

**STRESS IN FAMILIES OF CHILDREN WITH INTELLECTUAL
IMPAIRMENT AT DAGBREEK AND MÔRESON CENTRES IN THE
KHOMAS EDUCATION REGION OF NAMIBIA.**

A RESEARCH THESIS SUBMITTED IN PARTIAL FULFILMENT

OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF EDUCATION

OF

THE UNIVERSITY OF NAMIBIA

BY

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JANUARY 2013

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ABSTRACT

This study was undertaken with the specific aim of investigating stress experienced by families of intellectually impaired children at the Dagbreek and Môreson Centres in Windhoek and to find out how these families cope with such stress. For the purpose of this study, a qualitative approach was adopted. Phenomenology was the guiding theory and semi-structured interviews were carried out to collect data with a sample of ten families whose children attended school at the aforementioned Centres. The data collected was analysed using thematic content analysis. Four main themes were identified and from them it was discovered that the ‘overall experience of their children’s impairment’ by parents and guardians was unique since they had mixed feelings (both positive and negative) and had different reactions to the diagnosis of their children’s impairment. The study indicated that stress for parents and guardians is caused by the daily demands of physical care, medical care and schooling needs of their children. Demands on parents by their children differ from family to family and are caused by a combination of impairment and the family situation. The study further noted that the existence of an intellectually impaired child in the family has a major impact on family members, the relationships of parents, separation of parents, extended families as well as on the public or community members. Stress in families is further worsened by discrimination and stigmatization by some members of the community. In addition, the support which families received from internal and external sources was regarded as important in enabling them to accept as well as to cope with the demands of caring for an intellectually impaired child though some families have to live with stress owing to the lack of services. In conclusion, with various types of stress experienced by parents and guardians, recommendations were

made that could improve the welfare of families with intellectually impaired children. These included the presence of therapists at the two educational centres, educating the community to better understand the nature and needs of impaired children, and the provision of counselling services. More research could be conducted on how stress experienced by families which related to the care for children suffering from intellectual impairment could be managed.

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ACKNOWLEDGEMENTS

I acknowledge the support throughout the writing of this study by my supervisors, namely, Dr A. D. Möwes and Dr D.D. Zealand.

I also acknowledge the help from the Ministry of Education for allowing me to carry out the study at Dagbreek and Môreson centres for Intellectually Impaired Children in Windhoek. Special thanks to the two principals for availing the details about parents and guardians who took part in the study.

A sincere thanks to parents and guardians with intellectually impaired children in the Khomas Education Region, who participated in the study for their willingness and readiness to share their experiences through the interviews I conducted.

I am further most grateful to my colleague, Gedion Makoni, for his constant encouragement, motivation and support throughout this study. The same appreciation goes to Mrs Christa Schier for her assistance in the analyzing of the data and unfolding ideas. I am also grateful to Ms Helen Vale for language editing of my thesis with grate patience. In addition, special thanks go to my school principal for his constant motivational support.

Finally, it is my pleasure to thank the following colleagues: Aune and Sadrag-Panduleni for their kind assistance with technology and updating my documents. It is also my pleasure to thank my friends: Dr Amukugo, Mrs Kruger, Enos, Auguste, Kaarin and Adolf for their continuous support. I am indebted to family members: Me

Maria, Me Liina, Me Olivia, Me Kashipu, Natangwe, Kandeshi for their undivided attention and kindness. When I was about to drop out, one of them would remind me that I should finish the race I had started. Thanks to everyone who contributed positively to this study. Finally, thanks to the Almighty God for giving me strength, wisdom and faith to complete this study.

DEDICATION

This study is dedicated to my late grandmother (GwaNakapipi) who brought me up to be the person I am today and to my mother who has been my inspiration throughout my life. It is also dedicated to my daughter Ndatoolewe for her patience and encouragement. Lastly, this work is dedicated to the parents and guardians of intellectually impaired children for their valuable contribution that enabled me to complete this study.

DECLARATIONS

I, Aina Simson, declare hereby that this study is a true reflection of my own research, and that this work, or part thereof has not been submitted for a degree in any other institution of higher education.

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CHAPTER 1. INTRODUCTION

1.1 Background of the Study

In chapter 1, the study is contextualised and the rationale is explained. An outline of the problem statement, research questions, significance of the study, limitations, definition of the key concepts and the summary is provided.

The birth of a child is normally viewed with eager anticipation. As parents make preparations for their child, they may not only wonder about the gender and looks of their child but they may also wonder about the child's future. When the child is born with no complications or impairments, this process seems to evolve naturally. However, when there are prenatal or perinatal complications, or postnatal discoveries of developmental impairment, the idealised picture of having a normal child is shattered (Turnbull & Turnbull, 2001).

Families are the foundation of a child's development, socialisation, and formation of his/her values and beliefs. In addition, families are the source of great happiness, as well as stress (Marshak & Prezant, 2007). "Parenting any child can at times be a stressful experience" (Baker, 2002). According to Cunningham (1996), the birth of a child with an impairment is an unanticipated event. No family regardless of race, ethnicity, or socio-economic status is immune to any impairment; yet almost all are poorly prepared to cope with its occurrence (Evans, 2004). A study by Matson and Mulick (1991) revealed that awareness of the existence of children with intellectual

impairment, those children who learn more slowly than their peers and have difficulty adapting to social needs and demands, has been present for centuries.

Saloviita, Leinonen and Italinna (2003) reported that early research on families of intellectually impaired children reflected a pathological model in that families were automatically assumed to suffer as a consequence of the child's impairment. Furthermore, the view was echoed by Jacques (2003:39), who stated that "it is usual for the family to grieve the loss of the "normal" child while at the same time having to come to terms with the impairment both emotionally and practically". He pointed out that most families show resilience and common sense as well as experiencing emotional pain and stress. Studies conducted in the United States of America reported a large body of literature supporting the idea that family stress is a more common phenomenon among family members who provide care for intellectually impaired children than it is among other families (Quine & Pahl, 1991; Baxter, Cummins & Yiolitis, 2000; Grant & Whitell, 2000; Hassal, Rose & McDonald, 2005). However, (Saloviita, Leinonen & Italinna, 2003) disagree by saying that stress in families with intellectually impaired children is not necessarily a negative experience.

According to a study conducted in South Africa by Lombard (1990), it was reported that one of the most traumatic and emotional experiences a family could ever face is the diagnosis of a child with intellectual impairment. Another study by Streissguth and O'Malley (2000) found that in South Africa over 90 percent of children born with foetal alcohol syndrome had mental health problems, 60 percent were expelled

from school, 60 percent get in trouble with the law and 50 percent have been in jail. Because of these findings it seems necessary to research and compile a profile which will refer to specific characteristics such as hyperactivity and impulsivity and focus on the emotional behaviour of the child with foetal alcohol syndrome, so that parents, teachers and other individuals working with children with this syndrome know how to work with them. Families with intellectually impaired children will find it difficult to explain the challenges of having children with intellectually or physically impaired children to other people, as evidenced by the Namibian society where such information is withheld because of perceived negative labels by society. Many families thus hide their intellectually impaired children (The Voice, National Federation of People with Disabilities, 2009).

A study, conducted in Namibia by Brand (2005), stated that in some complex societies, which place a high premium on features like intelligence, the realization that a child is intellectually impaired can be a huge disappointment to parents. The question remains whether families are ignorant or lack understanding, or is it a taboo connected to their cultural perceptions. It remains to be confirmed through the literature review whether corresponding studies are available from the Namibian perspective, with special reference to Dagbreek and Môreson Centres (these are two institutions in the Khomas Education Region which accommodate learners with intellectual impairments). In this study, stress in families of children with intellectual impairment will be highlighted. The researcher finds it important to pursue such a research topic, which will investigate types of stress, causes, impact associated with stress in families with intellectually impaired children and coping strategies to be

employed. This is because in such a study, from a Namibian perspective, the stress in families with intellectually impaired children can be identified and advocacy measures recommended.

1.2 Statement of the Problem

All child-rearing involves stress and requires coping to accommodate and adapt to that stress (Glidden, Bilings & Jobe, 2006). In addition, parents of children with intellectual impairment are likely to encounter some challenges far more frequently than parents of typically developing children (Stonemann & Gavidia-Payne, 2006).

A national survey by the Dutch Coalition on Disability and Development (2005) revealed that households with mentally disabled people have lower standards of living and less access to services such as schools. As such school attendance is low, 28% to 35% of mentally disabled children have never attended school, which thereby generates pressure on family members who will economically support them, and results in stress for the family. In addition, most learners with intellectual impairment in Namibia are not accommodated in centres catering for intellectually impaired children, as evidenced by the long admission waiting lists at Dagbreek and Môreson Centres. Such a situation is likely to cause problems of care of the impaired children at home (Du Plessis, Personal Communication, 19 April 2008), which is at odds with The Namibian Constitution, which in Article 21 states that all children have the right to education.

The major problem facing Môreson Centre is that some parents do not collect their children once schools close for the holidays. Consequently, the school struggles to feed and care for the uncollected children, since government supplies cease when schools close (Strauss, Personal Communication, 13 June 2008). An observation study (2008) carried out by the researcher at Dagbreek Centre for intellectually impaired learners inspired the researcher to further investigate this problem. In conclusion, this study investigated types of stress, causes, and impact on families of children with intellectual impairment at Dagbreek and Môreson Centres and the strategies used by families to cope with stress. Accordingly, in order to tackle the issue of stress effectively, it is necessary to address it at family level.

1.3 Research Questions

The main questions of the study are:

- a) What types of stress do families of intellectually impaired children experience?
- b) What causes stress in families of intellectually impaired children at Dagbreek and Môreson Centres?
- c) What impact do children living with intellectual impairment have on their families?
- d) What coping strategies do families with intellectually impaired children use?

1.4 Significance of the Study

In Namibia, the well-being of intellectually impaired children has not significantly improved since Namibia independence when owing to limited services. This study hopes to assist the Ministry of Education and other stakeholders such as the National Institute for Educational Development (NIED) when developing syllabi and formulating policies for improving the well-being of intellectually impaired children in Namibia. It is hoped that the information gleaned from this study will assist professionals in the field of Inclusive Education or psychologists who are working with families of individuals diagnosed with an intellectual impairment. The study might also provide useful information for the affected families, Social Welfare Organisations, Non-Governmental Organisations such as the Namibian Association for Children with Disabilities, on the current state of families with intellectually impaired children and offer possible solutions to their challenges.

The tone and frequency of concerns raised in this study might harness full collaboration of both educationalists and policymakers in enacting rules and regulations to support families with intellectually impaired children. It is hoped that the welfare of intellectually impaired children will improve as specialist equipment and therapy will be provided to families of intellectually impaired children. Furthermore, it is hoped that the results will help the professionals to understand the interaction of variables related to family adaptation, the nature of the stresses, and the successful coping strategies used by families with intellectually impaired children.

1.5 Limitations of the Study

Some of the limitations which arose in the study are as follows:

- a) In Namibia little research has been carried out in the area of this study. This limited the researcher with regard to compiling a literature review.
- b) Language barriers. Some of the parents were not able to express themselves well in English so that the interviewee's real feelings were not finely articulated. In the case of language barriers, the researcher made use of interpreters from the same family.
- c) The rhythm and momentum of data collection were at times disturbed when some parents postponed proposed appointments for interviews.
- d) One of the participants was not comfortable with the interview being recorded; therefore she opted to respond on the interview question as a questionnaire. Thus, probing questions could not be asked.

1.6 Definition of Terms

For the purpose of this study, terms are defined as follows:

Autism – This is a physical disorder of the brain that results in a developmental delay. There are no physically identifiable characteristics. One should look for signs in the child's language, and in his or her personal, social and emotional behaviour. They are engaged in repetitive activities and unusual movements (Ross & Deverell, 2004).

Coping – This is defined as the conscious cognitive and behavioural efforts that one interposes between oneself and an event perceived as threatening or uncontrollable in order to master, tolerate, or decrease the event's impact on one's physical and psychological well-being (Folkman & Lazarus, 1997).

Down Syndrome – This condition is caused by a chromosomal or genetic defect. It affects the child's physical appearance, intellectual functioning, and language and social skills (Luyt, 2004).

Epilepsy- This is a condition in which a sudden disturbance or change in brain electrical impulses results in seizures. It is characterised by an exceptionally high discharge of electrical impulses for a long time or very short period of time. During this time a person has a seizure, or a 'fit' or an epileptic attack, and in such an attack there is a reduction or loss of consciousness and oddities of movement, sensation, behaviour and perception (Kapp, 2002).

Foetal Alcohol Syndrome- This syndrome is caused when a mother habitually drinks an excessive amount of alcohol during pregnancy. The child can be identified by physical characteristics such as unusual features (big head, eyes on the level of the ears, a flattened and long lip area, poor co-ordination, learning disabilities and social difficulties (Nolan, Grant & Keady, 1996).

Intellectual impairment – This is a set of conditions involving deficits in abilities of cognitive functioning and adaptive skills. It can also affect a person's ability to

reason and understand, to acquire skills and master developmental milestones within “typical” age ranges, to problem-solve and adapt to new situations, and to learn and remember as easily as others (Hassal, Rose & McDonald. 2005).

Trauma – This refers to a body wound or shock produced by sudden physical injury, as from violence or accident (Meriam-Webster’s Collegiate Dictionary, 1993).

1.7 Summary

This chapter provides an outline of the problem statement, research questions, significance of the study, and limitations of the study and definitions of the key concepts used in the study.

CHAPTER 2. LITERATURE REVIEW

2.1. Introduction

This chapter reviews the literature relating to earlier models and theories on family stress that forms the basis of this study. The first section of this chapter provides a theoretical framework for the study while, the second section discusses the concept of stress and family stress. The third section focuses on the types of stress in families with intellectually impaired children and the fourth section focuses on the causes of stress. Finally, the fifth section reviews the impact of children living with intellectual impairment on their families while, the sixth section addresses coping strategies of families with intellectually impaired children as evident in the reviewed literature.

2.2. Theoretical Framework

2.2.1 The Double ABCX Model of Family Stress Theory

In the last decade, Reuben Hill's (1949) ABCX Model has been used as the foundation for studying family stress. Therefore, the theoretical framework for this study will be based around a transactional Double ABCX Model, to understand stress in families with intellectually impaired children. In this theory, (A) the stressor event interacts with (B) the family's resources to deal with crises, and (C) the family's definition of the stressor event to produce (X) the crisis (McCubbin & Patterson, 1983a; McCubbin, & Patterson, 1983b). Some families who experience stress may not even reach a crisis, depending upon their ability to restore stability, and use existing resources.

The stressor (A) is defined as a life event or transition that produces, or has the potential of producing change in the family social system (McCubbin & Patterson, 1983a). Hardships are defined as those demands on the family that are associated with the stressor event. Examples of the demands will be a change in the family routine to accommodate hospital visits to a sick family member or the need for extra support or cooperation in caring for that individual.

Family resources (B) are the family's ability to cope with the specific stressor or crisis. Family resources include an individual's personal resources, the family system's internal resources, social support, and coping strategies (McCubbin, & Patterson, 1983b). These authors also stated that personal resources, which include finances, education, health, and psychological resources, have been the most researched area. According to Quine and Pahl (1991) family resources are the strengths the family has available to them, which help the family adapt to the stressful event. The family itself can be a major source of social support; however, support can also be found outside the family. Ufner (2004) defined family's coping resources as individual and collective strengths that help the family adapt at the time the stressor event occurs. Examples of family and individual strengths would include finances, health, intelligence, communication skills and social support.

The (C) factor involves the family's definition perception of the stressful event. This is a critical factor in determining the severity of the stressor event and whether or not the family will experience a crisis (McCubbin & Patterson, 1983a). The subjective definition of the stressor event is influenced by family values, the family's previous

experience with stress, the cultural definition of the stressor, and the community's image of the event (McCubbin & Patterson, 1983b).

According to Orr, Cameron and Day (1991), the original ABCX Model focuses on the stress associated with the single crisis event and the variables that account for the family's capability to cope with a stressful event. The Double ABCX Model, developed by McCubbin and Patterson (1982, 1983a), expands upon Hill's original ABCX Model by adding other life stressors or changes that may influence the family to achieve adaptation (McCubbin & Patterson, 1983b). McCubbin and Patterson (1983b) also pointed out that the Double ABCX Model is much more dynamic, because families rarely do deal with a single stressor, but a wide variety of stressors resulting from the individual, family and the community.

In this model, the family struggles to maintain a balance between the individual, family and the community. Many authors (Orr, Cameron and Day, 1991; Folkman and Lazarus, 1997; Grant and Whitell, 2000; Tobin, 2002) believe that in this model, any event, such as the impairment in a family will have different meanings and effects for each individual and that only the individual can appraise whether the effect is distressful or stressful. As has been alluded to earlier, the study looked at the types, causes, impact of stress in families with intellectually impaired children within this model in order to find coping strategies in assisting these families.

2.3. A Brief Historical Perspective of Intellectual Impairment

After World War I, the focus turned to intellectual impairment as a result of the use of standard testing on a large scale by the military (NSW Health, 2003). This resulted in many young men being found unfit for military service because of low intelligence. At the same time professionals shifted their interest to the development of intelligence tests to identify the intellectually impaired. Not much progress was made for another three decades (Jones & Passey, 2003). Jones and Passey also noted that the idea emerged that the intellectually impaired are part of us, not from us, and that they and their families must be treated accordingly. However, the implication of this was that the intellectually impaired would be integrated as much as possible into the community.

In dealing with a chronic non-progressive condition like intellectual impairment, the use of prevalence, namely, the number of cases present in a given population is preferred to incidence, which is a measure of the rate of new cases appearing in a defined population over a specified period of time (Heller & Caldwell, 2006). According to the World Health Organisation, the prevalence of severe intellectual impairment (IQ<50) is approximately 3 to 4 per 1000 in the general population, while that of mild intellectual impairment (IQ 50-70) is 20-30 per 1000 population (NSW Health, 2003).

2.4 The Concept of Stress and Family Stress

2.4.1 What is Stress?

Stress is a normal part of life and everyone will experience stress in different degrees, depending on a person's tolerance level; it is a difficult concept to define because it is based on an individual's perspective (Romas & Sharman, 2000). Folkman and Lazarus (1984) defined stress as a complex rubric, emotion or cognition, rather than as a simple variable. Instead, stress is defined by many variables and processes that are reflected in the person's appraisal of a relationship with the environment as relevant to well-being and taxing or exceeding his/her resources. According to Merriam-Webster's Collegiate Dictionary (1993) one definition of stress is ' a constraining force or influence such as a physical, chemical, or emotional factor that causes bodily or mental tension and may be a factor in disease causation' (p.1164). Stress can be an outcome resulting from interactions with people, situations, and the environment (Heller & Caldwell, 2006). When someone goes through tension, this tension creates stress, which requires some types of change or adaptation (Callanan, 2000).

2.4.2 The Concept of Family Stress

Unlike individual stress, family stress involves every family member. The family is made up of a variety of subsystems, that all influence one another (Orr, Cameron & Day, 1991). A change in an individual or group relationship will cause change throughout the entire family system (McCarthy, Cuskelly, van Kraayenoord & Cohen, 2006). Family stress varies depending upon the nature of the family's

psychological and material resources, and the definition the family makes of the event (Seligman & Darling, 2007). Seligman and Darling proceed to define family stress as ‘a state that arises from an actual or perceived imbalance between demand (for example, challenge, threat) and capability (for example, resources, coping) in the family’s functioning’. A stressor event in the family produces a change in any part of the family’s system: boundaries, values, structures, or goals (Heller & Caldwell, 2006). Family stress may come from within the family, such as adding or losing a family member, or outside the family, such as environmental stressors (Marshak, Seligman, & Prezant, 1999).

2.5 Types of Stress Experienced in Families of Intellectually Impaired Children

A family focused intervention places the parents in a pivotal role whilst developing and maintaining family resilience (NSW Health, 2003). Rolland (2003) noted three major types of stress, namely stress by choice, situational stress and chronic stress. An example of stress by choice would be joining committees, accepting job promotion or becoming a parent. Situational stress is likely to be more damaging than stress by choice, because it catches us unexpectedly; however, it is mostly short-term and can be reduced once the initial crisis is over. Chronic stress is the most harmful type of stress, because the human body is unable to tolerate high levels of stress for an unlimited period of time. Some researchers have investigated factors that are common to illness and impairment and noted five areas of stress commonly experienced by families as a consequence of either chronic illness or impairment

(Marshak & Prezant, 2007). These areas are intellectual stress, instrumental stress, emotional stress, interpersonal stress and existential stress.

2.5.1 Intellectual Stress

According to Seligman and Darling (2007), intellectual stress is mostly associated with the process of first information, that is, when determining an accurate diagnosis occupies the parents' attention. Marshak and Prezant (2007); Hanson and Lynch (2004) and Marshak et. al. (1999) revealed that certain crisis periods are especially traumatic for parents of children with impairment, including when parents first learn or suspect that their child is impaired, age of school-entry, time of leaving school and when parents become older. Of these different periods, the crisis of first information of impairment is probably the most difficult and families' needs for support are greatest at that time.

The birth of a child with impairment has been shown to arouse a variety of emotions, with past research suggesting that grief and loss of normalcy occur within stages, generally beginning in sadness and ending in acceptance (Landsman, 2000). According to Kearney and Griffin (2001), the reaction of parents/guardians to the news of their child's impairment can be grouped into three main phases. They further explained that these phases were created from results obtained in a study that aimed to identify various emotions experienced by parents/guardians in bringing up an intellectually impaired child. The news of their child's impairment often gives rise to shock and disappointment. Turnbull and Turnbull (2001); and Marshak et al., (1999),

developed an extensive model to describe the reactions of parents and guardians as primary, secondary and tertiary phases. These phases will provide a basic outline for parental reactions to their children's diagnosis.

a) Primary phase

This refers to reactions of parents and guardians that include shock, denial, suffering and depression. These are crises resulting from a sudden change in the perceptions of the parents and guardians of themselves and their family and their future. Sen and Yurtsever (2007) and Turnbull, Turnbull, Erwin and Soodak (2006) stated that shock is the first reaction by parents and guardians when they learn that their child is impaired, regardless of the nature of that impairment. What follows is a sense of helplessness, hopelessness and disappointment which are the most of the constant emotions experienced by parents and guardians whose children are impaired. A study by Seligman and Darling (2007) revealed that some parents are disappointed, unable to accept that their children has an impairment and such an impairment may cause them to reject their children. Landsman (2000) describes this denial as a defence mechanism and common reactions of parents to the discovery that their child has impairment. In addition, Turnbull et al. (2006) noted that some parents experience feelings of denial because of the uncertainty and insecurity the future holds to help their child. Another reaction experienced by parents is depression which gives them a transitional period in which former dreams and fantasies about the normal child are re-adjusted to reality (Marshak & Prezant, 2007). Depression for most families is temporary or episodic, possibly coinciding with a particular phase of the family life

cycle. As parents realize that their child will not improve significantly, feelings of guilt, anger and shame and ambivalence develop.

b) Secondary phase

The second phase or group comprises reactions, which include feelings of guilt, anger and shame and ambivalence. This phase is described as an emotion of shame and feeling that one has done something wrong (Landsman, 2000). It is further noted that these feelings of guilt and shame are known in the case of giving birth to a child with impairment. The next reaction of ambivalence is a negative feeling which is usually accompanied by guilt, which makes some parents dedicated to their children whilst others totally reject their children (Sen & Yurtsever, 2007).

c) Tertiary phase

According to Marshak et al. (1999), the last group of reactions includes acceptance and adaptation, which are clustered together. They further described adaptation as reduction in the feelings of anxiety and other intense emotional reactions while acceptance is used to describe what is considered to be a healthy response to the fact that one's child has impairment. A study by Marshak and Prezant (2007) revealed that acceptance is not surrender to the idea that the impairment is unchangeable. Rather, parents accept the need to learn skilful ways to alter the negative effects of the condition. The acceptance phase can result in a perception or realization that one is blessed in being chosen to be the parent of a child with impairment.

Hornby (2000) noted that it is not uncommon for parents of children with certain impairments to engage in the frustrating process of consulting a number of specialists. On the other hand, with some impairment, there can be several misdiagnoses before a correct one is given. Once the diagnosis is made, parents usually experience a compelling need for information (Marshak & Prezant, 2007). Studies by Rolland, (2003) and Marshak et al. (1999) reported that the quest for information regarding etiology, prognosis, and treatment may be very anxiety provoking. They concluded that parents may engage in 'doctor shopping' which may make them susceptible to 'quack' treatments, although some shopping around may be necessary to find a professional who is emphatic, responsive with impairments and can make a definitive diagnosis.

2.5.2. Instrumental Stress

This involves tasks that are necessary to incorporate the child's care and treatment into the lifestyle of the family (Turnbull et al. 2006). The goal is to achieve as much balance as possible in the family system. While simultaneously attending to their child's needs and their own needs, the parents must also attend to the needs of other family members. Marshak et al. (1999) noted the following instrumental challenges:

- Managing finances.
- Determining the division of labour in the family so that adequate care is provided for the child with impairment.
- Accomplishing necessary household chores in addition to caretaking.

- Becoming aware of signs that indicate a negative impact of the illness or impairment on family members.
- Knowing when and how to seek assistance.

Hornby (2000) indicated that the financial demands on a family are often given short shrift in the professional literature. Both direct medical care and in-home and self-care expenses, as well as expenses for special diets, special schools, time lost from work, home modifications, and the like, constitute significant sources of stress. These financial demands can interfere with potentially restorative and interpersonally rewarding family activities, such as vacations (Rolland, 2003).

2.5.3. Emotional Stress

According to Marshak et al. (1991), emotional stress is a response to the demands of care-giving that might include lack of sleep, loss of energy, and excessive worry and anxiety. A factor contributing to the emotional response to illness and impairment is uncertainty regarding prognosis and responses to periodic exacerbations (Rolland, 2003; Hanson & Lynch, 2004, Turnbull et al., 2006). Furthermore, the uncertainty and ambiguity that can accompany illness or impairment can compromise one's sense of perceived control (Pollin, 1995).

Parents of children with rare disorders may feel particularly isolated, which increases their emotional stress, because it is unlikely that they will encounter another family with a child who has the same condition. Another contributor to emotional stress is the heart-wrenching experience of watching a child suffer and not being able to

relieve that suffering (Seligman & Darling, 2007). Also, in the case of medical illness, heightened vigilance for signs of relapse or disease exacerbation can add to stress and anxiety Rolland (2003); Seligman & Darling (2007).

2.5.4. Interpersonal Stress

It has been suggested that impairment, whether it is an impaired husband, wife or child has an effect on the relationships and opportunities of the family as a whole (Burke & Cigno, 2000). According to Zinck and Newen (2008), previous research suggested that when a child has impairment it may potentially affect family members, the family as a system, and the parental role. Thus, in attempting to investigate the experiences of families with children who are intellectually impaired, the relationships within the family system need to be taken into account. This is a necessary aspect because the family is often described as an interdependent system that is interactive and reactive to the physical, social and emotional functioning of every member of the family (Sen & Yurtsever, 2007). Therefore, a problem experienced by one family member can affect the entire family.

Although divorce rates among these families tend to be roughly equivalent to rates in families in which there is no illness or impairment, the review of studies of marital adjustment in families of children with intellectual impairment, Marshak and Prezant (2007); Lavee, Sharlin, and Katz (1996) noted that the influence of stress was negative in some cases and positive in others. The available research suggests that having a child with impairment does not necessarily lead to divorce or major marital

problems, although some families are challenged by this situation while others seem to grow stronger (Brinthaupt, 1991; Siegel 2003; Rolland, 2003). Interpersonal distress exists in other family members because children who are not impaired and extended family members are also affected by childhood impairment (Marshak et al. (1999). Finally, interpersonal stress emerges from potentially stressful encounters with the public (Heatherton, Kleck, Hebl & Hull, 2000). Baxter (1986) in Seligman and Darling (2007) found out that worry about the child's behaviour in public can increase over time, as the child turned out to behave in a different way. Such behaviour may limit the family's opportunities for social participation.

