064</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>Error</td>
<td>834.561</td>
<td>63</td>
<td>13.247</td>
<td>p&lt;0.01</td>
<td></td>
</tr>
<tr>
<td>C at B₁</td>
<td>192.971</td>
<td>1</td>
<td>192.9711</td>
<td>14.5671</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>C at B₂</td>
<td>14.7925</td>
<td>1</td>
<td>14.7925</td>
<td>1.1166</td>
<td>N/S</td>
</tr>
<tr>
<td>Error</td>
<td>834.561</td>
<td>63</td>
<td>13.247</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The analysis of simple main effects indicates a significant difference (F = 7.1880; p<0.01) between parent of male mentally handicapped children depending upon the type of care in which the child is placed, i.e. day-care or residential. Parents with a male child in residential care show greater stress, as measured by the QRS-F sub-scale on Child Characteristics; whereas parents with a male child in day-care show less stress. The reverse trend is apparent for parents of female mentally handicapped children. A significant difference indicates (F = 4.8064; p<0.05) that parents with a female child in residential care show less stress, as measured by the QRS-F sub-scale on Child Characteristics; whereas parents with a female child in day-care show greater stress. The latter trend was exhibited in ANOVA 1 and ANOVA 2, but in both cases failed to reach significance.

The analysis of simple main effects also indicates a significant difference (F = 14.5671; p<0.01) between parents of children placed in residential care, depending upon the gender of that child. Parents with a male child in residential care show greater stress; whereas parents with a female child in residential care show less stress. No such trend was indicated for parents of mentally handicapped children placed in day-care.
5.2.5. ANOVA

QRS-F Sub-Scale 4: Physical Incapacity of Child (Score Range: 6-12)

Table 5.2.5.1. Means and Standard Deviations.

<table>
<thead>
<tr>
<th></th>
<th>C1 Male</th>
<th>C2 Female</th>
<th>C1 Male</th>
<th>C2 Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1 Fathers</td>
<td>7.77</td>
<td>7.66</td>
<td>7.33</td>
<td>8.00</td>
</tr>
<tr>
<td></td>
<td>(1.39)</td>
<td>(1.32)</td>
<td>(0.50)</td>
<td>(1.06)</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>9</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>B2 Mothers</td>
<td>8.00</td>
<td>7.66</td>
<td>7.11</td>
<td>8.00</td>
</tr>
<tr>
<td></td>
<td>(1.50)</td>
<td>(1.41)</td>
<td>(0.33)</td>
<td>(0.86)</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>9</td>
<td>9</td>
<td>9</td>
</tr>
</tbody>
</table>

Table 5.2.5.2. Anova Summary Table

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (parent gender)</td>
<td>0.0000</td>
<td>1</td>
<td>0.0000</td>
<td>0.00</td>
<td>N/S</td>
</tr>
<tr>
<td>B (type of care)</td>
<td>0.4923</td>
<td>1</td>
<td>0.4923</td>
<td>0.39</td>
<td>N/S</td>
</tr>
<tr>
<td>C (child gender)</td>
<td>1.3675</td>
<td>1</td>
<td>1.3675</td>
<td>1.07</td>
<td>N/S</td>
</tr>
<tr>
<td>AB</td>
<td>0.2188</td>
<td>1</td>
<td>0.2188</td>
<td>0.17</td>
<td>N/S</td>
</tr>
<tr>
<td>AC</td>
<td>0.0000</td>
<td>1</td>
<td>0.0000</td>
<td>0.00</td>
<td>N/S</td>
</tr>
<tr>
<td>BC</td>
<td>4.4307</td>
<td>1</td>
<td>4.4307</td>
<td>3.47</td>
<td>N/S</td>
</tr>
<tr>
<td>ABC</td>
<td>0.2188</td>
<td>1</td>
<td>0.2188</td>
<td>0.17</td>
<td>N/S</td>
</tr>
<tr>
<td>Error</td>
<td>80.4444</td>
<td>63</td>
<td>1.2769</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

No significant 3-factor, or 2-factor interaction effects or main effects are apparent. Hence, no further analysis is required.
5.3. NON-PARAMETRIC ANALYSIS

The other variables on which data was gathered in this study were subjected to $X^2$ tests of association.

In a number of cases the original tables were reduced for the purpose of analysis. The $X^2$ test may be used if fewer than 20% of the cells have an expected frequency of less than 5 and if no cell has an expected frequency of less than 1 (for contingency tables with df 1). If these requirements are not met by the data in the form in which it was originally collected, as was the case in this study for certain variables, adjacent categories may be combined in order to increase the expected frequency in the various cells. After such combination, and given that the requirements for the execution of a $X^2$ test are then met, a $X^2$ may be meaningfully applied to the data (Siegel, 1956).

5.3.1. Significant Results

Table 5.3.1.1. Table of $X^2$ results: Type of Care x Income of Family

<table>
<thead>
<tr>
<th>Income p.a. (R000's)</th>
<th>Type of Care</th>
<th>Day-Care</th>
<th>Residential</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below 5 000</td>
<td></td>
<td>0</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>5 000 - 10 000</td>
<td></td>
<td>8</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>10 000 - 15 000</td>
<td></td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>15 000 - 20 000</td>
<td></td>
<td>6</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>20 000 - 30 000</td>
<td></td>
<td>6</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td>30 000 - 40 000</td>
<td></td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>over 40 000</td>
<td></td>
<td>12</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>36</td>
<td>36</td>
<td>72</td>
</tr>
</tbody>
</table>

$X^2$ value = 20.733, df = 6, $p < 0.01$
collar or professional).

This result is reflected in Table 5.3.1.2. Hence a pattern of low occupational status, low income and high occupational status, high income, is apparent. Since both variables are indicators of S.E.S. and are very highly correlated (Pearsons r = 0.88; df = 69; p < 0.01) one could infer that families with a child placed permanently in residential care generally have a lower socio-economic standing than families with a child resident at home, and attending a day-care centre regularly.

Table 5.3.1.3. Table of $X^2$ results: Stress, as measured by QRS-F

<table>
<thead>
<tr>
<th>Income of family</th>
<th>QRS-F Global Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Below $\bar{x}$</td>
</tr>
<tr>
<td>below 15 000</td>
<td>21</td>
</tr>
<tr>
<td>15 000 - 40 000</td>
<td>12</td>
</tr>
<tr>
<td>over 40 000</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
</tr>
</tbody>
</table>

$X^2$ value = 10.911, df = 2, p < 0.01

1 case had incomplete data

Table 5.3.1.3. is a reduced table of the variables stress and income per annum since the original data did not meet the requirements for a meaningful computation of an $X^2$ test (Cochran & Cox, 1956) i.e. more than 20% of the cells had an expected frequency of less than 1. Hence adjacent categories were combined in order to increase the expected frequencies in the various cells.

The $X^2$ test yields a significant difference between families of different income levels and parental stress. Parents in the lower income bracket (i.e. below R15 000 p.a.) report stress levels below the mean on the QRS-F, whilst parents in the higher income bracket report stress levels above the mean on the QRS-F.
The above result indicates a difference between the day-care and residential families with regard to their incomes per annum, at the 1% level of significance. Families with a handicapped child in residential care have a significantly lower income per annum than families whose mentally handicapped child remains at home and attends a day-care centre. This is particularly clear at the extremes of the income brackets - ten 'residential families' earn less than R5 000 p.a., yet no 'day-care families' fall into this category; whilst 12 day-care families earn over R40 000 p.a., whereas only half that number earn this salary who have a child placed in residential care.

Table 5.3.1.2. Table of $X^2$ Results: Type of Care x Occupation of Father

<table>
<thead>
<tr>
<th>Occupation*</th>
<th>Day-Care</th>
<th>Residential</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unskilled</td>
<td>0</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Semi-skilled</td>
<td>4</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>Skilled</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>White-collar</td>
<td>12</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Professional</td>
<td>16</td>
<td>14</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>36</td>
<td>72</td>
</tr>
</tbody>
</table>

* Bread distinctions in socio-economic level; coded in accordance with Schlemmer & Stopforth (1979).

$X^2$ value = 14.133, df = 4, p < 0.05.

From the above it is evident that a significant difference exists between fathers with mentally handicapped children in residential care and those with children who live at home and attend a day-care centre, in terms of their occupational status. Fathers with children in residential care tend to occupy jobs of lower occupational status (i.e. unskilled or semi-skilled) whereas fathers with children at home tend to occupy jobs of greater occupational status (i.e. white-
It should be noted that there is a tendency for the QRS-F data to cluster around the mean (range = 39.00; largest obtained value, 93; smallest obtained value, 54; largest possible, score 104; smallest possible score, 52). However, it is felt that this tendency does not invalidate the results of the $X^2$ test, and that a distribution which approximates normality could be expected.

Table 5.3.1.4. Table of $X^2$ results: Stress, as measured by QRS-F Occupation of Father

<table>
<thead>
<tr>
<th>Occupation</th>
<th>QRS-F Global Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>below $X$</td>
</tr>
<tr>
<td>Low occ status</td>
<td>18</td>
</tr>
<tr>
<td>White-collar</td>
<td>5</td>
</tr>
<tr>
<td>Professional</td>
<td>18</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
</tr>
</tbody>
</table>

1 case had incomplete data

$X^2$ value $= 8.584$, df $= 2$, $p < 0.025$

Table 5.3.1.4. as Table 5.3.1.3. is a reduced table of the variables Stress and Occupation of father. Similarly, the requirements for the computation of a $X^2$ test were not met, and adjacent categories had to be combined for meaningful statistical analysis.

Computation of a $X^2$ test indicates a difference between the occupational status of fathers and parental stress, at the 2.5% level of significance. It would appear that in families where the father holds low occupational status, parents report lower stress. This finding corresponds to the previous finding of parents in the lower
income brackets reporting stress levels below the mean. Given that, as mentioned previously, income and occupation are both indicators of SES and that they are highly correlated. Parents in the mid-occupational status category appear to experience the greatest stress; whilst those in the highest occupational status category report less than the middle category, but greater stress than those in the lowest category.

Table 5.3.1.5. Table of $X^2$ results: Stress, as measured by QRS-T x Personal History of Parents

<table>
<thead>
<tr>
<th>Personal History</th>
<th>QRS-F Global Score</th>
<th>below $X$</th>
<th>71.10</th>
<th>above $X$</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td></td>
<td>5</td>
<td></td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>Physical</td>
<td></td>
<td>3</td>
<td></td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>None</td>
<td></td>
<td>33</td>
<td></td>
<td>16</td>
<td>49</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>41</td>
<td>30</td>
<td>71</td>
<td></td>
</tr>
</tbody>
</table>

1 case had incomplete data

$X^2$ value = 6.030, df = 2, $p<0.05$

As in the case of the previous two tables, Table 5.3.1.5, is a reduced table.

The results of a $X^2$ test yield a significant difference between parents' stress, and their previous personal history, i.e. the presence or absence of earlier psychological or physical difficulties. It is apparent that parents who have in the past suffered some severe psychological or physical problem generally report stress levels above the mean; whereas parents who have no personal history in this regard
report with greater frequency stress levels below the mean on the QRS-F.

Table 5.3.1.6. Table of $X^2$ results: Stress, as measured by QRS-T x Level of Education of Parents

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>QRS-F Global Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Below X</td>
</tr>
<tr>
<td>Matric &amp; above</td>
<td>16</td>
</tr>
<tr>
<td>Below matric</td>
<td>25</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
</tr>
</tbody>
</table>

1 case had incomplete data

$X^2$ value = 5.295, df = 1, p < 0.025

The above result indicates a difference between parental level of education and stress, at the 2.5% level of significance. Thus, parents who have obtained a higher educational level, i.e. matric or above, report stress levels above the mean on the QRS-F, whereas parents who have obtained a lower educational level, i.e. below matric, report stress levels below the mean on the QRS-F.

This result further substantiates earlier findings which indicate that parents of lower occupational status and lower income p.a. report lower stress than parents of higher occupational status and greater income per annum. All three variables, income p.a., occupation and education - may be assumed to be indicators of SES, and the inter-correlations of these variables are very high as revealed by Pearson's product moment correlations. (df = 69, p < 0.01).
Table 5.3.1.7. Table of Correlations between variables regarded as indicators of socio-economic status

<table>
<thead>
<tr>
<th></th>
<th>occ.</th>
<th>edu.</th>
<th>income</th>
</tr>
</thead>
<tbody>
<tr>
<td>occupation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>education</td>
<td>.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td>income</td>
<td>.88</td>
<td>.78</td>
<td></td>
</tr>
</tbody>
</table>

Table 5.3.1.8. Table of $X^2$ results: Stress as measured by QNST x Religiosity of Parents

<table>
<thead>
<tr>
<th>Religiosity</th>
<th>QRS-F Global Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Below $\bar{X}$</td>
</tr>
<tr>
<td>Played significant role</td>
<td>17</td>
</tr>
<tr>
<td>Played some role</td>
<td>14</td>
</tr>
<tr>
<td>Played no role</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
</tr>
</tbody>
</table>

1 case had incomplete data

$X^2$ value = 5.298, df = 2, $p<0.01$

A $X^2$ computation on the reduced data of variables stress and religiosity of parents yields a significant result, at the 1% level of significance. A close examination of Table 5.3.1.8. reveals that parents who felt that religion played a significant role in their lives, reported less stress than parents who described religion as playing some or an 'average' role in their lives, or those who described themselves as not being religious. There is little apparent
difference between parents who consider themselves to be 'averagely' or not religious, with regard to their stress.

5.3.2. NON-SIGNIFICANT RESULTS
A number of variables which were subjected to analysis yielded non-significant results. Thus, no association between these variables and parental stress was found. The following table gives details of these findings.

Table 5.3.2.1. Table of Non-significant $X^2$ Results

<table>
<thead>
<tr>
<th>Variable</th>
<th>$X^2$</th>
<th>df</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital history</td>
<td>1,206</td>
<td>4</td>
<td>$p &gt; 0.05$</td>
</tr>
<tr>
<td>Age of parent at birth of child</td>
<td>11,968</td>
<td>12</td>
<td>$p &gt; 0.05$</td>
</tr>
<tr>
<td>Family recognized defect</td>
<td>6,579</td>
<td>4</td>
<td>$p &gt; 0.05$</td>
</tr>
<tr>
<td>Number of children</td>
<td>15,190</td>
<td>20</td>
<td>$p &gt; 0.05$</td>
</tr>
<tr>
<td>Family history of mental handicap</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Country of origin (in- or outside South Africa)</td>
<td>5,377</td>
<td>4</td>
<td>$p &gt; 0.05$</td>
</tr>
<tr>
<td>Age of child on 31/12/85</td>
<td>17,885</td>
<td>12</td>
<td>$p &gt; 0.05$</td>
</tr>
<tr>
<td>Age of child at first recognition of handicap</td>
<td>4,236</td>
<td>2</td>
<td>$p &gt; 0.05$</td>
</tr>
</tbody>
</table>

5.3.3. OTHER MISCELLANEOUS RESULTS
Certain variables were compared since the relationship between them has been considered important in previous research. However, due to sampling bias with respect to these variables, and the fact that
statistical analysis was not therefore possible, these results are included only as a source of interest.

Table 5.3.3.1. Table of $X^2$ results: Stress, as measured by QRS-F global score, x Aetiology of Child's Mental Handicap

<table>
<thead>
<tr>
<th>Aetiology</th>
<th>QRS-F Global Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>below $\bar{X}$</td>
</tr>
<tr>
<td>Unknown</td>
<td>7</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>0</td>
</tr>
<tr>
<td>Congenital abnorm.</td>
<td>0</td>
</tr>
<tr>
<td>Brain Damage</td>
<td>5</td>
</tr>
<tr>
<td>Environmental dep.</td>
<td>8</td>
</tr>
<tr>
<td>Downs Syndrome</td>
<td>21</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
</tr>
</tbody>
</table>

1 case had incomplete data

Table 5.3.3.2. Table of $X^2$ results: Physical Incapacity of Child* x Aetiology of Mental Handicap

<table>
<thead>
<tr>
<th>Aetiology</th>
<th>Physical Incapacity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>below $\bar{X}$</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>2</td>
</tr>
<tr>
<td>Congenital abnorm.</td>
<td>0</td>
</tr>
<tr>
<td>Brain Damage</td>
<td>3</td>
</tr>
<tr>
<td>Environmental dep.</td>
<td>8</td>
</tr>
<tr>
<td>Downs Syndrome</td>
<td>24</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
</tr>
</tbody>
</table>

* Physical incapacity of child is measured by a sub-scale of the QRS-F.
In the above two cases (Refer Tables 5.3.3.1. and 5.3.3.2.) it was not meaningful to compute a X² test since more than 20% of cells have an expected frequency of less than 5 and a number of cells have an expected frequency of less than 1 (Cochran, 1954). However, when the two tables are compared, a general trend becomes apparent. That is, parents with children of greater physical incapacity also (Table 5.3.3.2, column 2) appear to suffer greater stress, as measured by the QRS-F global score (Table 5.3.3.1, column 2). Hence there may be some association between the degree of the child's physical incapacity and parental stress, irrespective of the aetiology of the handicap. Clearly, due to the bias in the sample with regard to aetiology and the inability of the data to meet the criteria for statistical analysis, this trend must be seen to be tenuous. Further study, with more adequate sampling is necessary if inferences are to be drawn.

A X² test was computed to determine whether gender of parent was associated with religiosity. No significant association was found.

