COPING SKILLS FOR PARENTS OF CHILDREN WITH BARRIERS TO LEARNING

by

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DECLARATION

I hereby declare that the thesis titled "Coping skills for parents of children with barriers to learning" is a product of my own efforts and furthermore that all sources used or quoted are completely referred to and acknowledged.

SUMMARY

Past research has shown that one of the most traumatic emotional experiences parents face is the diagnosis of having a child with barriers to learning. For various reasons they do not always receive the necessary follow-up professional support after diagnosis.

This study was undertaken with the specific aims of identifying various coping skills that enable these parents to raise their children to their full potential, to determine the value of these coping skills for parents, to identify strengths, weaknesses, opportunities and threats in such households and to make recommendations on appropriate approaches and strategies.

The study revealed that parents are able to make changes in their approach and behaviour to adapt to the new stressful environment. Restraining factors having a negative impact on the functioning of parents or families have been identified, together with identification of various opportunities and driving forces that serve as the foundation for mitigating, accepting and dealing with the problem. Based on these findings, recommendations are made to provide guidelines to advise and support parents in raising children with barriers to learning.

KEYTERMS

Barriers to learning; Single-parent families; Nuclear family; Parent; Mentally retarded; Epilepsy; Cerebral Palsy; Autism; Down's Syndrome

OPSOMMING

Een van die mees traumatiese ervaringe van ouers is die diagnose dat hul kind leergestremd is. Sodanige ouers het om verskeie redes nie die nodige professionele ondersteuning ontvang nadat die diagnose gemaak is nie.

Die spesifieke doelwitte van die studie was om die hanteringsvaardighede, wat sodanige ouers instaat sal stel om die kind tot sy volle potensiaal te laat ontwikkel, te identifiseer; die waarde van hierdie vaardighede te bepaal; die sterk punte, swakhede, geleenthede en bedreiginge wat die gesin se optrede bepaal uit te lig en om aanbevelings vir gepaste benaderings en strategieë te maak.

Die bevindinge toon dat ouers instaat is om gewensde veranderinge in hul benadering en gedrag te maak ten einde by die veeleisende omstandighede aan te pas. Faktore wat remmend en negatief op die ours/gesin se funksionering inwerk tesame met verskeie geleenthede en veranderingspositiewe kragte, is geïdentifiseer en dien as die basis vir verligting, aanvaarding en hantering van die probleem. Aanbevelings vir riglyne en advies aan geaffekteerde ouers is op hierdie bevindinge gebaseer.

AKNOWLEDGMENTS

LIST OF ABBREVIATIONS

STM	Short-term memory
LTM	Long-term memory
EEG	Electroencephalogram

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COPING SKILLS FOR PARENTS OF CHILDREN WITH BARRIERS TO LEARNING

CHAPTER 1: ORIENTATION

1.1 Background

> " Ek bid dat jy jou lewe lank sal onthou hoe spesiaal jy vir God is"
> Psalm 139:14

Parenting is something wonderful! Krause-Wiid (2002:23) stated in her book that a baby in a house offers a fountain of joy and that children are a gift from God. Parenting can also be a great frustration if things don't work according to someone's expectations (Darling 1979:17). The family has to come to terms with altered expectations for the child, an altered perspective for the future, and the cultural stigma which attaches to the label (Abbott & Sapsford 1988:47; Gargiulo 1985:13).

There are no rules for parents and no parent is perfect (Luyt 2004:20) – each parent does what he thinks is best for his children. If you are a happy parent, it is likely that you are happy in all other aspects of life i.e. marriage, work, sports, friends (Rose-jannes, *pers. comm*. 2005). "Die lewe is wat jou gedagtes daarvan maak. Dink vrolik!" (Marcus Aurelius) as cited by Smit (1999:20).

If parents don't have guidelines or a support group(s), they can get depressed, withdrawn from society, jump to wrong conclusions, or seek for help at the wrong places, persons or institutions (Kosky, Eshkevari & Carr 1991:41; Smit 1999:36).

The adjustment of a parent to a child with barriers to learning is not a well-researched topic and is inadequately covered in literature. In a complex society like ours, which places such a high premium on features like intelligence, the realization that a child has barriers to learning can be a huge disappointment to parents (Kruger 2004:102). Research proved that one of the most traumatic emotional experiences a couple or an individual could ever face is the diagnosis of such a child. The revealing of such news could be even more devastating for a single parent than for couples (Heaton-Ward & Wiley 1984:7).

When working with parents of children with barriers to learning, it is always inspiring to see that some of them integrate such a child as a significant part of the family. It is typical for expecting parents to proudly send out birth announcements pertaining to the new family member. Usually, these announcements are full of excitement and expectation. But how do such unfortunate parents convey to other people that their newborn is exceptional? Most of the time, this information is carefully disguised or withheld because of the perceived negative biological and psychological associations of people to these problems (Heaton-Ward & Wiley 1984:9).

1.2 Analysis of the problem

1.2.1 Awareness of the problem

There were two significant incidents in the life of the researcher that inspired her to explore this field. Firstly, an employee of the researcher complained of her child being slow, but strongly denied the possibility of him being learning-disabled. Any possibility of mental retardation was vehemently opposed. The child did not show progress at all during his pre-primary year and unfortunately he was forced by his mother to go to Grade 1. School readiness evaluations together with psychometric evaluations pointed out that this seven-year old boy functioned on a three-year old level with the possibility of being mentally retarded. The child therefore was in dire need of special education at a special educational institution. The response of the mother was one of absolute shock and she refused to take him to a special school (Penderis, *pers. comm.* 2003). Despite a second opinion, with the same results, she enrolled him in a mainstream school. Needless to say, he failed Grade 1 at the end of 2004 and was placed in the special class. Again he was recommended by the school for special education at a school that caters specifically for children with mild and severe barriers to learning (Penderis, *pers. comm.* 2004).

The researcher was very interested in the different stages that the mother immediately went through. Other aspects of her life were also tumbling apart. She and her husband seemed to disagree on this matter. He supported the special education programme. Eventually their marriage seemed to take a huge dip (Penderis, *pers. comm.* October 2003). This is in line with the view of Abbott & Sapsford (1988:49) that the relationship between husband and wife may well deteriorate. The researcher desperately wanted to support them, but lacked the wisdom to do so.

The second event emerged with the birth of the researcher's first child. "My husband and I were so excited about having a child and we had such a lot of dreams for this child. We were feeling so complete and untouchable. But then the burdensome questions started to conquer us: What if we were to face the news that she has barriers to learning? What would my reactions be; what will I feel or do; how will I deal with similar news? Where would we go for help? Who will we trust with all our inner emotions and hurtful feelings? Will our friends still accept us? Will we have the courage to face society? How will people treat us if this happens to us?"

Following all these concerns the researcher decided to investigate the coping abilities of parents and to make recommendations on how to support such parents.

1.2.2 Investigation of the problem

Existing literature on barriers to learning focuses entirely on the problems faced by the individual and ignores the very different but equally serious problems faced by the parents and siblings of the exceptional child. Anything that happens to the child with barriers to learning or any special alterations that are made or denied will also affect the immediate family (Seligman & Darling 1989:7). Other members of the family and the

dynamics that are interlinked must be taken into account whenever a plan or treatment or management strategy is considered (Kennedy 2000:165). The client should not only be the child with barriers to learning but the client's entire family (van der Merwe & le Roux 2003). The approach should be to provide services on a family basis rather than simply to the one individual presenting problems (Seligman & Darling 1989:7).

According to Lougher (2001:88) the family was seen as the "system" and each family member was viewed as an equally important part of this system. This is a positive trend in many respects, but it also carries with it the negative connotation of treating the entire family as if there is something wrong with them. In one of the researcher's case studies a parent complained that psychologists, psychiatrists, physicians and social workers often seem to assume that a parent of a child with barriers to learning has psychological reactions which need treatment (Rose-jannes, *pers. comm.* January 2005). Somehow, according to her, it is automatically assumed that the family is in need and requires help, whether this help was asked for or not. She further claims that parents are often described as people with a guilt complex, who feel sorry for themselves, cannot justify themselves and who are incapable of raising their child properly (Rose-jannes, *pers. comm.* January 2005).

As most of the family dynamics are affected by the child with barriers to learning, family members should be able to adjust their attitudes and approach in order to mitigate the impact of the problem on the entire family (Hodapp, Burack & Zigler 1990:306-307).

It must be kept in mind that the parents of children with barriers to learning are human beings and that people differ (Seligman & Darling 1989:35). Some are mentally healthy, well-adjusted, and functioning at an effective level, while others may be poorly adjusted, some even before the birth of their exceptional child. For obvious reasons, their reactions to their child with barriers to learning are going to be tailored by their own personalities and attitudes (Heaton-Ward & Wiley 1984:7).

Researchers like Gargiulo (1985:22-37), Seligman & Darling (1989:28), Lessing & Strydom 2001:5-13) and Fortinash & Worret (2003:351-355) found that family adaptation goes through different stages. The three stages are shortly described:

1. Primary phase, characterized by shock, then denial, and finally grief and depression.
2. Secondary phase, marked by ambivalence, followed by guilt, then anger, shame, and embarrassment;
3. Tertiary phase, beginning with bargaining, then adaptation and reorganization, and finally acceptance and adjustment.

1.2.3 Statement of the problem

Five types of coping resources can moderate the effect of stress. At the clinical level, experienced physicians and patients have long felt that illness seems to occur after stressful life events (Butler & Corner 1984:2). Furthermore, these resources may help

families cope with the stress that may arise in adapting to a family member with barriers to learning. They can be summarized as follows:

The physical and mental health of a family member (i.e. parent) may help the individual to cope with the stress of care-taking, behaviour management, school conferences etc. that are required with a child with barriers to learning (Lougher 2001:5-8).

1. Problem-solving skills, including the ability to search for and analyze information and generate various courses of action, can help the family member in either a crisis or a long-term problem situation (i.e. the child is approaching 21 and will finish school) (Lougher 2001:6).
2. Social networks of supportive relationships can help families maintain community involvement and cope with problems (Mittler & McConachie 1983:117). While the presence of a person with barriers to learning does require family adjustment, the process is an evolving one influenced by many factors besides the parent and child (i.e. financial resources, educational opportunities and social support) (Kennedy 2000:144-148). Byrne (1988:88) states that each family member has relationships with people outside the immediate family. These may be relatives, close friends, neighbours, acquaintances, colleagues at work, other members of clubs and institutions to which the family member belongs and other people seen regularly. All of these people constitute the family member's social network.
3. Utilization of resources such as income is directly linked to family adaptation (Seligman & Darling 1989:53).
4. Personal beliefs that serve as a coping resource for the individual including feelings of self-efficacy and their religious faith (Fortinash & Worret 2003:357).

Individuals, their biological systems and groups of people all vary in their capacity to respond to challenge and therefore in their abilities to adapt (Butler & Corner 1984:117).

The researcher would like to look at adaptations to the family's coping resources. A good approach to understanding family adaptation is to examine some potential phases and study how families may alleviate their stress during each phase. Another might be to teach new skills to the parents of the child with barriers to learning, and to manage problem behaviours. Research shows that parents can be effective teachers to their child with barriers to learning and can change the child's socially inappropriate behaviours. Siblings also can be effective teachers. Helping a child with barriers to learning to acquire new skills may make family life more pleasant (Kosky *et al.* 1991:83).

In conclusion, the coping skills that parents use to bridge or mitigate the problem of caring for and living with a child with barriers to learning are inadequately covered in literature and further research is needed to provide affected parents with practical guidelines. The influence of these resources is hypothetical and future research with families should evaluate their impact.

1.3   Aims of the research

1.3.1 General aim

The range of reactions expressed by parents of handicapped children reflects the difficulties they confront in attempting to meet their own needs and those of their children (Garguilo 1985:13-14). Society has charged parents with the responsibility of raising handsome, healthy, intelligent, and socially acceptable children.

Parents as patients operate under considerable stress. Psychological treatment regimes are unlikely to succeed if they do not provide the parents with other benefits such as:
a) An understanding of the nature of mental retardation; and
b) Information to help them identify and meet the needs of the children.
Helping the parent to deal effectively with his emotions and grief is also very important (Abbott & Sapsford 1988:75).

Unfortunately, parents of children with barriers to learning have not always received the help they need from professionals. They deal with parents in an unproductive and pejorative manner (Darling 1979:23; Seligman & Darling 1989:214). Parents frequently have difficulty in receiving a correct diagnosis from professionals. Parents may already suspect barriers to learning and the receiving of the correct diagnosis can be very emotional. Medical professionals are aware of the parents' anxieties and still they do not always attempt to reduce their anxieties (Seligman & Darling 1989:218). Therefore, relationships between professionals and parents can be designed with cooperation and coordination in mind.

The general aim of the present research therefore is to propose an approach through which parents of children with barriers to learning could be exposed to improved or alternative options of professional services and support in order to meet the demand of raising them.

1.3.2 Specific aim

The researcher's aim would be to focus on parents: their feelings, emotions and the psychological fight inside their minds. The researcher wants to support them in their struggle they have to undergo. All the feelings of incompetence, low self-esteem, guilt etc. must be used to arrive at the bigger picture.

Against this background **the specific aims** are:
1. To identify the various coping skills that will enable parents with children with barriers to learning to raise their children to their full potential;
2. To determine the role of these coping skills in the lives of parents;
3. To identify strengths, weaknesses, opportunities and threats in such households and
4. To recommend future approaches and strategies based on these findings.

Specific aims will be achieved through:

1. Literature study
2. In-depth interviews
3. Informal and telephonic interviews
4. Questionnaires
5. Field observations
6. Official documents
7. Personal documents

1.4   Research methods

For the purpose of this study, a qualitative approach, where data is collected in the form of words and pictures, is used. The data collection techniques used are mostly field research.

Case studies were conducted on a small group of people for a certain period of time. The field research began with a loosely formulated idea or topic. From this point, the researcher selected a social group or site for study. Once the researcher gained access to the group, the researcher adopted a social role in the setting and began observing. The researcher observed and interacted in the field setting for an unknown period of time. The researcher got to know the people being studied personally and conducted informal interviews and different sets of questionnaires. Detailed notes and transcribed interviews were taken. Most of the interview took place at the parents' home or a place convenient to them. Sometimes the interviews were restricted only to the parents and sometimes open for the whole family to interact. The idea of the interviews was to be informal, tailored to the interviewee and open ended (i.e. without a fixed set of questions or answer categories). The researcher asked permission to use a tape recorder for transcribing reasons. Permission was also asked to use quotes. After the interview the researcher reread her notes, wrote reports and compared the literature study to the field research.

1.5   Demarcation of the research

The research was conducted in Windhoek, the capital city of Namibia. Samples were taken from the two schools for children with barriers to learning of the National Institution for Special Education, which are Môreson and Dagbreek. Samples consisted of nuclear families, single parents and divorced parents (mainly mothers) and reconstituted families.

Samples for this research were more specifically postnatal trauma (resulting from an accident), chromosome abnormalities (Down's Syndrome), epilepsy, cerebral palsy and autism.

1.6   Clarification of concepts

The problem of terminology must be addressed. Throughout this research, children with barriers to learning are described in accordance with current systems of classification. This terminology helps with consistency and prevents using terms such as *fool, idiot, imbecile, moron, feebleminded and mental defective,* which are also offensive (Wikipedia 2005:3). The terminology used to describe the lower end of the range of intellectual and cognitive difference has changed over time and continues to vary in different countries and contexts (Engelbrecht & Green 2001:191).

Terms and concepts used throughout this research will now be described.

Barriers to learning – this is a broad term that encompasses a variety of conditions whose defining characteristic is a significant impairment of intellectual functioning (Bennet 2003:303).

Single-parent families – Single-parent homes in which a woman is the sole head of the household. Although the majority of these children were left in the custody of their mothers by the courts in divorce proceedings, other children have been abandoned by their fathers. Among black families with one or more children under 18, almost 48 percent are headed by women with no spouse present (Sadock & Sadock 2003:45; Kaplan & Sadock 1997:50).

Nuclear family – This is a family consisting of the child's biological mother and biological father, with or without other siblings from the parents. Byrne, Cunningham and Sloper (1988:4) say a family is a system in which all of the elements interact with and influence all other elements. The "whole is more than the sum of the parts" in that the family has properties of its own over and above those of its individual members.

Parent – It is normally an adult who is responsible for a young child who is still dependent on him/her.

Mentally retarded – "mental retardation is defined as "significant limitations in adaptive functioning," with an onset before the age of 18. Impaired functioning must accompany intellectual functioning, as assessed by a standard intelligence test, at an IQ of around 70, but environmental, physical, and other factors influencing both adaptive and intellectual functioning must be taken into account. DSM-IV allows for four grades of severity: mild, moderate, severe, and profound mental retardation. Mental retardation consists of a combination of below-average intellectual functioning and impairment in adaptive skills that manifest itself prior to the age of 18 years." (Sadock & Sadock 2003: 1161 –1162; Kaplan & Sadock 1997:1137; Fortinash 2003:209-210).

Epilepsy – The word 'epilepsy' comes from the Greek word for 'seizures'. It is an altered chemical state of the brain causing bursts of excessive electrical activity (Engelbrecht & Green 2001: 125).

Cerebral Palsy – It is defined as a motor impairment such as paralysis, weakness, or in coordination that results from a brain dysfunction. Cerebral palsy is not a single handicap but is a general term encompassing a variety of symptoms (Kapp 2003:277).

Autism – It is characterized by a failure to develop the ability to make sense of the world, communication problems and bizarre and asocial behaviour. Many people who are autistic also have other learning difficulties, but display exceptional talent in performance of specific tasks such as feats of memory or performance skills like fitting and assembly tasks. The syndrome tends to develop in early childhood (Fortinash & Worret 2003:211-212; Sue, Sue & Sue 2003:495; Ellis 1996).

Down's Syndrome – Down syndrome occurs in approximately 1 out of every 600 live births. Down syndrome arises from an abnormality on chromosome 21. Chromosome pair 21 is the smallest of the 23 human chromosome pairs, possessing only about 1,5% of the total genetic material. (Bennet 2003:306; Cicchetti & Beeghly 1995:ix).

1.7   Research programme

In Chapter 2 a broad literature study is done on the different conditions mentioned above. Their causes and biological features are defined. Authoritative sources were selected and consulted on the relevant topic of research. The primary sources (the parents) were consulted and the findings of the initial case study verified. Where possible, the relationship between the literature and the central topic is stated. Arguments and viewpoints were accurately, critically, systematically and logically consolidated, to the best of the researcher's ability.

Chapter 3 describes the qualitative investigation that was used. The correct ethics were followed with regard to confidentiality, the interviews and the questionnaires. The appropriate selection of data collection and the substantiating of methods is also discussed. The population is defined and the sampling methods indicated. The method of participant selection is also discussed. The researcher prioritizes the account for validity and reliability or trustworthiness. The selection of appropriate data analysis techniques is clearly described. The researcher intended to interpret narrative data accurately and comprehensively.

In Chapter 4 the case study is discussed. The main trends in the data i.e. the emotional reactions and coping skills are identified and interpreted. The researcher provides a substantial foundation for conclusions. The limitations of the study are highlighted and feasible recommendations for improved practice are made. Possible areas for future research are indicated. The chapter ends off with a meaningful summary of the study.

In Chapter 5 final recommendations and guidelines are discussed and highlighted.

1.8 Summary

Many people are becoming interested in the problems faced by families with children with barriers to learning. According to Darling (1979:13) the interest in a sociological perspective on birth defects is wide-ranging, and many are ready to accept a view that challenges the traditional, victim-blaming concept of birth defects as an individual problem of adjustment. However, more research is still needed and should thus be encouraged. Along with this, it must be kept in mind that certain future problems, like demographic changes, can occur. More teenage mothers, single parents and working mothers are at present already experiencing a huge problem. Therefore it is important to study the family structure, rather than focusing on one member in isolation from the family.

As already mentioned, not much reliable research on this topic has been done, but we do know that the parents of a child diagnosed with barriers to learning are apt to have a range of emotional reactions (Darling 1979:57). We should work towards a more caring professional, who should be realistic yet positive in presenting a diagnosis and helping parents face the future. Great help can be given to the family by steering them toward various formal and informal sources of support. Educators can also help the parents by cooperating in the child's educational programmes (Mittler & McConachie 1983:141-152).

CHAPTER 2

LITERATURE RESEARCH: BARRIERS TO LEARNING

2.1 What are "barriers to learning"?

2.1.1 Definition

"Barriers to learning" is a broad term that encompasses a variety of conditions whose defining characteristic is a significant impairment of intellectual functioning (Bennet 2003:303). Throughout this research all children with intellectual deficits, however profound, will be referred to as having "barriers to learning" (Bennet 2003:303).

Because of the legal status of the label "barriers to learning" (Kellerman 2002:1), it is important that barriers to learning be defined clearly, reliably, and in such a way that all people who could benefit from special programming for the retarded be included, but excluding those people for whom the potential harm resulting from being so labelled would outweigh the benefits.

Traditional attempts to define barriers to learning can be placed roughly into three categories, a) definitions based on intelligence test scores, b) definitions based on a failure of social performance, and c) definitions based on the cause or essential nature of barriers to learning, such as traumatic brain injury (AAMR 2005:1; Bennet 2003:304; Silka & Hauser 1997:1). Although barriers to learning is classified as an axis II disorder in DSM-IV, it is not considered a mental illness as such, with its own unique signs and symptoms. It is a term for identifying groups of people who need social support and special educational services to carry out tasks of everyday living (Sebastian 2002:2).

Every once in a while, someone questions the use of the term mental retardation (Kellerman 2002:1). Kellerman (2002:3) summarized the article by the Surgeon General's Report on Health Disparities and Mental Retardation (February 2002): "The Office of the Surgeon General is aware that there is a controversy around the use of the term 'mental retardation' and that self-advocacy groups and professional associations are currently discussing various alternatives such as 'cognitive developmental disabilities' and 'intellectual disabilities'. Until a consensus is reached, and with the goal of drawing attention to the great health disparities faced by people with what has been traditionally known as mental retardation in mind, the term 'mental retardation' will be used in official media information on the Surgeon General's initiative." Once again, for the purpose of this research and to minimize the prejudice often expressed in relation to this group of people (Bennet 2003:304) the term barriers to learning will be used.

For a person to be classified as having barriers to learning, three criteria must be met. First, there must be "significantly sub-average intellectual functioning" (Sadock & Sadock 2003: 1161; Kaplan & Sadock 1998:1139). In practice, this means that the person

must score at least two standard deviations below the norm for his or her age group on a standard intelligence test. The standard deviation indicates how far above or below the norm the subject's score is (Ford-Martin 2004:2). This means that the person's IQ must be below 70-75 on the Stanford-Binet or below 70 on one of the Wechsler Scales. In 1905, Alfred Binet and Theodore Simon devised a system for testing intelligence, with scoring based on standardized, average mental levels for various age groups (infoplease 2000:1).

However, a low IQ by itself does not define a barrier to learning. The individual must also show a deficit in adaptive behaviour (Silka & Hauser 1997:1). This criterion is somewhat more difficult to specify, but basically, what it means is that the individual's adjustment to the demands of his or her age-mates will not be met. Because there are different social expectations at different ages, deficits in adaptive behaviour will manifest themselves differently in younger children than they will in older children or adults (Abbott *et al.* 1988:73). For infants and preschoolers, adaptive behaviour may represent potential deficiencies in adaptive behaviour. For school-age children, adaptive behaviour deficits may be manifested by difficulties in the application of basic academic skills to daily life activities, or in the application of appropriate reasoning and judgment in the mastery of the environment, as well as by deficits in social skills (Seligman & Darling 1989:55-59). In late adolescence and adulthood, vocational performance and social responsibility become important, and thus, adaptive behaviour may be determined by the extent to which the individual is able to maintain himself or herself independently in the community (Sue *et al.* 2003: 481). An interdisciplinary team looks at the following adaptive skills in assessing a person's functioning level: communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics, community use, and work (Texas Adoption Resource Exchange 2005:1)

The deficit in adaptive behaviour and sub-average intellectual functioning must be manifested during the developmental period, which is from conception to age 18 (Sadock & Sadock 2003: 1161; Kaplan & Sadock 1998:1139). This means that barriers to learning is conceived as a developmental disorder. The individual who reaches adulthood after normal development can never be considered as having barriers to learning. Those people whose intellectual powers have deteriorated because of senility or traumatic brain injury in adulthood, are not classified as having barriers to learning, but can be categorized as having dementia (Sue *et al.* 2003:481).

