THE RELATIONSHIP BETWEEN SOCIAL SUPPORT, COPING AND STRESS RESOURCES OF PARENTS WITH MENTALLY HANDICAPPED CHILDREN IN THE CAPE PENINSULA

by

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Submitted in partial fulfilment of the requirements for the M.Psych degree in the Department of Psychology, University of the Western Cape, Bellville

September 2000

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ABSTRACT

The impact a mentally handicapped child has on parents and family members can be seen as a stressful life event. Numerous studies have been implemented in an attempt to understand how these families cope. Families with mentally handicapped children face unique challenges and require assistance in helping them preserve a harmonious family life. Social support is regarded as an alternative resource that could help these families deal with raising a mentally handicapped child.

The aim of this study is to investigate the relationship between social support, coping and stress resources of parents with mentally handicapped children in the Cape Town Metropolitan area. A sample (N=50) of parents with moderately to severely mentally handicapped children was drawn from three special care centres in the Cape Town Metropolitan area. The study utilized the short-form of the questionnaire on Resources and Stress (QRS-F), the Inventory of Socially Supportive Behaviour (ISSB) as well as the Network Orientation Scale (NOS) to measure the relationship between social support and stress and coping resources of parents with mentally handicapped children in the Cape. Town Metropolitan area.

The quantitative results of this study were inconclusive as no statistically significant relationship between social support and coping and stress resources of parents with mentally handicapped children was found. The qualitative results, however, indicate that there is a positive relationship between the variables.

DECLARATION

I hereby declare that this dissertation, unless specifically indicated to the contrary in the text, is my own original work and that I have not submitted it, nor any parts of it, for a degree at any other university.

MS C. PETERSEN

ACKNOWLEDGMENTS

Firstly, I thank my Lord for giving me the strength, courage and inspiration to succeed in this endeavour.

A big thank you to my colleagues and friends, Reneë Klink, Meg George, Trudy Leukes, Tyrone Pretorius, Prof Simbayi, Maria Florence and the late Evan Ramjoo-Mia. I am forever grateful for your support and inspiration.

My sincere thanks to my supervisor, Tania Vergnani, for your patience and guidance.

Thank you to the Centre for Science Development for funding my research project.

To my family, mom and dad: thank you for your love and support. Lastly to my partner, Eddie: thanks for having faith and believing in me.

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QRS- F

ISSB

NOS

CHAPTER ONE

INTRODUCTION

1.1 Statement of problem

Raising a mentally handicapped child can be described as a stressful life event that may trigger emotional conflict and contributes to changing the basic life pattern of an individual or family (Blacher, 1984; Crnic, Friedrich & Greenberg, 1983; Flynt, Wood & Scott, 1992; Henderson & Vandenberg, 1992; Holmes & Rahe, 1967). Parenting mentally handicapped children presents situations for which most parents have not been trained or prepared. As a result parents not only need education and information regarding the nature and the treatment of their child's condition, but also require help and support to enable them to cope with the stresses involved in raising such a child. From research findings (Flynt et al.,1992; Fotheringham & Creal, 1974; Gallagher, Beckman & Cross, 1983; Gath, 1978; Lea & Foster, 1990; Molteno & Lachman, 1996) it becomes apparent that social support is a crucial variable in helping parents cope with the situation.

It is difficult to established the prevalence of mental handicap amongst South African children due to the lack of reliable census statistics. The lack of information highlights the previous apartheid government's indifference to census information and it reflects the continued marginalisation of the mentally handicapped (Parekh & Jackson, 1997). It is estimated that in a developing country such as South Africa the prevalence could be 2 - 8% higher than that of a developed country (Desjarlais, Eisenberg, Good & Kleinman, 1985). According to Parekh and Jackson (1997) we could expect to find approximately 1 236 000 to 1 648 000 adults and children who have some

sort of mental handicap in South Africa. Lazarus (1991) estimated that there are 150 000 - 250 000 moderate to severely mentally handicapped persons in South Africa. The prevalence of mental handicap amongst children in South Africa will probably be much higher than in developed countries given the relationship between poverty, malnutrition and intellectual deficit.

For South African parents, the psychological impact of having to deal with and care for a mentally handicapped child is further influenced by the poor availability and quality of the existing support services. A study by Grover, Cooke, Hollingshead and Rip (1987) indicated that there was a glaring deficiency in service provision in the Western Cape. In the Western Cape only 5,4% of the African mentally handicapped population's needs were met. In the Coloured community only 36% of their needs were met, while 86% of the White community's needs were met. Eichorn (1985) indicated in her study that service provision for the Coloured and African community in the Western Cape was grossly inadequate and this could be attributed to the state's apartheid policy. In comparison with these previous studies, Molteno, Roux, Kench and Selfe (1994) indicated that service provision for the Western Cape had improved, particularly for the black population, though discrepancies still persisted.

According to the Western Cape Forum for the Mental Handicap (Personal communication, April 2000), they provide services and training to ± 23 schools for learners with Special Education Needs (ELSEN schools, previously known as training centres), ± 36 special care centres, 20 group homes and 14 protective workshops for the mentally handicapped of all races in the Cape Town Metropolitan area.. These facilities are available to the mentally handicapped and are mostly run by non-governmental organisations and community based centres in the Western Cape. These organisations are dependent on funds and human resources for their continued existence.

Some of these facilities are facing closure due to the lack of funding. Although there has been an improvement in the service provision for mentally handicapped in the Cape Town Metropolitan area facilities still seem to be inadequate and insufficient.

In the light of the limited and inadequate mental health services for families with mentally handicapped children in South Africa, social support networks could play an instrumental role in moderating the effects of stress on these families (Flynt et al., 1992; Gallagher et al., 1983; Molteno & Lachman, 1996; Thoits, 1986). In a recent study by Kwai-Sang, Matthew and Li-Tsang (1999), the availability of a small and a intense social support network is one factor that was found to enhance family coping and facilitate parental adjustment to their mentally handicapped child. Freeman (1989) also supports this notion and indicates that for these families natural helping resources should be strengthened and utilized. Natural helping resources in this context refer to support networks such as the family, friends and the community (Smith & Hobb, cited in Holahan & Moos, 1981).

According to Molteno et al. (1994), most research on stress and coping of parents with mentally handicapped children has been done in developed communities, whereas studies pertaining to stress and coping in developing communities, such as South Africa, are scarce. The lack of research on families with mentally handicapped children has helped contribute to their neglect. According to Minnis (cited in Luiz, Lombard & O'Brien, 1994) the research area of families with mentally handicapped children has often been limited by conceptual and methodological problems. One such problem is the tendency to move towards a more clinical orientation, where maladaptive and pathological behaviour becomes the focus, rather than the coping and adaptation of parents to a mentally handicapped child. There is thus a need for more theoretically-based research and

an improved methodological approach to enhance and develop this area of research (Cole, 1986; Holroyd, cited in Luiz et al., 1994).

Very few social support studies have been done in the South African context (Pretorius & Diedericks, 1991). A limited number of research studies (Chinkanda, 1988; Lea, 1986; Levitz, 1993 ; Philpott, 1994) have focussed on social support and mental handicap in the South African context while others have focussed on stress and coping resources in families with mental handicap. In this study both variables, social support and coping and stress resources of parents with mentally handicapped children will be investigated.

It is against this background that social support and coping and stress resources of parents with mentally handicapped children will be investigated in this study.

1.2 Focus of present study

The broad aim of this present study is to investigate the relationship between social support and coping and stress resources of parents with moderate to severely mentally handicapped children in the Cape Town Metropolitan area.

The objectives of the study are to investigate the following:

(i) To examine the relationship between dimensions of social support of parents with moderate to severely mentally handicapped children and parental coping and stress in the Cape Town Metropolitan area.

(ii) To examine the extent that social support plays a predictive role in parental coping and

stress with a mentally handicapped child, that is, to determine whether dimensions of social support are significant predictors of parental coping and stress.

(iii) To examine the relationship between parents' network orientation, that is, the parents' willingness to make use of social support and parental coping and stress.

(iv) To examine the influence of demographic variables such as gender, family size and marital status on social support, coping and stress of parents with mentally handicapped children.

1.3 Methodology

The subjects used in the study are parents of mentally handicapped children, who fall within the moderate to severely handicapped category, in the Cape Town metropolitan area.

The sample comprised of 50 parents (18 males and 32 females) with moderate to severely mentally handicapped children, who have an intellectual functioning within the IQ range of 55-25 (DSM 1V, 1994). The parents who participated in the study had children who attended three special care centres and training centres for mentally handicapped children in Gugulethu, Khayelitsha and Mitchells' Plain in the Cape Metropolitan area. A self-administered questionnaire was used to collect the data for this study. The questionnaire comprised three scales namely: The Short Form of the Questionnaire on Resources and Stress (QRS-F) that measured the coping and stress of parents with mentally handicapped children (Friedrich, Greenberg & Crnic, 1983), The Inventory of Social Supportive Behaviour (ISSB) that measured the structure and characteristics of social support (Barrera, Sandler & Ramsay, 1981), while the Network Orientation Scale (NOS) measured parents' willingness to make use of social support (Vaux, Burda & Steward, 1986).

In addition ,the questionnaire included a Personal Details Questionnaire (PDQ) that measured the demographic variables of the parents with mentally handicapped children (Lea, 1986). Included in the PDQ were open-ended questions that asked for in-depth information on support, coping and stress of parents with mentally handicapped children.

1.4 Key concepts

The core concepts used in this study are mental handicap, families with mentally handicapped children and social support. These concepts will be broadly defined in the following section.

1.4.1 Mental Handicap

Great confusion surrounds the conceptualization of mental handicap. This confusion can possibly be attributed to the fact that a diversity of conditions/deficits are often grouped together under the one category of mental handicap (Edgerton, 1979). The standard view of mental retardation refers to *"the significant sub-average general intellectual functioning (2 standard deviations below the normal) existing concurrently with deficits in adaptive behaviour and manifested during the developmental period"* (Kaplan & Sadock, 1981: 851). This view regards individuals as mentally handicapped because they suffer primarily from intellectual deficiency that impairs their ability to function as fully competent human beings.

Different sub-categories exist within this broad categorisation of mental handicap, namely, mild, moderate and severe mental handicap (Kaplan & Sadock, 1981). The mildly mentally handicapped are often referred to as educable mentally handicapped. Traditionally these individuals are educated in self-contained environments and are often only identified when they enter school. The mildly handicapped usually develop social and communication skills similar to those of the non-

handicapped (Kaplan & Sadock, 1981). According to the American Association for Mental Deficiency (AAMD) classification, mild mental handicap falls between the 55-69 IQ range (Kaplan & Sadock,1981). The moderate mentally handicapped, often cannot benefit from traditional schooling, but need specialized training. According to the AAMD classification in Kaplan and Sadock (1981) the moderately mentally handicapped fall within the 40-54 IQ range.

The severely and the profoundly mentally handicapped are in most cases identified at birth or soon after birth. This group is in most cases unable to care for their personal needs, such as eating and drinking. These individuals are often confined to a wheelchair and/or to a special institution. According to the AAMD classification in Kaplan and Sadock (1981), this group falls within the 25-39 IQ range.

The label of mental handicap has changed over the years. In the past terms such as "idiot", "moron", "imbecile" were used to describe individuals with limited intellectual functioning. Today more sensitive terms, namely, mental handicap and intellectually deficient are used (Lea & Foster, 1990). The changing terminology reflects a shift in the medical profession's consensus regarding mental handicap as well as the changing political and social agenda in society (Landesman & Ramey,1989). According to Khan (cited in Lea & Foster, 1990:205) *"the shift from one label to another is an attempt by professionals to militate against the humiliation, segregation and discrimination associated with the label mental handicap".*

Many researchers feel that by using a more appropriate and more sensitive term, the stigma associated with this label will be reduced. A number of researchers (Seed, 1980; Braginsky & Braginsky, 1971; Lea & Foster, 1990) suggest that the term mental handicap should be critically

re-examined. According to their view, mental handicap is a convenient category created by the medical profession for controlling those people who do not confirm to societal norms and attaching a label of mental handicap will always have stigmatizing consequences. Ryan (1980) also supports this view. According to this researcher mental handicap is seen as a "social problem", a social construction, because of society's intolerant attitude towards individuals who do not act according to social norms and are, therefore, regarded as social deviant.

In this study mental handicap is understood as a condition where an individual has a deficient intellectual ability or suffers from a intellectual impairment that limits or prevents the fulfilment of a role that is normal depending on age, sex, social and cultural factors, for that individual (United Nations Action Programme, 1983). In this study the focus will be on moderate to severely mentally handicapped children with an IQ range of 55- 25.

1.4.2 **Families with mentally handicapped children**

Mental handicap is a permanent condition (Cooke, Hollingshead & Tickton, cited in Lea & Foster, 1990), therefore families of mentally handicapped children have to accommodate and adapt to lifelong caring, coping and providing for these children. Research by Plienis, Robbins and Dunlap (1988) indicates that parents usually see their children as an extension of themselves. For most parents, giving birth and raising a child is an experience which involves loving, caring and providing. Producing a healthy child presents parents with a sense of psychological and physical adequacy. In the case of parents with a mentally handicapped child, the reaction to the birth and the feelings and behaviour of parents towards the child are usually different to those shown towards normal children. Parents often see the birth of a mentally handicapped child as a reflection of their own inadequacies (Gowan, Demos & Koskaska ,1972). This sense of

inadequacy is frequently closely linked to feelings of anger, denial, guilt and rejection. These feelings can also be described as feelings of loss, because they are similar to parents' reaction when they lose a child (Solnit & Stark, cited in Lea & Foster 1990; Kennedy, 1970; Kromberg, cited in Lea & Foster, 1990). Some researchers (Kubler- Ross, 1970; Worden, cited in Hornby, 1996) indicate that families with mentally handicapped children pass through stages of loss as part of the adjustment process.

Research has also indicated that caution should be taken when using these stage theories and not to apply them in a rigid manner (Bristol, 1984). The adjustments and reaction of parents to mentally handicapped children are not necessarily the same for everyone. It is an individual process where each family has its own unique factors operating within the family. These factors will determine the effect that a mentally handicapped child will have on the family functioning. In some cases parents and families never fully adjust to the idea of raising a mentally handicapped child. However, according to Levitz (1993), in most families there are a common cluster of reactions such as shock, anger, sadness, denial and reorganisation until the stage of adaptation is reached.

According to Cunningham and Davis, (cited in Levitz, 1993:51) *"it is not really possible to make precise predictions about which factors are likely to have effects on particular families at particular times"*. In some instances families will exhibit certain similarities in terms of reactions and adaptation, while in other situations these reactions might differ (Levitz, 1993). According to Garguilo (cited in Levitz , 1993) some families see the birth of a mentally handicapped child as a crisis that can be resolved, for other families it is a tragedy, while other families regard it not as a problem in itself, but as an additional element in their struggle for survival. According to

Northern and Downs (cited in Levitz , 1993:51) *"Whatever the factors are that determine parental attitudes to raising a mentally handicapped child, there is perhaps no easy way to cushion the shock of finding out that a child is handicapped"*. Parenting mentally handicapped children presents situations and problems for which few parents have been trained or prepared. For most parents this is a traumatic period and could be characterized by a strong emotional upheaval. This stressful life event (Flynt et al.,1992) may trigger emotional conflict and it is during this time that social support is very important.

When looking at the impact of a mentally handicapped child on the family it is important to take cognisance of the family culture, socio-economic class, parental coping resources, family size, religion, severity of the handicap and the family's adaptation to raising a mentally handicapped child (Levitz, 1993). A recent study by Kwai-sang et al. (1999) found that a consistent pattern of factors will enhance family coping and facilitate parental adjustment to a mentally handicapped child. These factors include quality of personal resources, marital relationship, characteristics of the mentally handicapped child and the availability of a small intense social support network.

1.4.3 **Social support**

Social support refers to the strength and the sustenance that individuals provide for each other through their interactions (Chamber, cited in Braude & Francisco- La Grange). Social support in this research draws on Thoits' (1986) definition of social support. This definition states that social support is *"helpful functions performed by significant others such as family members, friends, co- workers and neighbours and thereby enhances the individual's physical and psychological well-being"* (Thoits 1986: 417).