A further X² test was computed to determine whether there was an association between the number of children in a particular family and that family's functioning. Family functioning was determined by means of a sub-scale of the QRS-F Parent and Family Problems. No significant association was found.

5.4. FURTHER ANALYSIS: STRESS FACTORS

On completion of the X² tests, a number of variables were found to be significantly associated to parental stress. These included personal history, religiosity and the three variables considered to be indicators of socio-economic status - paternal occupation, income per annum and level of education.
Thus it was decided to examine the relative contribution of each of the independent variables to the dependent variable, i.e. parental stress. The execution of a multiple regression analysis was considered. However, the fundamental assumptions underpinning multiple regression were not met. None of the independent variables was measured on a scale of higher than an ordinal level, nor was the principle of homoscedasticity upheld by any of the independent variables.

Nevertheless, the robust nature of multiple regression has been increasing acknowledged (Miller, 1984). Provided that results are interpreted with caution, the use of multiple regression where assumptions have not been met may prove useful. For this reason, a step-wise multiple regression was conducted. Results revealed the following variables to be contributing significantly to the variance in the dependent variable: socio-economic status, personal history, age of parent at birth of child and aetiology. Socio-economic status was a composite variable of the variables: paternal occupation, level of education and income per annum, thus the problem of multicollinearity as described by Neter and Wasserman (1974) was avoided. A total of 30.11% of the variance was accounted for. Given the limitations of this analysis, it is considered inappropriate to discuss these findings in any greater depth.

The three socio-economic variables and personal history appeared to be of greatest significance in contributing to parental stress - both in the $X^2$ and regression analyses. It was therefore decided to subject these variables to further analysis. The use of simple 2-way ANOVAs was appropriate.
An analysis of variance was computed for each of the independent variables which appeared to be significant in the regression equation.

5.4.1. ANOVA 6

Socio-economic status, as indicated by the variables paternal occupation, level of education and income per annum, was found to be the major factor contributing to the variance in the dependent variable, i.e. stress, as measured by the global score on the QRS-F.

Table 5.4.1.1. Means and Standard Deviations (Occupation)

<table>
<thead>
<tr>
<th></th>
<th>B1 Unskilled/semi-skilled</th>
<th>B2 White collar</th>
<th>B3 Professional skilled</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1 Residential</td>
<td>67.75</td>
<td>85.33</td>
<td>72.07</td>
</tr>
<tr>
<td></td>
<td>(11.58)</td>
<td>(5.20)</td>
<td>(4.98)</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>A2 Day-care</td>
<td>63.25</td>
<td>73.18</td>
<td>69.38</td>
</tr>
<tr>
<td></td>
<td>(7.38)</td>
<td>(9.57)</td>
<td>(9.09)</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>11</td>
<td>16</td>
</tr>
</tbody>
</table>

Overall mean 66.25 78.76 70.64

Overall Mean 72.36 69.80
Table 5.4.1.2. Anova Summary Table

<table>
<thead>
<tr>
<th>Source</th>
<th>Ss</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (type of care)</td>
<td>519.7736</td>
<td>1</td>
<td>519.7736</td>
<td>6.75</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>B (occupation)</td>
<td>1973.5894</td>
<td>2</td>
<td>986.7947</td>
<td>12.01</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>AB</td>
<td>143.9840</td>
<td>2</td>
<td>71.9920</td>
<td>0.93</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>5006.1483</td>
<td>65</td>
<td>77.0177</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

No interaction effect was apparent. The main effects for both variables, type of care and occupation, were found to be significant at the 5% and 1% level respectively. To determine which of the means are significantly different from one another, post-hoc comparisons or a posteriori procedures (Howell, 1982) were applied.

A number of methods have been devised for testing the significance of post hoc comparisons. Tukey's T method was originally devised for experiments containing equal-sized samples; and one is cautioned that although the T method is sufficiently robust to moderate small departures from this assumption, where sample sizes are vastly different this method may not be reliable (Berenson, Levine & Goldstein, 1983). Scheffe's method of multiple comparisons was chosen as the most suitable techniques for analysis of the present data since it has "advantages of simplicity, applicability to groups of unequal sizes, and suitability for any comparison" (Hayes, 1973). Moreover, according to Hayes (1973), this method is also known to be relatively insensitive to departures from normality and homogeneity of variance.

Since there are only two levels of Factor A, type of institution, and the main effect of this variable is significant, it is evident that parental stress differs in accordance with the type of institution.
the mentally handicapped child attends.

Scheffe's multiple comparisons on variable B, occupation, revealed significant differences between all of the groups. Thus, at the 1% level, there was a significant difference in parental stress between unskilled/semi-skilled/skilled parents and 'white-collar' parents ($F = 25.405, p < 0.01$), and between 'white collar' parents and professional parents ($F = 12.048, p < 0.01$). At the 5% level, there was a significant difference in parental stress between unskilled, semi-skilled/skilled parents and 'white-collar' parents ($F = 4.411, p < 0.05$).

Examining the overall means, it appears that parents who fall into the 'white collar' bracket experience the greatest stress, whereas 'professional' parents experience less stress and parents who occupy the lowest occupational bracket experience the least stress (Refer Figure 5.4.1.1.).

![Figure 5.4.1.1. Mean Parental Stress associated with Father's Occupational Status](image-url)
Table 5.4.2.1. Means and Standard Deviations (Level of Education)

<table>
<thead>
<tr>
<th>Source</th>
<th>below high school</th>
<th>high school</th>
<th>matric</th>
<th>above matric</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A1 Residential</td>
<td>59.75 (5.20)</td>
<td>75.08 (10.53)</td>
<td>80.75 (7.17)</td>
<td>72.50 (4.28)</td>
</tr>
<tr>
<td>A2 Day-care</td>
<td>61.0 (5.66)</td>
<td>69.38 (11.57)</td>
<td>73.33 (7.81)</td>
<td>69.93 (8.88)</td>
</tr>
<tr>
<td>Overall Mean</td>
<td>60</td>
<td>72.12</td>
<td>77.57</td>
<td>70.86</td>
</tr>
</tbody>
</table>

Table 5.4.2.2. Anova Summary Table

<table>
<thead>
<tr>
<th>Source</th>
<th>Ss</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (type of care)</td>
<td>163.6795</td>
<td>1</td>
<td>163.6795</td>
<td>2.12</td>
<td></td>
</tr>
<tr>
<td>B (level of educ.)</td>
<td>1223.8008</td>
<td>3</td>
<td>407.9336</td>
<td>5.28</td>
<td>p&lt; 0.01</td>
</tr>
<tr>
<td>AB</td>
<td>109.8235</td>
<td>3</td>
<td>36.6078</td>
<td>0.47</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>4865.2555</td>
<td>63</td>
<td>77.2263</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

No interaction effect was apparent. The main effect for variable B, level of education, was found to be significant at the 1% level. Further analysis, using Scheffe's multiple comparisons, was conducted.

No significant differences in parental stress were evident between parents who completed high school as opposed to matric (F = 2.652,
p > 0.05), those who completed high school as opposed to those who obtained some form of tertiary education (F = 0.149, p > 0.05), and parents who completed matric as opposed to those who obtained some form of tertiary education (F = 3.60, p > 0.05).

Various significant differences in parental stress were, however, apparent. These differences occurred between those parents who attained an educational level below high school, and each of the other groups respectively. Thus, there were significant differences in parental stress between parents who attained an educational level below high school and parents who completed high school (F = 9.27, p < 0.01), parents who completed matric (F = 15.69, p < 0.01), and parents who obtained a tertiary education (F = 7.41, p < 0.01).

Examining the overall means it would appear that parents in the two middle educational groups, high school and matric, experience the greatest stress, followed by parents in the highest educational group, with parents in the lowest group experiencing the least stress (Refer Figure 5.4.2.1.).

![Figure 5.4.2.1. Mean parental stress associated with level of education](image)

Figure 5.4.2.1. Mean parental stress associated with level of education
5.4.3. ANOVA B

Table 5.4.3.1. Means and Standard Deviations (Income)

<table>
<thead>
<tr>
<th></th>
<th>$B_1$ below R15 000</th>
<th>$B_2$ R15 000-R30 000</th>
<th>$B_3$ above 30 000</th>
<th>Overall Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>$A_1$ Residential</td>
<td>65.00</td>
<td>77.86</td>
<td>75.63</td>
<td>72.83</td>
</tr>
<tr>
<td></td>
<td>(9.46)</td>
<td>(8.37)</td>
<td>(8.28)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>14</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>$A_2$ Day-care</td>
<td>63.82</td>
<td>75.92</td>
<td>69.17</td>
<td>69.63</td>
</tr>
<tr>
<td></td>
<td>(6.42)</td>
<td>(8.06)</td>
<td>(10.56)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>12</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Overall mean</td>
<td>64.47</td>
<td>76.95</td>
<td>71.736</td>
<td></td>
</tr>
</tbody>
</table>

Table 5.4.3.2. Anova Summary Table

<table>
<thead>
<tr>
<th>Source</th>
<th>$Ss$</th>
<th>$DF$</th>
<th>$MS$</th>
<th>$F$</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (type of care)</td>
<td>174.6911</td>
<td>1</td>
<td>174.6911</td>
<td>2.31</td>
<td></td>
</tr>
<tr>
<td>B (income p.a.)</td>
<td>1999.5548</td>
<td>2</td>
<td>999.7774</td>
<td>13.24</td>
<td>$p&lt;0.01$</td>
</tr>
<tr>
<td>AB</td>
<td>84.9056</td>
<td>2</td>
<td>42.4528</td>
<td>0.56</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>4907.8089</td>
<td>65</td>
<td>75.5048</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

No interaction effect was apparent. The main effect for variable B, income per annum, was found to be significant at the 1% level. Scheffe's multiple comparisons were applied.

No significant difference in parental stress was evident between parents of the middle income group, R15 000 to R30 000 per annum, and parents of the upper income group, above R30 000 per annum. ($p = 2.326, p > 0.05$).
Significant differences were found between the lower income group and the other two groups. That is, there is a significant difference in parental stress between parents of the lower income group, below R15 000 per annum, and parents of the middle income group. \( F = 20.513, p < 0.01 \); and there is a significant difference in parental stress between parents of the lower income group and parents of the upper income group \( F = 7.181, p < 0.01 \).

Examining the means, it would appear that the middle income group experiences the greatest stress, followed by the upper income group, with the lower income group experiencing the least stress (Refer Figure 5.4.3.1.).

![Figure 5.4.3.1. Mean Parental stress associated with income per annum](image)

5.4.4. ANOVA 9

Personal history, the second factor in the regression system of significance, was subjected to a two-way analysis of variance. Again, the dependent variable was stress, as measured by the QRS-F.
Individuals who were classified as having 'no' personal history, reported no previous serious physical or psychological difficulties.

Table 5.4.4.1. Means and Standard Deviations (Personal History)

<table>
<thead>
<tr>
<th></th>
<th>( B_1 ) 'No' personal history</th>
<th>( B_2 ) serious physical history</th>
<th>( B_3 ) serious psychological history</th>
</tr>
</thead>
<tbody>
<tr>
<td>( A_1 ) Residential</td>
<td>69.88 (10.35) 24</td>
<td>79.0 (6.78) 4</td>
<td>76.5 (10.41) 8</td>
</tr>
<tr>
<td>( A_2 ) Day-care</td>
<td>68.4 (9.39) 25</td>
<td>69.2 (8.29) 5</td>
<td>77.4 (10.85) 5</td>
</tr>
</tbody>
</table>

Overall mean 69.12 73.56 76.85

Table 5.4.4.2. Anova Summary Table

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>DF</th>
<th>MS</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (type of care)</td>
<td>125.6505</td>
<td>1</td>
<td>125.6505</td>
<td>1.31</td>
<td></td>
</tr>
<tr>
<td>B (personal hist.)</td>
<td>689.7481</td>
<td>2</td>
<td>344.8740</td>
<td>3.60</td>
<td>( p &lt; 0.05 )</td>
</tr>
<tr>
<td>AB</td>
<td>164.2281</td>
<td>2</td>
<td>82.1140</td>
<td>0.86</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>6220.6250</td>
<td>65</td>
<td>95.7019</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

No interaction effect was apparent. The main effect for variable B, personal history, was found to be significant at the 5% level. Scheffe's method of multiple comparisons was applied to determine
where the differences between the means lie.

No significant difference in parental stress was evident between parents who had no serious personal history and those who reported previous physical history of a chronic nature \( (F = 1.934, p > 0.05) \). Further, no significant difference in parental stress was evident between parents who reported previous physical history of a chronic nature, and those who reported severe psychological difficulties in their past. \( (F = 0.438, p > 0.05) \).

A significant difference in parental stress, however, was found to exist between parents who had no serious personal history and those who reported severe psychological difficulties in their past. \( (F = 6.269, p < 0.025) \). Examining the means of these two groups, parents with a history of psychological disturbance exhibit greater stress than parents who report no physical or psychological history.

5.5. CONCLUSION

Quantitative analysis of the data yielded a number of findings of major significance. Results from the major factorial analysis i.e. gender of parent x gender of child x type of care, consistently revealed a significant interaction effect. In three of the five ANOVAs conducted an interaction effect between gender of the mentally handicapped child and type of care in which the child was placed, was apparent. No effect due to gender of parent was in evidence. Two of the ANOVAs did not attain significance; although trends operating in the same direction as the remaining ANOVAs were present.

The non-parametric analysis revealed two indicators of socio-economic status to be significantly associated with the type of care to which the mentally handicapped child was committed. In general, families
of low socio-economic status, as indicated by income per annum and paternal occupation, tended to place the child in residential care; whereas families of high socio-economic status tended to keep the child at home, and attending a day-care centre. Socio-economic status was also significantly associated with the degree of stress experienced by parents - this was analysed further by parametric means.

A number of other variables were subjected to non-parametric analysis, but only previous personal history (medical or psychological) and parental religiosity appeared to be significantly associated with stress.

Further analysis proceeded, following the identification of several variables significantly related to stress. A step-wise multiple regression analysis was performed as an exploratory measure. Variables of significance to the regression equation were then subjected to further parametric analysis. The computation of ANOVAs consistently revealed a significant relationship between socio-economic status and parental stress. Parents of low socio-economic status experienced the least stress in relation to the handicapped child, parents of median socio-economic status experienced the greatest stress, whilst parents of high socio-economic status experienced less stress than the middle group, but greater stress than the lower group.

In short, the variables of gender of child and type of care, in interaction, and the various indicators of socio-economic status were shown to be of the greatest significance in the quantitative analysis.
CHAPTER SIX

QUALITATIVE FINDINGS

6.1. INTRODUCTION

In the previous chapter the quantitative findings were discussed. These findings were based upon data obtained from scales completed by the participants in this study. As mentioned earlier, all participants were also interviewed in depth by the researcher. These interviews form the basis of the discussion in this chapter. Each interview was transcribed and loosely content analysed. In this way certain themes and trends became apparent. This data, in part, support the findings of the earlier quantitative work. Moreover, it also sheds greater light on some of the material analysed in the previous chapter, and raises entirely new issues.

Results which further substantiate the findings of the quantitative analysis are reported. Additional findings regarding the three major comparative variables in this study, i.e., type of care, gender of child, and gender of parent, are discussed. And finally, considerable attention is devoted to the notion of interpersonal social support which became apparent as a central issue in the qualitative analysis.

6.2. STRESS: TYPE OF CARE AND GENDER OF CHILD

Two of the major comparative variables in this research were the type of care in which the mentally handicapped child is placed, and the gender of that child. It was a primary aim of this study to establish whether these two variables had a significant effect upon the level of stress parents experienced.
The results of the parametric analysis of stress factors (discussed fully in Chapter 5, Section 5.2.) revealed that in three of the Anovas gender of child and type of care were significantly affecting degree of parental stress. The nature of this effect was interactive. Thus, type of care and gender of child were, in some combination, influencing parental stress. Neither variable had influence on it's own.

To reiterate, it was found that:

1. Parents of male children in custodial care manifested greater stress, as measured by the QRS-F, than parents of male children in day-care.


The findings of the depth interviews lend some support to the above.

The majority of parents stated that the gender of their handicapped child was of little significance. However, evidence gleaned from personal histories in the course of the interviews was in contradiction with this assertion. Parents with male children in custodial care appear to have experienced the greatest difficulty in accepting their handicapped child. Most reported still feeling tense when thinking or speaking about their son. Moreover, these parents spoke with greater frequency of prolonged and severe emotional reactions in response to their children's deficit. The following quotation provides a clear example:
My doctor said to me, 'you look here. This is your second nervous breakdown, and there will be a third and a fourth if you don't put this child in ______'. Then I really fell apart. I felt so guilty for sending him there. I've failed as a mother ...

(Mrs. N.)

Persistent feelings of guilt and inadequacy were common to the majority of parents of both girls and boys who had been institutionalized. This was not found to be the case in parents whose children remained within the nuclear family. Rather, these parents reported feeling more stress related to coping with the child at home. The primary means of coping reported by the latter parents was to concentrate on "getting through each day rather than worrying about tomorrow" (Mrs. W.). The following quotations were typical:

We live one day at a time  
(Mr. D.)

We just live from day-to-day  
(Mrs. V.)

We don't say we'll always be able to cope, but for the moment we can and things are fine  
(Mr. F.)

In short, parents whose children are in custodial care would appear to experience stress of a different nature to parents whose children live at home, and attend a day centre.