Therefore, if an individual is to be considered retarded, all three of these criteria must be met (Fortinash & Worret 2003:209-210). There are many individuals who meet one or two of these criteria, but they do not have barriers to learning. For example, children from culturally deprived backgrounds frequently perform poorly on standardized intelligence tests, but they show little impairment in adaptive behaviour. They have no trouble learning the skills necessary for survival in their world. They are not delayed in basic maturational milestones such as the age at which they begin to speak or the age at which they learn to dress themselves. They have no unusual difficulty in learning their way around the neighbourhood or getting along with their peers. These children should not be considered as having barriers to learning (Wikipedia 2005:2).

2.1.2 Levels of barriers to learning

A system of diagnostic classification of the person having barriers to learning was developed based on the individual's level of functioning, principally the IQ. Individuals with IQ's between two and three standard deviations below normal are labelled having *mild learning difficulties*, those with IQ's between three and four standard deviations below normal are labelled with *moderate learning difficulties*, those with IQ's between four and five standard deviations below average are labelled with *severe learning difficulties* and those who score greater than five standard deviations below normal are labelled with *profound learning difficulties* (Smith 2003:2; Bennet 2003:304).

Table 2.1 below shows this system with IQ scores for the Wechsler and Binet tests adapted from Silka & Hauser (1997:2); Smith (2003:2); Sue *et al.* (2003:483); Bennet (2003:304) and Fortinash & Worret (2003:210)

Table 2.1. Levels of barriers to learning

Level	Binet IQ (s.d. = 16)	Wechsler IQ (s.d. = 15)	Mental Age at Adulthood
Mild	68 – 52	69 – 55	8.3 – 10.9 yr
Moderate	51 – 36	54 – 40	5.7 – 8.2 yr
Severe	35 – 20	39 - 25	3.2 – 5.6 yr
Profound	<19	<24	<3.1 yr

The last column shows the adult mental ages of each of the four levels. This gives a good indication of the expected level of functioning of an individual at various levels.

Bennet (2003:304) supported the following example:
- An adult with mild barriers to learning is usually capable of doing most of the things that a child from 8 to 11 years old is able to do such as reading, calculating to the third- to fifth-grade level, taking care of personal needs such as dressing and grooming with negligible assistance, holding down a simple job manifesting essentially normal coordination, and showing adequate social interaction (Heaton-Ward & Wiley 1984:69).
- An adult with moderate barriers to learning can be expected to function at the level of the average 5 to 8 years old. This person needs occasional assistance with personal care and grooming, can read only at a minimal level if at all, and probably cannot live independently, but could hold a job if special provision were made for the handicap as in a sheltered workshop (Heaton-Ward & Wiley 1984:69).
- An adult with severe barriers to learning would be functioning at the level of the average preschooler. While this person could look after basic bodily needs such as dressing, feeding and toileting and could probably communicate with simple language, he or she would certainly require considerable supervision throughout his or her life (Yule *et al.* 1980:143-160). This person would not be able to get around town independently, may have some coordination problems, and may not be able to hold a job even in a sheltered workshop.

- A person with profound barriers to learning has a mental age of less than three years at adulthood. Thus, many people with profound barriers to learning cannot even be expected to take care of basic bodily needs. Most are not fully toilet trained; many need assistance with dressing while some do not even feed themselves. This category also includes many bad cases that never even learn to walk. Language skills would be minimal (Bennet 2003:304; Hallas, Fraser & MacGillivra 1983:102-120; Heaton-Ward & Wiley 1984:69).

Other classification systems involve the categories of moron, imbecile, and idiot. A moron was an individual with an IQ of 50 to 75, an imbecile was a person with an IQ of 25 to 50, and an idiot was someone with an IQ of less than 25. These labels are no longer used because the terms have come to have degrading connotations (Wikipedia 2005:3-4). According to Mwamwenda (1996:439-441) educators classify children with barriers to learning into the categories of educable barriers to learning, trainable barriers to learning, and severe barriers to learning. The label educable barriers to learning correspond roughly to mild barriers to learning. Educable refers to the fact that these people can be taught basic academic skills such as reading, writing, and arithmetic. Trainable barriers to learning correspond roughly to moderate barriers to learning. Trainable children cannot ordinarily learn academic skills beyond a very basic level such as writing their name or reading MEN or WOMEN on bathroom doors, but they can be trained in basic self-care skills and simple vocational abilities (Hallas *et al.* 1983:93). People having severe and profound barriers to learning are also sometimes referred to as custodial or sub-trainable people because frequently they cannot even be taught basic self-care skills. They have traditionally been excluded from public schools (Lesotho Society of Mentally Handicapped Persons 2001:7).

2.1.3 Diagnosing barriers to learning

If barriers to learning are suspected, a comprehensive physical examination and medical history should be done immediately to discover any organic cause of symptoms (Smith 2003:1). Because barriers to learning are defined in behavioural terms, only a psychologist can technically make a proper diagnosis (Taylor 1997:33-50). In practice this is not always the case.

There are a number of different ways in which children are diagnosed with barriers to learning. If the barrier to learning is profound or if it is accompanied by obvious physical abnormalities or associated with a specific syndrome such as Down's syndrome, then the child may be diagnosed having barriers to learning by birth. However, diagnosis at birth is the exception (Seligman *et al.* 1989:39-40). Because so little in the way of adaptive behaviour is expected from a newborn, a child who will later be diagnosed as having severe barriers to learning may be considered normal for many months after birth. Severe barriers to learning is often diagnosed by delayed motor development and general apathy, but such gross motor skills as rolling over, sitting, and walking are often only slightly delayed in moderate barriers to learning and frequently not delayed at all in mild barriers to learning (The Medicare Family Health Guide 2004:1-2). Occasionally, the moderate level is not diagnosed until the child is two to four years old when the parents notice that

their child is not developing as rapidly as other children (Seligman *et al.* 1989:36-40). An important diagnostic clue is delayed language. Children who have more than mild barriers to learning almost always manifest some delay in the acquisition of language. The customary diagnostic procedure for moderate, severe or profound barriers to learning is that the parents will notice some peculiarity in their child and bring this to the attention of a physician, who will then normally refer the child to a specialist for further clarification. A psychologist will usually measure the child's mental development, and if there is any suspicion of neurological damage, various tests may be made (Seligman *et al.* 1989:40). According to Smith (2003:4) a complete medical, family, social, and educational history is compiled from existing medical and school records (if applicable) and from interviews with parents. Individuals who receive a diagnosis of having barriers to learning frequently suffer from additional mental disorders as well (Virginia Commission on Youth 2001:4).

However, many children with mild barriers to learning are not classified as such until they reach school age. The early development of many children with mild barriers to learning does not differ significantly from the normal (Bennet 2003:304). As previously mentioned, they can acquire practical and vocational skills, acquire reading and math skills up to Grade 3 to 6 level, and conform socially (Daily, Ardinger & Holmes 2000:2). Thus, the first suspicion of mild barriers to learning is usually made not by the parents but by the teacher. If a child is having unusual difficulties in school, the most frequent procedure is for the teacher, with the consent of the principal and the parents, to refer the child to the school psychologist for assessment. The school psychologist will normally administer a standard intelligence test and then determine whether the child has barriers to learning or not. The child may also be placed in a special class (Bennet 2003:308). Unfortunately, psychologists frequently rely solely on an intelligence test in determining barriers to learning, ignoring the child's adaptive behaviour. Arguments have been raised against the use of IQ scores (Sue *et al.* 2003:481-482). Tests have almost always been developed on and standardized on a population of normal children. Any child for whom traumatic brain injury, emotional disturbance, barriers to learning, or other abnormality is suspected is routinely dropped from the standardization sample. Therefore it is important to verify that the Wechsler and Stanford-Binet tests are as reliable and valid with children having barriers to learning and with other handicapped groups as they are with normal children. The Wechsler Intelligence Scales are a series of standardized tests used to evaluate cognitive abilities and intellectual abilities in children and adults (Ford-Martin 2004:1). In 1905, Alfred Binet and Theodore Simon devised a system for testing intelligence, with scoring based on standardized, average mental levels for various age groups (infoplease.com 2000:1). The Standford-Binet Intelligence test is an individually administered test that is quite often used as part of a larger diagnostic process such as the identification of a learning disability or as a screening procedure in a special educational placement (Royer 2004; Taylor 1997:13-15).

Various types of screening clinics are designed to provide a wide range of diagnostic procedures to children born at risk (i.e. children born to low-income families who do not ordinarily receive adequate medical attention). It would be advised that such clinics do the diagnosis of having barriers to learning and other developmental disabilities for free.

In Namibia these screening clinics are part of the Ministry of Health and Social Services' State Clinics. They generally administer a short developmental test and assess the child's vision and hearing, and do a complete physical examination. The purpose of these clinics is to detect any abnormalities of development as young as possible, because it is usually the case that the younger any disorder is discovered, the greater the probability that it can be effectively treated. Unfortunately, this is the theory, but falls far from practice in Namibia.

2.2 What is Traumatic Brain Injury?

2.2.1 Definition

The term traumatic brain injury refers to the physical destruction of brain tissue or brain cells resulting from inadequate oxygen supply, trauma or other cause (Random House Unabridged Dictionary 1997:1). Such nervous system damage has a wide variety of causes and thus there are numerous different types of traumatic brain injury. In other words brain trauma is a physical wound or injury to the brain – the greater the tissue damage, the more impaired the functioning (Sue *et al.* 2003:466). Most traumatic brain injury in children is not confined to one area of the brain but is diffuse; many cells throughout the brain are either killed or else their metabolism is interfered with so that they do not function properly. Damage to the left hemisphere often results in intellectual disorders and damage to the right hemisphere often results in affective problems (Sue *et al.* 2003:467).

2.2.2 Causes of traumatic brain injury

Any condition that can result in injury to a normally developing brain causes brain injury. Head injury or traumatic brain injury are terms used to describe a physical injury to the brain, by an external mechanical force or projectile, that results in loss of consciousness, post-traumatic amnesia and neurological deficits (Carr & Shephard 2000:279; Physical Medicine & Rehabilitation 2001:1). This includes prenatal and postnatal infections, toxic conditions, some types of metabolic and nutritional disorders, endocrine disorders such as hypothyroidism, gross brain diseases such as tuberous sclerosis and the various cranial anomalies. The only major category of disorders that is not generally considered to be a cause of traumatic brain injury is the chromosome disorders such as Down's syndrome, since this results in malformations of the nervous system starting at conception. Traumatic brain injury is one of the most common causes of disability and death in adults (Physical Medicine & Rehabilitation 2001:1).

Each of these conditions can result not only in barriers to learning, but also in a variety of other conditions such as cerebral palsy and epilepsy (Sue *et al.* 2003:466-478). Traumatic influences, such as a difficult birth, may cause a strain to the tissues from twisting, overstretching, or compression. If the trauma is small, the body may be able to "fix" it on its own. If it is moderate to large or the recuperative capacity is too compromised, it cannot "fix" itself. Then the nervous system will hold these distortions, in an attempt to

negotiate balance. If the forces are too great, the nervous system cannot fully compensate and the imbalance will appear extreme (Dolgin & Rosen 2002:1-2).

2.2.3 Diagnosis of traumatic brain injury

Because a physician cannot usually examine a child's brain directly, traumatic brain injury must often be inferred from the child's functioning and behaviour. The Soft Sign for Neurological Damage (NEPSY) is widely used. Abnormal muscle tone, either too rigid (hypertonic) or too flaccid (hypotonic), can also indicate a nervous system dysfunction (Fuzy 2000:26).

2.3   Biological causes of barriers to learning

The subjects participating in this research all had children with barriers to learning. More specifically, as described in Section 1.5, the different fields that were studied were: postnatal trauma (traumatic brain injury), chromosome abnormalities (Down's Syndrome), epilepsy, cerebral palsy and autism. Each of these conditions is caused by traumatic brain injury and will be described shortly to give insight into the parents' situation.

2.3.1 Trauma and other physical agents - disorders associated with the birth process

a) Perinatal trauma

Unlike most other organic causes of barriers to learning, which have their origins in conditions prior to birth, physical injury is unlikely to occur during the prenatal period because the developing embryo is fairly well protected by the mother. The time when physical injury is most likely to occur is the perinatal period, the time of the actual birth. The birth process is fairly complex, and there are many things that can go wrong. This leads to trauma. According to Giller (2003:1), in everyday language, it means a highly stressful event. "Thus, a traumatic event or situation creates psychological trauma when it overwhelms the individual's perceived ability to cope… The individual feels emotionally, cognitively, and physically overwhelmed. The circumstances of the event commonly include abuse of power, betrayal of trust, entrapment, helplessness, pain, confusion, and/or loss" (Giller 2003:1).

Perinatal Anoxia: The most crucial aspect of the birth process is the transfer of respiration from the mother to the child. During gestation the child receives its oxygen from the mother's blood, but as soon as the child becomes detached from the mother's circulatory system, this source of oxygen is no longer available and the child must breathe on its own for the first time. Cells need a constant supply of oxygen to function, and if the child is without oxygen for more than a few minutes, cells begin to die. Brain cells are among the first to succumb, and they are unique in that they cannot be replaced. The condition of lack of oxygen is known as anoxia (Kapp 2003:245).

Mechanical injury: During the birth process, the newborn is subject to a number of physical stresses. In the normal birth, the infant's head is down and this opens up the birth canal. The bones of the skull are still flexible and frequently the head of a newborn is misshapen. Ordinarily, this is not a cause for alarm, but occasionally, if the stresses of birth are too great, internal haemorrhaging may occur resulting in traumatic brain injury. The Cambridge Advanced Learner's Dictionary (2003:1) gives the definition of haemorrhaging as to loose a large amount of blood in a short time. Haemorrhaging is a secondary result of anoxia. It damages the walls of the blood vessels which may cause seepage of blood (Kapp 2003:245). This is particularly likely if the labour is very short or if the infant, instead of being born head first, is presented buttocks first, a breech delivery (Carr & Shephard 2000:281; Kapp 2003:250). "Because of advances in technology, brain injury, in general, is more likely to have a positive outcome than it did several years ago" (Johnson 2002:1).

According to The Law Offices of Masry & Vititoe (2005:1), traumatic brain injury may result in paralysis, loss of voluntary or involuntary motor functions, loss of reasoning and thinking abilities, memory loss, sensory loss such as sight, speech or hearing, emotional disabilities including depression, anxiety and post-traumatic stress disorder.

b) Postnatal trauma

After infection, the most frequent cause of postnatal acquired brain injury is physical injury of some sort, resulting either from an accident or from deliberate aggression (Kapp 2003:252). In response to injury, old connections can be terminated and new connections made; sometimes their new connections are inappropriate or not functional (United Cerebral Palsy 2005:1). Obviously, these injuries take a wide variety of forms, and there is no precise pattern of symptoms. Traumatic brain injury, also referred to as Head Injury or Acquired Brain Injury, is a dysfunction of the brain that results from physical force outside of the individual that causes an alteration in the way the brain functions at a structural, biochemical, or behavioural level (Thomas & Hersen 2002:331)

Child abuse: One variant of physical injury is the battered child syndrome - injuries that result from deliberate punishment by the parents or other caretakers. Hahn (2004:1) listed a few results where brain atrophy (up to 100 %) and irregularity and fragmentation of metaphyses are among the most common. Estimates of the frequency of child abuse were difficult to obtain at the Woman and Child Protection Unit and Katutura Hospital in Windhoek because parents generally deny that they inflicted the wound and physicians are often reluctant to accuse parents unless child abuse is undeniable. As with many other causes of retardation, child abuse is more frequently found in the lower socio-economic groups (Leena, pers. comm. February 2005).

2.3.2 Chromosome abnormalities

One of the most important categories of organic syndromes associated with barriers to learning is the category of chromosome aberrations. All normal human beings have 46 chromosomes in each cell in their body (with the exception of sex cells). These 46

chromosomes can be divided into 23 pairs and under certain conditions these chromosomes can be examined under a microscope (Irishhealth 2005:1).

Each chromosome contains many thousands of genes, and thus, with one exception, it makes no sense to say that a given chromosome is responsible for given characteristics. The one exception is the last chromosome pair. These are called the sex chromosomes because they determine the sex of the individual. There are two types of sex chromosomes. A relatively large one, which is referred to as the X chromosome, and a very small one, called the Y chromosome. Normal males have one of each, an X and a Y, and normal females have two X chromosomes. Occasionally an individual is born with something other than the normal complement of 46 chromosomes, usually 47, but occasionally 48 or more, and in the case of one syndrome, only 45. The presence of this extra chromosome material results in various abnormalities that range in severity from barely noticeable to lethal. One of the more common symptoms associated with the presence of an extra chromosome is lowered intelligence (Smith 2003:3).

a) Down's syndrome

Down's syndrome is by far the most frequent of the organic syndromes of barriers to learning. The incidence is estimated to be about one in 600 live births (Daily *et al.* 2000:5). This syndrome is the best-known example of a prenatal disorder (Sebastian 2002:2). The most obvious symptom is impaired intelligence. This ranges from a few who never even learn to walk, to some who have only mild barriers to learning.

Chromosome aberrations are of two basic types, those in which the extra chromosome is an autosome (any chromosome other than an X or Y chromosome) or those in which the extra or missing chromosome is a sex chromosome. The former will be discussed first. By far the most important aberration is Down's syndrome or mongolism, which results from the presence of an extra chromosome number 21. Because there are three of chromosome 21 rather than the usual two, another name for this disorder is trisomy 21 (Sebastian 2002:2).

There are actually three different types of Down's syndrome depending on how the individual happened to acquire the extra chromosome. In about 90 percent of the cases, the extra chromosome results from a process called non-disjunction. Normally, in the formation of gametes, the 46 chromosomes of the parent cell are divided equally between the two daughter cells so that each has 23 chromosomes, one of each type. Non-disjunction is an error in this process in which the chromosomes are not divided equally between the two daughter cells, rather one receives 24 chromosomes and the other 22. In trisomy 21, both of the chromosomes numbered 21 go to one daughter cell, neither to the other. The cell with only 22 chromosomes never produces a viable individual, but the gamete with 24 chromosomes can be fertilized, producing a cell with 47 chromosomes (Sebastian 2002:2-8). The resulting child has Down's syndrome. Thus, in non-disjunction, both parents have normal chromosomes, and there is no such thing as a carrier. The probability of parents of a child with Down's syndrome giving birth to a

second child similarly afflicted is very small if the syndrome resulted from non-disjunction. Non-disjunction is clearly related to the age of the mother.

A second error that can produce the identical syndrome is called translocation. In translocation, chromosome 21 of one of the parents has become attached to another chromosome, usually 15. When the chromosomes of this parent are examined under a microscope, only 45 can be seen, but chromosome 15 is larger than usual because it also contains all the genes of chromosome 21. Because the parent is not lacking any genetic material there is no abnormality manifest in the phenotype. However, when the parent's cells divide to produce gametes, a sperm or ovum may be produced which contains the genetic material of chromosome 21 replicated twice. If conception occurs with this cell the result will mimic trisomy 21.

A third, much rarer type of Down's syndrome is called mosaicism. In mosaicism, the defect occurs after conception. The initial zygote has a normal number of chromosomes, but some time in one of the early cell divisions during prenatal development an error occurs with one cell receiving 47 chromosomes and the other 45. The cell with only 45 dies, but because chromosomes always reproduce themselves exactly, the one with 47 chromosomes will continue to produce cells with 47 chromosomes. Thus, in the case of a mosaic child, some of the cells have a normal 46 chromosomes and others have the atypical 47. The more normal cells the individual has, the more normal he or she is. Mosaics form a sort of continuum between Down's syndrome and normalcy.

There are numerous physical features associated with Down's syndrome. Perhaps the most obvious is the peculiar oriental eyes. There is also a characteristic shape to the skull, small and flattened in the back. A small mouth and ears are all characteristics (Sebastian 2002:3). A flat nasal bridge is prominent of Down's syndrome children (Down Syndrome Characteristics 2002:1). Another characteristic feature of Down's syndrome is a large, fissured, protruding tongue. This is one factor contributing to speech problems (Miller 2005:1-7). They also tend to be considerably shorter than the general population. Their hands tend to be squared, with short, stubby fingers. The little finger is frequently missing a joint and may bend inward. There is often a space between the big toe and the other toes. There is a characteristic line on the palms of their hands called the simian line (Bennet 2003:306). They are also quite susceptible to various other disorders. Many have congenital heart deformities of various types, such as an opening between several chambers. They also have greatly lowered resistance to respiratory infections, and, as a result, a chronic runny nose is a common feature. Children with Down's syndrome have a reputation for being very cheerful, friendly, good natured, and affectionate (Down Syndrome Characteristics 2002:1).

2.3.3 Traumatic brain injury and related conditions

There are a number of conditions besides having barriers to learning, which are either definitely caused by or widely assumed to be caused by traumatic brain injury. The conditions include Alzheimer's disease, Parkinson's disease, meningitis, epilepsy, cerebral palsy, hyperkinesis and perceptual problems (Sue *et al.* 2003:466-477).

a) Epilepsy

This is a general term that refers to a set of symptoms rather than to a specific etiology (Sue *et al*. 2003:476). It is a paroxysmal disorder characterized by abnormal neuronal discharges (Browne & Holmes 2000:8). Epilepsy is a general term used to describe a condition of recurrent seizures or convulsions due to disorder of the brain cells (Dekker 2002:3). There are a number of different kinds of epileptic seizures and a wide variety of different causes. Research showed that "epilepsy is one of the most common serious primary brain disorder(s), affecting 40 million people worldwide" (Engel 2005:v). Epilepsy is considerably more common among males than females and children are far more likely to have seizures than adults. Epileptics are three to four times more likely to have barriers to learning than are non-epileptics. Seizures disorders are associated with many other diseases including infections, metabolic imbalances, toxic agents, brain hypoxia, brain lesions, brain defects, brain trauma and strokes (Burch 2004:1).

The classic seizure that most people associate with epilepsy is called a grand mal seizure. Events like the individual abruptly losing consciousness and falling to the ground as all the muscles tighten up, characterizes a grand mal seizure. After a few seconds of this tonic stage, the person begins to thrash around violently. Rapid, violent, uncontrolled movements distinguish this phase, called the clonic stage. This stage can be quite dangerous, as the person may injure him or herself as he bangs into walls, furniture or the floor, and he may bite the tongue or lips. This stage is frequently characterized by frothing at the mouth, and the whole episode has a frightening appearance to observers. After several minutes of the clonic stage, the individual lapses into a coma like sleep, which may last for several hours. When the person awakens, he or she typically has no recollection of the seizure, although he or she knows that one has occurred. "Symptoms of grand mal seizures may vary on an individual basis for each patient" (Wrong Diagnosis.com 2005:1).

Grand mal seizures are the most familiar type, but another common variety of seizures is called petit mal. A petit mal seizure is a temporary disturbance of brain function caused by abnormal electrical activity in the brain and characterized by abrupt, short-term lack of conscious activity (absence) or other abnormal change in behaviour (Campellone 2004:1). This is far less serious and is characterized by only a brief lapse of consciousness that may last a few seconds. The child may blink the eyes rhythmically or experience a sudden jerking or loss of posture and may drop what he or she is doing, but there is none of the violent thrashing around which is so typical of grand mal seizures. Petit mal seizures are far more frequent among children ages 6 to 12 (Campellone 2004:1). It tends to clear up with age. Although people suffering from grand mal seizures are more common than are those with petit mal, some children with petit mal seizures may have up to 200 per day. However, many go unnoticed because of their mildness.

Epileptic seizures result from the normal electrical activity of the brain going out of control. The immediate cause of this is always some sort of brain dysfunction, and thus the etiology of epilepsy is the same as for many other types of traumatic brain injury. It is found more frequently among those cases with a history of birth complications, lead

poisoning, encephalitis and physical injury. The epilepsy generally begins in a specific region where damage has occurred. The seizure does not originate from the dead cells, but frequently a region of malfunctioning cells will develop around the site of an injury, and this type of cell is likely to induce a seizure. The EEG is often used to determine the location of the origin of the epilepsy, but it is not always reliable because many individuals with a clear history of seizures have a normal EEG, and many normal, seizure-free people have an epileptic-like EEG.