Many researchers see social support as instrumental in parental adjustment to raising a mentally handicapped child (Fotheringham & Creal, 1974; Gallagher et al.,1983; Gath, 1977). Other researchers (Barrera, 1981; Du Bois, Felner, Meares & Krier, 1994; Pretorius & Diedericks, 1991) indicate that social support acts as a buffer against stress. It can moderate the effect of a stressful life event such as the occurrence, adaptation and raising of a mentally handicapped child (Flynt et al., 1992). It appears from this research that especially emotional support, assistance and informational guidance is necessary to help parents cope with their mentally handicapped child. Social support networks such as the family, friends and community resources can be seen as natural helping resources. A social network is formed when a group of people are organised together in a community and have a common purpose (Braude & Francisco-La Grange, 1993).

1.5. Chapter Overview

In **Chapter Two** families with mentally handicapped children will be discussed in detail. The issues that will be focussed on are the raising of a mentally handicapped child as a stressful life event, the effects of the mentally handicapped child on the parents and siblings, the role of socio-economic status, religion, social support services and other intervening variables that might impact on stress for parents of mentally handicapped children.

In **Chapter Three** an overview of the concept social support will be presented. Stressful life events such as raising a mentally handicapped child and the need for social support will also be discussed. **Chapter Four** comprises an overview of the methodology. In **Chapter Five** the results of the research will be reported. In **Chapter Six,** the results highlighted in chapter five are discussed and recommendations are made in the light of the results obtained.

CHAPTER TWO

FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

2.1 Introduction

This chapter is an overview of the literature pertaining to the impact of a mentally handicapped child upon the family. The main focus will be on how parents and siblings cope, as well as on the various factors which influence this stressful situation.

Parents who experience the birth of a mentally handicapped child will encounter a greater level of stress and will require greater adjustment (Bradshaw & Lawton, 1978; Chetwynd, 1985; Levitz, 1993; Molteno & Lachman, 1996; Scott, Sexton, Thompson & Wood, 1989) than those parents who do not have mentally handicapped children.

2.2 Impact on the nuclear family

The reaction of parents to a mentally handicapped child are usually different to those of giving birth to a normal child . Parents experience feelings of anger, denial, guilt and rejection that can be described as a feeling of loss (Solnit & Stark, cited in Lea & Foster, 1990). Researchers such as Hornby (1996) and Kennedy (cited in Lea & Foster, 1990) indicate that families with mentally handicapped children pass through these stages of loss as part of the adjustment process. However, caution should be taken when applying these stage theories too rigidly (Bristol, 1984). According to Flynt and Wood (1989) coping with a mentally handicapped child is an individual process, and in some cases parents and families never fully adjust to the idea of raising a mentally handicapped child. The adjustments and reaction that parents of mentally handicapped children

experience are not necessarily the same for all parents, but according to Levitz (1993) in most families there are certain similarities of reactions. According to Cunningham and Davis (cited in Levitz, 1993:51), *"It is not really possible to make precise predictions about which factors are likely to have an effect on particular families at particular times"*. In some instances families will exhibit certain similarities in terms of reactions and adaptation, while in other situations these reactions might differ (Levitz, 1993). According to Garguilo (cited in Levitz, 1993), some families see the birth of a mentally handicapped child as a crisis that can be resolved, while other families regard this as a tragedy and as an additional element in their struggle for survival.

Parents of mentally handicapped children are often presented with situations and problems for which they have not been trained or prepared to deal with effectively. For most parents this is a stressful event and could be characterized by strong emotional conflicts and it is during this time that social support, like counselling, is often sought (Flynt et al., 1992, Prescott & Hulnick, 1979). According to Molteno and Lachman (1996) moderating variables such as social support can enable families to cope more successfully with this stressful situation.

Cooke, Hollingshead and Tickton (cited in Lea & Foster, 1990) indicate that mental handicap is a permanent condition and families of these children have to accommodate and adapt to lifelong caring, coping and providing. The manner in which families react and adapt to this stressful situation depends on the severity of the handicap, the stability of the family and the amount of social support available in and outside of the family (Petersen, cited in Levitz, 1993). Other factors that we need to take cognisance of when looking at the impact of a mentally handicapped child on the family are the family structure and family size, the culture and religion of the family and socio-economic-status of the family. According to a recent study by Kwai- Sang et al.

(1999), a strong marital relationship, personal resources as well as a small but an intense social support network is necessary to facilitate parental adjustment to a mentally handicapped child.

2.2.1 **Impact on parents**

When focussing on the impact that a mentally handicapped child has on parents, it is important to take cognisance of the parents total life situation (Kotze & Folscher, cited in Levitz, 1993). Parents' own personal characteristics such as coping style, psychological well-being as well as health issues must be taken into account and these characteristics will determine parental reactions and feelings of coping with a mentally handicapped child (Levitz, 1993).

According to Holt (cited in Gath, 1977), some ill effects on the physical and psychological health of parents with mentally handicapped children have been found. Parents with mentally handicapped children were found to visit hospitals with various health problems more frequently than parents without mentally handicapped children. According to a South African study Kromberg and Zwane, (cited in Parekh, 1988) parents with Down's syndrome children often have difficulty with depression, tiredness and sleeplessness and this could contribute to ill health. The severe emotional stress associated with having a mentally handicapped child could thus make individuals more vulnerable to illnesses and psychosomatic problems. Other studies also indicate that emotional manifestations such as depression, anxiousness, anger, psychosomatic problems and a decrease in social mobility and isolation are common amongst parents with mentally handicapped children (Cummings, Bayley & Rie, 1966, Holroyd, 1974).

A study by Cummings et al. (1966) indicates that mothers of mentally handicapped children often experience greater depression than fathers. Mothers tend to be more preoccupied with the child,

show less enjoyment of the child and greater possessiveness. Mothers of mentally handicapped children also appear to have higher levels of stress (Holroyd & McArthur, 1976). According to Molteno and Lachman (1996) more stress is reported by mothers in single parent families. This research indicates that single mothers see themselves as having too many demands and responsibilities placed on them and they do not get any support from the father of the mentally handicapped child. This might lead to the stifling of the mother's own personal development. A South African study by Philpott (1994) on the mentally handicapped in the Amaoti community, in Kwazulu-Natal, also indicates that the task of caring for the mentally handicapped falls almost entirely on women. This responsibility restricts working class women from employment and job opportunities.

Whereas there are a number of studies focussing on the reactions and the affective states of mothers with mentally handicapped children, very few studies focus only on fathers of these children. One study that focussed on fathers with mentally handicapped children is that of Cummings (1976) which shows how fathers are adversely affected by the presence of such a child in the family.

A number of studies (Lea ,1986; Lombard, 1992; Parekh, 1988; Van Rooyen, 1989) show that fathers and mothers experience different types of stress related to having a mentally handicapped child. Fathers report more stress in relation to the acceptance of the child, while mothers experience stress as a result of having to cope with the child. Fathers of mentally handicapped children tend to be depressed, have lower self-esteem and lack interpersonal satisfaction. They also appear to have more knowledge regarding their child's condition and show less emotional involvement with the child than mothers (Cummings, 1976). Fathers also tend to perceive the

child more instrumentally, focussing on how the child will fit into the society or on the child's achievements, while the mother is more expressive in terms of caring and nurturing (Parsons & Bales,1955). According to Turnbull and Turnbull (1986) raising a mentally handicapped son will have a more adverse effect on the father than on the mother. One possible explanation for this could be that fathers are more concerned with achievements and the development of their children, especially of their sons (Cunningham & Davis, 1985).

2.2.2 Impact on the siblings

Research has indicated that the presence of a mentally handicapped child in the family also effects the siblings (Fischer & Roberts, 1983; Marcus, 1977). Parents may be more accepting of the mentally handicapped child if there are normal siblings in the family. Especially in larger families more family members are available to assist and care for the mentally handicapped child and this could help relieve some of the strain that is placed on the parents (Turnbull & Turnbull, 1986).

Various studies (Gath, 1974; McKeever, 1983) indicate that siblings however may be negatively effected by the presence of a mentally handicapped brother or sister. High degrees of anxiety, conflict with parents, lower sociability, problems with interpersonal relationships, stigmatisation and deprivation in levels of parental attention have been reported (Gath, 1974; Lea, 1986; McKeever, 1983).

In a South African study by Parekh (1988) on the quality of sibling relationships in families with mentally handicapped children, it was found that there is a strong and a positive bond between the siblings and the mentally handicapped child. The study also indicated a lack of rivalry and aggression towards the handicapped child. Other studies show that siblings of handicapped

families are not necessarily a "population at risk" (Gath,1974; Gath & Gumley,1987; McKeever,1983).

Studies (Dyson, Edgar & Crnic, 1989; Mink & Nihira, 1987) also indicate that sibling reactions toward the mentally handicapped sibling are influenced by psychological factors related to the parents' reactions, their stress and coping resources, family relationships and their stability. These factors will be a predictor of how the siblings will adjust to the presence of a mentally handicapped child in the family.

To summarise, research indicates that parents raising mentally handicapped children do experience more stress than those who do not have mentally handicapped children. When focussing on the impact that a mentally handicapped child has on the nuclear family, the life situation of the parents as well as the siblings should be taken into consideration. Parents' own personal characteristics, such as coping style, their physical as well as psychological well-being will determine their reactions and coping with a mentally handicapped child. These psychological factors related to parents' reactions, their coping resources and family relationships could possibly have an influence on how siblings will react towards their mentally handicapped sibling.

2.3 Factors that impact on family functioning

2.3.1 Socio-economic status (SES)

A family's socio-economic status includes the level of income of the family, the level of education of the family and the social status implied by their occupation and wage earnings (Turnbull & Turnbull, 1986). The association between stress in the family with a handicapped child and socio-economic status is well described in various research studies (Parekh,1988; Turnbull & Turnbull,

1986). According to Turnbull and Turnbull (1986) the assumption that families with higher SES have more resources available to cope with a mentally handicapped child, is not necessarily true. This study indicates that families with higher SES do not always cope better, because high SES groups tend to be more achievement orientated. Having a mentally handicapped child in the family may be seen as a disappointment. Lower SES families value achievement less and are more focused on family closeness, happiness and survival. According to Parekh (1988) low SES black families with mentally handicapped children in South Africa experience additional stress, as their already limited financial resources are stretched by the presence of a mentally handicapped child. This is supported by Baldwin (cited in Molteno and Lachman ,1996) who found that having a mentally handicapped child can result in loss of earnings, additional cost for medical and special care facilities and special equipment. Lea (1986) on the other hand is of the opinion that low white SES families with mentally handicapped children experience less stress than parents with mentally handicapped children in the middle or higher SES groups, because these families tend to be more achievement orientated. Lombard (1992) also argued that white parents with mentally handicapped children experience more stress than black parents as a result of a lack of social support, over-involvement with the child and a lack of family integration. Black families on the other hand reported greater stress than their white counterparts in relation to the child's incapacity and the child's ability to perform self care tasks. This could be related to a lack of facilities and resources available to families with handicapped children in the black community.

Molteno and Lachman (1996) report that the current social changes in South African society such as lack of facilities and financial restrictions may provide additional stressors for families with mentally handicapped children.

Families living in disadvantaged communities where unemployment, poverty, overcrowding and violence are common, might experience extreme levels of stress.

2.3.2 Religion

Religion has been identified as a mediating factor in parents' adaptation to a mentally handicapped child. Religion plays an important role in the acceptance and coping with a mentally handicapped child (Parekh, 1988; Shea & Bauer, 1985). A number of studies suggest that families with strong religious convictions have greater acceptance, more positive adaptation, less stress and a greater orientation for caring of the mentally handicapped child at home (Parekh, 1988).

2.3.3 Social Support

Social support has also been reported to be instrumental in parental adjustment to a mentally handicapped child. Researchers like Barrera (1981), Du Bois et al. (1994), Molteno and Lachman (1996) and Pretorius and Diedericks (1991) indicate that social support acts as a buffer against stress. This can moderate the effect of a stressful life event such as the raising of a mentally handicapped child.

The quality and the quantity of social support available to parents with mentally handicapped children will have an impact on the coping and stress of parents. According to Lea (1986) different types of social support are available to parents with mentally handicapped children. The most intimate form of social support is the support given by close family and friends and this type of social support seems to be more beneficial to parents than the social support from the wider community. According to Kwai-Sang et al. (1999), a small, but intense social support network facilitates parental adjustment to a mentally handicapped child.

2.3.3.1 Social support services for the mentally handicapped in the Cape Town Metropolitan area

The availability of appropriate social services which serve the needs of the mentally handicapped and their families is crucial and could help alleviate the stress of parents with mentally handicapped children.

Institutional facilities such as Lentegeur and Valkenberg psychiatric hospitals previously constituted the main service delivery for the moderately to severely mentally handicapped in the Western Cape. Over the past twenty years the focus has changed to community care services. These services are provided via special care centres, ELSEN schools as well as work and occupational centres for the mentally handicapped. A few non-governmental organisations also play a major role in providing services for the mentally handicapped. The Western Cape Forum for the Mentally Handicapped is one such organisation. They provide services to ± 23 ELSEN schools, 36 special care centres, 20 group homes and 14 protective workshops for the mentally handicapped.

Most of these services are provided in the form of day-care or residential care and are dependent on funding and human resources for their continued existence. These day care centres require a range of educational, recreational and medical services to provide an adequate service to the mentally handicapped, but due to limited funding this is not always possible.

Due to the limited community based facilities for the mentally handicapped, parents often decide to make use of institutional placement for their mentally handicapped children. Only a few institutional placements are available in the Western Cape. These institutions play a role in

managing the educational, emotional as well as medical needs of the mentally handicapped. But these institutions are also faced with the difficulty of subsidy cuts and some are even facing closure. It would appear that the service provision for the care of the mentally handicapped at present in the Western Cape as well as the rest of South Africa is still inadequate and that an imbalance in provision of services for the various population groups with mental handicap, still exists. In the light of this, alternative service provision in the form of social support could play a role in alleviating the stress of parents with mentally handicapped children.

Alternative service provision could thus be in the form of support groups for parents and community based support for families with mentally handicapped.

2.3.4 Coping Resources of Parents

How parents deal with stress will determine how they will cope with the raising of a mentally handicapped child. According to Peterson (1987), coping depends on the severity of the mental handicap, stability of the family, social support within and outside of the family and the availability of services. Specific parental characteristics may also influence their ability to cope with stressors in general and specifically in dealing with mentally handicapped children. According to Rabkin and Streuning (cited in Gallagher et al., 1983) factors such as SES, intelligence, verbal skills, morale, personality characteristics, past experiences, age and occupation play a role in mediating the perception of stress. This research also indicates that individuals who have versatile defence mechanisms and experiences with particular sources of stress will handle it better. According to Lavelle and Keogh (cited in Gallagher et al., 1983) parents' perceptions and views of the cause of the mental handicap condition may affect their behaviour towards the child and also how they cope with the situation. Rosenberg (cited in Gallagher et al. ,1983)

reports that a lack of education, limited income, parental illness and limited intellectual abilities of parents will influence the parents ability to care for the mentally handicapped children.

Marcus (1977: 393) reports that coping with such an emotionally demanding situation will require "resourcefulness and resilience" of parents. This refers to parents intrinsic personality factors such as resourcefulness and resilience which will affect how parents cope under stress.

2.3.5 **Coping process and reactions of parents**

The concept of coping is seen as relative to that of stress. The two concepts are, in most research, associated with one another (Lazarus, 1966). In some research, coping is seen as a process, while other researchers see it as a response or an outcome to a stressor (Lazarus, 1966). Most literature focuses on the process of coping of parents with mentally handicapped children (Lazarus, 1966). This process of coping is often referred to as the adaptation process (Lazarus, 1966) This adaptation process can be describe in terms of different phases and stages such as protest, despair and detachment (Kromberg, 1977). According to Wright (1976), reactions such as shock, denial, guilt, anger and recovery are also part of the adaptation process that parents have to go through in order for them to make a successful adaptation to a stressful situation.