Differences were revealed in the quantitative results between the female-residential sub-sample and the male-residential and female-day-care sub-samples respectively.
Significantly, eight of the 18 female residential parents with a handicapped daughter were recognized by the interviewer to be of limited intellect. Consequently, these eight parents lacked insight into their daughter's impairment, not recognizing her intellectual handicap. In each of these cases the child had been clinically diagnosed as suffering environmental deprivation, compounded by genetic or familial factors. As a result of the parents' inability to recognize anything different about their daughters, they felt no stress in relation to their handicaps. For example, when asked by the interviewer when the parents first noticed anything different about their child, one father replied 'What do you mean?' These parents believed that their daughters had been placed in the institution by 'the Welfare' to receive an education. Mr. L. explains why his daughter was placed there:

X was becoming a bit of a handful, you know. Girls are little terrors when they start to grow up! So anyway, the priest suggested she go to _______ to calm her down a bit and to give her a bit of a training in cooking and cleaning. We were quite pleased really. She's grown up a lot since she's been there.

The above provides some explanation for why these eight parents received extremely low stress scores on the QRS-F. This sizeable proportion of low scores amongst the female-residential sub-sample may therefore have influenced the results of this study; accounting for the significant difference between the female-residential sample and the other groups, i.e. male-residential and female day-care.
Nevertheless, from the interviews conducted it would appear that differences do exist between residential and day-care samples - with regard to parental feelings concerning the type of care in which the child is placed. All parents, but one, whose children attended the day-care centre, felt positive about their handicapped children's placement. Further, the majority of these parents believed the centre to have ameliorated some of their stress, as the following quotation illustrates.

I never had any peace before M went to the day-centre. Before I was always on my nerves, going crazy. I used to shake. The day-centre has given me space to calm down. It gives me a break until two every week-day which I never had before. Also they do good work with the kids there, more than I could do.

(Mrs. S.)

Almost all of the day-care parents felt similarly to Mrs. S. with only one exception. The latter couple was unhappy with the day-care as a result of negative personal experiences. Notably, the day-care parents unanimously viewed the institution in this study with distaste. The following comments are exemplary of their general opinion:

We went and saw _______. I could NEVER put my child there. It's the worst kind of institution.

(Mr. K.)

I've always viewed that place as the ultimate horror. It would be the last place to my mind. I would fight to get her in somewhere else.

(Mrs. T.)
By comparison, parents from the residential sample had less definitive views. Some of these parents were critical of the institution, others positive, and still others ambivalent. A number of parents—interestingly, all with male children—could not stand to visit the institution because they found it too disturbing. This appeared to be related to an inability to accept the child's handicap, and associated feelings of guilt for placing the child in custodial care. Mr. W., who repeatedly stated, "I just can't accept this thing" throughout the course of the interview is a clear example of the latter type of parent:

It's the atmosphere of the place. It is upsetting. I just can't go there. As long as they have those kind of people there, I won't go there if possible. Maybe I'm too sensitive. I feel guilty but I can't make myself change. It's so bloody hard for me to accept that one of my children should be in a place like that.

Other parents expressed relief and gratitude toward the institution for having accepted their child when they were "at our wits end" (Mr. C.). Thus they spoke positively of the work at the institution, expressing the belief that the child was "better off there, than at home" (Mrs. J.). The following comment is exemplary:

Hulle is daar onder hulle matjies. Hulle kry hulle regte opvoeding daar. Hulle kry allehande dinge daar wat nie hier gekry word nie.

Finally, some residential parents experienced ambivalence concerning the institution. They were grateful for finding a placement for their child, expressing the recognition that they could not have the
handicapped child in the home. However, many of these parents, and mothers in particular, felt guilty about placing their children in an institution. This is clearly reflected in the following extract from an interview with a mother of a 12 year old Down's girl:

You often think, if I'd had her at home, it would have been different. I could have given her more attention. She would have walked sooner, and it does happen. You see other little Mongols wherever you go and you see that this little child talks and walks like any other child. Wouldn't it have been the same if I'd kept mine? Then you feel so guilty. Maybe it could have been different ... but no .... I don't think I would have coped .... I don't know ....

(Mrs. V)

Although the present data lack clarity, and findings derived from the female residential sample must be viewed in the light of a possible bias, various themes were in evidence. In brief, differences are apparent between day-care and residential parents with respect to their feelings about their children's placement. Generally, day-care parents seem content with the centre, and believe it functions to reduce their stress. Residential parents, however, have mixed feelings about the institution to which they have committed their child. Only approximately one third of the latter parents felt content with their children's placement, whilst the rest experienced guilt, with associated increase in tension and stress.
6.3. STRESS: GENDER OF PARENT

Another of the major comparative variables in this study was the gender of the parent of the mentally handicapped child. The question was posed - do mothers and fathers of mentally handicapped children experience the same degree of stress, and is the nature of this stress the same for both parents?

The results of the parametric analysis of stress factors (for full discussion refer Chapter 5, Section 5.2.) consistently revealed no significant differences in parental stress, as measured by the global score and four sub-scales of the QRS-F. However, the findings of the depth interviews appear to contradict this. A number of trends became apparent which seem to suggest that mothers and fathers experience different types of stress and that, in general, both mothers and fathers perceive mothers to be subject to greater long-term stress than fathers. It is important to note that these findings are merely trends. They are therefore put forward tentatively and should be treated as speculative. Clearly, rigorous empirical research is necessary if greater claims are to be made.

The apparent difference between mothers' and fathers' stress must be made explicit. It appeared that fathers experienced greater stress associated with accepting that they had produced a deficient child. Over 50% of mothers reported that their husbands had suffered far more than they themselves had, when learning of the child's impairment.

One mother's comment gives some insight into this attitude:

It took F (husband) a long time to accept this.

You know it's different for a man. He doesn't carry the baby for nine months. He can't breast-feed. Biologically I think the mother is naturally
closer to the baby. That's why it's harder for her to reject it. However, for the man, who has a lesser part, it's easier to cut off and therefore more difficult for him to accept the retarded child. It's easier for him to say 'I had nothing to do with this, it can't be mine'.

(Mrs. P.)

Generally, mothers seemed to be able to accept their baby with less difficulty than fathers. However, since the major responsibility for the care of the handicapped child fell to the mother, most parents believed the mother to be under greater stress. This illuminates the differential stress mothers and fathers may experience - whereas fathers find it more difficult to accept the child, mothers experience greater difficulty coping with the daily schedule associated with caring for a mentally handicapped child at home.

Most parents had not considered the traditional allocation of roles in their homes; there was no question that the women would perform the nurturant and maternal duties. Some husbands were more understanding of the daily pressures with which their wives were faced than others:

I really admire my wife, for what she has achieved with D. For nine years before he went to the permanently, she dedicated her life to him. At least I could go out to work every day you know. It was much harder for her.

(Mr. M.)

I said to her in the beginning, look this thing is going to tie you to the house. But she wouldn't
give him up until recently. Now she's old before her time.

(Mr. Y.)

Some wives felt bitter that their husbands did not have to stay at home and care for what was usually a difficult child. Fathers left for work as the child was waking and returned home after the child had been put to bed, or shortly before his or her bedtime. Thus they were rarely exposed to the daily "drudgery" (Mrs. R.) of coping with the child. One of the day-care mothers expresses her frustration:

He goes to work, he gets out and has a break from this madhouse for the greater part of the day. I, on the other hand, sit here and wash and clean and feed, and more wash and clean and feed. By the time he gets home I'm too exhausted to move. I don't think he really understands quite what I have to do every day. (Mrs. B.)

Within the residential sample four mothers were not prepared to continue being "a nurse-aid for the rest of my life", as one mother put it. Consequently, the child was admitted to the institution. Mrs. L. explains her position:

I felt at that stage - now he's got to go. I did not feel anything in here. I'd had enough. He's got to go. I was going crazy. I'm not a housewife really. I was just in the house all the time. I never went out and R was driving me
mad all day.

Over one quarter of mothers felt that their husbands had chosen to work later after the child was born, or they had suddenly taken up a sport which would mean their leaving the house. Most mothers felt they themselves were not in a position to do similar things since the burden of child-rearing fell to them. Some mothers described their husbands as 'running away' - from household duties, and from the child, in that, as mentioned earlier, men seemed to experience greater difficulty accepting the deficit. Others felt that the responsibility for "keeping the family together" fell to them, whilst their husbands "did their own thing" (Mrs. P.). The following quotations are exemplary:

He plays golf on Sundays. I get little opportunity to get out of the house however. He's running away from T. He actually can't bear to be at home - because then he'll have to face T and he can't accept it.

(Mrs. W.)

Before M. went to __________ I hardly saw my husband. He found it difficult to accept that a child of his should be like that, so he avoided M. To avoid M he stayed away from home as much as possible ... whilst I bore the full brunt of the thing.

(Mrs. D.)
An extreme case is that of Mrs. N.:

My husband changed a lot after she was born. There were nights he'd never come home. He started drinking. One day he just never came back. For four years I didn't know where he was. Men can run away, it's easier for them to do so. They don't work with the child every day.

To summarise, the findings of the depth interviews suggest that fathers and mothers experience different types of stress in relation to their mentally handicapped child. Fathers appear to experience greater difficulty in accepting the child. This may result in their working longer hours, or remaining away from home in severe cases. More generally, fathers lived a 'normal' family life whilst "silently doing battle with the fact that he has produced an abnormal child" (Mrs. O.). Mothers, on the other hand, are perceived by both parents to be subject to greater stress. This may be attributable to the very direct nature of their source of stress, that is, coping daily with a child with demanding and special needs. Almost all mothers, both day-care and residential, had assumed full responsibility for caring for the child. Whereas residential mothers were freed from this responsibility once the child was placed in custodial care, most day-care mothers had dedicated a large portion of their life to the handicapped child.
6.4. STRESS: THE ROLE OF DEMOGRAPHIC VARIABLES

The role of so-called demographic variables was systematically analysed by quantitative means (Refer Chapter 5, Section 5.3.). Although it was not a focus of the depth interviews to tap data regarding these variables, certain themes emerged with respect to these variables which in part support the earlier quantitative findings. These are briefly reported here. It should be noted that these results remain tentative and should be interpreted with caution.

A number of parents who were classified as having high socio-economic status commented on how this had served to reduce the stress they experienced in relation to the handicapped child. It was apparent that financial assets allowed these parents access to a number of resources, such as full-time servants, educational toys, medical and recreational facilities, which other parents without financial means could not attain. These resources served to reduce parental stress in a number of ways, as following quotations illustrate:

If it wasn't for the full-time nanny we had, I would certainly not have coped. Whenever he was driving us mad we would call her and she would come and take him away.

(Mrs. S.)

You know, I think we're very lucky because we can do everything for this child. We know we're doing everything and therefore that she'll reach her full potential. That helps us. I mean we took her to Jo'burg, to Windhoek, to Germany twice for live-cell implants, to Switzerland for another kind of treatment. We know we've
done our best.

(Mrs. T.)

Parents of low socio-economic status explained how having a mentally handicapped child did not cause them much concern. These parents appeared to experience little stress in relation to the child and yet had limited financial resources. The following comments shed some light upon this:

Oh well, my wife and I only have a Std. 4 education. It doesn't matter to us that K is slow. We didn't do so well ourselves! What difference does it make so long as she's happy.

(Mr. W.)

Look, he's a little behind but when he's old enough he can come and work at sheltered employment. If it's good enough for me, it's good enough for him.

(Mr. R.)

A second factor of significance to parental stress was religious conviction. All parents who described themselves as holding firm religious beliefs felt that religion had played a major role in their coping with the mentally handicapped child. Religion seemed to offer some parents an explanation for the child's handicap, as Mr. V's comment reveals:

We see this as God's will. God has chosen us to care for this special child. We, in a sense, are honoured to do His will.
Other parents described how religion provided them with an attitude towards crises in general, rather than offering a specific explanation:

"It is not our place to question God, to ask 'why me?' God will give us the strength to cope with this thing if we look to Him.... He has given us strength, without God to guide them. I don't know how other parents cope."

(Mrs. B.)

In short, parents who held firm religious beliefs had found strength and hope in their faith, and appeared to experience less stress in relation to the handicapped child than parents for whom religion was not significant.

A third 'demographic' variable which appeared to be associated with parental stress was the previous personal history of parents. That is, parents who reported experiencing psychological difficulties in the past, appeared to experience greater stress in relation to the handicapped child than parents who reported no such personal history. The following quotations are exemplary:

"I was always a nervous person. I'd had a couple of nervous breakdowns before H was born. Now I'm doubly nervous."

(Mrs. G.)

"My husband always had problems, he's had ECT and been to the mental hospital. Since we found out L was retarded things have got worse. He's so bad now, they've laid him off work - early retirement they called it."

(Mrs. A.)
In summary, certain trends became apparent during the analysis of the interview data with respect to three demographic variables: socio-economic status, religious conviction and personal history. The number of participants upon whom this data is based, is however, small since these variables were not the focus of the qualitative study. For this reason, these findings should be regarded as speculative.

6.5. THE ROLE OF SOCIAL SUPPORT

Research interest over the past decade has focused upon factors such as social support and coping strategies that may ameliorate the impact of stress (Kessler, Price & Wortman, 1985). The rationale behind this shift is that chronic stress situations are implicated in the development of psychopathology; and yet not all persons subjected to intense stress develop significant psychological disorders (Leavy, 1983). Consequently the role of buffer (Thoits, 1982) or moderator variables (Antonovsky, 1974) has come under increasing scrutiny.

The conceptual model proposed by House (1981) forms the theoretical framework within which the notion of social support is considered in this study. As mentioned earlier House identifies four types of support behaviours: emotional, instrumental, informational, and appraisal support. Through these, the person receives guidance and feedback from others which enables him or her to emotionally master a stressful life episode (Caplan, 1974). The present author further differentiates between two major sources of support. These are:

(a) 'Intimate' support i.e. from persons with whom the individual has a close relationship, such as spouse, children, close family and friends; and

(b) 'Public' support i.e. from persons with whom the individual may be acquainted, but maintains a distant relationship, such
as members of the general public, medical professionals, and others involved in the provision of social services.

Different sources of support may offer different types of support. Thus, those individuals, classified as 'intimate' sources will probably provide greater emotional support than persons who would be regarded as 'public' sources. For the purpose of the following discussion, the data will be discussed in terms of these various sources of support.

6.5.1. Intimate Sources of Support

6.5.1.1. Marital Partner

The marital relationship incorporates what is frequently viewed as a major potential source of support - support from spouse. The birth of a defective infant, or later discovery of the presence of handicap in the child, may have a substantial impact upon the marital relationship of that child's parents. This may in turn affect the quality of support each partner can offer to the other.

Approximately one third of parents in this study reported that their marital relationship had, in general, improved since the detection of mental handicap in their child. These parents spoke of 'ups and downs' initially, but felt that this traumatic experience had ultimately brought them closer together. Comments such as the following are exemplary:

Like any major knock I think it drew our family closer together, our marriage has gone from strength to strength.

(Mr. V.)
He (husband) was the strong one. He's my old rock. I don't know what I would have done without him. We've got so much nearer to one another through this.

(Mrs. S.).

Most of these parents had managed to keep their child within the family circle, and he/she attended a day-care centre. In fact, only one couple from the residential sample spoke of the child's bringing them closer together. They had, against their will, been forced to place their child in custodial care through economic necessity.

Parents who found the handicapped child a disruptive influence to both marital and family life, placed the child in residential care in most cases. This was characteristic of the greater percentage of the residential sample. The majority of these parents reported an improvement in the quality of their marriage following the child's placement:

Ons huislike lewe is nou baie beter. Haar senuwees was op, my senuwees was op. Ons was van mekaar af. Jy kommunikeer nie met mekaar nie. Ons was gedurig op die vaak. Jy's nooit gerus nie. Jy lewe jy en jou vrou verby.

(Mr. L., father of 2 Down's boys)

Thus, by placing the child in permanent care, familial stability was reported to have been restored. Parents also commented that they felt more capable of coping with daily life, and of supporting one another.

All parents interviewed in this study spoke of at least some period for which their marital relationship was adversely affected. This
lasted from three weeks to as long as six years before the marriage was reported to stabilise. On average parents spoke of a period of six months to two years before they felt a sense of equilibrium return. The most common reaction reported was that the wife, particularly, "felt cold" and was withdrawn for a time. Both parents, however, expressed feelings of numbness and shock, during which they felt immobilized and unable to support one another.

Some couples, i.e. approximately one fifth of the total sample, felt that the handicapped child had irrevocably damaged their marital relationship. Interestingly, the greater number of these were parents who had kept the child at home. Four of the latter couples had divorced, the mother taking custody of the child in each case; while the remainder maintained distant and strained relationships with their husbands, but had no intention of pursuing divorce proceedings. The following quotations are illustrative:

My husband wasn't prepared to accept the child. Eventually he gave me an ultimatum - him or the child. As I said to him, he's big enough to look after himself, the child needs me.

(Mrs. G.)

This thing has really affected us. We are like two strangers in this house ....

(Mrs. J.)

In summary, it would seem that where the marital relationship withstands the impact of the handicapped child, it remains in nature supportive. Usually the child is kept within the family domain, and parents report
increased marital harmony. By contrast, where the marital relationship degenerates and becomes largely unsupportive, one of two things may occur. The parents may place the child in residential care, and thereby hope to restore stability to their marriage and to family life. Alternatively, parents may continue to keep the child at home despite difficult circumstances. This again may lead to one of two things - divorce, or the continuation of an unhappy marriage. Both parents usually then seek support and relief from persons other than the spouse.

