

SUPPORT TO PARENTS WITH CHILDREN WITH LEARNING DISABILITIES

by

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DECLARATION

Student number: 3211-128-2

I declare that the dissertation entitled “Support to parents with children with learning disabilities” is my own work and that all the sources used or quoted have been indicated and acknowledged by means of complete references.

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MRS. V J M RÖRICH

.....
DATE

SUMMARY

This dissertation attempts to understand what support from the school parents would most value when their child has been diagnosed with a learning disability. The method employed was qualitative in nature, using eight in-depth interviews with the mothers. The interviews confirmed that parents experience emotions similar to those when grieving. They also tend to feel isolated from their communities. Before embarking on a support program the school needs to recognize the depth of these emotions. The interviews also revealed that parents require timeous communication from the teacher. Parents concerns should be taken seriously or time goes by without the disability being attended to. The terminology used by professionals is often not fully understood by parents, and this causes them to feel unsure of how therapy is helping their child in the classroom and what its value is. Various guidelines are offered to support parents with regard to the above-mentioned aspects.

KEY TERMS

Nature, causes, diagnosis, types of learning disabilities; behavioural and social problems; parental reactions; impact on child with learning disability; communication with the school; communication with professionals; support groups; emotions including shock, denial, guilt, anger, and isolation.

DEDICATION

I would like to dedicate this work to my mother.

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CHAPTER 1

ORIENTATION

1.1 Background

“So as my stomach grew bigger, we imagined cheering our child on at little league soccer and watching him toss his cap in the air at his high school graduation. Like most parents, we dreamed our child would be the smartest, strongest, best-looking kid on the block” (Jennifer Hill in Canfield, Hansen, Hawthorne & Shimoff, 1997:107).

What happens when these dreams don't come to fruition? What happens when the school calls a parent in for a meeting to discuss why their child is not coping at school? The parents may for a while have had a suspicion that their child was not coping as well as the other children in the class, and may feel relieved that the school would now be able to help their child. Other parents are caught more off-guard. Apart from the shock when they hear that their child may have a learning disability, is their lack of understanding of what the problem actually is. Parents are not familiar with terms such as 'auditory synthesis and analysis' or 'visual synthesis and analysis'. When you try to explain to them that it means a 'processing' problem, it still doesn't really make sense. Parents have to cope with their dreams for their child being shattered as well as a whole lot of jargon that means nothing to them. They are left with overwhelming feelings of frustration and helplessness (Gould, 2005:vi).

Guidelines that attempt to assist parents should have as their basic premise that parents need help to understand themselves, their child and their child's learning disability (Roth & Weller, 1985:487). In understanding themselves parents may be able to come to terms with their child's learning problem more easily. They may need to understand how their ambitions for their child have been changed, and that *their* ambitions may not, in fact, be their child's ambitions. Guidelines could also assist the

school in formulating constructive ways to support parents emotionally and in any other way to alleviate the intensity of the diagnosis of a learning disability in their child.

1.2 Analysis of the problem

In the analysis of the problem attention is given to the awareness of, the investigation of and the statement of the problem.

1.2.1 Awareness of the problem

Much of the awareness of what happens in a school often starts in what is called 'car park' chat. It is in this setting that one would hear, time and again, of parents who are furious with the school, the headmaster, the teacher, or the remedial department, in relation to their child who has been diagnosed with a learning disability. They often ask questions such as, "Why didn't they tell me sooner?" "Why did they say such ridiculous things to me?" "Why didn't they listen to me when I suspected there was a problem?" "Why do they see medication as the only solution?" These are all emotionally charged questions. Parents often remove their children from a school at this stage because they believe the problem was handled so insensitively.

It seems that, somehow, there exists a gap in communication between the school and the parents which allows such an emotionally intense situation to develop. The news that one's child has a learning disability is often an emotional crisis in the family, apart from also being a practical one (Russel, 2003:144). If it *is*, in fact, an emotional 'crisis', then it may be appropriate to provide support to parents.

The aim of this research is to determine what kind of support would be required by parents in order to make the 'crisis' more bearable. This support may take the form of emotional support, or support groups, or possibly parents may need more information to help them understand their child's disability.

1.2.2 Investigation of the problem

The following description gives a clear picture of the nature and consequences of a learning disability: “Carolyn got a call from her son’s classroom teacher, who wanted to talk about Jonathon’s progress. Before the teacher said another word, Carolyn knew what was coming. She knew her son was having trouble at school. His report cards were not as good as she thought they should be. His teacher often sent work home to be corrected, and Jonathon couldn’t tell what he had done wrong. Homework sessions were nightmares. She knew he was having difficulty outside of the classroom too. She had watched him play games with children his age. They had no trouble reading the directions, but Jonathon wouldn’t even try. She suspected he might have a learning disability, and she was sure that was the reason for the teachers call” (Tuttle & Paquette, 1993:7).

Parents’ reaction to news like this is covered in greater depth in the literature study, chapter 2.

The term ‘barriers to learning’ is used in a South African context. International literature uses the term ‘learning disability’ (see 2.2). The term learning disability will be used in this dissertation. Barriers to learning, according to the South African White paper 6 (2001), as well as including ‘learning disabilities’, as defined below, also includes environmental factors such as the school itself, and the language used for teaching as factors that can contribute to learning difficulties. A number of descriptions of learning disability are discussed in the literature study, but a brief one is provided here to place the problem in context. Gould (2005:4) provides a relatively simple description of what a learning disability is. She says it is when a learner has an average to above average intelligence, with normal vision and hearing, and receives the same teaching experiences as other learners his age. He, however, underachieves. He is unable to keep up with his peers and generally cannot cope with the demands of the school.

When parents have a child whom they feel is clearly intelligent but is underperforming at school they begin to feel frustrated. They then often begin to look for solutions to their

concerns, and this is when they are likely to find out that their child has a learning disability. This often leaves parents feeling confused, anxious, in denial, ignorant and inadequate. They may also then seem uncertain about their plans for their child's future (Gould, 2005:2). There will probably also be financial implications. These could include the cost of extra lessons with various specialists. The child might have to change schools in order to attend a school that focuses on teaching children with learning disabilities (Sperry & Duffy, 2002:430). This is when parents need support. The research question will try to uncover what kind of support would be most beneficial.

According to various literary sources parents undergo emotions that can be equated to those experienced in a grieving process, when they hear that their child has a learning disability (McLoughlin, Clark, Mauck & Petrosko, 1987:357; Oeckerman, 2001:11). Oeckerman (2001:11) discusses the phases parents go through when they learn their child has a disability. Usually the first reaction is that of shock, followed by denial; there may be feelings of guilt and anger; sadness and depression may follow. The final phase is one of acceptance (see 2.7.1). It is the intensity of these phases and their equivalence to the grieving process that persuaded the researcher that support should be given to parents whose children are diagnosed with a learning disability.

Support can be offered to parents at this stage; it may be to support them in their grief and to help them see their child's strengths. Prezant and Marshak, (2006:31) noted that the *kind* of help that is offered to parents at this stage is important. Help that can open doors and expand options is the kind of help that is needed. Some research indicates that professionals can take on a proactive stance whereby they offer information and counseling to parents before it has been asked for (Case, 2001:847). It is important that parents come to terms with their child's learning disability as they then become a source for helping their children (Case, 2001:849). The relationship between parents and professionals is important. If professionals provide information that assists with optimizing the future outcomes of their child then parents become an asset in their child's development (Prezant & Marshak, 2006:44).

Parents may be supported by an empathic understanding of their experience by professionals. This helps to promote their understanding of the child's experience. Parents begin to understand this when they have more information and knowledge about learning disabilities (Palambo, 2001a, Palambo & Benernberg, 1999 in Amerongen & Mishna, 2004:42). Norris and Closs (1999 in Quinn, 2001:10) also indicate that parents believe they need to become informed if they are to understand their children and the learning disability. Professionals should consider the possibility that their attempts to support a parent may or may not meet the perceived needs of parents, "...regardless of positive intention or academic prescription" (Prezant & Marshak, 2006:44). Seeing that there does not exist any support program offered at the school where the research is being undertaken it would be relevant to find out what, in particular, parents would consider as support when their child has been diagnosed with a learning disability.

In doing research on support to parents, studies by Hudson, Matthews, Gavidia-Payne, Cameron, Mildon, Radler and Nankervis (2003:240) and Gavidia-Payne and Hudson (2002) were found. These studies focus on support to parents concerning the behavioural problems of their children with a learning disability. Another study by Evans, Jones and Mansell (2001) evaluates support groups for the brothers and sisters of children with learning disabilities, and also the challenging behaviour of the child with a learning disability.

The focus of this research is on parents' need for support when they learn their child has a learning disability, because "if the therapist focuses too soon or too exclusively on the child's needs without regard for the parents' experience the parents may feel misunderstood, injured and thus find it difficult to accept the information" (Amerongen & Mishna, 2004:43).

1.2.3 Problem statement

Preliminary research indicates that parents suffer an emotional reaction equated to grieving when they hear that their child has a learning disability (see 1.2.2). It is

commonly known that when people grieve over the loss of a loved one therapeutic support is made available from professionals or groups, such as a hospice. However, there is no support offered at the school where this research is being done for parents whose children are diagnosed with a learning disability, and there is not an abundance of literature available on what parents would like in the way of support. Some research indicates professionals should be proactive in the support they give to parents. In order to be effectively proactive professionals should understand what kind of support parents may need.

Parents need to advance through the process from denial to acceptance to best enhance their child's prospects of success. The perspective of the parents is necessary in planning programs that will provide them with support (Prezant & Marshak, 2006:32). It is this perspective that the researcher will be trying to obtain in formulating assistance to parents at this difficult time.

From the awareness of the problem, the preliminary investigation and the problem statement, the following research question emerged: **How can parents be best supported when their child has been diagnosed with a learning disability?**

1.3 Aims of the research

The general aim and then specific aim are discussed.

1.3.1 General aim

Parents need support from the school when they are informed that their child has a learning disability. They suffer shock and grief when they hear of their child's learning disability (see 1.2.2). Support from teachers and professionals at this stage may alleviate the stress. The general aim of this dissertation is to determine how the parents viewed the approach of the school at the time of diagnosis of their child's learning disability. Did they feel comfortable with the proceedings? Did they receive any emotional support? What kind of support would they have preferred?

1.3.2 Specific aim

The specific aim of this research is to provide guidelines to assist in alleviating the stress and intense emotion that parents experience when their child is diagnosed with a learning disability. What approach could the school use that would make the situation more bearable rather than aggravate it? The focus is thus on the parents' emotions and how best they can cope with them.