An alternative approach to understand how parents cope with a mentally handicapped child is that which considers coping as an outcome or a response to a stressful situation. Hutt and Gibbey (1979) distinguish between three types of coping strategies that parents with mentally handicapped children use. These coping strategies are called, "the accepting parent", "denying parent" and "the disguising parent". The accepting parent is regarded as having coped most adequately with the stress of raising a mentally handicapped child. The accepting parent can be

regarded as having made a positive adjustment to the child. The denying and the disguising parent are described as having coped least adequately with the stressful situation. They are regarded as not having come to terms with the child's handicapping condition. The disguising parent will attempt to conceal the child's defect from others.

They often acknowledge something is wrong, but will attribute it to something else. The denying parent refuses to accept that the child suffers from any condition and regards the child as normal.

These coping strategies assist parents in coping with a stressful situation. Rutter (1981) however claims that these strategies are not always effective in assisting parents in their coping process. Shapiro (cited in Lea, 1986) distinguishes between the individuals' coping resources and coping responses. Coping responses refer to the actions, feelings and thoughts elicited by the stressor. The coping resources on the other hand are defined as aspects that are related to the individuals' internal and external environment over which the individual has little or no control. Internal coping resources refer to the parents' personality attributes, such as self-concept and psychological well-being whereas the external coping resources refer to the external environment such as the social class and social support of parents.

In summary various extraneous factors such as socio-economic status, religion, social support play a role in the family functioning of parents with mentally handicapped children. These factors can either exacerbate or ameliorate the impact of a mentally handicapped child on family members.

2.4 Models of family functioning

The concept of the "family" is complex, but in most research it has been conceptualized as a

system (McCubbin & Patterson, cited in Hornby, 1996). The family can be viewed as a system where all components are in interaction with each other (both within the family system and in the environment) and is located within a number of other societal systems, each with its own characteristics and relationships. These components do not operate in isolation, but interact both within and between systems. Changes within one component of the family system will have an impact on the other component.

2.4.1 The ecological model of family functioning

The ecological model of family functioning according to Mitchell (cited in Hornby ,1996) fits into the systemic approach to family functioning. This model suggests that human development and behaviour cannot be understood in isolation or independently from the social context. Thus parents with mentally handicapped children are also influenced by the social context in which they live. The ecological model looks specifically at the functioning of families with mentally handicapped children and how they function at different levels, that is, namely the microsystem, the mesosystem the exosytem and macrosystem.

2.4.1.1 Microsystem

The family of the mentally handicapped child constitutes the microsystem. This usually includes the mentally handicapped child, parents and the siblings who have a reciprocal influence on each other. The family functioning depends greatly on the different variables of the mentally handicapped family member. This includes the features, such as the severity of the condition, the age of the mentally handicapped child and the physical characteristics of the child (Mitchell, cited in Hornby, 1996).

2.4.1.2 **Mesosystem**

The family's microsystem is influenced by the mesosystem in which it is embedded. The mesosystem comprises a range of settings like the extended family and the community in which the family is based. The extended family, such as the grandparents can play an important support role in determining how a family with a mentally handicapped child will cope. If the extended family is understanding and supportive it can have a significant influence on the family functioning (Mitchell, cited in Hornby, 1996).

Neighbours, work mates and friends can also have a positive or negative influence on the family with a mentally handicapped child. Parents contact with social workers, teachers and doctors also help to promote healthy family functioning if these professionals are supportive. Parents with mentally children often have contact with professionals in health, education and social welfare. These professionals can be an invaluable source of support and guidance.

2.4.1.3 **Exosystem**

The exosystem consists of social settings which indirectly affect the family. Examples of this are the media, education system and agencies that work with mentally handicapped children. The way these children are portrayed in the media, newspaper or television will have an impact on the family. The quality and types of health, education and social welfare services available to families with mentally handicapped children will have a definite influence on how these families cope. The availability of voluntary societies and support groups play a significant role in how families cope (Mitchell, cited in Hornby, 1996).

2.4.1.4 **Macrosystem**

The macrosystem refers to the attitudes, beliefs, values and the ideologies that are inherent in the society (Hornby, 1996). This will have an influence on the family and how they will function. The culture in which the family is living will have a major effect of family functioning. If the culture has humanitarian values, the attitude towards people with handicap will likely be positive. The specific type of community in which the family lives will also have an influence on how the family with a handicap will function in a developing country (Hornby, 1996).

The Ecological model of family functioning looks at all levels of interactions within the family system and within the environment. Effective functioning at all levels, that is, within the family system and in the environment, will help parents cope and adapt to raising a mentally handicapped child. In this study the main objective is to focus on the relationship between social support, parental coping and stress resources. The Ecological model focuses on all levels and types of social support and looks at the impact that all these factors have on families with mentally handicapped children.

According to Gottlieb (1981) three levels of social interaction exist between the individual and the social environment, namely the micro, mezzo and macro level of social interaction. These three levels of social interaction also exist within the definition of social support. The micro levels includes the intimate relationships like the family and other close friends, the mezzo level includes social networks, whereas the macro level includes the members of the community.

The ecological model of family functioning fits into this framework of social support used in this study in that it looks at all levels of interaction and different types of social support and how this

will impact on families with mentally handicapped children.

2.5 Conclusion

Having a mentally handicapped child affects parents in varying ways. The situation of each parent is different and unique and cannot be stereotyped in terms of behaviour patterns. The family functioning cannot be considered simply as a response to a mentally handicapped child in the family, but it will be more meaningful to consider the familial adaptation as a response to the mentally handicapped child. Mediating factors such as SES, religion, social support, the parents coping resources, their resilience and the ecological environment of the family all play a vital role in how families with mentally handicapped children adapt.

CHAPTER THREE

SOCIAL SUPPORT

INTRODUCTION

In this chapter the focus will be on the concept of social support, models for understanding the concept of social support and the impact of social support on stressful life events.

3.1 Conceptualisation of social support

Social support and social support networks are two concepts that are often used interchangeably. According to Braude and Francisco-La Grange (1993), the term social support network refers to a group of people who are organised together in a community and have a common purpose. Social support networks are the linkages and interrelationships between people and these networks fulfill important functions (Braude & Francisco-La Grange, 1993). This view is supported by Antonucci (1985:96), who indicates that *"social support networks can be conceived of as vehicles through which social support is distributed or exchanged "*.

The term social support refers to the strength and the sustenance that individuals provide for each other through their interaction (Braude & Francisco-La Grange, 1993). Social support can thus be defined as helpful resources or social supportive resources that are provided by significant others, such as the family, friends and relatives, through their social network.

The social supportive resources include information giving, material assistance, physical comforting, empathic listening and assistance in problem solving.

From the above, it can be concluded that social support networks are social networks that provide supportive resources and that perform helpful functions for individuals by significant others. According to Naran (1991) large social networks do not always mean that individuals will receive social support within those networks. Homogeneous social networks that are dense, durable and have intense relationships and ties are more likely to provide individuals with social support (Walker, Macbride & Vachon, cited in Naran, 1991; Kwai- sang et al., 1999).

The merits of social support and its contribution to psychological and physiological adjustment have been highlighted by a number of researchers (Barrera et al., 1981; Hardy, Richman & Rosenfield ., 1991; Naran, 1991; Pretorius & Diedericks, 1991; Rook, 1987; Sarason, Liviene, Bashan & Sarason, 1983; Wilcox, 1981). The available literature suggests that social support may either have a direct effect on psychological adjustment (Bowlby, 1969) or can operate as a stress buffer, moderating the relationship between stressful life events and psychological disorder (Cobb,1976). Empirical support for both roles of social support have been reported (Pretorius & Diedericks, 1993). There have, however, also been studies that failed to confirm either the direct or stress-buffering effects (Hirsch, 1980). Some of these studies indicate a direct relationship between social support and psychological distress (Hardy et al., 1991; Holahan & Moos, 1981; Hirsch, 1980).

The literature reviewed indicates a diversity of results and consequently a diversity of definitions of social support. These inconsistencies can be traced to the variety of conceptually different instruments that have been used to measure social support. Procidiano and Heller (1983) support this view and point out that there is a conceptual vagueness about the term social support. According to their research the definition and the measurement of social support has been too

simplistic and this has further contributed to the inconsistency of results. The rise in popularity of the concept social support can also be seen as one possible reason why various definitions have been put forward (Barrera & Ainley, 1983). Lieberman (1986:461) also points out that because of *"the expanding conceptual inclusiveness of social support, a morass has been created that signifies the absence of a unitary body of knowledge"*.

From the literature reviewed (Barrera & Ainley, 1983; Brownell & Shumaker, 1984; Lieberman, 1986; Procidiano & Heller, 1983) it becomes apparent that the current theoretical foundation of social support is in disarray. According to researchers (Leavy, 1983; Pretorius & Diedericks, 1991; Sandler & Barrera, 1984) a multi-dimensional approach to social support is necessary and could counteract some of the problems mentioned above.

3.1.1 **Broad definition of social support**

Literature (Lin, Dean & Ensel, 1986) indicates that although most researchers have adopted their own definitions on social support, these definitions have recurrent and common themes. A definition broad enough to capture all the commonalities and themes of the different definitions is thus necessary. A broad definition of social support is: "*Social support refers to the helpful functions performed for a distressed individual by significant others such as family members, friends, co-workers, relatives and neighbours*" (Thoits, 1986: 417). This definition includes a wide range of relationships that operate at different levels and focus on different types of social support.

According to Gottlieb (1981), three levels of social interaction exist between the individual and the social environment namely the micro, mezzo and macro level of social interaction. These three

levels of social interaction also exist within this broad definition of social support. The micro level includes intimate relationships like the family and other close friends; the mezzo level includes social networks and relatives whereas the macro level includes the members of the community. The ecological model of family functioning of Mitchell (cited in Hornby, 1996) fits into this framework of social support.

This definition of Thoits (1986) also includes different types of social support, namely instrumental, expressive and informational support. Instrumental support refers to material aid, for example, money and clothing. Expressive support refers to emotional and behavioural types of support provision, for example, showing affection physically and verbally, while informational support refers to imparting information and giving advice.

For the purpose of this study social support will be understood as the helpful functions or supportive resources that are provided for individuals (parents with mentally handicapped children) by significant others, such as the family, friends and neighbours, in times of need, to enhance their physical as well as their psychological well-being.

3.2 **Models for understanding social support**

Literature proposes various conceptual models for determining and understanding the effect of social support (Hardy et al.,1991; Pretorius, 1991). The four models of social support that will be discussed in this section are the health sustaining model, stress reducing model, network orientation model and interaction model.

3.2.1 The Health Sustaining Model

The central theme of this model is that social support is a basic human need and is necessary for psychological and physical well- being (Sandler & Barrera, 1984). This model postulates that social support has a direct effect on the experience of psychological well-being. This direct effect approach stems from a basic human need that must be satisfied in order for an individual to enjoy a sense of well-being (Sandler & Barrera, 1984). This model is also known as the main-effect model of social support and is best described by the direct-effect hypothesis (Antonucci, 1985). Hardy et al. (1991:130) describe the essence of this model as follows: "*The more effective social support an individual receives, the better his/her mental and physical health. Conversely ineffective or insufficient social support reduces the psychological and physiological well-being*".

The health sustaining model has been discussed by a number of researchers (Antonucci, 1985; Hardy et al., 1991; House, 1981; Turner, 1981), but very little reference has been made to the assessment of this model.

3.2.2 The Stress Reducing Model

This model of social support is by far the most accepted and supported by researchers (Barrera, 1981; Cohen & Willis, 1985; Thoits, 1986; Wilcox, 1981). The stress reducing model (Buffer effect) indicates that there is an interactive relationship between social stressors, social support and psychological distress. Rook (1987: 244) describes the essence of this model as follows: " *Social support cushions or buffers people from the harmful effects of life stress and the lack of social support is problematic only if people are experiencing specific life changes*".

According to the stress reducing model (Gottlieb, 1981) the moderating effect of social support is two fold:

(a) High levels of stress, together with high levels of social support result in lower levels of anxiety and depression and vice versa.

(b) High levels of stress, together with significantly low levels of social support, result in high levels of anxiety and depression.

Hardy et al. (1991) and Pretorius (1991) suggest that both the main effect and buffer effect models should be used together to enhance the multi-dimensional nature of social support and to account for the different influences of variables on social support. It is thus for this reason important to view the two models as complimentary units.

3.2.3 The Network Orientation Model

The network orientation model looks at an individual's willingness to make use of social support and how this plays a role in reducing stress (Lin et al., 1986). The effects of stress on the psychological well-being of individuals is moderated by the person's orientation, that is, his/her willingness to make use of social support and that in turn leads to high or low levels of anxiety and depression (Lin et al., 1986; Vaux et al., 1986).

3.2.4 The Interaction Model

This model is an extension of all the models discussed thus far. This model postulates that environmental influences (social support) interact with an individual's orientation (individual's predispositions) and has an influence on psychological well-being. In other words, this means that

a person's psychological well-being is determined by the interaction between the effectiveness of available support and the person's willingness to make use of available social support (Vaux et al., 1986).

For the purpose of this research study, the interaction model of social support will be used as the theoretical model. The present study is located within the interaction model which combines both the stress buffering as well as the network orientation model. This study attempts to assess/measure social support and parental coping and stress of parents with mentally handicapped children.

3.3 Stressful life events and social support

Stressful life events have been defined as *"any set of circumstances or events which require or signal change in the basic life pattern of an individual "*(Holmes & Rahe,1967:60) and also refer to events that cause psychological pain (Snyder, Ford & Harris, 1987).

Various studies (Barrera, 1981; Cohen & Willis, 1985; Wilcox, 1981) indicate that there is a significant relationship between life events and physical and psychological distress. According to Holmes and Rahe (1967) stress is a stimuli or a situation that disrupts an individual's life pattern. Stress can also be defined in terms of an organism's response to stressful conditions and stressors, consisting of a pattern of psychological and physiological reactions (Rabkin & Streuning, 1976).

According to Sarason and Sarason (1985) most studies on stressful life events link negative life events to symptomatology based on the assumption that: a) life changes requires adaptation and

that life changes are stressful and b) life changes make individuals susceptible to psychological and physical distress. Feelings that are usually associated with negative life events are anxiety, tension, nervousness, depression and frustration (Constantini, Braun, Davis & Iervolino, 1973). Thoits (1986) and Cohen and Willis (1985) indicate that social support could act as a buffer against stress. According to these researchers, social support provides the individual with greater resources and alternatives to deal with the distress. These alternatives could act as a buffer against the stress the individual experiences.

Examples of stressful life events and the impact of social support can be identified in the studies of Wilcox (1981); Barrera (1981) and Ruch and Leon (1986). Wilcox (1981) studied the impact of divorce on women and the role of social support. The results of this study indicate that there is a positive relationship between psychological adjustment and social support in coping of divorced women. According to studies done by Ruch and Leon (1986), social support also played a significant role in the adjustment of rape victims. In a study by Barrera (1981) on the adjustment of pregnant teenagers and the role of social support, a significant relationship between the two variables was found. In a study by Collins, Dunkel-Schetter, Lobel and Scrimshaw (1993) the results indicate that social support plays a significant role in the psychological and physical well-being of pregnant teenagers.

Studies done on families with mental handicap (Blacher, 1984; Crnic et al.,1983; Flynt et al.,1992; Henderson & Vandenberg, 1992; Molteno & Lachman, 1996) indicate that raising a mentally handicapped child can be described as a stressful life event. This stressful life event may trigger emotional conflict and contribute to a change in the basic life patterns of individuals and/or families. Many researchers see the role of social support as instrumental for parental

adjustment to raising a mentally handicapped child (Dunst, Trivette & Cross, 1986; Fotheringham & Creal, 1974; Flynt et al., 1992; Gath, 1978; Gallagher et al.,1983; Molteno & Lachman, 1996). These studies all indicate that there is a positive relationship between social support and parental adjustment to raising a mentally handicapped child. From this it can be concluded that social support does appear to have a buffering effect against stressful life events such as raising a mentally handicapped child.