A distinction is sometimes made between two types of epilepsy, idiopathic and secondary. Secondary or symptomatic epilepsy can be traced to a specific cause, such as physical injury or lead poisoning, while the term idiopathic epilepsy describes those cases of epilepsy where there is no apparent brain injury. There seems to be a hereditary component to idiopathic epilepsy since some cases have a history of seizures in the family.

There are certain kinds of environmental conditions that seem to induce epileptic seizures. Seizures are more common when the person is overtired or under stress. Even things like the weather or a woman's menstrual cycle are correlated with the rate of epileptic seizures. Occasionally, flickering lights can trigger a seizure. Some children can apparently voluntarily induce a seizure. The researcher has come across such a case where prolonged physical and emotional abuse made the client induce seizures as a coping mechanism. On the other hand, focusing attention on a task seems to reduce the possibility of petit mal seizures.

b) Cerebral palsy

Cerebral palsy is defined as a motor impairment such as paralysis weakness, or in-coordination that results from a brain dysfunction. Like epilepsy, cerebral palsy is not a unitary condition (single handicap) but is a general term encompassing a variety of symptoms (Kapp 2003:277). Cerebral palsy may be acquired after the birth of a child. This results from damage to the brain in the first months or years of life. The injury may be a brain infection (bacterial meningitis, viral encephalitis) or head injury following an accident. Lack of oxygen to the brain or trauma to the head during labour and delivery can cause cerebral palsy (Lawyers Incorporated, P.C. 2004:1).

Spasticity: There are a number of different types of cerebral palsy. The most common is spasticity, a condition of disharmonic muscle activity caused by damage to the motor areas of the brain (Kapp 2003:274). The definition of spastic according to The American Heritage Stedman's Medical Dictionary (2002:1) is "relating to or is characterized by spasm and affected by spastic paralysis." More technically, spasticity refers to an exaggerated contraction to muscles that are stretched. Thus, when the person tries to perform a movement such as raising an arm, as soon as the arm muscles begin to stretch, they contract reflexively. The result is clumsy, uncoordinated movements. The person's muscles become excessively rigid, and voluntary movements can be made only with difficulty. A similar condition is called rigidity, when there is increased resistance to

passive movements of the limbs. In offensive slang it is called clumsy or inept (The American Heritage Dictionary Of the English Language 2000:1).

Athetosis: This condition is the second important category of cerebral palsy. It is defined as "slow, writhing movements of the fingers and hands and occurs in approximately 5 % of people with CP" (Spasticity and Movement Disorders Clinic 2005:1). These uncontrollable movements increase when the person tries to control them or when attempting a voluntary act. Interestingly, the involuntary movements subside or may stop when the person is asleep (Kapp 2003:275-276).

Ataxia: The third common type of cerebral palsy is ataxia. Ataxia results from damage to the cerebellum. According to the definition of the Birth Disorder Information Directory (2002:1), ataxia is described as "failure of muscular coordination, irregularity of muscular action." It is characterized by difficulties in balance, co-ordination and body posture. The person walks as if intoxicated and speech is frequently slurred. There are a number of other rarer types of cerebral palsy, and sometimes several types are found in the same person. There is tremendous variability in the degree of impairment of cerebral palsied people. Some cases are very minimally impaired, and their condition results in little more than slightly lessened coordination or increased clumsiness (Kapp 2003:277). At the opposite extreme are individuals so impaired that they are unable to do anything for themselves; they do not have enough control of their limbs to even feed themselves. Most cases lie somewhere between these two extremes. Many cerebral palsied people have the additional handicap of impaired speech. If the articulatory muscles are affected, they may have difficulty communicating their needs to others. It seems quite feasible that within the next decade, we may be able to determine the gene that is damaged in most inherited cerebellar degenerations. As these data become known, it may also be possible to target specific therapies (Hain 2004:1).

Because cerebral palsy is caused by brain injury, it is usually found in conjunction with other handicaps associated with neurological impairment such as sensory loss, perceptual disorders, epilepsy and learning disabilities.

2.3.4 Pervasive developmental disorders

The term pervasive is used to describe the category of disorders in which several areas of development – social interaction, verbal and nonverbal behaviour and activity – are severely affected. Pervasive developmental disorders result in severely impaired social function (Fortinash & Worret 2003:211).

a) Autistic disorder

Autistic disorder usually manifests before age 3, with lifelong course. Individuals rarely are able to become totally independent because of their impaired IQ (Fortinash & Worret 2003:211). For a DSM diagnosis to be made, a total of at least six symptoms must be present, with at least two from the first section and at least one from each of the second

and third sections taken from Bennet (2003:312), Sue *et al.* (2003:493-494), Sadock & Sadock (2003: 1210) and Kaplan & Sadock (1998:1180). Symptoms are the following:

1. Impairment in social interaction:
- Impairment in the use of non-verbal behaviours such as eye-to-eye gaze, facial expression, and gestures to regulate social interaction
- Failure to develop peer relationships
- Lack of spontaneous seeking to share enjoyment, interests or achievement with other people
- Lack of social or emotional reciprocity

2. Abnormalities in communication:
- Lack of spontaneous make-believe play or social imitative play
- Delay in, or total lack of, the development of spoken language
- In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation
- Stereotyped and repetitive use of language or idiosyncratic language

3. Restricted, repetitive and stereotyped patterns of behaviour, interests and activities:
- Inflexible adherence to specific, non-functional routines or rituals
- Stereotyped and repetitive motor mannerisms
- Persistent preoccupation with parts of objects

Children with autism are often diagnosed as having barriers to learning (Sue *et al.* 2003:495). Interestingly, some children with autistic disorder possess unusual or extraordinary abilities or "islands of genius". For example, a person can calculate a large range of numbers but is unable to understand their significance or an individual may be able to play a musical instrument without ever taking lessons or being able to read music (Fortinash & Worret 2003:212).

According to Bennet (2003:315) there is a significant genetic component to the risk for autism. The opioid theory suggests that the condition is the result of an early overload of the central nervous system by opioids. The excess opioids are thought to be the result of incompletely digested dietary gluten and/or casein found in barley, rye, oats and milk products. These result from a lack of chemicals within the gut known as peptidases which break down natural opioids found in these foodstuffs into innocuous metabolites. An excess of opioids may also result from inflammation of the bowel wall. There may be a link between the MMR (measles, mumps, rubella) vaccine and autism.

2.4 Cognitive and learning & memory development in the child with barriers to learning

2.4.1 Cognitive learning

The developmental approach tends to view mental functioning as being very different at different ages. The actual mental processes – learning, memory, mediation, and perception – change qualitatively with age. An outstanding example of this developmental approach is the work of the Swiss philosopher Jean Piaget.

Loughner (2001:37-38) and Engelbrecht & Green (2001:107) summarized Piaget's stages of mental development as follows:

1. Sensor motor period. As the name implies, the infant uses senses and motor abilities to understand the world, beginning with reflexes and ending with complex combinations of sensor motor skills (Boeree 2003:2). The child's thinking is limited to the here-and-now; the child's primary mode of perceiving and understanding his environment is by action rather than by symbolic representation. During this period the child gradually develops an object concept and the knowledge that objects exist independently of the child's experiences. Also during this time the child begins to develop an understanding of space, time, and cause-effect relationships.
   The sensor motor period is divided into six sub stages:
   Exercising innate reflexes
   Primary circular reactions
   Secondary circular reactions
   Coordination of secondary circular reactions
   Tertiary circular reactions
   Invention of new means through mental combination (Hutchison 2003:125)

2. Pre-operational period. The child is able to represent symbolically things and events that are not present. However, thinking during this period is still largely non-logical. The child is perceptually bound; he takes all of his perceptions literally. The child is centred; he can only focus on one dimension of a stimulus at a time. The child is egocentric; he is not aware of the viewpoints of others. The child cannot understand the ideas of classes or sets, and he gives immature answers in various conservation problems; he believes that the amount of liquid changes when it is poured from one container to another, that the number of objects can change when their configuration changes and so on (Hutchison 2003:126,546).

3. Concrete operational period. The child's thinking begins to manifest logical properties. He understands most kinds of conservation and can use classes in his thinking. The major limitation is that the child's thinking is limited to concrete rather than abstract objects and ideas, and thus it is impossible for him to outline a series of possibilities in his mind and test them systematically (Hutchison 2003:126,536).

4. Formal operational period. The child begins to see reality as a subset of the possible. He can test a series of hypotheses systematically, he can understand second-order conservations such as conservation of volume, and he can perform operations on abstract ideas (Hutchison 2003:126; Mentkowski & Associates 2000:184-185).

2.4.2 Learning & memory

2.4.2.1 Learning in the child with barriers to learning

The most widespread conception that distinguishes the child with barriers to learning is some sort of weakness, slowness, or deficiency in basic cognitive skills such as learning, thinking, verbal skills and the like. The term learning encompasses many different kinds of learning (Kavale & Forness 1995:1-21).

a) Classical conditioning

Conditioning involves pairing a specific response to a specific stimulus or stimulus situation. There are two basic kinds of conditioning paradigms. One is called classical or respondent conditioning. The other is operant or instrumental conditioning (Bennet 2003:38-39; Lougher 2001:41). Pavlov did the best-known experiment demonstrating classical conditioning in 1927. According to Atherton (2004:1-2) classical conditioning is a disciplined account of our common-sense experience of learning by association or contiguity (in the jargon), although that is often much more complex than a reflex process, and is much exploited in advertising. Note that is does not depend on us doing anything. Such associations can be chained and generalised (for better or for worse): thus "cookies and tea" associates with "kitchen at home in childhood" associates with "love and care" (Atherton 2004:1-2).

b) Operant conditioning

Operant conditioning is the name given to changes in behaviour that result from rewards and punishments. When an organism emits behaviour (does something), the consequences of that behaviour are reinforcing, it is more likely to emit (do) it again. What counts as reinforcement, of course, is based on the evidence of the repeated behaviour, which makes the whole argument rather circular (Atherton 2004:1-2). Skinner did the classical experiment on operant conditioning in 1938. The underlying pattern behind all operant conditioning is that an organism learns to perform behaviour in order to get a reward, or, more precisely, reinforcement. Organisms tend to repeat those behaviours that are reinforced and tend not to repeat those behaviours that are not reinforced. Operant conditioning forms the basis of the technique of training and therapy known as behaviour modification (Bennet 2003:39-40; Lougher 2001:42).

c) Discrimination learning

Discrimination learning involves placing two stimuli in front of the subject and allowing the subject to select one of the two. If the subject selects the correct one, he or she gets

reinforcement such as candy and if the subject chooses the wrong one, he or she gets nothing. Discrimination learning was originally conceived as a measure of perceptual abilities, but is has evolved into a method of study concept learning and problem solving. The easiest kinds of problems are called junk discriminations because the subjects are simply required to distinguish between two everyday objects (Mwamwenda 1996:186-187; 222)

d) Paired associate learning

Paired associate learning involves the pairing or connection made by the learner between a known or unknown stimulus and a known or unknown response (Ursuline College 2004:1-2). In paired associate learning, a stimulus word is presented and the subject must learn to give a certain word in response. The stimulus and response words can be presented to the subject either in written form, orally, or with pictures. With subjects with barriers to learning, the latter mode of presentation is the most frequent.

2.4.2.2 Memory processes in the child with barriers to learning

A number of different information processing models and theories have been proposed. The assumption of each of these models is that information passes through several different types of storage, and each type of storage has different characteristics. Information is first encoded in a sensory register, sometimes referred to as iconic memory, which simply provides a very brief (usually less than a second) memory trace of the physical features of the stimulus. This information is quickly lost unless it is transferred into short-term memory (STM). STM has very limited storage capacity and can only hold a few items at a time. It is also possible to maintain items in STM more efficiently by elaboration. Examples are by using mnemonic devices to make the material more meaningful or by chunking, combining several items together into a single unit (Mwamwenda 1996:235-237). Some items in STM are transferred into long-term memory (LTM), where material is stored for long periods of time out of consciousness. It is generally assumed that nothing is ever forgotten from LTM, although a particular piece of information may not be available (retrievable) at a particular time. LTM is unlimited in capacity; an infinite amount of information can be stored in it without any information ever being bumped out (Levine 2001:7-8).

a) Short-term memory

Short-term memory, sometimes referred to as "primary" or "active" memory, is that part of memory which stores a limited amount of information for a limited amount of time (roughly 30-45 seconds) (Wikipedia 2005:1-3). When the nervous system is not intact, the memory traces fade more rapidly. Therefore, a child with barriers to learning has a particular defect in their short-term memory. Ellis found in his research in 1970, that there are two types of STM, primary memory and secondary memory. Primary memory can retain only two or three items at best and only for a very brief period of time, while secondary memory can retain several more items and over a longer period of time if the subject rehearses them.

To summarize, a lot of researches are supporting the latter. STM is represented as two separate processes, the former being essentially passive but with rapid decay, the latter requiring active rehearsal on the part of the subject. Subjects with barriers to learning have no unusual difficulty with primary memory (memory for events within the past few seconds), but they have a considerable deficit in secondary memory (that requires active rehearsal) (Mwamwenda 1966:235). It is presumed that the main reason why they show such a deficit is that they fail to rehearse. Rehearsal of items to be remembered is one example of what is called control processes in information processing models, those processes that are voluntary and that determine what information is stored and where it is stored. A synonym for these control processes is strategies. People with barriers to learning seem to be generally deficient in the use of such strategies, and this deficiency contributes to their poor learning performance. There are three reasons for this, the first is that the subjects with barriers to learning persist in attending to inappropriate characteristics of the stimulus long after they have been shown to be wrong, and thus it takes them many more trials to reach the criterion. The second is the use of mediators in paired associate learning. The third reason is the failure of retarded subjects to use rehearsal strategies in learning a series of digits or letters (Levine 2001:66-75). Hutchison (2003:411) refers to the STM as primary memory and supports the above-mentioned.

b) Recognition memory

If the deficit in the memory of subjects with barriers to learning is due primarily to inadequate rehearsal strategies, there ought to be little or no difference in performance between subjects with barriers to learning and normal subjects in memory tasks where rehearsal strategies are not possible. One such task is recognition memory for pictures. The general procedure is to show subjects a large number of pictures, often several hundred, and then show the subject a series of pairs of pictures. In each case, one of the pairs was in the original set and the other one was not, and the subjects must identify which of the two pictures they have seen before. Normal adult subjects do remarkably well at this. When subjects have to only identify whether they have seen a picture before or not, apparently the memory capacity is nearly infinite. This task is different from many other memory tasks in that no rehearsal or other type of strategy is necessary for good performance, and, as a result, one might predict that subjects with barriers to learning would show little or no deficit in recognition memory. Several studies have shown that this is the case. The performance of subjects with barriers to learning is nearly as good as that of normal adults, most getting more than 95 percent correct (Mwamwenda 1996:236). Hutchison (2003:411) refers to recognition memory as secondary memory.

c) Long-term memory

Long-term memory (LTM) lasts from over 30 seconds to years (Wikipedia 2005:1). Once an item has been stored in long-term memory, no rehearsal or other organizational strategy is necessary to maintain it, and as a result, it is predicted that the long-term memory – memory over a period of hours, days, and weeks – of subjects with barriers to

learning would also not differ from normal subjects (Levine 2001:80-93). Hutchison (2003:412) refers to LTM as tertiary memory.

2.5 Language development in the child with barriers to learning

2.5.1 Nature of language

It is widely assumed that language is necessary for higher-order thinking (Hutchison 2003:166-167). The vast majority of the items on most intelligence tests involve a verbal stimulus, a verbal response, or both. Both the delay and deficit views recognize that cognitive development is essential for language development. The delay position implies that development in cognition is sufficient for language to develop, and the deficit view recognizes that additional child characteristics are necessary for language growth (Miller 2005:2). The deficit in language skills is perhaps the single most important characteristic that distinguishes a person with barriers to learning from a normal person (Aitchison 2001:215).

In a period of about three years, the typical child progresses from being an essentially nonverbal organism to having a vocabulary of thousands of words and being able to speak and understand complex sentences (Hutchison 2003:128-129). Language refers to a system of rules by which thoughts are translated into a series of sound waves in order to communicate information. The term language refers to the system itself, and thus it is distinguished from speech, which is a term referring to the actual behaviour of an individual (Mentkowski & Associates 2000:372-373). Children must learn how to speak, but, more importantly, they must learn a highly abstract system or code. Languages are infinite in capacity; there are an infinite number of acceptable sentences in any language. Syntax, the linguists' term for what most people call grammar, is a system of rules by which the words of a language are combined together to make sentences. The rules of syntax are remarkably complex (Robinson 2002:49).

2.5.2 Language acquisition

Both knowledge and the ability to use it are essential requisites for communication (Douglas 2000:33). The acquisition of language in normal children is a remarkable process in a number of ways. First, children are able to learn whatever language is spoken around them incredibly fast. Most normal children master the fundamental rules of their language. Any language has an infinite number of correct sentences, and most of the sentences that children hear and speak, they have never heard before. This means that children cannot learn a language simply by copying what they hear; they must learn a highly abstract set of grammatical rules for combining words to make sentences. Children all over the world seem to go through the same steps in learning their language, regardless of what language they are learning or how much or how little they are deliberately taught or corrected by their parents. According to Buckley & Bird (2004:1), it seems that a minimum vocabulary of 250 words is needed before early grammatical

markers for possessives, plurals and tenses are learned. For this reason, it has been suggested that language acquisition and, in fact, language itself, is part of people's biological nature (Hutchison 2003:166-167). Previous research on children with barriers to learning has resulted in several very general conclusions about their communication. The language performance of such children has been described as following the same developmental pattern as normal children when matched for mental age or linguistic stage. Despite differences in etiology, the majority of research has documented similar performance across linguistic domains. While language and communication skills are clearly delayed relative to chronological age, many of the differences disappear when children with barriers to learning are compared to children of similar mental abilities (Miller 2005:2).

There are several different levels of language, and thus several kinds of disorders associated with the communications process. One level is a speech disorder, in which the individual has difficulty articulating the correct sounds. Examples of speech disorders include substituting one sound for another, omitting sounds entirely, and stuttering (Kuder 1997:8-9).

More serious than speech disorders are language disorders, difficulties in understanding and using vocabulary and the rules of syntax of language. People with barriers to learning also have many language difficulties, although to some extent, these can be accounted for by their lower mental age. Research by Lacey & Ouvry (1998:50-54) with children with barriers to learning has generated the following conclusions:
1. Children with barriers to learning acquire language skills in essentially the same fashion as normal children.
2. The rate at which they acquire language skills is slower than that of normal children. As a result, when children with barriers to learning are compared to normal children of similar chronological age, the child with the barrier to learn shows a distinct deficit.
3. Because language acquisition ceases sometime around puberty, many children with moderate barriers to learning and most children with severe and profound barriers to learning may not develop complete language skills.
4. On the average, children with barriers to learning are delayed in language development even when they are compared to normal children of similar mental age. In other words, children with barriers to learning have a particular deficit in language skills.
5. Children with barriers to learning have particular difficulty in acquiring the more complicated grammatical rules such as the rules of inflection.
6. The language of the child with barriers to learning is more concrete than is the language of normal children.
7. The variance in language skills is greater among children with barriers to learning than in a normal population. At a given developmental level, one is likely to find a relatively wide range of verbal abilities.

According to Buckley & Bird (2004:1) it is possible to improve their mastery of grammar and syntax and its use in their everyday speech. According to a study done on 81 patients

by Fuess, Bento & da Silveira (2002) the most common risk factors for the delayed maturation pattern were parental consanguinity, prematurity, perinatal anoxia and jaundice, and postnatal seizure and infection.

2.6 Personality of the child with barriers to learning

Barriers to learning are primarily a cognitive disorder and most research has been done on the cognitive processes. However, the secondary effects on the exceptional individual's personality and emotions are far more serious and present more of a barrier to effective adjustment than do the problems presented by deficient cognitive abilities.

2.6.1 Personality traits of the child with barriers to learning

There are a number of personality characteristics that are generally found more often among these children than in the general population. Among these are the following:

1. People with barriers to learning are likely to expect to fail. This expectancy means that they are likely to be failure avoidant rather than success striving; and they are likely to be outer-directed, relying on other people rather than their own ideas to make decisions.
2. People with barriers to learning are likely to develop a general feeling of helplessness, a feeling that they are not in charge of their own destiny.
3. As a result of social isolation, people with barriers to learning are apt to have an increased need for social interaction and to adopt unusual strategies to maintain contact with other people for as much time as possible. According to Scouting with the Disabled (2000:13) social integration is the most difficult aspect to achieve, although Down's syndrome children are usually affectionate, cheerful and friendly (irishhealth.com 2005:2).
4. People with barriers to learning have defective ego functioning. This means that they are more likely to rely on very primitive defence mechanisms such as repression or denial to reduce anxiety.
5. People with barriers to learning are likely to go to great lengths to demonstrate to other people and to themselves that they are "normal", a process known as passing. Thus, they might park an old car in front of their house and show it off to other people even though they cannot drive because "normal" people have cars.

One common feature of people with barriers to learning, particularly the institutionalised, is stereotyped behaviour, the compulsive repetition of a purposeless behaviour that is often self-destructive. While one feature of stereotypic behaviour is that it appears to be non-adaptive and purposeless, behaviour-analytic research suggests that stereotypic and other self-stimulatory activities serve to provide and regulate sensory input from the environment (Daversa 2001:5). Daversa (2001:1) is of the opinion that viewing these inappropriate behaviours as variations of normal functioning is effective in understanding possible functionality of these behaviours.

2.7 Effects on the family of a child with barriers to learning

2.7.1 Parents

2.7.1.1 Impacts on the parents

Virtually all parents react with extreme shock and disappointment to the news that their child has barriers to learning. Post Traumatic Stress Disorder (PTSD) is the psychological term for a set of reactions anyone may experience when something traumatic, scary or bad happens. It is a normal reaction to an event that involves the threat of death or injury to self or others (TABS 2003:1). There are three stages parents show when receiving this news. The first stage or crisis is one that results from a major unanticipated change in one's life and one's conception of oneself. Thus, this is not a reaction to the diagnosis *per se*, but to the abrupt change in one's circumstances. The second stage is a crisis of personal values. Most people have been reared with the idea that competence and achievement should be valued. Thus, when it suddenly becomes necessary for parents to love someone who has few of these desirable traits, the parent is put in a conflict situation and a good deal of stress can result. The third stage is the reality crisis. This stems from the fact that there are a number of very concrete concerns that face the parents of the exceptional child, financial worries, limitations on their ability to take vacations, the extra time involved in caring for such a child and so on. Cohen (2005:1) is of the opinion that a particular disability will not be addressed because parental reaction to almost any disability appears to follow certain stages. One participant stated that the severity of the handicap and the degree of dependency by the child on their family is the most important factor in their acceptance, than whether he has cerebral palsy or spina bifida (Williams, pers comm. May 2005).

These three stages taken from Gargiulo (1985:22-30) will provide a basic outline for a discussion of parental reactions to their child's diagnosis.

a) Primary phase

Shock: The crisis results from a sudden change in the parent's perception of themselves and their family and their future. According to Williams (2001:2) it takes time to learn how to deal with the confusion, the physical demands, the behavioural challenges, the special expenses, feelings of embarrassment and feelings of loneliness when others don't always understand. According to Lessing and Strydom (2001:5) some parent may show irrational acts by excessive crying. Having a child with a disability brings challenges and adjustments that impact the whole family, not just the mother and the father.

Denial: The second common reaction of parents to the discovery that their child has barriers to learning is the defence mechanism of denial. Denial is a defence mechanism that I've come to understand as a gift. We use defence mechanisms whenever we're in a situation where we feel we are over our head and we know we don't have the ability to cope. Defence mechanisms can be a gift that allow people to accept the truth just a little

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at a time and make it more bearable (Williams 2001:2). This denial takes many forms. Lessing and Strydom (2001:22) outlined four of the most common forms.

- Refusing to recognize the child's disability.
- Rationalizing the disability.
- Seeking professional confirmation that there is not anything wrong with the child.
- Quickly becoming too cooperative with professionals.