The aims can be stated as follows:

- To conduct a literature study that aims to put into perspective what a learning disability is, its causes and manifestations (see 2.2 & 2.3).
- It also aims to understand more about the parents' reaction to the diagnosis of a learning disability (see 2.7).
- To determine what it is parents think the school could do to alleviate the pain and make acceptance of the diagnosis easier to bear, and also to determine what they would like in terms of information and assistance (see 2.9).
- To understand the importance of the parents' relationship with professionals involved (see 2.10).

Specific aims will be achieved by

- doing an in-depth literature search;
- identifying families relevant to the research;
- doing in-depth interviews with the mothers concerned, covering issues such as their initial reactions to the news, their reactions to the approach of the teachers and the school, and what they thought would have been most helpful at the time; and
- comparing the responses to determine what the parents' expectations are.

1.4 Paradigmatic perspective

“Paradigms include not only thinking, ways of seeing and evaluative judgments but also, crucially, practices. Each paradigm means a different i) set of assumptions,

ii) framework of thought, iii) and way of perceiving, thinking and doing associated with a particular vision of reality” (Naicker, 2000:5).

The concern of educational research is to explore and understand social phenomena which relate to educational issues. There are various paradigms which can frame research. This research will be guided by an approach known as anti-positivism. It essentially emphasizes the understanding and interpretation of phenomena and making meaning out of this process. It is a qualitative approach. Phenomenology is a school of thought within anti-positivism. Phenomenology believes individuals’ behaviour is determined by their experience (Dash, 2005:3). The experience that parents have at a school when they learn that their child has a learning disability may determine their behaviour.

By means of this study the researcher would like to understand parents’ experience at a specific preparatory school in Mpumalanga to determine what support would be required to ultimately encourage behaviour that reflects the acceptance of their child’s learning disability, and to provide an environment at the school that facilitates this.

Further to a phenomenological approach, this dissertation will be informed by a systemic frame of reference. The systems theory proposes that no person exists in isolation, rather that “systems consist of smaller elements or subsystems, but in turn, are also part of larger supra-systems” (Meyer, Moore & Viljoen, 1997:557). Children are part of a family system, and the family itself is part of a system that forms the community, which includes the school. It is relevant to use a systems perspective in this dissertation since not only the child’s learning disability is important, but also the needs of the parents, the impact on siblings, and communication with teachers and professionals. The parents are part of the family system. A systems-approach is relevant when dealing with broader systems such as the school and the family; the parents and professionals. An approach called the ‘collaborative-resource approach’ is introduced from the family systems-theory in which professionals collaborate with parents to facilitate the process of, amongst others, adapting to intellectual disability (Ho

& Keiley, 2003:239). According to this approach, professionals are encouraged to engage with families as equal partners on a trans-disciplinary team. In other words, professionals do not work in isolation and from a hierarchical position, rather their work is informed by the interaction with parents. This is in keeping with the approach of the systems theory. Teachers can be engaged in the counseling process if a systems theory model is used. This can benefit the child, the family and the school (Volker & Ray, 2006:58).

1.5 Definition of concepts

Terms and concepts that will be used throughout this research are defined below.

Learning disability (barrier to learning) – the internationally accepted definition refers to a learning disability as a “neurobiological disorder in one or more of the basic processes involved in understanding spoken or written language. This brain variance may influence an individual’s ability to speak, listen, read, write, spell, reason, organize information, or do mathematical calculations” (Lerner & Kline, 2006:2). These disabilities are inherent in the child. In the South African Education White Paper 6 the term used is ‘barriers to learning’. It refers to learning barriers occurring as a result of environmental factors such as poor facilities, inappropriate instruction language, inflexible curriculum, and unsafe environments. They also include learning needs arising from neurological and developmental impairments (Department of Education, 2001).

In this dissertation the international term, namely ‘learning disabilities’, will be used.

Parents – The biological, or not biological, parents with whom the child is living. It also includes the divorced parent with whom the child may not be living.

Siblings – Brothers and/or sisters (Van den Aardweg & Van den Aardweg, 1993:220) who live with the child who has a learning disability.

Family system – The people who make up the family. It could be a single parent family, or any variation that makes up the immediate circle of family of the child.

The importance of the influence of the family on an individual is emphasized by Sue, Sue and Sue, (1991:A7).

Underachievement – Underachievement is experienced by individuals who work well below their potential (Van den Aardweg & Van den Aardweg, 1993:246).

Support – Help the parents might need to come to acceptance of their child's learning problem. This could come from the school, the various therapists, or in the form of group support.

Grief – Grief is an emotional response to a bereavement (Bishop, 1994:430).

In the case of parents hearing their child has a learning disability the bereavement entails the loss of their original dreams for their child.

Learner – in this situation it relates to children who are at school.

1.6 Research methods

There are two aspects to the method to be used in this research project. The first one is an in-depth literature study and the second is an empirical study.

1.6.1 Literature study

The literature research aims at collecting information on the phenomenon being researched. The content is summarized in table 1.1. The information from books, journal articles, masters' dissertations and doctoral theses, and articles from the internet are included. The list of research materials referred to in table 1.1 is not conclusive.

Table 1.1 The literature study

Section	Major Headings	Research sources consulted
2.2	The nature of learning disabilities	Lerner & Kline, 2006; Gardynik & McDonald, 2005; Reiff et al., 1993; Gettinger et al., 2001; McDermott et al., 2006; Flack, 2005; Margalit et al., 1996; Mayes et al., 2006; Naidoo, 2006.
2.2.1	Levels of learning disabilities	Sternberg et al., 1999; Education White Paper 6.
2.2.2	Characteristics of children with learning disabilities	Tuttle & Paquette, 1993; Brand, 2005.
2.3	Causes of learning disabilities	Hallahan et al., 1999; Wong, 2004; Clike-Semrud 2005; Rourke 2005; Tuttle and Paquette 1993; Swanson et al 2003; Girenko et al., 1997; Galburda, 2005; Plomin et al., 2005; Sawyer, 2006; Swanson et al., 2003.
2.4	Diagnosis of learning disabilities	Gettinger et al., 2001; Greg et al., 2000; Mercer et al., 1996; Dombrowski et al., 2006; Klassen et al., 2005; Moore-Brown et al., 2006; Dean et al., 2006; Healey, 2005; Flack, 2005; Buchman, 2006.
2.5	Types of learning disabilities	Wallach, 2005; Fletcher et al., 2007; Hultquist, 2006; Lerner, 2006; Davis, 1997.
2.6	Impact of learning disabilities	McDermott et al., 2006; Amerongen et al., 2004; Forness, 2005; Tuttle et al., 1993; Wren, 2006; Maag, 2005; Yu et al, 2005; Bernard, 2007; Myers, 2005; Murray et al., 2006; Vaughn, 2005.
2.7	Parents' reaction to a diagnosis of learning disabilities	Russel, 2003; Clark, 1995; Niedecken, 2003; McLoughlin et al., 1987; Oeckerman, 2001; Kubler-Ross, 2005; Lerner et al., 2006; Brand, 2005; Ho et al., 2003; Lessing & Strydom, 2001; Roll-Pettersson, 2001; Rump, 2002; Hastings et al., 2004.
2.8	Impact of a child with a learning disability on the family	Buchman, 2006; Bender, 2008; Sperry & Duffy, 2002; Margolis, 2005; Walsh et al., 1997; Van Heerden, 2002;

		Hudson et al., 2003; Des Noyers et al., 2004; Evans et al, 2001; Pickering, 2002; Margolis, 2005; Martinez, 2006; Murray et al., 2006.
2.9	Parental needs and expectations and their interaction with the school	Russel, 2005; Case, 2001; van Heerden, 2002; Amatea et al., Williams, 1999; Felber, 1997; Raver, 2005; Oeckerman 2001; Mann, 2006; Robinson et al., 1994; Welsh, 1987; Bender, 2008; Williams, 1999.
2.10	Relationships between parents and professionals	Jupp, 1992; Murray, 200; Williams et al., 1997; Wong, 2004; Buchman, 2006; Quinn, 2001; rump, 2002; Bodine et al., 2002; Prezant et al., 2006; Tuttle et al., 1993; Maharaj 1998; Hastings et al., 2004; Connor, 2005; Hallahan, 1999; DesNoyers Hurley et al., 2004; Amatea et al., 2006; Raver, 2005; Hastings et al., 2004; Gavida-Payne et al., 2002.
2.11	The learning disabled child growing up	Milsom et al., 2005; Maduas, 2006; Tarleton et al., 2007.
2.12	Views of the child	Kelly, 2005; Lee, 2005; Tuttle et al., 1993; Pickering 2002.

The literature research begins with a definition of the term 'learning disabilities'. It continues with the causes of learning disabilities, which include the brain structure, genetic research, neurobiological investigations and environmental factors. The diagnosis of learning disabilities is then covered. This includes information on the discrepancy model and also, alternatives to the assessment of learning disabilities. Next holistic perspectives are discussed. This includes various levels, as well as types of learning disabilities, e.g. dyslexia, dysgraphia, dyscalculia, phonological dyslexia and orthographic dyslexia. Moving onto the children themselves, the characteristics of children with learning disabilities are explained. Learning disabilities have an impact on learning, including behaviour and social problems. The impact of the child's behaviour on parents is discussed, as well as the impact of the behaviour problems on the child's self-concept, and how to build a positive self-concept. The parents' reaction to the diagnosis of a learning problem is discussed, covering the possible phases of the reaction. Differences in the parents' reaction, and determinants of parental reaction are

included. The home life and how it is affected, siblings and how they are affected, discipline at home, and the interaction between parent and child are discussed in the next section. The needs and expectations of the parents are considered, as well as the importance of the partnerships between parents and teachers, and the parents' relationships with professionals. A systems-theory perspective on helping the family is explored. A short section on the child with learning disabilities growing up is included. The literature research is concluded with a short section on the views of the child in relation to what information they want for themselves about their learning disability.

1.6.2 Empirical study

The literature study is supplemented by an empirical investigation to determine what support would be beneficial to parents whose children have been diagnosed with a learning disability. For the purposes of this study a qualitative approach will be used. The data collection technique will be in-depth interviews with the mothers of children who have been diagnosed with learning disabilities. An in-depth interview is characterized as a "conversation with a goal" (McMillan & Schumacher, 2001:42). The goal of these interviews will be to determine what most affected the parents at the time of learning of their child's learning disability and how they would have liked the situation to be handled.