3.4 Social support studies in South African context

A limited amount of research has been documented regarding social support within the South African context (Diedericks, 1991; Pretorius & Diedericks, 1993). Some of the research studies on social support have been conducted by Braude and Francisco- La Grange (1993); Diedericks (1991); Pretorius and Diedericks (1991) and Pretorius and Diedericks(1993). Chinkanda (1988) and Lea, (1986) have specifically focussed on aspects of social support and mental handicap in the South African context. The findings of their research have indicated that social support is a mediating factor for stressful life events and that the quality and the quantity of the social support available to families of the mental handicap will help them cope with the demands of caring for children with mental handicap.

Various measuring instruments such as the ISSB and QRS-F have been used to measure the impact that a mentally handicapped child has on the family. The instruments used in this study as well as in other studies will be discussed in the next section.

3.5 Research studies using the QRS-F and the ISSB & NOS as measuring instruments

In this study the QRS-F, ISSB and NOS were used to measure social support and coping and

stress resources of parents of mentally handicapped children. Focus will be placed on research studies that have used these instruments to measure the impact that a mentally handicapped child has on the family. The psychometric properties of these instruments will be discussed in more detail in chapter four.

The QRS has been used in various studies internationally (Dunst et al., 1986; Flynt et al., 1992, Friedrich et al.,1983 & Holroyd, 1974). Holroyd (1974) designed and used this instrument extensively to measure stress levels within families. This instrument was used to measure stress in families of institutionalised and non-institutionalised autistic children. According to Holroyd (1987), the QRS is a multi- dimensional, objective self-report questionnaire that may be considered as a culture-fair instrument that can be used in different cultural settings. The QRS questionnaire was revised by Friedrich et al. (1983) and a short-form of the QRS-F was designed. Friedrich et al. (1983) used the QRS-F to measure the coping behaviour of mothers with mentally handicapped children. Three variables, marital satisfaction, child's residence and child's sex, were found to be significant predictors of coping behaviour.

The QRS-F has also been adapted to and used in the South African context. Lea (1986) used this instrument to measure the coping and stress resources of white parents with mentally handicapped children. The research indicated that parents of male mentally handicapped children in custodial care manifested greater stress than parents with male mentally handicapped children in day care. Parents of female children in custodial care manifested less stress than parents with female mentally handicapped children in day care. The gender of the mentally handicapped children was found to play a role in the degree of stress parents experience, this could be due to gender stereotyping, parents' expectations of their child's performance and role within society. Lea

(1986) also indicates that there is no significant difference in the degree of parental stress between mother and father, but they do experience different types of stress. She, however, indicated that the QRS-F is not sensitive enough to measure the different types of stress as experienced by males and females. Its only purpose is to measure stress within the family as a whole.

Berzon (1987) used the QRS-F in a study where he looked at the development of lifestyles and coping patterns in families with mental handicap in South Africa. The study was done with two groups of parents (that is parents of younger and older children). The findings of this study indicated that parents of younger mentally handicapped children when compared to parents with older mentally handicapped children tended to deny the impact of the child on the family as a whole. The parents with the older mentally handicapped children were more able to achieve a certain degree of adaption and adjustment. This stage of recognition and adaption leads to the development of coping patterns and this will influence the family's lifestyle.

Lombard (1992) looks at the stress patterns of families with mentally handicapped children in South Africa. Two population groups were used in a study, namely whites and blacks in which family members suffered from either mental handicap or physical handicap. The QRS-F was used to measure the family stress. The findings of the research indicate that white parents experience more stress than their black counterparts as a result of a lack of social support, over- involvement with the child and a lack of family integration. The black families reported greater stress than their white counterparts in relation to the child's incapacity and the child's inability to perform self-care tasks. This stress could be related to the lack of facilities and resources available to families with mentally handicapped children in black communities.

The Inventory for Social Supportive Behaviour (ISSB) has been used internationally (Barrera et al., 1981, Sandler & Barrera, 1984) to measure adjustment in families of autistic children and adjustment of pregnant women. The ISSB was developed to measure actual supportive behaviours or aid provision, and assesses how often individuals receive various forms of assistance. Research findings (Barrera et al., 1981) indicate that social support acts as a buffer and helps in the adjustment of families with autistic children.

The ISSB has been used in the South African context to measure the social supportive behaviour of students at universities (Pretorius & Diedericks, 1993). The ISSB was used to measure the relationship between dimensions of social support and loneliness amongst undergraduate students at the University of the Western Cape. Research findings (Pretorius & Diedericks, 1993) indicate that social support is a significant predictor of loneliness, namely the less social support the greater the degree of loneliness. It was found that network size, the frequency of guidance and emotional support are the main predictors of loneliness.

According to Pretorius and Diedericks (1991) further aspects of the ISSB need to be addressed to strengthen the usefulness of this instrument. It is suggested that the ISSB needs to be translated into other indigenous languages, such as Xhosa and Zulu. Given the illiteracy rate in South Africa it would also seem appropriate to develop an interview version of the ISSB.

The Network Orientation Scale (NOS) was designed to measure an individual's willingness to use social support in times of need (Lin et al., 1986, Vaux et al., 1986). Their research findings indicate that the effects of stress on the psychological well-being of individuals can be moderated by their willingness to use social support. This could either lead to high or low levels of anxiety,

depression and so on. From the above discussion it is clear that these instruments were all used successfully internationally as well as nationally and proved to be highly reliable (Barrera et al., 1981; Pretorius & Diedericks, 1993; Vaux et al., 1986).

3.6. Conclusion

To conclude, the researcher wishes to reiterate the sentiments of Pretorius and Diedericks (1993) that there exists a great need for researchers to address the backlog in the research area of social support, especially social support and mental handicap in the South African context. In South Africa the services for the mentally handicapped have been severely criticized as being inappropriate and inadequate. Molteno et al. (1994) indicate that service provision for the mentally handicapped and their families have improved over the years, but that a discrepancy still exists regarding the different race groups. In the light of this, the utilisation of natural support resources like the family, friends and co-workers could play a crucial role in providing for the psychological and physical needs of parents with mentally handicapped children.

Cowen (1983) and Thomas (1987) support the above statement by saying that support systems or supportive ties are a crucial aspect of primary prevention in mental handicap and can be seen as one of the pillars that support the physical and psychological well being of individuals and community.

CHAPTER FOUR

METHODOLOGY AND RESEARCH DESIGN

4.1 Focus of present study

The broad aim of this study is to investigate the relationship between social support and coping and stress resources of parents with a mentally handicapped child.

More specifically the following questions were investigated.

1. What is the relationship between dimensions of social support and coping and stress of parents with moderate to severely mentally handicapped children?
2. To what extent does social support play a predictive role in coping and stress of parents with a mentally handicapped children. Are dimensions of social support a significant predictor of parental coping and stress?
3. What is the relationship between network orientation, that is the parents' attitude and willingness to make use of social support and parental coping and stress?
4. What are the influence of demographic variables such as gender, family size and marital status on social support and coping and stress of parents with mentally handicapped children?

4.1.1 Hypotheses

Literature indicates that social support plays a crucial role in helping parents cope with raising a

mentally handicapped child (Flynt et al., 1983; Gath, 1978 & Gallagher et al., 1983). The following hypotheses were drawn from research that indicates that there is a significant relationship between social support, stress and coping resources of parents with mentally handicapped children:

- There is a significant relationship between dimensions of social support (measured by ISSB) and coping and stress (measured QRS-F) of parents with mentally handicapped children.
- High dimensions of social support, that is guidance, emotional and tangible support, are significant predictors high parental coping and low stress.
- There is a significant predictive relationship between network orientation, that is, parents' willingness to use social support and dimensions of parental coping and stress resources.
- There is a significant relationship between certain demographic variables such as gender, family size and marital status of parents, and social support and parental coping and stress.

4.2 Methodology

4.2.1 Subjects

The subjects used in this study are parents of mentally handicapped children who fall within the moderate to severely mentally handicapped category in the Cape Town Metropolitan area. A sample of convenience was used and it comprised 50 parents (18 males and 32 females) with moderately to severely mentally handicapped children who have an intellectual functioning that falls within the IQ range of 55-25 (DSM IV,1994). The parents who participated in the study had children in one of the three special care centres for mentally handicapped children in Gugulethu, Khayelitsha and Mitchell's Plain. These three centres were approached, because ready

access was available. Permission was given by the principal of the special care centres to approach parents to participate in the study.

Both parents were asked to complete the questionnaires to establish the differences in terms of gender regarding their perceptions of social support and their coping and stress resources. In some cases both mother and father filled in the questionnaires, while 64% of the mothers completed the questionnaires on their own. Some fathers (N=8) were reluctant to fill in the questionnaires, others were never available or refused to discuss the issue of their child's handicap with the researcher.

A pilot study was conducted to determine whether the language usage in the questionnaires was appropriate. Ten parents at the three centres volunteered to participate in the pilot study. The questionnaires were piloted amongst the parents, after changing the difficult language terminology to more appropriate terms, the questionnaires were distributed.

4.2.2 **Data collection**

Teachers and child care workers at the special care centres were approached and asked to assist in distributing the questionnaires to the parents. One hundred and fifty parents at the three centres were approached to participate in the study. Only 60 of the 150 parents at the three centres indicated a willingness to participate. It is also important to note that not all of the one hundred and fifty parents attended the parent meetings. The questionnaires were distributed at the parent meetings to the participants who volunteered to complete the questionnaires at their homes.

The nature of the questionnaires and the purpose it would serve, was explained by the researcher to all the participants. The participants were also informed about confidentiality of the questionnaires. The questionnaires were self-administered, parents filled the questionnaires in at home and returned them to the researcher. Sixty questionnaires were distributed amongst the parents. Ten of the questionnaires were half completed and had to be recorded as missing cases. Fifty questionnaires were completed and returned. Due to time constraints no follow-up was done on the questionnaires that were half completed. The response rate of the questionnaires in this study was more than a third. (According to Terre' Blanche and Durrheim (1999) the common trend of return rate for survey research is usually one third of the surveys).

4.2.3 Demographic description of subjects

TABLE 1: Gender

Gender	N	%
Male	18	36
Female	32	64

As can be seen from the table above more females than males (64% and 36% respectively) participated in the study.

TABLE 2: Marital status

Marital status	N	%
Married	39	78
Divorced	3	6
Single	8	16

Seventy eight percent of the participants were married. Six percent of the participants were divorced (all of them females) and sixteen percent of the participants were single parents (all of them females).

TABLE 3: Age

Age	N	%
22 - 30	10	22.7
31- 40	13	29.6*
41 - 50	14	31.8*
51 - 58	7	15.8

* Six missing cases were reported

The age of parents who participated in the study ranged between 22 and 58 years. Sixty one percent of the parents fall within the 31-50 year old category. The average age of parents that participated in the study is 39.5 years

TABLE 4: Educational level of parents

Educational level	N	%
Primary school	22	44
High school	25	51
College/university	1	1
None	1	1

One missing case was reported.

Most of the participants in the study had some form of formal education. The educational level of the participants ranged from primary school education (44%), high school education (51%)

to only one participant with tertiary education. Only one participant indicated no formal education.

TABLE 5 Living arrangements of parents

Living arrangement	N	%
Semi - detached	8	16.3
House	31	63.3
Shack	10	20.4

* One missing case

Most of the participants (sixty three percent) lived in detached houses or semi-detached houses (sixteen percent) as indicated in the table. Twenty percent indicated that they live in shacks.

TABLE 6: Family size

Family size	N	%
2	2	4.1
3	4	8.2
4	14	28.6
5	10	20.4
6	8	16.3
7	1	2.0
8	8	16.3
9	2	4.1

* One missing case

The size of the families ranged between two to nine individuals living together in a house. The family size of fourteen (28,6%) and ten (20.4%) individuals were the highest. The mean family size is 5.

TABLE 7: Wage earnings

Wage earn per month	N	%
R160-250	7	1.5
R300-700	16	43.5
R800-1500	8	22.4
R1000-2500	5	14

Forty three percent of the participants earned between R300-R700 per month. The mean wage earnings is between R500 - R1000. Some of the parents did not fill this section in on the questionnaire. Fourteen missing cases were reported. This could be due to either participants being unemployed or that the participants did not want to disclose confidential information. This could invalidate the results of the research study because some information was withheld.

4.3 Instruments

A battery of three self-administered questionnaires was used in this study to investigate the relationship between social support and parental coping and stress. The three scales were: The short-form of the Questionnaire on Resources and Stress (QRS-F) that measured the coping and stress resources of parents with mentally handicapped children (Friedrich et al., 1983), the Inventory of Social Supportive Behaviour (ISSB) that measured the structure of social support and the characteristics of social support (Barrera et al., 1981), while the Network Orientation

Scale (NOS) measured parents' satisfaction and willingness to make use of social support (Vaux et al., 1986)

The Personal Details Questionnaire (PDQ) measured the demographic information of the parents and the mentally handicapped child. Included in the PDQ were open-ended questions that asked for in-depth information on social support, coping and stress of parents with mentally handicapped children. These will be discussed in Chapter 5.

4.3.1 **Personal Details Questionnaire (PDQ)**

The self-administered questionnaire was designed to assess for demographic information of the parents and the mentally handicapped child. The PDQ covers the following categories of standard demographic information: Gender, age, psychological history, family composition, educational and occupational history as well as socio-economic data. Included in the PDQ were open -ended questions that focussed on the difficulties, the needs, social support and the religious convictions of parents with mentally handicapped children. The open-ended questions provided a greater depth of information on social support, coping and stress of parents with mentally handicapped children. (See Appendix B)

4.3.2 **Short - form of the Questionnaire on Resources and Stress (QRS-F)**

The short-form of the Questionnaire on Resources and Stress (QRS-F) measures the stress and coping resources of parents with mentally handicapped children. This 52-item questionnaire is designed to measure four dimensions, namely of parent and family problems, pessimism, child characteristics and physical incapacitation pertaining to families with mentally handicapped children (Friedrich et al., 1983). Due to the length of the Questionnaire on Resources and Stress

designed by Holroyd (1974), the short form of the questionnaire the QRS-F was designed by Friedrich et al. (1983). (See Appendix B).

The aim of the QRS-F is to produce a score which will indicate a person's stress and coping resources (Holroyd, 1987). The higher the score, the greater the stress level and the lower the coping resources and adjustment of parents. Holroyd (1987) designed the QRS to identify the relevant variables that might contribute to stress in families with mentally handicapped members and how these influence the family's reaction to stress.

The QRS has been used in various studies (Dunst et al., 1986; Flynt et al., 1992; Holroyd, 1987; Lea, 1986; Luiz et al., 1994) and has proved to be a highly reliable measuring instrument, especially regarding different population groups, for example, different race and cultural groups. According to Holroyd (1987), the QRS is a multi-dimensional, objective self-report questionnaire that may be considered as a culture-fair instrument which has been used in different cultural settings.

The questionnaire has also been used effectively in South Africa with white and black parents with mentally handicapped children (Lea,1986; Luiz et al., 1994; Van Rooyen, 1989). According to research (Luiz et al., 1994) the QRS was used to measure stress patterns in families with mental handicap, physical handicap and chronic illness in South Africa and proved to be a highly reliable and valid instrument. It appears that the QRS provides a reliable and valuable measurement of family stress that covers a wide range of family functioning and has proved itself to be an invaluable measurement that measures what it was designed for (Luiz et al., 1994). In the present study the alpha coefficients for the different subscales of the QRS-F were satisfactory. Only one

dimension, physical incapacity, had a low score of .45 which shows a low reliability. Otherwise the instrument proves to be reliable and consistent with other research findings.

TABLE 8: Reliability of subscales for QRS-F in present study

Measure	Alpha Coefficient.
Subscales of QRS-F:	
Parent and Family problems	.87
Pessimism	.61
Child characteristics	.81
Physical incapacity	.45

4.3.3 The Inventory of Socially Supportive Behaviour (ISSB)

The ISSB (Barrera et al., 1981) was developed to measure actual supportive behaviour or aid provision and to assess how often individuals receive various forms of assistance. This questionnaire consists of 40 Likert-scale type items that measure helping behaviour. The dimensions that are measured are guidance, emotional and tangible behaviour. This questionnaire has been used in previous studies to measure adjustment in families of autistic children (Sandler & Barrera, 1984) and adjustment of pregnant women (Barrera, 1981). (See Appendix B).