Grief and depression: Grief is a necessary and useful reaction and should not be avoided. It provides the parents with a transitional period whereby former dreams and fantasies about the 'perfect child' are readjusted to present-day reality. Grief also makes it possible for the parents to progress from the state of initial shock and disbelief to that of awareness for the disappointment. There is no definite ending to grief and depression (Lessing and Strydom 2001:7).

b) Secondary phase

Ambivalence: This phase represents a clash of personal values. When it suddenly becomes necessary for a parent to love someone who has few of these desirable traits, the parent is put in a conflict situation and a good deal of stress can result. These negative feelings are usually accompanied by guilt, to which certain parents respond with total dedication and others with rejection. Rejection of the child is part of the parents' defence against their pain. Rejection can also be the consequence of the parents' anticipation of the constant demands of lifelong emotional and financial responsibility. To institutionalise the child can be an outflow of this. The neglect of other family members may result in marital discord.

Guilt: Guilt and the accompanying emotion of shame are the feelings that one experiences when one has done something wrong. These feelings of guilt and shame are quite irrational in the case of giving birth to a child with barriers to learning. Guilt is often a part of that working-through process (Williams 2001:3).

Anger: Anger can be manifested in two ways: Firstly parents want to know "Why me?" and secondly they direct their anger and rage toward others. Parents easily blame doctors, teachers, spouse or siblings.

Shame and embarrassment: Parents often learn to anticipate the social rejection, pity and ridicule that others in society have for their child. Since parents usually identify with their children and often perceive them as extensions of themselves, a defect in the child could easily be interpreted as a defect in oneself. This is a threat to parents' self-esteem.

c) Tertiary phase

Bargaining: This is a very personal and one of the final stages of adjustment. They hope to bargain a deal with God or professionals.

Adaptation and reorganization: This stage can vary in the length of time and reduction in the feelings of anxiety and other intense emotional reactions. Parents become confident in their parenting skills, which leads to increased levels of interactions with their child. Families start to rely and support each other.

Acceptance and adjustment: It is unfortunate that much of what has been written about parental reactions to having a handicapped child stresses the negative aspects of the coping process, the guilt, the developing of irrational defence mechanisms and the like. While it is certainly the case that many parents do resort to various maladaptive behaviours at one time or another, the more positive processes of acceptance and adjustment tend to be de-emphasised. Many parents are able to successfully resolve their crisis in values and accept their child with barriers to learning for what the child is. "I began to accept Moira, unconditionally, as the little girl she was, and not as someone who was just "this much" behind the little girl I wanted" (Baker 2002:3).

Brown and Westbrook (2004:793) said that coping is conceptualised as "cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person".

The word acceptance is often used to describe what is considered to be a healthy response to the fact that one's child has barriers to learning. This process of acceptance involves a number of characteristics:

1. The accepting parent is able to accurately perceive the child's abilities and his potential, being fully aware of both his weaknesses and his strengths.
2. The accepting parent is able to view the child's shortcomings realistically, recognizing that it is sometimes an inconvenience for the family. Acceptance also involves not becoming so overwhelmed with self-pity or sorrow or quilt that the functioning of the family is impaired. Such parents should be able to discuss their child freely, both among themselves and with neighbours and relatives without feelings of shame.
3. The accepting parent should attempt to provide the best possible medical, educational, and recreational services available within his/her means without neurotically searching for a miracle cure.
4. The accepting parent is able to provide the retarded child with as much love as is provided for other children, not rejecting the child, but not over-loving the child either, not smothering the child with so much love that the child fails to develop a certain degree of independence. The accepting parent should not devote so much time and attention to the child with barriers to learning that the parent neglects the other children and spouse.

This concept of acceptance involves striking a balance between recognizing the child's disabilities and making compensation for them but not permitting the handicap to completely dominate family interactions. Obviously, judging whether a family has reached this level is entirely subjective, and thus it is impossible to say what percentage of parents have accomplished this. However, there are certainly many families for whom having a child with barriers to learning is not viewed as the enormous tragedy that it is widely believed to be. It is important to remember that such a value crisis is only an

important source of stress for parents who place high value on success and achievement. In less competitive cultures where a place can be found for almost everyone regardless of competence, retardation is not considered to be the tragedy that it is among achievement-oriented middle-class people.

Gargiulo (1985:30-37) describes two other emotions often experienced by parents as well:

Over-protectiveness: Another frequently described pattern of parental behaviour is over-protectiveness. Some parents, usually mothers, devote all of their time to their child with barriers to learning to the exclusion of the other children and spouse. They consistently treat the child as if the child is less capable than he or she is. Such parents never let their child out of their sight, and they give up all their social life and other interests to care for their poor child. One interpretation of this behaviour is that it is a type of reaction formation. Reaction formation is a defence mechanism in which one denies an unacceptable impulse by emphasizing its opposite. Thus, the other appears to be saying: "See how much I love my child. I am sacrificing everything for him," but in fact the mother is trying to hide both from her and from others the fact that she unconsciously dislikes and resents the child. Such an admission would be too painful and so she emphasizes the opposite.

Sorrow: It is speculated that almost all parents who have a child with barriers to learning suffer chronic sorrow throughout their lives. The extent of this sorrow may differ from one parent to another, but most will manifest this to some degree. This sorrow is in no way a neurotic reaction but is a perfectly natural and normal response, although many parents will try to hide their depression and sorrow in public. Reactions such as grief and mourning can be included. It is suggested that in a sense the reaction of a parent to the knowledge that their child has barriers to learning is similar to the reaction of a parent who loses a child through death. When we have a child with a disability, often there is a sense of loss, loss of hopes and dreams that we had for that child. There is the loss of the child we thought that we were being given. There is also grief over the loss of the goal of having what we envisioned as an ideal family (Williams 2001:3).

2.7.1.2 Determinants of parental reactions

Parents differ widely in their reactions and their attitudes toward their child with barriers to learning and it is worthwhile to consider why some parents react well and others badly.

- One variable that seems to be important is the socio-economic status of the parents. It is reasonable to assume that middle-class parents might tend to react somewhat differently to a child with barriers to learning than would a low-income family.
- A tragic crisis is one in which the aims, aspirations and the anticipation of a happy family life are frustrated.
- Obviously, how the doctor breaks the news to the parents is an important determinant of the extent of the primary phase.
- Another type of crisis is the rile organization crisis. In this case, the parents are more concerned with the day-to-day problems imposed by the exceptional child. This crisis

is more typical of low-income groups. Such parents are too overwhelmed by daily events and crises to be very concerned with the long-term development of their children. Parents are very wrapped up in the financial problems of the child with barriers to learning, obtaining proper medical and educational services and the like.

- One characteristic that is clearly related to the parents' acceptance of their child with barriers to learning is their understanding of the nature of the problem and what causes it, particularly the cause in their own child. Parents who have this understanding are far less likely to manifest feelings of guilt and shame and are less likely to use defences such as denial. It follows from this that an important principle of counselling these parents is to provide them with as much information about barriers to learning as they can readily absorb.

- Perhaps the single most important determinant of parental reaction toward their child is the parents' own level of adjustment. Parents who, prior to the birth of the child with barriers to learning, are functioning at an effective level, who are relatively free of defences, and whose marriage is stable will tend to have few problems with acceptance. On the other hand, parents who were having difficulty coping with their lives and who had tendencies toward pathological symptoms prior to the birth of the child will probably continue to have difficulties with coping and are likely to use irrational defences such as denial.

It has been said that the presence of a child with barriers to learning does not generate new problems in family integration but only magnifies already existing problems.

2.7.1.3 Social influences

Those who emphasize the social structure, centre their attention on functional role relationships taking place in immediate social encounters, for example, in the context of work and family, in which there are all sorts of social pressures, opportunities and socially derived expectations (Darling 1979:235-240). Much of our time and energy is spent adapting behaviourally to the requirements of living, dealing with social and environmental demands, capitalizing on resources and opportunities to further personal or group values and goals and managing our actions in accord with social constraints, which if violated could lead to harm. To evaluate the effects of the emotion process on adaptation, we must be able to assess how effectively a person functions in the world. Because the behaviour of the environment is a crucial factor, however, a good outcome can result from a coping process that is unsound and a poor outcome from one that is sound. It is therefore important to consider the environmental conditions (Stone 2001:55-57). Some people do well because they experience favourable conditions of life, whereas others do well in spite of hardship; still others do badly because of refractory conditions, or do badly regardless of favourable ones.

2.7.1.4 Emotions and health

In recent years, research has increasingly recognized that emotion plays an important role in influencing attitudes and behaviour (Brown & Westbrook 2004:792). Emotions are an independent variable that affects three kinds of long-term adaptation outcome: somatic

health, subjective well-being and social functioning (Townsend & McWhirter 2005:195; Bennet 2003:18-20).

With respect to emotion and somatic health, one first confronts the difficulties of defining health and the absence of solid knowledge about the relationships among the three levels of analysis – the physiological, subjective and social. Not only must we deal with problems in assessment but also with methodological difficulties of doing sound research on the emotional causes of ill health. These include problems such as confounding of variables, subjective versus objective measurement, the multivariate nature of health outcomes, the stability of health status over long periods, and the difficulty of finding representative samples of the emotion process during the period that we are evaluating.

2.7.2 Brothers and sisters of children with barriers to learning

One of the concerns of many parents is that their other children, the brothers and sisters of the child with barriers to learning, will be harmed in some way by the presence of the child in the home, and this is occasionally given as an excuse to institutionalise the exceptional child (Mittler & McConachie 1986:131). Living with a brother or sister, including one with a disability, can be rewarding, confusing, instructive, and stressful (News Digest 2005:1). There are also occasional practical problems. A sibling, usually a sister, may be called on to help care for the child with barriers to learning, and this can interfere with her social life (Seligman & Darling 1989:11). Occasionally, children are so ashamed of the brother or sister with barriers to learning that they refuse to bring friends home. However, such a reaction of shame is almost always learned from the parents. Even small children pick up the attitudes of the parents, and if the parents seldom talk about the retarded child and seem to be ashamed, then the normal siblings are likely to acquire the same attitudes (Byrne *et al.* 1988:40).

According to a study done by an unknown researcher in 1972, the ability of the normal sibling to adapt to having a child with barriers to learning in the family seemed to be closely related to how well the parents accepted the problem as well as how openly the parents discussed the exceptional child (Seligman & Darling 1989:127).

Siblings can experience this positively or negatively. Some siblings feel that they have benefited from having a child with barriers to learning in the family, while others may feel that they have been harmed and express feelings of guilt and shame (Mittler & McConachie 1986:131-132). This is accompanied by negative feelings toward the exceptional child because the parents devote so much attention to the child with barriers to learning (Byrne *et al.* 1988:40-41). Examples of positive feelings are that some people have a greater understanding for affected families and are more tolerant of them. They have more compassion, are more sensitive to prejudice and have greater appreciation of their own good health and intelligence. Siblings can often be very significant figures in a young child's life (Mittler & McConachie 1986:131) "Since the age of six when my younger brother was born with Down's syndrome I have lived a life that was incredibly different from my peers. John brought us to view the world with an entirely different sort of vision. Yes, I was crying – incredibly so for my mother. But this vision has affected

my immediate family, my husband, his family, and of course now my children. Would life have been simpler without John? Yes, but so much poorer." (American Public Media 2005:6). Younger caregivers are more predisposed toward seeking outside help and have higher expectations of the service system than older caregivers. However, younger caregivers report significantly more unmet service needs and rate significantly more of them as a critical or an emergency need. Older caregivers are more likely to seek spiritual support and the younger caregivers more apt to mobilize their families to acquire and accept help (Hopkins 2001:67).

2.7.3 Counselling parents of children with barriers to learning

Treating psychopathology in children carries the risk of strained relations with the patient's family. The risk increases exponentially for developmentally disabled children, as they have little or no input and their parents are extremely sensitive to their needs. Further, the revelation that the parents might have somehow failed to avert or anticipate danger to the child complicates their emotional response (Krassner & Kraus 2003:5).

With all of the various types of problems facing parents of children with barriers to learning, it is not surprising that many of them seek some sort of counselling with their problems, both practical and emotional (Seligman & Darling 1989:158).

2.7.3.1 Meaning of counselling

The term counselling refers to so many different kinds of services that it has lost whatever meaning it once had. Counselling can be a single session where the counsellor explains the results and prognosis of a diagnostic study and tries to calm their worst fears. It can also be a long series of sessions in which the parents discuss their deepest feelings among themselves and toward their child with barriers to learning. It can also take the form of group counselling where parent seminars and educational groups are offered. Parents may need counselling at the time when the diagnosis of barriers to learning is first confirmed, but many parents are too distraught at that time to absorb much information or effectively face their feelings. As a result, a number of sessions, perhaps spread out over a considerable length of time, may be required in order to assist parents in working out their feelings and recognizing the ramifications of their child's problems. New types of crises are continually presenting themselves as the child develops (Byrne *et al*. 1988:143). In all life's different situations, the parents are likely to want to seek guidance and advice, and as a result, whoever does the initial counselling with the family should encourage the parents to seek help whenever they feel that they need it. They should be informed that such help is always available (Byrne *et al.* 1988:143). Counselling is also concerned with primary education as well as the client's feelings and attitudes. Counselling then resembles psychotherapy directed towards the child, their marriage and their lives. The goal is to make the parent aware of his resilience, defences and anxieties. Counselling's primary function can also be to increase the parents' knowledge about the causes and probable prognosis in their own child and of specific management techniques (du Preez & Steenkamp 1986:127-128)

Most of the principles of counselling parents of the disabled are the same as they are for any other type of counselling. Here are a few guidelines for counsellors (taken from case study 1 parent R):

1. Treat the parents with acceptance and respect. The counsellor helps them to overcome their feelings of shame and the loss of self-worth (Tolan 2003:66-67).
2. The parent must be led to realize that having a child with barriers to learning is nothing to be ashamed of and that the child in no way reflects poorly on them.
3. Permit total freedom in the expression of emotions. Parents need a place where they can express their feelings to a sympathetic listener. The parent can realize that these feelings are perfectly normal and then feel better (Tolan 2003:60-65).
4. Let the parents make decisions for themselves. They are the ones who will have to live with the child. Outline various options that are available.
5. Be honest. Do not mislead or encourage the parents by presenting an overly optimistic picture of the child's potential because such a strategy can only lead to frustration later on (Tolan 2003:157).
6. Do not pretend to be more knowledgeable than you are. If the counsellor cannot answer a question, (s)he should say that (s)he doesn't know rather than try to fake an answer (Tolan 2003:157).

2.7.3.2 Goals of parent interviewing

A person's psychical activities are usually described in terms of one's cognitive, affective and conative components (Gouws, Louw, Meyer & Plug 1979: 6).

a) Affective goals

This is the collective noun for feelings, emotions and moods (Gouws *et al.* 1979: 6).

i) The traumatized parents get the opportunity to verbalise their emotions and feelings. Being a parent of a child with barriers to learning can create anxiety, depression, grief and hate. These issues can be addressed.
ii) Feelings of loneliness and isolation get addressed. Parents become aware of other parents going through the same process as themselves.
iii) The development of altruism is an alternative to this self-centredness.

b) Cognitive goals

This term refers to aspects and functions related to thoughts and ideas (Gouws *et al.* 1979: 153).

i) Congruence and harmony in a person's feelings, attitudes and behaviour (Gouws *et al.* 1979: 154)
ii) Perceptions of guilt and punishment should make way for feelings of peace and of enjoying their child to the fullest.
iii) Correct information should be conveyed if participants lack the information.

c) Behavioural goals

Behavioural change is brought about through the use of conditioning or using the principles of the learning process (Gouws *et al.* 1979: 95).

i)   Parents should live their lives to the fullest and forget about feelings of being ashamed and spoken about. Effective socializing skills should be adopted. Socializing with different people and giving the correct information to your friends could be beneficial.
ii) Parents should get alternative ways of dealing with their grief and anxiety.

d) Conative goals

i)   A positive and realistic future outlook and mind shift is important to feel successful.

e) Parenting goals

i)   Support systems should be established and open, honest communication between parents is very important. Chidester, Dexter & Wilmot (2003:200) stated that a primary function of the modern family is the regulation of balances in the personalities of the adult members of both sexes. They saw the emotional support between husband and wife as one of the means through which this is achieved. This is important because the family is now relatively isolated from the wider kin network, which means that the couple is in a "structurally unsupported" position if things go wrong.
ii) Changes regarding irrational feelings and thoughts, isolation, self-centeredness and socializing should be actively tackled.
iii) Establishing rational short and long-term goals.

f) The role of the therapist

i)   The therapeutic relationship is very important and should be treated with respect all of the time.
ii) The therapist should convince the participants of new beliefs and changes that they should try. The therapist should hold on to the trust that was built in the relationship.
iii) The therapist should work with solutions in mind, then the negative and averse feelings of the participants will reduce.
iv) The therapist should always model the correct behaviour, positiveness and respect.
v)   The therapist should always be very well prepared.

2.7.3.3 Group counselling

Parents who seek professional support for their problems are far more likely to find themselves in a group setting rather than meeting individually with the counsellor. Reasons for this may be economical, but also the counsellor's time is used more efficiently and parents are able to benefit from the experiences of other parents. They see

that there are other families with problems as difficult or worse than their own, and this frequently gives them a new perspective on their own problems. "Coming together and meeting other parents of disabled children has given us courage! We used to hide our disabled children away but now we have the confidence to bring them outside our homes" (Lesotho Society of Mentally Handicapped Persons 2001:3).

There are different techniques in group counselling. The purpose can range from strictly educational to informal and unstructured groups where the emphasis is entirely on feelings rather than on practical problems. The number of sessions can also differ tremendously. Much thought should be given to specifying goals or integrating the group sessions into a systematic programme. Many parents are undoubtedly able to benefit from a well-organized discussion group made up of people with problems similar to their own. A few benefits follows:
1. It is comforting to be aware that there are families with similar problems.
2. There is an opportunity to talk about their problems with a group of sympathetic listeners.
3. The process leads to breaking down defences such as denial and this enables the group members to make more realistic decisions about their children.
4. Parents are often able to help each other with everyday management problems and with information about the availability of community services.
5. The support and encouragement provided by the group members in time of unusual difficulty is invaluable.

2.7.3.4 Parent education

Probably the single most important factor that contributes to parental acceptance of a child with barriers to learning is the parents' knowledge about the difficulty. According to Williams (2001:2) one of the best ways of dealing with this is to start to learn about the disability. Try to read as much as you can. Find out as much as you can about your child's diagnosis. Seek out information about that particular disability. Therefore the dissemination of information is so important. Parents frequently join a counselling group not so much to work out their feelings, but to obtain practical knowledge in the management of their child. When it is possible for the child to go to a school, the most heartening experience for parents is when teachers include their children in the classroom and encourage other children to work with them as classmates (Lesotho Society of Mentally Handicapped Persons 2001:2).

2.7.3.5 Genetic counseling

A particular concern of many parents is whether subsequent children will also have barriers to learning and whether their normal children might have affected offspring. As information accumulates about the inheritance patterns of various forms of disability, genetic counselling has assumed an important role in the overall management of the parents (Bennet 2003:17-20). Counsellors obtain the information, both about the probable cause of the disability and the pedigree of the parents. The chances are then determined for any subsequent child having disorders. Many parents need more information than just

the simple probability of having another exceptional child. If the disability is caused by a genetic problem, this cannot only be a severe blow to self-esteem, but the parents may require practical information about various forms of birth control and sterilization procedures. Information about adoption should be available.

2.7.3.6 Parents as teachers

"We realise that the way we treated our children at first may have made their disability worse" (Lesotho Society of Mentally Handicapped Persons 2001:1). Parents are trained to provide a more stimulating and enriched environment for their children because child-rearing methods have an important impact on the mental development of the child. "We know that with homogeneity in our classrooms we will have a system that is grouping learners and thus excluding and providing a sense of stability which is fatal to development. While in a system that can allow for and value diversity we will find inspiration to and ideas for development" (Eklindh 2001:68). Parent involvement is an important component in any child's development. The aim of educational programmes is to involve the parents to such an extent that they can easily become the teachers as well. The programme can range from training in self-care skills to language stimulation to specific training in cognitive skills to generally encouraging the mother to interact with her child more often. Cummings (2004:117) said that she could see that parents grow in confidence and knowledge. She also observed that the more parents are involved with their child's learning, the more it had an effect on their own personal growth and development.

2.7.3.7 Parents as behaviour modifiers

Most parents' concern revolves around day-to-day management. Behaviour modification techniques might be a solution to this problem. The principles of behaviour modification are so simple that the most limited parents are able to carry out the programme. Inclusion means being together. They learn something from us and we learn something from them (Lesotho Society of Mentally Handicapped Persons 2001:2).

2.7.3.8 Books for parents

Many counsellors recommend that parents read one or more of the many books that have been written about disabilities specifically for parents. This is a great way to gather information about retardation. Tait (2004:55) said that for those parents who do become involved in their children's learning there are many benefits, relating to both their understanding of their children and their own raised self-esteem.

2.7.3.9 Organising self-help groups

"Over the last two decades, community based rehabilitation programmes for people with disabilities have increased the coverage of services in different countries… Issues of "participation", "ownership" and "mutual support" are gaining increasing emphasis….Many field level programmes have started organising self-help groups of

persons with disabilities and their families, to enable them to access the benefits of developmental processes" (Thomas & Thomas 2003:49).

2.8   What about the future?

Parents can undergo all the stages of mourning and grief and get the best educational programmes together with counselling, but what they really need is constant support. The future is not at all predictable; therefore careful planning with the whole family should be a priority. Children with autism become adults with autism and most with additional learning disabilities will require care and supervision all their lives (Humphries 2000:1-2). Each sibling's expectations and future plans should be on the table. Realistic decisions about the exceptional child should be made and each one's feelings and plans should be taken into consideration. The aim of this is that each member of the family knows exactly what will happen if something unforeseen happens to the parents, e.g. a trust should be opened, a testament, who will become the primary caretakers etc. (Rose-jannes, pers. comm. June 2005). This is not an easy task, but once done, each member will feel relieved and prepared. This should be discussed with the child also. No parent wants to think about making a will or designating a guardian for a child. But when a child is born with a developmental disability such as autism or cerebral palsy, these uncomfortable issues take on greater urgency. Some families turn to financial planners who focus on children with special needs (Schafer 2004:2). What will happen after schooling has finished? "…the day eventually arrives when, poof!, your kid is suddenly an adult" (Baker 2002:2). About their job, parents may feel mixed emotions about the child with disabilities growing up and going to work. They may share the child's excitement about future possibilities, but they may also worry about the child's vulnerability of possible failure at a job. Helping children develop job skills is one of the biggest gifts parents can give because it enriches children's sense of self esteem and builds potential for their future" (SEE/HEAR 2004:1-2).

CHAPTER 3

METHODOLOGY

3.1   Introduction

In Chapter 3, the focus will be on:
- The qualitative interventions that were given priority in Chapter 2.
- The research design/plan will be discussed, followed by the investigation group/sampling.
- The measuring instruments and structure of the programme will then be discussed.
- The goals of treatment and factors that facilitate the effectiveness of the programme then follow,
- There will be an evaluation of the programme.

3.2   Research design

According to Huysamen (1993:11), the design of a research plan is the blueprint where information will be collected in a valid and economical way to test the research hypothesis. In this chapter this blueprint is described in terms of the goals of research, the research outline, purposeful sampling, instruments and techniques used and the analysis of acquired data.

3.2.1 Research goals

The broad goal is to establish the parent's feelings and emotions and the coping skills they have developed for themselves. The word emotion carries a lot of weight: indeed, it is overburdened with meaning … emotion simply indicates what might be called an experience of involvement. It is this experience that is emotion, not the subject's thoughts about their experience, or the language of self-explanation arising from the experience, but that immediate contact with the world through personal involvement (Barbalet 2002:1).

According to Berg (2001:3) quality refers to the what, how, when, and where of a thing – its essence and ambience. Qualitative research thus refers to the meanings, concepts, definitions, characteristics, metaphors, symbols and descriptions of things. Therefore, qualitative strategies like sampling, data collection and analysis have been used to arrive at a conclusion. A therapeutic goal, like the relieving of guilt and anxious feelings (through investigating the programme), is also aimed at.