A pilot interview will be done to ensure that the focus of the interview is relevant to the research question. A content analysis of the in-depth interviews will be done to determine what the issues were that the parents had at the time of diagnosis and what kind of support they needed at that stage.

1.7 Research programme

Chapter 1 serves as an orientation to the study. The focus is on the purpose of the research. The aims and objectives are stated; a demarcation of the field of study, the research methods and ethical considerations are discussed. Key terms are identified.

Chapter 2 contains a broad literature research, defining various terms, and conditions. It covers various emotional responses of parents, and the impact a child with a learning disability may have on the entire family. The interaction between parents and professionals, and the views of the child with a learning disability are also covered.

Chapter 3 is a description of the research design. It contains the aims of the empirical study, the research design and the research methods. Ethical measures and measures used to ensure trustworthiness are covered. The sample, data collection and the research method are fully discussed. The data processing is also included.

Chapter 4 explains the research results.

The conclusions, recommendations and limitations are explicated in chapter 5.

1.8 Conclusion

The idea to do research on what support is required for parents whose child has been diagnosed with a learning disability was developed as a result of the researcher coming into contact with parents who suffered so much pain and anger. By means of in-depth interviews the researcher hopes to gain information that will fill the gaps that exist in the school system, and also help Educational Psychologists in their support to parents who have been informed that their child has a learning disability.

Chapter two covers the literature research. It reflects on various aspects regarding learning disabilities and their possible causes, as well as the emotional impact on the parents and families involved. It reflects on the relationships between parents and teachers, and parents and professionals. A short section covers the continued support that is needed as the child with a learning disability grows up. In supporting parents who have a child with a learning disability the view of the child, especially if one looks from a systemic perspective, is important.

CHAPTER 2

LITERATURE RESEARCH

SUPPORT TO PARENTS WHEN THEIR CHILD IS DIAGNOSED WITH A LEARNING DISABILITY – A CONCEPTUAL FRAMEWORK.

2.1 Introduction

The empirical investigation of the research question requires a well-grounded theoretical framework about the nature of learning disabilities. In this chapter attention will be given to the nature of learning disabilities; to the levels of learning disabilities, in relation to the strengths of children with learning disabilities; the characteristics of learners with learning disabilities; possible causes of learning disabilities under the headings: brain structure, genetic research, environmental and medical factors, and intelligence; and the diagnosis of learning disabilities and types of assessment that are used. Two models, namely the discrepancy model and dynamic assessment will be discussed. A definition will be given of the types of learning disabilities, including dyslexia, phonological and orthographic dyslexia, dysgraphia, dyscalculia and dyspraxia.

Learning disabilities impact on the learner's behaviour and social life, and this influences his/her self-concept (McDermott, Goldberg, Watkins, Stanley & Glutting, 2006:230) which, in turn, impacts on parents, siblings and the home life. The parents' emotional reaction to the diagnosis of their child's learning disability is followed by a discussion of the main phases of this reaction. The difference in reactions of the father and the mother to the news of their child's disability will also receive attention. The parents' needs and expectations in their interaction with the school are important to understand what support is required, as are the relationships between parents and professionals. A brief indication of the necessity of support to parents later on, as the child with a learning disability grows up, is included. An overview will be given of the

views of the child, as a systemic paradigm cannot ignore the voice of any part of the system.

2.2 The nature of learning disabilities

Various definitions of learning disabilities are presented. Each has its own particular emphasis. The levels as well as the manifestations of learning disabilities are included in this section.

According to Lerner and Kline (2006:7) one of the most influential definitions of learning disabilities is the definition in the Individuals with Disabilities Education Improvement Act (IDEA): “The term ‘specific learning disability’ means a disorder of the basic psychological processes involved in understanding or using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Such term does not include a learning problem that is primarily a result of visual, hearing, or motor disabilities; of mental retardation; of emotional disturbance; or of environmental, cultural, or economic disadvantage.” In addition there are regulations which state that “ A student has a specific learning disability if: (1) the student does not achieve at the proper age and ability levels in one or more specific areas when provided with appropriate learning experiences and (2) the student has a severe discrepancy between achievement and intellectual ability in one or more of these seven areas: (a) oral expression, (b) listening comprehension, (c) written expression, (d) basic reading skills, (e) reading comprehension, (f) mathematics calculation, and (g) mathematics reasoning.”

The National Joint Committee on Learning Disabilities (2005) defines ‘learning disabilities’ as ‘A general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning or mathematical abilities, etc.’ (Gardynik & McDonald, 2005:209).

Hamill (1990, in Reiff, Gerber and Ginsberg, 1993:114) delineated nine significant elements, including:

- a) underachievement determination,
- b) central nervous system (CNS) dysfunction etiology,
- c) process involvement,
- d) presence throughout the lifespan,
- e) specification of spoken language problems as potential learning disabilities,
- f) specification of academic problems as potential learning disabilities,
- g) specification of conceptual problems as potential learning disabilities,
- h) specification of other conditions as potential learning disabilities,
- i) allowance for the multi-handicapping nature of learning disabilities.

More recently learning disabilities are considered to be “neurological deficits that interfere with a student’s ability to store, process, or produce information and create discontinuity between one’s ability and performance leading to significant academic and social difficulties” (McDermott *et al.*, 2006:230).

The White Paper 6, produced by the South African Department of Education in July 2001, uses the term ‘barriers to learning and development’ (Department of Education, 2001:12). This definition is different from the former in that it includes external causes for a learner’s inability to learn. Learning disabilities, according to the South African White Paper, can be curriculum based or may also be as a result of other environmental factors, such as the physical school environment, where the buildings may be unsafe, inappropriate language is used for teaching, or the non-recognition and non-involvement of parents. The White paper uses the internationally accepted term ‘learning disability’ when referring to ‘those learners whose learning disabilities and development are rooted in organic/medical causes’. The term ‘barrier to learning’, as used in South Africa, usually refers to learners who have an average to above-average intellectual potential but who manifest academic difficulty, particularly with regard to literacy (Flack, 2005:321).

The term 'children with learning disorders' focuses on a group of children who are not functioning as is expected from them in their age-related academic tasks (Margalit & Efrati 1996:69; Mayes & Calhoun, 2006:147).

Definitions of 'disability' are not at odds with one another; rather, they complement one another in focusing the attention on alternate dimensions within the analysis and definition of 'disability' (Naidoo, 2006:595).

2.2.1 Levels of learning disabilities

Learning disabilities are seen to occur at different levels. Sternberg and Grigorenko (1999:4-6) believe that all individuals have some level of learning disability. They believe that the label 'learning disability' is the "result of interaction between the individual and the society" (1999:4) in which one finds oneself. They make three important points:

- 1) Individuals with specific learning disabilities often have considerable strengths in other abilities.
- 2) These individuals should see themselves as victors who capitalize on their strengths.
- 3) Modifications of the curriculum that excuse these individuals from learning important skills or from the normal experiences of schooling may be well intentioned, but they often end up hurting those individuals more than helping them.

By implying that the structures of society, such as the formality of a school environment, can create a learning disability (as is also apparent in the South African White Paper 6, 2001) Sternberg and Grigorenko (1999) create an opportunity for parents and teachers to look beyond the learning disability to strengths that the learner may have. The three points mentioned above are important in that they provide a positive focus for parents and teachers. This positive approach may be crucial in terms

of facilitating support to parents whose child has been diagnosed with a learning disability.

2.2.2 Manifestations of children with learning disabilities

Tuttle and Paquette (1993:5) state that learners with learning disabilities commonly manifest the following:

- Difficulty with academic skills including reading, writing, speech, and mathematics.
- Difficulty with fine-motor skills such as handwriting and copying.
- Difficulty with long- and short-term memory.
- Difficulty with attention (short attention spans, distractibility, hyperactivity, impulsivity).
- Difficulty with sensory integration.
- Difficulty with organizational skills.
- Extreme gaps in sections on IQ tests (for example, high verbal scores but poor performance scores).
- Difficulty in making and keeping friends.
- A low self-esteem.

In addition to these characteristics are other factors which might occur:

- These learners expect to fail. They are then likely to avoid failure rather than to go for success (Brand, 2005:30).

These manifestations impact on the learner's ability to perform adequately in a classroom situation. It is important that these factors are treated. If a learner is only referred for educational instruction and these factors are not dealt with it is likely that the learner will continue to exhibit a poor response to instruction (Fletcher, Lyon, Fuchs & Barnes, 2007:82).

2.3 Causes of learning disabilities

Neurobiological investigations indicating structural differences in children with learning disabilities will now be discussed. A further discussion includes indications that genetic heritage might be an important component. Environmental and medical factors, as well as intelligence, are considered to be factors that may play a role in the cause of learning disabilities.

2.3.1 Brain structure

Currently most professionals subscribe to a viewpoint that learning disabilities emanate from some kinds of differences in brain structure or functioning, and the most widely used definition suggests that the causes are neurological rather than environmental (Hallahan, Kauffman, Lloyd 1999:36; Semrud-Clikeman, 2005:243; Wong 2004:25). Neurobiological investigations suggest that there are subtle structural differences in several regions of the brain among children who are learning to read normally and children with reading disabilities (Wong, 2004:25). The neurobiological correlates believed to underlie these deficits are centered around the left-temporal-parietal region (Swanson, Harris & Graham, 2003:250). As concerns symptoms typifying Attention Deficit Hyperactivity Disorder (ADHD), neuro-imaging and neuropsychological studies have implicated the structural and metabolic abnormalities in the prefrontal and frontal regions of the brain (Augustyniak, Murphy & Phillips, 2005:281).

The issue of learning disability has undergone rather intense scientific study. As a result, professionals in the field feel fairly confident that there are strong relationships between brain dysfunction and learning disabilities (Rourke, 2005:112).

2.3.2 Genetics

It has been demonstrated in genetic research that the risk in the offspring of a parent with a reading disability is eight times higher than in the general population (Hallahan *et al.*, 1999:51; Tuttle & Paquette, 1993:4; Wong, 2004:25). Neurofibromatosis Type 1 (NF-1) is one of the most common single-gene disorders. Crowe, Schull and Neel found in 1956 that “approximately 50% of all cases of NF-1 are familial, inherited in an

autosomal dominant manner, with the remaining cases being spontaneous mutations”, a fact that was subscribed to by Cutting and Denckla in 2003(128). A learning disability is reported in approximately 25% to 61% of children with NF-1 (Riccardi 1981, Stine & Adams, 1989 in Cutting & Denckla, 2003:129).