The ISSB has also been used in the South African context in studies that measured the social support of different population groups (Diedericks, 1991; Pretorius & Diedericks, 1993). According to Pretorius and Diedericks (1993), the ISSB has been adapted to and validated for the South African context and can be seen as a valuable and reliable instrument for measuring

social support. Previous research on the reliability of ISSB indicates high alpha coefficients (Barrera et al., 1981; Pretorius & Diedericks, 1991).

TABLE 9: Reliability of subscales of ISSB in the present study

Measure	Alpha Coefficient.
Subscales of ISSB:	
Guidance	.86
Emotional	.82
Tangible	.79

4.3.4. **Network Orientation Scale (NOS)**

The Network Orientation Scale (NOS) was designed to measure an individual's willingness to use social support in times of need (Vaux et al., 1986). The NOS consists of twenty items to which the participants respond on a 4-point agree-disagree scale. High scores on this scale reflect a negative network orientation, that is, negative attitude towards using social support resources. A low score reflects a positive network orientation, that is a positive attitude towards using social support resources. (See Appendix B).

The psychometric properties of the instrument are well documented (Vaux et al., 1986). According to this research the reliability coefficient for this instrument was r = 0,60- 0,88. Pretorius (1991) also used this scale within the South African context and reported that the scale appears to be adequately reliable and can be used for research purposes. In the present study the alpha coefficient for this scale was r = .35 and proved to be not very reliable.

TABLE 10: Reliability of NOS scale in present study

Measure	Alpha Coefficient
NOS	.35

4.4 Statistical analysis of data

For the purpose of this study the statistical package for Social Science (SPSS-PC) was used to analyse the various questionnaires (Nie, Hull, Jenkins, Steinbrenner & Bent, 1975).

The relationships between the following variables were analysed:

* Social support and parental coping and stress resources
* Social support, network orientation and parental coping and stress resources
* Gender of parents, social support and parental coping and stress resources
* Marital status, social support and parental coping and stress resources
* Family size, social support and parental coping and stress resources

The subprogramme RELIABILITY of the SPSS-PC programme was used to measure the reliability of the scales. According to Diedericks (1991) this is a necessary procedure for any study that makes use of adapted scales.

The FREQUENCY subprogramme of the SPSS-PC programme was used to describe the demographic variables.

The CORRELATION Subprogramme of the SPSS-PC programme was used to determine whether a significant relationship exists between the demographic variables, social support and parental coping and stress. T-tests were also used to determine whether there were significant difference in the responses of males and female respondents in terms of social support and parental coping and stress. One-way analyses of variance were used to determine the differences between the different groups as well within the groups in terms of marital status, social support, coping and stress resources.

CHAPTER FIVE

ANALYSIS OF RESULTS

INTRODUCTION

The aims of the study were firstly to examine the association and predictive relationship between social support and parental coping and stress of parents with mentally handicapped children. Secondly, to examine the association and predictive relationship between network orientation, that is, parents attitude and willingness to make use of social support and parental coping and stress. Thirdly, to examine whether the demographic variables such as gender, family size and marital status of parents play a significant role in their social support and parental coping and stress and fourthly to interpret the responses from the open- ended questions .

The above-mentioned aims of the study (see Chapter 4) led to the formulation of various hypotheses, which will be discussed in the following sections.

5. QUANTITATIVE RESULTS

5.1 Relationship between dimensions of social support, parental coping and stress of parents with mentally handicapped children

Null Hypothesis : There is no significant relationship between the dimensions of social support as measured by the ISSB and parental coping and stress as measured by the QRS-F of parents with mentally handicapped children.

Correlation analysis was conducted to test hypothesis1. Data relating to the hypothesis 1 are

presented in the table below.

Table 11: Correlations between dimensions of social support and parental resources and stress

Social Support (ISSB)	Parental coping and stress (QRS-F)			
	Parent and Family Problems	Pessimism	Child characteristics	Physical incapacity
Guidance	-.1690	-.1788	-.1558	-.3471
Emotional	-.0691	-.1739	-.0618	-.0823
Tangible	.3552	-.0714	.4724	.3229

$p > 0.05$

The above table shows that none of the associations between the subscales measuring social support and parental coping and stress were significant at either the .05 or .01 level. The null hypothesis is supported by the results, indicating no significant association between the dimensions of social support and parental coping and stress. Although the associations between the subscales measuring social support and parental coping and stress were not significant, the direction of three correlations between the different subscales were positive. Table 11 reveals a non-significant, yet positive association between tangible social support, parent and family problems, physical incapacity of the child and child characteristics. Because of the non-significant association and low to moderate correlation between the variables, regression analysis could not be conducted and therefore a predictive association between these variables was not possible.

	q_1	q_2	q_3	q_4	q_5
yes	6	3	5	8	8
No	2	3	3	0	0

Organizing questionnaires responses into categories and assigning a unique code to each response prior to data entry.

5.2 The relationship between parental willingness to use social support and parental coping and stress resources

Null Hypothesis: There is no significant predictive association between the network orientation, that is, parental willingness to make use of social support (measured by the NOS) and the dimensions of parental resources and stress (measured by the QRS-F).

Correlation analysis was conducted to test this hypothesis. Data relating to this hypothesis is presented in the table below.

Table 12:Correlations between network orientation and parental resources and stress

Network orientation	Parent Family Problems	Pessimism	Child Characteristics	Physical incapacity
Network	.2811	.2909	.3361	.0821

P>0,05

The significance of the above associations was tested at 0,5 and 0,1 level. The above table shows that there was no significant association between the subscales of the NOS and the QRS-F, measuring the network orientation, that is, parental willingness to use social support and parental coping and stress. Although the associations between network orientation and parental coping and stress were non-significant, the direction of all the correlations between the NOS and QRS-F was positive. A positive association exists between parental willingness to make use of social support and dimensions of parental coping and stress (family problems, pessimism, child characteristics and physical incapacity). Because of the non-significant association between the two variables, regression analysis could not be conducted and therefore a predictive association

between these variables was not possible.

5.3 The impact of gender difference of parents on social support, network orientation and parental coping and stress resources

Null Hypotheses: There is no significant difference between males and females in terms of their social support, network orientation and parental resources and stress.

An independent t- test was used to determine whether the responses of males and females differ in terms of social support.

Table 13: Summary of the mean scores and the t-test scores on the impact of gender of parents on social support

Type of SS	X	N	T-Values
Guidance	Male 2.8367	Male 7	.43
	Female 2.6758	Female 13	.41
Emotional	Male 2.4821	Male 12	-1.45
	Female 2.9082	Female 21	-1.37
Tangible	Male 2.3000	Male 10	.54
	Female 2.1660	Female 23	.57

P > 0,05

The results of the t-test analysis for gender of parents and social support showed no significant differences. This would imply that gender differences do not have a significant impact on parents social support and the type of social support they require. Thus the null hypothesis is supported by the results.

A t-test was also conducted to determine whether a difference exists between males and females and parental coping and stress.

Table 14:Summary of mean scores and t-test scores on the impact of gender of parents on parental coping and stress

Dimensions of QRS-F	X	N	T-Values
Family Problems	Male 28.5833	Male 12	.58
	Female 27.6364	Female 22	.58
Pessimism	Male 22.9231	Male 13	-.74
	Female 23.5714	Female 21	-.73
Child characteristics	Male 32.5000	Male 14	.60
	Female 31.6364	Female 22	.59
Physical incapacity of the child.	Male 20.3571	Male 14	.69
	Female 19.8846	Female 26	.69

$p > 0,05$

The above table shows that the gender of parents does not play a significant role in parental coping and stress.

The results indicate that no significant differences exist between males and females for the following dimensions of the QRS-F: Family Problems, Pessimism, Child Characteristics, Physical Incapacity of Child.

The null hypothesis is supported by the results.

Table 15: Summary of mean scores and t-test scores on the impact of gender of parents on network orientation

NOS	X	N	T-Values
Network orientation	Male 2.5654 Female 2.4759	Male 13 Female 27	1.51

P > 0.05

As can be seen from the above table no significant difference between males and females in terms of their willingness to use social support was found. The null hypothesis is supported by the results.

5.4 The relationship between family size and social support, network orientation and parental copying and stress resources and stress

Null Hypothesis: There is no significant association between the dimensions of social support, network orientation and parental resources and stress and family size (demographic variables).

5.4.1 The relationship between Social support and family size

Table 16: Correlations between social support and family size

Social Support	Children in the house	Living in house	Number of people in house
Guidance	.3808	.3808	.2322
Emotional	.3088	.3088	.4316
Tangible	.2841	.2841	.4082

p>0,05

The association between social support and family size was tested at the 0,5 and 0,1 levels. Both levels indicated a non-significant relationship between the variables. The direction between all the variables however indicates a positive association. A positive association between the variables could indicate a possible increase in social support as the number of family members increase. The null hypothesis is supported, as no significant relationship between the variables was found.

5.4.2 The relationship between Network Orientation and Family size

Table 17: Correlations between network orientation and family size

NOS	Children in house	Living in house	Number of people in house
	-.1475	-.1475	-.4002

p>0,05

The association between network orientation, that is, parental willingness to make use of social support, and family size were tested for significance at the 0,1 and 0,5 levels. The association between the variables indicates a negative and low correlation. There is thus no significant relationship between network orientation, that is, parental willingness to use social support and family size. Thus, the null hypothesis is supported by the results.

5.4.3 The relationship between parental resources and stress and family size

Table 18: Correlations between parental coping and stress and family size

QRS-F	Children in house	Living in house	Number of people in house
Family problems	-.2913	-.2913	-.2706
Pessimism	-.6417	-.6417	-.6192
Child Character	-.1159	-.1159	-.1021
Physical Incapacity	-.5599	-.5599	-.3192

p>0,05

The correlations between coping and stress resources of parents and family size were tested for significance at the 0.1 and 0.5 levels. An association between some of the variables were non-significant. Two of the subscales of QRS-F, that is, pessimism and physical incapacity do however indicate a significant relationship with family size. The null hypothesis should be rejected for subscale physical incapacity, pessimism and family size, but not for the other subscales of the QRS-F.

The null hypothesis should be rejected for subscales, physical incapacity, Pessimism (QRS-F) and Family size. These variable do have a significant relationship with each other. The other correlations are non-significant, thus the null hypothesis for these subscales of QRS-F should be supported.

5.5 The relationship between social support, network orientation and parental resources and stress and marital status

Null hypothesis: No significant association exists between social support, network orientation, parental coping and stress and marital status.

A one-way analysis of variance was use to analyse the relationship between the groups of married, single and divorced parents and the dimensions of social support.

Table 19: Summary of the F-scores of the one-way Anova on the relationship between guidance (dimension of social support) and marital status of parents with mentally handicapped children

Source	Sums of squares	Df	Mean of squares	F-ratio
Between groups	.6810	1	.6810	1.1278
Within groups	10.8688	18	.6038	

p >0,05

No significant difference was found between the means of the groups, that is, for married, single and divorced parents or within the same group of married, single and divorced parents in terms of their relation to the dimension of social support: guidance.

Table 20: Summary of F-scores on the one-way Anova on the relationship between tangible support and marital status of parents with mentally handicapped children

Source	Sums of squares	Df	Mean of squares	F ratio
Between Groups	.0982	1	.0982	.2247
Within Groups	13.5427	31	.4369	

p >0.05

The table indicates no significant difference between the means of the three groups (married, single divorced parents) and tangible support (dimension of social support).

Table 21: Summary of the F-scores on the one- way Anova on the relationship between emotional social support and marital status of parents with mentally handicapped children.

Source	Sums of squares	Df	Mean of squares	F ratio
Between Groups	3.68532	2	1.8426	3.0334
Within Groups	18.2238	30	.6075	

$p > 0.05$

No significant difference was found between the means of the three groups (married, single and divorced) in relation to the emotional support, dimension of social support. The results indicate that marital status does not play a role or have an effect on the type of social support, that is, guidance, tangible and emotional, that parents require or utilise. The null hypothesis is thus supported by the results.

Table 22: Summary of the F -scores on the one way Anova on the relationship between family problems (a dimension of parental coping and stress resources) and marital status

Source	Sums of squares	Df	Mean of squares	F ratio
Between Groups	9.0039	2	4.5020	.2089
Within Groups	66.79667	31	21.5473	

$p > 0.05$

No difference was found between the means of the groups in relation to family problems (dimension of parental coping and stress). Marital status does not have an influence on the family problems of parents with mentally handicapped children. The null hypothesis is thus supported by the results.

Table 23 **Summary of the F-scores of the one-way Anova on the relationship between pessimism and marital status**

Source	Sums of squares	Df	Mean of squares	F ratio
Between Groups	6.8126	2	3.4063	.5425
Within Groups	194.6286	31	6.2783	

p>0,05

From the above table it appears that there is no difference between the means of the groups in relation to pessimism (dimension of parental coping and stress resources). Marital status thus does not have an influence on parental coping and stress.

Table 24: **Summary of the F-scores of the one-way Anova on the relationship between child characteristics and marital status**

Source	Sums of squares	Df	Mean of squares	F ratio
Between Groups	34.6746	2	17.3373	.9997
Within Groups	572.2976	33	17.3424	

p>0,05

No difference exists between the means of the groups in relation to child characteristics (dimension of parental coping and stress). Marital status does not have an influence on child characteristics (dimension of parental coping and stress resources).

Table 25: **Summary of the F scores of the one-way Anova on the relationship between physical incapacity and marital status**

Source	Sums of squares	Df	Mean of squares	F ratio
Between Groups	9.0667	2	4.5333	1.0695
Within Groups	156.8333	37	4.2387	

p>0,05

No statistically significant difference was found between the means of the groups in relation to physical incapacity (dimension of parental coping and stress). According to the results, marital status does not have an influence on the dimension of physical incapacity (dimension of parental coping and stress resources).

The null hypothesis is supported by the results because no significant relationship was found between marital status and the dimensions of parental coping and stress.

Table 26: Summary of the F-scores of the one-way Anova on the relationship between network orientation and marital status

Sources	Sums of squares	Df	Mean of squares	F ratio
Between groups	.1301	2	.0651	2.1811
Within groups	1.1039	37	0.298	

p>0,05

No statistically significant difference was found between the means of the groups in relation to network orientation, that is the parents' willingness to make use of social support. The results indicate that the marital status of the parents does not have an influence on their willingness to make use of social support. The null hypothesis is thus supported by the results.

5.6 QUALITATIVE RESULTS

The qualitative results were drawn from Section C. of the questionnaire. In this section a number of open-ended questions focussed on parental support, the needs and worries of parents with mentally handicapped children as well as issues related to parental coping and stress (see Appendix B).

The information extracted from the open-ended questions differs from the quantitative results in that it shows that a positive relationship does appear to exist between the variables of social support and parental coping. This will be discussed in the following sections.

5.6.1 . Social support

In response to the question regarding the difficulties parents experienced with their mentally handicapped child (Question 1), the majority of the parents indicated that they had difficulty raising their child and that they needed support from their families to help them cope.

This is illustrated by the following:

"I cannot cope with him alone" (mother)

"He is very difficult to handle, he cannot do anything for himself" (father)

"I cannot leave him alone, he needs to be taken care of 24 hours a day (father)"

" I find it difficult to cope if my husband and the rest of the family do not help out" (mother)

Both mothers and fathers with mentally handicapped children have a need for support and experience stress, but the nature of their stress appears to be different. It was found that mothers with mentally handicapped children experience stress that is more related to caring and the physical nurturing of the child, whereas fathers experience stress that is more related to the acceptance of the child.

This is illustrated by the following:

" It is difficult to accept my son's condition" (father)

"I wonder if my son will ever fit into society" (father)

"I need more support from my family and friends" (mother)

" I cannot cope alone" (mother)

" She needs 24 hours care" (mother)

It was also apparent that although parents do receive some support from their families, they have a need for more support. This is reflected in the following statements:

"I need more support from family and friends"

" The community must give more assistance"

In short, the above appears to indicate that these parents do experience stress related to having to care for their mentally handicapped child and they need support to help them cope.