2.5.5 Existential Stress

According to Rolland (2003), this area is used to discuss the family's ability to construct an explanatory framework of meaning for its experience. Seligman and Darling (2007) found that childhood impairment is an affront to the assumed developmental order of the family cycle. Childhood is supposed to be a time of well-being and not a time of threats to viability or function (Romas & Sharman, 2000). Parents grapple with such existential issues as "Why me? or Why my family? Existential questions regarding, 'Why me? or Why us? are salient questions which are relevant to children with impairments and their families (Turnbull et al., 2006). Furthermore, a child with an impairment may be perceived as a reflection of the parents' own inadequacy. In situations where a child is viewed as salvaging an unstable marriage, the birth of a child with impairment may be another indication that the marriage is doomed to failure. On the other hand, as noted by Ainsworth and

Baker (2004), the infant may be seen as a divine gift, a sign of grace. Some parents appear to be able to explain their child's impairment within the framework of a particular life philosophy, whereas others alter or abandon their previous religious or spiritual commitments. It is apparent that existential stresses are a formidable challenge for parents of children with chronic illness or impairments (Brinthaup, 1991).

2.6 Stress in Families of Intellectually Impaired Children.

Researchers have sought to provide a useful conceptualisation for a particular type of stress, family stress. Jones and Passey (2003) acknowledge the assumption that stressors are multi-dimensional, both in source and kind. They noted that this assumption led to identification of three major source domains of stressors for parents:

1. Child characteristics
2. Parent characteristics
3. Situational /demographic characteristics

Child characteristics include factors such as the child's adaptability, need for care and level of hyperactivity. Some characteristics of the parents include level of stress, attachment to the child and sense of competence as a parent. Situational life stress includes events such as changing jobs, marriage, divorce or death of a family member. Ainsworth and Baker (2004) also commented that, based on their experience of working with parents, they consider the emotional interpretation of situations by parents to be just as important as the characteristics of the children with regard to the experience of family stress. They further pointed out that evaluating

family stress may be somewhat complicated in that there are potentially several components to consider based on interactions of the child, parent and environmental variables. Hence, it is important to investigate family stress.

A study by Mak, Ho and Law (2006) noted that families of children with intellectual impairment are frequently bombarded by questions and concerns regarding their children's impairment, in addition to having to deal with society's negative attitudes towards children who are different. Therefore, families who have children with intellectual impairment experience greater levels of stress than families of children with no-intellectual impairment (Grant & Whitell, 2000). The extent to which families will experience stress depends on many factors including the child's characteristics, the structure of the family, family resources and coping strategies (Hastings & Beck, 2004). However, not all families will experience a high amount of stress, despite the greater risk for stress (Hassal et al., 2005).

On the other hand, one stressor for families who have children with intellectual impairment is that they may continue to care for their children for an extended period of time, which can be physically and emotionally draining (McCarthy et al., 2006). Another stressor that is chronic for families with intellectually impaired children is society's negative attitude towards their children. Similarly, reflecting on personal experience and research, Mak et.al,(2006) and Stonemann and Gavidian-Payne (2006) reported a sense of isolation and loneliness that many families experienced. Thus, the families' social and recreational patterns may be altered owing to the added care needed by intellectually impaired children. Alternatively, family stress may also

be related to attempts to locate appropriate services and education for their children among the maze of human service agencies which often have confusing and overlapping boundaries (Tobin, 2002).

In the beginning, parents may lack information regarding their child's diagnosis and how to care for their child, therefore, they feel dependent on professionals for the answers until they become more comfortable in their interactions with their child and professional, which can also be a source of added stress (Marshak et al., 1999). A study by Marshak and Prezant (2007) revealed that the child with an impairment requires extra time for feeding, toileting and taking to and from appointments. They further noted that the hardest things families face is balancing the demands of the normal life of the family (including other children) against the demands of the impaired child. Considering all this information, it is assumed that families who have impaired children are at risk for added stress.

2.7 Causes of Stress in Families with Intellectually Impaired Children

According to Orsmond and Seltzer (2000, p. 43), "day-to-day care is needed by a severely impaired child and the caring is a 'daily grinding of care. For some families the care is 24 hours a day, 7 days a week, and for many years. The stress can be relentless and drain the family physically and psychologically. Cunningham (1996); Jones and Passey (2003); Grant and Whitell (2000), did not explain what causes family stress, however, they did discuss several factors that appear to be associated with greater family stress. Their findings have indicated that socio-economic status

was one of the strong indicators of family stress, since they noted that families with lower economic status reported significantly higher levels of stress. In addition, financial worries may exist, thereby posing economic difficulties which can have a negative effect on the social or recreational activities of family members. Similarly, stress related to financial worries can have a negative impact on affection and self-esteem (Turnbull et al., 2006).

On the other hand, Gupta and Singhal (2004) concluded that the only consistent demographic variables related to family stress were family income. Specifically, families with a higher income reported lower levels of stress. Such families perceived themselves as more competent and reported better relationships with their spouses. Mak et al. (2006), found some contrasting evidence to the previous studies, such that higher socioeconomic status was associated with increased family stress. In addition, they pointed out that economic troubles are caused by high expenditure on drugs and treatment. The other factor found by Jones and Passey (2003) was the influence of the child's age on family stress. They reported that younger children were perceived as more stressful to the family than older children. On the other hand, Mak et al. (2006) indicated that older children appear to more significantly influence family stress. They also pointed out that the higher the number of children in the family; the more family stress is experienced. Although, this was a marginal association, it would seem that the literature is consistent in maintaining that economic factors are strong predictors of family stress.

In addition, problems of all shapes and sizes beset families who are bringing up children with intellectual impairment (Walker, 2000). Jacques (2003) agrees that a number of practical problems make living with an intellectually impaired child too demanding in many areas such as tasks of baby-sitting and day-care activities. These include bathing, feeding, and toileting, lifting and carrying which are common features of looking after an intellectually impaired child. Quine and Pahl (1991) indicated factors that were associated with stress in parents, especially mothers, such as night time disturbances. Such a situation influences both the mother's work and career, in terms of change to their working conditions. McCarthy et al. (2006) assert that when an impaired child needs constant physical attention, the mother in the family will get less sleep at night which results in fatigue and an accumulation of stress. They further pointed out that intellectually impaired children with a variety of different impairments can create a range of problems for their families.

A study by Gupta and Singhal (2004) stated that the existence of an intellectually impaired child in the family includes a number of strains: poor communication, not accepting the situation, denying the situation, not expressing or hiding emotions, and acting in ways that break down relationships and destroy trust. They noted that marital difficulty is one of the more frequently reported adjustment problems. This view was also supported by Cunningham (1996) who indicated that marital problems include more frequent conflict, feelings of marital dissatisfaction, temporary separations, and divorce. He maintained that it is often impossible for the spouses to go out together and have any recreation because of the child. It is always necessary to make sure that there is somebody staying with the child, which often means that

the parents must go out separately. Therefore, it is not uncommon for the social relations of the family to decline, so that it becomes isolated from the rest of the community. In contrast, some families report no more frequent problems than comparing families without impaired children (Mak et al., 2006).

However, Shaban, Jevne and Sobsey, (2003), reported that some marriages have improved after the diagnosis of a child's intellectual impairment whilst other families suffered as a result of an impaired child. Although the data regarding marital dissatisfaction and divorce are contradictory, some marriages are under stress but are able to cope while others simply fail. They further noted that for some families, the burden of care is chronic. Instead of independence, growth, self-fulfilment, and differentiation, a family may see only despair, dependence and social isolation. According to Evans (2004), family members who are distressed and depressed may need family counselling. That is, living with an impaired child over many years can psychologically, physically and financially contribute to feelings of exhaustion, despair and resignation. Clearly, all the above are assertions concerning causes of stress in families with intellectually impaired children and warrant further study.

2.8 Impact of Children with Intellectual Impairment on their Family

Even though there are inconsistencies and contradictory findings, in general, the available literature suggests that families of children with intellectual impairment and other childhood impairment are at risk of numerous problems in comparison to families with children without impairment (Marshak & Prezant, 2007). As noted

above, Shaban et al. (2003) reveal that families with intellectually impaired children are confronted by challenges and bear burden unknown to other families without impaired children. Having an impaired child may also bring in the concept of stigma, which relates to the visibility of an impairment, its perceived controllability, and its perceived danger. Stigma causes anxiety and stress in those who are stigmatized. According to Miller and Major (2000) anxiety is experienced by stigmatized people when others make derisive comments, or because they are excluded, discriminated against, or are the victims of violence. People who are stigmatized are almost always the target of prejudice, avoidance, and rejection. Fraser et al. (1991) argue that the public have a tendency of stereotyping all those with an intellectual impairment as completely lacking in social competencies. Parents may face reactions from others that are quiet hostile. As the child grows older the discrepancy between their size and apparent age and their mental functioning may tend to increase, thus making the child more noticeable. On the other hand, Cunningham (1996) disagrees with these findings when he stated that the child with intellectual impairment is not a burden. A mother who shared her experiences in caring for an intellectually impaired child reported that:

I think that it has made my husband and me closer. We celebrate her accomplishments with our extended family, parents and in-laws. I guess it made us more conscious of things like quality family time and doing things together (Jones & Passey, 2003).

The above statements clearly confirm that families of intellectually impaired children can be affected either positively or negatively. The literature mentions several factors that may have an impact on the intellectually impaired children's families. These impacts seem to be related to family relations, to siblings and to economic demands. Each of these factors is outlined briefly below.

2.8.1 Impact on Family Relations

A family with an intellectually impaired child has been shown to be subject to significant changes and challenges (Heiman, 2002). A study by Sen and Yurtsever, (2007), outlines the following challenges that a family with an impaired child may encounter:

- a) The family experiences a lower standard of living because of increased expenses regarding their impaired child such as needs for a special school, availability of transport to school as well as for therapy sessions.
- b) Social isolation may occur, as the family can no longer go out and may have difficulty in entertaining friends, visiting friends or going on vacation as a family. Social isolation is greatest when the child is cared for within a single-parent family. Often, such a family may be vulnerable to such stress, although we should not assume that social support is lacking in all such cases.
- c) Lastly, anxiety about the future may cause internal conflicts within the family, owing to the stress and pressure it may experience in caring for an intellectually impaired child.

With regards to the above-mentioned challenges, it would be incorrect to view families with an intellectually impaired child as pathological. Rather, it is of greater benefit to view the strong and positive relationships that develop between family members, particularly parents (Heiman, 2002). In addition, personal accounts provide rich insight into the question of impact as a mother (Seligman & Darling, 2007) alluded to how she cares for her child. Many times, problems surrounding the

care of an intellectually impaired child will surface and its effects may be felt throughout the family. Families differ widely in their reactions and attitudes toward their children with intellectual impairment and it is worthwhile to consider why some families react well and others badly. Existing research reveals that very often parents have a negative attitude towards their children with intellectual impairment (Gupta & Singhal, 2004). This view is supported by Grant and Whitell (2000) who said that negative attitudes adversely affect the parents. Herring Gray, Taffe, Tonge, Sweeney and Einfeld (2006) have pointed out that a child's intellectual impairment affects the family's living conditions and way of life, for example by alterations that may have to be made at home. Their findings confirmed that other physical tasks needed in families with intellectually impaired children, include the treatment and care required by the child and hospital visits and rehabilitation, all of which take up a lot of time.

A study by Shaban et al. (2003) noted that having an impaired child had influenced some parents not to take a new job (in a new area) if the current service system was working for their child. Family members of intellectually impaired children are often perceived to experience harmful psychological effects that might lead to depression and marital dissatisfaction (Mak et al., 2006). In addition, Gupta and Singhal (2004) supported the idea by saying that the existence of the intellectually impaired child in the family includes financial strains, prolonged dependency in basic care, continuous attention and heavy demands on the family's time and energy through needing continuous supervision to keep the impaired child out of danger. Many researchers, along with many families themselves, have rejected these negative notions (Shaban et al. 2003; Jones & Passey, 2003; Gupta & Singhal, 2004). These studies stated that

positive attitudes help to bolster psychological and physiological consequences of stress. The fact that the spouses support each other and share caretaking tasks and other housework equally had a great importance in marital relationship.

2.8.2 Impact on Siblings

Given that the family is regarded as a system, it is fair to assume that the experience and impact of impairment on one member of the system will have effects on other members of the system. Siblings who comprise part of the system have been shown to be affected by the presence of a brother or a sister with an intellectual impairment. Similar to their parents, siblings share in the anticipation and excitement of a new child in the family. However, they also share in the grief, pain and challenges that may accompany the birth of an infant with impairment (Lyon & Knickelbaum, 2005).

Personal accounts from siblings suggest that although many siblings cope well, others may be 'at risk' psychologically and again may adopt a number of roles (Moore, 2006). These roles may include becoming a substitute mother, a friend, a supportive sibling or a pillar of strength for other members of the family. The literature is uniform in reporting that the relationship of siblings is complex and of an infinite variety and hence some could experience high level of stress (Gupta & Singhal, 2004). It is also noted that having a child with impairment affects not only the parents, but also siblings and the relationships among family members. It is natural for families to try to invest a great deal of time and energy into the child with

the most significant needs. On the other hand, siblings of children with impairment often express feeling neglected or jealous because of the extra attention perceived to be paid to their impaired sibling (Jacques, 2003). According to Swenson (2005) siblings' actions towards the impaired child are usually connected with the parents' reactions towards the impaired child. If the parents accepted their child's impairment then the siblings will accept it, too, and any adjustment will be dependent on what kind of attitude their parents have. Siblings can experience this positively or negatively (Swenson, 2005). Swenson also noted that where siblings' experience is negative, it is in fact the older siblings who appear to be vulnerable, perhaps because of the extra child care undertaken by them.

In a study conducted by Orsmond and Seltzer (2000) a variety of positive outcomes among siblings were evident such as patience and tolerance, love, justice and advocacy of those in need.. On the other hand, some siblings may feel that they have been harmed and expressed feelings of guilt, shame and embarrassment (Jones & Passey, 2003). In addition, such a reaction of shame is almost always learned from the parents. It can, therefore, be concluded that the impact of intellectually impaired children on siblings varies according to the background, culture and personality traits of individual siblings.

2.8.3 Economic Demand

According to Seligman and Darling (2007), caring for an intellectually impaired child may directly or indirectly have an economic impact on families over and above its psychosocial impact. This includes both direct costs such as expenses for child care, medical care such as therapy, hospital bills as well as medication and special and adaptive equipment; and indirect costs, such as loss of work time, special residential needs and interference with career advancement. Seligman and Darling (2007) also pointed out that since these children require access to services and greater commitments of their parents' time than other children; the family's overall economic situation may be adversely affected.

As has been pointed out earlier, financial worries may exist and the family becomes at risk of coping difficulties. In the same vein, the financial implications of having to care for an intellectually impaired child cause the families to have extra expenditures (Jacques, 2003). In addition, Swenson (2005) agrees that the budget of families with intellectually impaired children may be strained to provide special medical care, transportation, or remedial programmes. Owing to greater financial responsibilities, families may find themselves in a situation where they need to cut back on other expenses. On the other hand, Blacher and McIntyre (2006) reported that some parents may reject opportunities for career advancement because services for their children may not be as good as in a new location. Thus, the disruption to life and finances remains a constant worry to many families with intellectually impaired children and as such they contribute heavily to stress on families.

2.9 Coping Strategies of Families with Intellectually Impaired Children.

People differ in the way they cope and manage situations and feelings. Parents and guardians adopt a variety of coping strategies, which can either be maladaptive or adaptive in order to adjust to their new life (Heiman, 2002). Jones and Passey (2003) define coping strategies as how families try to deal with problems and reduce the strains or stress they cause. It is also what family members actually do, think, and feel with the available resources.

Based on the work of McCubbin and Patterson (1983b), the coping styles of families can be classified as internal and external strategies (Turnbull et al., 2001). Internal strategies mainly involve cognitive aspects of passive appraisal and reframing. External coping strategies involve more behavioral repertoires; including seeking social support and spiritual support (Marshak et. al., 1999). Becoming a parent of an impaired child can be a time of stress and change (Swenson 2005). This author also pointed out that the diagnosis of a family having a child who is impaired may disrupt the family system and requires a new level of organisation or balance. Lack of resources to deal with a situation is likely to increase strain or stress on the families' situation. Hence, Jacques (2003) discusses the need for coping strategies. Such strategies range from passive - wishful thinking (hoping the problem will go away), stoical (philosophical and patient about the problem) through to active strategies which lead to problem solving.

2.9.1 The Social Support

The literature has focused on a variety of stressors and variables considered as mediating some of the effects of stress. One such mediating variable that has received significant attention is that of social support (Jones & Passey, 2003). Social support can be defined as individuals, groups, or institutions that provide assistance to help other individuals overcome stresses that strain a person's resources (Bauman, 2004). It appears to play a part in the amount of stress experienced by parents or guardians.

Support arises in a variety of situations and from a number of people, therefore the availability and accessibility of support may influence the management of the demands placed on a family with an impaired child. Three forms of support have been identified: a) emotional support b) social support and lastly c) instrumental support. These will be briefly discussed. Emotional support has been described as paramount in assisting parents to manage and deal with the rejection and isolation they may feel, as a result of the stigma attached to having an impaired child. Additionally, parents may feel isolated because of the intense involvement of care for their child with an impairment (Marshak et al., 1999). Social support is also valuable as it entails the extent to which families are able to obtain assistance from others (Monteith & Kelly, 2003). Lastly, studies have shown that the availability of information and guidance has been proved to be valuable when the initial diagnosis of a child's impairment is made (Sen & Yurtsever, 2007). This access to information and support services is known as instrumental support.

Researchers have identified several major elements of social support: financial, emotional, educational, material, formal and informal (Plant & Sanders, 2007). Heller and Caldwell (2006) described two factors associated with successful coping: formal and informal support. Informal sources of support include support from individuals, from extended families, grandparents, friends, neighbours, other families with similar issues and groups such as churches. In terms of formal support, there are suggestions that appear helpful: family-centred practice as opposed to child-centred intervention; empowering families; keeping an eye on meso-, exo-, and macrosystem issues; and involving parents in teaching or treatment. Abbeduto, Seltzer, Shattuck, Krauss, Orsmond and Murphy, (2004) have shown that informal support has more positive effects than formal support. Positive effects of social support on stress in families has been widely reported (Walker, 2000). Ylven, Bjorck-Akesson and Granlund (2006) maintain that broadly based support systems are composed of friends of all ages, neighbours, co-workers, and others in the community who offer family resources, emotional aid, models of behaviour and sources of information.

Indeed, research in the area of family stress provides evidence that support from grandparents gives a buffer that contributes to coping with life's challenges (Trute, 2003). This was supported by Green, (2001) when he stated that more than relatives, friends or neighbours, grandparents are a common source of assistance. Having a child with intellectual impairment may cause some negative, or even disruptive, changes between the child's parents and grandparents. Parents may receive less support from the child's grandparents, especially those who are paternal. Grandparents are also vulnerable because of their unique position as parents to the

mother and father of the impaired child. They tend to grieve at two levels; firstly, for the loss of the expected child, second, at the knowledge of the increased burden placed on their own offspring. The degree to which grandparents are impacted is reflected by the degree to which they can be supportive and provide encouragement to parents (Seligman & Darling, 2007).

A study by Gupta and Singhal (2004) examined the importance of social support on raising an intellectually impaired child and found that mothers with high stressors but high support had few outcome problems compared to mothers with high stressors but low support. The ability to obtain levels of social support will vary depending upon individual characteristics, availability of resources and the culture in which one lives. Individual family members and families themselves will vary in the type of social support they need (Olsson & Hwang, 2006). These researchers further noted that social support in the form of marital happiness and family social climate have been found to be associated with more effective coping strategies. Turnbull et al. (2006) noted that a supportive husband, even one who does not participate in child care, seems to be an important predictor of a mother's sense of well-being. Spouses who are unhappily married are likely to suffer stress from the strain in their marriages and one could assume that the strain in their marriages is exacerbated by stress in other areas of their life (Oelofsen & Richardson, 2006). A number of authors claim that divorced and single parenthood lead to financial, psychological and instrumental problems (Turnbull et al. (2006); Seligman and Darling (2007). There is need for people from outside to intervene in assisting families to reach their goals in bringing up their children.

Other forms of social support including social support networks are also associated with reduced stress levels in families. Such networks, in particular, may provide a necessary buffer against stress for families of children with intellectual impairment; as many families consider the onset of school age as the beginning of their involvement in their social network. Stonemann (2000) supported the view by saying that the help given by outsiders such as financial support, taking children for a walk and transport services greatly assists those families with intellectually impaired children to maintain a normal life. However, Ylven et. al. (2006) report that families without socially supportive networks are likely to suffer from a wide range of negative physical and psychological health consequences such as depression. It is important that professionals encourage families with intellectually impaired children to join parent support groups, to extend their social resources and friendships as well as to receive additional support (Mak et al., 2006). It is useful to get as much help as one can from professional and other service providers, which at times turn out to be difficult. (Glidden et al., 2006). Thus, families need professional advice from the appropriate specialist services.

According to Cunningham (1996), professional services may be needed to support both the family, and to provide the information and skills to enable the informal network to help. The extent and type of needs may differ widely from one family to the other within the life cycle of the same family. Such needs may range from needs for information, counselling or advice, to needs for specific services (Gupta & Singhal, 2004). In contrast, some research has shown the negative effects experienced by families in dealing with professionals such as not being listened to or

not being understood by professionals (Jones & Passey, 2003). The study by Jones and Passey also indicated that there is need for professionals who work with families of intellectually impaired children to be aware of cultural differences and consider these as they provide services.

A study by Neely-Barnes and Dia (2008) confirms that it is the families' responsibility to get access to a trusting person to talk things over with them. This practice has a tendency of lightening challenges as it instils in the affected person an element of hope. They further noted that in this stage of adaptation, looking for the positive things in each situation or challenge should be seen as stepping stones to solutions. This is supported by Oelofsen and Richardson (2006) when they indicated that it is advisable to take one's mind off things in some ways like reading or watching television. This practice has the effect of refreshing the mind. Gupta and Singhal (2004) concur that one is expected to learn how to set priorities. Thus, one result of setting priorities could be drafting a realistic and workable budget.

2.9.2 Spiritual Support

Spirituality can be described in various ways: faith in humanity, ethical behaviour, concern for others or interaction in relation to a greater Being (Gupta & Singhal, 2004). Gupta and Singhal further observed that many people find spiritual support in the form of prayer, literature, participation in religious activities, joining organisations or attending religious services. Neely-Barnes et al., (2008) showed that faith and religious coping methods are the most frequently reported coping strategies

among families with intellectually impaired children. Thus, religion offers guidelines for living and offers a sense of stability. The question has been raised as to whether more people use religion as a coping strategy compared to other types of strategies, and whether more people turn to religion in times of crisis than at other times of their lives. It was found that individuals appear to involve themselves with religion to a greater extent in more stressful situations than in less stressful moments of their life (Bauman, 2004). McCubbin and Patterson (1983a) explained how spiritual support played an important role in the families' ability to manage stress, particularly in the most severe situations.

Lustig (2002) looked at three different approaches in religious coping: self-directed approach, deferring approach and collaborative approach. The self-directed approach places more coping responsibility on the individual rather than God. The deferring approach is described as an individual passively putting responsibility onto God. In the collaborative approach, both the individual and God are active participants in the coping process. The collaborative approach has been associated with a greater sense of self-esteem; personal control and a lower sense of control by chance (Lustig, 2002). Lustig broke down religious coping strategies into different categories in order to determine which type of religious coping is helpful or harmful (Poston & Turnbull, 2004). Spiritual support, congregational support, prayer and benevolent religious reframing were found to be helpful whereas congregational support was considered harmful. Neely-Barnes et al. (2008) confirm that religious people cope better with very stressful events than those who lack the comfort of personal faith. It must be mentioned that it is important that individuals continue to examine family

coping strategies and the resources that help buffer the amount of stress in the lives of families with intellectually impaired children. Thus, it must be understood what coping strategies parents utilise and which ones are most helpful for them.

2.10 Summary

This chapter provides the review of literature relevant to this study. It looks at the theoretical framework for understanding stress experienced by families of children with intellectual impairment. It also presents the types of stress, causes of stress, and impact of children with intellectual impairment on their families. Finally, it presents a discussion on coping strategies used by families to reduce stress in those families with intellectually impaired children. In the following chapter, the research methodology is discussed.

CHAPTER 3. METHODOLOGY

3.1. Introduction

This chapter outlines the methods that were used in the study to collect and analyse the data. This includes research design, the population, the sample and sampling techniques, the research instruments, pilot study, data collecting procedures and methods of data analysis and ethical considerations.

3.2. Research Design

This study made use of the qualitative research design in order to follow a suitable research plan and to gather the necessary data that answer the research questions of the study. A qualitative study was conducted, allowing participants to tell their stories in detail. Qualitative methods attach importance to individuals' subjective experience and how they understand events in their lives (Gay, Mills & Airasian, 2009). This design was appropriate for the study as the researcher aimed to gain understanding of the families' experiences of having an intellectually impaired child. In addition, a qualitative method allowed the researcher to examine the experiences of the parents/ guardians as understood through their own words.

The qualitative method is open-ended by nature and is useful when seeking to describe human experience or behaviour (Gay et al., 2009). Qualitative research is a multi-method approach to research that aims to study phenomenon in their natural settings, trying to make sense of, or interpret happenings in terms of the meanings

people bring to them (Clough & Nutbrown, 2008). There are different types of qualitative research theories such as phenomenology, ethnography, grounded theory, and historical research. This research is guided by the phenomenological approach, which “believes that individual behaviour is determined by the experience gained out of one’s direct interaction with the phenomena” (Dash, 2005, p.2). For the purpose of this study, a phenomenological approach was used to generate rich descriptive data from people’s experiences (Johnson & Christensen, 2008). This approach is considered suitable because it attempts to highlight how one or more families with intellectual impairment experience stress (McMillan & Schumacher, 2006). So far, the information that had appeared fragmentary and disjointed began to reveal interconnections and assumed new significance. In this study, information was gathered from the families of intellectually impaired children at Dagbreek and Môreson Centres in the Khomas Education Region of Namibia.

3.3. Population

According to McMillan and Schumacher (2006), a population is a group of elements or cases, whether individuals, objects or events, that conform to specific criteria and to which we intend to generalise the results of the research. The population of the study was made up of families of intellectually impaired children at Dagbreek and Môreson Centres in Windhoek, in the Khomas Education Region. There are one hundred and ten (110) families with children at the Dagbreek Centre while at Môreson Centre there are children from one hundred and twenty (120) families. Therefore the population was two hundred and thirty (230) families.

3.4. Sample and Sampling Techniques

The researcher made use of purposive sampling, particularly with the critical case sampling. This meant that the participants were selected because of some defining quality that made them holders of the data needed for the study. The sampling decisions were made precisely in order to obtain the richest possible information to answer the research questions (Nieuwenhuis, 2007). It has to be noted that critical-case sampling involves selecting cases that are believed to be particularly important for the study at hand (Johnson & Christensen, 2008). Critical-case sampling was done so that the samples represent the above mentioned population and are unbiased. Samples were drawn from moderate to severe cases of each of the following conditions associated with intellectual impairments, namely: Down's syndrome, Autism, Epilepsy, Trauma and Foetal Alcohol Syndrome as per the comprehensive list provided by these centres. Children of the participants ranged from ten to sixteen years in age. The researcher chose 10 families who had a child with one of these listed impairments as participants for the study. The samples included five families at each of the Centres.