Several studies implicate chromosomes 6 and 15 in reading disabilities (Galaburda, 2005:108; Miller, Sanchez & Hynd, 2003:249;). There is a 25% probability that each child of a parent with genes hypothesized to cause dyslexia will inherit those genes (Miller *et al.*, 2003:249). Although no genes as yet have been reliably identified as associated with learning disabilities, several linkages to chromosomal regions have been found for learning disabilities (Plomin & Kovas, 2005:609).

The contention that dyslexia occurs in families across generations has been recognized for a long time now (Sawyer, 2006:98). This researcher would bear this in mind when formulating an interview with parents to determine what support they may need when their child’s learning disability is diagnosed. Parents who struggled at school themselves may recognise their child’s difficulties.

2.3.3 Environmental factors

The role the environment plays in causing learning disabilities is not excluded. Extremely poor parenting or teaching can put learners at risk to develop learning difficulties (Hallahan *et al.*, 1999:55). Socio-economic circumstances and the quality of schooling may have an impact on a learner’s ability to learn (Fletcher *et al.*, 2007:3). Specifically in South Africa, the Education White Paper 6, Department of Education (2001:24) considers a number of environmental factors which can contribute to learning disabilities, including inaccessible schools, the curriculum, learning materials and also the language in which a learner is taught.

2.3.4 Medical factors

Medical factors that may play a role in the development of learning disabilities include premature birth, diabetes, meningitis, cardiac arrest and pediatric aids (Hallahan *et al.*,

1999:55). Alcohol and drug abuse during pregnancy may be contributing factors, as well as lead poisoning and a low birth weight (Tuttle & Paquette, 1993:4). It is possible that if any of these factors are a cause of a learner's learning disability, parents may feel more responsible, thereby causing more guilt. This would have to be explored in the support given to parents whose child has been diagnosed with a learning disability.

2.3.5 Intelligence as a factor

According to Siegel (2003:160) no reliable evidence can be found indicating that IQ level plays a causative role in the development of reading skills. On the contrary, evidence from a number of sources indicates that reading is not strongly related to intelligence, where intelligence is measured by IQ scores. IQ scores account for only about 25 percent of how well people do in school, and even less for their success in adult life (Hultquist, 2006:46).

2.4 Diagnosis of learning disabilities

The more traditional discrepancy model is discussed, followed by assessment alternatives and the need for a holistic interpretation of a learner's learning disability.

2.4.1 The discrepancy model

To be diagnosed with a learning disability in the United States, there has to be a larger than expected difference (discrepancy) between a person's intelligence quotient and his ability to carry out functions required for reading, writing and/or maths (Rodis, Garrod & Boscardin, 2001:170). The discrepancy model looks at the difference between a learner's academic achievement and his obtained intelligence quotient score. This procedure is criticized, as a learner is removed from his natural learning environment and tested with material that might not be relevant to his learning experience. Identification of learning disabilities should occur at classroom level (Klassen, Neufeld & Munro, 2005:299).

In the light of this criticism, the field is ready to discard the discrepancy model, after four decades of use, for purposes of diagnosing a learning disability. But it still needs to be

resolved how to define and diagnose learning disabilities (Dombrowski, Kamphaus, Barry, Brueggeman, Cavanagh, Devine, Hekimoglu & Vess, 2006:362).

In Western Australia learning disabilities are no longer typically defined by means of IQ achievement discrepancy models. Professionals in the field continue to say there have been numerous calls for a move away from the discrepancy model to identification of learning disabilities based on other markers, such as deficits in various psychological processes, lack of responsiveness to intervention or to low achievement, where intervention is provided to low performing students (Klassen et al., 2005:297).

2.4.2 Assessment alternatives

Dynamic assessment is put forward as an alternative to the discrepancy model (IQ assessment related to achievement) for learning disabilities. Dynamic assessment is an interactive assessment process in a test-teach-retest format. This means that a learner is assessed at his current level of achievement. Once his ability is assessed an intense period of teaching the learner on that specific task is undertaken. After this he is re-tested. If there is an improvement the learner is not considered to have a learning disability. The test (and retest) portion of the assessment process consists of the measurement of the targeted area (Moore-Brown, Huerta, Uranga-Hernandez & Pena, 2006: 210).

Any assessment that hopes to be relevant in the educational context should not occur in isolation, since learners do not learn in isolation. It is important to evaluate the broader context of the individual learner who is failing. This is the fundamental difference to the discrepancy model. Assessment stimuli within the learner centered deficit model are likely not to be relevant to daily activities in the classroom (Dean, Burns, Grialou & Varro, 2006:160). Dynamic assessment makes assessment relevant to what is happening in the classroom. It is related to tasks that teachers and parents may understand better whereby possibly enhancing the support to the child and the parent.

To diagnose a learner competently each learner must be studied and understood in depth (Healey, 2005:115). A comprehensive, holistic view of the learning disability is needed. This focus can only develop by looking at the life experiences of the learner. This may be done by researching his/her lives in context, that is, examining the lived experiences of the learner with learning disabilities (Flack, 2005:325). Not only professionals but also parents need to see the whole picture: "It was often difficult to see that there was a whole child there, not one just with a mass of difficulties but with plenty of abilities as well" (Buchman, 2006:76). This is in keeping with the systems frame of reference.

2.5 Types of learning disabilities

"The majority of learning disabilities are language-based and difficulties using oral and written language remain the single most significant deterrent to educational growth" (Wallach, 2005:294). Understanding the types of learning disabilities and their possible impact on a child gives parents more tools in their quest for support for themselves and for their child. Various types of learning disabilities are discussed below. Each one of them can hinder a learner when it comes to keeping up with the class in day to day activities.

2.5.1 Dyslexia

The Orton Dyslexia Society defines dyslexia as follows: "Dyslexia is one of the several distinct learning disabilities. It is a specific language-based disorder of constitutional origin characterized by difficulties in single-word decoding, usually reflecting insufficient phonological processing. These difficulties in single word decoding are often unexpected in relation to age and other cognitive and academic abilities; they are not the result of generalised developmental disability or sensory impairment. Dyslexia is manifest by variable difficulty with different forms of language, often including, in addition to problems with reading, a conspicuous problem with acquiring proficiency in writing and spelling" (Rodis *et al.*, 2001:233). This deficit leads to a profound disturbance of reading ability that pervades different domains of academic achievement. Comprehension is dependent upon one's ability to decode rapidly and to

recognize single words in an automatic fluent manner (Fletcher *et al.*, 2007:86). A spelling deficit also occurs in dyslexia – in isolation or in context. Slow reading fluency emerges as a central academic skill deficit even when spelling is adequate.

2.5.1.1 Phonological dyslexia

Phonological dyslexia denotes the disability where people have trouble making sense out of speech sounds and their connections to letters (Hultquist, 2006:95). Speech sounds, or phonemes are the smallest part of speech that make a difference in the meaning of a word. A learner's primary task in the early development of reading and spelling in an alphabetic language is to develop an understanding of the alphabetic principle (Fletcher *et al.*, 2007:87). Phonological awareness is the ability to attend to and decipher the speech-sound structure of words. Very good phonological awareness in preschool is a predictor of high reading ability (Rodis *et al.*, 2001:234).

2.5.1.2 Orthographic dyslexia

Hultquist (2006:94) describes orthographic dyslexia as the disability where people have trouble remembering how letters and words look. Problems with orthographic processing can lead to trouble with reading, spelling and maths (Hultquist, 2006:23). It can often lead to slow reading, and making more errors when there are lots of words on a page. Lines might be skipped while reading. "Earlier research found that children have difficulty writing due to an inability to sustain the writing effort. Students with learning disabilities fail to access the knowledge they possess, and their difficulties in the mechanics of writing interfere with the process of generating content, leading to meager output" (Swanson *et al.*, 2003:10).

2.5.1.3 Dysgraphia

Dysgraphia is characterized by a difficulty with learning to write, not attributed to "general cognitive delay, psychiatric or neurological disorder, sensory impairment, or inadequate instruction" (Thomson & Raskind, 2003:256). Berninger and her associates (in Fletcher *et al.*, 2007:239), reported that "automaticity in the retrieval and production of alphabet letters, rapid coding of orthographic information, and speed of sequential

finger movements were the best predictors of handwriting skills.” Automaticity of handwriting “predicted compositional fluency and quality. A deficit of fine motor skills also constrained handwriting, especially in the beginning stages of writing” (Fletcher *et al.*, 2007:239).

2.5.1.4 Dyscalculia

Disorders of mathematics involve difficulties with computations and also often with problem-solving. It is associated with a neurological dysfunction (Lerner & Kline, 2006:G-3). Maths disability is associated with “concept formation, procedural learning and visual-motor integration” (Fletcher, Morris & Lyon, 2003:41). In order to solve a problem a learner must “be able to master the rules for problem solving, develop categories for sorting problems that require similar solutions, and be aware that novel problems are related to previously solved problems” (Fuchs & Fuchs, 2003:307). If the above cognitive processes are impaired in learners with learning disabilities in maths, including working memory, language, and inattention, it follows that they might have difficulty with maths.

2.5.1.5 Dyspraxia

Dyspraxia is when motor difficulties can affect body movements. It may present itself as clumsiness, handwriting problems or speech difficulties (Davis, 1997:245). Dyspraxia is not often associated with dyslexia as it does not directly affect reading, writing, spelling or maths. “In dyspraxia the senses of balance and movement are temporarily distorted or inherently inaccurate showing as clumsy behaviour” (Davis, 1997:63).

The full implications of each kind of learning disability in the classroom, and how they can affect a learner’s work, is important information for a parent with a child who has been diagnosed with a learning disability. It allows them to understand what type of difficulty their child is experiencing and how they can assist him/her in their struggle to keep up with the class and attain better levels of achievement.

2.6 The impact of learning disabilities

Learning disabilities impact negatively on a child's daily life as well as on the lives of his/her family members. This impact can range from mild to severe. Academic underachievement or failure is seen as being the most common outcome of having a learning disability (McDermott *et al.*, 2006:230). The following section considers the fact that children with learning disabilities manifest behaviour and social problems which have an impact on their parents and on their self-concept. It is important to assist the child in an effort to improve his/her self-concept.

2.6.1 Behaviour and social problems

Dyslexia can lead to social, emotional and behavioural difficulties (Hultquist, 2006:38). Behavioural problems may include the following: "impulsive throwing, grabbing, hitting, or blurting out 'inappropriately', along with tantrums, stubbornness, bossiness, non-compliance, defiance, argumentativeness and blaming others" (Amerongen & Mishna, 2004:36; Forness, 2005:317; Tuttle & Paquette, 1993:3).