3.2.2 Formulating of the research focus

3.2.2.1 It appears that parents of children with barriers to learning present with feelings of guilt, depression, anxiety, anger, shame, over protectiveness and relationship

problems. It also appears that parents of children with barriers to learning have a need for coping resources.

3.2.2.1 Having these coping resources available has a positive effect on parents' feelings and their way of living.

3.2.3 Research outline

Interactive qualitative research is an inquiry in which researchers collect data in face-to-face situations by interacting with selected persons in their settings (McMillan & Schumacher 2001:395). The purpose of this research is to describe and analyze people's individual and collective social actions, beliefs, thoughts and perceptions. The researcher interprets phenomena in terms of the meanings people bring to them (McMillan & Schumacher 2001:395).

Qualitative research is based on a constructivist philosophy that assumes reality as multiplayer, interactive, and a shared social experience interpreted by individuals. The goal of qualitative research is first concerned with understanding the social phenomena from the participants' perspective. Understanding is acquired by analyzing the many contexts of the participants and by narrating participants' meanings for these situations and events (McMillan & Schumacher 2001:396).

In this research, a case study was first used as a protocol, and many facts and questions arose from this interview. The interviewed person also helped with the designing of the research programme, but was not willing to be part of the project. According to Flyvbjerg (2002:66), a case study is the detailed examination of a single example of a class of phenomena. A case study cannot provide reliable information about the broader class, but it may be useful in the preliminary stages of an investigation since it provides hypotheses which may be tested systematically with a larger number of cases.

3.2.4 Sampling

A research problem has always at some or other stage to do with a population (Huysamen 1993:38-40). 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 generalize the results of the research (McMillan & Schumacher 2001:169).

The researcher made use of probability sampling (McMillan & Schumacher 2001:170; Berg 2001:30). Subjects were drawn from a larger population in such a way that the probability of selecting each member in each category of the population was known, though probabilities were not necessarily equal (McMillan & Schumacher 2001:170).

Yaffee (2000:4) stated that the sampling should be done so that the sample is representative of the population. For this reason it is important that the sample should represent the population and be unbiased.

As the sample had to be chosen randomly, the most effective way of getting a representative in each category of barriers to learning was to use stratified random sampling. According to Flyvbjerg (2002:78), the purpose of stratified sampling is to generalize for specially selected subgroups within the population. Samples were drawn randomly from each subgroup: the subgroups being epilepsy, autism, Down's syndrome, trauma and cerebral palsy. A non-proportional sampling was used. The researcher selected the same number of subjects in each subgroup of the sample. The two schools specializing in special education in Namibia, namely Dagbreek and Môreson, were used. One representative within each subgroup was chosen from each school. Thus four families were selected from Dagbreek and three from Môreson. The sample size was sufficient for the purpose of the research, namely to investigate the coping resources of parents that have children with barriers to learning.

3.2.5 Data collection techniques

For the purpose of this research, where a qualitative approach is used, the researcher made use of in-depth interviews, informal interviews, field observations, documents and artifacts and supplementary techniques like questionnaires. Qualitative techniques collect data primarily in the form of words rather than numbers (McMillan & Schumacher 2001:41). According to Alvesson and Skoldberg (2001:20), data can be described in vague terms as something empirical, often some event, often in the form of an incident, often in the form of some social interaction.

In-depth interviews were held with all the participants. Berg (2001:80) is of the opinion that interviews can be extremely rewarding and interesting situations for both the interviewer and the subject. Three interviews, plus one session purely for debriefing, were held with each participant over a period of time. There was no structured interview, but rather a few general questions to pursue the topic. The researcher's objective was to encourage the participants to talk in detail about the topic. The interviews were recorded and transcribed. This helped to get common trends and themes from their descriptions and experiences.

Because the city of Windhoek is small it was likely that we would bump into each other. It happened that participants shared some information or a thought in the spur of the moment during these encounters. Thus information was also collected through informal interviews.

The vast majority of the information was collected through fieldwork. The researcher was very fortunate to have direct interaction with most of the participants and could also witness their everyday social actions and family set-ups.

Documents, artifacts and the narratives of experiences and beliefs were also included:

a) Official documents

"… personal documents involve any written record created by the subject that concerned his or her experiences" (Berg 2001:227). The researcher was very privileged in that some of the participants shared their comprehensive medical files and communications with her, to and from various specialists, doctors, occupational therapists, institutions and medical aids. Various documentary sources of information were at her disposal, namely:

- Letters to the national newspaper seeking help to cover their medical expenses.
- Letters where they informed the church to no longer be a member because negative remarks from the church were presented to her.
- Very intensive educational programmes that were being followed at home with the child.
- School reports, worksheets and art works.

b) Personal documents

Very precious information from one participant's therapy notes. Photo albums were shown and there was sharing of dreams and hopes when looking through them again.

The use of supplementary techniques: Questionnaires were used to provide credible findings and to help interpret and analyze the findings. Telephonic interviews and consent letters were also part of this.

3.2.6 Analyzing the data

Qualitative data analysis is primarily an inductive process of organizing the data into categories and identifying patterns (relationships) among the categories (McMillan & Schumacher 2001:461). The researcher worked systematically in the process of categorizing and interpreting the data. A deductive mode of thinking was used at appropriate times. The interpretation or understanding of the situation also led to increased empathy. This experience is supported by Alvesson and Skoldberg (2001:54).

Some discovery strategies were used during the fieldwork. Many observer comments were written down during interviews and informal talks. Summaries about the interviews helped the researcher to re-focus and pinpoint important information or issues. New ideas developed during the course of time and where the researcher contradicted the literature it was important to revert back to literature and read about it again.

The process of pattern seeking was used to analyze the large amounts of data collected. Major topics were selected and put into appropriate categories. The search to identify patterns still continues from these topics and categories.

3.3 The research group and ethical considerations

According to McMillan and Schumacher (2001:169), the subjects under investigation are those individuals who participated in the study; it is from them that data were collected. Describing the population of interest identifies the subjects. The letter of consent to participate in the study is attached in Appendix A.

All the names were changed in order to ensure confidentiality. The researcher must ensure the rights, privacy and welfare of the people and communities that form the focus of their studies (Berg 2001:39)

Enclosing criteria for participants:
• Children should have barriers to learning and be in need of special education
• Parents should be willing to take part in the research project
• Parents should be willing to share their coping mechanism and expertise with others

There were no age restrictions for the parents. It was also important that the child should receive some form of special education. The parents were sometimes also in need and therefore provision was made that support groups be established from which they could benefit.

The subjects and corresponding parents are described in Table 3.1 and 3.2.

Table 3.1: Names of subjects and the subgroup to which they belonged.

Subjects	Date of birth	Subgroup	School
Claud	29-03-1989	Autism	Dagbreek
George	12-07-1992	Down's syndrome	Dagbreek
Jonathan	18-05-1984	Trauma	Dagbreek
Patricia	17-04-1991	Epilepsy	Dagbreek
Janine	30-11-1995	CP	Môreson
Pedro	11-08-1990	Epilepsy	Môreson
Ashley	12-12-1996	Down's syndrome	Môreson

Table 3.2: Names of parents and some corresponding demographic information.

Subjects	Language	Ethnic group	Family composition	Socio-economic status
Mr. & Mrs. Rose-jannes	German	German	Core family – 1 brother	Father – architect Mother – Manager of Autism Nam
Mr. & Mrs. Gibbons	English	English	Reconstructed family	Father – MD SAL Mother – Housewife
Mrs. Young	Herero	Herero	Single mother – no siblings	Cleaner
Mrs. Carew	English	Kenyan	Divorced – 1 adopted sister	Lawyer

Mr. & Mrs. Williams	Afrikaans	Coloured	Core family – 2 sisters	Mother – Auditor Father – Builder
Mrs. Wenneth	Afrikaans	Nama	Divorced – 2 brothers	Mother – Nurse
Mrs. Stoddard	Afrikaans	Damara-Nama	Single mother	Litigation officer

All the participants were very willing to share their personal experience, knowledge and demographic information.

3.4 Evaluation instruments / Structure of the programme

An interview is not just an informal chat but comprises a controlled interaction with verbal exchange as the main method of asking questions. An interview has a direction and a shape; it serves a specific purpose and it involves both the interviewer and the respondent in a dynamic relationship (Keats 2001:5). The research interview is not intended to be an agent of change, although participating in an intensive interview can alter a person's attitudes and later also his/her behaviour (Keats 2001: 19). The interview has the advantage that additional information can be obtained by probing the initial responses. Reasons for the participant's response can be explored and all questions can be responded to without loss (Keats 2001:20).

3.4.1 Initial interview

Because the researcher appreciates the importance of the relationship between the interviewer and the respondent, much care was given to the initial interview. The unbiased collection of data was a priority. Therefore a good rapport between the interviewer and the respondent was very necessary. Keats (2001: 22) is of the opinion that the interview begins when the interviewer makes the first contact with the respondent. This was made by the researcher through letters requesting their cooperation, followed by a telephonic conversation to set a date for a first meeting. The first interview was thus used to introduce the researcher to the participant(s) and to fully inform them about the purpose of the research project, to hand them a questionnaire, ask permission to record the conversation, build rapport and to set a date for the next interview. Cameron (2001: 70) made a few suggestions regarding the therapist's attitude, namely, that they should make eye contact, have a relaxed posture, their gestures should be natural and that they should smile.

These initial ways of making contact with the participants were pursued and were found very useful in determining their cooperation, attitudes and beliefs, which are all part of the coping resources under investigation.

See Appendix B – Structure of the interviews

3.4.2 Questionnaire

Questionnaires encompass a variety of instruments in which the subject responds to written questions to elicit reactions, beliefs and attitudes (McMillan & Schumacher 2001:40).

The reasons why the researcher made use of a questionnaire were to ensure that all participants were subject to the same questions and to ensure anonymity by using pseudonyms.

A questionnaire is an economical, reliable and valid technique to test attitudes and coping resources. The researcher used the guidelines set out in McMillan & Schumacher (2001:257-260) to ensure an effective questionnaire which were:
- Make the items clear
- Avoid double-barreled questions
- Respondents must be competent to answer
- Questions should be relevant
- Short, simple items are best
- Avoid negative items
- Avoid biased items or terms

Because of the confidential information on history, pregnancy and birth, some questions were in closed form. Where the participant's attitude and beliefs were asked, the open form was used. A word on its own does not actually say anything and does not convey "a whole thought". For this purpose, more complex semantic entities are necessary. This means one can build on words and arguments (Cruse 2000:90). A pilot testing of the questionnaire was conducted on a subject who was not willing to be part of the research project, but was willing to assist the researcher on the technical aspects of the project, as discussed previously.

See Appendix C – Questionnaire

3.4.3 Second interview

During this interview, the main question was centered on the real topic of research. In this particular case the question identified the participant's coping resources. What was their present position pertaining to financial means, support systems and spiritual involvement? What was their child's level of adaptation, had it changed, how did they try to develop their own cognitive mind? During this interview the researcher tried to get as many coping resources as possible so that effective pattern-seeking could be done. The researcher was also sensitive for paralinguistic and non-linguistic signs accompanying their language. Examples of paralinguistic signs are abnormal volume, tempo, pitch, and voice quality. Examples of non-linguistic signs include pausing, emphatic gestures, and gestures which metaphorically depict, for instance, direction of motion (Cruse 2000:9).

3.4.4 Third interview

This interview had two sections. In the first, the participants could describe why they do not cope. What were their cognitive struggles and emotional burdens like guilt, sorrow and over protectiveness? In the second section, they could give their advice and share their expertise.

This interview was used to inform the participant that the research was drawing to its conclusion (Keats 2001:25). Both the interviewer and the respondent should be able to go away feeling that they have participated in a satisfying and worthwhile exercise (Keats 2001:25).

3.4.5 Last interview / Debriefing

Obtaining information of traumatic events in people's lives can be very hurtful and stressful and bring back emotions which were not dealt with effectively. Debriefing is necessary to help participants as well as the researcher to escape from the grief and negative connotations and carry on with their lives and daily activities.

At this stage appreciation was expressed for their participating and an invitation to come back and talk or to find support was extended. Information was given on when the project would be ready for them to read.

3.5 Factors influencing the effectiveness of the research

There are always some factors influencing the effectiveness and success of a research project. A few factors contributed to making the research go not as smoothly as one would have liked. These factors include:

3.5.1 Waiting periods

There was a rather long period that passed between selecting the participants, sending out the letters and the initial telephonic conversation.

Busy schedules from both sides made that some of the participants were seen long before the others. The researcher wanted the interviews to take place at more or less the same time, but in the end it was impossible to fit everyone into a short-term schedule. Some participants took really long to complete their questionnaires and others did not want to take part in the project any longer. At the end the researcher had to proceed with a separate schedule for each individual. This was at times very frustrating, but on the other hand it also helped to plan and execute the other interviews much better.

One of the most beneficial results of the project was that the researcher got to know the parents personally and could accompany some of them to meetings and sport days, while

waiting for the other participants to respond. At these occasions, the participants really opened their hearts and one could really interact intensely. One particular participant would never have opened up in the normal time scheduled for an interview, but at home she could take time to convey all the inner and deeper feelings – even her own secret emotions.

Some of the participants even followed the interviews up with telephonic conversations pertaining to things that slipped their minds during preceding meetings. This was encouraging, since they were keen to conclude the project with the best possible results and solutions.

3.5.2 Time aspect

Because the participating parents were occupied with their own jobs, it was difficult to make appointments after hours. Only one participant suggested that the interview could be done during office hours. In addition to their career responsibilities all of them had other commitments that needed to be taken care of – mostly after hours. That is why the interviews were scheduled from 19:00 onwards during weekdays. There was also only one participant who preferred to work on Saturdays. This hectic time frame made it difficult, because people are tired after a stressful day and need to rest or take part in recreational activities. Because of this, a number of sessions had to be re-scheduled.

There was no time restriction to the interviews. Some of the participants took this time to talk about all their other problems as well. This made it difficult to control because they always related it to the fact of having a child with barriers to learning.

3.5.3   Venue

The researcher wanted to interview the participants in their own environment and place where they would feel safe and comfortable. It was also important for the researcher to observe the interaction between parents and child in their natural environment. Therefore the researcher suggested to participants to meet him or her in their own home. Some welcomed the idea, while another preferred her work place and another suggested meeting at the researcher's office. Participants were scattered right across town and it was a new experience finding their homes and observing the huge gap in the standard of living between participants.

3.5.4   Transport

It required very good planning from researcher and participants to work out strategies to solve the transport problem. Some participants had no means of transport and the researcher had to pick them up at their work and take them to their homes in order to do the interviews.

3.5.5 Language medium

Because of the fact that the research was qualitative and the data collection technique occurred through interviews, verbal communication was inevitable. Like the Namibian population, the participants were multicultural. They descended from Otjiherero, Nama/Damara, German, English and Afrikaans families. All the families could speak English, because it is the official language of Namibia, but most could speak Afrikaans fluently and preferred to be interviewed in Afrikaans. We agreed that it was not important how they said something, but rather what they said. One particular participant preferred to work with a translator. Her sister translated from Afrikaans to Otjiherero and back. This could be seen as a limitation to the research, because her real feelings could not be finely articulated when translated.

3.5.6 Diversity of the sample

The composition of the sample was very diverse. Participants ranged from biological mothers and fathers in a core family, divorced mothers, single mothers and reconstructed families.

Participants were chosen from different subgroups in the mental retardation continuum i.e. autism, Down's syndrome, trauma, epilepsy and cerebral palsy.

Participants also originated from different cultural backgrounds. Ethnic groups such as Herero, Nama/Damara, German, Coloured, English and Afrikaans were represented. Racial and ethnic identity varies as a reflection of the influence of a complex of factors that push and pull individuals towards diffusion and assimilation, or the maintenance of social-cultural distinctiveness within the dominant society (Curran & Gurevitch 2000:50).

A big discrepancy between the statuses of participants ranging from lawyers and architects to cleaners also occurred.

3.6 Evaluation of the research project

A profound evaluation of any project is imperative. Alvesson & Skoldberg (2001:245) suggests reflection, where reflection means thinking about the conditions for what one is doing, investigating the way in which the theoretical, cultural and political context of individual and intellectual involvement affects interaction with whatever is being researched, often in ways that are not obvious. According to McMillan and Schumacher (2001:69-70), there are a few guidelines for evaluating qualitative research. The researcher used this to assess the appropriateness and value of the current project.

3.6.1 The value of therapeutic interviews

The presence of the therapist is therapeutic in itself. Sometimes participants spontaneously just conveyed their experience and impressions while the researcher could just listen. Some said that it helped them to get rid of excessive feelings of guilt, sadness and anger.

The therapist would have liked support groups to emerge. The purpose is to identify those parents who are emotionally stronger to become the group leaders and to help and guide other parents going through the same experiences. The seed was planted and we are now waiting for such a group to emerge.

Some of the participants admitted the need for formal psychotherapy. Some preferred to be treated on an individual basis while others were willing to be involved as part of a couple.

Participants also felt that parenting and socializing skills were helpful and should be incorporated in their daily lives.

3.6.2 Structure of the project

The fact that the research project was planned and executed in a predetermined structured way proved to be very valuable. A semi-structured plan, according to which interviews were done, helped to come prepared to the participants and prevented a situation where we were wasting each other's time.

Participants were initially anxious but, due to the pre-planned structure, the researcher could put them at ease and created a non-threatening and comfortable environment in which the interviews could take place.

It was also good to know in advance how many interviews and how much time was needed for the participants and the research as a whole. This left the researcher with enough time for each participant, without creating a "hurry-up"-feeling. Participants were also particularly curious about the outcome of the project. The structure, which provided for all the envisaged activities, helped to provide them with a time frame when to expect the findings.

3.6.3 Attendance and sample attrition

When appointments were made or re-scheduled, participants attended them punctually. This could be regarded as an indication of project effectiveness. The participants' eagerness and sincerity could be ascribed to their desire to get value from the interviews and research.

Subject attrition (also called subject mortality) occurs in a study when subjects systematically withdraw or are lost during the investigation (McMillan & Schumacher

2001:190). This was also the case in this study. In a few instances fathers i.e. Mr. Rose-jannes, dropped out after the initial interview leaving his wife alone with the project. Suggestions to accommodate him on an individual basis were rejected by him.

3.7 Summary

The research methodology was described in Chapter 3. The research design, research group, evaluation instruments / structure of interviews, goal, factors influencing the effectiveness and evaluation of the project were described in detail.

The empirical findings will be described in Chapter 4.

CHAPTER 4

FINDINGS

4.1 Introduction

Every family deals with stress. For many families, the stress is just an inevitable accompaniment to modern life, a background source of white noise that ebbs and flows with schedules, special events, and the nodal points of the family life cycle. For many couples and families, extraordinary stressors enter their lives. These stressors are unanticipated events that disrupt family life and can potentially damage individuals and their relationships. It is also true that each couple and family is different and every stressor is unique (Catherall 2005:1).

Stressors may be positive or negative. The stress response is a combination of physical reactions, thoughts (cognitions), emotions, and behaviours (Resick 2001:2).

Whether the experience results in growth and enrichment for yourself and your loved one's or in a lower level of functioning depends largely on previous problem-solving abilities, cultural values regarding illness and health, and current levels of social and economic support (Hoff 1989:3).

4.2   Background information on participants

4.2.1   Participant A – Family Rose-jannes

a) Demographic information

This German couple forms part of the upper bracket of society in Windhoek. The husband is an architect and his wife a private secretary at a renowned company. She is also chairperson of a nationally recognized welfare organization. They have two children which include the special child and a younger son. When the genogram of the family was investigated it was discovered that the husband's aunt also had a disabled daughter. No other indications of hereditary could be traced.

b) Pregnancy and birth

According to the wife it was not a planned pregnancy. In fact, she did not want to have children. She also confessed that she smoked during the whole duration of the pregnancy. Other than the possible detrimental influence of this habit she seemed to be healthy. The birth was normal and lasted for only three hours.

c) Awareness

According to the mother, he was colic and "delayed overall". He sat at 11 months for the first time and started walking at 24 months. His agility is poor, he has depth perception problems while his hearing and eyesight are good. At the age of 17, it is still not clear whether he is right- or left handed. He has speech problems (no functional language) and his level of speech is severely delayed. Signs of alexia are present. Claud is now 17 and his speech ability equals that of a two year old and his gross-motor activities equals a three and a half to four year old. Looking at his psychosocial development he experiences sleeping problems, especially when he does not follow the correct diet.

His father and brother have a significantly positive influence on his life. The relationship between him and his brother is good, but normally he prefers to be in isolation. He is in a special school and went to a "kindergarten", but always in the presence of an assistant. According to the mother she became aware of the deviating phenomena when her child was one month old. From there on they consulted various doctors, occupational therapists and physiotherapists.

d) Impact on the family life

First of all, the family's sleeping patterns are seriously disrupted and this sometimes results in the husband sleeping in the flat underneath the main house. The lack of enough sleep for days on end makes them irritable and has a detrimental impact on the younger son's schoolwork. Thereafter even the family has to join the son with a gluten- and mealie free diet. He is also sensitive to tomatoes, milk and mushrooms which lead to further frustration. Furthermore, he only allows the mother to give him his medication leaving the father with the feeling of being left-out or rejected. Claud prefers to be separate and therefore they cannot invite friends over.

In addition, there is also a programme of the occupational therapist that must be executed by the mother each day. This is putting a lot of responsibility on her shoulders and it is very time consuming. It is also only the mother that can understand him and they have developed a language of their own. Consequently it is very difficult for the father to communicate with him. Claud and his brother have also developed their own language and they communicate in a distinct way when they play together.

For a long time it was very difficult to visit friends or public restaurants. Eventually they decided to divide their responsibilities in terms of time and space i.e. only one of them will go to church or town or friends at a certain point in time while the other takes care of Claud. Now the husband and other son do everything together, such as going away during weekends for fishing or hunting. Both parents started to indulge themselves in their individual jobs/careers and are excelling in these specific areas. Although the wife longs to do things together as a family, she allows for separate interests and does not force them to do things together. Each one is allowed to break away and pursue his/her own interests. Both parents used to be very social and are still popular among their friends. They had to adjust their lives dramatically to cope with the prevailing situation. They

have worked out strategies for themselves to satisfy their needs and to excel in their respective jobs.

e) Coping skills and environment identified

The mother describes her family strategy, as "one of survival". They have been through such a lot of difficulties that they have forgotten about the fancy things in life. The following skills were adopted to cope with the situation in their daily lives:

- One of her coping skills is to ensure that she feels worthwhile. She knows that she is the only one who can take care of Claud and who fully understands him. She tries to teach him basic skills such as dressing himself and communicating. Even the smallest achievements with her child give her the satisfaction of doing something worthwhile.
- Another coping skill is to recall the devastating feeling when the diagnosis was made, the unbelievable strength that carried her through the years, the tangible results and the awareness that it is going to be difficult. She shouldn't give in now.
- Immediately after the diagnosis she started to collect as much information as possible and is still doing so. This knowledge base provided a profound foundation on which the future coping mechanisms were built. The couple did everything in their ability to get help as early as possible. Against this background she developed a proper understanding of the disability. Therefore they are able to have empathy when things are not going as envisaged or planned. She refers to herself as "knowing more than the specialists do".
- Achieving tangible results with their child served as a very strong incentive to persevere.
- The mother is innovative in trying to improve her relationship with Claud. An excellent example of such innovation is that she started to write their own "dictionary" in order to improve his communication skills. This "dictionary" serves many purposes. In the first place she wants to make it easier on herself. Secondly, she would like to leave a heritage to the remaining family to ensure continuing communication with her son in case something happens to her. Lastly it could help parents with a similar problem to pursue the same.
- Claud is enrolled in one of the two special schools in Namibia, which also allows a little bit of free time.
- Another coping skill that works extremely well for this family is the fact that each have their respective extramural activities and they can be themselves at certain times. Both are very active members of society and enjoy the opportunities away from home.
- In this regard it is also important for the parents to allow each one to do their own thing and not to burden or constrict the whole family simultaneously. In this way they create room for each other to grow and develop to the fullest.
- A very important coping skill for them is to assist other people where they can. No problem is too big for this couple. Cathy is involved in organizing conferences at national and international levels and this, together with her own presentations, gives her much pleasure. When attending a conference in another country, she regards it as her vacation.