3.5. Research Instruments

For the purpose of this study, the researcher employed an interview schedule in order to gather data that would answer the research questions of the study. Interviews are aimed at exploring participants' experience, feelings and views about intellectually impaired children (Johnson & Christensen, 2008). There are different types of interview methods that can be used to collect qualitative data. These include informal

conversational interview, interview guided approach, and standardized open-ended interview, and closed, fixed response interviews. The researcher used standardized open-ended interviews to get views and opinions on the phenomenon to be studied. The standardized open-ended interview was used because the method allows all respondents to answer the same questions, thereby guaranteeing comparability and consistency of interviewees' experiences. Another reason was that the standardized open-ended interview reduces interviewer effects and bias when several interviewees are involved (Gay et al., 2009). The content of the questions in the standardized open-ended interview was derived from the research questions and literature review that were mentioned earlier. The researcher made use of family based interpreters, where parents had problems in understanding English. The interview consisted of questions covering types of stress, causes of stress, impact and coping strategies to be used to overcome stress associated with families of intellectually impaired children. During the interview session, the researcher tape recorded the data that was then transcribed and later assisted in the analysis and data presentation.

3.6. Pilot Study

A pilot study of two families of children with intellectual impairments was undertaken at Oponganda Centre for Intellectually Impaired Children in the Khomas Education Region. The pilot study helped the researcher to see whether the research instruments were well designed and suitable for the study. The researcher made an appointment with the selected families to conduct an interview with them at their homes. The same process in the study was used during the main research study.

Participants were asked to indicate to the researcher if there were unclear or difficult questions. The pilot study was necessary to pre-test the interview questions and it was conducted in particular to determine whether:

1. There were ambiguities in any of the question;
2. The instrument would elicit the type of data anticipated by the researcher;
3. The type of data obtained could be meaningfully analyzed in relation to the stated research questions.
4. To provide criteria for determining the validity of the instrument.

3.6.1 Results of the Pilot Study

Results of the pilot study showed that the instrument was valid for the present study and that all answers to items in the standardized open-ended interview responses were anticipated by the researcher. However, the pilot study revealed that the first question of the instrument on additional comments was not clear. Initially the question read: *Tell me how did you react when you found out that your child is intellectually impaired?* As a result of the pilot study question 1 of the research instrument was rephrased in order to enhance participants' understanding. In order to achieve both clarity and simplicity of meaning, the aforementioned question was reformulated to read as follows: *Tell me how you felt when you first found out that your child is intellectually impaired?* The results of the pilot study were significant because they made it possible for the researcher to revise the interview schedule in order to make it a more reliable instrument for the main study. There was no further evidence that the respondents were confused by the questions. The responses were

good. This gave the researcher an indication of what to expect from the actual study. This process made it possible for the researcher to simplify and clarify the interview questions.

3.7. Data Collecting Procedures

A letter requesting permission, outlining the purpose of the study and its significance was sent to the Permanent Secretary of the Ministry of Education, Director of Education, and Principals of the selected Centres. After identification of potential participants through the two centres, participants were contacted telephonically and told about the nature of the study. Participants were invited to volunteer and take part in the study under no obligation. Once they had confirmed their availability to participate in the study, their residential address was recorded and an interview time was fixed that suited both the participants and the researcher. Interviews were conducted with parents/ guardians who have intellectually impaired children in their families/households.

For comfort and convenience, participants were interviewed at their homes. Most participants interviewed were mothers, mainly because they were the ones available. Each participant who had agreed to participate in the study was interviewed for approximately 45 to 60 minutes. Participants were interviewed separately by the researcher on different days at different times, which were convenient to the participants. Prior to each participant being interviewed, the researcher explained the

nature of the study, indicating her interest in their experiences with an intellectually impaired child.

Participants were informed about the study method, which included a standardized structured interview comprising open-ended questions. Furthermore, the participants were told that their participation was voluntary; they were not obliged to answer any question if they did not want to, and that they could withdraw from the study at any time, after which their informed consent was solicited. At this stage interviews were audio-recorded for the purpose of accurate data collection. The researcher informed the participants that direct quotes may be used from their interviews in the writing up of the research report but no identifying information would be documented, and that all the participants would be given pseudonyms.

3.8. Data Analysis

For this study, content analysis was used to capture meaning from the data collected. The content analysis is a form of qualitative research where a researcher is central to the analysis of information gained (Gorman & Clayton, 2005). Each interview was then transcribed to find meaning. The data was organized into themes, sub-themes and lastly categories using Microsoft Excel Spreadsheet (Johnson & Christensen, 2008). Participants' verbatim quotes were used as low- inference descriptions to support the sub-themes and categories identified. Interviews from participants support and clarify qualitative data analysis. The responses from parents and guardians relating to their experiences of having a child with intellectual impairment

were placed into themes, sub-themes and categories created by the researcher and guided by the data obtained. The data collection was undertaken through individual interviews, one participant at a time.

The researcher used an audio-recorder to collect all data which were transcribed verbatim and participants were assigned pseudonyms in order to respect anonymity. The central concepts were concluded from the themes and sub-themes. In accordance with the research questions, the following four main themes were identified: Main themes: a) Types of stress, b) Causes of stress, c) Children's impact on their families, d) Coping strategies. Each of these four themes was further divided into sub-themes that emerged from the subsequent creation of categories and coding of the transcript data. These themes will be presented and discussed in more detail in chapters 4 and 5. The analysis procedure was as follows:

1. Identify the main themes that correspond to the research questions;
2. Align the interview questions under the main themes (in Microsoft Excel);
3. Colour-code the main themes;
4. Code the interview responses by colour-coding and create categories;
5. List all categories under their corresponding main theme.

In spite of identification of categories, it is essential to this study to know that these sub-themes overlap. In addition, it is important to note that families are individually unique, and in turn have different reactions and methods of coping with, and responding to the child's impairment.

An example of how themes, sub-themes and categories were assigned can be seen in Table 1.

Table 1 An Example of Open Coding

Extract from Interviews	Categories/ Codes	Sub-themes	MAIN THEME
R8: It was like after birth, I did not know because he looked normal. I was a little bit shocked after few months when he got sick and was informed by the doctor that my son was a Down Syndrome.	Distressed/ shocked/ very sad/ heartbroken (-)	Intellectual stress	Type of stress
R1: We have to bath and clothe him daily. I am always at home especially after school, no plans, no entertainment, my days are repetitive.....I do not do anything for my own well-being	Constant presence of caregiver (-) Demanding daily physical care (-) Social isolation (-) Altered social life (-)	Physical care Interpersonal stress	Causes of stress
R7: From her mother's side people did not accept her but my family had accepted her and they support her.	Negative attitude of some family members - pretence, rejection; resentment (-) Positive relationship; love; support (+)	Extended family	Impact on relationships
R6: We attend church services as well as workshops prepared by church members just to encourage parents and families with intellectually impaired children. It really assisted us so much, by learning that you are not the only one in such a problem.	Spiritual support through targeted church intervention	Spiritual support	Coping strategies
R2: My friend Paula is always coming forward with help, she makes my life easier	Social support from friend (+)	Social support from others	Coping strategies

(+) = indicating positive effect of the intellectually impaired children on their families

(-) = indicating negative effect of the intellectually impaired children on their families.

3.9 Validity and Reliability in Qualitative Research

Validity is the degree to which the qualitative data that was collected accurately reflects the social phenomenon to which it refers (Babbie & Mouton, 2002). A common term used in qualitative research for validity is trustworthiness. The trustworthiness was established by evaluating the soundness of data gathering and analysis for the study. Accordingly, validity was ensured during the pilot study by asking participants in this study if the data obtained was a true reflection of the intellectually impaired child. The data obtained from the research instruments were systematically crosschecked to ensure the validity of the themes being generated (Gay et al., 2009).

Reliability refers to the degree of consistency with which the data is placed in the same category by researchers (Gay et al., 2009). This was achieved by examining the data in order to determine whether it could be consistently collected using the same techniques at different times. According to Johnson and Christensen (2008), a way to determine the reliability of a qualitative study is to test its quality. As such, the results of the pilot study helped to improve on the quality of the research instruments since any deficiencies were rooted out. The data was then organized into themes, sub-themes and categories. The responses from parents and guardians were analysed using Microsoft Excel Spreadsheet. Finally, the central concepts were concluded from the themes and sub-themes.

3.10 Ethical Considerations

Denzin and Lincoln (2005) write that qualitative researchers are guests in the private space of the participants' worlds. As a result, their manners should be good and their code of ethics strict and sound. Henning, Van Rensburg and Smit (2004) describe ethics as a body of principles of right, proper and good conduct. It is vital for the researcher to inform the participants about the study and secure consent from them in an effort to ensure that participants cannot be manipulated (Johnson & Christensen, 2008). Each participant was informed of the nature of the study (experience of dealing with an intellectually impaired child) as well as what participation entailed (structured open interview questions).

Informed consent: In order to participate in the study, participants needed to give their consent. In qualitative research informed consent is particularly important owing to the personal and in-depth nature of the data to be collected (Duffy, 2008). Participants were made to understand that their participation was voluntary, they could withdraw from the study at any time, and whom to contact with regards to questions about the study and their rights. Once this had been done, the researcher asked the participants if they had any further questions or concerns. Since an audio-recording was used to collect data from participants; permission to do this was requested (see Appendix D). Participants were told to be open as the information recorded will not be shared with other people apart from being used for the study. The researcher ensured that participants felt comfortable with this arrangement and answered any questions they had in this regard.

Informed consent was obtained from nine participants who were advised of their right to privacy. There was only one participant who was not comfortable with recording and the researcher therefore allowed her to be excluded from being recorded. The participants were assured that recordings will be kept until the completion of the study. A copy of the consent letter is attached as Appendix D. Respecting the human rights of a participant also means that the participants have to give their consent and be reassured of their anonymity and confidentiality. According to Johnson and Christensen (2004) research participants have the right to remain anonymous in the report or elsewhere and the identity of participants must be protected at all times.

Confidentiality and anonymity: The worth and dignity of the participants were protected at all times during the study. The researcher assured the participants that anything mentioned would remain confidential and in the event that direct quotes would be used in the study report, their anonymity would be guaranteed. This was ensured through the use of pseudonyms.

3.11 Summary

This chapter described the research method that was used to collect and analyse the data relevant to the research questions. The researcher purposively selected 10 families of children with intellectual impairments. A purposive sampling method was used to select 10 families of children with intellectual impairment who formed the sample for the study. Data were collected using standardized open-ended interview questions. The interview questions were analysed using Micro-soft Excel. Lastly, the

chapter looked at the ethical considerations of the study. The following chapter will present the findings of the study.

CHAPTER 4. RESEARCH RESULTS

Introduction

In this chapter, the researcher presents the research findings in answer to the main research questions as presented in chapter 1. The analysis of data included organizing data into themes, sub-themes and categories. The question centred around the following areas: types of stress that families of intellectually impaired children experience, causes of stress in families of intellectually impaired children, the impact of children living with intellectual impairment on their families and coping strategies that families with intellectually impaired children use. The presentation of results will be made according to the main themes, sub-themes and categories identified during data analysis in chapter 3 in relation to the main research questions (see table 2).

Table 2 Presentation of Main Themes, Sub-themes and Categories

Main Themes	Sub-themes	Categories
1. Types of stress	Intellectual stress	Acceptance; shocked/heartbroken; disappointed; acceptance with pain, crisis period when parents become older; crisis period when child is leaving school.
	Emotional stress	Demanding care; worry about child's condition; single-parent – father caring girl-child; unable to communicate with child; despair/pain; lifelong dependency of child; behaviour problems.
	Interpersonal stress	Negative attitude of the public; sense of isolation; distress amongst family members.
	Instructional stress	Financial expense/ loss; seeking assistance; negative impact on other family members; demanding physical care.
	Existential stress	Divine gift.
2. Causes of stress	Physical care	Demanding physical care, constant presence/ supervision of caregiver, no daily care concerns and initial physical care concern.
	Medical care	Constant/ regular medical care and minor medical care.
	Schooling	No Impaired school performance concern registered; Impaired school performance of previously healthy child
	Financial Barriers	Transport to school, insufficient funds/ low income/ unemployed, expenses for daily care, no serious financial implications, medical expenses school fees, no support from biological parents.

Table 2: Presentation of Main Themes and Sub-themes (continued)

3. Impact on relationships	Public/ community	Occasional negative attitude/behaviour, initial negative reaction but later accepted and accepted within the community.
	Parents/Couples	None widowed/ adopted by grandmother, both love and accept child, support and unity, father support; loves and accepts child (single mother), father's relationship to child ambivalent and father abandoned family; blames mother.
	Siblings	Love, acceptance, jealous about preferential treatment, support, and initially afraid but later accepted, resentment; not supportive and rejection.
	Extended Family	Positive relationship; love and support, negative attitude of some family members, full support; adoption and presence.
4. Coping strategies	Support from Partners and Siblings	Couple commitment and support, support from the father (single mother), siblings with daily care and mother supplements income.
	Support from extended Family	family support from extended family members (care giving) and financial support from extended family
	Social support from Others	Support from social network (mothers' group; church members; community,) social support from friends, financial support from friends, support from institution (hostel, medical aid) and support from neighbours (social contact) and seek financial assistance from employer
	Professional Support	Professional support - doctors, psychologists, therapists.
	Spiritual Support	Spiritual support – strengthened through belief, spiritual support through targeted church interventions, spiritual support- general (attend church service), motivation talks from spiritual leaders, spiritual support for child through friends, financial support from church groups and material support from pastor.

4.1 Theme 1: Types of Stress in Families with Intellectually Impaired Children

The first question enquired about the feelings of the parents and guardians after the diagnosis of their children as being intellectually impaired. The second question probed parents and guardians about the difficulties and disappointments that they experienced after having dealt with the reality of their intellectually impaired children. A follow up question which specifically requested the types of stress they experienced was presented.

- 1. Tell me how you felt when you first found out that your child is intellectually impaired?**
- 2. What were some of the difficulties and disappointments you experienced after having dealt with the reality that your child is intellectually impaired? If so, what types of stress do you experience?**

According to table 3, between 15% to 32% of respondents confirmed that four types of stress affected them. These were intellectual stress (32%), emotional stress (30%), interpersonal stress (20%) and instrumental stress (15%). On the other hand, only 3% of the respondents mentioned that they lived with existential stress.

Table 3 Responses on Types of Stress Experienced by Families with Intellectually Impaired Children

Types of stress	N	%
1.Intellectual stress	19	32
2.Emotional stress	18	30
3.Interpersonal stress	12	20
4.Instrumental stress	9	15
5.Existential stress	2	3
Total	60	100

The responses on the five types of stress are as follows:

The highest rated type of stress was intellectual stress:

4.1.1 Results on Intellectual Stress in Families with Intellectually Impaired Children

Parents and Guardians responses were classified into the following categories: *acceptance; shocked/heartbroken; disappointed; acceptance with pain; crisis period when parents become older and crisis period when child is leaving school.* According to table 4, 37% of parents and guardians accepted their children's condition, while 27% indicated that they were shocked/ heartbroken and 21% were disappointed when they first received the information that their children were intellectually impaired. On the other hand, 5% accepted the condition of their children with pain. The other 5% indicated that they were worried about the crisis period when they become older and the last 5% were also concerned about the crisis period when their child finally left school. Some of the responses were:

Acceptance

Rich: *"I didn't feel bad because I accepted it."*

Elliam: *‘I was not disappointed because he was my first born.’*

Liina: *‘I did not feel bad because I understood the impairment and accepted her as a normal child.’*

Shocked / Heartbroken

Sena: *‘I was very much shocked because my daughter was born normal. She was in a car accident and she sustained serious head injuries. She spent two years in hospital.’*

Man: *‘It was like after birth, I did not know because he looked normal. I was a little bit shocked after few months when he got sick and was informed by the doctor that my son was a Down’s syndrome.’*

Andy: *‘Really, when I realised for the first time in my life, that my daughter was a Down’s syndrome, I was totally down. I was indeed shocked and stressed.’*

Era: *‘I was very confused, shocked, and heartbroken when I realised that my son was epileptic at the age of eight months. I became worried as a younger mother.’*

Disappointed

Ayne: *‘He does not do well in school and this disappointed me till today.’*

Andy: *‘I was disappointed when I first found out that my daughter was a Down’s syndrome.’*

Man: *‘My son as Down’s syndrome was born with kidney- problems, as a result he became sick most of the time. I had to take him to the doctor almost every two weeks. I do not have medical aid. This is very difficult and disappointing.’*

Acceptance with pain

Emxine: *“I accepted her as she is because I could not oppose what God has given me but it pains me.”*

Crisis period when parents become older

Elliam: *“How shall we accommodate him at home for the rest of his life?”*

Crisis period when leaving school

Elliam: *“I started being worried now that he is growing. The question remains what will he do when he is out of school?”*

Table 4 Responses on Intellectually Stress experienced by Families with Intellectually Impaired Children

Category	N	%
Acceptance	7	37
Shocked / heartbroken	5	27
Disappointed	4	21
Acceptance with pain	1	5
Crisis period when parents become older	1	5
Crisis period when leaving school	1	5
Total	19	100

The second highest rated type of stress was emotional stress:

4.1.2 Results on Emotional Stress in Families with Intellectually Impaired Children

Parents and Guardians responses were categorised as follow: *demanding care; worry about child's condition; single-parent–father caring girl-child; unable to communicate with child; despair/pain; lifelong dependency of child, behaviour problems.* During the interviews conducted with ten parents and guardians, 22% confirmed that their children demand physical care, another 22% were indeed worried about their children's condition while 22% were single parents. On the other hand, 11% indicated that they were unable to communicate with their intellectually impaired children and the other 11% felt pain because of their children's condition. A further 6% experienced behavioural problems from their children while the other 6% were really worried about the lifelong dependency of their children (see table 5). Individual responses were:

Demanding care

Man: *“Look, the condition of my child wore me out as I have to bath, cloth and take him for regular check up to the doctor. I also have to care for my daughter. So, I have to satisfy both children.”*

Era: *“He was getting big and I could not carry him to the hospital because I did not have a wheelchair. ”*

Worry about child's conditions

Era: *“I became worried as a young mother. I used to cry a lot. I didn't know what to do since he was my first born.”*

Sena: *“It is very disturbing to see her not able to help herself. She was born as a normal child, only after the accident that she is like this. I am worried that she turned out a helpless child.”*

Single parent

Emxine: *“The sex difference makes it difficult because I am a man. I don’t know how to handle a girl- child.”*

Unable to communicate with child

Rich: *“Imagine your child trying to communicate with you and you do not understand. Such a situation leaves any parent worrying very much. It makes me sick.”*

Emxine: *“My daughter does not speak at all and it is difficult to tell what her problem is especially when she is sick.”*

Despair/ pain

Ayne: *“I was in pain when I realised that my son was not performing in school as other children of his age. It is not easy to handle him because I know that for the rest of his life he will not perform as he could have done before the trauma.”*

Lifelong dependency of child

Era: *“I have to bath, cloth and take him for regular check up to the doctor forever.”*

Sena: *“The situation around my daughter is very bad and difficult. She can no longer help herself after the accident.”*

Behaviour problems

Rich: *“When he speaks to us, we do not understand him and this makes him angry.*

Such a situation worries us most.”

Table 5 Responses on Emotional Stress experienced by Families with Intellectually Impaired Children

Category	N	%
Demanding care	4	22
Worry about child’s conditions	4	22
Single-parent	4	22
Unable to communicate with child	2	11
Despair/ pain	2	11
Lifelong dependency of child	1	6
Behaviour problems	1	6
Total	18	100

The third highest rated type of stress was interpersonal stress:

4.1.3 Results on Interpersonal Stress in Families with Intellectually Impaired Children

The responses of parents and guardians were grouped into two major categories: *negative attitude of the public; sense of isolation and distress amongst family members*. According to table 6, many parents and guardians (58%) indicated that they experienced discomfort due to the negative attitudes of the public towards their intellectually impaired children. Twenty five percent expressed a sense of isolation because of the demanding daily care of their children and 17% confirmed distress amongst family members largely due to other family members who are unwilling to assist in the care of their intellectually impaired children. Some of the responses were:

Negative attitude/behaviour of public

Elliam: *“My son at times behaves as a younger child. This makes him to be pushed away by people when he is among them.”*

Sense of isolation

Rich: *“No plans, no entertainment, my days are repetitive.....I do not do anything for my own well-being.”*

Era: *“The routine became difficult and eventually my school work was disrupted because I could not concentrate. My social life was cut because I had to look after him all the time.”*

Distress amongst family members

Edi: *“She was drooling a lot and I had to spoon feed her. When she was younger I had to take her to therapist, so that she can learn how to help herself. Such tasks are demanding and make the relationship in the house tense at times.”*

Table 6 Responses for Interpersonal Stress experienced by Families with Intellectually Impaired Children

Category	N	%
Negative attitude/behaviour of public	7	58
Sense of isolation	3	25
Distress amongst family members	2	17
Total	12	100

The fourth highest rated type of stress was instrumental stress:

4.1.4 Results on Instrumental Stress in Families with Intellectually Impaired Children

The responses given revealed the following categories: *financial expense/loss; seeking assistance; negative impact on other family members and demanding physical care*. According to table 7, 45% of parents and guardians experienced financial difficulties, while 22% sought assistance from friends. The same number of parents and guardians (22%) noted that the existence of intellectually impaired children in their families had a negative impact on other members of the family and 11% confirmed that these children demanded physical care.

Their responses were:

Financial expenses

Man: *“My son is Down’s syndrome, was born with kidney problems, as a result he became sick most of the time. I had to take him to the doctor almost every two weeks. I do not have medical aid and his medication is very expensive.”*

Liina: *“It is a challenge to have a child with an impairment. We still need to secure funds for her needs such as school, transport and daily needs.”*

Andy: *“My daughter was born with cataracts and this was difficult for us to maintain her medical bills. Private hospitals were expensive. It was later confirmed that she was Down’s syndrome.”*

Seeking assistance

Emxine: *“I always try to get assistance from others so that I assist my daughter.”*

Era: *“I didn’t know what to do since he was my first born. Later I started seeking for assistances from other people.”*

Liina: *“It is a challenge to have a child with impairment, so I sometimes seek for help from other people.”*

Negative impact on other family members

Edi: *“The relationship amongst us, in the house is sometimes bad because tempers are high. Other members do not want to always assist in the care. At times I have to spend time mending the relationships in the house.”*

Demanding physical care

Man: *“The condition of my child requires a lot when it comes to his physical care.”*

Table 7 Responses for Instrumental Stress experienced by Families with Intellectually Impaired Children

Category	N	%
Financial expenses	4	45
Seeking assistance	2	22
Negative impact on other family members	2	22
Demanding physical care	1	11
Total	9	100

The fifth highest type of stress was existential stress:

4.1.5 Results on Existential Stress in Families with Intellectually Impaired Children

The major category on existential stress was: *divine gift*. Twenty percent (20%) of parents and guardians accepted their intellectually impaired children because of religious beliefs, while 80% just accepted their children without any ties to religion.

Their responses were:

Divine gift

Emxine: “*I didn’t feel bad because as a Christian, I accepted it.*”

Liina: “*I did not feel bad because I accepted her as a gift from God.*”

Table 8 Responses for Existential Stress in Families with Intellectually Impaired Children

Category	N	%
Divine gift	2	20
Accepted children without any ties to religion	8	80
Total	10	100

4.2 Theme 2: Causes of Stress in Families with Intellectually Impaired Children

Questions 3 and 4 were asked to find out the causes of stress in bringing up intellectually impaired children. The questions that were put forward to the parents and guardians were:

3. What are your daily concerns in bringing up your intellectually impaired child in terms of physical care, medical care and schooling?

4. What in your opinion are the major causes of stress in your family, in terms of the financial implications of having an intellectually impaired child?

The parents and guardians of intellectually impaired children confirmed that stress in their families was experienced under the following sub-themes: physical care, medical care, schooling and financial barriers.

4.2.1 Results on Physical Care in the Upbringing of Intellectually Impaired Children

The main categories identified under this sub-theme were: *demanding physical care; constant presence/ supervision of caregiver; no daily care concerns and initial physical care concern*. According to table 9, 35% of parents and guardians of intellectually impaired children were really affected by the demanding daily physical care and 29% indicated the need of constant presence of caregivers. On the other hand, 29% did not register any daily physical care concern, while only 7% mentioned initial physical care concern about caring for their children.

Some of the responses were:

Demanding daily physical care

Rich: *“We have to bath and cloth him daily. I am always at home especially after school.”*

Emxine: *“I experience difficulties when it comes to bathing her, since she is a girl-child and I am a man. I have a concern because when I am not at home, I do not know whether the care taker was bathing or feeding her properly as I want.”*

Man: *“He (my son) can’t bath or feed himself. I have to do this for him. He needs regular attention. He bothers me all the time.”*

Era: *“This part is not easy because I need to feed and bath him. The routine is difficult. I constantly worry about him, because he needs assistance all the time. He cannot be left by himself. When I am not with him, I continuously worry about what is being done to him. Is he given food, medicine and bathed?”*

Sena: *“My life is very routinely with daily tasks of bathing and feeding her. Although she is trying to bath or feed herself, there is need for another person to be present in order to assist her.”*

Constant presence/supervision of caregiver

Edi: *“Because of her condition, there should be an adult to take care of her as she always gets fits. We should closely observe the symptoms to try and prevent her from getting hurt.”*

No daily physical care concerns

Elliam: *“He can cook and bath himself.”*

Edi: *“She can eat on her own and bath herself.”*

Ayne: *“He is fine in doing his own things. He can bath and feed himself.”*

Initial physical care concern

Andy: *“At the beginning she could not use the toilet, bath herself and speak properly, but with God’s grace she can now do all this.”*

Table 9 shows the responses for the physical care categories of upbringing intellectually impaired children.