Cohen (2001 in Amerongen and Mishna, 2004:39) describes how language is a means to control one's behaviour and emotions. Therefore a language disability may interfere with the process of controlling one's behaviour and emotions. A lack of control of behaviour and emotions can increase the likelihood of impulsive behaviour. Furthermore, when children are unable to make themselves understood and have a limited language capacity for repairing communications, this is more likely to lead to a situation where they become angry and engage in conflicts. These social problems are painful for both parent and child (Tuttle & Paquette, 1993:32). These problems, linked to learning disabilities, might mean that school is not the happiest of places for children with learning disabilities (Wren, 2006:87). Because of these behaviour problems, resulting from a learning disability, teaching learners social skills is as important as teaching them academic work (Maag, 2005: 169).

The results of a study done by Yu, Zhang and Yan (2005:329) suggest that children with learning disabilities report higher degrees of loneliness and lower levels of peer

acceptance when compared to children who are not learning disabled. They conclude that it is possible that behaviour problems and insufficient levels of social competence lead to learning disabled children being more likely to be rejected by their peers.

2.6.2 The impact of behaviour problems on the child's self-concept

Tuttle and Paquette (1993:17) maintain that children with a low self-concept display various symptoms: they may feel inadequate, exhibit low self-worth, blame themselves no matter what goes wrong, blame others for everything, or never taking responsibility. A low self-concept can also be the cause of behaviour problems, not only in the school but also during extra-curricular activities. Bernard (2006:106) reports that learners with learning disabilities demonstrate lower academic self-concepts than do normally achieving learners without disabilities.

Not only the self-concept but also depression may play a role in a learning disabled child's life. In a study done by Maag and Reid (2006:7) it was indicated that learners with learning disabilities have significantly higher depression scores than learners without learning disabilities.

A child's self-concept can be boosted by parents who assist their children with the improvement of their academic performance (Tuttle & Paquette, 1993:18). When children see an improvement, they begin to feel better. When the gap between their school performance and that of the rest of the class closes, children with learning disabilities begin to feel better about themselves. It is important to acknowledge their strengths in other areas. Parents can help their child find these areas. Success in other areas is just as important as academic success at school (Tuttle & Paquette, 1993:18).

A learning disability can be seen as a limitation for a child. Counseling children with learning disabilities will enable them to feel comfortable with who they are. Through counseling, they can learn coping skills such as improving their self-esteem and behaviour. This will help them to be able to deal better with their personal or social difficulties (Myers, 2005:442). A child does not live in isolation. Building his/her self-

concept through counseling could help with improving the child's self-esteem. Counseling that involves the family, and not merely the child, has the potential to improve a child's behaviour. The child's learning disability has an impact on the entire family (see 2.8). When counseling takes place with the entire family all family members can benefit (Vaughn, White, Johnston & Dunlop, 2005:55).

In addition to including the family in counseling, emotionally warm relationships among teachers and learners, characterized by open communication, support, and involvement can provide the child with a sense of security within the school setting. This can promote their social, emotional, and academic competencies (Murray & Greenberg, 2006:221).

2.6.3 The impact of behaviour problems on parents

Amerongen and Mishna (2004:42) found that the behaviour enacted by children with learning disabilities often leads the parents to feeling helpless and ashamed. Parents believe that the behaviour is a reflection of their lack of parenting capability. They frequently feel and may actually be blamed for their children's behaviour by the teachers, extended family and others. This may be the reason for their negative attitude towards others.

2.7 Parents' reactions to the diagnosis of learning disabilities

As parents wait for the diagnosis they go through "a hellish period of blame, accusations, self-accusations and feelings of guilt" (Niedecken, 2003:31). Understanding parents' emotional reaction to the news that their child has a learning disability is relevant when doing research on what support they may need. It also appears that the father's reaction may be different to the mother's. This has to be taken into consideration in a support program.

At the time of diagnosis of their child's disability parents' expectations are shattered. Many will need emotional support to adjust to their newfound situation, as well as to the continued care of their child (Clarke, 1995:218; Russel, 2003:144). Parents'

reactions to the diagnosis of a learning disability in their child can include shock, denial, blame/guilt, anger, and sorrow (McLoughlin *et al.*, 1987:357; Oeckerman, 2001:3). They may also exhibit feelings of fear and frustration. Tuttle and Paquette (1993:8) include relief as an emotion when parents have their suspicions confirmed.

2.7.1 Phases of the parents' reactions

Various stages of emotion after a loss are identified, namely denial, anger, bargaining, depression and acceptance. "They are tools to help us frame and identify what we may be feeling when we are faced with a loss. Not everyone goes through them in a prescribed order" (Kübler-Ross & Kessler, 2005:7; Lerner & Kline, 2006:153). These stages, suggested by Kübler-Ross, relate to the loss we feel when a person close to us dies. In the same way, when parents are informed that their child has learning difficulties, they are faced with the loss of the dreams they had for their child. Oeckerman (2001:11) suggests a number of stages in parents' reaction to the news that their child has a learning disability.

Shock is the first reaction on hearing the news that their child has a learning disability. The parents' dreams for their child's future are shattered. With shock comes denial. It is commonly known as the first reaction in a grieving process (Oeckerman, 2001:3). It is a defense mechanism used by parents as they feel unable to cope (Ho & Keiley, 2003:239). Lessing and Strydom (2001:7) outline four common forms of denial:

- Refusing to recognize the child's disability.
- Rationalizing the child's disability.
- Seeking professional confirmation that there is nothing wrong with the child.
- Quickly becoming too cooperative with professionals.

What Ho and Keiley (2003:239) call the collaborative-resource approach, is particularly useful for working with parents who are in denial of their child's intellectual disability. The collaborative-resource approach is in keeping with the systems theory where all parties collaborate and recognize one another's expertise.

The next stage is guilt. Guilt revolves around feelings about what one thinks one could have done. Parents often feel responsible for their children's learning disabilities, even when the children are well into their adult life (Niedecken, 2003:9). Hereafter parents may feel anger. Anger occurs as the denial breaks down and the child's condition becomes more real and apparent (Lerner & Kline, 2006:153). Anger is taken out on teachers, doctors, their partners or on other children.

Bargaining, as a stage, can be the time that is used to help one adjust to the new situation. By bargaining, in other words by hoping that by doing something things will change, one hopes that order will be restored (Kübler-Ross & Kessler, 2005:19).

Anger and bargaining may be followed by sadness and depression. It is necessary for parents to grieve. "Grief is a shattering of many conscious and unconscious beliefs about what our lives are supposed to look like" (Kübler-Ross & Kessler, 2005:78). The parents' dreams for their child's future are shattered. They have to come to terms with this through grief.

Brand (2005:20) includes shame and embarrassment as emotions parents may feel. What parents may perceive as a defect in their child may make them feel ashamed that their child is not 'normal' like other children. Parents may interpret it as a defect in themselves.

A final stage is when parents come to accept their child's learning disability. According to Kübler-Ross and Kessler (2005:25), acceptance is often confused with the notion of being all right or OK with what has happened. It is something parents learn to live with. Finally, healing and adjustment comes about when a person can take a firm stand, despite the fact that healing looks and feels like an unattainable state. "Acceptance is the stage at which the parents can look past the disability and accept the child as he or she is. A stage beyond acceptance is to *cherish* the child for these differences and for how that child has made the parents' lives better" (Lerner & Kline, 2006:154). The goal is to reach acceptance to be able to make decisions about how their child will be

helped, that are unclouded by undue emotionality. The goal is that parents accept their child along with his/her special needs, while continuing to live a normal life (Lerner & Kline, 2006:154).

The results of a study by Roll-Pettersson (2001:10) suggest that the parents' reactions are different. A few parents admitted that they experienced the phases described in the literature, beginning initially with shock and making the transition to acceptance.

2.7.2 Differences in the parents' reactions

Mothers and fathers generally deal with the news that their child has a learning difficulty in different ways (Hastings, Beck & Hill 2005:162; Tuttle & Paquette 1993:8). However, according to Rump (2002:19), both parents go through four phases:

- 1) denial of the problem;
- 2) resistance to seeking help;
- 3) exploration of needs and resources;
- 4) commitment to the child's future and care.

These are broadly similar to the phases indicated by Kübler-Ross and Kessler (2005) (see 2.7.1). Support given to parents at this time needs to bear in mind that, although fathers and mothers may be reacting differently, they may, in fact, be going through the same stages.

Most mothers eventually come to accept the diagnosis. They believe that the diagnosis would finally bring their child the help that is needed. It is more difficult for fathers to accept the diagnosis. There may be a variety of reasons why fathers tend not to accept their child's learning disability. Included in these is the fact that fathers still seem to have less to do with the school than mothers do. Because fathers are less involved with the daily life at school than mothers they have less opportunity to develop a relationship with the teachers. A father's denial has to be treated before a child can receive help (Tuttle & Paquette, 1993:9). Rump (2002:19) questions the fathers' lack of

involvement and his deferment of decisions about his child to the mother. She followed a study by Donald Meyer who interviewed fathers with children of different ages and different disabilities. She found that fathers felt their opinion was not valued.

It is important to involve the father during the process of accepting that his child has a learning disability. The majority of fathers, whether they live in the same household as their child or not, wants to and needs to be involved with the decisions affecting their child (Rump, 2002:20). Findings in Hastings and Beck's research (2004:1343) show that fathers seem to benefit from involvement in support groups.

Parents often differ with regards to their level of concern about the nature and extent of their child's learning problem and the best way to approach it. This is an important issue to consider in determining what support is required by parents (Sperry & Duffy, 2002:431). Mothers and fathers have different perceptions of the positive contributions of their child with a learning disability. These contributions include personal growth for the parent and the child, increased family closeness as they come to acceptance, and a greater sensitivity. In general, mothers reported more positive perceptions than fathers of their child's contribution to the family and themselves (Hastings *et al.*, 2005:162).

2.8 The impact that a child with learning disabilities has on the family

The diagnosis of a child's learning disability and the adaptations that have to be made in the family have an impact on the home life of the family, on the siblings in the family, the interactions between the parents and the child, and how discipline is dealt with.

"Unless you also have a child with what we've since learned to call *learning differences* (LD) or other major differences, you can't imagine the impact these issues have not just on your child but on you and the rest of your family" (Buchman, 2006:ix). Dyson (1996:280) demonstrated that having a child with a learning disability results in increased stress on the parents, which could negatively affect the parents' relationship with other children, and even the relationship between mother and father.