6.5.1.2. Siblings of the Handicapped Child

The mentally handicapped child has considerable impact upon his or her family. Although much has been written regarding the effect of the handicapped child on his or her parents, the impact of the child on the life of his or her siblings is also significant. This subject has, however, received less attention to date (Fischer & Roberts, 1983). There is evidence to suggest that siblings of the handicapped child, particularly older female siblings, may provide support to their distressed parents (Cleveland & Miller, 1977). In the case of very young siblings this is not feasible and normal children may, on the contrary, serve to increase parental stress.

Parents in this study described several 'types' of relationships between siblings and their handicapped brother or sister. These different relationships were regarded by parents as either ameliorating household tension, or, in other cases, as contributing to domestic stress.

Nearly one third of parents in the day-care sample spoke of a close and caring relationship between siblings and the handicapped child. Siblings involved in this kind of relationship tended to be female
and older than their handicapped brother or sister. Mothers, in particular, found such relationships a source of support in that these siblings willingly assisted in the daily care of the handicapped child. The importance of sibling support is clearly reflected in the following comment made with regard to a seven year old female who assisted with the care of her five year old Down's Syndrome brother:

Without her I don't think we would have achieved what we have with D, without her help. She loves her little brother, she knows that he is different and yet he is everything in her little life. She's like a little mother to him. When they go to a party for instance she knows its her duty to take care of him.

(Mrs. P.)

Most siblings in this category also offered to care for the handicapped child when their parents were no longer capable of doing so. Thus they displayed a preparedness to assume full responsibility for their brother or sister in the future. Parents, although in general not wishing that the handicapped family member should be the other children's responsibility, found their positive attitude reassuring and supportive. These siblings therefore not only assisted with the routine tasks associated with caring for the handicapped child, but showed a sensitivity and empathy for their parents' situation. This quality of relationship is not possible in families where the child is in custodial care.

Approximately half of the parents in each sample (residential and day-care) reported that siblings 'accepted' the handicapped member, but largely ignored him or her. Parents described a neutrality of affect - siblings displayed no overtly negative feelings towards their
handicapped brother or sister, they merely continued with their own lives as if he or she did not exist. In the day-care sample these children rarely assisted in caring for the handicapped child and offered their parents little emotional warmth or support. The parents in turn reported feeling 'guilty' about the impact of the handicapped child on the family. They felt it 'unfair' to ask the other children to assist with their handicapped brother or sister; the reason for this attitude being that the home situation was not 'normal' as a result of the handicapped child's presence. By not demanding the siblings' involvement, some parents felt that the children could lead lives which came closer to approximating normality. The following comment by Mrs. S. is exemplary:

The children don't object to him, they're neutral really. They have, on occasion, said they'd be prepared to look after him but parents are more realistic. They've got their own lives to lead and it's not really fair to impose this on them.

A number of parents who described their other children as being neutral or indifferent to the handicapped child, noted an improvement in sibling-handicapped child relationship following the placement of the handicapped family member in residential care. Siblings were said to have become more involved with their handicapped brother or sister. When he or she came home for the day or weekends, they assisted with feeding, dressing and bathing the child and some siblings even began to actively attempt to involve their handicapped brother or sister in play. Mr. R. explains how his other children reacted:

They're happy to see him now. Before he was a constant irritation to them. Now they are more
accepting of him because they know he's going back to _____. They actually go out of their way to be with him when he's here now. In the old days they just ignored him.

The majority of parents in this study reported some period during which difficulties with siblings were encountered. In general, these problems were said to be minor, of short duration, and attributable to the onset of adolescence. Siblings were reported to feel self-conscious about bringing friends home because of the presence of their retarded brother or sister. Mrs. E. cites a typical example:

She used to say to me 'Mommy, keep T in the kitchen. I don't want him in my room when my friends are here'. She suddenly just became very aware of his being different. Obviously at that age they're worried about what their friends think. Are they acceptable to others? I knew it was just a stage and did my best to oblige her wishes.

In approximately one fifth of cases parents felt that siblings had been a considerable source of additional stress. Prolonged periods of disruptive behaviour, lasting from two to six years were reported. Most parents believed that their 'normal' children had grown to resent the presence of the handicapped child and, in particular, the excessive attention he or she received. Some children, for example, refused to bring friends home due to their embarrassment of the 'abnormal' family member and two had begun to remain away from home as much as possible.
In a number of families parents decided to place the child in residential care in an attempt to restore familial harmony. Where this was the case, family life was reported to have benefitted and relationships between members improved. In those families where the child remained at home, parents continued to try to 'keep the family together'. In two cases, parents believed that only once the other children had left home would family life improve.

In summary, siblings of the handicapped child may be a source of support, or a source of additional stress to their parents. Where siblings assume a supportive role, the family appears to function adequately, and, in general, the handicapped youngster remains within the nuclear family. By contrast, where siblings are largely unsupportive of their parents' plight, parents experience greater stress, with two effects. In some cases this precipitated the placement of the handicapped child in residential care. Following placement some stability was reported to return to family life. Alternatively, in instances where the handicapped child remained within the family, and siblings are largely unsympathetic, the stability of the family continues to be threatened.

6.5.1.3. Members of the Extended Family

The extended family of parents of a mentally handicapped child may be a continued source of support to these parents. Extended family is used in this context to refer to the parents' own parents, brothers, sisters and other family members, to whom they feel particularly close. The reactions of such significant others in a person's life to a major event, such as the birth of a handicapped child, usually play a role in influencing that person's own reaction to the event.
The results of the present study indicate that over one third of the total sample of parents reported having considerable support from their extended family. The majority of these parents were, however, from the day-care sample. They felt that most family members had reacted positively to the handicapped child and entirely accepted him or her. Parents reported being given encouragement during difficult periods, and reassurance of their family's own commitment to support and assist them. Knowing that people 'who meant so much' to them were prepared to stand beside them through the crises had, parents believed, increased their own confidence to cope with the situation.

A number of parents reported that the presence of the handicapped child had served to bring the family closer together. The following statement, by Mrs. B., is exemplary:

They completely accepted him for what he is, right from the start. Our parents were tremendously supportive. I think that time consolidated my relationship with my in-laws, because I can never forget how wonderful they were, how marvellous at the time ... and since.

Not all parents reported such positive experiences however. Over one third of those in the residential sample felt that their extended family had been largely unsupportive. Some believed that members of the family had never accepted the handicapped child. In one case, for example, the parents of a nine year old Down's boy could not visit the child's paternal grandparents. Apparently the couple refused to accept their 'abnormal' grandson, and had gone so far as to tell their friends that the child had in fact died shortly after his birth.
Other parents described their families as being 'indifferent to', or 'uninterested' in, the handicapped child. Thus, although they were not directly negative toward the youngster, they avoided contact with the child and rarely spoke about him or her. Parents found this attitude on their families' part distressing, and most expressed a desire for greater support from people 'who should care'. Mr. G's explanation of how his mother reacted is illustrative:

"My mother just denies the whole situation. She never refers to the child. It's off limits. The people who really mattered were no support at all."

Parents whose extended family was largely unsupportive reported feeling considerable conflict. The people to whom they felt they should be able to turn, in spite of difficult circumstances, had 'renounced' them. As a result, some parents felt torn between their child, who had caused such disruption in their lives; and their extended family, who had "shunned their own flesh and blood because it was not perfect" (Mrs. F.).

Almost one fifth of parents had been advised by their families to place the handicapped child in a 'home'. Some parents had ultimately taken their parents' advice and placed the child in custodial care, although only when the stability of family life was threatened by the child's presence. Others were adamant that their children would remain part of the nuclear family. The following extract from an interview with Mrs. C. reflects how parents feel when their families offer advice which lacks sensitivity and understanding.

"I haven't had the kind of support from my family that I would have liked. I've actually been..."
advised by them to put him in an institution because 'he'll ruin my life and my marriage'. I've had that advice from my own bloody parents. Sensitive aren't they? I ask you, why should I put him in a home, he's in a home, one to which he rightfully belongs.

Relationships between parents like Mrs. C., and their extended families, were reported to become increasingly tense due to mutual misunderstanding and lack of communication. In four cases, parents rarely visited their family as a result.

In a small number of cases parents felt that although their extended family was supportive, the nature of that support was inadequate. The primary complaint was that family members did not fully appreciate the permanence of the handicap, and were therefore naively optimistic about the child's future development. Parents were reassured that the child would 'regain lost ground' and was merely a 'slow starter', for instance. This lack of insight into the child's condition, and by implication lack of understanding for the parents' position, was a source of much pain and frustration to parents. Mr. G. explains how his parents responded.

They said to us, maybe it'll wear off! Maybe she'll grow out of it. They still really don't appreciate the finality of the thing. She has Down's Syndrome! Even so, they are trying to be supportive and give us encouragement.

In summary, the response of the extended family to the handicapped child is significant to the parents of that child. Where parents received positive support and encouragement from their family, they
generally reported feeling better able to cope. The handicapped child usually remained within the nuclear family, whilst the family as a whole took responsibility for him or her. In certain cases, the extended family attempted to be supportive but through their lack of insight tended to 'say the wrong things' (Mr. K.). Despite the frustration this caused parents, their efforts were appreciated by parents, particularly at the level of instrumental support (House, 1981).

Where the extended family was largely unsupportive, most parents experienced conflict. They felt torn between the handicapped child and the extended family. Some parents eventually placed the child in residential care, thereby gaining the tacit approval of their parents. Others continued to keep the handicapped child within the family despite the opinions of the extended family. The resultant tension between nuclear and extended family caused relations to be severed in some cases.

6.5.1.4. Friends

The benefits derived from intimate social relationships have long been established (Argyle & Henderson, 1985). For many, friends fulfil the function of counsellor, when they are experiencing difficulties. In South Africa, in fields like mental handicap, where social services do not provide an adequate network of care, the role of friends in assisting with problems may assume greater importance.

The findings of the present work revealed an interesting difference between day-care and residential parents, with regard to intimate social relationships. With only a single exception, every couple from the day-care sample spoke of caring and close friendships with others. In the residential sample, however, only a third of parents reported similar relationships.
Parents involved in intimate friendships reported that their close friends had offered immediate comfort and support on learning of the mentally handicapped child. Some parents spoke of their friends also mourning the tragedy of the child's defect. Many friends assisted with basic tasks, particularly in the early months, such as supervising the other children where there were older siblings in the family. The element of primary importance to parents in these relationships was, however, their friends' unconditional acceptance of them, and also therefore their child. Parents spoke of a 'quiet warmth' and an 'implicit understanding' which friends could offer, but which close family could not.

Mr. S. explains his perspective:

Our friends were just there. They sat, they helped, they talked when we wanted to. They basically carried on with things but we felt their presence very strongly. If we needed them they would have dropped everything else. Family can't be this objective, they're too close, too involved.

In some cases, friends not only provided support to the family, but affected their response to the mentally handicapped child. Thus, the reaction of friends to the child, directly influenced parental adjustment to their handicapped son or daughter. This is clearly illustrated in the case of Mr. O.:

If it wasn't for the neighbour I don't know what we would have done. If she hadn't accepted the child I don't know, I would surely never have accepted it. She made us realize that you don't have to put it in a box and hide it away.
The remainder of the parents in the residential sample, i.e. two thirds thereof, spoke with mixed feelings about friends. At least half felt that they were relatively socially isolated and in fact did not have a close friend to whom they could turn for support. A few couples attributed this lack of friends to the presence of the handicapped child. The latter reported that friends gradually ceased visiting after the deficit was recognized. The child's behaviour and special needs also made it difficult for the family to go out. Although parents were free to socialise following the child's placement in an institution, they had by this time lost contact with friends and therefore remained socially isolated.

Other residential couples had maintained friendships but felt awkward in company because of the child. These parents experienced difficulty in taking the child out with them since they felt that friends were uncomfortable in the child's company. Consequently they rarely visited friends and did not invite friends to visit them at home either. Once the child was institutionalized these parents commented that they wished to rekindle friendships, but this was not possible as a result of the history of their relationship with those friends. Mrs. I's experience is typical:

We never went to people because they didn't actually want her. It's made it very difficult in terms of social life. People got agitated with her, you could see it. It makes you uncomfortable. Even now she's there (in the institution) I can't phone these people, not with them sitting and thinking .... I don't know what.
Most parents who lacked intimate social relationships expressed regret at this, feeling that with more adequate support from friends they may have coped better during times of crisis. A number of these couples were in fact so socially isolated that they felt the interviewer's contact was the first sign of friendship they had experienced since the child's birth - this was as much as 16 years earlier in one case.

In summary, it would seem that friends may play an important role in supporting the parents of a mentally handicapped child. The nature of this support extends from assisting with daily tasks to facilitating the parents' process of adjustment to the child. Moreover, the type of support offered in intimate friendships seems to encompass more than that given by family in that friendships provide space for some objectivity not possible within close family ties.

Where intimate social relationships did not exist, particularly within the residential sample, parents seemed to experience greater difficulty coming to terms with the child. No causal relationship should be inferred, however, without further evidence. Nevertheless, the data seems to suggest the correlation of certain factors, namely parental insecurity regarding the child's abnormality, feelings of unacceptability and the lack of intimate friendships - and by implication support.

6.5.2. Public Sources of Support

6.5.2.1. The General Public

Western capitalist society does not look with favour upon those members who are unproductive and therefore cannot contribute to its smooth running. The mentally handicapped fit the latter description.
Almost all parents, that is, with only one exception, felt the attitude of the general public toward the mentally handicapped to be negative. The majority of parents thought the public 'uneducated' and 'misinformed'. Through their lack of understanding they are seen to be insensitive, and even 'cruel', when confronted with a mentally handicapped person. The resultant stigma has repercussions for that individual's family. A number of parents, for example, had ceased to take the child out and had thereby themselves become housebound. This was particularly so for parents whose child's physical appearance was unnatural, and/or those whose children were behaviourally disturbed. In extreme cases this was one of the deciding factors in placing the child in residential care, as Mrs. V. explains:

I just couldn't bear to take her out. I just couldn't cope with it. People staring and passing remarks. So I stayed in the house all the time. I became totally housebound. Eventually I said to my husband either she goes there or I do.

A number of parents reported that members of the public seemed unable to distinguish between mental retardation and mental illness. The experience of Mr. J. is typical:

The public can be very cruel. They say things around here like: 'hulle het 'n mal seun, 'n seun wat nie heetemal reg in die kop is nie ... ópas vir hom ... hy's gevaarlik'.

The publics' inability to differentiate between mental retardation and mental illness provides the basis for the development and maintenance of myths regarding persons in both categories. This stems
firstly from lack of contact with people who are 'abnormal' and secondly, from the paucity of coverage 'abnormality' receives. A number of parents felt that greater use should be made of the media in educating members of the public, thereby gradually dispelling the myths and eliminating the stigma.

Parents thus experienced the attitude of society at large as unsupportive and uncaring. This negative attitude compounded the difficulties they already faced. Most parents felt that society was attempting to place the blame on them, as individuals, and was thereby saying "this is your problem, you look after it" (Mrs. C.). Not only was the full responsibility for the child theirs, but moreover their child was unacceptable and had few rights. The following quotations are illustrative:

I think the public must realise that a handicapped person IS a human being, one who is entitled to a life.

(Mr. B.)

People, when faced with a handicapped person tend to withdraw. They don't want to, society doesn't want to, acknowledge their existence. They'd rather deny it. They are in one sense part of society and yet they aren't really accepted by society.

(Mrs. M.)

Parental response to the lack of support forthcoming from broader society differed depending upon their feelings toward the handicapped child, and the availability of support from intimate sources. Those parents who felt sensitive about their child's condition, and had
little support from intimate relationships seemed to be more severely affected by societal attitudes. The majority eventually placed their child in permanent care. Parents who accepted the child, and who were involved in supportive relationships were generally less sensitive to public opinion. Most of these parents had managed to keep the child at home.

In summary, these findings suggest that the role of the general public may be of greater significance than at first assumed. It would seem that, in general, parents of handicapped children experience the public to be unsupportive and largely unconcerned. In particular for parents who themselves are experiencing difficulties accepting the child, and a lack of intimate supportive networks, this 'hostile' attitude serves only to compound their difficulties.

6.5.2.2. Medical Professionals

Medical professionals fulfil an important role in society - primarily the assessment, diagnosis and treatment of illness. However, more than this, doctors and their colleagues should be sensitive to their patients' needs and fears (Lipton & Svarstad, 1977). For this reason an ability to relate and communicate with others is important, as are the qualities of empathy and understanding.

All parents in this study felt that medical professionals were inadequately trained in human relations. Most parents experienced some difficulties with doctors, or other medical personnel, during the history of their children's conditions. The greater proportion of these had occurred when a diagnosis of mental handicap was made. Two major criticisms were levelled at medical professionals' handling of communicating devastating news.
Firstly, almost all parents believed that doctors did not possess the necessary skills to convey such information. Doctors were seen to be clumsy and insensitive, and often thereby caused the parents greater emotional stress than was warranted. This was particularly so where doctors imposed their own understanding of the phenomenon upon parents. Mr. A's personal experience is illustrative:

The way they explained it to me wasn't ... very diplomatic. They gave me some religious explanation. 'God decided this is yours because you are special! Here, now take it and get out.' I could have strangled the bastard.

There was no comfort, no help, no discussion ....