Table 9 Responses on Physical Care in the Upbringing of Intellectually Impaired Children

Category	N	%
Demanding daily physical care	5	35
Constant presence/supervision of caregiver	4	29
No daily physical care concerns	4	29
Initial physical care concern	1	7
Total	14	100

4.2.2 Results on Medical Care in the Upbringing of Intellectually Impaired Children

Categories identified were: *constant/regular medical care and minor medical care*. Information gathered indicated that 60% of parents and guardians expressed concern of constant medical care required by their intellectually impaired children, while 40% confirmed minor medical care concerns (see table 10). Their responses were:

Constant/ regular medical care

Emxine: *“It is difficult to take her to the hospital because I do not have a medical aid and she is always sick. This makes it very difficult to cater for her medical needs.”*

Ayne: *“The wound in the brain caused problems for him. We have to send him to hospital most of the time.”*

Edi: *“Because of her condition, there should be an adult to take care of her as she always gets fits. When symptoms occur of fits, we have to take her immediately to the hospital for treatment.”*

Man: *“My son became sick most of the time. He needs to be taken to the doctor almost every two weeks. I do not have medical aid. He is always sick and requires special medication from private doctors. This is a burden because I am a domestic worker.”*

Era: *“No medical aid since I am unemployed and he gets sick most of the time. I have to pay all the hospital bills by myself which is a lot. My son needs special food that will build up his body.”*

Sena: *“She got sick a lot and she has to visit the doctor very often.”*

Minor medical care

Liina: *“She is not a sick child and I take her to the hospital myself whenever she is sick. She mostly get flu, otherwise she is a healthy child.”*

Elliam: *“He is a healthy child. He gets cold and flu at times which I cannot really call that he gets sick.”*

Table 10 Responses on Medical Care for the Upbringing of Intellectually Impaired Children

Category	N	%
Constant/ regular medical care	6	60
Minor medical care	4	40
Total	10	100

4.2.3 Results on Schooling in Families with Intellectually Impaired Children

The following category was identified: impaired performance of previously healthy child. With regard to schooling, parents and guardians (80%) did not really register any concern, while 20% of them confirmed their concern about schooling arrangements. A typical registered response was as follows:

Impaired school performance of previously healthy child

Ayne: *“Because of the brain injury I was advised to take him to Dagbreek (the special school) due to his condition.”*

Sena: *“Her performance was affected after the accident as she sustained head injuries.”*

Table 11 Responses on Schooling in Families with Intellectually Impaired Children

Category	N	%
No Impaired school performance concern registered	8	80
Impaired school performance of previously healthy child	2	20
Total	10	100

4.2.4 Results on Financial Barriers on Families with Intellectually Impaired Children

The responses to questions on financial barriers gave rise to the following categories: *transport to school; insufficient funds/ low income/ unemployed; expenses for daily care; no serious financial implications; medical expenses school fees; no support*

from biological parents. Table 12 revealed that 32% of parents and guardians were affected by financial barriers when having an intellectually impaired child in as far as transporting them to school is concerned. On the other hand, 18% expressed insufficient funds/low income because of unemployment; the other 18% indicated expenses for daily care. Fourteen percent (14 %) showed no sign of serious financial barriers while 10 % noted the concern of medical expenses. In addition, 4% noted the concern of school fees while another 4% lamented the absence of support from biological parents. Some of the responses were:

Transport to school

Edi: *“There is transport to take her to school which I pay N\$360 per month.”*

Sena: *“There is hired transport to take her to school. This transport is paid on a monthly basis which is a lot to me.”*

Emxine: *“She is a day scholar and it is a burden to take her to school. I must raise funds for her transport to and from school. This transport doesn’t bring her home on time. Again, once I failed to pay the transport, she will not go to school.”*

Insufficient funds/low income/ unemployed

Man: *“I must always have money to buy him certain types of food and this is a burden because I am a domestic worker.”*

Sena: *“We have problems with funds to support her but we always try to find funds.”*

Expenses for daily care

Edi: *“I am the only one who is working and support her financially. She needs special care for instance; special shoes with a thick sole because of the way she walks.”*

Emxine: *“She only eats special food. I must raise funds for her school transport. Money should always be reserved for her medical care because she’s always sick. I also need to pay the nanny.”*

Era: *“As other children with impairment, he also receives a grant of N\$200 per month and it does not even cover for his medication, so it is not enough. His diet is costly and that is very stressful because there is no money. I am the only parent looking after him.”*

No serious financial implications

Ayne: *“I do not have financial barriers because the father supports him.”*

Rich: *“We do not have any serious financial barriers.”*

Medical expenses

Andy: *“We do not have financial barriers except the situation with the eyes.”*

Man: *“.....He is always sick and requires special medication from private doctors. This is a burden because I am a domestic worker.”*

School fees

Liina: *“School fees are expensive, the grant she receives is not enough to pay for her schools fees and for the hired transport to take her to school and I am unemployed.”*

No support from biological parents

Edi: *“Her mother is unreliable and the father is unemployed. They cannot assist her in any way.”*

Table 12 Responses on the Financial Barriers of Bringing up Intellectually Impaired Children

Category	N	%
Transport to school	9	32
Insufficient funds/low income/unemployed	5	18
Expenses for daily care	5	18
No serious financial implications	4	14
Medical expenses	3	10
School fees	1	4
No support from biological parents	1	4
Total	28	100

4.3 Theme 3: Impact on Relationships in Families with Intellectually Impaired Children

The following questions were asked to find out if parents and guardians experienced any problems concerning discrimination of the impaired children and whether the intellectually impaired children affect relationships between couples, among siblings and the extended families. The questions that were put forward to the parents and guardians were:

5. Have you experienced any problems relating to discrimination towards the impaired child? If so, from whom?

6. In what ways does having an intellectually impaired child affect the relationship between you as couples, among siblings and the extended families?

Information obtained from parents and guardians indicated that discrimination and negative attitudes of the public were displayed towards their intellectually impaired children in the following sub-themes: *public/ community, parents/couples, siblings, extended family.*

4.3.1 Results regarding Public/ Community towards Intellectually Impaired Children

The categories identified were: *occasional negative attitude/behaviour; initial negative reaction but later accepted and accepted within the community.* According to table 13, 78% of parents and guardians were affected by occasional negative attitudes of the public towards their intellectually impaired children, while 11% initially had negative reactions but later accepted their children and 11% were accepted by the community. Some of the responses were:

Occasional negative attitude/ behaviour

Rich: *“Indeed, negative attitude comes from children of his age and a few adults who stare at him.”*

Elliam: *“At times, out there, people look at my son and pass bad remarks such as: Can such a big boy behave like a five year old child? He needs to be beaten to stop it.”*

Edi: *“Regarding discrimination, there are always people who are trying to be funny towards her. These people would either say things or just stare at her. You can hear statements such as ‘How is this child?’”*

Sena: *“Yes, discrimination is always there. When she tries to join other children in play, they call her names because she easily forgets. Such a treatment stresses me a lot.”*

Man: *“The fact that a Down’s syndrome child is easily identified, people tend to reject him and pass remarks about him. Such comments make me sick and I worry about him.”*

Initial negative reaction but later accepted

Ayne: *“I did not experience any discrimination as such. Sometimes when he plays with other children, they tend to be irritated by his behaviour. He repeats things for a while before he moves on to the next play.”*

Accepted within community

Liina: *“The child is accepted within the family and in the community. I haven’t noted anything strange.”*

Edi: *“She greets people, especially when we go to the supermarket. She will greet almost everyone in that shop. Almost all people return the greeting from her”*

Table 13 Responses on the Impact of Intellectually Impaired Children on Public/Community

Category	N	%
Occasional negative attitude/behaviour	7	78
Initial negative reaction but later accepted	1	11
Accepted within community	1	11
Total	9	100

4.3.2 Results of Parents/ Couples in Families with Intellectually Impaired Children

The categories identified were: *none widowed/adopted by grandmother; both love and accept child; support and unity; father support; loves and accepts child (single mother); father's relationship to child ambivalent and father abandoned family; blames mother.* Table 14, revealed that 30% of parents and guardians of intellectually impaired children confirmed no significant effects since they are inspired and strengthened by the fact that they are single parents. Twenty percent (20%) indicated the presence of love, support and unity amongst couples, another 20% confirmed father support and love of single mothers while 10% experienced ambivalence. In addition, 10 % experienced total rejection of the intellectually impaired children by their biological fathers. Some of their responses were:

No negative attitude (widowed/ adopted by grandmother)

Elliam: *“His father passed away when he was four years old but he liked his son with his condition.”*

Emxine: *‘‘My wife passed away long back when she was five years old and she loved her so much.’’*

Edi: *‘‘My husband passed away long ago. She is just my grandchild whom I adopted and I love her dearly.’’*

Both love and accept child

Liina: *‘‘No, all is well because even the father has accepted her as god’s gift. My husband always feels bad when he noticed that someone has beaten his daughter because of her condition and she cannot fight back.’’*

Andy: *‘‘Basically there is no impact because my wife and I love her so much. We accepted her the way she is.’’*

Father support; loves and accepts child (single mother)

Ayne: *‘‘I do not have difficulties really. His father supports him because he stays with him.’’*

Man: *‘‘Am not with his father but he is helping him (his son) and loves him too.’’*

Support and unity

Rich: *‘‘No effect because my wife and I are supporting each other.’’*

Father’s relationship to child ambivalent

Sena: *‘‘Her father did not really accept her condition although he does not say it loud. At times one can just see how he speaks to the child.’’*

Father abandoned family; blames mother

Era: *“The father of my son didn’t take it well as I did. He was the weak one and didn’t bring his side as a father. He pushed everything away to me. He blames me for the child’s condition. He told me that his son was born normal, what could have happened to him? He refuses to understand the situation of our son, as a result he went away till today. We broke up. I am the only one who is looking after him.”*

Table 14 Responses on the Impact of Intellectually Impaired Children on Parents/Couples

Categories	N	%
No negative attitude (widowed/ adopted by grandmother)	3	30
Both love and accept child	2	20
Father support; loves and accepts child (single mother)	2	20
Support and unity	1	10
Father’s relationship to child ambivalent	1	10
Father abandoned family; blames mother	1	10
Total	10	100

4.3.3 Results of Siblings towards Intellectually Impaired Children

The categories identified were: *Love; acceptance; jealous about preferential treatment; support, and initially afraid but later accepted; resentment; not supportive and rejection.* Fifty five percent of parents and guardians of intellectually impaired children confirmed that love, acceptance and support existed amongst some siblings, while 18% indicated that some siblings complained about preferential treatment of the intellectually impaired children by parents and guardians. Nine percent (9%) of parents and guardians indicated total rejection by siblings. Another

9% revealed that siblings were initially afraid but later accepted the impaired child. An equal percentage (9%) showed complete resentment of the impaired child (see table 15). Some of the responses were:

Love, acceptance, support

Rich: *“Everything is fine because siblings have accepted him.”*

Elliam: *“Siblings love him so much.”*

Edi: *“All his siblings love her.”*

Liina: *“The siblings accepted her as she is and they assist her all the time. When I am not around they take turns to help her.”*

Ayne: *“All his siblings love him. They always play together.”*

Andy: *“She is a friendly child. Wherever she goes, she is like a teacher to other children.”*

Jealous about preferential treatment

Man: *“My daughter feels that only my son gets most of the attention. She is always jealous because I take his side especially when they are fighting. It makes her angry sometimes.”*

Liina: *“Some of the siblings do not like her much when she is protected by her father.”*

Initially afraid but later accepted

Era: *“My daughter used to be afraid of him but now she has accepted him after I explained that he is her brother and he will not harm her. Most of his siblings used to be afraid of him but later they get use to him.”*

Resentment; not supportive

Emxine: *“Brothers and sisters are always forced to take care of her. They do not make any effort to assist her on their own.”*

Rejection

Sena: *“It became obvious when she joins other children to play, others are pushing her away. They feel that she is not part of them. You just find her standing watching others playing and none of them is talking to her. She always looks lost among others. This experience worries me.”*

Table 15 Responses on the Impact of Intellectually Impaired Children on Siblings

Category	N	%
Love, acceptance, support	6	55
Jealous about preferential treatment	2	18
Initially afraid but later accepted	1	9
Resentment; not supportive	1	9
Rejection	1	9
Total	11	100

4.3.4 Results of Extended Family towards Intellectually Impaired Children

The responses to the questions on the extended family focused on the following categories: *positive relationship; love and support; negative attitude of some family*

members; full support; adoption and presence. According to table 16, 62% of parents and guardians of intellectually impaired children stated that a positive relationship really prevailed between the extended family and their families. Thirty percent (30%) displayed a negative attitude towards the intellectually impaired children. On the other hand, 8% confirmed the existence of full support of the extended family.

Their responses were:

Positive relationship; Love and support

Andy: *“My wife and I do not have any problem with our daughter. We all love her.”*

Liina: *“Every member in the family loves her and assists where they can.”*

Edi: *“Everyone in our family loves her.”*

Negative attitude of some family members: Presence; Rejection; Resentment

Elliam: *“Some of my family members feel that he demands most of the things in the family although he is big.”*

Edi: *“There are times that you will find one or two family members doing something towards the child which is not pleasing.”*

Sena: *“Some people do not accept her condition in the family after the accident.”*

Emxine: *People from her mother’s side (mother’s family) do not accept her at all.”*

Full Support; Adoption

Rich: *“No effect, they all support him.”*

Ayne: ‘‘Basically there is no problem because most family members sympathise with him and support him especially his grandmother (his father’s mother).’’

Emxine: ‘‘My family accepts her and they support her.

Table 16 Responses on the Impact of Intellectually Impaired Children on Extended Family

Category	N	%
Positive relationship; Love and support	8	62
Negative attitude of some family members; presence; rejection; resentment	4	30
Full support ; Adoption	1	8
Total	13	100

4.4 Theme 4: Coping Strategies in Families with Intellectually Impaired Children

The following questions were asked about coping strategies used by families with intellectually impaired children. The questions were:

- 7. How do you cope with your intellectually impaired child in as far as provision of the physical care, medical care and schooling demands are concerned?**
- 8. Who do you turn to for social and spiritual support of your child?**
- 9. What would you say could improve difficulties experienced by families with intellectually impaired children?**

The parents and guardians of intellectually impaired children felt that support by friends and a relative is important in assisting them to manage the challenges of physical and medical care. The following sub-themes were noted: *support from partners and siblings; support from extended family, social support from others, professional support, spiritual support and internal/ personal strategies:*

4.4.1 Results regarding Support from Partners and Siblings towards Intellectually Impaired Children

The responses given indicated the following categories: *couple commitment and support; support from the father (single mother); siblings with daily care; and mother supplements income.* Parents and guardians of intellectually impaired children (29%) confirmed that the support from partners greatly assist them to care for their children, while 29% of them stated that though single, the biological father of the children supported them. The same percentage of parents and guardians (29%) admitted that siblings assist with the daily care of their impaired children. On the other hand, 14% revealed that they work in order to supplement their income (table 17). Responses were as follows:

Couple commitment and support

Rich: *“We do not need extra support because my wife and I support each other.”*

Liina: *“My husband and I take care of her.”*

Andy: *“My wife and I are supportive therefore we do not need extra support.”*

Support from the father (single mother)

Ayne: *“His father takes him to school, Dagbreek Centre.”*

Siblings with daily care

Liina: *“I take care of her. Her siblings do assist with daily care.”*

Mother supplements income

Sena: *“It is not easy because when she got sick, she has to visit the doctor immediately. Her medications are quite expensive and have to struggle for the fund.”*

Era: *“Hmm! Taking him to school is another issue because at times, I have to find money elsewhere.”*

Table 17 Responses of Coping Strategies on the Support from Partner and Siblings

Category	N	%
Couple commitment and support	2	29
Support from the father (single mother)	2	29
Siblings assist with daily care	2	29
Mother supplements income	1	14
Total	7	100

4.4.2 Results regarding Support from Extended Family towards Intellectually Impaired Children

The categories identified were: *family support from extended family members (care giving) and financial support from extended family*. According to table 18, 83% of parents and guardians of intellectually impaired children noted that the extended family understood their situation and supported them in terms of care of their children, both financially and physically, while 17% showed negative attitudes. Their responses were:

Family support from extended family members (care giving)

Edi: *“My extended family members assist her to clean after bathing and eating.”*

Emxine: *“Some extended family members accept her and support her.”*

Era: *“I must say, I am lucky because my relatives are very supportive towards my son’s condition. Each one of them is bringing his or her side to help. It became a routine to us all in the family.”*

Sena: *“The extended family members love the child and they help in caring for her.”*

Ayne: *“My son’s grandmother is very supportive. I really depend on her for help.”*

Financial support from extended family

Emxine: *I look for funds from extended family members to cater for her needs like toiletries. I try to make her look presentable just like my other children.”*

Table 18 Responses of Coping Strategies on the Support from Extended family towards Intellectually Impaired Children

Category	N	%
Family support from extended family members (care giving)	5	83
Financial support from extended family	1	17
Total	6	100

4.4.3 Results regarding Social Support from others towards Intellectually Impaired Children

The categories identified were: *support from social network (mothers’ group; church members; community,) social support from friends, financial support from friends, support from institutions (hostel, medical aid) and support from neighbours (social*

contact) and seek financial assistance from employer. Parents and guardians of intellectually impaired children (33%) stated that they received social support from social network (mothers' group; church members; community). Seventeen percent (17%) indicated that they receive social support from friends, while another 17% confirmed financial support from friends. On the other hand, 17% indicated that they benefit from assistance from institutions (hostels). A further 8% revealed that they are assisted by neighbours and another 8% confirmed that they seek financial assistance from their employer in order to care for their children (see table 19). Some of their responses were:

Support from social network (mothers' group; church members; community)

Era: "I used to attend workshops to acquire information and knowledge on how to take care of my son since his father was not supportive. Sometimes I go to Onyose Trust where a group of mother's with intellectually impaired children gather to share ideas and support as well as to encourage one another."

Rich: "I also receive help from the mothers' group, in terms of information and support."

Sena: "Some community members love the child and so they help in caring for her."

Social support from friends

Elliam: "My friend Paula is always coming forward with help, she makes my life easier."

Financial support from friends

Emxine: "I always go out of my way to find money from relatives and friends to take her to the hospital when she is sick."

Andy: *“Although I take her to school every day, this drains us a lot. Sometimes we have to borrow money from our friends for fuel.”*

Support from neighbours (social contact)

Liina: *“My neighbours are good people, because if they do not see us for two days or so they always come to ask us if everything is fine now that they did not see us for the past two days.”*

Support from institutions (hostel and medical aid)

Elliam: *“He is a hostel boarder and so things are a bit lighter in terms of transport cost.”*

Seek financial assistance from employer

Man: *“When things get tough, my employer assists me financially”.*

Table 19 Responses of Coping Strategies on the Support from Others towards Intellectually Impaired Children

Category	N	%
Support from social network (mother’s group; church members; community)	4	33
Social support from friend	2	17
Financial support from friends	2	17
Support from institutions (hostel and medical aid)	2	17
Support from neighbours (social contact)	1	8
Seek financial assistance from employer	1	8
Total	12	100

4.4.4 Results regarding Professional Support towards Intellectually Impaired Children

The category that emerged focused on: *professional support - doctors, psychologists, therapists*. Thirty percent (30%) of parents and guardians pointed out that they receive professional support and assistance from doctors, psychologists, therapists. On the other hand, 70% were silent about seeking professional assistance (see table 20). Their responses were as follows:

Professional support -doctors

Man: *‘I had to take him to the doctor almost every two weeks.’*

Professional support -psychologists

Ayne: *‘He does not do well in school and this was a disappointment so the school referred us to a psychologist Dr Fourie.’*

Professional support -therapists

Edi: *‘Now that I adopted her, I put her on my medical aid which helps me to pay her medication and take her to a therapist.’*

Table 20 Responses of Professional Support towards Intellectually Impaired Children

Category	N	%
Professional support -doctors	1	10
Professional support -psychologists	1	10
Professional support -therapists	1	10
Silence about seeking professional assistance	7	70
Total	10	100

4.4.5 Results regarding Spiritual Support towards Intellectually Impaired Children

The main categories identified were: *Spiritual support – strengthened through belief; spiritual support through targeted church interventions; spiritual support- general (attend church service); motivation talks from spiritual leaders; spiritual support for child through friends; financial support from church groups and material support from pastor.*

Thirty percent of parents and guardians confirmed that spiritual support strengthened through belief greatly assist them to care for their children. On the other hand, 23% indicated that they receive spiritual support through targeted church interventions; while 15% indicated that spiritual support through church service assists them in the care of their children. An equal percentage (8%) of parents and guardians who mentioned support in each of the following four categories : motivation talks from spiritual leaders, spiritual support for child through friend, financial support from

church groups and material support from pastor greatly assist them to cope with the care of their children (see table 21).

Their responses were:

Spiritual support – strengthened through belief

Andy: *“We believe in God, and with him everything is possible.”*

Era: *“I also used to go to church where we received a lot of information and support.”*

Sena: *“I sometimes go attend women groups from church where they have lessons on educating women to help their children with impairment.”*

Emxine: *“I only listen to the gospel radio programs mostly on Sundays, just to comfort myself. After listening to this, I feel good just as if I was in church or at a gathering where we have people of the same problem as mine (of having an impaired child).”*

Spiritual support through targeted church interventions

Andy: *“We attend church services as well as workshops prepared by church members just to encourage parents and families with intellectually impaired children. It really assisted us so much, by learning that you are not the only one in such a problem.”*

Rich: *“My wife and I sometimes do attend workshops arranged by the church for families with intellectually impaired children.”*

Spiritual support- general (attend church service)

Elliam: *“I go to church where we receive a lot of information and support.”*

Edi: *“I go to a normal church service.”*

Motivation talks from spiritual leaders

Andy: *“We attend workshops prepared by church members just to encourage parents and families with intellectually impaired children.”*

Liina: *“We sometimes invite spiritual leaders to come talk to us when we have our gathering on Saturdays.”*

Spiritual support for child through friends

Elliam: *“The same friend is the one coming to visit us and when my son is around she always invites him to church. The day I am not going to church she always takes him with.”*

Financial support from church groups

Emxine: *“I make sure she receives help and look for funds from family members (younger brother) friends and church groups to cater for her needs like toiletries. I tried to make her look presentable just like my other children.”*

Material support from pastor

Man: *“Our pastor loves us so much. He always visits us, prays for my son’s health and gives some groceries. The whole process is comforting. He is assisting us a lot spiritually and materially.”*

Table 21 Responses of Coping Strategies on Spiritual Support towards Intellectually Impaired Children

Category	N	%
Spiritual support strengthened through belief; comforted	4	30
Spiritual support through targeted church interventions	3	23
Spiritual support general (attend church service)	2	15
Motivation talks from spiritual leaders	1	8
Spiritual support for child through friend	1	8
Financial support from church groups	1	8
Material support from pastor	1	8
Total	13	100

4.4.6 Results regarding Internal/ Personal Strategies towards Coping with Intellectually Impaired Children

The categories identified were: *Resilience/commitment–mother; cognitive–understanding impairment; no need for additional social support and resilience/commitment–father*. Forty –five percents of parents and guardians of intellectually impaired children clearly indicated that resilience/ commitment by mothers was a strong weapon in assisting them to manage their children. On the other hand, 22% revealed the cognitive- understanding of the impairment, while the same amount of 22% showed no need for additional social support. A further 11% confirmed resilience/ commitment of single father. Their responses were:

Resilience/ commitment–mother

Sena: *‘It is not easy because when she gets sick, she has to visit the doctor immediately. Her medication is quite expensive and I have to struggle for the funds’*.

Rich: *“It is difficult, but we are coping because I try everything to help him. At times his siblings used to take him for a walk and this gives us a good relief.”*

Liina: *“To get her to school, there is transport which is paid monthly. It is a struggle to find money because I am unemployed. There are other children in the house who need to be supported just like her.”*

Cognitive–understanding impairment

Liina: *“I did not feel bad because I understood the impairment and accepted her as a normal child.”*

No need for additional social support

Rich: *“We do not need extra support because my wife and I support each other.”*

Resilience/ commitment–father

Emxine: *“Schooling is a very demanding issue because I must always pay for her transport. Once I fail to do so then she won’t be taken to school. I have to organise funds to pay for her transport.”*

Table 22 Responses of Coping Strategies on Internal/ Personal Strategies

Category	N	%
Resilience/ commitment–mother	4	45
Cognitive–understanding impairment	2	22
No need for additional social support	2	22
Resilience/ commitment–father	1	11
Total	9	100

The last interview question was asked to make suggestions for the improvement of the welfare of parents and guardians with intellectually impaired children. The following sub-themes were revealed: *personal input and family support, community awareness campaigns, financial support, information and advice and education.*

4.4.7 Results on Personal Input and Family Support towards Intellectually Impaired Children

The categories identified were: *mutual support and positive attitude of care givers are crucial; parents must not reject their impaired children, especially fathers; parents must accept children's impairment; give love and attention to impaired children; parents must be proactive and get assistance from family members.*

According to table 23, 16.67% of parents and guardians with intellectually impaired children confirmed that all consecutive categories have positive effects when caring for their children. These include, mutual support and positive attitude of care givers, parents must not reject their impaired children, especially fathers, parents must accept children's impairment, give love to impaired children and parents must be proactive and get assistance from family members.

Their responses were:

Mutual support and positive attitude of care givers are crucial

Rich: *“It is best when people help each other, stay positive and take the situation as it is. I also feel that our community leaders should take a lead to bring information closer to people.”*

Parents must not reject their impaired children, especially fathers

Andy: *“Parents must not reject their children, especially men.”*

Parents must accept children’s impairment

Emxine: *“Parents must accept their children’s impairment. Parents must not sit idle because they don’t have money.”*

Give love and attention to impaired children,

Andy: *“These children need a lot of love and attention.”*

Parents must be proactive

Emxine: *“They must go look for funds to help their children.”*

Get assistance from family members

Edi: *“People must get assistance from their family members. It will help a lot.”*

Table 23 Responses of Strategies for Improvement on Personal Input and Family Support towards Intellectually Impaired Children

Category	N	%
Mutual support and positive attitude of care givers are crucial	1	16.67
Parents must not reject their impaired children, especially fathers	1	16.67
Parents must accept children’s impairment	1	16.67
Give love and attention to impaired children	1	16.67
Parents must be proactive	1	16.67
Get assistance from family members	1	16.67
Total	6	100

4.4.8 Results on Strategies/Suggestions for Improvement on Community Awareness Campaigns towards Intellectually Impaired Children

For the strategies and suggestions for improvement on community awareness the following categories were identified: *community should not view impairment as a curse; educate society on the care of intellectually impaired children; reduction of*

negative comments (discrimination) through awareness campaigns and government to undertake an awareness campaign on the welfare of impaired children.

According to table 24, 25% of parents and guardians with intellectually impaired children simultaneously stated that community should not view impairment as a curse, educate society on the care of intellectually impaired children, reduction of negative comments (discrimination) through awareness campaigns and government should undertake an awareness campaign on the welfare of impaired children.

Their responses were:

Community should not view impairment as a curse

Rich: *“I also feel that our community leaders should take a lead to bring information closer to people. We have people out there who do not know what to do with their impaired children. Awareness should be raised to inform people that impairment is not a curse.”*

Educate society on the care of intellectually impaired children

Era: *“It is important to educate the society on how to take care of intellectually impaired children. Medical staff must be sympathetic as they should know how to talk to people.”*

Reduction of negative comments (discrimination) through awareness campaigns

Elliam: *“The community should be aware of the children’s intellectual conditions. When the community is aware of the impairment conditions, a lot of staring, unnecessary statements will be reduced.”*

Government to undertake an awareness campaigns on the welfare of impaired children.

Sena: *‘I feel that as families of children with impairment, we need the government to have a campaign through the Ministry of Health to educate the nation about any type of impairment. Our people are not well informed about children living with impairments, and as such they do not know where to take their children for school.’*

Table 24 Responses of Strategies/ Suggestions for Improvement on Community Awareness Campaigns towards Intellectually Impaired Children

Category	N	%
Community should not view impairment as a curse	1	25
Educate society on the care of intellectually impaired children	1	25
Reduction of negative comments (discrimination) through awareness campaigns	1	25
Government to undertake an awareness campaign on the welfare of impaired children	1	25
Total	4	100

4.4.9 Results on Strategies/Suggestions for Improvement on Financial Support towards Intellectually Impaired Children

The categories identified were: *increase of existing grant by government; government support in terms of medication and schooling fees; parents must look for funds to help their children; government to exempt impaired children from payment of services and set up organisation that can fund medical and schooling expenses.* According to table 25, 50% of parents and guardians with intellectually impaired children strongly indicated that financial support would greatly improve the well-

being of such children. An equal percentage, 12.5% from four responses echoed the idea that government must support them in terms of medication and school fees, parents must look for funds to help their children, government must exempt impaired children from payment of services and set up organisations that can fund medical and schooling expenses as way of assisting them to cope with the care of their children. Some of their responses were:

Increase of existing grants by government

Elliam: *‘It will be a good idea for our government to revisit the amount of grant given to these children at least to a better figure, even N\$ 450 per month. The current grant is too little to cater for their needs.’*

Edi: *‘The grant given is too little compared to children’s needs which start with medications, food and schooling. Some children even require special clothing and shoes.’*

Man: *‘The grant received by these children is not enough and children are growing. It will be best if these can be looked at to the amount of our pensioners which is N\$550 per month.’*

Era: *‘On the part of grant given to the impaired children, it is too little for their needs.’*

Government support in terms of medication and schooling fees

Man: *‘The government must support families with intellectually impaired children financially in terms of medication and schooling.’*

Parents must look for funds to help their children

Emxine: *“Parents must not sit idle because they don’t have money. They must go look for funds to help their children. We need organisations that can fund us to help our children in terms of medical aid and schooling.”*

Government to exempt impaired children from payment of services

Emxine: *“At times I think of the government through the Ministries of Health and Education to exempt these children from any payment for any services rendered to them.”*

Set up organisation that can fund medical and schooling expenses

Emxine: *“We need organisations that can fund us to help our children in terms of medical and schooling.”*

Table 25 Responses of Strategies/Suggestions for Improvement on Financial Support towards Intellectually Impaired Children

Categories	N	%
Increase of existing grant by government	4	50
Government support in terms of medication and schooling fees	1	12.5
Parents must look for funds to help their children	1	12.5
Government to exempt impaired children from payment of services	1	12.5
Set up organisation that can fund medical and schooling expenses	1	12.5
Total	8	100

4.4.10 Results regarding Strategies/Suggestions for Improvement on Information and Advice towards Intellectually Impaired Children

The responses to the question on strategies for improvement of the welfare of families with intellectual impairment focused on the following categories: *Organisations to help parents obtain information and advice on how to care for their children; parental guidance regarding the handling of their impaired child; community leaders to take a lead in informing parents; information on how and where to apply for social grants; information on how and where to apply for schooling; relevant ministries to inform parents about the services of psychologists and medical staff must be sympathetic to families with impaired children and refer them to therapists.* According to table 26, an equal weighting of 14.3% of the respondents suggested that organisations should help parents to obtain information and advice on how to care for their children, parents should seek guidance regarding the handling of their impaired children, community leaders should take lead in taking information to parents, information should be provided on how and where to apply for social grants, information on how and where to apply for schooling, relevant ministries should inform parents about the services of psychologists and medical staff must be sympathetic to families with impaired children and refer them to therapists.