2.8.1 Home life

Added stress is indicated in the home life of a family with a learning disabled child. Besides financial demands and sacrifices parents typically experience fatigue and significant demands on their time. Driving the learning disabled family member around is time consuming and tiring. There are also, seemingly, a never-ending series of appointments with, amongst others, the pediatrician, speech therapist, occupational therapist, and tutor. When not in the car or waiting room the parents may be reading books and articles on learning problems (Sperry & Duffy, 2002:430). Initially it may feel that the disability is all-encompassing. This can put relationship and career restraints on the parents.

Added to these stressors, the parents and the child who is struggling are often exasperated by homework. They find homework difficult, frustrating and laborious (Margolis, 2005:5; Tuttle & Paquette, 1993:20). Efforts to assist the child with a learning disability in the family may detract from the needs of other children in the family, and disrupt the quality of family life as a whole (Walsh & Williams, 1997:144).

These problems can negatively impact on the family's sense of their own future (Sperry & Duffy, 2002:431). Their contention (2002:431) is that a family counselor should look after the family as decisions are made that have an influence on the whole family.

Turnbull and Ruef (1996, in Hudson et al., 2003:240) give a list of the perceived needs of families in dealing with children and their challenging behaviours. The following were included in the list:

- assistance in establishing structures in the home routine;
- assistance in dealing with stress;
- aid with the provision of respite care; and
- assistance with engaging advocacy.

A counselor who has insight and understanding of the family as a system, and who is aware of the characteristics of a family and the influence a child with a disability has on the family, will be more effective in heeding the needs of parents and children (Van Heerden, 2002:10).

2.8.2 The impact that a child with learning disabilities has on siblings

“I had no idea how much it would affect Annie, the non-LD learner, and how much impact it would have on the family dynamics overall” (Buchman, 2006:95). Research suggests siblings are drawn into the complex phenomenon of parental adjustment (DesNoyers Hurley & Levitas, 2004:77). Tuttle and Paquette (1993:28) say that siblings of children with a learning disability often feel that they do not get as much attention as the child with the disability does. According to Hallahan *et al.* (1999:166), research on whether siblings of the child with a learning disability experience more problems in adjustment, is mixed. However, there is little doubt that these siblings are at a greater risk of having problems in their relationships (Hallahan *et al.*, 1999:166). Siblings can become jealous about the extra attention the child with a learning disability receives. They might feel that the child with the disability is given extra support at home or has modified assignments and appears to do less work (Hultquist, 2006:39).

In research done by Evans *et al.*, (2001:70) half of the siblings participating required help with living with their brother or sister with a learning disability and challenging behaviour. Results of Evans’ study indicate that support groups for siblings of children with learning disabilities were effective in that the groups helped build the learning disabled child’s self-esteem. They also helped in understanding the siblings’ needs, and with the involvement with the siblings at home. However, according to Hultquist (2006:39), a feeling of relief may be felt by everyone in the family when the disability is finally diagnosed.

2.8.3 Dealing with discipline

At the time of the diagnosis of a learning disability in their child parents may begin to feel that their child should be less disciplined than usual. Parents may need support in this respect in the form of information and parenting skills.

For a parent it is important to know if his/her child has a learning disability, because it provides an explanation for the child's struggles. This should, however, never be used as an excuse. Because a child has a learning disability it does not mean that he/she does not have to work, study, learn to write, learn to spell, obey school rules, and so on. All it means is that the child needs to be accommodated and needs special teaching (Hultquist, 2006; Pickering, 2002:7). Discipline should be maintained as with the other siblings. Providing safe boundaries and structure in the child's life will make it easier for him/her to cope (Margolis, 2005:5).

2.8.4 The interaction between parent and child

To support parents they need to know how valuable and necessary their input is in the lives of their children.

Parents who are involved in their children's lives can be a positive influence on their school motivation, as well as on other non-academic outcomes (Martinez, 2006:207). In one study of adolescents' perceptions of support from parents, teachers, and peers, learning disabled children identified parental support as the most important factor in terms of creating a positive orientation towards learning and pursuing academic goals (Murray & Greenberg, 2006:221). Furthermore, if parents are involved in after-school activities and sport, it fosters positive relationships between them and their child with a learning disability and this, in turn, will improve motivation at school and in other non-academic areas (Martinez, 2006:207). Children benefit from parental involvement as the parents' knowledge and interest may be reflected in the increased interest of the child (Welsh, 1987:235). Any support given to parents should bear in mind the positive impact of their involvement with their child.

2.9 The needs and expectations of the parents and their interaction with the school

In trying to determine what support might be required by parents whose child has been diagnosed with a learning disability it is important to consider the literature covering the expectations parents have for their children and the assistance they would like from the school. Constructive interaction with the school can benefit all parties concerned. Relationships between parents and teachers are important. In meeting the needs and expectations of parents there is widespread agreement that parent-school partnerships are essential to improving educational outcomes for all learners, including those with learning disabilities (National Joint Committee on Learning Disabilities, 2005:252).

Parents' expectations of their children's progress at school are important. These expectations are the ones that need to be reassessed when parents find out that their child has a learning disability. A greater understanding about the origins and outcomes of parents' expectations concerning their child's education can provide information about opportunities available to help them achieve their goals, and in so doing improve the relationships between home and school (Russel, 2005:119).

Not only the parents' expectations, but also their needs should be met. These needs include information, advice, support and practical help (Russel, 2005:118). It is important that parents receive information, advice and support that are both clear and appropriate, from professionals (Case, 2001: 850). In Summers and Jenkins (2001:58) it is written that there is no doubt that parents' and their families' needs should be met. It is, however, *how* they are met that is likely to be empowering. This should be carefully considered when determining what support is required by parents.

2.9.1 The relationships between teachers and parents

The relationship between teachers and parents and how they communicate is important in the process of diagnosing a learning disability and in relating the news to the parents.

Parents often view school problems, such as difficulty with work or behaviour problems that their children experience, as negative reflections on their parenting skills. Generally schools contact parents when their child is experiencing academic difficulty or problems with behaviour. Therefore parents across the socio-economic spectrum believe that any invitation from the school will be “bad news about the child” (Amatea, Smith-Adcock & Villares, 2006:184). On the other hand, a positive parental interaction style with teachers is directly related to significant positive developmental outcomes (Williams, 1999:153). It takes considerable effort to establish positive relationships between parents of children with learning disabilities and teachers. It is important that teachers and parents communicate their goals for and expectations of the children to each other. In this way they can create the best possible environment and facilitate the learning process (Felber, 1997:20). A collaborative relationship between parents and teachers where parents are involved in all the decisions about the child, e.g. assessment, transition planning and intervention programs, will foster better relationships between parents and the school (Raver, 2005:11).

Oeckerman (2001:12) sets out five ways in which teachers can enhance the interaction between themselves and the parents of the child when a learning disability has been diagnosed. The following need to be understood:

- The grief process should be accepted as natural and good.
- Teachers should acknowledge that not all parents go through the same grief process.
- They should understand that grief may reoccur.
- Teachers should be prepared with the information the parents may need.
- They should help parents celebrate the success of their child.

Teachers can further help by differentiating the curriculum to focus on areas of strength rather than only remediating weaknesses (Mann, 2006:113).

Teachers need to be sensitive in how they communicate information to parents. Skills that support parent-teacher communication include accurate listening and appreciating the other person's frame of reference (Robinson & Fine, 1994:15).

2.9.2 Creating an environment conducive to communication

As the parents go through various emotional phases at the time of the diagnosis of their child's learning disability, the creation of an environment that leads to constructive communication is important. Robinson and Fine (1994:16) mention six important points:

- The parties should be introduced to the purpose of the meeting. It is important to create an atmosphere which is open and non-defensive.
- The teacher should use accurate listening skills to explore the parents' view of the situation.
- The objective of the meeting is for the teacher and parent to reach a common understanding of both the problem and the solution.
- The options should be reviewed.
- Agreement on a specific plan should be attained.
- The success of the plan should be evaluated. The involved persons should discuss what has worked and what not.

Robinson and Fine (1994:8) believe that a systematic approach such as the above helps the participants to stay on task and to eventually achieve a peaceable solution. This kind of structured communication benefits all parties involved, as a positive atmosphere is brought about when questions and doubts can be responded to quickly, before they become problems (Welsh, 1987:236).

In their communication with parents it is important for teachers to remember that parents know their children much better than the teachers are likely to because parents typically spend much more time with them. Parents see their children interact with others in a wider variety of environments than teachers do. With this knowledge of their

children, parents have a great deal to contribute to the educational and social development of their children, and this knowledge can be put to very good use in planning the individualized educational program for the child with learning disabilities (Bender, 2008:129; Williams, 1999:150).

2.10 The relationships between parents and professionals

As communication between parents and teachers is important, so is the communication between parents and other professionals concerned with the diagnosis of a learning disability.

The stage of the diagnosis of an impairment is often very traumatic for parents (Jupp, 1992, Mason, 1995, in Murray, 2000:691). Parents are inevitably shocked when they hear the news that their child has a disability, and this is compounded by the way they are told and the treatment they receive from professionals at the time (Murray, 2000:692). It is crucial that the professionals involved with the parents be sensitive, accepting and non-judgmental (Walsh & Williams, 1997:150). Furthermore, when professionals speak to parents about their child's learning disability parents may experience problems understanding the scientific language that is being used. These discussions may alienate parents from a collaborative process (Wong, 2004:527).

2.10.1 Informing parents of their child's learning disability

"I eagerly awaited the findings from all the tests. At the end, we were handed four pages of 'this is your child', with charts and test scores and evaluations that left me speechless. I read the results. And read them again. And again. There were lots of mysterious, vaguely unsettling findings, some quantitative, some verbal" (Buchman, 2006:36). "It was the beginning of the most painful period of my life" (Buchman, 2006:38).

When parents are informed by a teacher or other professional that their child might have special educational needs, parents may develop various concerns and/or negative feelings. The announcement will be distressing and leave parents feeling

isolated from the process which will evolve to assist the child (Quinn, 2001:2). If the parents are informed and involved, crises can be dealt with effectively and efficiently to benefit the family, the professional and the child (Rump, 2002:18). The anger that parents may feel as a result of the diagnosis indicate that good conflict resolution strategies are necessary. These include listening to understand, speaking to be understood, and reframing emotionally charged statements into neutral, less emotional terms (Bodine, Crawford & Schrupf, 2002:11).