It would appear that doctors themselves are often traumatized by the presence of an 'abnormality' in a child and that this results in their 'insensitivity'. However, most parents remarked that they should be better equipped to deal with sensitive issues, both at the time of informing parents, and later, to offer guidance and support. A number of mothers, in particular, reported feeling largely unsupported by medical personnel during their stay in hospital, following the infant's birth. Hospital staff purportedly avoided these mothers, probably because of their own discomfort and feelings of inadequacy. Other negative hospital experiences were also common, for example, at least five mothers were informed of the child's defect whilst alone. On the whole parents believed that medical professionals had exacerbated their trauma, rather than proved to be a source of comfort and support.

The second major criticism parents had of the manner in which they
were told of the infant's defect, centred around the information they were given. Most parents (approximately four fifths) complained of being informed of very little regarding the nature of the child's condition, its aetiology, and prognosis. Some complained that although doctors had come directly to the point in making a diagnosis, they had offered no further explanation or information. Moreover, their manner was often described as cold, clinical and even brusque. The following quotation is exemplary:

He (the paediatrician) was very straight about it. He certainly didn't beat about the bush or anything. He just marched across to me and said, look this is the position. Bang, bang. One, two, three - it was all over and I was left standing speechless.

(Mr. K.)

Other parents were informed by doctors who were less clinical, but also failed to provide them with the basic facts. The latter appeared to be trying to break the news gently, but were ultimately vague and unhelpful. Mrs. L. explains the effect this had upon her:

They give it to you in bits and pieces, not to shock you, I think. Instead you get more anxious - not knowing what's going on. They waffled on and on. I think they should tell you gently, but explicitly.

Over one fifth of the sample in this study reported being given advice whilst they were informed of the child's defect. The most frequent form this advice took was that parents should place the child in
custodial care. With somewhat lesser frequency, parents were informed that the reason institutionalization was recommended was because the child was only a 'vegetable', 'cabbage' or some other derogatory name, which would disrupt their lives, marriage, the lives of their other children and so forth. In a number of cases it was even suggested that the parents forget about the existence of the 'abnormal' child and try to have another as soon as possible.

All parents felt that doctors had no right to give advice in this manner, and found the experience to be unbeneficial. One father, himself a doctor, had the following to say of his colleagues:

I think they need a vast amount of education. They are not given any guidance in sensitivity and understanding. I know my colleagues shy away from it. Their counselling is well-meant but misguided. You have to go at the mother's pace and stay with it. You can offer alternatives when she's ready but you can't tell her what to do; especially since most doctors don't really understand the impact such a child has upon the family.

Finally, parents unanimously expressed concern about the gulf between themselves and medical professionals. At least one third of parents perceived them to be unapproachable - for two reasons. Firstly, doctors were seen to be very busy and highly pressurised, and parents were reluctant to request more of the doctor's time. Secondly, doctors were viewed as intellectual and 'operating at a different level'. As a result some parents felt 'too stupid' to contact the doctor to clarify points of confusion. This perception on the
parents' part inhibits the supportive function medical professionals may play. However, some parents believed that doctors themselves encouraged and upheld the latter image. This serves only to increase the alienation between parents and doctors, as the following comment by a mother, herself a paediatrician, illustrates:

What the medical profession needs is more empathy and less thinking that because society expects doctors to know everything and play God, they should do so. They should be able to say 'look, I don't know, I can try and be with you through this, but I'm not sure.' They should come down from that very shaky pedestal and be with their patients.

In summary, the relationship between the majority of parents in this study, and medical professionals, appears strained. It would seem that at all levels of dealing with parents of the mentally handicapped, present medical training is inadequate. As in other countries, doctors in South Africa receive relatively little instruction in mental handicap, despite the fact that general practitioners inevitably will have to deal with mentally handicapped people and their families (Ryan, 1980). Moreover, they receive almost no training in the psychological aspects of illness; that is, in the effect that illness has upon the individual and her family. Consequently, most medical professionals handle sensitive issues with difficulty.

Thus, the potential role of doctors and other medical personnel in guiding and supporting their patients through periods of medical-related crisis, is not being realized. At present this is, in part, being maintained by the predominant image of medical professionals as 'demigods'; and by the medical professionals themselves who feel
 honour-bound' to uphold their status.

6.5.2.3. Social Services

The availability of social services in a given community is clearly of benefit to its members. Most social services offer advice, guidance, care and support. With the increasing emphasis upon caring for the mentally handicapped child at home, and a de-emphasis on custodial care, the supportive role of services in the 'community' becomes more important. Parents seek services which reinforce rather than replace their efforts to care for their own children (Ayer, 1984).

All parents in this study reported some degree of dissatisfaction with services for the mentally handicapped. Most felt that, compared to other countries, the facilities available in South Africa were inadequate. With one exception, all parents stated that there were too few services. Experiences of long admission waiting lists and difficulty in placing the child, in either day-care or residential care, were common. Those who could not afford to pay fees had experienced greater difficulty in finding suitable care for their child. Without financial means and aware of the few places available to them, a number of parents felt it unwise to pass up any opportunity for care. They reported feeling 'without a choice'. Thus, when these particular parents were offered a place in the institution in this study for their child, they thought it unwise to refuse, although they were not satisfied with the type of care he or she would receive there. Mrs. E's experience is exemplary:

I was really battling with S all day at home.
We were on waiting lists everywhere. The problem is we're poor. We can't pay much. Eventually I was tearing my hair out. Then they offered
us a place at _______. Although I don't like the place we took it. I just couldn't stand it anymore and who knows when we would have got her in elsewhere.

Approximately 50% of parents believed the State should play a greater role in the provision of social services. They expressed regret that, at a time when quantity of services is insufficient and quality in general poor, the government should effect tremendous cut-backs on spending in this sphere.

Most parents felt the present trend, which regards the home as the main locus of care for the handicapped child, to be positive; with the proviso that adequate services were available. Day-care families believed that with better services in the community they would be under less stress. For example, most parents could not go away for a holiday or even a weekend without the handicapped child. However, to take the child with them was, for many, "worse than not having a holiday at all" (Mr. C.). Thus, the greater number of parents never went on holiday, and felt therefore that they "never had a break" and were "constantly tense" (Mrs. D.).

A second concern of the day-care families was the fate of the child should the parents suddenly die. These parents were unanimous in this fear. The lack of assurance of finding a placement at short notice was a source of continual worry. These parents not only felt concerned about coping with their child on a daily basis, but were also concerned for his or her future. Some parents had therefore made arrangements, in the event of their deaths. This usually took the form of trusts and policies, and most parents had requested a close family member or friend to take charge of the situation. Other
parents had made no final plans, particularly where they themselves were still young. Their attitude was generally "we'll get round to it when we're a bit older" (Mr. S.). Interestingly, a few admitted that they would probably place their child in permanent care at some later stage.

Clearly parents in the residential sample do not share either of the above concerns. The handicapped child does not reside at home and therefore the family may take a holiday at any time; and secondly, were the parents to die suddenly, the child's continued placement in the institution is assured. Nevertheless, residential parents were also affected by the lack of adequate services in the community. A number of these parents felt that given better facilities they would probably not have placed their child in custodial care. Many mothers and fathers had put the child in the institution because they could 'no longer cope'. However, it was stated that if they had had better support from services they would have preferred to keep the child at home. For example, parents expressed the desire for facilities where they could have sent their children for a weekend, or the school-holidays and thereby given themselves a break. Mr. R's experience is illustrative of how some of the parents felt:

The State should have a different attitude - saying try to keep your child at home for as long as possible but if at any time you need to place the child in a centre, there is a place for them. I think more of us would be prepared to keep the child then, knowing there was a back-up if one needed it. If this was available I definitely think we would have kept M at home.
Almost all parents in this study felt that where services were in existence, they were operating poorly. Parents spoke of two problems. Firstly, services were inevitably operating beyond their maximum capacity; and secondly, due to bureaucratic inefficiency, they were operating uneconomically. Most parents felt that there was little communication between the different services. Thus, families transferred from one facility to another had to repeat personal histories, the previous medical history of the child and so forth. This unnecessary duplication of procedures was considered a waste of time to parents themselves and to the staff concerned. Mr. Q., himself an active member of various organizations for the handicapped, put forward the following opinion:

There's no link between services. There should be a continuous routing, for instance, from hospital social worker to day-care or institution social worker. The social workers should know and explain the alternatives open to the families. Each centre should know what is going on in the others. Procedures are duplicated unnecessarily. Parents go through the whole history at each new place when it's all in the file anyway!

A number of parents envisaged a network of social services, with a central co-ordinating body, as a viable solution to the inadequate nature of the present services. They believed that if such a structure was possible existing services would be more economically utilized.

Finally, almost all parents complained of being unaware of what services are available to them. Approximately 50% had heard of the centres which their child attended 'by word of mouth'. Only 10% felt
confident about what was available for their child in the Cape Province. Parents felt that doctors and other medical professionals should be able to explain to parents what services there are or at least refer parents to someone who does know. The following comment by one mother is exemplary:

I ask you, how does one know what is available? No one ever said to us, there's this and this and that. We've had to hear via the grapevine of this place. It's unbelievable. You really are out there on your own. You feel like you are in a vacuum, that no one else has the same problem because no one tells you anything, where to go.

(Mrs. V.)

In short, the greater majority of parents were dissatisfied with present social services. Families who could not afford fees appeared to experience the greatest difficulty in finding an adequate day- or residential-care facility for their handicapped child. Most parents felt that there were insufficient services to meet the needs of families with handicapped children. Others felt that existing services were run inefficiently. Parents almost unanimously felt that the range of services available was not well advertised. Generally, this lack of supportive facilities in the community appears to be a factor contributing to parental stress. Ironically, services are presumed to fulfill an ameliorative role; yet this research would suggest that this may not always be the case.

It must be noted that the above discussion was levelled at services in general. Both residential and day-care parents expressed gratitude
towards the present centre in which their children were placed. Parents were relieved that their children "were in good hands" (Mrs. W.). The day-care parents in particular were satisfied with the nature of attention their child was receiving. (Refer Section 6.2. for full discussion of specific services.)

6.6. CONCLUSION

This chapter has examined the qualitative findings of the present study. Certain of these findings lend support to the quantitative results described earlier (Refer Chapter 5). Some shed greater light upon the quantitative findings, whilst still others raise entirely new issues.

The earlier findings with regard to the demographic variables of socio-economic status, religious conviction and personal history were, in part supported. Families with a high level of socio-economic status felt that their considerable financial resources had served to ameliorate their stress in relation to the handicapped child. Some families described religion as being of major significance in their coming to terms with their child's handicap whilst others felt religion played a nominal role, or no role at all. Mothers and fathers who reported serious psychological difficulties in the past appeared to be experiencing greater distress than other parents.

The qualitative analysis shed greater light upon the interaction effect of the variables gender of child and type of care. Trends in the data revealed that parents experienced greater difficulty in accepting the mental handicap if the child was male. Furthermore, parents who had committed their child to permanent residential care appeared to experience feelings of guilt and inadequacy with greater frequency than parents of day-care children. Day-care parents reported stress
associated with the daily routine of child-care.

The non-significant difference in parental stress between mothers and fathers was not substantiated. Patterns of difference between mothers' and fathers' stress emerged. Maternal stress was predominantly associated with coping with child on a daily basis, whereas paternal stress appeared to be significantly related to difficulty in accepting that the child was handicapped.

Findings pertaining to the role of 'intimate' sources of social support highlighted the significance of this factor in ameliorating or exacerbating parental stress. Parents who received positive support from an intimate source generally reported feeling better able to cope with the handicapped child. On the other hand, parents who received negative social support, or perceived intimate social relations to be unsupportive, more frequently expressed feelings of being unable to cope, associated with increased stress.

The qualitative findings with respect to 'public' sources of social support were overwhelmingly consistent. Parents unanimously perceived the general public as holding negative attitudes toward mentally handicapped persons. Medical professionals were generally regarded as unskilled and insensitive in dealing with parents of handicapped children. Furthermore, almost all parents were dissatisfied with the nature of existing social services. The general lack of support provided by these potential sources of support, served to compound the difficulties parents faced and increase the stress they experienced in relation to the handicapped child.
CHAPTER SEVEN
DISCUSSION

7.1. INTRODUCTION
Throughout the previous chapters the course of the present study has been described. The pertinent literature has been reviewed, the methodology expounded and the results made explicit. In this, the final chapter of this work, the findings will be interpreted with particular reference to implications for future research, and bearing in mind the limitations of this study. An initial section of this chapter is concerned with summarising the major findings, thereby simplifying the complexity of results set out in Chapters 5 and 6.

7.2. SUMMARY OF RESULTS
The findings of the present research were gleaned from a careful analysis of both quantitative and qualitative data. With respect to certain areas of investigation, quantitative and qualitative sources of data corroborated one another, whilst in some areas neither source informed the other, and in one instance quantitative and qualitative sources appeared contradictory. Due to the dual methodology employed in this study a wealth of data was collected, and it is therefore the purpose of this brief section to summarize succinctly those findings which are of greatest salience.

Quantitative analysis, and the concomitant use of inferential statistics allows the researcher to generalise the results of the sample to the population at large (Miller, 1984). This is not possible, with any degree of certainty, where solely qualitative methods have been employed. Applications of both methods, however, yields a breadth and depth of data neither method could attain in isolation. For this reason the findings regarded as being of greatest significance in
the present study are those which are the product of both quantitative and qualitative analyses.

7.2.1. Gender of the Parent

Quantitative and qualitative findings revealed contradictory evidence with respect to the relationship between the variables gender of parent, and parental stress. The results of several parametric analyses showed no effect due to gender of parent to be in evidence. In contradiction with this, trends highlighting differences in the perceived degree, and nature, of stress experienced by mothers and fathers of mentally handicapped children emerged from the qualitative analysis.

Both mothers and fathers perceived mothers to be subjected to greater stress than fathers due to the demands placed upon them as the primary caretaker. It was not possible from the qualitative analysis to ascertain whether mothers actually experienced greater stress than fathers. It was, however, apparent that mothers and fathers experienced different types of stress. Maternal stress seemed to be a function, primarily, of the daily "burden of care" (Tizard & Grad, 1961) associated with rearing a mentally handicapped child. Paternal stress, on the other hand, appeared to be predominantly linked to an inability to accept the child's mental deficit, a difficulty mothers did not report experiencing.

From the above it is apparent that the present research hypothesis (Refer Chapter 4, Section 4.3.1.), stating that mothers of mentally handicapped children manifest greater stress than fathers, is neither fully supported nor refuted. It remains unclear as to why the evidence pertaining to the variable, gender of parent, is contradictory. It is possible that the instrument used to measure stress in this
study is not sufficiently sensitive to discriminate between different types of stress (Refer Section 7.5. for greater detail). However, the latter possibility is merely speculative and further research is necessary to shed greater light on this issue.

7.2.2. Gender of the Handicapped Child

Quantitative and qualitative findings revealed the gender of the handicapped child to be implicated in the degree of stress experienced by the parents of that child. The calculation of ANOVA's, however, revealed a significant interaction effect between the gender of the child and the type of care in which that child was placed, i.e. residential or day-care. Parents of mentally handicapped children in residential care experienced differential stress depending upon the gender of the mentally handicapped child. In short, parents of mentally handicapped **male** children experienced greater stress than parents of mentally handicapped **female** children, when those children were placed in residential care.

This finding was supported by the results of the qualitative analysis. Parents of mentally handicapped **male** children in residential care reported considerable tension and distress associated with that child. This appeared to be less evident amongst parents of mentally handicapped **female** children in residential care. Thus the present research hypothesis (Refer Chapter 4, Section 4.3.2.), predicting differential stress in parents depending upon the gender of the child, is supported with respect to parents of children in residential care. It is not, however, supported with respect to parents of children in day-care. No difference in parental stress, depending on gender of child, was found amongst day-care parents.
7.2.3. Type of Care

Quantitative and qualitative findings revealed the type of care in which the mentally handicapped child was placed, to be of some significance to the stress experienced by the parents of that child. The calculation of ANOVAs, however, revealed a significant interaction effect between gender of child and type of care. Parents of mentally handicapped male children experienced differential stress depending upon the type of care in which that child was placed. In short, it was consistently revealed that parents of male children in residential care experienced greater stress than parents of male children in day-care. In this respect, the present research hypothesis (Refer Chapter 4, Section 4.3.3.) predicting parents of mentally handicapped children placed in residential care to experience greater stress in relation to that child than parents of children in day-care was supported.

This finding was, in part, supported by the results of the qualitative analysis. Persistent feelings of intense guilt regarding the placement of the child in permanent care, and associated feelings of personal inadequacy as a parent, were common to parents who had placed their mentally handicapped child in residential care. Such feelings were absent in families who had retained the child within the nuclear family. The latter described tensions associated with the daily routine of caring for a handicapped child. The precise nature of the interaction between gender of child and type of care remains unclear. Thus it is difficult to interpret the presence of an inverse trend amongst the sub-sample of parents with a mentally handicapped female child. In one instance, parents of female children in day-care experienced greater stress than parents of female children in residential care, refuting the present research hypothesis. A part explanation for this anomaly may be found in the possible bias with
the sample of parents of the female, residential sample (Refer Chapter 6, Section 6.2 for detailed discussion). However, it is argued that to attain greater clarity on the nature of relationship between gender of child and type of care further empirical evidence is necessary.

7.2.4. Secondary Stress Variables

7.2.4.1. Socio-economic Status

Quantitative findings revealed socio-economic status to be significantly associated with the type of care in which parents placed the mentally handicapped child (Note: socio-economic status was a composite variable, refer Chapter 5 for details). Thus, parents of low socio-economic status tended to have placed the mentally handicapped child in residential care; whilst parents of high socio-economic status tended to have retained the mentally handicapped child within the nuclear family, and placed that child in a day-care centre.