Their responses were:

Organisations to help parents obtain information and advice on how to care for their children

Liina: *“We need organisations that will help parents to look after their own children. It will be a big relief when parents and guardians are informed, advised how to help their children.”*

Parental guidance regarding the handling of their impaired child

Rich: *“It is best when people help each other, stay positive and take the situation as it is.”*

Community leaders to take lead in informing parents

Rich: *“I also feel that our community leaders should take a lead to bring information closer to people. We have people out there who do not know what to do with their impaired children.”*

Information on how and where to apply for social grants

Edi: *“It will be very important if our community is well informed about taking care of their impaired children in terms of where to go for any assistance, where to apply for social grants. The grant given is too little compared to what the child’s needs are.”*

Information on how and where to apply for schooling

Edi: *“It will be very important if our community is well informed about taking care of their impaired children in terms of where to go for any assistance, where to apply for schooling.”*

Relevant ministries to inform parents about the services of psychologists

Ayne: *“People should be informed of services of psychologists, who can help our intellectually impaired children. I think the Ministry of Health and the Ministry of Education should give the information to the community so that parents and guardians know what to do with their impaired children, not only to sit with their children at home.”*

Medical staff must be sympathetic to families with impaired children and refer them to therapists.

Era: *“Medical staff must be sympathetic as they should know how to talk to people. Children with impairment should be taken to a therapist.”*

Table 26 Responses of Strategies/Suggestions for Improvement on Information and Advice towards Intellectually Impaired Children

Category	N	%
Organisations to help parents obtain information and advice on how to care for their children.	1	14.3
Parental guidance regarding the handling of their impaired child	1	14.3
Community leaders to take lead in information for parents	1	14.3
Information on how and where to apply for social grants	1	14.3
Information on how and where to apply for schooling	1	14.3
Relevant ministries to inform parents about the services of psychologists	1	14.3
Medical staff must be sympathetic to families with impaired children and refer them to therapists	1	14.3
Total	7	100

4.4.11 Results regarding Strategies/Suggestions for Improvement on Education towards Intellectually Impaired Children

The categories identified were: *Enrol impaired children at special centres; introduction of therapy lessons in special centres; special centres should give feedback on performance of children to parents; government to build more centres for intellectually impaired children; and government to come up with programmes to accommodate impaired children over 18 years when they leave school.* Table 27, revealed an equal weighting of 20% for five respondents who each made a suggestion - that parents and guardians should enrol impaired children at special centres that should introduce therapy lessons, special centres should give feedback on performance of children to parents, government should build more centres for intellectually impaired children and government should come up with programmes to accommodate impaired children over 18 years when they leave school.

Their responses were:

Enrol impaired children at special centres

Edi: *“Parents must take children with impairments to special centres.”*

Introduction of therapy lessons in special centres

Andy: *“Centres for intellectual impairment children must introduce therapy lessons to help the children with physical exercises.”*

Special centres should give feedback on performance of children to parents

Andy: *“The schools, mostly special schools should involve the parents in a sense of informing the parents of the child’s school work and behaviour. We are not aware of what she (our daughter) learns at school.”*

Government to build more centres for intellectually impaired children

Era: *“The government should help constructing centres countrywide that can cater for intellectually impaired children’s needs. And these centres need to have trained staff members.”*

Government to come up with programmes to accommodate impaired children over 18 years when they leave school.

Sena: *“The concern is for the Ministry of education to come up with programmes that will accommodate children once they are out of these two centres when they turn 18 years of age. Normally, these children are only sitting at home. In the end, knowledge and skills learned in schools will be wasted.”*

Table 27 Responses of Strategies/Suggestions for Improvement on Education towards Intellectually Impaired Children

Category	N	%
Enrol impaired children at Special Centres	1	20
Introduction of therapy lessons in special centres	1	20
Special centres should give feedback on performance of children to parents	1	20
Government to build more centres for intellectually impaired children	1	20
Government to come up with programmes to accommodate impaired children after 18 years when they leave school.	1	20
Total	5	100

4.5 Summary

This chapter presented the summary of the results collected from the interviews and identified types of stress experienced by families with intellectually impaired children. The findings of the study indicated that parents and guardians of the intellectually impaired children experienced stress at different levels such as shocked, heartbroken, disappointed and sad. The study also examined the causes of stress in families, where parents and guardians indicated having difficulties in terms of meeting the demanding care as well as medical problems for their impaired children. In addition, the study identified the impact of intellectually impaired children on their families. Parents and guardians noted discrimination practices from members of the community through negative comments and bad behaviours towards the impaired children. Finally, the study found out the coping strategies used by families. Parents and guardians mentioned a number of strategies that could improve the welfare of families with intellectually impaired children such as spiritual support, social support from extended families, friends and employers. They also cited awareness about the plight of the impaired children such as availing of funds and constructing more centre for such children.

The presentation of the results took the form of summary tables and descriptions of phenomena. In the next chapter these results will be discussed in more detail to show any confirmation of stress in families with intellectual impaired children at Dagbreek and Môreson Centres. The literature on this subject will be compared with findings from this study. Finally, remarks will be made to form the recommendations and

conclusions of the study. Chapter 5 which follows will look at the discussion, recommendations and conclusions of the study.

CHAPTER 5: DISCUSSION

Introduction

This chapter takes a reflective view to establish whether the main research questions of the study on stress in families of children with intellectual impairment were realised. The aim of this chapter is to interpret the results of the study and examine the possible implications of these results. The discussion will be followed by conclusions of the study. Recommendations were made to the education system and all stakeholders. Areas that were investigated included the following research questions:

- What types of stress do families of intellectually impaired children experience?
- What causes stress in families of intellectually impaired children at Dagbreek and Môreson Centres?
- What impact do children living with intellectual impairment have on their families?
- What coping strategies do families with intellectually impaired children use?

All the listed research questions were confirmed as expected by the study.

5.1 Discussion on the Types of Stress Experienced by Families of Intellectually Impaired Children.

The discussion of the types of stress experienced by families of intellectually impaired children will be done in the following manner. Firstly, the discussion of intellectual stress experienced by families of intellectually impaired children will be

presented. This will be followed by a presentation of emotional stress, interpersonal stress, instrumental stress and lastly the existential stress experienced families with intellectually impaired children.

5.1.1 Discussion on Intellectual Stress Experienced by Families of Intellectually Impaired Children.

Findings revealed that each family's experience of having a child with impairment is unique in the light of their specific circumstances, the nature of the impairment, and available resources and support for the family. Parents and guardians clearly showed six different reactions to the diagnosis of their children's impairment. These were: acceptance, shock/ heartbreak, disappointment, acceptance with pain, crisis period when parents become older and crisis period when child is leaving school. The six responses that emerged from the findings of this study need to be explored further. The first response was the acceptance of the children's condition by fewer than half (37%) of the parents and guardians (see table 7). One (mother) said: *"I did not feel bad because I understood the impairment and accepted her as a normal child."* This finding is consistent with the findings by Marshak and Prezant, (2007) who revealed that acceptance does not imply surrender to the idea that the impairment is unchangeable.

The most prominent message here is that some parents indicated that they did not feel negative as they understood that their children were impaired and hence accepted their condition. Parents and guardians who accepted their children are able to provide the much needed love and service such as medication, education as well as

caring for their child. It appears that they assumed a realistic outlook of the child's impairment, hence they managed the situation. The attitudes of these parents suggest that they could have raised other children before having their impaired child. The acceptance phase could result in a perception or realization that one is blessed in being chosen to be the parent of an impaired child.

The second response was that of shock/heartbreak by about a quarter (27%) of parents and guardians. One (mother) responded: *'It was like after birth, I did not know because he looked normal. I was a little bit shocked after few months when he got sick and was informed by the doctor that my son was a Down's syndrome.'*

These findings were in line with the findings by Sen and Yurtsever, (2007) and Turnbull et al. (2006) who emphasised shock as the first diagnosis response by parents when they learn that their child is impaired, regardless of the nature of that child's impairment. This view was further echoed by Kearney and Griffin (2001), when they stated that the feelings of parents and guardians to the news of their child's impairment often give rise to shock. The experience in discovering that their children are intellectually impaired was indeed a painful and stressful experience.

The message here could be that these parents did not have knowledge about the impairment or any preparation to have an impaired child or it could be a taboo in their community to be associated with an impaired child. Hence, this reaction by parents and guardians constitutes a problem which requires to be attended to by medical professionals. There is need for parents to be educated about their children's impairment, seek information and read more about that particular impairment of their

children. Parents could join counselling groups or support groups of parents with similar problems in their communities, in order to obtain practical knowledge to manage their children's condition. At such gatherings, parents could discuss and share their children's conditions freely among themselves without feeling shame. These gatherings could give them a different perspective regarding the care of their children.

The third response was that of disappointment by less than a quarter of parents and guardians (21%). One parent (father) reacted: *'I was disappointed when I first found out that my daughter was a Down's syndrome.'* In line with the above comment Seligman and Darling (2007) revealed that some parents are disappointed, unable to accept that their children have an impairment and such a condition may cause them to reject their children. It is natural for parents to expect a normal child at birth; however, when an impaired child comes they are disappointed.

The deduction here is that it is necessary to be disappointed as it makes it possible for parents and guardians to move from a state of disbelief to that of awareness of the impairment. The level of disappointment could differ from one parent to the other. Accordingly, some parents could experience the disappointment for a short period, while others the disappointment may last longer. Notably, the disappointment displayed by these parents and guardians could also confirm a lack of self-confidence in dealing with the impairment. Overall, such a situation is unlikely to remain ongoing as parents and guardians may change their attitude with time. It is suggested

that parents and guardians should join community support groups in order to enable them to understand and accept the impairment.

The fourth, fifth and sixth responses had the same value of 5% by a very few of parents and guardians. The fourth response was acceptance with pain. One (father) said: *‘I accepted her as she is because I could not oppose what God has given me but it pains me.’* These findings are in line with the findings by Marshak and Prezant, (2007), who confirmed that parents accept the need to learn skilful ways to alter the negative effects of the condition. The challenge here is that parents and guardians experience pain which is likely to cause stress. These findings suggest that parents and guardians bemoaned the condition of their children. It appears that they gradually gained an element of hope and hence, accepted the impairment of their children, though with pain. In addition, their acceptance will then lead them to explore best ways of how to provide for the needs of the child. The main point to make here is that when parents and guardians accept their children with pain, they in fact show a grasp of the reality of the impairment. It is suggested that by sharing the problem with other people they could reduce the feeling of anger and hence improve the welfare of both the parent and the child.

The fifth response was that of parents going through a crisis period when parents become older. One (mother) said: *‘How shall we accommodate him at home for the rest of his life?’* The sixth response was that of the crisis period when leaving school. Another parent (mother) said: *‘I started being worried now that he is growing. The question remains what will he do when he is out of school?’* The

finding ties in with the findings of Turnbull et al. (2006), who noted that some parents experience feelings of denial because of the uncertainty and insecurity the future holds to help their child. These uncertainties of what will become of the child once he leaves school and when the parents become older and less able, or even unable, to care for him any longer have been identified as crisis periods by Marshak & Prezant (2007) and Hanson & Lynch (2004).

The fifth response felt by parents was going through a crisis period when parents become older. It must be pointed out that parents and guardians admit the inability of the impaired children to support themselves when they become older. Most considered the idea that they would not be around to care for their children one day. This idea created in them fear and concern about the well-being of their children. Although it is not uncommon for parents to think about the future of their child, the nature of the impairment could determine whether the child could do anything for him/herself or nothing at all. However, regarding the concern for the child's future, parents and guardians could secure the financial future of their children through Trust funds and insurance policies to look after them when the parents/guardians become old.

The sixth response reflected by parents was going through a crisis period when the child finally leaves school. The message here is that the child is dependent on parents and guardians; hence the worry about what will happen when the child leaves school. Depending on the nature of impairment, little could be done for severe conditions. Perhaps, for the moderate conditions, life-long skills could be imparted to the

children to enable them to stand on their own after leaving school. It is suggested that as parents look ahead to their children's future, attempts should be made to obtain assistance from organisations to help with the impaired child.

5.1.2 Discussion on Emotional Stress Experienced by Families of Intellectually Impaired Children.

Parents and guardians experienced seven different emotional aspects related to having a child with intellectual impairment. These were: the demands for care made by the child; worry about child's condition; difficulties of a single-parent father caring for a girl-child; inability to communicate with child; despair/pain; concern over lifelong dependency of child and concern of behavioural problems. The seven emotional aspects that emerged from the findings of this study need to be explored further.

The first three emotions had the same value of (22%) of fewer than a quarter of parents and guardians. The first emotion of this group was that of the demands of the child's condition for care (see table 8). A parent (mother) said: *“Look, the condition of my child worn me out as I have to bath, cloth and take him for regular check up to the doctor. I also have to care for my daughter. So, I have to satisfy both children.”* The second emotion was that of worry about children's conditions. One parent (mother) said: *“It is very disturbing to see her not able to help herself. She was born as a normal child, only after the accident that she is like this. I am worried that she turned out a helpless child.”* The third emotion was that of the challenges faced by a

single parent who is a different gender from the impaired child. The parent (father) said: *“The sex difference makes it difficult because I am a man. I don’t know how to handle a girl- child.”* These findings portray the findings by Jaques (2003) who emphasised that families of intellectually impaired children bear burdens unknown to other families without impaired children, such as bathing, feeding, toileting and carrying. This was further supported by Marshak et al. (1991), who reported that emotional stress is a response to the demands of care giving that might include lack of sleep, loss of energy, excessive worry and anxiety.

The first emotion was occupied by the demands for care arising from the child’s condition. Clearly, such concerns suggest an element of perceived burden on the part of parents and guardians. Intellectual impairment also seems to bring about emotional responses in people to such an extent that it influences their attitude, including their own negative feelings. The challenge here is on the nature of demands made by the constant caring for the impaired child care; as such assistance could be rendered by other people in order to reduce the work load of such parents and guardians.

The second emotion was occupied by the worry about the children’s conditions. The deduction here is that parents and guardians usually identify themselves with their children and mostly perceive them as representing them. Accordingly, any impairment in their children could be taken to imply an impairment in them. It follows that the inability to improve the situation generates a great deal of worry on the part of parents and guardians. However, with time, some parents and guardians

could become used to the condition of their children so much so that they perceive the situation as normal.

The third emotion was occupied by the challenges faced by a single parent. This underscores the concern portrayed by a single parent (father) who talked about the problem that he did not really know how to handle a girl-child and yet the situation demanded him to assist the child. Not only is he faced with the challenge that his impaired daughter does not speak and thus cannot articulate any discomfort or problem she experiences, but being a male, he does not feel comfortable to handle his female child physically, such as bathing his daughter. It is suggested that the challenge he is currently facing could be alleviated if other female family members move in and assist in the care.

The fourth and fifth emotions had the same value of (11%) by about one tenth of the parents and guardians. The fourth emotion was that of being unable to communicate with the child. One parent (father) said: *“Imagine your child trying to communicate with you and you do not understand. Such a situation leaves any parent worrying very much. It makes me sick.”* The fifth emotion was that of despair/pain. A parent (mother) said: *“I was in pain when I realised that my son was not performing in school as other children of his age. It is not easy to handle him because I know that for the rest of his life he will not perform as he could have done before the trauma.”* Seligman and Darling (2007) portray this situation when they reported that another contributor to emotional stress is the heart-wrenching experience of watching a child suffer and not being able to relieve that suffering.

The fourth emotion was occupied by inability to communicate with the child. The message here is the lack of communication between child and parents. Indeed, it is painful for parents to see their child suffer while knowing that the condition cannot be reversed. As such, they are likely to develop anxieties concerning their children's uncertain future. It follows that they face challenges to manage their children's health and any attempt to provide some form of training for routine life skills should be encouraged. Looking further, their major concern could be that of the child having an occupation and hence becoming independent in the future. The path parents and guardians are walking is likely to be characterised by stress and uncertainty. It is suggested that the teaching of sign language to both parties could greatly alleviate the barrier with communication.

The fifth emotion was occupied by that of despair/pain. The challenge here is the realisation of the limits of a child's performance in school. The emotional pain could be brought about by a comparison with what other children of his age can do. It follows that parents and guardians perceive the impaired child as abnormal, hence, the pain that is generated in them. It is suggested that such parents should accept reality and instead work hard in collaboration with the educational centre for the best interests of the child.

Again, the sixth and seventh emotions had the same value of 6%, representing very few of parents and guardians. The sixth emotion was that of concern about life-long dependency. One parent (mother) said: *"I have to bath, clothe and take him for regular check up to the doctor forever."* Finally, the seventh emotion was that of

concern over behavioural problems. Another parent (father) said: “*When he speaks to us, we do not understand him and this makes him angry. Such a situation worries us most.*” This finding is in line with the findings by Seligman and Darling (2007) who stated that another contributor to emotional stress is the heart-wrenching experience of watching a child suffer and not being able to relieve that suffering.

The sixth emotion was occupied by concern over life-long dependency. The realisation that their impaired child would need unremitting, lifelong care was of great concern to these parents. Clearly, such concerns suggest that parents may have to care for their children for an extended period of time. Such tasks could be physically and emotionally draining. It is usual for parents to be anxious about the future of their impaired child. However, such anxiety should take into account the fact that they may be unable to change the situation. It is suggested that training programmes should be attempted to enable the impaired children to acquire skills which they could use in the future.

The seventh emotion was occupied by concern over behavioural problems. The deduction here is that the child cannot articulate his/her feelings, as such communication becomes difficult. This situation is characterised by anger displayed by the child. Indeed, any parent is likely to worry about such a state of affairs. It must be pointed out that a deliberate programme of teaching the sign language could ease the friction between the child and the parents. It is suggested that access to behaviour management programmes through organisations for people with impairment should be undertaken.

5.1.3 Discussion on Interpersonal Stress Experienced by Families of Intellectually Impaired Children.

The findings from the study revealed that parents and guardians of intellectually impaired children experienced three different challenges as they came into contact with the public. These include: negative attitude/ behaviour of public; a sense of isolation; and distress amongst family members. The three challenges that arose from the findings of this study need to be looked into further. The first was that of negative attitude/behaviour of the public towards their children experienced by more than half (58%) of parents and guardians. One parent (mother) said: *“My son at times behaves as a younger child. This makes him to be pushed away by people when he is among them.”* These findings are supported by Heatherton et al. (2000) who stated that interpersonal stress can emerge from potentially stressful encounters with the public. The observation was further confirmed by Baxter (1986) in Seligman and Darling (2007), who found out that worry about the child’s behaviour in public increases over time, as this child tends to behave in a different way in public than in private.

Overall, the findings of the study indicated that the family, as a system, is reactive to the presence of impairment because of negative comments made by the community. Heartening is the fact that the parent takes note that the action of her son does not correspond with his age but does not approve the treatment given to her child by the public. The parent clearly understands that the behaviour of her child is caused by the impairment. It follows that this negative attitude by the community towards the impaired children was associated with high levels of stress on the part of parents and

guardians. However, not all families of children with an impairment are victims of the perceived public attitude towards their families, as some parents ignore any such negative comments. It is suggested that such problems could be alleviated if the public is educated so that it becomes sympathetic to the burden of care of families with intellectually impaired children.

The second challenge was the sense of isolation experienced by a quarter (25%) of parents and guardians because of the demands of providing care on a daily basis to their children. A parent (mother) said: *“The routine became difficult and eventually my school work was disrupted because I could not concentrate. My social life was cut because I had to look after him all the time.”* Sen and Yurtsever (2007) reported that social isolation may occur, as the family can no longer go out and may have difficulty in entertaining or visiting friends or going on vacation as a family. Social isolation is greatest when the child is cared for by a single-parent. Often, a single-parent family may be vulnerable to such stress, although we should not assume that social support is lacking in all such cases. The message communicated here is that the care needed by the impaired child is so demanding to the extent that the parent cannot attend social events. Thus, the findings confirmed that the parent lives in isolation owing to the constant demands of giving daily care of the impaired child. It is suggested that some understanding family members should be asked to assist with the care of the child at the times when the parents have to attend to other social events.

The third challenge was that of distress amongst family members expressed by under a fifth (17%) of parents and guardians because of the demands of providing daily care to their children. Furthermore, tense family relationships existed because of some members who did not want to assist with the care of the impaired children. A parent (grandmother) said: *“She was drooling a lot and I had to spoon feed her. When she was younger I had to take her to therapist, so that she can learn how to help herself. Such tasks are demanding and make the relationship in the house tense at times.”* This perspective is in line with Zinck & Newen (2008), who explained that when a child has an impairment it may potentially affect family members, the family as a system and the parental role. This view was also supported by Burke and Cigno (2000) who noted that whether it is an impaired husband, wife or child, impairment has an effect on the relationships and opportunities of the family as a whole.

The findings suggest that some family members who were unwilling to assist indicated that they developed a feeling of rejection towards the impaired child, hence affecting the relationship in the family negatively. In as far as tense family relationships are concerned; they could be improved by limiting the task of care to the family members who are co-operative. It is hoped that in the long run, other family members would willingly join in the care of the impaired child.

5.1.4 Discussion on Instrumental Stress Experienced by Families of Intellectually Impaired Children.

The findings from the study revealed that parents and guardians of intellectually impaired children experienced four main challenges in the care of their children. These were: financial expenses; seeking assistance; negative impact on other family members and demanding physical care. The four challenges that rose from the findings of this study need to be looked into further. The first was that of financial expenses by nearly half (45%) of parents and guardians (see table 10). A parent (mother) said: *‘It is a challenge to have a child with impairment. We still need to secure funds for her needs such as school, transport and daily needs.’* Parents and guardians further indicated that they had to take their children to the doctor almost every two weeks. This practice was difficult as it demanded expensive medical care. One parent (mother) said: *‘My son is Down’s syndrome, was born with kidney problems, as a result he became sick most of the time. I had to take him to the doctor almost every two weeks. I do not have medical aid and his medication is very expensive.’* This view was also shared by Rolland (2003), when he confirmed that financial demands can interfere with potentially restorative and interpersonally rewarding family activities, such as vacations.

It is clear that there are major concerns about finances which are required to support the impaired child. Indeed, parents and guardians struggle to secure funds for school, transport, medical and food expenses. It is suggested that family members and others need to establish some form of income generating projects in order to supplement the little financial resources at their disposal.

The second and the third challenges had the same value of (22%) of less than a quarter of parents and guardians. The second was that of seeking assistance. Another parent (father) stated: *‘I always try to get assistance from others so that I assist my daughter.’* This is in line with Marshak et al. (1999) who reported that instrumental challenges include when and how to seek assistance. As a result, parents and guardians had to seek other forms of assistance from individuals in order to care for their children.

The meaning from the findings confirms that when individuals are faced with any form of challenge, they look around for possible assistance. There is a clear indication that most parents and guardians who sought the assistance were often unemployed. Although, parents indicated seeking assistance from others, the process of doing so could be characterised by guilty conscience and a mixture of love and rejection for the impaired child. It is suggested that individuals should co-operate with families of impaired children in order to lessen the burden of care they experienced.

The third challenge was that of negative impact on other family members. One parent (grandmother) revealed: *‘The relationship amongst us, in the house is sometimes bad because tempers are high. Other members do not want to always assist in the care. At times I have to spend time mending the relationships in the house.’* These findings were supported by Turnbull, et al. (2006) who stated that parents and guardians of intellectually impaired children had a variety of concerns

that involves tasks which are necessary to incorporate the child's care and treatment into the lifestyle of the family. Overall an impaired child seems to affect parents and the family differently. It must be pointed out that the presence of an impaired child does not only affect the family members' interactions, but also their living conditions and way of life. Some family members may see the task of caring for the child as a burden and as such they may not co-operate in the care. It is suggested that, as a family, they need to work together to meet the challenges presented by the impaired child and to provide the care.

The fourth challenge seen by about one tenth (11%) of the parents and guardians was that of demanding physical care. Demanding physical care needed to look after an impaired child was cited as a challenge confronting them in their day to day life. A parent (mother) stated: *“The condition of my child requires a lot when it comes to his physical care.”* This finding is in line with the findings by Hornby (2000) who reported that financial demands, expenses for special diets, special schools and home modifications constitute significant sources of stress. The use of the phrase ‘demanding physical care’ implies that parents and guardians find it difficult to care for their children. It must be pointed out that the degree of care needed for the child depends on degree of impairment. As referred to earlier, the burden of care could be alleviated by assistance from family members and other friends.

5.1.5 Discussion on Existential Stress Experienced by Families of Intellectually Impaired Children.

The findings revealed that parents and guardians of intellectually impaired children experienced two feelings in the care of their children; one was that the child was perceived as a divine gift and the other was that the child was accepted (without any ties to religion). The first was that of divine gift by one fifth (20%) of parents and guardians. One parent (mother) said: *“I did not feel bad because I accepted her as a gift from God.”* The second was that of acceptance of children without any ties to religion by a four-fifths (80%) of parents and guardians. These findings are supported by Ainsworth and Baker (2004), who stated that some parents and guardians appear to be able to explain their child’s impairment within the framework of a particular life philosophy.

It appears from the study that the presence of the impaired child was considered as a “special gift” from God, so parents and guardians perceived this phenomenon as “special attention” from God. This could mean that they accept their children and their difficulties and devoted them totally to attend to their needs as they believe that the impaired child is a gift from God. Parents and guardians’ philosophy of life and their faith could have led them to believe that they had been selected to provide comfort and care to the impaired child. While it is commendable that parents and guardians accepted their children as a gift from God, it is further suggested that they should not sit back but rather continue to work hard in order to improve the welfare of their children.

The second feeling was that of acceptance of the child without any ties to religion by a high percentage (80%) of parents and guardians. The silence demonstrated that they indicated that they concentrated on caring for their children instead of seeking explanations. Whether an impairment is explained or not, it still remains an impairment, as such what is important is to face the challenge of care.

5.2 Discussion on the Causes of Stress Experienced by Families of Intellectually Impaired Children.

The discussion focuses on the main causes of stress in bringing up intellectually impaired children and it will be conducted in the following manner. Firstly, on the demands for physical care experienced by families of intellectually impaired children will be investigated. This will be followed by looking at the demand for medical care, for schooling and for finances, all challenges faced by families with intellectually impaired children.

5.2.1 Discussion on Physical Care Demand Experienced by Families of Intellectually Impaired Children

The findings from the study revealed that parents and guardians of intellectually impaired children experienced four challenges in the area of physical care in the upbringing of their children. These ranged from that of demanding physical care; need for the constant presence/supervision of caregiver; no daily care concerns and initial physical care concern. The four challenges that rose from the findings of this study need to be explored further. The first was that of demanding physical care by just over one third (35%) of parents and guardians. A case of a father having to care

for his daughter was the most prominent. This father revealed: *“I experience difficulties when it comes to bathing her, since she is a girl-child and I am a man. I have a concern because when I am not at home, I do not know whether the care taker was bathing or feeding her properly as I want.”* This finding is congruent with the findings by Orsmond and Seltzer (2000), who reported that day-to-day care is needed by a severely impaired child and the caring is a daily grind.