A significant issue emerging from a study by Quinn (2001:10) was that parents wanted to be well informed. Tuttle and Paquette (1993:15) affirm that knowledge is power. When parents learn more about their child's learning disability they feel less powerless. The more they learn the more control they can have over the process. Informed and involved parents can be an asset in optimizing future outcomes (Prezant & Marshak, 2006:44). Parents also need information on what an 'evaluation' is (Tuttle & Paquette, 1993:106). They often do not know what it entails, nor what information will be obtained from it. Added to this is the fact that it is important to ensure that parents and families are able to interpret the results of an assessment of their child and to understand how these results will be used (Brink, 2002:254). When parents understand test results and how they will be used they will be more able to support their child.

2.10.2 Resistance to professional help

Maharaj (1998:10) found that the initial contact with parents was extremely stressful. According to him this was because parents were unaware of how to cope, firstly, with the fact that their child had a learning disability and, secondly, with how to go about assisting their child with a learning disability.

A dilemma arises when parents refuse to allow professionals to provide services to their children because they believe their children are functioning normally. This can result in the children missing out on invaluable early interventions that are crucial for later development (Ho & Keiley, 2003:246). Support to parents at the stage of the

diagnosis of a learning disability needs to take this possible resistance to professional help into account. Hastings' and Beck's (2004:1345) findings conclude that a model where one person works closely with the family, and who can mediate between family and other service providers, leads to more positive outcomes for parents.

In planning support to parents a professional should take note of the following unhelpful actions listed by parents, as indicated in a study by Prezant and Marshak, (2006:36):

- the professional performed the job poorly;
- the professional held low expectations;
- non-compliance with regulations and recommendations;
- discouraged inclusion;
- demeaned parent or child; abused power;
- ignored parental input;
- recommended institutionalization;
- physical abuse.

These actions are not conducive to a positive relationship between the professional and the parent. They do not provide an optimistic or positive future for the child with a learning disability, nor do they show respect for the parents and their input and knowledge of their child. Professionals tend to relegate parents to a minor role in the process that leads to obtaining services for the child who struggles in school (Connor, 2005:165). In order to communicate effectively, the position of the professional needs to be that of listener/learner. To engage in meaningful collaboration with parents means letting go of the alienating expert stance that positions professionals above parents rather than beside them (Wong, 2004:528).

Parents listed the following actions they would like:

- listening and respecting parental input;
- being competent and providing information;
- collaborating and communicating.

“Good communication between professionals and parents is the key to successful programming for students with learning disabilities” (Hallahan *et al.*, 1999:172). Parents need to hear about the good they have done; they should frequently get enthusiastic praise (DesNoyers Hurley & Levitas, 2004:79). Assisting parents to put their feelings and thoughts into words is very helpful (DesNoyers Hurley & Levitas, 2004:79). Drawing out family strengths in the midst of difficulties helps to counter helplessness, failure, and despair and reinforces pride and confidence (Amatea *et al.*, 2006:186). To create respectful interactions, asking parents frequently about their concerns, ensures that parents have an opportunity to discuss their child’s development and behaviour with the concerned professional (Raver, 2005:11). Contextualizing family members’ distress as natural or understandable in a crisis or stressful situation can soften their reactions and reduce blame, shame and guilt (Amatea *et al.*, 2006:186).

Professionals who facilitate supporting networks for parents of children with learning disabilities may be creating effective support for parents (Hastings & Beck, 2004:1340). In terms of successful outcomes, parents identified four key characteristics supporting parents and their relationship:

- perceived sameness of the child’s situation and parent personalities;
- being in a comparable situation as a means of learning directly applicable skills;
- being available at any time on the telephone;
- the mutuality of support.

Support groups should be easily accessible to parents. It is important that support to parents is offered early in the process in an effort to alleviate distress.

2.11 The learning disabled child growing up

Parents are faced with the initial shock at the news of their child’s learning disability. Although this research covers the support that is needed at the time of diagnosis it is important to remember that support may be an ongoing need. It may be that a learning

disability affects the child for life. Parents need to be supported and prepared for the long-term future of their child.

Transition from school is an important milestone for a learning disabled child. School counselors can play an important role in helping learners with learning disabilities with this transition (Milsom & Hartley, 2005:437). Parents need information connected to their concerns and questions regarding what it means for a student with a learning disability to attend a tertiary institution. Counselors should be able to provide this information. They should anticipate the concerns and questions of parents (Milsom & Hartley, 2005:440). This also relates to the transition from educational institutions to employment. It is one of the most important transitions that people make in their lifetimes (National Institute on Disability and Rehabilitation Research, 2002 in Madaus, 2006:20).

In a study done by Tarleton and Ward (2005:73) parents generally recognized that transition is about their child growing towards adulthood and adult responsibility. They were, however, concerned about their young adult's ability to take on these responsibilities and how they would be treated by the wider public. Parents commonly lacked any understanding of the transition process and did not realize that transition planning at school should cover all aspects of the young adult's life, not just the move from school. Parents often talked of being scared or frightened about not knowing what their role was in the transition process. Also, they were aware of the lack of adult services available and that they might have to fight to get their young one the support he/she needed.

2.12 Views of the child

This study focuses on what support a parent would need at the time of the diagnosis of their child's learning problem. It has not considered the needs of the child. It seems imperative, however, to take note of the views of the child in the ability to support the parent.

In her study Kelly (2005:263) found that most parents avoid discussing their learning difficulties with the children. However, she also found that children who had received explanations from their parents understood it in the way it was presented to them and were able to accurately repeat their parents' explanations when talking about themselves. Kelly (2005:271) believes there is a need for adults to allow children to communicate their views and experiences of their particular disability in a supportive environment. There is also a need for the children to be consulted and to fully participate in the planning and delivery of support services.

“The system was doing its best to accommodate for my language disability; however, no one, including my parents, was able to communicate with me about what was going on inside my brain. This silence left gaps in the understanding of my learning style, and ultimately plagued my self-worth” (Lee, 2005:182).

It is important that parents explain to their children and help them understand the reasons why they need help, and the importance of its relevance to their academic work. Tuttle and Paquette (1993:14) maintain that as the children's academic skills improve, so will their social skills. What may initially be thought of as harmful to the child is in fact beneficial to ultimately building up their self-esteem.

“The most important thing a parent can give a child is love. The child with a learning disability may need the parents' love demonstrated more than do most children. Discuss your child's problem with him. He has a right to know what causes his difficulties in school. He is usually quite relieved to know that he is not 'stupid' or 'dumb'” (Pickering, 2002:7).

2.13 Conclusion

The most recent definitions describe a learning disability as being caused by neurological deficits. These deficits hamper the child's ability to store, process or produce information. Such deficits also create discontinuity between the child's ability and his/her actual performance, which leads to academic and social difficulties.

The discrepancy model for diagnosing learning disabilities has become outdated. Dynamic assessment is being put forward as a more valid procedure.

Much detail is given to the parents' emotions at the point of diagnosis as support in this area is what the research revolves around. Parents go through a grieving process as their expectations for their child's future are shattered. The final stage in the grieving process, acceptance, is an important stage for parents to reach as it is at this stage that they can begin to support their child. It is possible that if adequate support is given to parents, acceptance can be attained sooner rather than later.

In accordance with the systems theory, the home life and siblings are affected by a child with a learning disability in the family. It is important to consider these factors when deciding upon a support program.

Communication between teachers and professionals impacts on parents. Depending on how communication is handled, it can provide support to parents or anger them. How the child sees communication about his or her disability was discussed in this section. Support to parents at the time of diagnosis is just one aspect of the support they need. As learning disabled children grow up they are faced with challenges that need support. This aspect was briefly touched upon, in an effort to maintain a holistic picture.

The research design will be discussed in chapter 3.

CHAPTER 3

RESEARCH DESIGN

3.1 Introduction

“The whole rationale for undertaking research is to increase our knowledge, so that we can then apply that knowledge to making improvements to how we do things, for the purpose of increasing the effectiveness of the services that society provides, in order to improve the quality of people’s lives” (Evans, 2002:201).

The above quotation encapsulates the sentiments behind this research project, which aims to provide a service to parents that will improve the quality of their experience at their child’s school, and hopefully alleviate the emotional hardship in relation to the diagnosis of a learning disability in their child. This chapter reflects on the aim of the research. This is followed by the research method, which includes data collection, stages of data collection, sources of data, the number of sources used, the location and frequency of data collection and finally, the data collection instruments. The selection of the sample is covered, followed by data analysis. Ethical measures, including informed consent, the use of deception, debriefing of subjects, the subject’s right to withdraw, and confidentiality and anonymity are considered. The validity and reliability of interview data, relating to experimenter effects and subject effects, will be discussed.

3.2 Aim

The aim of this research is to ascertain what kind of support can be given to parents whose child/children has/have been diagnosed with a learning disability. “It is possible that the attempts of professionals to ‘help’ may or may not meet the perceived needs of parents, regardless of positive intention or academic prescription” (Prezant & Marshak, 2006:44). The parent–professional relationship is established at the time of sharing the diagnosis of their child as having a learning disability with them. It is therefore particularly important that professionals be sensitive to parent perceptions of this event

at this time (Maharaj, 1998:49). According to Case (2001:837) professionals are now addressing the need for clear and appropriate information and intervention. He believes there is also beginning to be an acknowledgement of parental needs. By speaking to parents about their particular experiences of their children being diagnosed with a learning disability the researcher hopes to gain information that will assist professionals and the school in providing a service that will support parents with their particular emotional experience. Feedback from parents regarding what they feel they need as parents of children with learning disabilities may assist professionals to offer a better service. The more parents are supported the better they will be able to support their children – thus the relevance of this research.

3.3 Research method

A qualitative method of research will be used in this study. “Perhaps the central characteristics of qualitative research are its commitment to understanding social issues in their natural context in all its complexity” (MacArthur 2003:545). The social issue in this case is to understand how the emotional difficulties experienced by parents whose children have a learning difficulty can be alleviated. The social setting or natural context is the school. “A qualitative approach is an assessment of a situation expressed in words” (Van den Aardweg & Van den Aardweg, 1993:197). It can also be presented as information from a newspaper, and also visual, for example from photographs (Breakwell, Hammond & Fife-Schaw, 1997:259). In this case interviews will be held, thus the situation will be expressed in words. Since qualitative interviewing can provide “an in-depth exploration of an aspect of life about which the interviewee has substantial experience, often combined with considerable insight” (Charmaz 2001:676) it is possibly the approach that will present the most information relevant to this research.