- They belong to Autism South Africa and she manages the Autism Society in Namibia.
- They maintain contact with other parents of autistic children, share information and experience and support each other.
- A very valuable coping skill is that they have made peace with the fact that they may not always be there for Claud. Alternative arrangements are provided for and this brought a lot of relief. They are living their lives to the fullest and they have no regrets. The younger brother will assume responsibility in case the parents pass away. In order to prevent an unexpected and impossible financial burden on the younger brother they founded a Trust and took out endowment policies to cover the concomitant financial needs.
- Information was gathered and a preliminary booking was made for "sheltered living". This means that if the parents pass away before the younger brother is able to look after Claud, he has the option to stay in a institute almost similar to a hostel.
- They are financially well endowed. The husband has a good stable income.
- They have a very good medical aid scheme covering most of the expenses pertaining to treatment.
- The parents said that they learned fairly early in their lives not to worry about what other people think and say about you.
- Don't take yourself too seriously if you think you cannot go on. (Do not underestimate your own coping abilities). You have far more strength than you can ever imagine.
- Both parents have reached a phase where they accept their child's disability and their inevitable circumstances.
- They also try to deal with their emotions effectively.

f) The value of the coping skills and environment

According to the family they have built on their strengths (i.e. intellectual ability, gained knowledge, perseverance, innovativeness, supportive institutional environment, financial endowment) and surmounted the weaknesses (irritation, negative feelings and attitudes, unworthiness, initial lack of knowledge) in their internal environment. Some of these constraints (insecurity, home/family confinement) were even changed into new opportunities i.e. social participation, insurance policies, taking part in conferences and societal arrangements. They succeeded in functioning as an entity and were relying very much on each other for help and support, triggering a process of mutual appreciation and respect.

It forced them to take some immediate actions and to plan for the future.

4.2.2 Participant B – Family Wenneth

a) Demographic information

The mother belongs to the Nama ethnical group and is fluent in Damara/Nama, Afrikaans and English. She is a single mother who raised three children and resides in Katutura. As

a nurse she is employed by the Ministry of Health and Social Services, stationed at the Katutura State Hospital. She is religious and is a member of the Old Apostolic Church. She is still grieving the sudden death of her talented second son at the age of 17 years. He was on his way to Germany as an exchange student, but tragically died because of a heart attack. Her oldest son turned schizophrenic overnight and her third son, Pedro, suffers from epileptic seizures. According to the genogram, Pedro's grandfather was asthmatic and his aunt a hypertensive patient. His grandmother from his father's side showed mental deviations. Among his uncles there is also a history of heart and kidney problems and poor vision. It was reported that Pedro used to see ghosts who are fighting with him and trying to eat him.

b) Pregnancy and birth

According to the mother the pregnancy was not planned. She did not mention any habit related abnormalities, but confessed that she suffered from depression and that it could have an influence on her health. Pedro was a premature baby and the birth was prolonged. He was colic, but other than that there were no problems reported immediately after birth.

c) Awareness

At the age of two he had his first convulsion. He was taken to the doctor who diagnosed him with epileptics. Despite the epileptic attacks, his mother still believed that he would adapt once he is taken up in a mainstream school. He went to a crèche at the age of four but did not improve. After a month at primary school, he was transferred to the Môreson Special School. The doctor was very informative and explained the whole phenomenon with its possible consequences to her.

In terms of physical development, he was breast fed up to one year, sat at 6 months, crawled at 7 months and walked at 10 months. His agility is average, hearing good, eye sight good and he tends to be right handed. Regarding his mental development, his reading, writing and spelling is poor, while his concentration is average. His mother tongue is Nama and he speaks it fluently. He can also speak Afrikaans and has no speech problems. His progression at pre-primary school, primary school and after school care is poor. Regarding his psychosocial development he shows signs of tension through nightmares and hyperactivity. Problem behaviours e.g. lying and aggressiveness do surface. His mother and nephew are significant positive persons in his life.

d) Impact on the family life

Pedro has certain food allergies and more of them are still being discovered. Help from a professional dietician was sought. Medicine is also prescribed which is given by the mother or the aunts. His upbringing was the sole responsibility of the mother, because the father left them for another woman. This was a very tough time for her, because she had these feelings of inadequacy and loneliness and on the other hand she had to be mentally strong for the sake of Pedro and his brother. Pedro sometimes gets aggressive and his

schizophrenic brother is not able to handle such a situation. He once held a knife against Pedro's throat. Fortunately the neighbours saw what was going on and called her. The mother feels very depressed whenever the brothers are fighting because they are all so dear to her.

As a family they also have their pleasant moments, especially when they are singing, doing window-shopping or preparing meals together. Attending church as a family is also a very encouraging experience. Her career as a nurse is very demanding. Sometimes she has to work night shifts and when she gets home in the morning, she still has to dress and feed both children, take them to school and only thereafter she can enjoy the luxury of a couple of hours rest until the routine of preparing for lunch, personal attention and assistance with home work starts again. At seven o'clock she has to be at work again. This routine puts a lot of stress on her and the little sleep has an impact on her quality of work and level of tolerance. The fact that her family members and the teachers at school assist her, serves as a huge support mechanism for her.

She has made friends with mothers of epileptic children and this mutual companionship and exchange of information serve as a welcome breeze in dealing with her own problems. She is a very positive person by nature and her career helps her to remain focused. She counts her blessings when she sees problems of a more devastating nature than her own in her working environment. She also tries to be instrumental in creating a positive working environment and supports her colleagues where possible.

e) Coping skills and environment identified

- Financial assurances in terms of a good medical scheme and a fairly good and stable income.
- She relies on professional advice and therefore they visit specialists in the medical field. She could go from the clinic, to general practitioners, to psychologists, to dieticians and eventually the specialist. For this reason they were in good hands from the onset.
- The specialist usually made time available to look after the mother's emotional/psychological well-being. Knowing there is someone who cares for her and whom she can trust means the world to her.
- Pedro is under medication on a continuous basis.
- They do a lot of recreational activities together and they enjoy being with each other.
- The mere satisfaction that he is enrolled at a good school and that his needs are properly addressed.
- The teachers stay in contact with the mother and keep her alert.
- Another coping skill is her personal burning desire that he should finish school and get a job.
- She cries a lot and this makes her feel better. After that she pulls herself together and carries on.
- She has a big family which supports her very much.
- She has neighbours who assist in watching the children when they are playing in the afternoons.

- She improves her knowledge continuously through reading a lot of articles in relation to epilepsy and the consequences.
- She works in a professional environment and makes use of the information and advice available to her. She has good working relationships with expert doctors and nurses.
- She also became friends with mothers who have epileptic children.
- The fact that she has a professional qualification and experience in the medical field.
- She deals with a huge variety of diseases/patients and realizes very well that there are people with more serious problems than her own and that there are still many reasons to be thankful.
- She is a very positive person and tries to exert a positive influence every day and in every situation.
- She is very religious and believes God has a special plan for her life.

f) The value of the coping environment and skills

There are times when she simply feels she cannot cope with the convulsions and abnormal behaviour of her affected child anymore, but when thinking about her family, friends and teachers supporting her, she finds new strength and encouragement to carry her own cross.
The medical environment surrounding her as well as her own skills in the medical field is also very reassuring. She realizes that she is well equipped to deal with an emergency situation more effectively than most mothers in a similar situation.

The fact that she is doing everything in her ability to improve Pedro's condition provides a great deal of comfort and makes her "feel good". Her personal desire to assist other parents and sick people in their moments of despair results in a strong incentive for herself to carry on and it creates a sense of worthiness.

As a religious person she puts her hope and trust in God Almighty to support and carry her through difficult emotional and physical situations.

4.2.3 Participant C – Family Stoddard

a) Demographic information

Dominique is a single mother who was never married. She and the father broke up shortly after the birth. Dominique and Ashley still stay with Dominique's mother in Katutura. Their home language is Damara/Nama and they are in the Evangelic Lutheran Church. Ashley is an only child. Dominique is a legal clerk employed by the Ministry of Justice based at the Magistrate's Court in Katutura.

b) Pregnancy and birth

According to Dominique it was a planned pregnancy and she was very healthy. However, there were some complications during the birth and a caesarian had to be done.

c) Awareness

Ashley was diagnosed with Down's syndrome a few weeks after her birth. As an infant, Ashley experienced problems with sucking, but Dominique managed to breast feed her up to 14 months. She sat at 8 months, crawled at 10 months and only walked at 24 months. Her agility and hearing is average and her eyesight is good. She writes with her right hand. Ashley only started to speak at the age of seven and still it is not fluent. Her reading and spelling is poor and her writing and concentration is average. Her progress at after school care is good, but it is average at school. Regarding her psychosocial development she shows some stress in the form of aggressiveness. Ashley shows signs of tension through hyperactivity. She is very social and has a lot of interaction with her friends and family. Her mother and grandmother are significant persons in her life.

d) Impact on the family life

Because the father left them, they moved back to the grandmother's house. Here they became a very devoted family. They try to consider each other and to help wherever they can. Dominique and the grandmother take turns in bathing, feeding and taking care of the schoolwork. Dominique's friends have also accepted her child and she takes her along when visiting them. There were some slight adaptations to the new situation, but according to her, they were not worth mentioning because she accepted her child as is and looks forward to what tomorrow holds. Her religion is important to her and provides her with a lot of hope and encouragement. She also gets a lot of support through her family and friends. At that stage Dominique was without a job and had no medical aid. She said she was really struggling, until years later she had a stable job.

e) Coping skills and environment identified

- Ashley's grandmother is a very significant person in her life and Dominique mentioned that being one of her coping skills. Life would be so much difficult if Ashley did not accept the grandmother as the one caring for her.
- It is also a big relief for Dominique that Ashley accepts her and loves her as a mother. She said that it would break her heart if Ashley felt otherwise.
- The sister on duty at the clinic was very caring and informative and Dominique felt comfortable and safe with her. She expressed all her concerns and the sister did her best to answer, give guidance, assistance and hope. This helped her a lot and she is still today relying on some of the information and guidance.
- Medication and the concomitant effective treatment serve as valuable coping skills. Without it, their routine and lives would be so different.

- Dominique is trying to spend quality time with her daughter. Therefore it was important to determine Ashley's interests and now they are focusing on doing it together as part of their fun time.
- Finding space and having her child enrolled in a special school brought relief and Dominique is adamant that she should finish school.
- Dominique is grateful to have a good stable job, which offers a good salary and benefits like medical aid and pension. The people at work also show their understanding for her situation.
- She also confessed that she is grateful that there are no other problems regarding Ashley e.g. epilepsy etc.
- Dominique is religious and as a Christian she learnt that one must accept that all people are not the same. She just accepted that her daughter's specific problem couldn't be changed. This made it easy for her to fully accept Ashley for the person she is.
- They have wonderful friends who accept Ashley and who are good to the family. Their friends take them along to church and town.
- Her mother is her biggest support system. She takes care of Ashley while Dominique can carry on with her career. She is very grateful to the Lord for having her mother available.
- In general, Dominique is a very positive person and this keeps her going to face the difficulties in life.
- Dominique also mentioned that Ashley is her first and only child, so she has no one to compare her with. Ashley is her only experience in having a child and it gladly happens to be a good experience. She added that Ashley has a lovely personality and is very active.

f) The value of the coping environment and skills

Dominique has the benefit that she can carry on with her career and earn money while her mother is caring for her child. Furthermore she attends a good school during the mornings. This means that Dominique can live a normal life, excel in her work and still socialize with friends.

4.2.4   Participant D – Family Williams

a) Demographic Information

Janine is the second of three children. They are staying with their parents in Khomasdal. Her father is a builder and her mother a bookkeeper. Their home language is Afrikaans. According to the genogram there are other physical deformities in the family as well.

b) Pregnancy and birth

Janine was planned and her mother had no adverse habits like smoking or drinking. Long after Janine's birth it was discovered that the mother and father have incompatible blood groups. Due to this the mother, Genna, had two miscarriages at two and a half months

and three months respectively. She also had a threatening miscarriage with Janine at six months. Janine was born prematurely and the labour was prolonged – nearly three days. She mentioned that there were complications and she was a colic baby. Genna also confessed that Janine is partly water headed.

c) Awareness

Both parents suspected that something was wrong immediately after she gave birth. When she was 5 days old she developed jaundice. She was rushed to Windhoek by ambulance and had a blood transfusion. She then developed muscle spasm. The pediatrician then informed the parents that she would have difficulty walking, and suggested a brain scan. A second opinion was obtained from another doctor with the same prognosis. He added that the ball and claw disintegrated. She was bottle-fed up to 6 months and sat at 36 months. She couldn't crawl, but instead slid on her bottom. She started walking at 108 months. Her hearing and eyesight are good and she is right handed. Her mother tongue is Afrikaans and she started to speak at the age of 8 years, but is still not fluent. She is unable to read and write, but can concentrate for short periods.

Janine started school at the beginning of this year and this event was an absolute highlight for the family. Regarding her psychosocial development Genna stated that Janine is hyperactive, but socializes without problems. Her brother and sister and parents are significant positive persons in her life.

d) Impact on the family life

The fact that they were exposed to other family members with similar or other disabilities made it a lot easier for them to accept their situation. They said they were able to handle the pressure from society and the demands to care for her as they knew how to work with people with disabilities. Both parents said that their relationship with God improved and that is one of their main coping mechanisms. As a family they received a lot of support and donations. They are a close family and the love and mutual acceptance among them is visible.

e) Coping skills and environment identified

- The fact that this family was exposed to such a disability before made them extremely well prepared when realizing that they also have a daughter with a similar disability.
- Both parents have a good relationship with the doctor and they have a good faith in him. The doctor was always available to attend to their physical and emotional well being and they could rely on him during times of difficulty.
- They have a good medical aid scheme, but because of the excessive time spent in hospital, in visits to the doctor and medical treatment, the benefits were exhausted quickly. They have had to rely on support and sponsors from the public, which they received in abundance.

- A very experienced psychologist who really cares about their troubles also supports the family. Her door is always open and this gives the family substantial peace of mind.
- Both parents are meticulously involved in Janine's rearing. They show tremendous appreciation and respect to each other and in this process their biggest support system is seated within themselves. As such they serve as an excellent example to the other children and friends. When, for example, Janine was rushed to hospital from Rehoboth to Windhoek Gerhard (her father) was working in Grootfontein (almost 500 kilometer away) and he left the building site without any hesitation and hurried to Windhoek to support his wife and to be with his daughter.
- Because they've accepted her with her shortcomings and enjoy doing things together, they promote her interests extensively. Janine thrives under all the attention.
- The parents were very concerned about Janine getting absorbed in a special school. Fortunately she was enrolled at the beginning of 2005 which removed a lot of stress from their shoulders. Although she can drop out at any stage when it becomes too much for her, they wanted to give her the opportunity to attend school. Janine is happy in school and made friends easily.
- This family is benefiting from an extensive support system. The people at both parents' work are continuously involved and sincerely interested. Their families as a whole are supportive, understand the situation and are of great assistance through their inputs and cooperation.
- The parents have worked out hand signs to communicate and this proved to be very effective. They are also teaching her key words so that she can communicate her needs to them.
- The family is deeply religious and they are vesting their trust in the Lord. They pray together as a family and praise Him for any positive change – physically and emotionally. They confessed that their relationship with the Lord has become stronger, better and more personal since Janine's birth.
- The parents are feeling comfortable that they did what they could to get the best help possible for Janine's condition. They consulted specialists, doctors, occupational therapists, clinics, psychologists, internet, media and support groups.
- They have already agreed with some family members to take care of Janine in case they pass away unexpectedly. This was hard, but it had to be done inevitably. They also gave signing rights to these family members on their cheque account in case of emergencies.
- They still have hopes and dreams for Janine, and are not prepared to abandon them. They desperately want to see her being more independent and to help herself.
- Both parents love this child dearly and fully accept her.

f) The value of the coping environment and skills

Having coped so well with the situation enabled both parents to build their respective careers. There is an atmosphere of peace, tranquility and understanding in the house and they can spend quality time with all their children. They are able to focus on what is important and can ignore unnecessary time-consuming exercises.

4.2.5 Participant E – Family Young

a) Demographic information

Jonathan is a Herero speaking boy living in Katutura. He is the first of three children. His father is a farmer and his mother a cleaner. There are no signs of mental illness in both the families. They are from the Ruwno denomination.

b) Pregnancy and birth

Anne, Jonathan's mother, admitted that the pregnancy was not planned. Her health was in excellent shape and she had no habits of smoking or drinking. She was in labour for four hours and gave normal birth to a son of 3 kg.

c) Awareness

Jonathan was a colic baby and showed various allergies. He reached his developmental milestones at the appropriate ages. He was breast fed up to 8 months, sat at 6 months, crawled at one year and walked at 14 months. His agility is good, hearing and eyesight also good and he is right-handed. Regarding his mental development, he started to speak at 18 months and could speak fluently at the age of three. He was fluent in both Herero and Afrikaans. At the age of seven, Jonathan was in a terrible car accident and sustained serious injuries to his head. Anne suspected that something was wrong when he recovered. She went from doctor to doctor, but no one could explain what was wrong. Only about a year later, a new doctor diagnosed him as mentally retarded. He had serious speech problems (stuttered). He couldn't read, write or spell and his concentration was very poor. His progress at pre-primary and primary school was very poor. Regarding his psychosocial development he has sleeping and eating difficulties. He is very sociable and a Herero boy living near his home is the significant positive person in his life.

d) Impact on family life

The raising of the child was solely the responsibility of the mother because the father lives on the farm. Her biggest concern was where and whether Jonathan would be able to attend a special school. Luckily he was enrolled and Anne was employed at the same school. This gave her peace of mind, because she could escort him to school, was around if her help was needed and she knows all the teachers personally. The dynamics in the household did not change much, because he is the oldest and the others still respect him for that. Her friends and the two siblings are at times sad for what had happened to Jonathan, but they try to act as normal as possible. Anne's concern is about his future – she trusts that he will get a good job and be happy.

e) Coping skills and environment identified

- Anne said that Jonathan has no deviating problem behaviour. This means a lot to her, because she can go to work having no extra worries about Jonathan.

- She also feels no guilt that she did something wrong during her pregnancy. His condition was caused by an accident and there was nothing she could do to prevent it.
- Anne accepted that it was an accident and holds no grudges against the drunk driver who caused the accident.
- Anne regards herself very fortunate to be part of an excellent medical scheme. She uses it wisely in order to be prepared for tomorrow.
- She tries to carry on with their lives as normally as possible, doing their daily tasks together. This alleviates the feeling of being sorry for him.
- She is also stimulating his interests and because she loves doing this it does not feel like an additional burden to her.
- She is also very grateful to the principle of the school where she is employed, because he ensured that Jonathan was enrolled there. The schoolteachers form the basis of her support system.
- Anne has a special aptitude for working with disabled children. She takes care of an autistic child after school and during the holidays.
- It was very important to her that he should finish school. Finally Jonathan completed his school career successfully and is presently getting in-service training for a future job.
- Her whole existence and fate is founded on her religion.

f) The value of the coping environment and skills

With all the coping mechanisms at her disposal Anne feels in charge of her life and handles her children and house the way she regards as prudent. She has lots of support from people in her working environment, which enables her to enjoy her work. The fact that she made peace with Jonathan's trauma motivated her to carry on. She even bought her own house and is very proud of that.

4.2.6 Participant F – Family Carew

a) Demographic information

Patricia's parents were divorced shortly after her birth. Her mother, Nicky, is a lawyer at one of the most formidable companies in the country and thrives in the life style of the rich and famous. She is Herero speaking and an outspoken Christian. Patricia was the only child, but recently a girl was adopted. According to the genogram there were no signs of retardation in any of the families involved.

b) Pregnancy and birth

The pregnancy was planned and Nicky had no difficulties other than a delayed delivery. She was 36 hours in labour, which led to a caesarian.

c) Awareness

Patricia was a colic baby. According to the mother, Patricia developed slowly up to the age of 9 months. She developed high fever at 9 months, which resulted in convulsions. At that time they were living in the UK. She was then taken to a clinic and the nurses picked up the phenomenon. The psychologist working at the clinic revealed the fact that Patricia is autistic. Nicky breast-fed her up to 6 months. Patricia sat at 9 months, crawled at 78 months and walked after the age of 7 years. Her hearing and eyesight is good and she is right-handed. Regarding her mental development she is unable to read, write or concentrate and she is non-verbal. Referring to her psychosocial development, she is restless and unable to sleep through the night most of the time. She shows signs of tension by being hyperactive, but is very sociable once she sense that the other person recognizes and accepts her. Her mother, the caretakers and her sister are significant positive people in her life.

d) Impact on family life

This devastating news was too overwhelming for the husband and he stayed in the UK. After the divorce, Nicky struggled on her own to finish her studies as a lawyer and to raise Patricia. She stated that there was good help available from the professionals and social welfare framework. Once she got her degree, she returned to Namibia, where she started her career. She appointed two people to take care of Patricia on a full-time basis and this took the excessive work load from her shoulders. Nicky witnessed that she would not be able to work outside her home without these employees. Patricia needs to be taken care of most of the time. When the caretakers are enjoying a weekend off, the load of taking care of Patricia fulltime can become overwhelming for Nicky. She sleeps restlessly and needs attention intermittently. Consequently Nicky is exhausted at the end of the weekend. She longs for a daughter with whom she can have a normal mother-daughter interaction. She still has dreams for Patricia, but altered it dramatically e.g. she prays that she can walk independently and feed and dress herself. Her family does not offer any help and she learned not to ask. She would rather try to do things on her own. Therefore one of her coping mechanisms is to expect little help from others. If help is however offered, she is happy to accept it. She is religious and "my faith and the gospel of Jesus Christ taught me to accept everything that happened to me as God's will". They have designed their lives around Patricia's situation and try to treat her as normal as possible. Luckily Nicky is financially in a position to alter the house and the surroundings to suite Patricia's shortcomings.

e) Coping environment and skills identified

- Although Patricia is autistic, the mother is proud to say that she does not show any behavioural problems. It is just a pleasure having her around in the house.
- After Patricia's birth they met a doctor who really cared for their emotional well-being but unfortunately he left Namibia about five years ago.
- Nicky stated that Patricia has no allergies and fortunately she can eat anything.

- Nicky speaks of her two caretakers with the utmost respect. She admits that she cannot cope without them. They take care of Patricia, feed her, give her medicine and play with her.
- Having caretakers on a full-time basis, even during most weekends, makes it so much easier and it creates a relaxed atmosphere at home. This enables her to truly enjoy their weekends and holidays with Patricia.
- Nicky takes much interest in Patricia's well-being and therefore tries to develop and establish new skills in her on a continuous basis.
- Patricia is also a learner at Dagbreek Special School and is allowed to attend school accompanied by her assistant. In this way the two assistants can also relieve each other.
- Nicky is very aware of Patricia's disabilities and therefore it is not crucial that Patricia finishes school. However, she is grateful and it gives her peace of mind that the opportunity is given to her daughter.
- When Patricia was nine months old they were living in the UK. From the onset Patricia was exposed to the best professional aid at hand. She also had a large and good medical support system. This means that she could build the child's future on a sound knowledge base.
- Nicky admitted that it took several years before she could abandon the blame for herself and the doctor who treated her child at the stage when the condition developed. This made her feel free and she could face life with a new spirit again.
- A huge mitigating factor for Nicky is that she managed to ignore Patricia's tantrums and demands. Since doing that, she could start having "a new life at home".
- She also stated that she expects no or little help from others and that made her independent from other people's "you owe me" mercy.
- Nicky is also religious and is an active member of the Gospel of Jesus Christ church. She believes that eternal life will change everything for Patricia.
- She also learned to accept that what happened to Patricia was the will the God and not she or anyone else could change that.
- Nicky adapted by re-arranging her life style to accommodate and suit Patricia. She even built flats for the assistants on the same premises.
- The fact that everyone tries to treat Patricia as normal as possible also serves as a mitigating factor.
- Nicky is financially very well off. This enables her to occasionally fly the whole family as well as the assistants overseas where:
  - The assistants can get training
  - Everyone gets the opportunity to relax and have fun
  - Especially Patricia would be exposed to fun and recreational activities i.e. swimming with dolphins etc.