Quantitative findings also revealed a significant relationship between socio-economic status and parental stress, thereby lending support to the explanatory hypothesis formulated with respect to these variables (Refer Chapter 4, Section 4.3.). Parents of low socio-economic status were found to experience the least stress in relation to the mentally handicapped child. Parents of median socio-economic status were found to experience the greatest stress in relation to the mentally handicapped child; whilst parents of high socio-economic status were found to experience less stress than the latter group but greater stress than the former group. These findings were, in part, supported by those of the qualitative analysis. The latter revealed, amongst parents of low socio-economic status, low levels of stress in relation to the handicapped child. Furthermore, greater
stress was evident amongst the middle and upper groups. However, parents of high socio-economic status appeared to cope better than parents of median socio-economic status, due to the availability of considerable financial and material resources.

7.2.4.2. Parental Religiosity
Quantitative findings revealed a significant association between parental religiosity and parental stress, thereby providing support for the exploratory hypothesis formulated with respect to these variables (Refer Chapter 4, Section 4.3.4.). Parents who described their religious beliefs as playing a significant role in their lives, reported less stress in relation to the mentally handicapped child than parents who described themselves as having 'average' or no religious beliefs. Similarly the results of the qualitative analysis showed that among parents of strong religious conviction, stress in relation to the mentally handicapped child was low.

The latter parents described how religion offered a framework within which they could understand, and come to terms with, the child's deficit.

7.2.4.3. Personal History
Quantitative findings revealed a significant association between parents' previous personal history (i.e. medical and/or psychological) and parental stress, thereby lending support to the exploratory hypothesis formulated with respect to these variables (Refer Chapter 4, Section 4.2.). Parents who reported suffering serious physical or psychological difficulties in the past experienced greater stress than parents who reported suffering no such previous history. This finding is, in part, supported by those of the qualitative analysis.
The latter showed only parents who reported serious psychological difficulties in the past (e.g. severe depression) to be experiencing greater stress in relation to the mentally handicapped child. No difference in parental stress was discernible between parents who reported no previous history and those who reported a history of serious physical difficulty.

7.2.4.4. Social Support

The notion of social support was investigated by qualitative means alone. Two sources of support were distinguished, i.e. intimate and public (Refer Chapter 6, Section 6.4, for greater detail). Findings revealed social support to be of considerable importance to parents of mentally handicapped children, and support for the present research hypothesis (Refer Chapter 4, Section 4.3.4.) was therefore gained. Generally, where social support was described as positive, parents expressed feelings of being able to cope with the handicapped child and associated diminishing stress. On the other hand, where social support was absent or described as negative, parents expressed feelings of being less able to cope with the handicapped child and an associated exacerbation of stress. This was particularly pertinent to parental relations with close family and friends, i.e. intimate sources of potential support. In short, the greater the positive social support, the less the stress experienced by the parent in relation to the mentally handicapped child. Supportive relations with one intimate source could, however, counteract the negative effects of unsupportive relations in another intimate sphere.

Similarly at the level of public sources, it was found that parents benefited from positive social support, and experienced heightened stress where support was absent or considered negative. The degree
of influence of public sources of support appeared to be less intense than that of intimate sources. However, the majority of parents described public sources of potential support as predominantly unsupportive. Parents had therefore tended to rely upon intimate sources of support, where these were available to them.

7.2.4.5. Other Stress Variables

A number of other variables were hypothesized to be associated with the stress experienced by parents of mentally handicapped children. These included parent, child, family and demographic variables (Refer Chapter 4, Section 4.2, for greater detail). Neither quantitative nor qualitative findings supported the significance of any of these variables in affecting parental stress.

7.3. INTERPRETATION OF RESULTS

The findings of the present research have been summarized in an attempt to systematize the wealth of data obtained. It is now appropriate to attempt to establish the meaning of these findings, within the context of a broader theoretical framework.

The primary focus of this study was the notion of stress. It has been stated elsewhere (Refer Chapter 4, Section 4.2.) that due to strong consensus in the literature regarding the mentally handicapped child as a considerable source of stress to parents, the question of whether or not such a child is indeed a stressor was not specifically addressed here. Nevertheless, the findings of this study support the findings of others in the field (e.g. Fotheringham et al., 1972; Holroyd, 1974). It was clearly evident, during the course of the depth interviews in particular, that the presence of a handicapping condition in a child represents a major source of stress.
to the parents of that child.

The central issue with which this study was concerned was whether stress represented a variable process. That is, did all parents experience stress similarly in relation to the handicapped child, or did stress vary between parents? The findings strongly support the notion that stress is a variable process; variable with regard to degree, and in nature. Thus there are two means in which the stress, experienced by parents of mentally handicapped children, may vary. Firstly, certain parents may experience greater or lesser degrees of stress than others (i.e. the question of how much stress). Secondly, certain parents may experience stress which is different in nature to that experienced by others (i.e. the question of what type of stress).

Having established that parents experience different degrees and types of stress, it is appropriate to consider why this should be so. It is the author's contention that there are essentially two major sources contributing to these differences. Firstly, there are what the author has termed "core vulnerability factors". These factors are considered to be characteristics of the parent, and associated with that parent's position within broader social structures, which he or she would have difficulty changing and which bear influence upon how that parent reacts to the environment. Thus, identifying data such as gender or age, and demographic data such as socio-economic status, would be regarded as core vulnerability factors, for example. Secondly, there are what the author has termed "peripheral vulnerability factors". These are factors which may impinge upon any parent, almost irrespective of who that parent is, and his or her particular position within broader social structures. Examples of these factors include religious convictions and social support.
The term 'almost irrespective' is used since the author is aware that an argument can be made against such a dichotomy on the basis that one's position in society dictates the accessibility of even such things as religion and social support. Indeed, with respect to 'public' social support, and social services in particular, it has been shown that these services are less accessible to the working classes (Hollingshead & Redlich, 1958). Nevertheless, provided one remains aware of this consideration, it is the author's contention that the above distinction is of utility.

Little attempt has been made to date in the field of mental handicap to formulate a working model of the impact of the mentally handicapped child upon the parents. Shapiro (1983) has proposed a general conceptual framework of coping. However, her dichotomy of internal and external coping resources is not seen as adequate by the present author. Firstly, Shapiro does not sufficiently highlight the differential effect of the various coping resources, nor does she make adequate note of the possible interaction of these coping resources. Secondly, socio-economic variables are placed on a par with variables such as the aetiology of the disease or handicap. Hence the present author has attempted in her conceptual framework to take account of the differential impact of factors, consider the possibility of interaction between factors, and begin to introduce a relative contribution of factors, i.e. core versus peripheral. In this way a means of understanding the impact of the mentally handicapped child upon the parents is proposed - with the recognition that this model is inevitably somewhat simplistic and may require further revision in the future.

On the basis of the findings of this research and a comprehensive review of the peripheral literature, the following framework documenting the contribution and operation of core and peripheral
vulnerability factors is proposed. The various core and peripheral factors are discussed in turn.

7.3.1. Core vulnerability factors
Four factors appeared to be central in determining the nature and degree of stress experienced by parents of mentally handicapped children. One of these factors, gender of child, was found to interact with a peripheral vulnerability factor, type of care. Hence these two factors are discussed together, and provide a useful example of the possibility of interactive effects mentioned earlier.

7.3.1.1. Gender of the Parent
Although the evidence from this study is somewhat contradictory with respect to gender of the parent (Refer Chapter 6, Section 6.3. for greater detail), it would appear that this variable bears some influence upon the nature of the stress experienced by the parents of handicapped children. Research interest to date has focused almost exclusively upon the mother of the handicapped child (Gumz & Gubrium, 1972). This reflects the common assumption that the impact of the mentally handicapped child is greater upon the mother since she fulfils the primary caretaking role (Jordan, 1962). Considering the contribution of research on gender-stereotyping, it would appear justifiable to assume that mothers are more affected by the handicapped child than fathers. Firstly, mothers inevitably care for the handicapped child on a daily basis; and secondly mothers are expected generally in terms of sex-trait stereotypes to be more sensitive and emotional than fathers. Numerous investigators in the field of mental handicap assume this difference between mothers and fathers, but few have attempted to empirically verify this assumption.

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The findings of the present study suggest that the widespread acceptance of this assumption is unfounded. Indeed, mothers and fathers were shown to experience no difference in degree of stress, according to the QRS-F. Thus fathers, although hitherto neglected, are equally subject to the impact of the mentally handicapped child. This supports the work of Cummings (1976) who has noted that fathers too are deeply affected by the stressful experience of having to rear a handicapped child.

However, according to the findings of this research, fathers do experience stress that is different in nature to that experienced by mothers. Whilst mothers were concerned with the daily burden of care associated with rearing the handicapped child, fathers were more concerned with the acceptability of the child - to themselves and to others beyond the nuclear family. These findings, in part, support the work of Marcus (1977) who compared the attitudes and perspectives of mothers and fathers of psychotic children. Marcus noted that since mothers were typically closer to the situation (fulfilling household and domestic duties), they were more aware of the child's limitations and felt more responsible for the child. Fathers, on the other hand, had less direct contact with the situation (fulfilling their roles as 'breadwinner') and tended to be emotionally distant and to intellectualise the problem.

In short, mothers and fathers are equally vulnerable to stress associated with the handicapped child. Differences in the nature of stress experienced by mothers and fathers respectively may be understood in terms of sex-role stereotypes. Traditional role allocation is typical in 'handicapped families' (Fotheringham & Creal, 1974), and hence parents experience stress dependent upon whether they fulfil
the maternal or paternal role. It is therefore perhaps not gender of parent per se that accounts for the variation in stress between mothers and fathers, but the operation of sex-role stereotypes.

7.3.1.2. Gender of the Handicapped Child - and Type of Care

The second core vulnerability factor implicated in the degree and nature of stress experienced by parents, is the gender of the mentally handicapped child. The specific influence of this factor is not, however, clearly understandable due to the presence of an interaction effect between gender of child, and type of care (Refer Chapter 5, Section 5.2. for greater detail).

This finding is therefore illustrative of how, within the present conceptual framework, core and peripheral vulnerability factors may interact with one another. The following discussion therefore pertains to both gender of child and type of care, and interprets this finding within the broad arena of sex stereotyping.

Williams and Best (1982) define sex-trait stereotypes as "the constellations of psychological traits that are said to be more characteristic of one sex than another" (p.15). They differentiate sex-trait stereotypes from sex-role stereotypes; the latter referring to beliefs concerning the general appropriateness of various roles and activities for men and for women. Sex-trait stereotypes are seen as the bases for the development of sex-role stereotypes. Societal notions of 'what is manly' based on innumerable studies (e.g. Constantinople, 1973; Bem, 1974; Maccoby & Jacklin, 1974) with various populations, dictate that men should be self-reliant, dominant, assertive, competitive, active, autonomous, successful, non-emotional, and achievement oriented. On the other hand, the qualities which are deemed socially desirable of women include: dependency, passivity,
submission, nurturance, warmth, affection and emotional expression. These traits determine the different tasks men and women are expected to perform in society. Thus men are expected to enter the labour market and become bread-winners and women are expected, in the long run, to assume domestic and maternal duties.

Sex-trait stereotypes lead to the development of expectations about a person's behaviour; certain behaviour is anticipated from men, and from women. Similarly, it is anticipated that men and women will fulfil sex roles which are, in general, congruent with sex-role stereotypes.

The large body of socialization literature reveals that depending on the gender of the child, parents adopt different socialization emphasis. That is, in adhering to prevailing societal norms, parents engage in sex-typing and thereby tend to enforce sex differences in their children (Block, 1984).

In this way, sex-trait stereotypes and sex-role stereotypes are maintained. Some would argue (Miller & Dollard, 1944; Bandura & Walters, 1963) that in this manner children become the products of their parents' making and fulfil expectations. This view, however, tends to see the child as a passive recipient upon which the process of socialization is imposed. Hunt (1980) and others before her (e.g. Kohlberg, 1969) prefer to see the child as playing an active role in her socialization. Thus Hunt refers to the child's 'adoption' of male and female gender, and Kohlberg argues that once gender stabilizes, at about the same age the child acquires language, the child structures experience in accordance with his or her gender identity.
It is within the parameters of the above that one can come to some understanding of the findings of the present work. It could be argued that the characteristics considered to be more appropriate for females are more typical of the mentally handicapped individual, than are those characteristics usually associated with masculinity. For instance, the majority of mentally handicapped persons are dependent on others at least to some extent, for their well-being. Further, characteristics such as self-reliance, assertiveness, competitiveness, and achievement orientation are rarely used to describe those who are mentally handicapped.

Here one needs to look deeper, to the level of another stereotype; namely, the characteristics generally attributed to those labelled as 'abnormal'. Society again has certain beliefs and expectations about those who are labelled 'abnormal', including the 'handicapped'. These beliefs are not, in the main, positive but rather tend to view the handicapped as lesser beings, unable to fulfil that which society demands.

It could be argued that, as women are inferior to men, so are the handicapped inferior to the 'normal'. Various levels of acceptability can be seen to exist - the normal male occupying the most prestigious position, followed by the normal female. The present writer argues however that it is more acceptable to be seen as a 'handicapped' female than a 'handicapped' male, since females in Western patriarchal society hold inferior status in any case. The individual most likely to be stigmatized, and more clearly acting out of character, is the 'handicapped' male, who not only fails to meet expectations of normality, but moreover embodies essentially what can be seen as feminine traits. Support for this position is found in Hunt (1980)
who states that female divergence from gender norms is more acceptable than male deviation from gender norms - this at the level of normality. It is argued that with mental handicap the same principle applies, just at a different level.

It is therefore proposed that the intense degree of stress experienced by parents of institutionalized males stems, at least in part, from the parent's own socialization experience and their traditional expectations of children. Why, for parents whose mentally handicapped child resides at home, is there no significant gender-related difference in parental stress?

The qualitative results of this research clearly demonstrate that parents whose children are institutionalized, experienced greater difficulty in coming to accept the handicapped child, than those whose children remained at home. It is argued that if a child is normal, it is expected that he or she will behave in accordance with his or her gender identity. If however, a child is handicapped, the handicap itself excuses gender inappropriate behaviour. Therefore gender is not an issue since the child is not required to meet the criteria usually expected of males and females.

In general, the day-care and residential parent samples are characterized by acceptance and non-acceptance of the handicapped child, respectively. If there is acceptance, parents recognize the fact that the child will never achieve the standards usually expected of him or her by society. The gender of the child becomes less significant in the face of the normality-abnormality dichotomy. However, if parents fail to accept the handicapped child, they try to view the child as 'normal' thereby gender remains a significant issue, in that if the child is normal, he or she must behave like
a boy or girl.

In short, parents whose children live at home have generally accepted the child's limitations and therefore do not expect him or her to fulfil a 'normal' role in society, whether it be masculine or feminine. On the other hand, parents whose children are in residential care have generally not accepted the child's handicap. They continue to attempt to normalize the child - even if only at the level of fantasy - and therefore expect the child to assume masculine or feminine traits in accordance with his or her gender.

A further finding of the present research was that fathers generally appeared more concerned than mothers with their children's development into 'masculine' boys and 'feminine' girls. This supports an earlier finding by Hunt (1980), who, in her study of gender and class conscious noted:

Fathers seem to be marginally more concerned than mothers with 'correct' gender training...

(1980: 10)

Hunt describes how fathers are more likely to see their sons as "extensions of their own life projects", which are themselves defined in masculine terms. She comments that this self-realization through one's own offspring is not likely to be as clear-cut in the case of mother-daughter relationships. This corroborates the results of the present research. Interestingly, this trend was found to be more apparent for the fathers in the residential sample. The implications hereof are that fathers who view their children in this light, and who have a mentally handicapped son whom they cannot accept, will themselves feel inadequate since by the 'failure' of their son, they have failed.
The depth interviews revealed a second trend. It seemed to both parents to be more important for boys to develop gender-appropriate behaviour than for girls. This again supports the findings of Hunt who noted in this regard:

... both parents seem to be more concerned with the adequacy of the sons' masculinity than a daughters' femininity.

(1980:10)

Moreover, this substantiates the earlier argument in which it was stated that female divergence from gender norms is more acceptable than male deviation from gender norms. This trend too was found to be more apparent in the parents of the residential sample; the latter parents being more preoccupied with the development of gender-appropriate behaviour in general, but more concerned still with the son's 'masculinity'.

In sum, parents of institutionalized mentally handicapped children had greater difficulty in coming to terms with their child's handicap. This was exacerbated by the child's inability to develop gender-appropriate behaviour. Fathers were more concerned about this lack, but both parents were more concerned that boy develop gender-appropriate behaviour than girls. Given this it is proposed that one could predict greater stress in parents who:

a) experience difficulty accepting the mentally handicapped child - particularly if that child is male, and

b) hold traditional expectations of their children, with respect to sex-trait and sex-role stereotypes.

It is tentatively proposed that the foregoing may partly account for the differential contact between parents of institutionalized boys.