In response to the question on how the family assists with the mentally handicapped child (Question 2), responses indicate that help and assistance given by family members and friends are very important to parents and that this helps them to cope. The respondents mentioned that family and friends provide support in different ways. These could be classified into physical and/or emotional support.

The following statements reflect physical support parents received from family and friends::

"The family helps out at home"

"They fetch him/her from the special care centre in the afternoon"

"They look after him if I am not at home"

"They will feed, bath and dress her in the mornings before they go to school"

Examples of emotional support that parents received are reflected in the following statements:

" They listen to me when I feel down"

" My neighbours are always there for me"

In response to Question 4, "What are your worries and needs regarding your mentally handicapped child?, most of the parents expressed concern about finances, placements and for the future of their child.

This is illustrated by the following statements:

"Placement for the mentally handicapped at different centres are not always available"

"Limited finances, high medical costs"

"Worry about my child's future"

In order to help them cope better, these parents indicated a need for social support, emotional, information and financial support. The parents also indicated that they would not only benefit from support provided by the microsystem, that is, the close family and friends, but also need support from the mesosystem which includes social welfare services, health services and other support groups for the mentally handicapped.

This is reflected in the following:

"The nurses and social workers must give us more information about our child's condition" (Information)

"We need support groups for parents" (emotional)

"The disability grant should be increased" (financial)

"Placement for the mentally handicapped at the different centres are not always available"

5.6.2 Stress

From the responses it is clear that the parents experience different types of stress related to raising a mentally handicapped child. Much of this stress is related to limited finances, placement facilities and a lack of social support.

A few parents also indicated that the presence of a mentally handicapped child caused friction within the family. A number of respondents mentioned that the child has an effect on their marital relationship as well as on sibling relationships. This is illustrated in the following statements:

" His brothers and sisters do not want to bring their friends home"

"My husband is never home , I think it is because of our retarded son"

" My marriage is not the same since the birth of our child, my husband abandoned the family"

A further area of great stress is related to uncertainty about the future of the mentally handicapped child, which in turn can be seen as a reflection of a lack of available social support. A number of parents have a need for more long-term support in the form of financial support, emotional support as well as care facilities and resources. This is reflected in the following statements:

" I worry about what will happen to her, if I am not there anymore"

"Will my family still provide for him if I am dead?"

" What will happen to my son if he grows older, will he find work, will he ever live a normal life?"

" Placement centres for our children are closing down. Placements are not readily available."

"We need financial support, it is difficult to cope with limited funds"

Parents with mentally handicapped children also have the burden of limited financial resources, additional medical costs as well as the expenses for special equipment. Black families with mentally handicapped children from low SES communities such as Mitchell's Plain, Khayelitsha and Gugulethu do experience additional stress as their already limited financial resources are stretched by the presence of a mentally handicapped child. This is illustrated by the following statement:

"*We need financial support, it is difficult to cope with limited funds*"

In summary, a number of factors related to having a mentally handicapped child appear to cause stress in these families. These include factors related to limited finances, inadequate and limited care facilities as well as a lack of social support. In addition a number of parents experience stress related to marital strife and this appears to be particularly related to difficulties that husbands have in accepting the child.

5.6.3 Coping

In response to Question 2 on how the rest of the family reacted towards the mentally handicapped child, the replies indicate that acceptance of the mentally handicapped child by the rest of the family appears to play an important role in helping the parents cope. This is reflected by the following statements:

"*The accept her, they see her as part of the family*"

"Her brothers and sisters are very protective over her"

"The rest of the family accepts him and treat him as normal, this makes me feel that I can cope"

Religion also seems to play a mediating role in how parents cope with a mentally handicapped child. The majority of the parents indicated that they are very religious and that religion helps them to cope. This also helps them to keep the family bond and plays a role in strengthening the marital relationship. This is illustrated in the following:

"God bless the family with a special child"

"She is a gift from God"

"God gives me strength everyday"

"Gebed gee krag"

"Slegs deur gebed kan ons deur moeilike tye kom en vir ons seun sorg"

" Dis deur God se genade dat die familie nog te same is"

5.7. Summary

The quantitative results do not show any significant relationship exists between the variables of social support and coping and stress resources of parents with mentally handicapped children. Most of the demographic variables also did not have a significant influence on these variables.

The results do, however indicate a positive direction between some of these variables. Positive directions were found between tangible support (ISSB), physical incapacity and child characteristics (QRS-F). Positive and moderate correlations were also found between parental coping and stress (QRS-F) and family size (demographic variable). It could be speculated from these trends that higher levels of social support could lead to lower levels of stress and better coping. This could also further indicate that higher levels of social support could be a predictor of low levels of stress and better coping.

It is also speculated that a large family size could possibly lead to more support, less stress and better coping for parents with mentally handicapped children.

In summary, despite the non-significant relationships between the main variables the above, a relationship could however possibly exist between the variables, social support and parental coping and stress resources, but due to methodological constraints this is not reflected in the results (for further discussion see Chapter 6).

This is substantiated by the replies to the open-ended questions that indicate that a relationship does appear to exist between social support, coping and stress resources of parents with mentally handicapped children. The replies indicate that parents experience stress in raising their mentally handicapped children and that they need support from family, friends and the wider community to help them cope. Social support given to parents with mentally handicapped children will thus help alleviate their stress.

This stress appears to be especially related to a lack of social support, limited financial support and lack of care facilities. Although these parents do appear to get some support from family and friends, many of them express a strong need for more support from the wider community and the government in terms of long-term financial support and placement facilities.

CHAPTER SIX

DISCUSSION

6.1 Introduction

In the previous chapters literature on mental handicap, social support and coping and stress resources has been reviewed, the methodology described and results reported. In this chapter, the results will be interpreted with particular reference to their implications for future research.

6.2. Quantitative Results

6.2..1 Correlations between dimensions of social support (ISSB) and coping and stress resources (QRS-F) of parents with mentally handicapped children

In this study a low non-significant correlation between social support (as measured by the ISSB) and coping and stress resources of parents with mentally handicapped children (as measured by the QRS-F) was found (see Chapter 5 for results). This contradicts the findings of other similar studies. For instance, Flynt et al. (1992), Gallagher et al. (1983) and Molteno and Lachman (1996) found social support to be a crucial variable in helping parents cope with a mentally handicapped child. According to Chinkanda (1988) and Lea (1986) the quality and the quantity of social support available to families with mentally handicapped children will help the family cope. Social support thus acts as a buffer against stress and can moderate the effect of a stressful life event such as having a mentally handicapped child.

Although the findings of the quantitative analysis are mainly contradictory to other studies and the results indicated a low and non-significant relationship between the variables, three of the

correlations did however indicate a positive direction between them. This could indicate that a positive association does exist between some of the variables of ISSB and QRS-F. This association between the sub-scales, tangible support (ISSB) and the sub-scales, parent and family problems, physical incapacity and child characteristic (QRS-F) could further indicate that a possible increase on social support (ISSB) could lead to a possible increase on parental coping and lead to possible lesser stress (Lea, 1986) (see Chapter 5). This is also similar to the findings of the qualitative analysis. One possible reason for the non-significant as well as contradicting results of this study could be ascribed to methodological problems and limitations which will be discussed later in this chapter.

6.2.2 Correlations between network orientation, that is, parents' willingness to use social support (NOS), and parental coping and stress resources (QRS-F)

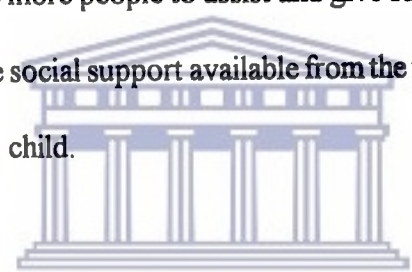
The results indicated a low, non-significant correlation between NOS and QRS-F. The results indicate that there is no significant relationship between parental willingness to use social support and parental coping and stress resources. Other studies however indicate that a relationship does appear to exist between these variables. According to Lin et al. (1986) and Quittner, Glueckauf and Jackson (1990) the effects of stress on psychological well-being is moderated by a persons' willingness to make use of social support and thus could either lead to high or low levels of stress, anxiety or depression. The contradictory results of this study could possibly be ascribed to difficulties within the methodology, which will be discussed later on in this chapter

It is also important to note that although the results were non-significant, a positive relationship was found between the variables of the NOS and QRS-F. This could indicate that an increase in willingness to make use of social support, could lead to an increase in parental coping and

lesser stress. This is supported by the studies of Lin et al. (1986) and Quittner et al. (1990).

6.2.3 Correlations between dimensions of social support, network orientation, parental coping and stress and family size

The results indicate a non-significant, low correlation between the dimensions of social support (ISSB) and family size. In this study family size does not appear to play a role in social support of families with mentally handicapped children. Other findings (Turnbull & Turnbull, 1986) however indicate that larger families with a mentally handicapped child tended to be less distressed by having a handicapped child in the family, than smaller families. The reason for this may be that in larger families there are more people to assist and give support. This is confirmed by Lea (1986) who found that the more social support available from the family, the better parents can cope with a mentally handicapped child.



Some of these correlations do however indicate a positive direction between the variables and this could be interpreted that an increase in family size (siblings, extended family) could lead to a possible increase in social support (see Chapter 5).

A low, non-significant correlation between dimensions of family size and parents' willingness to use social support (NOS) was also found in this study. This contradicts Turnbull and Turnbull's (1986) research that found that larger families with mental handicapped members tend to be less distressed and more inclined to use social support within the family. Lea (1986), however, indicated in her study that if the social support is negative, that is, not a buffer against life stress, then the family size (siblings, extended family), will not have an influence on the parents' willingness to make use of social support.

The results also indicate a non-significant and low correlation between family size and dimensions of coping and stress resources of parents. The correlations between physical incapacity and family size and pessimism and family size do however indicate a significant and moderate correlation. This could indicate that the more social support from family members, the better parents cope with a mentally handicapped child. This is also supported by Lea (1986) who found that increased support from family members (intimate source of support) could serve to alleviate parental stress and facilitate their ability to cope.

The findings of this study once again contradict the findings of other similar studies. These contradictory findings could be ascribed to possible methodological shortcomings.

6.2.4 The role gender plays in terms of social support (ISSB), network orientation (NOS) and parental coping and stress resources (QRS-F)

An analysis of scale scores according to gender indicates that gender does not appear to influence the type of social support parents require (see Chapter 5). This implies that both males and females require similar types of social support.

The results also indicate that no difference exists between males and females regarding their coping and stress resources. Other research studies (Lea, 1986), however, indicate that both mothers and fathers with mentally handicapped children experience stress, but the nature of their stress is different. It was found that mothers with mentally handicapped children experience stress related to the caring of the child, whereas fathers experience stress that is more related to the acceptance of the child. In this study more than half of the males approached refused to fill in the questionnaires. This could indicate that males find it more difficult to talk about their experiences

and their child's condition, whereas females in this study found it easier to talk about their experiences. Lea (1986) ascribes these differences between males and females to societal norms that assume that mothers are more affected by the presence of a mentally handicapped child.

6.2.5 The relationship between social support, network orientation, parental coping and stress resources and marital status

The results of the quantitative analysis showed a non-significant relationship between marital status and social support and willingness to make use of it. The results also indicate that there is no difference between married, divorced and single parents of mentally handicapped children in terms of the types of social support they require and marital status does not influence their willingness to use social support (see Chapter 5). Marital status also does not play a role in the coping and stress resources of these parents. These results contradict those of Lea (1986) and Parehk (1988), which indicate that marital status does play a role. According to their studies, single mothers with mentally handicapped children, experience more stress than mothers who are married. Lea (1986) also indicates that the stress caused by the mentally handicapped child in the family could be a contributing factor to divorce in the family. Some families place their mentally handicapped child in residential care and this improves their coping as well as the quality of their marital relationship (Lea, 1986), but on the other the hand it is also argued that the presence of a mentally handicapped child could strengthen the quality of the marital relationship and the bond within the family.

In this study the results of the quantitative analysis were in contrast to other studies as they indicate that there appears to be no relationship between marital status and coping and stress of parents with mentally handicapped children. Once again methodological limitations (as discussed

later in the chapter) could have played a role in influencing the results.

6.3 Discussion of qualitative results

The results from the open-ended questions, however, are in contrast to the quantitative results and indicate that social support from families and friends does appear to play a role in helping parents cope Acceptance of the mentally handicapped child by the rest of the family appears to play an important role in this. This is also supported by Lea (1986) who found that increased support, assistance from and acceptance of the mentally handicapped child by the rest of the family leads to better coping and less stress for parents.

The results of this study also indicate that both mothers and fathers with mentally handicapped children expressed a need for greater social support. Needs for different types of social support, namely tangible , emotional and guidance regarding their child's condition and welfare were expressed by both parents. Parents also indicated a need for support from the wider community such as the state, social services and health services. This could play a role in reducing their worries about their child's future. Many of these parent expressed a fear for their child's future, which could be linked back to the lack of financial support, inadequate social support services and resources. Many of these families living in disadvantaged communities, such as Khayelitsha, Gugulethu and Mitchell's Plain, where unemployment, poverty, overcrowding and violence are common are therefore likely to experience extreme levels of stress related to these issues. The presence of a mentally handicapped child in these families also places an additional strain on the marital relationship as well as sibling relationships. In addition to this inadequate state subsidies also contribute to their stress.

The expressed need for more support from the family, as well as from the wider community indicate that social support plays a core role in helping parents with mentally handicapped children cope and that the social support they receive at present is often inadequate. In the light of limited and inadequate mental health services for families with mental handicap in South Africa social support could play an instrumental role in moderating the effects of stress on these families (Molteno & Lachman, 1996).

The results also indicate that both mothers and fathers experience similar amounts of stress in raising their mentally handicapped child, but the types of the stress they experience are different. This is supported by studies of Lea (1986) and Cummings (1976) in which both parents with mentally handicapped children experience stress, but the nature of their stress is different. In this study it was found that mothers with mentally handicapped children experienced more stress related to caring and nurturing of the child, whereas fathers reported more stress in relation to the acceptance of the child as well as the child's future.

Despite the above-mentioned need for social support expressed by parents with mentally handicapped children in the answers to the open-ended questions, the findings indicate that parents seem to have some coping skills, but factors such as the severity of the mental handicap, the stability of the family, long- term social support within and outside of the family play a role in how these parents cope (Peterson, 1987). Religion also seems to play a mediating role in helping parents to cope . Most of these parents indicated that their religion strengthens their family bond as well as the marital relationship and helps them to cope.

6.4 Limitations and shortcomings

The quantitative findings of this research study indicate that the relationship between the variables, social support and coping and stress resources of parents are non-significant, even though positive trends between some of the variables were found. This contradict the findings of other similar studies as well as the findings of the qualitative section of this study. It is thus necessary to look at possible reasons why these results are different. One possible explanation is related to the methodological limitations of this study.

The sample used in this study was not randomly selected, it was a sample of convenience, because access was readily available to the researcher. The sample size (N=50) of this study was also small. A small sample size (N=50) does raise queries about the validity of the inferences made from the non-significant results (Pretorius, 1995). This also posed a limitation in the statistical analysis as the small sample size made it impossible to implement regression analysis. The issue of generalization of the research findings is also a limitation. Due to the small sample size used in the study and the fact that it was not randomly selected, the results are not representative of the population as a whole. Only certain population groups were included in the sample, thus making it impossible to make cross-cultural generalizations.

The low correlations between the different variables in this study could also possibly be ascribed to certain characteristics of the sample. In this study the low correlations between the variables social support and coping and stress resources of parents with mentally handicapped children could be due to the restricted range of the sample that was used, that is, parents of only three special care centres for the mentally handicapped were selected to be part of the sample. When interpreting the correlations based on a selected group of individuals like in this study, the results

could become distorted (Pretorius, 1995).

According to Pretorius (1995), caution should be exercised when interpreting a correlation based on subjects which represent samples from two or more population groups combined into one sample. In this study the data of males and females as well as different language groups were combined into one sample. This could have contributed to the low correlations between the variables and the distortion of the true relationship between the variables.