  The purpose is to have everyone "recharged" for their tasks and responsibilities once they are back.
- She established a trust and trustees for Patricia if something unforeseen happens to her. Patricia, her sister and the two caretakers would be able to continue the lifestyle they are used to by continuing to live in the house and following their normal routines. A professional nurse will also come and stay with them.

- Nicky has a very demanding job and is in and out of the country. Attending international forums helps her to focus on her work. Strangely this helps her again to spend quality time with her daughters when she is home.
- She has a good medical aid scheme, which covers all Patricia's expenses.
- Nicky sees a psychologist occasionally when she feels she cannot cope with her own emotional fluctuations. In this way she manages to stay on track.

f) The value of a coping environment and skills.

Her ability to persevere and qualify herself as a professional under difficult circumstances paved the way for having a very good career and income. She excelled in her career and became what she always dreamt of. This enabled her to create an environment in which she could cope and thrive as a parent. At the same time she made it possible to ensure the best possible living standard and quality of life for Patricia as well as the other daughter She is mentally and psychologically a very strong woman who is able to centre her planning and life style around the needs of her disabled child without neglecting the other one.

Nicky said her philosophy is built on a statement made by Albert Einstein: "Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning." Indeed, you should not stop questioning your own ability to find solutions for any problem.

4.2.7 Participant G – Family Gibbons

a) Demographic information

George lives with his mother, Lara, stepfather and stepsister in Windhoek. George's parents got divorced shortly after his birth. His mother re-married and George's new father is very fond of him. He totally accepted George as his own and is intensively involved in every aspect of his life. George's father is a marketing manager and his mother is a bank clerk. His sister is now fourteen and in secondary school. Their home language is Afrikaans.

b) Pregnancy and birth

George was planned and therefore the mother adopted no bad habits like smoking, drinking etc. She was very healthy and she gave normal birth with the help of an induction. There were no problems during the birth.

c) Awareness

The mother became aware of the deviating phenomenon three days after birth, when the doctor informed her. He explained to them what "Down's syndrome" is and what it entails. George was actually a healthy child with the normal infant ailments. He weighed 4,1 kg at birth and was bottle-fed. He sat at nine months. His agility, hearing and eyesight

are good and he is left-handed. According to his mental development history, he started to speak at the age of 15 and is still unable to speak fluently. He speaks in a telegraphic way, but his parents, siblings and their friends can understand him. Whenever George tries to write he writes from right to left. His progress in school can be described as average. He shows no symptoms of stress, tension or problem behaviour. He socializes extremely well with people, but has no specific friends. His stepfather is the most important person in his life.

d) Impact on the family life

George has no allergies, sleeping disorders or behavioural problems. He does not use medication or other professional assistance like occupational therapy. George can function independently – he can bath and dress himself. In general, it is reported that it is nothing else than a pleasure to have George around and they never experience him as a burden. His mother admitted that his biological father could not bear the thought of having a disabled child and subsequently left them shortly after birth. Her parents cared for George during the first two years of his life. This period represented a very difficult time in the life of the mother. Then she met this wonderful man who cared for them, loved them and totally accepted George as if he was his own child.

e) Coping environment and skills identified

*   George is described by his mother as a "heavenly child". She says that his presence is causing no trouble whatsoever and this makes is easy for them to carry on with their daily lives. He is not demanding in terms of their time and he is very, very special to them.
*   At first she thought she did something wrong in the eyes of God and that he wanted to punish her. It was only later that she learnt it was an unfortunate chromosome bonding that caused the deviation and that it could not have been prevented. This came as a huge relief to her and gave a new meaning and justification for her existence.
*   Therefore she learnt to accept her situation and to appreciate her child as he is. Thereafter she could face the world with the necessary confidence again. There was no need to hide him anymore and they could do things together.
*   She was still in hospital when her nephew brought a visitor who also had a Down's syndrome child and that person told her everything there is to know. This information formed the basis of her new approach to life and fueled her to discover and reach new horizons.
*   Her doctor also attends to her emotional well-being. He knows their background and is always available to assist George.
*   They have a good medical aid scheme, which enables them to balance the bill.
*   Her parents' assistance is of immense importance to her. They took care of George for the crucial first two years and this was followed by continuous moral support and encouragement.
*   Her husband is undoubtedly her biggest support pillar and perhaps the figurative life artery that keeps her heart beating. He loves George as if his own and supports him in

everything he is doing. As father and head of the family his contribution is indispensable.

- Holidays and sight-seeing trips are high on their annual priority list. Recreation and quality time together form an integral part of the long-term treatment of George and each one who looks after him.
- Their desire to profoundly understand George paves the way for appropriate responding to his needs and to create an environment of tranquility and peace in their home. This approach can be regarded as on of the best ameliorative measures to prevent tension and failure in dealing with a disabled child.
- They stimulate his interests and are very much involved in what he is doing. This strengthens the cohesiveness in the family and ensures quality time together.
- He is also enrolled in one of the special schools. Although he is not academically strong it teaches him to be independent and allows the parents to concentrate on what is important for them too.
- At first she thought no one would like to be friends with her, but later on she learnt that she has wonderful friends who also support her.

f)   The value a coping environment and skills

Lara said that if it wasn't for the favourable coping environment described above she would never have developed a proper understanding of the problem, she would not be able to bridge certain misconceptions and the loser in the final instance would have been the family as a whole. The combination of knowledge, a loving family environment, friends and family members who really care for you, and a supportive institutional framework (doctors, therapists, schools, clinics etc.) is indispensable for successful raising of a disabled child.   She learned to look the world straight in the eye and not to be ashamed of her child. She also realized how grateful she ought to be. She has so many blessings and her life is not at all bad or disrupted. She is also now in the situation where she offers her help to other people and assists them through difficult times on hearing their diagnosis.

Personal skills need to be developed and continuously improved to cope with such situations. A sound relationship between husband and wife with love as the outstanding feature will be a certain recipe for success. This is what her second husband gave her and it trickled through to the children with their disabled child as the main beneficiary.

4.3   Results and discussions of case studies

4.3.1 Emotional phases following problem identification

When a discrepancy develops between parents' expectations of their child and the reality, it can put them under tremendous pressure (Lessing & Strydom, 2001:4).

Lessing and Strydom (2001:4) made use of three emotional reactions that parents tend to show when they learn their child has a problem.

- Cannot accept the problem; therefore they reject the child
- Feel concerned and this leads to over-protectiveness
- Accept the child and try their best to provide for his/her needs

Gargiulo (1985:22-37) developed an extensive model to describe the reactions of parents and divided it into three phases, namely primary, secondary and tertiary phases. This model was used to evaluate and address parents' general reactions.

4.3.1.1 Primary phase

a) Shock

Every single parent experienced the emotion of total shock and disbelief when the diagnosis was given. None of the parents expected a child with barriers to learning; therefore the overwhelming news left them lame and trembling. Exclamations like " This is not true", "This could not be happening to me", "You lie, I want a second opinion", were uttered. Most mothers confessed that they over-reacted and their thinking was very irrational. Some parents cried a lot and one started to pray for almost the whole day. All of them reported that they felt very discouraged.

b) Denial

It is human to deny something that does not correlate with your way of doing or thinking. You try to get away from reality and the consequences associated with the problem. Lessing and Strydom (2001:6) stated that parents experience feelings of denial because of the uncertainty and insecurity the future holds and they doubt if they are competent to help their child.

One particular parent is still so much in denial that she did not even try to find out what the origin of Down's syndrome is. She blames the doctors that made her wait while in labour. Another parent said it was because she was defending someone in court in a very tough case, where she gave everything and won, therefore her child is autistic. Other parents said that there is not much wrong with their child, and that the child will recover in time with the right help. All the parents went for second, third or fourth opinions and still even asked the researcher for confirmation whether there is something wrong with the child. It is sad to see the stacks of reports from different paramedical professionals and still the parent is in search for a final answer. In one case the parent immediately started to get professional help all over the world and wanted to devote her life to helping her child.

Denial is a precursor for acceptance, because it gives you time to re-organize and restructure your life (Lessing & Strydom 2001:6).

c) Sadness and depression

Overwhelming feelings of sadness can dominate you entirely. Feelings of disappointment, personal failure and guilt, concern for the child's future and the family setup, feelings of loss and grief, excessive crying and withdrawal were all experienced. One parent described it as nostalgia, because of the traumatic accident her child was in. Nostalgia is a direct means of attributing meaning to oneself and one's activities. It is a way to express the discontents of today. Nostalgic stories attribute quality, caring and altruism to the past and find them missing in the present. They are infused with sadness (Barbalet 2002:102). Some parents suffered from depression when the sadness continued for too long and some parents never got out of the depression. One parent described her feelings as wistfulness. Depression can also be the result of one's own inabilities and faults that could have been avoided. Lessing and Strydom (2001:7) are of the opinion that sadness is a natural and useful reaction because it forces parents to go into a transition period where they can alter their dreams by accepting reality. It is necessary to grieve and show sadness, because it shows the progression from the shock phase.

4.3.1.2 Secondary phase

Feelings of ambivalence, guilt, anger and shame are experienced in this phase.

a) Ambivalence

Some parents had the shocking experience of feeling ambivalent towards their child. In some cases it was the fathers who rejected the child accompanied by feelings of guilt because they did not meet their responsibilities, they left the family and went on with their separate lives. One parent tried to compensate for this feeling by totally dedicating her whole life to the child, and others got assistance in the form in full-time caretakers as they excelled in their work. Some got annoyed when people empathized with them and some tried to seek empathy wherever they went. One parent was deeply frustrated with her situation and even thought of either leaving the family or suffocating the child.

b) Guilt feelings

This is the one feeling that was experienced by all parents. The guilt switches from judgments that they did something wrong in the past, to how they can give their child a better life, to confessions about what they neglected to do during the pregnancy. All the parents felt that they could have done something to prevent it. One parent confessed that she did not know that it was normal to feel guilty. "Some feel guilty that they are not experiencing what they believe to be the appropriate amount of sadness" (Worden 2000:45). She felt so relieved that she changed her outlook dramatically.

c) Anger

According to Lessing and Strydom (2001:10) there are two kinds of anger:

- It is generally accepted that parents ask: "Why me?" This question is normal and could be rationalized.
- The second way is to misdirect anger where other people should rather suffer the consequences. A lot of resentment was expressed towards the medical profession, that with all the advanced technology they could still not manage to pick up some of the deviations. According to Worden (2000:43) this anger is real and it must go somewhere, so if it is not directed toward the real target, it may be deflected onto other people such as the physician, the hospital staff or a family member.

d) Shame and embarrassment

"In the history of peoples, shame has always been associated with honor and pride." (Kaufman 1989:5). In the research conducted it was obvious that very few parents struggled with this emotion. In exceptional cases the thought crossed their mind, but in general they said that they tried to accept the child and did not feel ashamed by the child's presence. There was one who hid her child before she was properly informed about the real cause.

4.3.1.3 Tertiary phase

When the shock and disappointed have shifted to the background a bit, final reactions are forthcoming.

a) Negotiating

This is a very personal feeling. Parents were not open to speak about it, but when pushed some of them confessed that they still pray for a miracle or would keep on searching for new medical technology. Some are negotiating by "If You heal my child, I will devote my life to the church", etc. This phase is essential in order to accept the reality.

b) Adapting and re-organizing

Parents now begin to realize that the problem will not disappear/vanish. They start to get involved in projects, workshops, try to regroup with friends and plan for the future. Some parents established trust funds or altered their will. Assistance was sought in the form of nannies or day care. One parent sent their healthy son away to complete his schooling, so that enough attention could be given to the ill-fated child.

c) Acceptance

"Only people who are capable of loving strongly can also suffer great sorrow, but this same necessity of loving serves to counteract their grief and heals them"
 (Tolstoy as cited by Worden 2000: unnumbered)

There is a sense in which mourning passes, when people regain an interest in life, feel more hopeful, experience gratification again, and adapt to new roles (Worden 2000:19).

Most of the parents in this research had reached the point of acceptance. They saw the problem and actively tried to understand and handle it. Previous reactions fluctuated as the situation changed, but they had at least arrived at a point of acceptance. Some parents witnessed that they accepted their child in the same way as others and did not distinguish between them. One said that since it was her only child she could not compare and therefore she fully accepted the child. Another stated that their child was so lovable and cute that they just could not refrain from accepting and loving the child.

4.3.2 Qualitative interpretation of emotional reactions

Family members appear to engage in a circular process through which parents and children respond to one another's stress responses, with the parents ultimately serving as the model for how to cope with the traumatic event (Catherall 2005:81). The family response patterns that meet the criteria for persistent re-experiencing of the traumatizing event include the following:

- The parents spend a significant amount of time and attention on the overall health and welfare of the child;
- They focus on the possibility that the child may die;
- They have anxiety about a prognosis of permanent disability;
- They have many fears about the child's unknown future; and
- They are preoccupied with the child's specific injuries and associated pain.

The experts observed that the families would be preoccupied with these concerns and would ask the same questions over and over again, soliciting answers from physicians, nurses and other support staff (Catherall 2005:82).

This indicates that the majority of family response patterns focus on some aspect of (a) the child's experience of the traumatic event, (b) the medical care being provided, and/or (c) the child's future functioning (Catherall 2005:82). Family members are concerned about personal and family vulnerability, exerting significant energy to convince other family members that everything is going to be alright (Catherall 2005:83). Catherall (2005:83) supported the belief that family members demonstrate affective, cognitive, and behavioural changes following the traumatic event. He proposed the term systemic traumatic stress for the sudden demands imposed on each member of the family system and the resultant changes in relationship patterns. If family members do not attend to the stressors of the environment, then familial interactional patterns could escalate into arguments, resentments, triangulation, attention-seeking behaviours and fault finding / blame.

Catherall (2005:84) is also of the opinion that avoidance of feelings is normal and more often a sign of being overwhelmed, rather than an indication of an absence of feelings. Therefore, it is important for family members to have space for quiet reflection and attentive listeners who allow them to speak when they are ready. Family members also demonstrate symptoms of increased arousal and will show evidence of attempts to maintain some semblance of control in their lives. Finding a reason for this catastrophic event (or a source of blame) is an intellectual process that allows family members to

avoid feelings of fear and helplessness and enables them to feel more in control of the situation.

4.4 Cumulative summary of participant's experiences

Weaknesses	Threats	Strengths	Opportunities
• Habits: Smoke during whole duration of pregnancy • Lack of knowledge and experience: • Father feeling left-out or rejected • Feeling inadequate and lonely • Feeling of personal failure • Feels depressed • Single mothers • Father broke up shortly after birth • Parents divorce after birth • Raising of child is solely mother's responsibility • Low income group • Family does not offer to help Biological father could not bear having a disabled child	• Sleeping patterns are seriously disrupted • Makes them irritable • Detrimental impact on siblings' schoolwork • Family follow the same diet • Isolated child – cannot invite friend • Cannot visit friends or public restaurants • Lack of long-term security • Suffer from depression • Has an influence on health • Father left family for another woman • Own career is demanding • Relationship broke up • Medical aid was exhausted • No medical aid • No work at that stage	• Excellent health • Normal birth • No adverse habits like smoking during pregnancy • Significant positive people in their lives • Deeply religious • Believes in God • Perseverance Support by husband /wife • Support through family and friends • Good stable job • Fringe benefits like medical aid and pension • Employed at same school • Spend quality time together • Trusts and trustees for the unforeseen • Appointment of assistants • Assistants stay on same premises • Future planning – family can take care of the child • Improve communication skills – dictionary and hand signs • Accept child's disability and inevitable circumstances. • Believe in yourself • Grandparents • New father accepts him as his own	• Enrolled at "kindergarten" • Enrolled at special school • Presence of assistants • Consulted various doctors, nurses, occupational therapists, physiotherapists, psychologists • Allows mother to give medication • Programme from occupational therapist • Divide responsibi-lities in terms of time and space • Indulge themselves in individual jobs • Very active members of society • Feels worthwhile • Collect as much information as possible • Assist other people where they can • Organizations at national and international levels • Preliminary bookings at institutions • Availability of doctor • Availability of medicine • Attending church as a family • Teachers at school is a big support • Friends with parents with similar situations • Do recreational activities together • Exposed to other family members with

			disabilities
			• Receive donations from an extensive support system
			• Nurses at clinic picked up the phenomenon
			• Doctor see to emotional well-being as well

4.5 Table representing the coping patterns / environment / skills of parents

4.5.1 Support

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Work / Job • School • Teachers	• Husband / wife • Parents /grandparents • Other family members • Friends • Work / Job • Involvement in community • Support groups e.g. "experienced parents" • Parents with similar problems	• Neighbours • Other family members • School • Teachers • Media, books etc. • Parents with similar problems	• Husband / wife • Parents • Other family members • Friends • Work / Job • Community / church • School • Teachers • Support groups e.g. "experienced parents" • Media, books etc. • Appreciate each other	• Husband / wife • Full-time caretakers • Support groups e.g. "experienced parents" • Media, books etc. • Respect one another

4.5.2 Finances

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Job security, Income • Medical Aid • Supplementary sources of income	• Job security, Income • Medical Aid • Pension	• Job security, Income • Medical Aid	• Medical Aid • Community support by raising funds • Sponsors	• Job security, Income • Funds, trusts, endowment policies • Medical Aid • Insurance policies • Preliminary bookings at an institute

4.5.3 Child's level of adaptation

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Stimulate child's interests • The child as an integrated entity of the family • Good sleeping patterns • No allergies • Good behaviour	• Stimulate child's interests • Counting of existing blessings • Can't compare, because it is only child • Compare – I'm better off • The child as an integrated entity of the family • Medical treatment • Important to finish school • No problem behaviour • Describe as "heaven child" • Knows child very well	• Counting blessings • Medical treatment • Should finish school • Get a good job	• Stimulate child's interests • Emphasize child's strengths • Significant positive people in her life • The child as an integrated entity of the family • Diagnosis • Socialize without problems • Like doing things together	• Stimulate child's interests • Achieving tangible results • Significant positive people in their lives. • No behaviour problems • Know child's abilities

4.5.4 Professional framework

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Doctors • Teachers	• Doctors • Sisters (Medical)	• Doctors • Specialists • Dieticians	• Doctors • Specialists • Psychologist • Nanny • Problem solving skills	• Doctors • Specialists • Psychologists • Nanny • Therapists • Problem solving skills

4.5.5 Problem solving skills

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Plan for the future		• Search and analyze information • Collecting information	• Work out strategies to communicate • Focus on what is important in life and what not	• Search and analyze information • Generate courses of action • Collecting information • Introduce programmes of action • Share information and strengths with other families • Belong to Autism SA and Nam • Plan for the future

4.5.6 Education

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Special schools	• Special schools	• Special schools	• Special schools • Parents as teachers • Siblings as teachers	• Special schools • Parents as teachers • Caretakers as trainers • Assistants allowed to go to school

4.5.7 Spiritually

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Very religious • Maintain own emotional stability	• Very religious	• Very religious • Go to church together • Maintain own emotional stability	• Very religious • Only anchor in life	• Very religious • Actively involved in church activities

4.5.8 Physical health

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Adequate sleep	• Adequate sleep	• Adequate sleep • Self-efficiency		

4.5.9 Cognitive / Mental health

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Understanding the nature of the problem • Positive attitude and outlook • Acceptance • Dealing with their emotions effectively • Going through the phases and complete them effectively • Aptitude to work with these children	• Positive attitude and outlook • Acceptance • Dealing with their emotions effectively • Going through the phases and complete them effectively	• Excel in work • Positive attitude and outlook • Acceptance • Having a professional qualification • Self-efficiency	• Provision for life-long needs • Excel in work • Positive attitude and outlook • Acceptance • Exposed to disabilities in family • Any positive change makes them excited	• Provision for life-long needs • Understanding the nature of the problem • Know everything better than the specialist • Excel in work • Go away for business often • Ignore the child – attention to other child instead • Acceptance • Dealing with their emotions effectively • Going through the phases and complete them effectively • Self-efficiency • Never give up • Early interventions • Having empathy with own situation • Extra-mural activities • Help other families • Positive outlook • Enjoy the time together – not immortal • Each grow and develop to their fullest • Ignore negative attitudes of people • Believe in yourself/ strengths • Child is a pleasure to have • Know your child very well • Ignore tantrums

4.5.10 Emotional well-being

Trauma	Down's syndrome	Epilepsy	CP	Autism
• Try to act as normal as possible • Trust that he gets a job • Trust that he will be happy • Relieved that his condition was not her mistake • Feels in charge of her life • Enjoys her work	• Is accepted by their child • Sister in hospital cared for her • Having quality time together • After acceptance, could lift head again • Do almost everything together • Doctor looked after her emotional well-being	• Doing fun things together • Supporting others • Proud of job • Seeing a specialist • Cries a lot and pulls oneself together • Feelings worthwhile in community	• Doctor saw to it • She can drop out of school anytime • Give her the opportunity to make friends • Ask family members to take care of her • Still have hopes and dreams for her • Love her very much	• Feeling worthwhile • Professionals taking care of you • Truly enjoys quality time with child • Arrange lifestyle to suit situation best

4.6 Summary of results

According to the research done on parents that have children with barriers to learning, it is evident that parents present unwanted emotions. These emotions represent guilt, depression, anxiety, anger, shame, over-protectiveness, relationship problems etc. and form a significant part of their lives. It is therefore evident that parents have or need some form of coping resource.

Secondly the value of coping resources was investigated. Many parents have created or developed some form of coping skills or coping environment to live by. The general coping skills that were detected by the parents were briefly listed in Tables 4.5.1 to 4.5.10. They include various systems of support structures and social networks (i.e. schools, clinics, hospitals, family and friends), financial means and security, professional framework of support and their prevailing physical, mental and educational levels. Having these coping skills available and internalizing them makes it more bearable for parents to live with a child with barriers to learning.

CHAPTER 5

RECOMMENDATIONS

5.1 Introduction

The relevant literature was examined as background for the current study. The methodology employed and the results obtained have been presented. The primary focus of this study was to determine what are the coping skills of parents having a child with barriers to learn here in Namibia. Additionally the study aimed at giving the parents a sort of Do It Yourself to help them even more in their situations, as well as for parents hearing the diagnosis for the first time. Therefore, this chapter focuses on creating opportunities for parents to cope in their present situations. A conclusion about limitations, successfully achieving the aim, validity and future recommendations will be put forward.

5.2 Conclusions

5.2.1 Coping skills

In identifying the coping skills presented in Chapter 4, it became clear that the personal or internal environment, as well as the external socio-economic environment in which parents find themselves, play a very important role in dealing with the problem. In finding solutions for the newly discovered problem of having a child with barriers to learning, certain driving forces (positive) plus other restraining factors (negative) will determine the extent to which a person adapts his behaviour in order to meet the challenges of problem-solving or coping with the situation.

This implies that a parent must move from his or her problem-free behaviour level (before diagnosis) to a situation where the problem is efficiently addressed. The restraining factors must be identified and removed or mitigated while the driving forces need to be strengthened as far as possible. Movement from level A to B, C, D and so on requires a profound process of problem-conceptualization by parents. Problem-conception embraces the parent's perception of his or her own situation (present) as well as his or her perception of possible ways to address the problem (desired). This process will finally determine the parent's new perception of the situation (Düvel 1980:21-28).

Pertaining to the above, the following findings are presented:

- Factors that are within a parent's control and which could be changed (Internal restraining forces/weaknesses)
  - Lack of knowledge and experience to address the problem.
  - Feelings of personal failure, inadequacy and loneliness.
  - Parents feel very depressed. Single mothers, especially, experience this condition much more intensely if they get divorced shortly after birth.

- ➢ Raising a child with barriers to learning is the sole responsibility of the mother and this puts additional stress on her.
- ➢ Lack of support from spouse or family.
- ➢ Feelings of being left out, especially by husbands.
- ➢ Finding time to pay attention to the personal needs and desires of the parents and to prevent from being isolated from society.
- ➢ Inability to establish proper communication systems between a problem child, its parents and the rest of the household.
- ➢ Inability to accept the problem and therefore the child. The cause of the problem is projected on to someone else. A period of shock, shame, embarrassment, shyness, denial and anger follows, which needs external influence to bridge this psychological phase.
- ➢ Neglect of siblings.