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and girls. On average the parents of male children in the residential centre in this study had far less contact with the child than did parents of female children. To see the reality of the male's deficiency in the institutional setting, and faced with an inability to accept the child for what he is, is quite obviously a stressful experience. Females in institutions such as the one forming part of this investigation are usually engaged in domestic and maternal duties. Moreover, their dependent behaviour is relatively acceptable, dependency being a female trait. Males on the other hand perform menial tasks not synonymous with the male role in society at large; and they too are dependent, which is not an acceptable role trait. The dissonance parents of handicapped boys may feel at seeing their child, whom they already have difficulty accepting, so 'misplaced' in the institutional setting may lead parents to seek as little contact with the child as possible. The latter conflict was articulated by many of the residential parents with mentally handicapped males.

The lack of contact these parents have with their sons may be explained not only in terms of emotional conflict, but also within the stereotype of masculinity. Sex-trait stereotypes create the expectations that 'boys should stand on their own two feet', thereby not needing to be visited regularly by their parents. Parents' irregular and infrequent contact with their sons may be part of their attempt to 'normalize' the child they find unacceptable. Indeed, a number of parents viewed the institution as a 'type of boarding school' where their son 'got on with it'. Statements such as these seem to encompass the traditional image of the need to toughen young men up - amongst parents who cannot accept the child's deficiency.
7.3.1.3. Socio-economic Status

The socio-economic status of the family is a critical demographic characteristic (Gallagher et al., 1983), and is therefore regarded as a core vulnerability factor in terms of the present framework. Moreover, the findings of this study showed socio-economic status to be of considerable significance to the stress experienced by parents in relation to the mentally handicapped child. Parents of low socio-economic status experienced the least amount of stress, parents of median socio-economic status experienced the greatest amount of stress, whilst parents of high socio-economic status experienced greater stress than the former group but less stress than the latter group.

Hollingshead and Redlich (1958) extensively examined the relationship between social class and mental illness, and concluded that "far more abnormal behavior is tolerated by the ... lower classes" (p.172). The present study supports the findings of these researchers. Parents of low socio-economic status appeared less concerned about the stigma attached to mental handicap, and more tolerant of the child's limitations, than parents of either median or high socio-economic status. Other studies have, however, provided contradictory evidence. Quine and Pahl (1985), for example, found the inverse relationship in their study of mothers of mentally handicapped children. On the basis of mothers in families with high incomes, producing significantly lower scores on the Malaise Inventory (Rutter, Graham & Yule, 1970) than mothers of low-income families, they conclude that the latter experience lower stress than the former. Chetwynd (1985) has proposed that low-income families who have the double burden of limited resources and a handicapped child could be expected to experience greater stress. However, the present study, and others (e.g. Bradshaw & Lawton, 1978), do not support this. Moreover, since the validity
of the Malaise Inventory has been seriously questioned (Refer Chapter 1, Section 1.4.1.2. for greater detail), Quine and Pahl's findings must be viewed with caution.

Parents in the middle and upper socio-economic brackets experienced significantly greater stress than those of low socio-economic standing. Previous lines of argument have presented a number of reasons for this phenomenon. Certain authors argue that the impact of labelling a child 'mentally retarded' is greater amongst families of higher socio-economic status. According to Farber (1968) this is because the stigma associated with mental handicap is greater within this section of the population; the stigma being less amongst the low socio-economic group since it suffers a multiplicity of stigmata. Weller et al., (1974), on the other hand, assume a somewhat different stance. They propose that amongst these groups the mentally handicapped child is regarded as a failure and, since the child is essentially a reflection of the parent, parents experience difficulty in coming to terms with the fact that the child is 'abnormal'. This may shed some light upon the finding that these parents are generally 'more aware' of the child's handicap than parents of low socio-economic status (Hollingshead & Redlich, 1958). Still others (e.g. Wolfensberger, 1967) have postulated that families of high socio-economic status experience greater stress in relation to the handicapped child because they have higher expectations of their children to succeed than parents of low socio-economic status. In short, a number of authors have documented the greater impact of the mentally handicapped child upon families of median or high socio-economic status and therefore corroborate the findings of this study.

However, this study revealed a further difference between parents of the middle and upper socio-economic groups. Parents of the latter
group experienced significantly less stress than parents of the former group. This would seem to contradict certain earlier work in this field which has described a positive correlation between socio-economic status and the impact of the mentally handicapped child, as indicated by parental stress. Generally, these studies indicate, the higher the socio-economic status, the greater the stress experienced by the parent in relation to the handicapped child (e.g. Farber, 1968).

The qualitative findings of this research provide a possible explanation for this anomaly. It is suggested that the substantial material and financial resources available to families of high socio-economic status serve to alleviate parental stress, to some extent, and facilitate coping. For example, parents at this level may employ a number of staff to care for the child. Furthermore, these parents are aware that they can provide whatever the child requires to achieve his or her fullest potential. Thus, parents in this bracket are not subjected to the strenuous daily routine associated with caring for a handicapped child, and neither are they plagued by feelings of doubt as to whether they are doing everything they can to help the child. Consequently, their stress is lower than that of parents in the median socio-economic bracket, who do not have such financial or material resources at their disposal. However, the stigma associated with mental handicap remains great amongst families of high socio-economic standing, hence these parents experience greater stress than parents of the low socio-economic group.

7.3.1.4. Personal History

Parents' experience of severe physical or psychological difficulties prior to the birth of the handicapped child, appear to have bearing upon parental stress following the diagnosis of deficit. The findings
of this study suggest that parents with such a personal history experience greater stress and report being less able to cope than parents who report no serious problems in their past. This is particularly the case for parents who report previous psychological difficulties.

Few writers, with the exception of Shapiro (1983), have taken into account the role of past experience with stressful situations in affecting the individual's subsequent coping abilities. Furthermore, there appear to be no empirical studies pertaining to the relationship between past modes of coping, and the manner in which parents cope with the handicapped child. The present research has, however, established that some relationship between previous psychological experience, in particular, and parental stress does exist.

It could be argued that parents who have encountered serious psychological difficulty earlier (usually described by the parent as a 'nervous breakdown'), do not possess much 'resilience' (Rutter, 1981), on what others have referred to as 'resistance' (Kessler et al., 1985) or 'psychological hardiness' (Shapiro, 1983). Thus, when faced with the crisis of the mentally handicapped child they may experience excessive stress, and be poorly able to cope. By contrast, parents who report no previous psychological difficulty may have greater personal resilience, and therefore experience less stress and be better equipped to cope with the crisis of the mentally handicapped child, than the former parents.

The results of the quantitative study implicated earlier severe physical difficulty in the nature and degree of stress experienced by parents in relation to the handicapped child. The findings of the qualitative study did not clearly support this. However, it is
possible that where previous physical illness or disability continues to affect the parent, the parent may experience greater stress and feel less able to cope than parents who are free of such physical affliction.

7.3.2. Peripheral vulnerability factors

Thus far the role of core vulnerability factors in influencing the impact of the mentally handicapped child upon the parents has been discussed. The role of peripheral vulnerability factors will now be considered. These, to reiterate, are factors which may impinge upon any given parent 'irrespective' of who that parent is, and his or her particular position within the broader social structures. It must be noted that these factors may operate in interaction with core vulnerability factors, and that each may have differential impact upon any given parent.

7.3.2.1. Religious Conviction

The findings of this study suggest that the presence or absence of religious beliefs may influence parents' stress, and ability to cope with the mentally handicapped child. Parents who held firm religious beliefs experienced less stress, and reported feeling better able to cope with the child than parents who described themselves as holding 'average' or no religious beliefs.

A number of researchers have referred to the 'benefits' of strong religious conviction for parents of mentally handicapped children (e.g. Zuk, 1959; Holroyd, 1974), and various reasons for this have been proposed. Firstly, belief in God appears to offer certain parents an explanation for why their child is mentally deficient. These parents may regard the child as a 'gift from God' (Zuk, 1959; Stokes,
Thus, parents may come to view their situation positively, interpreting it as a sign from God acknowledging their devotion and therefore choosing them in particular to raise a 'special' child. Secondly, religion may offer parents 'strength and hope' (Michaels & Schucman, 1961) during times of crisis, thereby being a 'source of comfort' (Schmitt, 1978) to them.

Parents who held 'average' or no religious beliefs did not describe religion as being helpful to them with respect to the mentally handicapped child. In fact, in one instance a set of averagely religious parents felt religion had exacerbated their stress and diminished their ability to cope. These parents had interpreted the birth of their handicapped child as a punishment from God for their past sins—a finding also reported by Schild (1971). However, in general, for parents who did not hold strong religious beliefs, religion did not play a role in either easing or exacerbating the burden of the handicapped child.

In short, as a peripheral vulnerability factor religious conviction, where firm, may bear positively upon parents' adjustment to the mentally handicapped child. Nevertheless, it must be noted that religious beliefs may also cause parents to interpret their situation negatively and thereby exacerbate the stress they experience. As yet it is unclear as to what circumstances elicit a positive as opposed to a negative interpretation.

7.3.2.2. Social Support

The findings of the present study suggest that the role played by social support in influencing the impact of the mentally handicapped child upon the parents, is substantial. The benefits of positive
social support were demonstrated, and the additional pressures associated with negative social support, and 'social isolation' (Quine & Pahl, 1985) recognized. Thus, this study offers some support for the buffering-hypothesis, which postulates that social support may 'buffer' or mediate against the adverse effects of a stressful life event (Cobb, 1976; Henderson et al., 1978). However, in line with Rutter's (1981) criticism of much of the social support literature, it was found that social support may not in all cases be of benefit to parents. Hence, the need to challenge the assumption that personal relationships have a protective effect, buffering the parent against the impact of the mentally handicapped child, is highlighted.

The occurrence of a major life event, such as the diagnosis of mental handicap in a child, may alter the support available to the individual (Thoits, 1982). Clearly, once a child is identified as handicapped, parents are exposed to a number of 'public' (House, 1981) sources of support previously unavailable to them. These include medical professionals and social services. In terms of the buffering hypothesis it would be expected that the increased support from these sources would serve to alleviate parental stress and facilitate their ability to cope. By contrast, the findings of this research revealed considerable dissatisfaction amongst parents with respect to medical professionals and social services for the mentally handicapped. General opinion was that these sources of potential support either failed to provide any support at all, or provided what may be termed 'negative social support'. By negative social support the author is referring to occasions when support does not 'buffer' against the deleterious effects of the life event, but rather exacerbates the stress experienced by the afflicted individual.
A number of authors have documented the comparative failure of professionals, and the services they render, to meet the needs of parents of mentally handicapped children (e.g. Zwerling, 1954; Ayer, 1984; Quine & Pahl, 1986). This study lends support to these earlier findings. However, previous writers have not considered inadequate counselling or false information to constitute social support. It is the author's contention however that this does constitute social support - a negative social support. Counselling which provides relief to parents or social services which offer parents useful information, are regarded as sources of support when they prove beneficial to parents. However, when the same services are provided, with negative or adverse results, they are no longer termed social support. It is argued that the term social support has come to connote positive social support, but that in fact social support may be positive or negative in its effect. In short, investigators to date have set out to prove the benefits of social support, and finding no benefits have therefore concluded that social support was absent, rather than entertaining the notion that social support may, at times, itself have deleterious effects.

Social support, as provided by intimate sources (e.g. spouse, close relatives and friends), may also be positive or negative in nature. The findings of the present study suggest that positive social support, provided by an intimate source, may play a major role in mediating the impact of the mentally handicapped child upon the family. This corroborates the findings of earlier studies, such as those of Fotheringham and Creal (1974) and Wille et al. (1979). Parents who received little support from intimate sources expressed feelings of increased tension and fears regarding their ability to cope. The latter was also applicable to parents who received negative social
support from intimate sources. Where social support was not regarded as positive by parents, steps were usually taken to terminate that personal relationship. Thus, friends who displayed insensitivity to parents' feelings or who showed little understanding of parents' situation, were gradually no longer contacted and the friendship lapsed. This would perhaps explain the findings of others who report that parents of handicapped children have significantly less social supports than parents of non-handicapped children (e.g. Friedrich & Friedrich, 1981).

In short then the author is proposing that the present dichotomy assumed in much of the social support literature to date is inadequate; that is, social support versus no social support. Rather, the notion of social support is more complex—it may be positive, negative or absent. Furthermore, when social support is regarded as negative, a process ensues between supporter and supportee whereby the personal relationship is terminated. Hence social support which is experienced as negative comes to absent.

7.3.2.3. Type of Care

The type of care in which the mentally handicapped child is placed appears to be implicated in parental stress. However, type of care (a peripheral factor) and gender of child (a core factor) were involved in interaction with one another; hence it is not possible to discuss these factors individually. An interpretation of this interaction effect is provided earlier (Refer Section 7.3.2.) and will therefore not be repeated here. The reader is, however, reminded that this interaction represents a useful example of how factors incorporated in this framework may be inter-related.

- 231 -
An attempt has been made to formulate a composite 'model' of the stress experienced by parents of mentally handicapped children. The bases of this model are the findings of the present research, and the general theoretical literature which pertains to the impact of the mentally handicapped child upon the parents. It must be noted that the framework just described is by no means exhaustive, and there are almost certainly other core and peripheral vulnerability factors which may be identified by future researchers. It was the author's intention to propose a basic framework upon which others may build, rather than to provide the final product.

The above framework deals primarily with the notion of stress and, by implication, the notion of coping. Social support is defined as a peripheral vulnerability factor. However, the concept of social support has been heralded as "the issue of the 1980s" (Rowitz, 1985: 165) and, indeed, was found to be of considerable importance to parents of handicapped children in this study. For this reason the author has examined the relationship between social support and coping more closely and attempts, in the following section, a unification of the theory pertaining to each.

7.3.3. Coping and Social Support

The process by means of which parents come to terms with their mentally handicapped child, i.e. how parents cope, has been described in an abundant literature. Essentially a grief process is documented within which parents pass through various phases of mourning. Ultimately, by 'working through' their grief parents achieve a positive adjustment to the handicapped child and are said to have 'coped'. This process has been comprehensively described earlier (Refer Chapter 1, Section 1.5.) and will not therefore be reviewed here. Various vulnerability
factors impinge upon this process and affect the outcome thereof. A peripheral vulnerability factor of particular salience is that of social support, and the role of social support in influencing parental distress is being increasingly recognized. The question therefore arises of how the process of coping, shown to be central to the resolution of parental grief, is influenced by social support, shown to be significant in affecting parental stress and ability to cope. An attempt has been made to address the interface between these two concepts.

The main thesis of this argument is that at various phases of the grief process different forms of positive social support are necessary to facilitate parental coping. That is, at any given point in the grief process the need for a particular form of support will be ascendant. In accordance with House (1981) four broad classes of supportive behaviour are defined (Refer Chapter 1, section 1.6, for greater detail); these are: emotional, instrumental, informational and appraisal support. It is proposed that these different forms of support merge with the particular needs and crises of parents as they pass through the various phases of the grief process. Thus, at different points in time during this process parents experience different needs and therefore require different forms of support, dependent upon those needs.

Kromberg (1977) and others (e.g. Schild, 1971) have described the emotional reaction parents experience on learning of the child's mental deficit, i.e. the earliest phase of the grief process. This involves feelings of shock, disbelief, numbness, and general emotional turmoil. It is therefore proposed that at this time parents' primary need, in terms of social support, is for positive emotional support. This
is not to say that other forms of social support provide no benefit at this point, but rather that they assume secondary significance. In the face of severe emotional confusion, positive emotional support would seem to be the most appropriate.

The latter half of the first phase of the grief process is characterized by parents 'searching for magic cures', and the consultation of medical professionals may be frequent (Kromberg, 1977). McCormack (1978) has described parents as entering a period of 'information gathering'. As parents recover from the initial shock of discovering the child to be handicapped, they begin to gather information regarding the child's condition. Thus, they wish to fully understand the implications and ramifications of the diagnosis. It is therefore argued that at this time parents' greatest need is for positive informational support. To reiterate, other forms of social support may also be of benefit to parents at this time, but the provision of information is seen as paramount.

The second phase of the coping process, as described by Kromberg (1977), is characterized by parental feelings of hopelessness, helplessness and guilt. Parents, now fully informed regarding the implications of the child's condition, lapse with despair. Typically they question, 'Why me?', and may attempt to explain the phenomenon in terms of their own past misdemeanours. At this time it would seem that parents are most in need of appraisal support; that is, reassurance and encouragement. Parents need to be told that they are coping adequately, that what they are experiencing is normal and not idiosyncratic, and that there are other parents who suffer the same fate. Thus, appraisal support, it is argued, is ascendant during this phase, whilst other forms of positive social support assume somewhat lesser significance.
Finally, parents enter and pass through the phase of detachment at which point they are regarded as having affected a "constructive adaptation to the situation" (Kromberg, 1977: 34). This final phase marks the parents' full acceptance of the child and his or her handicap. No longer 'crippled' by emotional turmoil, no longer in search of further information, and confident in the knowledge that they can cope with the situation parents strive to regain a state of equilibrium in their domestic life. It is argued that, at this point, parents may value most highly the provision of instrumental support. Whilst they attempt to ensure a sense of stability within the nuclear family assistance from relatives and friends which would facilitate the smooth-running of the household appears to be most appropriate.

In short, it has been argued that with the provision of the appropriate form of positive social support at the time of particular parental need, parents may be facilitated in achieving a resolution of the grief process. By contrast, where social support is absent, negative or inappropriate, in that it does not meet the primary needs of the parent, it is argued that the resolution of the grief process may be achieved with greater difficulty or over a longer period of time. Thus, it is the author's contention that an optimal process of social support may be identified, having implications for therapeutic intervention. Clearly, other vulnerability factors, both core and peripheral, are concomitantly influencing the impact of the mentally handicapped child upon the parents. Nevertheless, due to the particular salience of social support, as evidenced in this and other studies (e.g. Gath, 1978), it is proposed that the above framework may shed greater light upon the manner in which parents come to terms with the handicapped child; i.e. come to cope with the child and,
by implication, experience-less stress in relation to that child.