The use of the phrase ‘demanding daily physical care’ implies in some way that these parents and guardians feel that their children are a burden. It is clear that the main concern is centred on the fact that a father (single parent) is not comfortable in dealing with his daughter and at the same time worried about whether the child is bathed and fed properly. However, the experience of the father suggests that having a child with impairment could enable him to develop compassion, love, care and value for life. Furthermore, it appears that the experience shows that parenting an impaired child helps to facilitate a hopeful attitude and empathy for such children. It is suggested that the concern of the parent could be solved by undertaking closer supervision of the work of the caregiver.

The second and the third challenges had the same value of (29%) by just under one third of parents and guardians. The second was occupied by the constant presence/supervision of caregiver. One parent (grandmother) stated: *“Because of her condition, there should be an adult to take care of her as she always gets fits. We should closely observe the symptoms to try and prevent her from getting hurt.”* This was supported by McCarthy et al. (2006) who asserted that when an impaired child

needs constant physical care the mother in the family will get less sleep at night which results in fatigue and an accumulation of stress. It must be pointed out that such a situation which needs a caregiver requires a great deal of planning in order to negotiate the special life circumstance. It follows that family members may need to help with care giving more than before. In addition to seeking help within the family there is also need to find outside help. However, in sourcing outside help, some families may feel guilty of dependence on other people. Whatever the arrangement of care giving, there is need for closer coordination of the work of the caregiver.

The third aspect was occupied by those parents and guardians who had no concerns about daily care. A parent (mother) said: *‘‘He is fine in doing his own things. He can bath and feed himself.’’* This finding portrays those of McCarthy et al. (2006) when they pointed out that the presence of an intellectually impaired child with a variety of different impairments can create a variety of problems for the families into which they are born. It appears that the use of the phrase ‘no daily physical care concerns’ focuses on the ability of the impaired child to look after him/herself and not on the impairment. It could, therefore, be misleading to assume that there are no worries associated with the impaired child. As such, the impairment remains although it is appreciated that the overall effect of a child who is able to perform certain tasks is less stressful on parents.

The fourth aspect was that of initial physical care concern by very few (7%) of parents and guardians. Another parent (father) said: *‘‘At the beginning she could not use the toilet, bath herself and speak properly, but with God’s grace she can now do*

all this.'' This finding is in line with those of McCarthy et al. (2006) who asserted that when an impaired child needs constant physical care, the mother in the family will get less sleep at night which results in fatigue and an accumulation of stress. It is noted that the child can now perform certain tasks on her own, but the overall impairment remains. Accordingly, what parents are quick to pick up is an improvement of the impaired child, which implies that the main problem still exists. Reference to the positive signs shown by the impaired child suggests that parents and guardians are worried and attempt to reduce the concern about their children. However, any positive attitude in the care of the impaired children lessens the worry associated with the impairment.

5.2.2 Discussion on Medical Care Demand Experienced by Families of Intellectually Impaired Children

Parents and guardians experienced two different medical concerns related to having a child with intellectual impairment. These include: constant/regular medical care and minor medical care. The two concerns that emerged from the findings of this study need to be explored further. The first concern was that of constant/regular medical care by almost two thirds (60%) of parents and guardians. A parent (mother) said: *"My son became sick most of the time. He needs to be taken to the doctor almost every two weeks. I do not have medical aid. He is always sick and requires special medication from private doctors. This is a burden because I am a domestic worker."*

The above findings are in line with Mak et al. (2006) who pointed out that economic problem for parents and guardians are caused by the high expenditure on drugs and treatment needed by an intellectually impaired child. Furthermore, this was in line

with the research conducted by Swenson (2005) who agrees that the budget of families with intellectually impaired children may be strained when it comes to providing for special medical care.

Although, the majority of parents and guardians felt stressed by the medical care demands by their children, they continued to provide that care. In addition, parents and guardians who found themselves with an impaired child had no choice but to attend to the demands of medical care of their children. However, such demands were not occasional but constant. It is indeed this frequency of care that made the parents and guardians exhausted and despairing. Given the fact that the child is impaired, it is suggested that the parents could approach the Ministry of Health and Social Services for the granting of an exemption from medical costs in government hospitals.

The second concern was that of minor medical care by nearly half (40%) of parents and guardians. One mother said: *“He is a healthy child. He gets cold and flu at times which I cannot really call that he gets sick.”* This finding links to the view by Hornby (2000) who emphasised that those expenses for special diets and medical care constituted significant sources of stress on the family. It must be stated that nearly half of the parents and guardians were generally managing the medical care demands of their children. Finally, it must also be pointed out that the medical needs of impaired children tend to overshadow their other needs like social needs.

5.2.3 Discussion on Schooling Demand Experienced by Families of Intellectually Impaired Children

The findings from the study revealed that parents and guardians of intellectually impaired children experienced two feelings regarding school performance related to their impaired children. These were: no impaired school performance concern and weaker school performance of previously healthy child. The two feelings that rose from the findings of this study need to be explored further. The first was that of no worsening of school performance by most (80%) of parents and guardians. It must be pointed out that this group of parents were quiet about the school performance concern. However, the fact that they were silent may not imply that they do not have schooling concerns. Perhaps, they are now used to the situation to such an extent that they take the whole problem as normal.

The second feeling was that of reduced school performance of a previously healthy child by one fifth (20%) of parents and guardians. A parent (mother) said: *“Because of the brain injury I was advised to take him to Dagbreek (the special school) due to his condition.”* This is in line with a study by Sen and Yurtsever (2007) who stated that families do experience a lower standard of living owing to increased expenses regarding their impaired child, such as special school needs, cost of transport to and from school as well as money for therapy sessions.

The message communicated here is that, parents and guardians generally take schooling as an accomplishment in life. Therefore, sending their impaired children to school alone gives rise to feelings that their children have an intellectual ability. For

some parents and guardians, the experience of schooling for their impaired children could have been improved by arranging sessions with psychologists and other special requirements. As such the whole process of placing the child at a centre is stressful. Thus, the experience of schooling for children with an intellectual impairment has been described by parents as challenging. Although, special centres are able to take care of impaired children, it is suggested that parents should not just leave their children at such centres. Instead, they should undertake regular visits to the centre in order to support their children and the centre. In addition, the government could also establish more such centres in order to reduce the problems faced by parents and guardians in as far as placement of their children are concerned.

5.2.4 Discussion on Financial Barriers Experienced by Families of Intellectually Impaired Children

Parents and guardians experienced seven financial concerns related to the upbringing of their impaired children. These are transport to and from school; insufficient funds/low income/ unemployment; expenses for daily care; no serious financial implications; medical expenses; school fees and no support from biological parents. The seven financial areas that come from the findings of this study need to be looked into further. The first was that of the need for transport to school by about one third (32%) of parents and guardians. A father stated: *“She is a day scholar and it is a burden to take her to school. I must raise funds for her transport to and from school. This transport doesn’t bring her home on time. Again, once I failed to pay the transport, she will not go to school.”* This is in line with the findings by Sen and Yurtsever (2007) when they reported that families do experience a lower standard of

living because of the increased expenses needed for their impaired children such as special school needs eg. cost of transport to school as well as for therapy sessions.

It appears that the financial barriers of bringing up an impaired child may be overwhelming. An impaired child requires special attention and has many needs; as such the financial factor remains a determining indicator of stress for parents and guardians. Many parents and guardians were either earning insufficient money or were unemployed and this made it very difficult for them to pay for transport to school. It is suggested that the problem of school transport could be solved by securing a boarding place at the centre where the child is enrolled.

The second and third financial concerns had the same value of less than one fifth (18%) of parents and guardians. The second concern was that of having insufficient funds, a low income or being unemployed. This situation posed a number of challenges in terms of the care of the impaired child. One parent (mother) said: *‘I must always have money to buy him certain type of food and this is a burden because I am a domestic worker.’*

The message communicated here is unanimous in terms of the scarcity of funds, largely due to low earnings. Such a situation makes the task of managing the costs of daily needs difficult. The challenges in terms of funds are understandable since most of the parents and guardians are single parents, earning little or are unemployed. It is quite evident that bringing up an impaired child is an economic burden. This appears to have a stressful impact on individuals who spend more time caring for such

children. As regards financial demands for food, parents and guardians could set up backyard vegetable gardens in order to supplement their diet. In addition, improved knowledge about the insufficient funds and how to deal with it could be pursued by the parents and guardians in order to reduce the severity of the problem.

The third concern was the cost of expenses for daily care. Another parent (grandmother) said: *‘I am the only one who is working and support her financially. She needs special care for instance, special shoes with a thick sole because of the way she walks.’* These findings are in line with Cunningham (1996); Jones and Passey (2003); Grant and Whitell (2000) who all reported that financial worries may exist and these difficulties can have a negative effect on social and recreation activities of family members. This view was further supported by Turnbull et al. (2006) when they noted that stress related to financial worries can have a negative impact on affection and self-esteem.

Overall, families with impaired children may experience a lower standard of living owing to increases regarding daily care. It must be stressed that the expenditure on daily needs such as food, medication and transport is not static; as such it worsens the welfare of the impaired family. Becoming a member of a medical scheme could help alleviate the burden of care in the short term, since benefits of medical schemes ceases when employees become inactive.

The fourth aspect was that of having no serious financial barriers in caring for an impaired child and was given by just over one tenth (14%) of parents and guardians.

A parent (mother) said: *‘I do not have financial barriers because the father supports him.’* This is in line with Seligman and Darling (2007), who reported that caring for an intellectually impaired child may directly or indirectly impose economic impact on families in addition to their psychological costs. The point here is that of the costs required to support the care of the impaired children. The nature of financial challenges around parents and guardians is largely determined by circumstance, some of them are working, while others receive assistance from other people, and then the financial challenge will be moderate. It is suggested that attempts should be made to acquire more skills about how to manage impairment; this will improve the parents’ overall welfare.

The fifth concern was that of medical expenses which was given by one tenth (10%) of parents and guardians. One mother stated: *‘He is always sick and requires special medication from private doctors. This is a burden because I am a domestic worker.’* This finding ties in with those of Swenson (2005) who stated that the budget of families with intellectually impaired children may be strained to provide special medical care. It is clear that medical expenses are incurred, particularly by families with intellectually impaired children. As such, parents and guardians who found themselves with an impaired child had no choice other than to attend to the demands of medical care of their children. However, such demands were not occasional but rather constant. It is indeed this frequency of care that made them exhausted and worried. Given the fact that the child is impaired, it is suggested that the parents could secure short-term endowment policies to cater for the period when they become unable to offer care.

The sixth and seventh concerns had the same value of (4%) by very few of parents and guardians. The sixth was that of school fees. A parent (mother) said: *“School fees are expensive, the grant she receives is not enough to pay for her schools fees and for the hired transport to take her to school and I am unemployed.”* Again, this finding is in line with the findings by Sen and Yurtsever, (2007) when they reported that families do experience a lower standard of living because of the increased expenses incurred by their impaired children such as special school needs: cost of transport to school as well as cost of therapy sessions.

The sixth concern was occupied by school fees. It appears that financial resources are generally scarce; and the challenge becomes even worse when the care of impaired children is involved. Such a situation makes the task of managing the costs of school requirements difficult. The challenges in terms of funds are understandable since most of the parents and guardians are either single parents or unemployed. It is quite evident that bringing up an impaired child has an economic cost. This appears to have a stressful impact on individuals who spend more time caring for such children. It is suggested that improved knowledge about the insufficient funds and how to manage what funds are available could be undertaken by the parents and guardians in order to alleviate the problem.

The seventh concern was where there is no support from biological parents for the impaired child. One grandmother said: *“Her mother is unreliable and the father is unemployed. They cannot assist her in any way.”* This finding is congruent with the findings by Pollin (1995) who stated that the uncertainty and ambiguity that can

accompany illness or impairment can compromise one's sense of perceived control. Overall, the findings demonstrate a negative impact on parents and guardians in terms of difficulties in meeting the demands of the impaired child. It appears that parents sometimes develop a negative attitude towards their children because of failure to reach a compromise between financial needs of the family and those of the impaired child. Unfortunately, such parents may respond by deserting their children. It is suggested that parents should talk over their problems with a trusted person who should assist them to establish priorities and then follow them.

5.3 Discussion on the Impact on Relationships both within and outside the Family of Intellectually Impaired Children

The discussion will focus on the impact on relationships both within and outside the family of intellectually impaired children. It will be done under sub-themes in the following manner. Firstly, the impact of public/community negative attitude towards intellectually impaired children on the family/parents. This will be followed by the impact intellectually impaired children have on parents/ couples, siblings and on extended family.

5.3.1 Discussion on the Impact of Public/ Community Negative Attitude towards Intellectually Impaired Children.

The findings from the study revealed that parents and guardians of intellectually impaired children experienced three challenges of the public's attitude towards their children. These were: occasional negative attitude/ behaviour, initial negative reaction but later acceptance and acceptance within the community. The challenges

that emerged from the findings of this study need to be looked into further. The first was that of occasional negative attitude/ behaviour of the public by a high percentage (78%) of parents and guardians. One parent (mother) said: *‘‘At times, out there, people look at my son and pass bad remarks such as: Can such a big boy behave like a five year old child? He needs to be beaten to stop it.’’* This finding was supported by Miller and Major (2000) who reported that anxiety is experienced by those people who are stigmatized when others make derisive comments or because they are excluded and discriminated against.

It appears that families with an impaired child almost always live under stress of being humiliated and socially stigmatized by the community. As mentioned in the quotation above some community members do pass negative comments on an impaired child. In addition, negative attitude towards the impaired child from the public/ community not only impact negatively on the child but also adds to the existing stress levels of the family. Such comments by the community might lead parents and guardians to feel as if they have been robbed of a chance to have a normal child, as well as their inability to be perfect parents or guardians. In all, the findings suggest that the pain associated with this feeling can be equated to some form of bereavement. It is suggested that awareness-raising activities should be particularly focused on the formation of advocacy groups representing impaired children.

The second and the third challenges had the same value of (11%) by about one tenth of the parents and guardians. The second challenge raised was occupied by the

initial negative reaction to an impaired child but later accepted by the public. Another parent (mother) said: *“I did not experience any discrimination as such. Sometimes when he plays with other children, they tend to be irritated by his behaviour.”* This finding is supported by the findings by Grant and Whitell (2000) who stated that negative attitudes adversely affect the parents. The message underscored here is that lack of public awareness about the potential of impaired children often acts as a barrier to their acceptance and even their participation in social events. Quite heartening, is that parents and guardians seem not to view their children as a burden; instead they are willing to resolve the situation more positively and overcome the situation graciously. Again, the problem of negative comments towards the impaired child by the public requires educational campaigns whose objectives are to make the public understand the problems of families with impaired children. Once this is achieved, the public could then shift from its negative stance to a positive perception of the impaired children.

The third challenge was that of acceptance within the community. One parent (mother) said: *“The child is accepted within the family and in the community. I haven’t noted anything strange.”* This finding illuminates the findings by Marshak et al. (1999) who indicated that acceptance is used to describe what is considered to be a healthy response to the fact that one’s child has an impairment. This was further supported by Cunningham (1996) who stated that the child with an intellectual impairment is not a burden at all. The deduction here is that the idea of acceptance implies recognising a child’s impairment and displaying sympathetic attitudes towards the family. Thus, parents and guardians, in turn, view their children’s

shortcomings realistically. In addition, it enables them to discuss issues of impairment without shame. However, in the process, parents and guardians could be devoting much attention to their impaired children while neglecting other children.

5.3.2 Discussion on the Impact of Intellectually Impaired Children on Parents/ Couples

The findings from the study revealed that parents and guardians of intellectually impaired children experienced six positive and negative responses, regarding the care of their impaired children. Such as: no negative attitude (widowed grandmother adopts the impaired child); both love and acceptance for child; father's support; love and acceptance of child (single mother); support and unity; ambivalence in father's relationship with child; and abandonment of family by father, blaming of the mother. The six responses/issues that emerged from the findings of this study need to be explored further.

The first issue was that of no negative attitude (widowed/ adopted by grandmother) by about one third (30%) of parents and guardians. Parents and guardians were inspired and strengthened by the fact that they are single parents (widowed grandmother adopts the impaired child). One parent (grandmother) said: *“My husband passed away long ago. She is just my grandchild whom I adopted and I love her dearly.”* This finding mirrors the findings by Shaban et al. (2003); Jones and Passey (2003), who described that positive attitudes help to bolster psychological and physiological consequences of stress. In all, the situation portrays acceptance of the

impaired children and providing support. It appears that having an impaired child can also be a challenge which strengthens the parents and guardians of such. However, having an impaired child can affect them negatively because of the burden of care, although positive attitudes towards the problem could overcome the stress associated with the care.

The second and the third response/issue had the same value of (20%) revealed by one fifth of the parents and guardians. This second response was that of a situation where there was both love and acceptance of the child. One father explained: *“Basically there is no impact because my wife and I love her so much. We accepted her the way she is.”* The deduction here is that parents and guardians have reached a point of acceptance which implies that they understand the challenge of care. This enables parents and guardians to open up and discuss their problems freely; as a result they may be able to provide for the needs of the child. It appears that they spend most of their time in taking care of and providing training for their child to learn basic daily life skills. In the process they could experience some stress.

The third response was that of a situation where the father supported; loved and accepted the child who was brought up by a single mother. Another parent (mother) said: *“I do not have difficulties really. His father supports him because he stays with him.”* These findings are consistent with the findings by Cunningham (1996), who stated that the child with intellectual impairment is not a burden.

In all, it appears that some parents and guardians viewed the impaired child as part and parcel of the family. The indication is that they were concerned about the well-being and future of the impaired child; as such the relationship between them becomes stronger and provides an environment of team work and hence improved communication between them. Thus, the picture here is that impaired child is not perceived as a burden but rather as a recipient of family care.

The fourth, fifth and sixth responses had the same value of (10%) by one tenth of the parents and guardians. The fourth was that of support and unity between the couple. One parent (father) said: *‘No effect because my wife and I are supporting each other.’* The findings are in keeping with the findings by Shaban et al. (2003), who revealed that families of intellectually impaired children are confronted by challenges and bear burdens unknown to other families without impaired children. Clearly, spousal support in the care of the impaired child gave a strong bond to the marriage and provided an atmosphere characterised by good communication. By so doing, the impaired child was accepted as a member of the family system, whose welfare was taken care of. Perhaps, the patience shown in the parental acceptance of the child could be based on a strong understanding of the impairment. Thus, this could serve as a source of comfort for the parents and helpful in creating a positive perception of the impairment.

The fifth response was that of a situation where the father’s relationship to the child was ambivalent. It was evident from the findings that a father did not play an effective role in the care of the child. One parent (mother) said: *‘Her father did not*

really accept her condition although he does not say it loud. At times one can just see how he speaks to the child.” Overall, this ambivalent reaction by some parents and guardians could imply that they feel that by caring for the impaired child, they experience decreased leisure time. Perhaps, awareness of an unequal distribution of the tasks of care gives rise to feelings of guilt. It can be interpreted that men may practise withdrawal, suppress feelings, and try to keep others from knowing how bad things are, while women seek strategies that help them to reach out to others, are more involved in caring activities and express feelings openly with other people especially to those with children in the same condition. It is suggested that in order to compensate for non-performance of duties as fathers, fathers could engage full-time caretakers to care for their children.

The sixth response was that of a situation where the father abandoned the family and blames the mother for the child’s condition. The mother said: *“The father of my son didn’t take it well as I did. He pushed everything away to me. He blames me for the child’s condition. He refuses to understand the situation of our son; as a result he went away till today.”* The message here is that parents and guardians felt that their child was placing greater restriction on family life; the greater the supervision needs of the child the greater the restriction on the family. Extra input of care required by an impaired child appears to be the pushing away factor for fathers. It is clear that fathers make light of serious problems affecting the family. The implication is that should the problem remain unsolved, it remains as a stressor. It is suggested that parents could use spousal support and participation in parents groups in order to go through challenges of care.

All these findings portray the findings by Gupta and Singhal (2004) when they stated that the existence of the intellectually impaired child in the family brings about a number of strains; poor communication, not accepting the situation, denying the situation, not expressing or hiding emotions, and acting in ways that break down relationships and destroy trust. Paralleling this finding is a study by Mak et al. (2006) who reported that family members of intellectually impaired children are often perceived to experience harmful psychological effects that might lead to depression and marital dissatisfaction.

5.3.3 Discussion on the Impact of Siblings towards Intellectually Impaired Children

The findings suggest five responses that parents and guardians experienced regarding the care of their impaired children on siblings. These were: love, acceptance, support; jealousy about preferential treatment; initially fear but later acceptance; resentment, lack of support and rejection. These issues emerged from the findings of this study and need to be explored further.

The first response was that of love, acceptance and support by the siblings reported by more than half (55%) of parents and guardians. A mother stated: *“The siblings accepted her as she is and they assist her all the time. When I am not around they take turns to help her.”* This finding was supported by Swenson (2005) who reported that siblings’ actions are usually connected with the parents’ reactions towards the impaired child. If the parents accepted their child’s impairment, then the siblings will accept it too, and adjustment will be dependent on what kind of attitude their parents

have. It appears that some siblings displayed a genuine concern for their impaired siblings. This could mean that those siblings who co-operate with impaired siblings do respond to natural bonds of birth and the culture of upbringing of that family. It can be deduced, therefore, that siblings possibly do not enjoy their childhood as they have to care for their impaired siblings.

The second response was that some siblings who displayed jealousy about the perceived preferential treatment of the impaired child and this was reported by less than one fifth (18%) of parents and guardians. One parent (mother) said: *‘My daughter feels that only my son gets most of the attention. She is always jealous because I take his side especially when they are fighting. It makes her angry sometimes.’* This is in line with Jaques (2003) who explained that siblings of children with impairment often express feelings of neglect or jealousy because of the perceived extra attention paid to their impaired siblings. This assertion was also supported by Jones and Passey (2003) when they stated that siblings may feel harmed and express feelings of guilt, shame and embarrassment.

The deduction here is that an impaired child can affect his/ her siblings in different ways, both favourably and unfavourably. The unfavourable effects may occur because parents may pay more attention to the impaired child and neglect other children in the family. It must be appreciated that parents usually tend to protect children who are viewed as weaker as a way of compensating for the impairment. It is suggested that parents could start communicating with their non-impaired children

by giving them simple explanations about their sibling's impairment in order to ease such feelings of jealousy.

The remaining issues third, fourth and fifth had the same value of (9%) expressed by just under one tenth of parents and guardians. The third issue was that siblings were initially afraid of the impaired child but later accepted him/her. A parent (mother) explained: *“My daughter used to be afraid of him but now she has accepted him after I explained that he is her brother and he will not harm her. Most of his siblings used to be afraid of him but later they get use to him.”* This finding is consistent with the findings by Moores (2006), who stated that whilst many siblings cope well, others may be at risk psychologically. The message communicated here is that parents could explain the impaired children's condition to the siblings and make them understand their sibling's situation in order for them to adapt to challenges posed by the impaired sibling. It is clear that, if parents took an optimistic and caring way, then siblings are more likely to do the same. Accordingly, it is suggested that siblings could develop an interest in assisting the impaired child, if the principle of positive reinforcement is applied.

The fourth issue was one of resentment - that siblings resented and did not support their impaired sibling. One parent (father) said: *“Brothers and sisters are always forced to take care of her. They do not make any effort to assist her on their own.”*

The deduction here is that siblings may have limited understanding of challenges of their impaired sibling. When siblings are not informed of their sibling's challenges, they may develop negative feelings about the impaired sibling that would also add on

to the existing stress levels of the family. It is suggested that there should be open communication within families, in order to reduce the unpleasant behaviour in siblings. In addition, provision of information could be made an ongoing process in order to minimise siblings' negative attitude towards the impaired child.

The fifth issue was that of rejection. It was disturbing to note that few siblings totally rejected the impaired sibling. A parent (mother) said: *‘‘It became obvious when she joins other children to play, others are pushing her away. They feel that she is not part of them. You just find her standing watching others playing and none of them is talking to her. She always looks lost among others. This experience worries me.’’*

This is in line with the findings by Gupta and Singhal (2004) who noted that having a child with impairment not only affects the parents but also the siblings. So it appears that some siblings are not sympathetic with the impaired child as they do not want to assist on their own. They only grudgingly assist the impaired sibling when they are reminded to do so. It is suggested that parents and guardians could always look at the few instances where the siblings sometimes do offer little help. Once this is noted, the action should be appreciated by thanking them in one way or the other. This kind of practice will in the long run, indirectly change the negative attitude of siblings to a positive one.

5.3.4 Discussion on the Impact of Extended Family towards Intellectually Impaired Children.

The findings suggest three issues that parents and guardians experienced with the extended family, regarding their impaired children. These were: positive relationship

such as love and support; negative attitude of some family members including rejection; full support shown by siblings and sometimes adoption took place. The three issues that emerged from the findings of this study need to be looked into further.

The first was that of a positive relationship, love and support by almost two thirds (62%) of parents and guardians. One parent (mother) said: *“Every member in the family loves her and assists where they can.”* This finding was supported by Green (2001) when he stated that more than relatives, friends or neighbours, grandparents are a common source of assistance. The deduction here is that the extended family sympathised with not only the impaired child but also the parents and guardians. This gives an assurance to parents and guardians as they are likely to view the child as ‘normal’ in spite of the impairment; hence the relationship bears a powerful positive impact. Such an encouragement could possibly make parents and guardians remain anxious about remaining alive long enough to provide care for their children. In all, the situation reflected a relationship of togetherness which makes parents and guardians to open up in terms of challenges they face in the care of their children.

The second was that of negative attitude of some family members including rejection stated by about one third (30%) of parents and guardians. A parent (father) said: *“People from her mother’s side (mother’s family) do not accept her at all.”* This finding is in line with the findings by Green (2001) when he pointed out that having a child with intellectual impairment may cause some negative, or even disruptive, changes between the child’s parents, grandparents and other family members.

Clearly, the extended family, particularly, from the mother's side rejected the impaired child. Perhaps, they could be busy with their own problems and find having to care for the impaired child to be too much work. It is quite painful that parents and guardians must attend to their own challenges and at the same time face the negative reaction of the extended family. In respect of the impaired children, parents and guardians may view the negative attitude of the extended family with considerable pain and despair. Overall, when the extended family fails to support the impaired children, this in fact adds to the family's burden. It is suggested that the extended family should assume a more positive role by providing the impaired child with access to services within the community through their own contacts with others.

The third response was that siblings displayed full support and in some case adoption was used. This response was given by less than one tenth (8%) of parents and guardians. A parent (mother) said: *“Basically there is no problem because most family members sympathise with him and support him especially his grandmother (his father's mother).”* This view tallies with the findings by Ylven et al. (2006) who noted that broadly based hands on support systems are composed of friends of all ages, neighbours, co-workers, and others in the community who offer family resources, emotional aid, models of behaviour and sources of information.

It is clear that the support and acceptance from the extended family make parents and guardians feel as if others have accepted their children as they are. This leads to a sense of hope in the care of their children. In this respect, such families could experience lower levels of stress and enables them to discuss issues of the

impairment of their children with confidence. Thus, impairment is not by choice, and friends and co-workers should be encouraged to sympathise with the challenges facing families with impaired children with a view to supporting them.

5.4 Discussion on Coping Strategies Experienced by Families of Intellectually Impaired Children.

The discussion focuses on the coping strategies of stress in bringing up intellectually impaired children. Firstly, the discussion of the support from partners and siblings towards intellectually impaired children will be presented. This will be followed by a presentation of the support from extended families, social support from others, professional support, spiritual support and internal/ personal strategies towards intellectually impaired children.