The suitability of the measuring instruments, that is, the ISSB, NOS and QRS-F could also be a factor that affected the results. Respondents reported that the questionnaires were too lengthy and/or that too difficult to fill in. This could have been reflected by the missing items on some of the completed questionnaires as well as by the fact that some of the questionnaires were not returned. It is also likely that some participants experienced difficulty understanding the language as the questionnaires were administered in English only. This is definitely a major shortcoming of this study and indicates the the importance of administering a questionnaire in the mother tongue of the respondents and of doing follow-up interviews. The pilot study was done in English, but subsequent language difficulties were not picked up. The reason for this could be that the sample (N=10) in the pilot study was not representative of the target population group in the study.

The literacy level of the participants probably also played a role in the filling in and understanding of the questionnaires. In this study the educational level of the participants ranged from primary school education (44%) to high school education (51%). The large number of participants with only primary school education probably found it difficult to fill in the questionnaires and this was

compounded by the fact that the questionnaires were not in their mother tongue.

Although the reliability coefficients of the self-administered inventories proved to be within the moderate to high range, the nature of the self-administered inventories are not always very reliable. Faking answers on some of the items is a possibility that cannot be controlled for and it is possible that in this study that respondents gave perceived desired answers to some of the items.

Another problem was that in this study the questionnaires were taken home by the participants to be filled in. This gave the researcher minimal control over by whom and how the questionnaires were filled in.

In short the present study suffers a number of serious limitations with regard to the sample itself, the instruments used and the administration of the questionnaires.

6.5 RECOMMENDATIONS

In view of the obtained results and the cited methodological shortcomings, the following recommendations are made:

6.5.1 Future Research

More research is needed to investigate the relationship between social support and parental coping and stress resources of parents with mentally handicapped children in South Africa. A bigger sample that is randomly selected should be considered for future research, so that generalisation can be made to the overall population. A bigger sample size will also make it

possible to implement an appropriate statistical analyses.

The research methodology should also be appropriate to the research question. The use of triangulation where qualitative and quantitative methods are combined, could provide a greater depth of information. This is substantiated by the replies to the open-ended questions in the questionnaire. Using techniques from both these methodologies, such as focus groups and semi-structured questionnaires, can provide us with more in-depth and valuable information (Mouton, 1983).

The instruments used to measure the variables should be appropriate for the population being studied and the literacy level and the language proficiency of respondents should be taken into consideration when administering the questionnaires. The structure and the length should also be appropriate. Pretorius and Diedericks (1993) indicated that given the literacy level in South Africa it is necessary to translate questionnaires into an indigenous language and to develop an interview version of questionnaires. This will enable researchers to gather more in-depth as well as valuable information. The results obtained from the open-ended questions in this study appear to elicit better data and thus substantiate the fact that the instruments used in this study were inadequate. This also substantiates the need for more qualitative research in this area.

6.5.2 General recommendations on how to assist families with mentally handicapped children.

From an educational point of view, more research focussing on the needs of parents with mentally handicapped children is necessary. In this study it became clear that most of the needs of the parents with mentally handicapped children have not been met. The current education situation

has implications for the mental handicapped in South Africa. The closure of ELSEN schools and inadequate funding and support services places severe financial and emotional strain on parents with mentally handicapped children (Report of NCSNET & NCESS,1997). Most of these children, however, fall within the range of moderate to severe mental handicap and mainstreaming will be difficult.

In the light of this, learning support teams could play an important role in providing clearer guidelines and information to parents regarding the changing educational needs of their mentally handicapped children. Learning support teams are specialised educators who provide support to learners with special needs. The major role players in the learning support team are the teachers, social/ health workers, remedial teachers as well as speech and language teachers. They offer specialised teaching, adapt the curriculum to facilitate learning as well using specialised equipment to facilitate learning (Report of NCSNET & NCESS, 1997). These support teams can play a pro-active and preventative role in assisting parents with mentally handicapped children in providing them and the special care centres with home-based programmes, support groups for parents, physiotherapy as well as occupational therapy . Learning support teams could play an important role in providing these parents with a badly needed social support service. It is recommended that research be conducted into exactly what role these learning support teams could play in this regard.

Community-based rehabilitation (CBR) is a strategy within community development that offers rehabilitation and social integration for individuals with special needs (Report on NCSNET & NCESS, 1997). This could be implemented through efforts of the handicapped themselves, their families and the wider community such as health services, education, social services. In the light

of inadequate service provision for the care of the mentally handicapped in South Africa, the provision of social support via community-based support groups could provide a valuable service to the families of the mentally handicapped.

In summary it is motivated that more state intervention, teacher support teams as well as community based support is necessary, to help parents with mentally handicapped children cope better and thus alleviate their stress levels.

6.6 CONCLUSION

In view of the research findings and the shortcomings of the present study, further research in the field of social support and coping and stress resources of parents with mentally handicapped children is warranted. The inconclusive findings of the quantitative results should be regarded as preliminary. There is a great need for developing more appropriate instruments for the South African context.

The results extracted from the qualitative findings, however, indicate that a relationship does appear to exist between social support and parental coping and stress. This research methodology is more suitable in that it elicited more information from the participants, many of whom had a low literacy level. Further use of a more qualitative approach to studying the problems experienced by parents of mentally handicapped children in the South African context appears warranted from these research findings.

The findings of this research study highlight the need for a more South African investigation, into what appears to be an established American and European research domain. In the South

African context, with its complex and multifaceted cultural experiences and the history of apartheid, such an investigation is much needed.

REFERENCES

Anastasi, A. (1982). *Psychological Testing.* New York: Macmillan.

Antonucci, T. (1985). Social support: Theoretical advances, recent findings and pressing issues. In I.G. Sarason & B.R. Sarason, *Social Support: Theory, Research and Application.* Dordrecht: Martinus Nijhoff .

Barrera, M. (1981). Social support in the adjustment of pregnant adolescents. Assessment issues. In B.Gottlieb (Ed.) *Social Networks and Social Support.* Beverley Hills: Sage.

Barrera, M. & Ainley, S.L. (1983). The structure of social support: A conceptual and empirical analysis. *Journal of Community Psychology*, **11**, 133-143.

Barrera, M., Sandler, I. & Ramsay, T.B. (1981). Preliminary development of a scale of social support: Studies of college students. *American Journal of Community Psychology*, **9,** 435-447.

Berzon, M. (1987). *Development of lifestyle and coping patterns in families with mentally handicapped children.* Unpublished Doctoral Dissertation, University of Witwatersrand, Johannesburg.

Blacher, J. (Ed.) (1984). *Severely Handicapped Young Children and their Families: Research in Review*. Orlando: Academic Press.

Bowlby, B. (1969). *Attachment*. New York: Basic Press.

Bradshaw, J. & Lawton, D. (1978). Tracing the causes of stress in families with handicapped children. *British Journal of Social Work*, **8,** 181-192.

Braginsky, D & Braginsky, B. (1971). *Hansel and Gretels: Studies of Children in Institutions for the Mentally Retarded.* New York: Holt, Rinehart & Winston.

Braude, D. & Francisco-La Grange, F. (1993). *Support systems in the life situation of children of divorce.* Co-operative research programme in marriage and family life. Pretoria: Human Sciences Research Council.

Bristol, M. (1984). Family Resources and successful adaption to autistic children. In E. Schopler & G.B. Mesibox (Eds), *The Effects of Autism on the Family*. New York: Plenum.

Brownell, A. & Shumaker, S.A. (1984). Social support: An introduction to a complex phenomenon. *Journal of Social Issues*, **40**, 1-9.

Chetwynd, J. (1985). Factors contributing to stress in mothers caring for an intellectually handicapped child. *British Journal of Social Work*, **15**, 295-304.

Chinkanda, E.N. (1988). Community care of the mentally handicapped child. *Social Work*, **24,** 25-30.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, **38,** 300-314.

Cohen, S. & Willis, T.A. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin,* **98,** 310-357.

Cole, D.A. (1986). Out-of-home placement and early adaption: a theoretical framework. *American Journal of Mental Deficiency,* **93,** 226-236.

Collins, W., Dunkel- Schetter, C., Lobel, M. & Schrimshaw, C. (1993). Social support in pregnancy: Psychosocial correlation of birth outcome and postpartum depression. *Journal of Personality and Social Psychology,* **65,** 1243-1258 .

Constantini, A. Braun, J. Davis, J. & Iervolino, A. (1973). Personality and mood correlates of the Schedule of Recent Experience scores. *Psychological* Reports,**32,** 416-418.

Cowen, E.L. (1983). Primary prevention in mental health: Past, present and future. In R.D. Felner, L.A. Jason, J.M. Moritsugu & S. Faber (Eds). *Preventive Psychology: Theory Research and Practice in Community Intervention*. New York: Pergamon Press.

Crnic, K., Friedrich, W. & Greenberg, M. (1983). Adaptation of families with mentally retarded children: A model of stress, coping and family ecology. *American Journal of Mental Disorder,* **88**, 125-138.

Cummings, S. T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically ill children. *American Journal of Orthopsychiatry*, **46**, 246-255.

Cummings, S., Bayley, H. & Rie, H. (1966). Effects of the child's deficiency on the mother: A study of mothers of mentally retarded, chronically ill and neurotic children. *American Journal of Orthopsychiatry*, **36,** 395-608.

Cunningham, C. & Davis, H. (1985). *Working with Parents: Framework for Collaboration.* Philadelphia: Open University Press.

Department of Education (1997). *Quality Education For All: Overcoming barriers to learning and development.* Report of the National Commission on Special Needs in Education and Training. Pretoria: Government Printers.

Desjarlais, R., Eisenberg, L., Good, B., & Kleinman, A., (1985). *World Mental Health: Problems and Priorities in Low Income Countries.* New York: Oxford University Press.

Diedericks, M. (1991). *The social support of university students in the transition from school to university: An exploratory study.* Unpublished masters thesis, University of the Western Cape, Bellville.

DSM-IV (1994). *Diagnostic and Statistical Manual for Mental Disorders.* Washington, DC: American Psychiatric Association.

Du Bois, D.L., Felner, R.D., Meares, H & Krier, M. (1994). Prospective investigation of effects of socio-environmental experiences, disadvantaged life stress and social support on early - adolescents adjustment. *Journal of Abnormal Psychology*, **103,** 511-522.

Dunst, C., Trivette, C. & Cross, A. (1986). Mediating influences of social support: Personal, family and child outcomes. *American Journal of Mental Deficiency,* **90**, 403-417.

Dyson, L., Edgar, E. & Crnic, K. (1989). Psychological predictors of adjustments by siblings of developmentally disabled children. *American Journal of Mental deficiency,* **94**, 292-302.

Edgerton, R. (1979). *Mental Retardation: The Developing Child.* London: Fontana/ Open Books.

Eichhorn, H. (1985). *Trainable mental retardation in the coloured and black community of Cape Town: Prevalence and provision of services.* Unpublished masters thesis, University of Cape Town.

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

Flynt, S. & Wood, T. (1989). Stress and coping of mothers of children with moderate mental retardation. *American Journal on Mental Retardation,* **94**, 278-283.

Flynt, W., Wood, T., & Scott, L. (1992). Social support of mothers of children with mental retardation. *Mental Retardation,* **30,** 233-236.

Fotheringham, J. & Creal, D. (1974). Handicapped children and handicapped families. *International Review of Education,* **20**, 355-373.

Freeman, M. (1989). Mental health care in crisis in South Africa. *Psychology in Society.* 1, 40-46.

Friedrich, W.N., Greenberg, M.T. & Crnic, K. (1983). A short-form of the Questionnaire on Resources and Stress. *American Journal of Mental Deficiency,* **88,** 41-48.

Gallagher, J., Beckman, P. & Cross, A. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional children,* **50,** 10-19.

Gath, A. (1974). Siblings reactions to handicap: A comparison of the brothers and sisters of mongol children. *Journal of Child Psychology and Psychiatry,* **15,** 187-198.

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

Gath, A. (1978). *Down's Syndrome and the Family: The Early Years.* London: Academic Press.

Gath, A. & Gumley, D. (1987). Retarded children and their siblings. *Journal of Child Psychology and Psychiatry,* **28,** 715-730.

Gottlieb, B. (1981). *Social Networks and Social Support.* Beverley Hills: Sage.

Gowan, J., Demos, G. & Koskaska, C. (1972). *The Guidance of Exceptional Children.* New York: David Mc Kay.

Grover, V.M., Cooke, J.P. Hollingshead, J. & Rip, M.R. (1987). Facilities for the mentally handicapped in Western Cape. *South African Medical Journal,* **71,** 85-87.

Hardy, C.J., Richman, J.M.& Rosenfield, L. (1991). The role of social support in the life stress/injury relationship. *The Sport Psychologist,* **5,** 128-139.

Henderson, D. & Vandenberg, B. (1992). Factors influencing adjustment in the families of autistic children. *Psychological Reports,* **72,** 167-171.

Hirsch, B. (1980). Natural support systems and coping with major life changes. *American Journal of Community Psychology,* **8,** 159-165.

Holahan, C. and Moos, R. (1981). Social support and psychological distress: A longitudinal analysis. *Journal of Abnormal Psychology,* **90,** 365-370.

Holmes, T. & Rahe, RH. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research,* **11,** 213-218.

Holroyd, J. (1974). The Questionnaire on Resources and Stress: An instrument to measure family responses to handicapped family members. *Journal of Community Psychology,* **2,** 92-94.

Holroyd, J. (1987). *Manual for the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members.* Brandon : Clinical Psychology Press.

Holroyd, J. & McArthur, D. (1976). Mental retardation and stress on parents: A contrast between Down's Syndrome and childhood autism. *American Journal of Mental Deficiency,* **80,** 431- 436.

Hornby, G. (1996). *Counselling and Child Disability: Skills for Working with Parents.* London: Routledge.

House, J.S. (1981). *Work Stress and Social Support.* New York: Addison-Wesley.

Hutt, M. & Gibbey, R. (1979). *The Mentally Retarded Child: Development, Training and Education.* Boston: Allyn and Bacon.

Kaplan, H. & Sadock, B. (1981). *Modern Synopsis of Comprehensive Textbook of Psychiatry.* Baltimore: Williams & Wilkins

Kennedy, J. (1970). Maternal reactions to the birth of a defective child. *Social Casework,* **7,** 410-416.

Kromberg, J. (1977). Responses of parents to the birth of a baby with Down's syndrome. *South African Nursing Journal,* **44,** 33-35.

Kubler-Ross, E. (1970). *On Death and Dying.* New York: MacMillan.

Kwai-sang, Y., Matthew, W.P. & Li-Tsang, P. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *British Journal of Developmental Disabilities,* **45,** 38-51.

Landesman, S., & Ramey, C. (1989). Developmental psychology and mental retardation: Integrating scientific principles with treatment practices. *American Psychologist,* **44,** 409-415.

Lazarus, R.S. (1966). *Psychological Stress and the Coping Process.* New York: McGraw-Hill.

Lazarus, R (1991). Book Review on Perspectives on Mental Handicap in South Africa. By S. Lea & D. Foster. *Psychology in Society* **15,** 82-85.

Lea, S. (1986). *The impact of the mentally handicapped child upon the parents: A comparative study.* Unpublished Masters Thesis, University of Cape Town.

Lea, S. & Foster, D.(Eds) (1990). *Perspectives on Mental Handicap in South Africa.* Durban: Butterworth.

Leavy, R.L. (1983). Social support and psychological disorder: A review. *Journal of Community Psychology,* **11,** 3-21.

Levitz, A. (1993). Some factors determining parental reactions to the birth of a handicapped child. *Rehabilitation in South Africa,* 50-53.

Lieberman, M.A. (1986). Social support, the consequences of psychologizing: A commentary. *Journal of Consulting and Clinical Psychology,* **54,** 461-465.

Lin, N., Dean, A. & Ensel, W. (1986). *Social Support, Life Events and Depression.* New York: Academic Press.

Lombard, M. (1992). *Mental retardation and physical handicap: A comparison of stress in families.* Unpublished Doctoral Thesis, University of Port Elizabeth.

Luiz, D., Lombard, M. & O'Brien, M. (1994). Stress and coping in families with a mentally or physically handicapped child. *South African Journal of Child and Adolescent Mental Health,* **9,** 12-20.