Finally, it must be noted that the source of positive social support may also be of significance, i.e. may also play a role in determining the efficacy of social support. Thus, emotional support provided by an intimate source (e.g. a close relative) is more likely to have a positive influence than if provided by a public source (e.g. a medical practitioner). Similarly, informational support provided by a public source is more likely to have influence than if provided by an intimate source. For example, a mother who is informed that her handicapped child will walk by the age of eight is more likely to believe the medical specialist than the next-door neighbour.

The author is therefore arguing not only for a differentiation of forms of support, but also for a differentiation of sources of support. For optimal resolution of the grief process with respect to social support, parents require different forms of social support at different times, and moreover different forms of support are sometimes better provided by one source than another.

The above framework represents a synthesis of the theoretical literature on social support and coping as it pertains to parents of mentally handicapped children. Although an investigation into the coping process of parents of handicapped children was not a focus of this study, the presence of such a process was taken into account. Through retrospective histories, no deviation from the process of coping, as described by others (e.g. Kromberg, 1977; Wright, 1976), was in evidence. Moreover, patterns of social support needs as described above appeared to emerge. Nevertheless, the above framework is essentially based upon a merging of theory and in order to assess the utility thereof, empirical investigation is necessary.
IMPLICATIONS OF FINDINGS AND DIRECTIONS FOR FUTURE RESEARCH

The findings of the present study have a number of implications—practical, theoretical, and in terms of future research. These will be briefly discussed in this section.

This research has been largely exploratory in nature, and has examined a broad range of issues pertaining to the parents of mentally handicapped children. Throughout the course of this investigation, two themes in particular recurred which have direct and practical implications for the field of mental handicap in South Africa. Firstly, and of particular urgency in the author's opinion, is the inadequate service provided by the majority of medical professionals to parents of handicapped children. Repeatedly, stories were told of the insensitive and uncaring attitude of professionals at the time of diagnosis but also on subsequent occasions of contact. It is clear that doctors in particular are, to cite a number of parents, 'uneducated' when it comes to dealing with families of handicapped persons. This not only causes parents additional pain and stress but may also build false expectations—either positive or negative. It is therefore suggested that the training of medical doctors be evaluated, and that a short course on mental handicap, from a medical and psychological perspective, be compulsory. Mental handicap is not after all a rare occurrence and most medical doctors will encounter this problem during their practise.

Secondly, the realm of social services needs to be addressed. A number of difficulties were encountered by the majority of parents, which have implications at a practical level. It became evident that services for the mentally handicapped were not equally accessible to all families with a handicapped child—even within the so-called
'white' population group. Families with greater financial means had, in general, access to better facilities and waited shorter periods of time for their child to be admitted to care. On the other hand, families of few financial means experienced difficulty in placing the child in care, and a number eventually placed the child in the government institution because they felt they had no alternative. With recent cuts in government spending on facilities for the mentally handicapped the situation has become increasingly dire. Clearly, to provide services to all persons, irrespective of socio-economic status or race, a change at the level of policy is needed. It is perhaps in this direction that professionals working in the field should begin to channel their energy.

The findings of this study also have implication for theory. As discussed in the earlier chapters (Refer Chapters 1, 2 and 3), little attempt has been made to develop a comprehensive theoretical framework in terms of which the impact of the mentally handicapped child upon the parents may be understood. The present author has proposed (Refer Section 7.3.) a manner in which such a basis could be formulated. However, as mentioned, this is in essence a beginning - the implications are that future researchers need to attend to the development of an adequate theory base, possibly drawing increasingly on the notions of stress, coping and social support.

The practical and theoretical implications of this research themselves have implications for the direction of future research. Investigators should, for example, address the relationship between medical professionals and parents of mentally handicapped children more closely, and identify possible means of improving this. Furthermore, a full investigation into the availability of social services is essential if areas of specific need are to be identified. Indeed,
a survey of this nature is at present proceeding on a nation-wide scale (M. Rip, personal communication, June 11, 1986).

This study has examined a breadth of data, characteristic of exploratory research. This has provided the author with "a context of meanings in which quantitative findings can be understood" (Stainbeck & Stainbeck, 1984: 407). Having established this 'context' empirically, and attempted to draw the findings together theoretically, it is now for future investigators to examine each facet of the whole more systematically. Hence, further study needs to be made of each of the vulnerability factors identified in this study. In this way greater scientific meaning, i.e. reliability and validity, may be lent to the framework within which the impact of the mentally handicapped child upon the parents, is understood.

Finally, the present study was limited to investigating the parents of mentally handicapped children who were classified 'white'. The reasons for this aspect of the experimental design have been outlined earlier (Refer Chapter 4, Section 4.6.). However, it is argued that future investigation should consider examining mental handicap in other 'population groups' a priority. The prevalence of mental handicap amongst so-called 'Blacks', 'Coloureds', and 'Indians' is difficult to estimate (Eichorn, 1985). However, it is, in all probability, greater than amongst the 'White' population group, since socio-cultural retardation is inevitable amongst persons living in the conditions to which many of these people are subject. Considering the paucity of facilities available to the former groups it is crucial that future research be directed at assessing needs, with a view to providing facilities for these sectors of the population.
7.5. LIMITATIONS OF THIS STUDY

The findings of this research have been discussed at length and it is therefore appropriate at this point to consider the possible limitations of the study. A number of issues have been identified and each will be briefly examined in turn.

Firstly, one needs to consider the issue of generalizability, i.e. are the findings of this study representative of the population as a whole? To address this issue the adequacy of the present sample needs to be examined. The sample used in this study may, at best, be described as incidental. Due to the constraints of the experimental design documented earlier (Refer Chapter 4, Section 4.4.), it was not possible to use sophisticated sampling techniques. If indeed such techniques had been employed, the sample size yielded would have been very small, making any generalization difficult. Thus, all parents who fitted the criteria specified were included in this study, yielding a sample size of 72. Clearly, the larger the sample, the more representative it is of the population; and, the more random the sampling technique, the greater the generalizability. However, almost all research involves the weighing up of various factors in order to achieve the best possible sample. In this case, the factors were sample size and sampling techniques - to achieve an adequate sample size, sophisticated sampling techniques had to be sacrificed. It is, nevertheless, the author's contention that given the constraints of the experimental design, an adequate sample was selected. Furthermore, it is felt that the findings of this research may be generalized to the population at large; that is, all 'white' parents of mentally handicapped children in South Africa. Generalization is limited to this group for although there are no clear foreseeable factors limiting further generalization.
it is unwise to make sweeping cross-cultural generalizations.

Secondly, the issues of reliability and validity need to be addressed. Two measuring instruments were employed in this study - the QRS-F, and the Personal Details Questionnaire. The former has been established to be "psychometrically valid" (Refer Chapter 1, Section 1.4.1.3. for greater detail), according to its authors (Friedrich et al., 1983). However, no measures of reliability have been calculated, and this instrument has not been standardized on a South African population. Furthermore, the findings of the present research indicates that this measure may not be sensitive to different types of stress, as experienced by mothers and fathers for example, and any future development thereof should possibly address this problem. Nevertheless, the utility of this instrument is obvious since it is the only objective measure designed for the purpose of assessing stress in families with handicapped members. The P.D.Q. was designed solely to obtain the biographical details of participants in an efficient manner. It appeared to achieve this objective and proved a useful instrument.

Finally, consideration needs to be made of the analysis of the wealth collected in this study. The material from the qualitative study was loosely content analysed by the researcher herself. It is possible that a more formal system of analysis could be developed in future and that the data should be analysed by a number of independent researchers. In this way measures of inter-rater reliability could be established. This would serve to guard against interviewer bias, and would increase the reliability and validity of findings. Finally, the notion of social support was exclusively examined by qualitative means. It is suggested that in future a quantifiable index of social support would be valuable to supplement the qualitative findings.
In short, the present study suffers a number of limitations with regard to the sample itself, the instruments used, and the analysis of data. Despite this, it is argued that the findings of the present research are of considerable significance to the field of mental handicap, and contribute positively to existing knowledge regarding the impact of the mentally handicapped child upon the parents.

7.6. CONCLUSION

In conclusion, the present study has aimed to explore the impact of the mentally handicapped child upon the parents, within a general theoretical framework and using a sound methodology. A wealth of quantitative and qualitative data was collected, the analysis of which yielded various findings. These, together with the general theory pertaining to stress, coping and social support, have formed the basis of the framework proposed by the author, within which the impact of the mentally handicapped child upon the parents may be understood. This work represents a contribution to the field of mental handicap in South Africa, and was intended to 'open up' this hitherto relatively unexplored area. The reader is reminded that this study is but one of the building-blocks needed to construct the entire edifice. It is hoped that, with the foundation laid, others may be encouraged to assist in the construction of a sound totality.
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APPENDIX A

PERSONAL DETAILS QUESTIONNAIRE

(P.D.Q.)
PERSONAL DETAILS QUESTIONNAIRE

The following questions are concerned with your personal details. Please be as accurate as possible in your answers; all information will be treated with absolute confidentiality.

Thank you for your help and co-operation.

SUSAN LEA

1985
NAME:
SEX:
DATE OF BIRTH:

A. Family History

1. What is your mother's age? (If deceased, at what age and what was the cause of death)

2. What level of education did your mother achieve? (Mark the appropriate box with an X)
   - Primary School
   - High School
   - Matric
   - Diploma
   - Degree

3. Did your mother ever suffer from any illness, disease or 'breakdown'? If so, please specify.
   - No
   - Yes

4. Did your mother ever suffer from any disability? (i.e. poor eyesight, hearing etc.) If so, please specify.
   - No
   - Yes
5. What is your father's age? (if deceased, at what age and what was the cause of death).

6. What level of education did your father achieve?

- Primary School
- High School
- Matric
- Diploma
- Degree

7. Did your father ever suffer from any illness, disease or 'breakdown'? If so, please specify.

- No
- Yes

8. Did your father ever suffer from any disability? (i.e. poor eyesight, hearing etc.) If so, please specify.

- No
- Yes

B. Personal History

1. Where were you born? (town and country)
2. If foreign, on what date did you arrive in South Africa?

3. How long have you lived at your present address?

4. Where did you live before this?

5. To what church or religion do you belong?

6. What level of education did you achieve? What was the name of the school/college/university, and when did you complete your training?

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7. What is your present occupation? (If not working at the moment, what was your previous job)

8. What wage do you earn per annum?

9. Have you ever suffered from any disease, illness or 'breakdown'? If so, please specify.

No

Yes
10. Do you, or have you in the past ever suffered from any disability? If so, please specify.
   No ☐
   Yes ☐

11. When did you marry your spouse? (month and year)

12. Were you married previously? (If so, how many times previously, and for how long)
   No ☐
   Yes ☐

13. How many children do you have?

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If any of the above children are from a previous marriage, please underline his or her name.
14. Do you live in a flat, cottage, semi-detached or free-standing house?

- Flat
- Cottage
- Semi-detached house
- Free-standing house

15. Do you rent or own the above?

- Rent
- Own

16. Do you own a car? If so, please specify the year and make.

- No
- Yes

17. How far is it from your home to Alexandra Care and Rehabilitation Centre?

............................................................ km(s) ............................................................

18. How long does it take you to get to Alexandra?

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

C. Handicapped Family Member

Name:

Sex:

Date of Birth:

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

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

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

............................................................
2. Who first told you of your child's handicap? (i.e. doctor, social worker)

3. From what does your child suffer?

4. Did your child ever attend a day-care centre? If so, give the name(s) of the school and the ages at which your child started and left there.

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5. Was your child ever a resident at any other homes, foster homes, places of safety or schools before his or her admission to Alexandra? If so, give the name(s) and the ages at which your child started and left there.

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APPENDIX B

THE SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-P)
QUESTIONNAIRE ON RESOURCES AND STRESS

Instructions

This questionnaire deals with your feelings about a child in your family. There are many blanks on the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions.

Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you and your family feel or do most of the time.

Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then.

Remember to answer all the questions.

Thank you.

Susan J Lea
doesn't communicate with others of his/her age group. T F
members of the family have to do without things because of T F
family agrees on important matters. T F
worry about what will happen to _________ when I can no longer T F
care of him/her.
constant demands for care for _________ limit growth and T F
development of someone else in our family.
_______ is limited in the kind of work he/she can do to make T F
living.
_______ have accepted the fact that _________ might have to live out T F
her life in some special setting (e.g. institution or group home).
_______ can feed himself/herself. T F
_______ have given up things I have really wanted to do in order to care T F
for _________
_______ is able to fit into the family social group. T F
sometimes I avoid taking _________ out in public. T F
in the future, our family's social life will suffer because of T F
raised responsibilities and financial stress.
_______ bothers me that _________ will always be this way. T F
_______ feel tense whenever I take _________ out in public. T F
_______ can go visit with friends whenever I want. T F
_______ on a vacation spoils pleasure for the whole family. T F
_______ knows his/her own address. T F
our family does as many things together now as we ever did. T F
_______ is aware who he/she is. T F
_______ is upset with the way my life is going. T F
_______ feel very embarrassed because of _________ T F
_______ doesn't do as much as he/she should be able to do. T F
23. It is difficult to communicate with _________ because he/she has difficulty understanding what is being said to him/her. T F

24. There are many places where we can enjoy ourselves as a family when _________ comes along. T F

25. _________ is over-protected. T F

26. _________ is able to take part in games or sports T F

27. _________ has too much time on his/her hands. T F

28. I am disappointed that _________ does not lead a normal life. T F

29. Time drags for _________, especially free time. T F

30. _________ can't pay attention very long. T F

31. It is easy for me to relax. T F

32. I worry about what will be done with _________ when he/she gets older. T F

33. I get almost too tired to enjoy myself. T F

34. One of the things I appreciate about _________ is his/her confidence. T F

35. There is a lot of anger and resentment in our family. T F

36. _________ is able to go to the bathroom alone. T F

37. _________ cannot remember what he/she says from one moment to the next. T F

38. _________ can ride a bus. T F

39. It is easy to communicate with _________. T F

40. The constant demands to care for _________ limit my growth and development. T F

41. _________ accepts himself/herself as a person. T F

42. I feel sad when I think of _________. T F

43. I often worry about what will happen to _________ when I no longer can take care of him/her. T F

44. People can't understand what _________ tries to say. T F

45. Caring for _________ puts a strain on me. T F
46. Members of our family get to do the same kinds of things other families do. T F
47. ______________ will always be a problem to us. T F
48. ______________ is able to express his/her feelings to others. T F
49. ______________ has to use a bedpan or nappy. T F
50. I rarely feel blue. T F
51. I am worried much of time. T F
52. ______________ can walk without help. T F
APPENDIX C

CORRESPONDENCE WITH PARTICIPANTS
Dear

Thank-you for your time and valuable contribution to my research on mental handicap. I am aware of the difficulty that you may have encountered in re-living past and often painful events; I am deeply grateful for your co-operation.

I plan to have completed the entire project by June/July 1986, and sincerely hope that my findings may precipitate moves in the arena of mental handicap which are beneficial to your family.

Yours,

Susan J Lea.
Dear Parent,

Results of Study (1985)

At last the data collected for the purposes of my research has been analysed, and written up. Your participation in this study has proved invaluable and the results are extremely interesting. As I mentioned at the time of our interview I intend to hold a meeting, during which I will share the findings of my research with you. I feel that this is the least I can do in view of your willingness to assist me in investigating the impact of the mentally handicapped child upon the family.

I have fortunately been granted study leave for the period 13 June to 19 July 1986, and am due to spend this time in England. During my visit I intend to examine the status of mental handicap in that country, and hope to bring back fresh insights and ideas, particularly with respect to the provision of social services.

Consequently I would like to postpone the 'feedback meeting' until after my return. In this way I can also contribute that which I have found overseas, for those who are interested. This meeting will therefore be held during August, and not during June/July as was my previous intention. You will receive further notification of the meeting on my return to South Africa.

Thank-you for your patience.

Yours faithfully,

Signed by candidate

SUSAN J. LEA
8 September 1986

Dear Parent

You are invited to attend a 'feed-back' meeting regarding the findings of the research in which you participated. An informal tea has been arranged to this end. This will be held at Alexandra Care and Rehabilitation Centre, in the Diagnostic Unit at 3.00 pm. on Saturday, 20 September.

I do hope you will join us.

Yours sincerely

PLEASE RETURN TO : SUSAN J LEA, PSYCHOLOGY DEPARTMENT UNIVERSITY OF CAPE TOWN, RONDEBOSCH, 7700

I will/will not be attending the informal tea on Saturday 20 September.

Number of guests _____ (including myself)

NAME :
30 September 1986

Dear Parent,

You are invited to attend a 'feed-back' meeting regarding the findings of the research in which you participated. An informal tea has been arranged to this end. This will be held at Glendale Teaching & Training Centre, at the school at 3.00 p.m. on Saturday, 18 October, 1986.

I do hope you will join us.

Yours sincerely,

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PLEASE RETURN TO: SUSAN J LEA, PSYCHOLOGY DEPARTMENT
UNIVERSITY OF CAPE TOWN, RONDEBOG, 7700.

I will/will not be attending the informal tea on Saturday 18 October.

Number of guests _________ (including myself)

NAME: ____________________________

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