5.4.1 Discussion on Support from Partners and Siblings towards Intellectually Impaired Children.

The findings suggested four coping strategies that parents and guardians used in the care of their impaired children. These were: couple commitment and support; support from the father (where a single mother is raising an impaired child); assistance of siblings with daily care and mother supplementing her income to help pay the additional costs of looking after an impaired child. The four strategies that arose from the findings of this study need to be looked into further.

The first, second and third coping strategy had the same value of (29%) by less than one third of parents and guardians. The first was that of couple commitment and

support towards intellectually impaired children. A parent (father) said: *“We do not need extra support because my wife and I support each other.”* The second was that of support from the father (as described by single mother). Another parent (mother) said: *“His father takes him to school, Dagbreek Centre.”* The third was that of support by siblings with the daily care. Yet another parent (mother) said: *“I take care of her as well as receiving assistance from siblings”*. The findings portray the findings by Turnbull et al. (2007) when they mentioned that a supportive husband even one who does not participate in child care seems to be an important predictor of a mother’s sense of well-being. This perspective was given further weight by Swenson (2005), when he reported that the ability of normal siblings to adapt to having a sibling with intellectual impairment in the family seemed to be closely related to how well the family accepts the problem.

The first coping strategy was couple commitment and support towards intellectually impaired children. The fact that spouses supported each other and shared tasks of looking after the impaired child is of great importance as it increases family cohesion and feelings of togetherness. Such a coping strategy is very helpful in the face of stress caused by the impaired child. It appears that the parents’ ability to work together to meet the challenges presented by the child strengthened their own well-being and quality of the care they provided for the child. In addition, the findings increases their self-confidence because they could feel that they can manage the demand of caring for the child, thus, offering more independence and self-sufficiency. Overall, support from spouses seem to have the effect of making parents

accept their child, maintain high commitment, strengthen and motivate them, thus experiencing a sense of relief from the challenges of caring for their impaired child.

The second strategy was support from the father (as described by a single mother). It appears, the support rendered by the father displays an optimistic attitude towards the challenges of care of the impaired child. Indeed, the father went through this difficult situation with some sense of courage and commitment. This means that child care was shared and hence reflects openness; such a situation improves the quality of both family life and the well-being of the impaired child. It must be pointed out that sending the child to Dagbreek Centre offered the family a resting period. The indication is that the parents appear to have trusted that the child was in good hands at the centre and hence, they could have some relief. In all, it seems that the input by the father enabled the family to speak openly with one another concerning the challenges of care, thus, this made them able to cope well.

The third strategy was assistance from siblings with the daily care of the impaired child. The deduction here is that the existence of the impaired child may bring many good things into the lives of the other siblings. As such, the effect on the siblings who assisted in the care could be pride and satisfaction at being capable of taking care of their impaired siblings. Perhaps, the co-operation in the tasks of care displayed by siblings was an emulation of the positive attitude reflected by parents. Overall, the support rendered by siblings could result in the development of a great sense of sympathetic behaviour. Thus, the input from siblings remains a valuable

contribution in alleviating the challenges faced by parents and guardians of impaired children.

The fourth strategy was that of the need of the mother to supplement income which was expressed by more than a tenth (14%) of the parents and guardians. A parent (mother) stated: “*It is not easy because when she got sick, she has to visit the doctor immediately. Her medications are quite expensive and I have to struggle for the fund.*”. The finding ties in with findings by Seligman and Darling (2007) who reported that caring for an intellectually impaired child may directly or indirectly impose economic burdens on families in addition to their psychosocial costs. This impact includes medical care: therapy, hospital bills as well as medication and special equipment. This was further supported by Swenson (2005) who agreed that the budget of families with intellectually impaired children may be strained to provide special medical care, transportation or remedial programmes.

Clearly, the challenge here is limited financial resources, particularly for a single mother. This could, therefore, mean that parents have problems in finding funds for the care of their impaired children. It implies that parents might be at a loss because of failure to meet the financial needs of their children. This causes worry, insecurity and helplessness on the part of the mother. Such a situation makes caring for the impaired child difficult and could make the parent develop feelings of sorrow. However, overall, parents tend to develop a sense of resilience and strength in meeting the challenges of care. In respect of these findings, it is suggested that active

support by social welfare organisations could improve the plight of families with impaired children.

5.4.2 Discussion on Support from Extended Families towards Intellectually Impaired Children.

The findings suggested two coping strategies regarding support from extended families used by parents and guardians in the care of their impaired children. These include: family support from the extended family (care giving) and financial support from the extended family. The two strategies that came out of the findings of this study need to be explored further. The first was that of family support from extended family members (care giving) reported by a high percentage (83%) of parents and guardians. One parent (mother) said: *“I must say, I am lucky because my relatives are very supportive towards my son’s condition. Each one of them is bringing his or her side to help. It became a routine to us all in the family.”* These findings are in line with Heller and Caldwell (2006) who described informal sources of support from extended families, friends, neighbours, other families with similar issues and groups such as churches. This was further supported by Abbeduto et al. (2004) when they stated that informal support has more positive effects than formal support.

The message communicated here is that support from extended families is essential for managing the care of the impaired child. It implies that, being close, the extended family are people who can help in the care of the child. Such help offers parents a rest and enables them to attend to other social functions. It appears that the effectiveness of the support from the extended family assists parents and guardians to

cope with the demands of care for their children. This support allows them to feel as if others had accepted their family as they are. Accordingly, it is clear that this support from the extended family was important in making them further accept their children's impairment, as they did not feel neglected. Although families with impaired children seem to manage their families, the additional support provided by the extended family enabled them to effectively cope with challenges of care.

The second was that of financial support from the extended family reported by nearly one fifth (17%) of parents and guardians. A parent (father) said: *'I look for funds from extended family members to cater for her needs like toiletries. I try to make her look presentable just like my other children.'* There is overwhelming support for this in Stonemann (2000) who maintained that the help given by outsiders such as giving money, taking children for a walk and transport services greatly assists the families with intellectually impaired children to maintain a normal life.

Clearly, financial resources appear to be the most important single factor in assisting parents and guardians to cope with the care of their impaired children. This kind of support comes as a relief to parents and guardians who find it as very helpful. In addition, the effect of this support seems to reduce the negative challenges faced by these families in their day-to-day care of their children. Overall, the assistance rendered by extended families gives hope and confidence to parents and guardians of the impaired children. It can, therefore, be concluded that families of intellectually impaired children received support from other family members that enable them to

cope with their child's situation. It is suggested that government should increase a social grant for impaired children with a view to alleviate the challenges they face.

5.4.3 Discussion on Social Support from Others towards Intellectually Impaired Children

The findings suggested six coping strategies regarding social support used by parents and guardians in the care of their impaired children. These were: support from social networks (mothers' group; church members; community,); social support from friends; financial support from friends; support from institutions (hostel, medical aid); support from neighbours (social contact) and financial assistance from employers. The six strategies that came from the findings of this study need to be explored further. The first strategy was that of support from social networks (mothers' group; church members; community) reported by one third (33%) of parents and guardians. A parent (mother) said: *'I used to attend workshops to acquire information and knowledge on how to take care of my son since his father was not supportive. Sometimes I go to Onyose Trust where a group of mother's with intellectually impaired children gather to share ideas and support as well as to encourage one another.'* This finding mirrors findings by Ylven et al. (2006) who reported that support systems composed of friends of all ages, neighbours and others in the community offer resources to the family, emotional support, and a model of behaviour and sources of information.

Naturally, individuals look around for support systems when they are confronted with problems. Accordingly, most parents and guardians appreciated the support

from the social network since it proved helpful to them, hence, it made the challenge of care more tolerable. However, the support given by the social network could make them experience feelings of inadequacy to manage their children. Whatever the situation, the interaction could make them understand the impairment of their children. Support groups should be promoted to enable the family network to improve their understanding of impaired children, hence, making parents and guardians cope well.

The second, third and fourth coping strategies had the same value of about one fifth (17%) of parents and guardians. The second strategy was that of social support from friends. Another parent (mother) said: *“My friend Paula is always coming forward with help, she makes my life easier.”* The third strategy was that of financial support from friends. One parent (father) said: *“Although I take her to school every day, this drains us a lot. Sometimes we have to borrow money from our friends for fuel.”* The fourth strategy was that of support from institutions such as hostel and medical aid. A parent (mother) said: *“He is a hostel boarder and so things are a bit lighter in terms of transport cost.”* These findings are consistent with those reported by Stonemann (2000) who stated that the help given by outsiders such as giving money, taking children for a walk and transport services greatly assists the families with intellectually impaired children to maintain a normal life.

If we look at more details at the second strategy of social support, it can be deduced that support from friends allowed parents to develop a feeling of confidence in caring for their children. This implied acceptance of the impaired child, thus making the

process of care easier. In addition, the interaction between parents and friends offered much needed encouragement and strength. Indeed, the care for an impaired child requires a great deal of courage and commitment. In all, it appears that the acceptance of friends provided for the integration of the impaired child into society, though to a limited extent. It is suggested that such a positive contribution to the welfare of the impaired children should be maintained and improved by all means possible.

The third coping strategy mentioned above was that of financial support from friends. The message communicated here is that friends showed the concern for the impaired child by providing financial resources and this increased feelings of togetherness among friends and the parents. This implies that the family's ability to cope was strengthened. Furthermore, the financial support given by friends was of great importance for the overall family well-being and cohesion. It is suggested that support groups that include friends should be promoted to enable them to continue providing financial assistance in order to enable parents and guardians to support their children.

The fourth coping strategy consisted of support from institutions such as hostel and medical aid. Clearly, this help was very important as it provided some form of respite to parents. It implied lessening their burden of care, at least for a certain period while the child is in the hostel. However, the efficacy of such support depends on the availability of certain facilities in institutions. It is suggested that the government should disseminate information regarding the availability of hostels and ways of

accessing help at such institutions in order to assist parents and guardians to care for their children.

The fifth and sixth strategies also carried the same value of (8%) and was reported by very few of parents and guardians. The fifth strategy was support from neighbours (social contact). A parent (mother) said: *‘My neighbours are good people, because if they do not see us for two days or so they always come to ask us if everything is fine now that they did not see us for the past two days.’* It appears that, being close, the support given by neighbours has far reaching positive effects on the welfare of the impaired child. This implies building confidence in such families and hence, enabling them to cope well. The heartening finding is that neighbours were described as ‘good’ which indicates that parents and guardians trust and value their assistance. Indeed, it reflects a feeling of satisfaction which helps them to manage their families. It is felt that good neighbours are friends in need and friends indeed; as such they should continue to support the impaired children.

The sixth strategy was to seek financial assistance from the employer. Another parent (mother) said: *‘When things get tough, my employer assists me financially’*. This finding is consistent with the findings by Bauman (2004) who defined social support as individuals, groups, or institutions that provide assistance to help other individuals overcome stresses that strain a person’s resources. The deduction here is that financial assistance lessens the challenge of care faced by parents and guardians and hence enables them to cope with their children. Indeed, this kind of support is so helpful that parents and guardians value it. The retention of staff at work places

requires employers to attend to staff problems, which in turn enables them to manage the challenge of care of their children. It is suggested that such a healthy relationship between employers and employees should prevail in order for parents and guardians to care for their children.

5.4.4 Discussion on Professional Support towards Intellectually Impaired Children

The findings suggested four strategies regarding professionals support used by parents and guardians in the care of their impaired children. These include: doctors, psychologists, therapists and silence about seeking general professional assistance. The four strategies that emerged from the findings of this study need to be looked into further. The first three strategies had the same value of (10%) expressed by one tenth of parents and guardians. The first was that of professional support from doctors. A parent (mother) said: *‘I had to take him to the doctor almost every two weeks.’*

The message communicated here is that parents and guardians closely and frequently interacted with doctors largely owing to the condition of their children. It implies that they had hope that scientific information could offer a solution to their problem. What is not clear is whether medical professionals displayed empathy and sympathy when dealing with impaired children. Care and commitment of doctors help to ease the challenge of care and hence is a cure in itself. Although the process to find professionals could have been difficult, parents and guardians persevered until appropriate help was rendered by health service providers. It is suggested that no

matter how difficult parenting an impaired child could be, parents and guardians should demonstrate a never give up attitude as they work with professionals.

The second was that of professional support from psychologists. Ayne (mother) said: *“He does not do well in school and this was a disappointment so the school referred us to a psychologist Dr Fourie.”* The third was that of professional support from therapists. Another parent (grandmother) said: *“Now that I adopted her, I put her on my medical aid which helps me to pay her medication and take her to a therapist.”*. There is overwhelming support for this in Glidden (2006) who reported that it is useful to get as much help as one can from professionals and other service providers which at times turn out to be difficult in terms of accessing such help. This was further supported by Cunningham (1996) who concurred, when he stated that professional services may be needed to support both the family and to provide the information and skills to enable the informal network to help.

It is evident that no matter how difficult dealing with professionals could be, parents and guardians persevered as they sought a solution to their children’s condition. The indication is that they hope and trust that the support from professionals could assist them in the care of their children. However, it is possible that they could not see the service providers as mostly needed by the condition of their children. In such cases, they could provide care in the way they considered most appropriate. It seems that dealing with professionals is one of the most helpful coping strategies at the disposal of parents and guardians. What is only required is to exercise patience when dealing with medical professionals.

The third strategy was to seek professional support from therapists. It appears that dealing with therapists happens to be a process which requires patience as the interaction undertakes the challenge step by step. Indeed, the process is characterised with long analysis and reviews. However, it must be pointed out that although some parents and guardians may want quick solutions to their problems, health providers operate on standard principles and procedures, and hence, there could be delays. It is likely that the manner in which professional interacted with parents could have influenced acceptance of their children. Accordingly, it is suggested that more such parents and guardians should seek assistance from medical professionals as it helps them to cope with care of their children.

The fourth strategy was occupied by silence about seeking assistance from professionals by a high percentage of (70%) of parents and guardians. The deduction here is that although, they were silent it does not necessarily imply that they did not seek professional assistance. This could therefore, mean that their energy was directed to the care of their children. Indeed, some parents and guardians do not feel comfortable in seeking outside help; instead they are pre-occupied with the caring business. It is suggested that advocacy groups should attempt to raise awareness on the need to obtain assistance from individuals and organisations.

5.4.5 Discussion on Spiritual Support towards Intellectually Impaired Children

The findings suggested seven coping strategies regarding spiritual support used by parents and guardians in the care of their impaired children. These were: spiritual support – strength coming through belief; spiritual support through targeted church

interventions; spiritual support- general (attending church service); motivational talks from spiritual leaders; spiritual support for child through friends; financial support from church groups and material support from a pastor. The seven strategies that emerged from the findings of this study need to be explored further. The first was that of spiritual support which was strengthened through belief by about one third (30%) of parents and guardians. One parent (father) said: *‘I only listen to the gospel radio programmes mostly on Sundays, just to comfort myself. After listening to this, I feel good just as if I was in church or at a gathering where we have people of the same problem as mine (of having an impaired child).’* In the same vein, Neely-Barnes et al. (2008) showed that faith and religious coping methods are the most frequently reported coping strategies among families with intellectually impaired children. Therefore, religion offers guidelines for living and offers a sense of stability.

These findings suggest that parents and guardians used spiritual support to alleviate challenges associated with the impairment of their children. It appears that the belief in a certain religion may be taken to explain events in life such as the occurrence of intellectual impairment. Hence, parents tended to accept their impaired child as something which is God given and thus, often show acceptance of the situation. Perhaps, the patience and passion they displayed could have been based on the belief that they will be rewarded by God in one way or another. Thus, belief in God was a source of comfort for them and helpful in creating a positive perception of their impaired child. Since people find hope in religion, it is suggested that parents and

guardians could be more involved in religious activities such as groups where information on how to manage their children can be shared.

The second strategy was that of spiritual support through targeted church interventions expressed by about one quarter (23%) of parents and guardians. Another parent (father) said: *“We attend church services as well as workshops prepared by church members just to encourage parents and families with intellectually impaired children. It really assisted us so much, by learning that you are not the only one in such a problem.”* This finding was supported by McCubbin and Patterson (1983a) when they reported that spiritual support played an important role in the family’s ability to manage stress, particularly in the most severe situations such as for those with intellectually impaired children.

The findings show a number of influences such as providing teaching and a framework for families with impaired children to view their situation more positively. This offered a way for parents to interpret their child’s impairment in a positive way. Furthermore, encounters in church gatherings convened specifically for discussing the challenges of care for impaired children makes the parents open up and accept their situation. In addition, the effects of the workshop may make parents and guardians realise that their problems are less challenging than others, hence, it make them feel encouraged in their duty for care. Accordingly, targeted church interventions greatly assisted them to care for their children. Therefore, it is suggested that awareness campaigns should be undertaken in order to make the community understand challenges amongst families with impaired children.

The third strategy was that of finding spiritual support in general through attending church services noted by over one tenth (15%) of parents and guardians. A parent (mother) said: *“I go to church where we receive a lot of information and support.”* This finding links to those of McCubbin and Patterson (1983a) when they explained how spiritual support played an important role in the family’s ability to manage stress, particularly in the most severe situations.

It is clear that spiritual beliefs and a sense of purpose in life enabled parents and guardians to accept their child’s condition in a positive way. Perhaps, their faith could have led them to believe that they had been specially selected to provide comfort and care to their children. Their regular attendance at church service made them perceive their impaired children as part of them, thus, their belief helped them to be calm and relaxed. It must be pointed out that the effect of such acceptance of the impaired child could have increased their spirituality. As parents and guardians used spiritual support to cope with the care of their children, it is suggested that they should arrange regular (mid-week) outreach sessions at one another’s houses.

The fourth, fifth, sixth and seventh strategy had the same value of under one tenth (8%) of parents and guardians. The fourth strategy was attending motivational talks from spiritual leaders. One parent (father) said: *“We attend workshops prepared by church members just to encourage parents and families with intellectually impaired children.”* These findings suggest that general church services may not be enough for providing coping strategies for parents and guardians with impaired children. It appears that for them to become effective in their parenting services they need to be

assisted in order for them to feel a greater sense of control over their children, hence, the need for motivational talks from spiritual leaders. Furthermore, their beliefs seem to have provided a coping resource for the challenge of caring their impaired children, thus, this enhanced and maintained their hope. Accordingly, it is suggested that other approaches and coping strategies need to be recommended and taught to parents with impaired children.

The fifth strategy was the giving spiritual support to the child from friends. One parent (mother) explained: *“The same friend is the one coming to visit us and when my son is around she always invites him to church. The day I am not going to church she always takes him with.”* This finding suggested that most parents and guardians valued assistance from their friends as a form of spiritual support for the care of their children. It implies that they viewed this kind of support as very helpful and thus they appreciated it. In addition, the will to support requires a great deal of religious commitment and sacrifice, hence, spiritual support rendered by friends to help parents and guardians to care for their children. Perhaps, what makes them to gladly accept and use it is the fact that it comes from close friends. This way, the parents felt strengthened in their duty of care. It is suggested that support from more sources be obtained in order to assist the process of both acceptance and coping the challenges of care of their children.

The sixth strategy was receiving financial support from church groups. One father said: *“I make sure she receives help and look for funds from family members (younger brother), friends and church groups to cater for her needs like toiletries. I*

tried to make her look presentable just like my other children.'' Clearly, religious convictions encourage church members to provide financial resources to impaired children. This indicates that they felt duty bound to relieve the challenges faced by families with impaired children. It appears that when parents and guardians do not find assistance elsewhere, the church is always there to provide financial support. Accordingly, spiritual support remains a vital factor in assisting them to manage their children. It is suggested that ways should be found to establish community based projects in horticulture in order to guarantee the availability of fresh produce and funds from sales.

The seventh strategy was that of receiving material support from a pastor. One parent (mother) said: *''Our pastor loves us so much. He always visits us, prays for my son's health and gives some groceries. The whole process is comforting. He is assisting us a lot spiritually and materially.*'' These findings are in line with the findings by Poston and Turnbull (2004) who reported that spiritual support, congregational support, prayer and benevolent religious reframing were found to be helpful. This perspective was further given weight by the same researchers who categorised religious coping strategies in order to determine which type of religious coping is helpful or harmful. It follows that the social nature of a religious community provides positive benefits to families with an impaired child and this includes material support from church members.

It appears that, it remains the obligation of other religious members to provide food and clothes in charity to the impaired children. Perhaps, the focus could be on

religious responsibility intended to achieve spiritual recognition by God. Since people often turn to religion, it is suggested that religious institutions and pastors should be trained to provide pastoral counselling to parents and guardians of the impaired child.

5.4.6 Discussion on Internal/Personal Strategies towards Intellectually Impaired Children

The findings suggested four internal personal coping strategies used by parents and guardians in the care of their impaired children. These were: resilience/commitment–mother, cognitive–understanding impairment, no need for additional social support and resilience/ commitment–father. The four strategies that emerged from the findings of this study need to be explored further. The first was that of resilience/commitment demonstrated by mother was noted by nearly half (45%) of parents and guardians. This view is evidenced by one parent (mother) who said of her child: *‘It is not easy because when she gets sick, she has to visit the doctor immediately. Her medication is quite expensive and I have to struggle for the funds.’* This finding supports the findings by Lustig (2002) when he described how internal strategies assist parents and guardians to care for their children. Lustig acknowledged the role of both God and the individual in a situation of need to deal with an impaired child and associated the development of personal coping strategies with a greater sense of self-esteem and personal control.

Clearly, economic challenges are caused by the presence of an impaired child to the family because of the often high expenditure on medical costs. This finding confirms

that parents and guardians have to attend to the needs of the impaired child when faced with several challenges. It appears that the main worry of the parent is about the demand of care for the child. Thus, parent's plight is further worsened since medical bills are a regular expense. However, parents continue to demonstrate commitment and self confidence, thus, they developed endurance in the face of challenges. It is suggested that families with impaired children should be assisted to develop a positive perception on the challenges of care.

The second and third personal coping strategies had the same value of (22%) held by just under one fifth of the parents and guardians. The second strategy was that of cognitive–understanding of impairment. One parent (mother) said: *“I did not feel bad because I understood the impairment and accepted her as a normal child.”* This finding confirms that parents accepted the condition of their child and displayed a positive attitude. It implies that there are some circumstances that cannot be changed, thus, parents focus their attention on solving the problem of care instead of lamenting about the challenge. In addition, understanding an impairment means acceptance, hence, it reduces worry, a situation which strengthens the coping of parents. Furthermore, such a situation improves the quality of well-being of both the parent and the child. Accordingly, it is suggested that awareness-raising activities need to be focused on advocacy groups for the welfare of such children.

The third was that there was no need for additional social support. One father stated: *“We do not need extra support because my wife and I support each other.”* This finding is consistent with the findings of Marshak and Prezant (2007) who revealed

that acceptance does not imply surrender to the idea that the impairment is unchangeable. This was further supported by Turnbull et al. (2007) when they mentioned that a supportive husband even one who does not participate in child care seems to be an important predictor of a mother's sense of well-being.

This finding points to the fact that the support couples give each other makes the task of care bearable. It appears that the willingness of parents to work together in facing the challenges of care strengthens and enables them to cope well. In addition, such a situation increases self-confidence and improves the quality of care they provide to their child. Parents, whether as parents of a normal or impaired child, have a natural love for their children. Naturally, they find themselves making use of personal love and strength in order to care for their children. A parent remains a parent. In all, the support from spouses is vital as it makes both parents able to remain high committed and loving towards their children. Since bringing up an impaired child demands a lot of attention, it is suggested that individuals and the community at large should find ways of relieving the burden faced by such parents.

The fourth coping strategy was that of resilience/commitment demonstrated by the father was reported by about one tenth (11%) of parents and guardians. One father declared: *“Schooling is a very demanding issue because I must always pay for her transport. Once I fail to do so then she won't be taken to school. I have to organise funds to pay for her transport.”* This finding is consistent with the study by Sen and Yurtsever, (2007) when they reported that families do experience a lower standard of living owing to increased expenses regarding their impaired child such as special

school needs: availability of transport to school as well as for therapy sessions. It appears that the demands of care of the impaired child are well accepted by the father, who, helps towards the transport costs of the child. Furthermore, parents' willingness to handle the situation positively assists in overcoming the challenges of care. It is suggested that studies should now focus on exploring ways that families can cope with different challenges of care instead of concentrating on the impairment of the child.

5.4.7 Discussion on Strategies for Improvement on Personal Input and Family Support towards Intellectually Impaired Children

The findings suggested six personal input coping strategies used by parents and guardians in the care of their impaired children. These include: mutual support, positive attitude; need not to reject the impaired child; need for acceptance of child's impairment; giving of love and attention; need to be proactive and get assistance from family members. The six strategies that arose from the findings of this study need to be looked into further. These strategies carried the same value (16.67%) reported by almost one fifth of parents and guardians.

The first strategy was that mutual support and positive attitude of the care givers are crucial. A parent (father) said: *‘It is best when people help each other, stay positive and take the situation as it is. I also feel that our community leaders should take a lead to bring information closer to people.’* This finding is in line with those by Ylven et al. (2006) who reported that informal support systems consisted of relatives,

friends of all ages, neighbours, co-workers, and others in the community offering family resources, emotional aid, and models of behaviour and sources of information.

The message here suggests that parents and guardians should be sympathetic to the impaired child and focus on the brighter side of the challenge. Clearly, impairment does not come by choice, and such families deserve to be supported. It implies that positive perceptions play a central role in the coping process. In addition, accepting the reality of the challenge of care has the effect of strengthening parents and increasing their internal motivation. It is suggested that practical ways should be found to help families develop a positive outlook on the challenges of care of their children.

The second strategy was that parents must not reject their impaired children, especially fathers. One father said: “*Parents must not reject their children, especially men.*” This finding was supported by Gupta and Singhal (2004) when they stated that the existence of an intellectually impaired child in the family brings various stresses including poor communication, non acceptance or denial of the situation, non-expression or hiding emotions, and acting in ways that break down relationships and destroy trust.

The deduction here is that fathers take the challenges of care lightly, to such an extent that the burden of care falls on mothers. It appears that the father may feel that their child was imposing on their time. This results in an unequal distribution of the

tasks of care for the child. Therefore, accepting the impairment could contribute to personal growth of the parents, family stability and hopefulness. It is suggested that attempts should be made to build awareness among parents and guardians on various aspects of the challenges of care with a view to make both mother and father contribute positively.

The third was that of need for parents to accept children's impairment. One father declared: *“Parents must accept their children's impairment. Parents must not sit idle because they don't have money.”* This finding calls for understanding of the child's impairment and ultimate acceptance which enables parents to open up and discuss their challenges freely. For parents to become effective in their parenting duties, they must have a sense of personal control through acceptance of the child's impairment. It is suggested that the focus should be on parental training programmes on positive behavioural support strategies that will have significant impact on positive perception of impairment and coping.

The fourth response was that of the need to give love and attention to impaired children. Another father said: *“These children need a lot of love and attention.”* This finding mirrors the findings by Shaban et al. (2003); Jones and Passey (2003), who described that a positive attitude helps to bolster psychological and physiological consequences of stress.

The deduction here is that parents and guardians should be sympathetic and recognise the child's impairment and as a result, accept and love the child. By

implication, the process of acceptance could provide them with a sense of strength to realise their inner potential to cope with the care of the child. Accordingly, the effects of the acceptance could shape parents' overall experience on hope in life. It is suggested that vigorous effort be done to make parents develop positive perception on impairment in order to enable them to cope with the reality.

The fifth strategy was that of the fact that parents must be proactive. One parent (father) said: *“They must go look for funds to help their children.”* This implies, setting aside the worry and instead deal with the demands of care of the child. Even though, the process could be stressful, the act of providing service to the child could be more rewarding and hence enable them to cope with the challenge of care. In any case, parents and guardians are expected to undertake their duties of care for their children, whether impaired or not. It is suggested that, for the parents to become strong in parenting, other people should assist them to achieve a sense of personal control over their children through training and further information.