Marcus, L.M. (1977). Patterns of coping in families of psychotic children. *American Journal of Orthopsychiatry,* **47,** 388-399.

McKeever, P. (1983). Siblings of chronically ill children. A literature review with implications for research and practice. *American Journal of Orthopsychiatry,* **53,** 209-218.

Mink, I. & Nihira, K. (1987). Direction of effects: Family life styles and behaviour of TAR children. *American Journal of Mental Deficiency,* **92,** 57-64.

Molteno, C. & Lachman, P. (1996). Stress in mothers of handicapped children. *South African Journal of Child and Adolescent Mental Health,* **8,** 13-20.

Molteno, C., Roux, A., Kench, E. & Selfe, S. (1994). Study of mentally handicapped children requiring special care in Cape Town. *Southern African Journal Adolescent Psychiatry,* **6,** 8-11.

Mouton, J (1983). Quantitative and qualitative methodology in human sciences. *South African Journal of Sociology,* **14,** 124-131.

Naran, R. (1991). Social support systems in black communities. *Psychological Quarterly,* **2,** 18-23.

Nie, L., Hull, C., Jenkins, J., Steinbrenner, K. & Bent, D. (1975). *SPSS Statistical Package for the Social Sciences.* New York: McGraw Hill.

Parekh, A. (1988). *An assessment of the impact of mentally retarded children on Indian family interrelationships.* Unpublished Doctoral Dissertation, University of Durban-Westville, Durban.

Parekh, A. & Jackson, C. (1997). Families of children with a mental handicap. In C. De la Rey (Eds), *Contemporary Issues in Human Development: A South African Focus.* Johannesburg: ITP.

Parsons, T. & Bales, R. (1955). *Family, Socialization and Interaction Process.* New York: The Free Press.

Peterson, N.L. (1987). *Early Intervention for Handicapped and At-Risk Children.* Denver: Love Publishers.

Philpott, S. (1994). Gender and Disability. *Agenda,* **20,** 85-93.

Plienis, A., Robbins, F. & Dunlap, G. (1988). Parent adjustment and family stress factors in parent training for the young autistic child. *Journal of Multi-Handicapped Persons,* **1,** 88.-95

Prescott, M.R. & Hulnick, H.R. (1979). Counselling parents of handicapped children: An empathic approach. *The Personal and Guidance Journal,* 2263-266

Pretorius, T.B. (1991). Towards a conceptual framework for research on the stress-illness epidemiological model. *Psychology Quaterley,* **2,** 13-17.

Pretorius, T.B. (1995). *Inferential Statistics: Hypothesis Testing and Decision Making.* Cape Town: Percept Publishers.

Pretorius, T. & Diedericks, M. (1991).(Eds). *Social support research by Psychology Department of University of Western Cape*, Psychology Resource Centre Publication, Bellville: University of Western Cape.

Pretorius, T. & Diedericks, M. (1993). A factorial investigation of the dimensions of social support. *Suid Afrikaanse Tydskrif vir Sielkunde*, **23,** 32-35.

Procidiano, M.E. & Heller, K. (1983). Measures of perceived social support from friends and from family: Three validation studies. *American Journal of Community Psychology*, **11,** 1-24.

Quittner, H.L., Glueckauf, R.L. & Jackson, D.N. (1990). Chronic parenting stress: Moderating versus mediating effects of social support. *Journal of Personality and Social Psychology*, **59,** 1266-1278.

Rabkin,JG, & Streuning, E.L. (1976). Live events and stress and illness. *Science*, **3,** 1013-1020.

Rook, K. (1987). Social support versus companionship: Effects on life stress, loneliness and evaluations by others. *Journal of Personality and Social Psychology*, **52,** 1132-1147.

Ruch, L.O. & Leon, J.J. (1986). The victim of rape and the role of life changes, coping and social support during rape trauma syndrome. In S.E. Hobtoll (Ed.). *Stress , Social Support and Women*. New York: Hemisphere.

Rutter, M. (1981). Stress, coping and development: Some issues and some questions. *Journal of Child Psychology and Psychiatry,* **22,** 323-356.

Ryan, J. (1980). *The Politics of Mental Handicap.* Harmondsworth: Pelican Books.

Sandler, I. & Barrera, M. (1984). Towards a multi-method approach to assessing the effects of social support. *American Journal Community Psychology,* **12**, 37-52.

Sarason, I.G., Liviene, H.M., Bashan, R.B. & Sarason, B.R. (1983). Assessing social support: Social Support questionnaire. *Journal of Personality and Social Psychology,* **44,** 127-139.

Sarason, I.G. & Sarason, B.R. (Eds.) (1985). *Social Support: Theory, Research and Applications.* Dordrecht: Martinus Nijhoff.

Scott, R.L., Sexton, D., Thompson, B. & Wood, T. (1989). Measurement characteristics of a short-form of the Questionnaire on Resources and Stress. *American Journal on Mental Retardation,* **94,** 331-339.

Seed, P. (1980). *Mental Handicap: Who Helps in Rural and Remote Communities?* Turnbridge: Costello Educational.

Shea, T.M. & Bauer, A.M. (1985). *Parents and Teachers of Exceptional Children.* Boston: Allyn & Bacon.

Snyder, C.R., Ford, C.E. & Harris, R.N. (1987). The effects of a theoretical perspective on the analysis of coping with negative life events. In C.R. Snyder & C.E. Ford (Eds), *Coping with Negative Life Events.* New York: Plenum Press.

Terre' Blanche, M. & Durrheim, K. (Eds) (1999). *Research in practice: Applied methods for the social sciences.* Cape Town: University of Cape Town Press.

Thoits, P.A. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology*, **54**, 416-423.

Thomas, T. (1987). The psycho-social pathology of the homeland. *OASSSA National Conference Proceedings,* **2,** 32-49.

Turnbull, A.P. & Turnbull, H.R. (1986). *Families, Professionals and Exceptionality: A Special Partnership.* Ohio: Merrill.

Turner, R. (1981). Social support as a contingency in psychological well-being. *Journal of Health and Social behaviour,* **122,** 357-367.

United Nations Programme (1983). *World Programme of Action concerning Disabled Persons.* New York: United Nations.

Van Rooyen, M.S. (1989). *Pervasive developmental disorder mental retardation: A comparison of mental satisfaction and family stress in parents.* Unpublished Doctoral Thesis, University of Port Elizabeth..

Vaux,A., Burda, M & Steward, D. (1986). Orientation toward utilization of support. *Journal of Community Psychology,* **14,** 159-170.

Wilcox, B. (1981). Social support, life stress and psychological adjustment. A test of the buffering hypothesis. *American Journal of Community Psychology*, **12**, 371-387.

Wilcox, B. (1981). Social support in adjusting to marital disruption. In B. Gottlieb (Ed.) *Social Networks and Social Support.* Beverly Hills: Sage.

Wright, L. (1976). Chronic grief: The anguish of being an exceptional parent. *The Exceptional Child,* **23,** 160-169.

APPENDIX A:

Private Bag X17
Bellville, 7535
South Africa
Telegraph: UNIBELL
Telex: 526661
Telephone: (021) 959-2911

University of the Western Cape

Universiteit van Wes-Kaapland

Privaatsak X17
Bellville, 7535
Suid-Afrika
Telegram: UNIBELL
Telex: 526661
Telefoon: (021) 959-2911

Dir. line/lyn .....

Dept. EDUCATIONAL PSYCHOLOGY ..... Ref./Verwys. .....

Dear Parent

I hereby wish to ask permission for the administering of questionnaires on Social Support for parents with mentally handicapped children.

I am presently registered as M.Psych student at the University of the Western Cape and I am doing research on the influence of Social Support on parent's coping with mentally handicapped children.

It will be highly appreciated if you could assist me in this research endeavour. Please be assured that all information will be kept strictly confidential

N.B.!! TWO QUESTIONNAIRES ARE INCLUDED FOR MOTHER AND FATHER AND SHOULD BE FILLED IN INDIVIDUALLY, WITHOUT CONSULTING EACH OTHER.

Thanking you for your assistance.

C Petersen

MISS C PETERSEN

APPENDIX B:

A. PERSONAL INFORMATION OF PARENT

Gender

Male	Female

Age: .....

Marital Status

Married	Divorced	Single

1. What level of education did you achieve?

Primary School	High School	College or University

2. What is your present occupation? If unemployed, for how long have you been unemployed?

_____

3. What wage do you earn per month? If working irregularly, indicate your average monthly income.

_____

4. How many children do you have? How many of them stay with you.

Name	Gender:	Age:	Staying with you or not
a.			
b.			
c.			
d.			

5. How many handicapped family members do you have living with you at present?

Handicapped member	Ages	Type of handicapped

a. _____ _____ _____

b. _____ _____ _____

c. _____ _____ _____

6. Do you live in a flat, semi-detached or free-standing house?

_____

7. How many people in total are living in the house? (Specify if any other family members are staying with you.

Number of people staying in the house:	

8. How do your child get to the training centre?

car	bus

9. Do you have to accompany your child to the training centre or special care centre?

_____

B. PERSONAL INFORMATION ABOUT MENTALLY HANDICAPPED CHILD

Gender

Male	Female

Age: .....

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).

_____

When? _____

3. From what type of mental handicap does your child suffer?

_____

Explain in detail: _____

_____

_____

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

No	Yes

Name of Centre age started age left reason for leaving

_____ _____ _____ _____

_____ _____ _____ _____

SECTION C

What are the main problems you experience with your mentally handicapped child?

_____

_____

_____

_____

How does the rest of the household react and respond towards the mentally handicapped child?

_____

_____

_____

QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-F)

Instructions

This questionnaire attempts to measure the coping resources and stress levels of parents with mentally handicapped children. There are many blanks on the questionnaire. Imagine your child's name filled in on one of the each blank spaces in the questionnaire. Give your honest feelings and opinions.

Please answer all of the questions, even if they do not seem to apply to your situation. 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.

Remember to answer all the questions.

THANK YOU

QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-F)

Circle one of response per item

1.	_____ doesn't communicate with others of his/her age group.	T	F
2.	Other members of the family have to do without things because of _____.	T	F
3.	Family agrees on important matters.	T	F
4.	I worry about what will happen to _____ when I can no longer take care of him/her.	T	F
5.	The constant demands for care for _____ limit growth and development of someone else in our family.	T	F
6.	_____ is limited in the kind of work he/she can do to make a living.	T	F
7.	I have accepted the fact that _____ might have to live out his/her life in some special setting (e.g. institution or group home).	T	F
8.	_____ can feed himself/herself.	T	F
9.	I have given up things I have really wanted to do in order to care for _____.	T	F
10.	_____ is able to fit into the family social group.	T	F
11.	Sometimes I avoid taking _____ out in public.	T	F
12.	In the future, our family's social life will suffer because of increased responsibilities and financial stress.	T	F
13.	It bothers me that _____ will always be this way.	T	F
14.	I feel tense whenever I take _____ out in public.	T	F
15.	I can go visit with friends whenever I want.	T	F
16.	Taking _____ on a vacation spoils pleasure for the whole family.	T	F
17.	_____ know his/her own address.	T	F
18.	The family does as many things together now as we ever did.	T	F
19.	_____ is aware who he/she is.	T	F
20.	I get upset with the way my life is going.	T	F
21.	Sometimes I feel very embarrassed because of _____.	T	F
22.	_____ 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 sport.	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

INVENTORY OF SOCIALLY SUPPORTIVE BEHAVIOURS

We are interested in learning about some of the ways that you feel people have helped you or tried to make life more pleasant for you over the past four weeks. Below you will find a list of activities that other people might have done for you, to you, or with you in recent weeks. Please read each item carefully and indicate how often these activities happened to you during the past four weeks.

Use the following scale to make your ratings:

A. **Not at all**
B. **Once or twice**
C. **About once a week**
D. **Several times a week**
E. **About every day**

If, for example, the item:

45. **Gave you a ride to the doctor.**

happened once or twice during the past four weeks, you would make your rating like this:

A · **B** **C** **D** **E**

next to the item.

Please read each item carefully and select the rating that you think is the most accurate.

During the past four weeks, how often did other people do these activities for you, to you, or with you.

1.	Looked after a family member when you were away	A	B	C	D	E
2.	Was right there with you (physically) in a stressful situation	A	B	C	D	E
3.	Provided you with a place where you could get away for awhile	A	B	C	D	E
4.	Watched after your possessions when you were away (pets, plants, home, apartment, etc.)	A	B	C	D	E
5.	Told you what she/he did in a situation that was similar to yours	A	B	C	D	E
6.	Did some activity with you to help you get your mind off things	A	B	C	D	E
7.	Talked with you about some interest of yours	A	B	C	D	E
8.	Let you know that you did something well	A	B	C	D	E
9.	Went with you to someone who could take action	A	B	C	D	E
10.	Told you that you are OK just the way you are	A	B	C	D	E

A Not at all	B Once or twice	C About Once a week	D Several times a week	E About every day

11.	Told you that she/he would keep the things that you talk about private - just between the two of you	A	B	C	D	E
12.	Assisted you in setting a goal for yourself	A	B	C	D	E
13.	Made it clear that what was expected of you	A	B	C	D	E
14.	Expressed esteem or respect for a competency or personal quality of yours	A	B	C	D	E
15.	Gave you some information on how to do something	A	B	C	D	E
16.	Suggested some action that you should take	A	B	C	D	E
17.	Gave you over R25	A	B	C	D	E
18.	Comforted you by showing you some physical affection	A	B	C	D	E
19.	Gave you some information to help you understand a situation you were in	A	B	C	D	E
20.	Provided you with some transportation	A	B	C	D	E
21.	Checked back with you to see if you followed the advice you were given	A	B	C	D	E
22.	Gave you under R25	A	B	C	D	E
23.	Helped you understand why you didn't do something well	A	B	C	D	E
24.	Listened to you talk about your private feelings	A	B	C	D	E
25.	Loaned or gave you something (a physical object other than money) that you needed	A	B	C	D	E
26.	Agreed that what you wanted to do was right	A	B	C	D	E
27.	Said things that made your situation clearer and easier to understand	A	B	C	D	E
28.	Told you how he/she felt in a situation that was similar to yours	A	B	C	D	E
29.	Let you know that he/she will always be around if you need assistance	A	B	C	D	E
30.	Expressed interest and concern in you well/being	A	B	C	D	E
31.	Told you that she/he feels very close to you	A	B	C	D	E

NETWORK ORIENTATION SCALE

Please indicate the extent to which you agree with the following items.
Use the following scale:

SD	-	Strongly Disagree
D	-	Disagree
A	-	Agree
SA	-	Strongly Agree

1.	Sometimes it is necessary to talk to someone about your problems	SD	D	A	SA
2.	Friends often have good advice to give	SD	D	A	SA
*3.	You have to be careful who you tell personal things to	SD	D	A	SA
4.	I often get useful information from other people	SD	D	A	SA
*5.	People should keep their problems to themselves	SD	D	A	SA
6.	It is easy for me to talk about personal and private matters	SD	D	A	SA
7.	In the past friends have really helped me out when I've had a problem	SD	D	A	SA
*8.	You can never trust people to keep a secret	SD	D	A	SA
9.	When a person gets upset they should talk it over with a friend	SD	D	A	SA
*10.	Other people never understand my problem	SD	D	A	SA
11.	Almost everyone knows someone they can trust with a personal secret	SD	D	A	SA
*12.	If you can't figure out your problem, nobody can	SD	D	A	SA
*13.	In the past I have rarely found other people's opinions useful when I have a problem	SD	D	A	SA
14.	It really helps when you are angry to tell a friend what happened	SD	D	A	SA
*15.	Some things are too personal to talk to anyone about	SD	D	A	SA
16.	It's fairly easy to tell who you can trust, and who you can	SD	D	A	SA
*17.	In the past I have been hurt by people I confided in	SD	D	A	SA
*18.	If you confide in other people, they will take advantage of you	SD	D	A	SA
19.	It's okay to ask favors of people	SD	D	A	SA
*20.	Even if I need something, I would hesitate to borrow it from someone	SD	D	A	SA