- • Factors that are beyond the control of parents and which they cannot change (External restraining forces/threats)
  - ➢ Inadequate or low income plays a huge role in having access to medical services, medicines and professional advice/assistance.
  - ➢ This also leads to a lack of long-term financial security for the child with barriers to learning i.e. insurance policies, establishment of a special Trust Fund, agreements to transfer responsibilities to relatives or friends.
  - ➢ The demanding nature of making the best of your career while finding time to meet all the needs of the child with barriers to learning, without neglecting the other children in the household. This puts an immense amount of burden and stress on parents.
  - ➢ Erratic sleeping patterns associated with certain conditions.

- • Factors under the control of parents that can act as driving forces (Internal driving forces/opportunities)
  - ➢ Support from members of the household i.e. brothers and sisters.
  - ➢ Support from relatives of parents like their parents, brothers, sisters, nephews etc.
  - ➢ Support from friends.
  - ➢ Existing organizations and societies dealing with problems of this nature. Parents can become members and benefit from the knowledge and experience of parents with the same problem.
  - ➢ Utilizing your own abilities including health, perseverance and intellectual ability. (Various parents mentioned that one should never underestimate your own ability to cope with the situation – believe in yourself).
  - ➢ Having a job that offers a monthly income and fringe benefits.
  - ➢ Medical aid schemes and insurance companies.
  - ➢ Religion.

- • Factors beyond the control of parents from which they can benefit (External restraining forces/strengths)

- The availability of general medical practitioners, specialists, psychologists, therapists and supportive medical staff.
- The existence of hospitals, clinics, crèches, schools, special schools and appropriately trained teachers.
- Access to governmental institutions for financially disadvantaged people to obtain medical services (i.e. clinics, medicines).
- Availability of medicines.
- Libraries and internet facilities to access information related to children with barriers to learning.

Table 5.1 serves as a summary of the coping mechanisms used by the participants in relation to the hurdles they had to face.   The copings skills represented here reflect the cumulative range of skills used and not those used by a single family. In general it seems, however, that most of them could be useful for parents in this position. The only exceptions could be those solutions that can only be afforded by wealthy people.

It also became clear that it is possible to design a basic crisis management plan (Table 5.1) to deal with children with barriers to learning based on:
- The mitigation/removal of internal and external restraining factors (weaknesses and threats) encountered by such parents.
- The strengthening/utilizing of internal and external driving forces (strengths and opportunities) available to parents and/or
- The changing of restraining forces into positive ones.

Table 5.1: Basic Crisis Management Plan

Weaknesses in household	**Converting problems into opportunities**
Lack of knowledge and experience.	Consult various doctors, psychologists, dieticians, occupational therapists and physiotherapists for professional advice. Obtain membership of an association to share information and experiences. Gather as much information as possible - library books, periodicals, journals, internet, attend presentations. Make friends with mothers with similar problems - exchange information. Build own child-specific experiences – develop own coping abilities.
Feelings of personal failure, shock, shame, embarrassment, anger, denial, guilt, inadequacy and loneliness.	Develop better understanding about the causes of the problem – replace misconceptions. Membership and active participation in societal activities. Strive to feel worthwhile – pursue specific development objectives for child. Assist other people where possible - organizing meetings, conferences at national and international levels. Share information and experiences and support each other. Learn to accept the condition of your child and refrain from projecting own responsibility to others. Believe in yourself.
Parents feel very depressed Feelings of being left out, especially by husbands.	Attend church as a family. Get professional treatment. Build family cohesiveness – loving environment, mutual respect and support. Ensure quality contact with friends and relatives. Learn to identify and count/appreciate your blessings.
Lack of support from spouse.	Make use of social welfare framework. Reach out to family and friends.
Personal needs and desires of the parents neglected.	Divide responsibilities between husband and wife and or children. Implement a relief system to ensure free time for individuals. If affordable, appoint assistant to take care. Seek occasional support of family.
Lack of communication with disabled child.	Work out hand signals to communicate. Write your own dictionary.
Inability to accept the problem.	Consult professionals.
Inadequate or low income – Lack of financial means.	Obtain better qualifications. Start a savings programme. Receive donations from community/organizations.
Lack of long-term financial security.	Establish a special Trust and trustees. Take out endowment policies. Make provision for "sheltered living". Join a medical aid scheme. Make agreements with family members and friends.
Dealing with time problem – career, children, family interests, own interests.	Spend quality time with the child when available. Appoint assistants. Request parents to care for the child on a relief basis.

	Find employment at the same school as child. Divide responsibilities in terms of time and space. Build a support system through family and friends. Send children to special schools.
Dealing with physical stress - career, child care, disrupted sleeping patterns, school activities, social responsibilities	Indulge themselves in their individual jobs/careers. Do a lot of recreational activities separately and together. Plan holidays and recreational tours.
Dealing with emotional stress.	Follow special diet, physical exercise programmes. Visit psychologists. Create a peaceful atmosphere at home. Do extra-mural activities. Accept the child as is. Religion – get consolation from Scripture.
Specialised training needs.	Get home training based on professional help. Develop communication system with child. Attend special and appropriate schools.
Detrimental impact on the school work/academic performance of other children in household	Spouse pays special attention to him/her. Separate rooms where siblings cannot be disturbed.
Single mother problem	Make use of goodwill in community

5.2.2 Evaluation of research design

5.2.2.1 Validity

A large diversity of family structures surfaced in this study. This is in stark contrast to the "myth" that households where children with barriers to learning occur, exist as a "normal" family consisting of a mother, father and children. In this study 42 % of the fathers left or divorced the mothers shortly after the diagnosis of the child with barriers to learning. This made it difficult to get a wider perspective of a father's role under such circumstances. Even where contact was made with affected fathers, they were very reluctant to get involved in the interviews. It was the mothers who fully participated and who were willing to share their knowledge and experience.

Only a limited number of parents were willing to participate in this study. The researcher was however able to select one household in each category of children with barriers to learning in the two special schools that exist for such children in Windhoek. This can be seen as a limitation because the coping skills identified in the study will not necessarily reflect all the coping mechanisms of parents in general. In addition informal interviews were held with people whose children were already out of school or who never applied for placement. It became evident that there is a large resemblance in coping skills between these two groups.

5.2.2.2 Achievement of goals

A number of factors played an important role in achieving the general aim as well as the specific aims of the study.

Affective emotions

In considering the parents' feelings, moods and emotions the researcher succeeded in creating a level of emotional intimacy which favoured the successful completion of the investigation. According to Tolan (2003:100), intellectual understanding of the parents is important, but not as important as understanding them with your heart. Although the interviews did not provide for therapy sessions, it was done in such a way that parents could talk about their feelings of depression, anxiety, grief and hate. This procedure brought a great deal of relief to parents and they gave permission to share their coping skills with other participants. At the same time it created an opportunity where their feelings of loneliness and isolation could be relieved. Some of the parents asked for contact details of parents in similar situations and they expressed the desire to become part of relevant associations and support groups. Socializing in this way also served as an important mechanism for mitigating or even overcoming these emotional feelings.

Cognitive contact

In achieving the cognitive goals, Tolan (2003:93) stated that cognitive contact involves a mental process that includes thorough thinking about and understanding a problem. Cognitive contact is about shared meaning and, like basic contact, it requires mutual interaction between researcher and participant. One participant, for example, did not understand the origin of Down's syndrome and only after having the real cause explained to her could she free herself from the anger and hatred toward the doctor and hospital staff. This enabled her to make peace with the situation. In another case the mother believed the child with barriers to learning was the result of a curse passed on her. Exposure to the factual situation changed her perception completely and she could live with herself again.

Various parents emphasized the important role of religion to reach acquiescence. They believed God would provide them with the necessary strength to deal with the situation and that this condition would be something of the past when they entered eternal life.

During the interviews it became evident that parents, because of a better understanding of the problem, had reached the stage where they could live in harmony and enjoy their child to the fullest.

Resistance to behavioural change

When describing new behavioural processes to the parents, a certain degree of resistance was noticeable. According to Manfield (2003:95) two types of resistance occur:
• Resistance against what is painful and unacceptable;
• Resistance from the super-ego, which stems from the patient's unconscious guilt and need for punishment. Its consequences are repetitive self-sabotaging, self-destructive behaviours.

Many parents mentioned that working out mechanisms through which they could still socialize and be honest with friends about their child's abilities, helped them cope. One way of making this possible was by means of sharing responsibilities or by relieving each other in daily tasks. The assistance of grandparents also made an indispensable contribution to have more time available for their own desires and needs. People who were financially better endowed made use of assistants to take care of the child. According to Worden (2000:52-54), there are several techniques that are used when grieving, some of which were adopted to help specific parents. It was suggested that a memory book be made. "This book can include stories about family events, memorabilia such as snapshots and other photographs, and poems and drawings made by various family members, including the children. This activity can help the family to reminisce and eventually to mourne a more realistic image…" (Worden 2000:53). Another technique is cognitive restructuring. According to Worden (2000:53) the underlying assumption is that our thoughts influence our feelings, particularly the covert thoughts and self-talk that constantly goes on in our minds. Gibson, Swartz and Sandenbergh (2002:45) stated that our past experiences influence our lives in the present. Understanding how the past influences the present enables us to see meaning in behaviour or feelings that at first seem confusing. If we know the reasons why we do things, we have more freedom to make other choices.

In this study two parents made use of a more or less similar strategy. They had designed a mechanism to communicate more effectively by means of a dictionary and by introducing hand signals. Not being able to understand what the child was trying to convey was very frustrating and these initiatives brought considerable relief to everyone in the household.

Conative approach

When discussing the parents' outlook and future plans it became clear that almost all of the parents became extremely positive and made a considerable mind shift which left them with a feeling of being successful. For any mind shift to occur there should be a change in the perception of an individual. (S)he must recognize a more desired situation to develop or pursue in future before deliberate actions to change the prevailing situation will take place. A typical example of such a mind shift was found in two ladies who realized the practical implications of having a child with barriers to learn. Both husbands left them and the only way they could cope was to ensure that they were properly qualified in order to generate adequate income to afford their envisaged mechanisms of coping i.e. appointment of assistants and recreational programmes. One became a lawyer and the other one a nurse. According to Fortinash and Worret (2003:215-217) such a person is steadily becoming more involved in life, energy is more plentiful and directed toward life, life seems more tolerable, although it may never reach the heights of previous joy. There may still be bouts of immense sadness and even panic, but they will gradually go away.

Parenting goals

Regarding parenting goals, it was established that parents provided for meaningful and appropriate short and long-term goals. Although these goals were not formally formalized, most of them pursued:

- improved knowledge about the problem and how to deal with it,
- being members of a medical scheme,
- having their children taken up in special schools,
- joining current support groups and
- securing the financial future of their children through Trust funds, insurance policies and family/friends to look after them. This gave the parents peace of mind and the satisfaction that the future of the child has been secured when they fall away unexpectedly.

Role of the therapist

Tolan (2003:16) summarized the role of the therapist aptly by saying "counselling can be a lonely business at times, particularly when we are traveling with clients through their most painful experiences. The clients may be feeling deeply hopeless, worthless, abandoned and alone and they may continue feeling that pain for an almost unbearable length of time."

As therapists, it would be inhuman if we do not render all the possible support to these people. A thorough understanding (intellectually and emotionally) of how and why psychological pain arises and how we can help, enables us to continue to stay in psychological contact with our clients. It is therefore the responsibility of the therapist to guide the client through an analytical process of identifying their own strengths, weaknesses, opportunities and threats. Built on this information the client should be guided and encouraged to identify their own goals and activities to achieve these milestones. It is also the responsibility of the therapist to have a proper aftercare programme in place and to see to the parents' emotional well-being.

5.2.2.3 Limitations

In the methodology a qualitative approach was used. It would have been ideal if more parents had been available for interviewing. The fact that other participants, who were not willing to be part of the study, were informally interviewed helped to support the findings in general.

There was not enough time to do individual psychotherapy with any of the participants. Some were in desperate need of help. This would however not change the validity and value of the coping skills identified.

Some participants who signed the consent form refused permission for the conversation to be electronically recorded. This turned out to be very time consuming as the researcher had to listen and write down all the detail.

As stated previously, the sample cannot be regarded as fully representative of the whole of Namibia. The researcher had to build the study on the few people who were willing to cooperate. The final findings and recommendations can however be regarded as a valuable guideline for future reference.

The fact that there are only two special schools for children with barriers to learning in the country, means that not all the children with this affliction in Namibia can be accommodated in these facilities. Therefore the total pool from which participants could be recruited was further limited.

5.3   Recommendations

As this study was the first of its kind in Namibia, parents were very suspicious when informed about it. A better awareness of the roles and values of therapy should be created through formal institutions such as schools and informal channels such as societies. Parents should know from the start that the researcher is there to look after and promote their interests.

Many parents wanted more out of the study than the researcher could give. Some saw it as a chance for therapy through which they could get rid of their sadness and wistfulness. This aspect should receive attention, especially when studies are executed at a national level.

More parents of the same socio-economic status should be included in future studies so as to make a proper comparison of how people in different socio-economic classes cope. There were large differences in lifestyles of the various households that were sampled - some were barely making a living while others were relatively wealthy.

In studies of this kind, one should keep in mind that the entire family is actually the client and all services should be directed at the family as a whole rather than at individuals. The challenge lies in adjusting their perceptions, attitudes, approaches and goals in order to mitigate the impact of the problem on the entire family. "Family therapy can be defined as the psychotherapeutic treatment of a natural system" (Rivett & Street 2003:62).

The identification of restraining forces as well as driving forces that impact in negative or positive ways on the behaviour of a family could form the basis of future therapeutic approaches. The design of a crisis management plan to deal with children with barriers to learning as well as with the rest of the family should therefore be based on:
• mitigation or removal of internal and external restraining factors (weaknesses and threats) encountered by such parents;

- strengthening or utilization of the internal and external driving forces (strengths and opportunities) available to parents; and/or
- changing restraining forces into positive ones.

Professional actions that may help the parent are:
1. referring the parent to services at the time of diagnosis;
2. stating the child's level of disability honestly, including acknowledgment of the imprecision in classification and the variability of children's progress (Mittler & McConachie 1983:118);
3. emphasizing the child's strengths and similarities to other children; and
4. referring the parents to other "experienced" parents and other professionals who could help them to locate resources to cope with the challenges.

5.4   Word of Hope

Sometimes parents feel alone in their grief and despair. The following poem was taken from the notice board at Dagbreek School, one of the special schools in Namibia.

Uiters gestrem, maar lieflik

Soveel jare soos my kinders oud is, vra ek al vrae en huil
ek trane, want hulle is wat die boek noem "uiters gestrem"
– fisiek sowel as verstandelik.

Onlangs sê die soveelste vreeemdeling op straat:
"Ai, dis seker vir jou baie swaar".

En amper sê ek ja – maar toe onthou ek hoe dikwels ek al
- vas in a geesdriftige, spoegerige omhelsing – besef het
hoe oneindig nader hulle is aan die beeld van Jesus as
enige ander mens wat ek ken.

Hulle kan nie praat nie, maar hulle kan ook nie lieg, vloek,
kritiseer, beledig, verwyt, verskree of beskinder nie.

Hulle kan nie loop nie, maar hul voete sal ook nooit
"hardloop na die kwaad" (volgens Spreuke) soos myne
so dikwels doen nie.

Hulle onthou omtrent niks, behalwe etenstye, maar hulle
vergeet ook die onredelike klap wat ek vyf minute gelede
uitgedeel het, asof dit nooit gebeur het nie.

Ek hoef nooit hul liefde en vergiffenis te verdien nie. Hulle
het almal ewe onbevange lief sonder snobisme of baantjies
vir boeties.

Hoe dikwels kan Jesus dieselfde sê van my met al my verstand en talente?

IK nie alles, Johannesburg.

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APPENDIX A

INFORMED CONSENT

I, ……………………………………………………. Identification number
……..……………………………… born on …………day of ……………19…..
am willing to participate in the research topic "Coping Skills of Parents with
Mentally Retarded Children", provided that the information is kept confidential.

Permission is herby given that the information emanating from the questionnaires
and interviews may be used for research purposes by the co-signing researcher.

I am fully aware of what the research entails and that the risks and benefits were
explained to me.

_____   _____
Participant   Researcher

_____   _____
Date   Date

APPENDIX B

INTERVIEW STRUCTURE

1. Initial Interview

Topic	Probes or reminders	Notes to researcher
Introduce self	The researcher wishes to thank the participants for taking part in the research. Introduction of researcher: I am Marlette Brand. I am an intern educational psychologist. The supervising university, Unisa, has approved this project with its concomitant subject.	
Motivation: Explanation of purpose of interview	The purpose of the research is to identify and investigate the coping resources of parents with mentally retarded children.	Be on the lookout for non-verbal language.
Confidentiality and anonymity	I undertake not to share or supply any of the information with other people - neither with participants or people not involved in the research. Pseudonyms instead of real names will be used.	
Format	There is a questionnaire to be filled out and roughly three interviews which include a debriefing session. The type of questions is also indicated.	
Confirm approximate length	The interview will last for an hour to an hour and a half per session.	

Tape recorder	What is to be said is very important to the researcher – no detail should get lost. The participant must consent to the use of a tape recorder. If (s)he wants to say something off the record, it must be indicated in order to switch off the apparatus.	
Invitation	Any question that the participant would like to ask at the onset of the interview.	
Consent	A consent form had to be signed to authorize the researcher to use opinions, beliefs and experiences of the participant for the purpose of the research.	

2. Questionnaire (Appendix C)

The interviewee is handed the questionnaire and helped to complete it where necessary.

3. Second Interview

Main questions	Probes or reminders	Notes to researcher
Coping resources of participant.	Does participant have a support system: • Spiritual • Financial means • Child's level of adaptation • Participant's cognitive stimulation • Participant's emotional stimulation	

4.Third Interview

Main questions	Probes or reminders	Notes to researcher
What prompts the participant not to cope?	Financial constraints Isolation Inappropriate feelings Neglecting family members	
What would you like to be available if you have to walk the path again. Share your advice and expertise.		
Inform participants that research draws to a close.	If you would like to add something or would like to have another interview or chat, you are welcome to contact me.	

5.Debriefing

Topic	Probes or reminders	Notes to researcher
Debriefing	Talking about hurtful and sad experiences can be very traumatic and needs to be debriefed again after all the interviews.	
Thank the participants for sharing their hearts and for their time and sacrifices.		
Invite them to come back and talk if they feel the need.		
Inform them when the project is ready to read.		

APPENDIX C

QUESTIONNAIRE: PARENT INTERVIEW

1. Identifying Particulars

Surname:……………………………..Name:……………………………………...

Residential Address:……………….…………………………………………………

Postal Address:……………………….…………………………………………..

Position – Father:……………………Tel (h):………………Tel (w):……………..

Position – Mother:………………….. Tel (h):………………Tel (w):…………….

Home Language:……………………. Denomination:…………………………….

Position in family:……………………child of………………children.

Date of Birth of child:…...……………….……………………………………………

Genogram:

2. Birth History of Child

Pregnancy:

Planned	Not planned

Mother's habits:

Smoking	Drug abuse	Alcohol abuse	Anxiety	Other:

Mother's general health:

Incompatible blood groups	Serious illnesses	Anemia	High blood pressure	Other:

Child's birth:

Premature	Overdue	Complications	Prolonged	Very short	Blue baby	Normal

How long in labor?……………………………………………………………..

3. Infant and Pre-school Years

Feeding problems:

Problems with sucking	Allergies	Colic	Behavioural problems	Other:

Serious illnesses:

Malaria	Bilharzias	Jaundice	Other:

Illnesses accompanied by high temperature? Mention.
…………………………………………………………………………………
…………………………………………………………………………………

Serious head injuries? Mention nature of injury.
…………………………………………………………………………………
…………………………………………………………………………………

Period of unconsciousness:
…………………………………………………………………………………
…………………………………………………………………………………

Accidents or traumatic experiences:
…………………………………………………………………………………
…………………………………………………………………………………

3.1 Physical development

Birth weight (kg):………………Breast fed / Bottle fed:…………….(months)
Sat at (months):………………….Crawled at (months):………………………
Walked at (months):………………………………………………………….…..

Agility:

Good	Average	Poor

Hearing:

Good	Average	Poor

Eyesight:

Good	Average	Poor

Handedness:

Right	Left

3.2 Mental development:

Language

Mother tongue: ……..…Started to speak:……….When fluent:……………
Other languages:………………………………………………………………
Speech problems:………………………………………………………..

Reading:

Good	Average	Poor

Writing:

Good	Average	Poor

Spelling:

Good	Average	Poor

Concentration:

Good	Average	Poor

Any deviations?

……….…………………………………………………………………………

General school progress:
At pre-primary:

Good	Average	Poor

At school:

Good	Average	Poor

At after school care:

Good	Average	Poor

At full day care:

Good	Average	Poor

3.3 Psycho-social development:

Stress:

Sleeping	Eating	Behavioural patterns

Other:…………………………………………….…………………………….
…………………………………………………………………………………

Specific signs of tension:

Nightmares	Stuttering	Enuresis	Hyperactivity

Other:…………………………………………………………………………..
…………………………………………………………………………………

Problem behaviours:

Lying	Truancy	Stealing

Other:………………………………………………………………………….
………………………………………………………………………………….

Socializing:

Interaction	Friends

Other:…………………………………………………...
………………………………………………………………………………….

Significant persons in the child's life (positive/negative):…………………….
………………………………………………………………………………….

4. Medical Information

Is there a family history of mental retardation?
…………………………………………………………………………………

Was there a chance that it could have been detected in the pregnancy phase?
…………………………………………………………………………………

How old were you when you were pregnant? (With specific child)

…………………………………………………………………………………………………

Do you have a general practitioner or do you go to the clinic?

…………………………………………………………………………………………………

Do you have a good relationship with your doctor?

…………………………………………………………………………………………………

Does your doctor also see to your emotional well-being?

…………………………………………………………………………………………………

In your opinion, is the treatment effective?

…………………………………………………………………………………………………

Do you have medical aid?

…………………………………………………………………………………………………

Does your child have any allergies?

…………………………………………………………………………………………………

Have you ever noticed any behavioural changes after eating e.g. dairy products?

…………………………………………………………………………………………………
…………………………………………………………………………………………………

Have you sought help at a professional dietician?

…………………………………………………………………………………………………

Is your child currently under treatment at an occupational therapist etc.?

…………………………………………………………………………………………………
…………………………………………………………………………………………………

Do you have other reports from para-medical professionals?

…………………………………………………………………………………………………
………….…………………………………………………………………………………………

Is your child under medication at this stage? What, for how long did (s)he use it?

…………………………………………………………………………………………………
…………………………………………………………………………………………………

5. Family Information

Who brought up the child? From which stage?

…………………………………………………………………………………………………
…………………………………………………………………………………………………

Who gives his/her medication?

…………………………………………………………………………………………

…………………………………………………………………………………………

Briefly list your child's interests

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

Are you stimulating his/her interest? In which way?

………………………………………………………………………………………….

Do you like doing it or is it a burden to you?

…………………………………………………………………………………………

What other things are you doing together?

…………………………………………………………………………………………

…………………………………………………………………………………………

How is the relationship between him/her and your other siblings?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

Is (s)he normally an isolated child or with friends?

…………………………………………………………………………………………

…………………………………………………………………………………………

6. Scholastic Information

Briefly give information on your child's school career?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

How do you feel about the fact that your child is in a special school?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

Do you strongly agree that your child should finish his school career or can he drop out at any stage?

…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………

7. Personal Information

When was your first awareness of the deviating phenomena in your child?

…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………

Who broke the news to you?

…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………

Was there any help at hand? Did you know where to go for help/ Was the diagnoses explained to you?

…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………

What was your reaction on hearing the diagnoses?

…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………

What emotions form part of your experience? Explain.

…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………

Which emotion(s) was the most prominent?

…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………
…………………………………………………………………………………………………

With which emotion did you struggle the most? Explain why.

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

Which emotion(s) presently forms a very prominent part of your life?

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

Is it becoming better or is it like a roller coaster?

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

What are your dreams or future expectations for your child?

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

8. Coping Mechanisms

Do you have a support network? Briefly name the most important figures/institutions.

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

If you could change something (from the past) – what would it be and why?

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

Which coping mechanisms have you worked out for yourself?

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

What were positive inputs in your life? What made you go on? What motivated you?

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

Which strategies work for your family setup?

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