The sixth strategy was to get assistance from family members. A parent (grandmother) said: *“People must get assistance from their family members. It will help a lot.”* This finding illuminates the findings by Marshak et al. (1999) who indicated that acceptance is used to describe what is considered to be a healthy response to the fact that one's child has impairment. This finding suggests that the most helpful form of support comes from the immediate family members. This implies that such members should display empathy and love towards the impaired child. As such, the ability of family members to work together to face the challenge

presented by the impaired child strengthens their quality of care and coping. Furthermore, support from family members could increase parents' self-confidence. The experience of self-sufficiency around them could enable them to cope well. It is suggested that ways should be explored to provide hope and strength to families with an impaired child.

5.4.8 Discussion on Strategies for Improvement of Community Awareness Campaigns towards Intellectually Impaired Children

Also emerging from the findings were four suggestions for coping strategies for improvement through community awareness campaigns to be used by parents and guardians in the care of their impaired children. These suggestions were that the community should not view impairment as a curse; there is need to educate society on the care of intellectually impaired children; negative comments (discrimination) should be reduced through awareness campaigns and government to undertake an awareness campaign on the welfare of impaired children. The four strategies that arose from the findings of this study had the same value of (25%) expressed by one quarter of parents and guardians and need to be looked into further.

The first was that of the need for the community not to view impairment as a curse. One father suggested: *“I also feel that our community leaders should take a lead to bring information closer to people. We have people out there who do not know what to do with their impaired children. Awareness should be raised to inform people that impairment is not a curse.”* The second suggestion was to educate society on the

care of intellectually impaired children. One mother recommended as follows: *‘‘It is important to educate the society on how to take care of intellectually impaired children. Medical staff must be sympathetic as they should know how to talk to people.’’*

Clearly, many parents and guardians find meaning through assuming new roles such as parent-group leaders and members of advisory councils for centres for an impairment. The sharing of common experiences in organised workshop for such parents could be a major contributor of resilience and hope. Therefore, sharing compassion and any similar experiences serves as strong support. It is suggested that positive attributes of hope should be explored to assist them to cope with the care of their children.

The third suggestion was the need to reduce negative comments (discrimination) through awareness campaigns. Another mother said: *‘‘The community should be aware of the children’s intellectual conditions. When the community is aware of the impairment conditions, a lot of staring and unnecessary statements will be reduced.’’*

Finally, the fourth suggestion was that government should undertake an awareness campaign on the welfare of impaired children. One mother recommended as follows: *‘‘I feel that as families of children with an impairment, we need the government to have a campaign through the Ministry of Health to educate the nation about any type of impairment. Our people are not well informed about children living with impairment, and as such they do not know where to take their children for school.’’*

These perceptions link to the study by Evans (2004), who noted that family members who are distressed and depressed may need family counselling.

The deduction here is that the pressure of discrimination on the impaired children from members of the community is real. Accordingly, positive perception about impairment may make parents and guardians more resilient in the face of subsequent stress and thus may protect them from ill health. This implies that they could focus on being compassionate, developing endurance and facing life with renewed boldness rather than submitting to fear. In addition, the desire to protect and support their children could make them speak out on their behalf. It appears that the effect of positive perceptions of families with impaired children may be satisfaction in providing care for them, sense of accomplishment in having done one's best and sharing love with the child. As such, community agencies and the government should educate the community about impairment and raise awareness of the difficulties of parents and guardians of impaired children. Thus, these suggestions could go a long way in changing the perceived negative attitudes by the community towards the impaired child.

5.4.9 Discussion on Strategies for Improvement on Financial Support towards Intellectually Impaired Children

The findings suggested five coping strategies for improvement on financial support towards the care of their impaired children. These were: increase of existing grant by government; government support in terms of medication and schooling fees; parents must look for funds to help their children; government to exempt impaired children

from payment of services and the setting up of organisations that can fund medical and schooling expenses. The five strategies that came from the findings of this study need to be looked into further.

The first suggestion was the need to increase existing grants by government was expressed by half (50%) of parents and guardians. One parent (mother) said: *“It will be a good idea for our government to revisit the amount of grant given to these children at least to a better figure, even N\$ 450 per month. The current grant is too little to cater for their needs.”* This finding was supported by Stonemann (2000) when he pointed out that the help given by outsiders such as financial services greatly assist the families with intellectually impaired children to maintain a normal life. It appears that economic resources contribute to the family well-being, thus grants are one of the major sources of such resources. Clearly, parents and guardians have been using government grants as important resources to cope with the challenges of care of their children. It implies that they are having problems in the allocation of funds in the care of their children, which affects them negatively. However, they need to develop a sense of resilience to meet the challenges of care. Accordingly, it is suggested that the government should increase the amount of their grants for impaired children.

The second, third, fourth and fifth remaining suggestions had the same value of just over one tenth (12.5%) of parents and guardians. The second suggestion was that government should support the impaired children in terms of medication and

schooling fees. One (mother) said: *“The government must support families with intellectually impaired children financially in terms of medication and schooling.”*

It appears that parents and guardians are having challenges in meeting expenses of medication and schooling fees. Indeed the condition of their impaired children makes their expenditure extraordinary. As a result, they might develop a negative attitude towards their children. However, they may endure the pressure to a certain extent, hence, the need for support from outside the family. As such, it is suggested that government should undertake urgent reviews of the levels of existing grants with a view of increasing them to realistic levels. This would greatly enable parents to cope with the challenges of care.

The third suggestion was that parents must look for funds to help their children. One parent said: *“Parents must not sit idle because they don’t have money. They must go look for funds to help their children. We need organisations that can fund us to help our children in terms of medical aid and schooling.”* Although, raising an impaired child has challenges, parents and guardians should stand behind their children and provide support. The findings reflect a heartening attribute of parents and guardians who still view their duty of care with courage and optimism. Such a positive attitude requires outside support in terms of financial resources in order to enable them to cope well. Accordingly, it is suggested that parents and guardians should look around for financial support from any positive individuals and organisations.

The fourth suggestion was that government should exempt impaired children from payment of services. One parent (father) said: *“At times I think of the government*

through the Ministries of Health and Education to exempt these children from any payment for any services rendered to them.” The message here is that the ultimate responsibility to protect life of citizens lies on the shoulders of the government. This implies that where families genuinely face challenges, the government has a constitutional obligation to move in and assist. Such a situation could enable them to cope well with the care of their children. It is suggested that ways should be explored for the government through relevant ministries to exempt impaired children from payment of services.

The fifth suggestion was that to set up organisations that could fund medical and schooling expenses. One parent (father) said: *“We need organisations that can fund us to help our children in terms of medical and schooling.”* These findings are in line with the findings by Swenson (2005) who reported that the budget of families with intellectually impaired children may be strained to provide special medical care, transportation, or remedial programmes. Families may find themselves in a situation where they need to cut back on other costs.

Clearly, collectively, the financial demands of care for the citizens of a country cannot solely be provided by government alone, hence, the need for other stakeholders to fill the gap. This finding illuminates the fact that parents and guardians remain positive and hopeful. Such a background is an important factor for proper coping. Therefore, it is suggested that the financial deficit faced by parents and guardians be provided by other organisations.

5.4.10 Discussion on Strategies for Improvement on Information and Advice about Intellectually Impaired Children

The findings suggested seven coping strategies for improvement on information and advice about the care of impaired children. These were: the establishment of organisations to help parents obtain information and advice on how to care for their children; guidance to parents regarding the handling of their impaired child; community leaders to take lead in informing parents; availability of information on how and where to apply for social grants; and availability of information on how and where to apply for schooling; relevant ministries to inform parents about the services of psychologists; medical staff to be sympathetic to families with impaired children and refer them to therapists. The seven strategies that came from the findings of this study had the same value of (14.3%) by just over one tenth of parents and guardians and need to be explored further.

The first suggestion was that organisations should help parents to obtain information and advice on how to care for their children. One mother said: *“We need organisations that will help parents to look after their own children. It will be a big relief when parents and guardians are informed, advised how to help their children.”* Clearly, parents and guardians expressed feelings of helplessness and insecurity owing to the demands of care of their children. It implies that they have inadequate information and advice on how best they can care for their children. The fact that they are lamenting for support in the form of information and advice suggest that they have a realistic image of their children’s impairment; hence, they expressed their wish to protect their future prospects. The indication is that availability of more

information and advice could enable them to manage the care of their children. It is suggested that relevant organisations such as the Namibia Association for Children with Disabilities (NACD) should provide information and advice on how to care for their children.

The second suggestion was the need for parental guidance regarding the handling of their impaired child. A parent (father) said: *“It is best when people help each other, stay positive and take the situation as it is.”* The deduction here is that parents and guardians value a spirit of togetherness and commitment to the needs of the impaired child. The finding suggests that parents adopt a positive attitude to their child’s impairment which strengthens family cohesion and hence their ability to cope well. In addition, such an attitude enables collective participation in the care of the impaired children. Accordingly, it is suggested that attempts should be done to educate families with impaired children and the community at large about managing such children.

The third suggestion was that community leaders should take lead in bringing information to parents. Another parent (father) said: *“I also feel that our community leaders should take a lead to bring information closer to people. We have people out there who do not know what to do with their impaired children.”* It seems that the authority and role of community leaders in disseminating information is valued by parents and guardians of impaired children. This suggests that the availability of information on the care of such children could develop self-confidence in the parents. Thus, it allows them more independence and self- sufficiency in caring for their

children. It follows that there is need to avail information about organisations and professionals who can assist in the care of impaired children.

The fourth suggestion was the need to give information to parents on how and where to apply for social grants. One father made the following recommendation: *‘‘It will be very important if our community is well informed about taking care of their impaired children in terms of where to go for any assistance, where to apply for social grants. The grant given is too little compared to what the child’s needs are.’’*

It is obvious that a gap exists between families with impaired children and possible service providers. The issue of the procedure of how to apply for social grants should be made public rather than parents struggling to access such information. Thus, the availability of information could enable parents to cope better since such a situation improves their well being and the overall quality of the care they can provide to their children. Accordingly, it is suggested that brochures should be printed in all languages and distributed among community members in order to ensure that information reaches all people.

The fifth suggestion was the need to give information to parents on how and where to apply for schooling. Another father stated : *‘‘It will be very important if our community is well informed about taking care of their impaired children in terms of where to go for any assistance, where to apply for schooling.’’* It appears that the availability of information is vital for families with impairment to effectively function in their duty of care. Furthermore, support through information may provide them with a spirit of confidence and hope for better prospect of their children’s

welfare. As such, it is suggested that deliberate plans should be put in place to educate the community about the placement procedures of their children.

The sixth suggestion was that relevant ministries should inform parents about the services of psychologists. Yet another parent (mother) said: *“People should be informed of services of psychologists, who can help our intellectually impaired children. I think the Ministry of Health and the Ministry of Education should give the information to the community so that parents and guardians know what to do with their impaired children, not only to sit with their children at home.”* This finding suggests that it is not enough to provide information about service providers for such parents; instead, for them to become effective in their duty of care they should be able to access the help. Then parents could feel a greater sense of control over their children. It appears that there is a lack of awareness in the community regarding service providers. It is, therefore, recommended that programmes should be implemented in order to enable parents to participate in community-based rehabilitation. This would provide them with greater management skills to care of their children.

The seventh suggestion was that medical staff must be sympathetic to families with impaired children and should refer them to therapists. One mother declared: *“Medical staff must be sympathetic as they should know how to talk to people. Children with impairment should be taken to a therapist.”* These findings are consistent with the findings by Glidden et al. (2006) who stated that it is useful to get as much help as one can from professionals and other service providers, which at

times turn out to be difficult. Thus, families need professional advice from the appropriate specialist services. The findings suggest that parents and guardians had contact with a number of professionals who could have handled them differently. Perhaps, professionals did not show empathy when dealing with such parents. However, parents still seem to have confidence in professionals so much so that the assistance given to them not only eases the problem but they also regard it as cure in itself. The fact that, parents and guardians are in constant interaction with professionals implies that they are coping through obtaining scientific solutions. In conclusion, medical professionals should be sympathetic when dealing with families of impaired children.

5.4.11 Discussion on Strategies for Improvement in Education for Intellectually Impaired Children

The findings suggest five coping strategies for improvement in education for the care of impaired children. These include: enrolment of impaired children at special centres, introduction of therapy lessons in special centres; giving of feedback to the parents by these special centres on performance of their children, building of more centres for intellectually impaired children by government who should also devise programmes to accommodate impaired children after the age of 18 years when they leave school. The five strategies that emerged from the findings of this study had the same value of one fifth (20%) of the respondents and need to be looked into further.

The first suggestion was that of enrolling impaired children into special centres. One parent (grandmother) said: *‘Parents must take children with impairments to special*

centres.” It appears that impaired children typically require a supportive environment where the capabilities of an individual can be developed and maximised. It is evident that programmes aimed at counteracting the potential development delay associated with child’ impairment should be set up in these special centres. In addition, enrolling an impaired child at such a centre offers relief to parents and guardians and hence enables them to cope better. Since parents and guardians acknowledged the importance of special centres, there is need for the government to construct at least one special centre in each region.

The second suggestion was that of introducing therapy lessons in special centres. Another parent (father) said: “*Centres for intellectual impairment children must introduce therapy lessons to help the children with physical exercises.*” This finding suggests that parents and guardians would make use of practical interventions to help them to cope. Therapists might want to concentrate on the families coping process by encouraging and supporting positive outlook on their life. In addition, the interaction that parents had with medical professionals could influence acceptance of their child. Furthermore, concern was about the absence of therapy infers that parents need specialised programmes to concentrate on physical abilities of their children to enhance their life-long skills, thus, providing parents with a sense of relief and the ability to manage their children better. It is, therefore, suggested that courses on family therapy should be introduced in order to establish a situation of self-help for the parents.

The third suggestion was that of special centres to give feedback on the performance of children to parents. A parent (father) said: *“The schools, mostly special schools should involve the parents in a sense of informing the parents of the child’s school work and behaviour. We are not aware of what she (our daughter) learns at school.”*

Although, parents and guardians understand that their children are impaired, they still bemoan the absence of regular feedback the progress of their children. Whatever performance is registered by their children the parents need to be kept informed in order to enable them to explore further ways of assisting their children. Therefore, the special schools should provide regular feedback on the progress of their children.

The fourth suggestion was that of government to build more centres for intellectually impaired children. Yet another parent (mother) recommended that: *“The government should help constructing centres country wide that can cater for intellectually impaired children’s needs. And these centres need to have trained staff members.”*

Evidently, the indication is that the current number of special centres in the country is inadequate to accommodate such children. It implies that the parents view education as an important investment for their children. In addition, the care and training provided at such centres embraces life-long skills for their children and hence gives parents a sense of hope for their children’s future. It is suggested, therefore, that the government should build more centres for intellectually impaired children.

The fifth suggestion was the need for government to come up with programmes to accommodate impaired children after 18 years when they leave school. Again,

another parent (mother) stated: *“The concern is for the Ministry of Education to come up with programmes that will accommodate children once they are out of these two centres when they turn 18 years of age. Normally, these children are only sitting at home. In the end, knowledge and skills learned in schools will be wasted.”* These findings are line with the findings by Cunningham (1996) who reported that professional services may be needed to support both the family, and to provide the information and skills to enable the informal network to help. This was further supported Gupta and Singhal (2004) when they stated that the extent and type of needs may differ widely from one family to the other within the life cycle of the same family. Such needs may range from needs for information, counselling or advice, to needs for specific services.

This finding shows the concern by parents and guardians for their child’s future. They felt that a provision needed to be made in order to cater for their children after leaving school. It implies that they understood the realistic challenge their children face and hence, the need to ensure that the future prospects of their children are assured. In addition, fostering independence of their children meant relieving other family members from having to provide full time care in the future. Thus, such a situation enables parents to cope well. It is suggested that the government should establish more centres that will provide life-long skills for impaired children after the age of 18.

5.4.12 Summary

This chapter discussed the results of the study in a detailed manner, in order to confirm the research questions. Indeed, the discussion identified the types of stress, the causes of stress, the impact and coping strategies used by families with intellectually impaired children. Accordingly, the discussion then formed the basis of the recommendations and conclusions.

5.6 RECOMMENDATIONS

The study was concerned with the issue of stress in families of children with intellectual impairment. It sought to explore and describe the types of stress experienced by families of intellectually impaired children, identify the causes of stress in those families, determine the impact that children living with intellectual impairment have on their families and suggest coping strategies for use by such families. The following recommendations were made with respect to the findings:

Types of stress

- The disclosure of the condition of the impaired child should be given to the parents or guardian immediately after birth.
- Parents and guardians should have access to services providers such as psychologists and counsellors who can provide empathetic and practical assistance to take them through the phases of reactions (primary, secondary and tertiary) to their children's impairment.

- Educational awareness should be undertaken to sensitise the community about the need to understand challenges facing families with impaired children.
- The government must increase the levels of social grants to impaired children in order to alleviate the challenges faced by their families.
- Families with a child who suffers from intellectual impairment need spiritual assistance in order to deal with the care of their children.

Causes of stress

- Parents and guardians need financial assistance in order to alleviate the challenge they face in the care of their children. Special focus should be placed on the government, the community and other stakeholders as possible sources of funds.

Impact on relationships

- It is recommended that families with impaired children should strengthen their understanding of the condition of such children and their sense of togetherness (unity) when caring for their children.
- Attempts should be made to build awareness among the community about the various aspects of challenges of impairment ranging from their dealing with the impaired child at home, his/.her education and rehabilitation at large.

Coping strategies

- There is need for individuals, government and organisations to actively support families of children with intellectual impairment. Focus should be placed on such support as financial, spiritual and professional services from medical doctors, therapists and counsellors.

- The government should enhance the implementation of its educational policies in order to provide access to education for intellectually impaired children.
- The government should construct more special centres with adequate equipment and professional staff.
- There is need for non-governmental organisations to design and implement stress-relief or management programmes in indigenous languages for family members of those families with children suffering from intellectual impairment.

Further research could be conducted on the support and care being provided for children suffering from intellectual impairment.

5.7 CONCLUSIONS

The objective of this study was to investigate stress in families with intellectually impaired children at Dagbreek and Môreson Centres in the Khomas Education Region. The overall findings of the study indicate that parents and guardians of intellectually impaired children suffered stress at different levels.

- Most of the parents and guardians were disappointed when they first realised that their children had an intellectual impairment. Some of the reasons given were late diagnosis of the impairment and mere denial of the reality.
- The majority of parents and guardians had difficulties with their intellectually impaired children in terms of the heavy demands of care. In some cases, the

situation was worsened by the existence of multiple medical problems and the fact that most parents were unemployed.

- Parents and guardians noted discrimination or stigmatising practices from members of the community through negative comments and behaviour towards the intellectually impaired children.
- The findings further revealed that parents and guardians indeed require spiritual support from the church and social support from their extended family, friends, relatives and employers.
- Finally, the majority of parents and guardians cited a number of strategies that could improve the welfare of families with intellectually impaired children. These strategies include increasing awareness about the plight of intellectually impaired children, the need for funding and construction of more centres for such children.

It is evident from the above findings that parents and guardians are stressed because of the burden of care they carry in looking after their children. However, it should be pointed out those parents and guardians are stressed at different levels, largely because of different personalities and different access to resources, whether social, financial or spiritual. The researcher recommends that government and non-governmental organisations should intervene in order to assist parents and guardians to care for their children.

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APPENDICES

APPENDIX A: INTERVIEW SCHEDULE FOR PARENTS OR GUARDIANS

Instructions for the respondents

Families are the foundation of a child's development, socialization, and formation of his/her values and beliefs. In addition, families are the source of great happiness as well as stress. No family regardless of race, ethnicity, or socioeconomic status is immune to any impairment; yet almost all are poorly prepared to cope with its occurrence. Parents do a lot of additional care for their impaired children. I am very much interested in your experiences in caring for your impaired child. As such, I have a number of questions to ask you.

Interview Questions

1. Tell me how you felt when you first found out that your child is intellectually impaired?
2. What were some of the difficulties and disappointments you experienced after having dealt with the reality that your child is intellectually impaired? If so, what types of stress do you experience?
3. What are your daily concerns in bringing up your intellectually impaired child in terms of physical care, medical care and schooling?
4. What in your opinion are the major causes of stress in your family, in terms of the financial implications of having an intellectually impaired child?
5. Have you experienced any problems relating to discrimination towards the impaired child? If so, from whom?
6. In what ways do having an intellectually impaired child affect the relationship between you as couples, among siblings and the extended families?

7. How do you cope with your intellectually impaired child in as far as provision of the physical care, medical care and schooling demands are concerned?
8. Who do you turn to for social and spiritual support of your child?
9. What would you say could improve difficulties experienced by families with intellectually impaired children?

Thank you for your time and information.

APPENDIX B: REQUEST FOR PERMISSION**UNIVERSITY OF NAMIBIA**

Private Bag 13301, 340 Mandume Ndemufayo Avenue, Pionierspark, Windhoek, Namibia



27 October 2010

To

The Permanent Secretary
 Ministry of Education
 P/Bag 13186
 Windhoek

Dear Sir/Madam

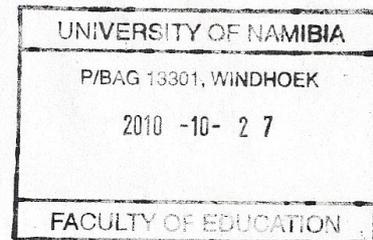
RE: Request for permission to conduct educational research study at Dagbreek & Moreson centres in the Khomas region

This letter serves to inform your office that Ms. Aina Simson (Student No: 8715653), is a registered Masters student at the University of Namibia this year 2010. Part of the university requirement is that the student must do research in his/her area of interest. Her topic is "*Stress in families of children with intellectual impairment at Dagbreek and Morison centres in the Khomas region*". She needs to start collecting the data from these centres as soon as possible. In light of this, please grant her permission to collect the data as required.

Thank you very much for your co-operation in this regard.

Yours truly,

Dr HM Kapenda
 Co-supervisor
 Lecturer Faculty of Education, UNAM



P O Box 25976
Windhoek
Tel: 061-237848
26 October 2010

The Permanent Secretary
Ministry of Education
Private Bag 13186
Windhoek

Dear Sir

**RE: REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY
AT DAGBREEK AND MÔRESON CENTRES.**

I am an M. Ed student at the University of Namibia and am intending to conduct an educational research for my thesis in order to fulfil the M. Ed requirements. The proposed study at Dagbreek and Môreson Centres will take place from the beginning to the end of November 2010.

My research topic aims at investigating stress in families of intellectually impaired children, types of stress, causes, impact and the coping strategies used by families. Face- to- face interviews will be conducted with selected parents / guardians of children attending school at the above centres.

Information collected through the interview will remain confidential and will only be used for the purpose of this research study. It is hoped that the findings of this study will provide valuable information to the Ministry of Education, schools, parents and other stakeholders. Accordingly, upon completion of the research study, a copy of the research findings will be given to the Ministry.

My supervisors are:

Dr A. D. Möwes (Tel 061 – 2063258)

Dr D. D. Zealand (Tel 061 – 2063020)

Your assistance in this regard would be greatly appreciated.

Yours sincerely

.....
Aina Simson
M. Ed Student: Faculty of Education

University of Namibia (Cell: 081 245 7456)

APPENDIX C: APPROVAL FOR RESEARCH STUDY



REPUBLIC OF NAMIBIA

MINISTRY OF EDUCATION

PROGRAMMES AND QUALITY ASSURANCE

Tel: 264 61 2933200

Fax: 264 61 2933922

E-mail: mshimho@mec.gov.na

Enquiries: MN Shimhopileni

File: 11/1/1

Private Bag 13186

Windhoek

NAMIBIA

23 November 2010

Ms Aina Simson
P. O. Box 25976
WINDHOEK
NAMIBIA

RE: REQUEST TO CONDUCT A RESEARCH AT DAGBREEK AND MORESON CENTRES IN KHOMAS REGION

Your letter, dated 26 October 2010, requesting permission to conduct a research at the two centres in Khomas Region, has reference.

Kindly be informed that the Ministry of Education does not have any objection to your request to carry out research activities at the centres referred to above.

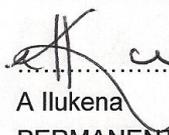
Nonetheless, you are advised to approach the Regional Council Office, Directorate of Education, for permission to visit the identified centres.

It is important to ensure that participation in the research activity is on a voluntary basis.

Kindly take note also that the research program should not interfere with the normal school programmes.

By copy of this letter the Regional Council Office, Directorate of Education, is made aware of your request.

Yours faithfully


A Ilukena
PERMANENT SECRETARY



cc: Director: Khomas Education Directorate



**REPUBLIC OF NAMIBIA
KHOMAS REGIONAL COUNCIL
DIRECTORATE OF EDUCATION**

Tel: [09 264 61] 293 4223
Fax: [09 264 61] 231 367

Private Bag 13236
WINDHOEK

Enquiries: Ms A. Sam
TEL: 061-2934223

14 June 2011

Ms Aina Simson
P.O. Box 25976
Windhoek
Namibia

Dear Ms Simson

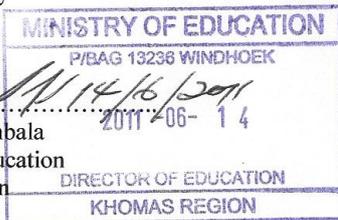
**RE: REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY AT
DAGBREEK AND MÔRESON CENTRES**

Your letter, dated 27 May 2011 is hereby acknowledged. You are hereby granted permission to conduct your research study in the two schools. During your research study, it is required that there will be no interruption of the normal school programmes. Parents' participation should be voluntary.

We are looking forward to receiving a copy of your research findings. I wish you the best of luck.

Yours faithfully

.....
Mr. J.S. Udjombala
Director of Education
Khomas Region



APPENDIX D: INFORMED CONSENT FORM**UNIVERSITY OF NAMIBIA****CONSENT TO PARTICIPATE IN RESEARCH**

Stress in families of children with intellectual impairment at Dagbreek and Môreson Centres in the Khomas Education Region of Namibia.

Parent

You are asked to participate in a research study conducted by Aina Simson, M Ed Student from the Department of Educational Psychology and Inclusive education at the University of Namibia. The results of the study will contribute to a thesis for the degree. You were selected to participate in the interview of this study because you were one of the family members of a child with an intellectual impairment at Dagbreek / Môreson Centres.

PURPOSE OF THE STUDY

The aim of the study is to find out how families cope on a daily basis and to provide useful information that could assist the improvement in the lives of families with intellectually impaired children.

PROCEDURES

The information obtained will be used in the thesis without disclosure of the participants' identity. All information obtained in this study will remain confidential.

POTENTIAL RISKS AND DISCOMFORTS

It will be expected of you to answer the questions asked honestly. Pointing out aspects that contribute to stress might cause some discomfort.

POTENTIAL BENEFITS TO PARTICIPANTS AND TO SOCIETY

It is hoped that the welfare of intellectually impaired children will improve as specialist equipment and therapy will be provided to families of intellectually

impaired children. Furthermore, it is also hoped that the results will help the professionals to understand the interaction of variables related to family adaptation, the nature of the stresses, and the successful coping strategies used by families with intellectually impaired children.

PAYMENT FOR PARTICIPATION

There will be no payment for the participation.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with permission or as required by law. Confidentiality will be maintained by using pseudo names and by describing the information with care so that you will not be identifiable. I will store the information in a safe place. Besides myself, only my study leaders will have access to the information.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in the study or not. If you choose to be in the study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Aina Simson at 081 245 7456/ 081 3133 011.

Email: ainasimson@gmail.com

Home address: Karlien Hof Hostel at Windhoek High School, Windhoek.

You can also contact my supervisors:

Dr A.D. Möwes

Dr D.D. Zealand

Faculty of Education

Department of Inclusive Education

Private Bag 13301

Windhoek

NAMIBIA

Tel: 264-61-2063258/2063230

amowes@unam.na/dzealand@unam.na

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this study.

SIGNATURE OF RESEARCH PARTICIPANT

The information above was described to me by Aina Simson in English and I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ She /he was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

Signature of Investigator

Date