MacArthur (2003:533) claims that there are a few general characteristics of qualitative research. Firstly, it is a focus on understanding people, events, and constructs in their “full social and cultural context”. Secondly, the qualitative investigation is open-ended by nature. Definitions of constructs, categories, and hypotheses, are avoided in favour of generating them during data collection. Initial interpretations and new questions can

guide further data collection if data collection and interpretation occur simultaneously. A third characteristic of qualitative research is “a focus on understanding the meaning of events and constructs from an insider perspective”. Fourthly, in qualitative research there exists the use of systematic procedure in gathering, analysing, and interpreting data. A final characteristic is that it seeks to understand particular cases in context rather than seeking to establish generalisable principles. Their theoretical stances and methods lead them to make claims only about the particular settings in the study. It is possible to generalise the information if the settings to which the research is applied is similar and if other studies support the findings.

Within qualitative research there are various schools of thought. This research is guided by the phenomenological approach. This is a theoretical viewpoint which “believes that individual behaviour is determined by the experience gained out of one’s direct interaction with the phenomena” (Dash, 2005:2). The parents who will be interviewed will have had direct experience with the school and teachers and their children will have been diagnosed with a learning disability.

There are typically four methods for gathering information in qualitative research. These are: participation in the setting; direct observation in the field; in-depth interviews; and analysis of documents and materials. There are also supplementary techniques which include the use of videos and photographs to capture the daily life of the group being studied. Focus groups as well as surveys can be used (McMillan & Schumacher, 2001:43). This research will make use of individual in-depth interviews.

3.4 Data collection method and context of the study

The data collection method includes the stages of data collection, the sources of the data and number of sources, the location and the frequency of data collection.

3.4.1 Stages of data collection

The data were to be collected over a period of three weeks. This was to allow time to transcribe the interviews. One appointment would be made with each interviewee. Each appointment would take approximately one hour. If there is any need to obtain further information during content analysis candidates knew that further contact might be made with them.

3.4.2 Sources of data

Data collection would be through parents whose children attend a preparatory school in White River, Mpumalanga, South Africa. A list of learners who have had contact with the Learning Support Unit at the school would be obtained to find suitable candidates, i.e., learners who have been diagnosed with a learning disability by a professional, either at or outside the school. Ten participants were selected. This is sufficient for qualitative research.

In-depth interviews with the mother would be conducted. The mother was selected because it is difficult to make an appointment with both parents for an hour at the same time, and it is usually the mother who has closer contact with the school.

A pilot interview would be held with two mothers (Appendix A). This interview is fairly structured and asks specific questions about how, by whom and when the problem was identified. It asks the mothers' reaction at each stage. Further questions relating to the information that was available, assessments and support would be asked, namely, how the results were conveyed, and the mothers' feelings at the time. At each point questions relating to the support given and the support required would be asked.

Using the pilot interviews as a guide, eight further in-depth interviews with different parents would be held.

In-depth interviews usually last about an hour. Certain standard questions would be asked, which include information on demographic data, additional information such as

name, age, sex, religion, number of persons in the family, race, occupation, marital status, socio-economic status, address, telephone numbers (Cohen & Swerdlik, 2005:425).

It is important to create a rhythm in an interview which takes the respondent through a set of issues that appear to be logically related (Breakwell, *et al.*, 1997:232). It is important that an interview schedule should be tested and refined. Breakwell, *et al.*, (1997:232) recommend the following stages:

- test whether your explanation of the interview is understood by a small sample drawn from the same population as those you intend to interview;
- use the same pilot sample to test the comprehension of particular questions which you know are difficult;
- test the revised explanation and all questions for comprehension;
- with a new sub-sample, use the interview schedule to establish whether the answers you are getting are the ones that interest you;
- a pilot interview would be done to ascertain the relevance of the questions and to determine whether they provide the information required by the research.

Since all respondents would be selected from the same school, it would facilitate the development of guidelines for a specific setting. Since the setting of a school system is probably universal the results and recommendations may be useful in other school settings. The researcher is aware that the findings may be limited to this specific setting, due to its particular nature. However, it is hoped that some reactions are universal and that if various procedures were to be used by teachers and professionals the stress and emotions of parents may be alleviated in other settings as well. The researcher would like to determine what can alleviate the strong emotional response directed at the school that parents feel when hearing that their child has a learning disability.

3.4.3 Number of data sources to be accessed

In total ten mothers would be interviewed. This is sufficient for a qualitative research. The first two interviews would be pilot interviews. The following eight will follow from there.

3.4.4 Location of data collection

To make it easier for the mothers who were to be interviewed, the interviews would be held at the mother's home. This allows for an interview in a quiet and familiar setting.

3.4.5 Frequency of data collection

The interviewer would make one appointment with each interviewee. If further clarification is necessary during the analysis of the data, the interviewer would ask for a further interview with the mother.

3.4.6 Data collection instruments

Data would be collected by means of one interview with each mother. It would be audio-recorded. Each recording would then be transcribed. The data collection would take place in each parent's home, where it is quiet and the interviews can be carried out without interruption. Observations would also be noted, e.g., laughing or crying. The interview would proceed with the interviewer asking various pertinent questions.

3.5 Selection of sample

The sample would be selected from a preparatory school in White River, Mpumalanga, South Africa. The school has a Learning Support Unit which consists of an Educational Psychologist, Occupational therapists, and language and remedial teachers. It is coordinated by the Head of the Unit. The class teachers of the school were requested to report the matter to the Learning Support Unit Coordinator if they think a learner who is not coping in class should be assessed. The Coordinator contacts the parents and discusses the school's concerns about the learner's performance with them. If the parents agree, the learner is referred to the Educational Psychologist for an assessment. For the purposes of this research respondents would be selected from a

list provided by the school, of learners who have been diagnosed with learning disabilities. This is a process of purposeful sampling. By means of this method it is possible to obtain in-depth information, and it also increases the usefulness of the information obtained even though only a small sample is used (McMillan & Schumacher, 2001:401). The two candidates used for the pilot interviews were personally know to the researcher. This was done to facilitate a more constructive working session in the interview to try and develop an interview protocol that would best allow mothers to be able to tell their story. The following eight were selected randomly from a comprehensive list provided by the schools learning support unit. They all agreed to participate in the study. Important criteria in the selection of the parents were that their child had been diagnosed while attending this specific school. The names on the list fit in with this criteria. This is important, since the researcher's intention is to ascertain what makes the process so difficult for parents at this specific school when their child is diagnosed with a learning disability. The researcher would like to determine what support would help parents during this difficult period. The learners do not necessarily still attend the school; some of them having been transferred to a remedial school in the White River area. The age of the learner when diagnosed is not relevant. Mothers were approached by means of a phone call from the researcher. The purpose of the research was explained and a request for participation was made. The parents were insured of confidentiality.

3.6 Data analysis

Data analysis in qualitative research usually employs deductive reasoning. This is when descriptions of peoples' perceptions are obtained, and from these descriptions information is obtained to explain the issue Mc Millan & Schumacher (2001:91). The information from the interviews will serve as the descriptions from which the researcher will obtain information. All the interviews would be transcribed where after data analysis will be done. This involves a number of steps which are described by Rubin and Rubin as follows (1995:227-241). First the data would be coded. This is a process of finding themes, concepts and ideas while reading though the transcribed documents and marking them with a code, e.g., Emotion - EM. A list of codes would be developed

as the researcher reads and re-reads through the transcripts. According to De Vos (2005:340) and Gilgun (2005:16) data should be coded to firstly determine meaningful data that relates to the question. This coding should be grouped in order to make connections between the data. The literature study will probably determine this grouping. Finally a core of coding is determined. This comes about as data is grouped and put into categories. It is determined by recurring themes in the interviews combined with relevance to the literature. Once the interviews have been transcribed, by reading them, various themes will be found to recur. These will be grouped accordingly. There will also be themes that relate to the literature study and these might form part of the recurring themes, or they may be new. The new ones will be coded separately. The coding will relate to the themes that recur, relate to the literature study, or stand out as something different.

When this coding is complete the data that is grouped into different categories will be used to facilitate comparison of what different mothers said, and how the themes relate to one another. It is important to look for the repetition of information that seems to be important to the participants. Some concepts may not be labeled by the participants but may be by the researcher. It is important to look for underlying meanings and to link themes together. Once individual themes and concepts have been found they would be added together to build an integrated explanation.

It is possible that coding can be influenced by the researchers' assumptions. Since the coding was based on the literature review and recurring themes it is more likely that the coding was not influenced by the individual assumptions of the researcher.

1.8 Ethical measures

When doing research there are various important principles that should be adhered to. Ethical measures include informed consent, the use of deception, debriefing of subjects, the subject's right to withdraw, confidentiality, validity and reliability, and experimenter and subject effects.

The Psychological Association of South Africa has set out an ethical Code for psychologists. Under the section 'Basic assumptions' it is stated in subsection (i) that: "psychologists are committed to the pursuit of knowledge and scientific endeavour which will enhance the understanding of themselves, of others and of man's environment and its effect on him", in the context that "the psychologist's view of man is reflected in respect for the dignity and worth of a person, irrespective of race, language, economic status, sex or creed." It is essential that a researcher complies with the specific guidelines set out by the Psychological Association of South Africa when doing research. "This includes taking responsibility to evaluate the ethical acceptability of the research to establish a clear and fair agreement with the research participants, prior to participation i.e. informed consent. The freedom of individuals to participate, or not, should be respected by the researcher. If there is any potential harm that can be caused to participants, whether physical or psychological, the researcher should be sure to remove these possible consequences. The confidentiality of information obtained during the research procedure should be maintained." (Principle 7).

During an in-depth interview often very personal information can be obtained. A further ethical consideration revolves around the question how deeply the interviewer can probe. A researcher should take the lead from the participant (Gubruim & Holstein, 2001:115). In an effort to look after the psychological well-being of the participants they would be informed of the research topic before having to agree to participate. If, during the interview, participants become upset, the researcher would be available for further counseling or debriefing.

As discussed above, ethical guidelines include a number of issues, such as informed consent, deception, confidentiality, anonymity, harm to subjects, and privacy. These issues will be discussed below.

3.7.1. Informed consent

It is an ethical requirement to obtain consent from participants (Appendix B). Consent includes the supposition that participants not only *know* what the research entails but

that they also *understand* what it entails (Gillham, 2005:104). Before the research commences, interviewees have the right to know why they are being interviewed and what the research is for. They also need to know to whom the information would be released. If they know this they will be able to give informed consent as regards participation in the study (Cohen & Swerdlik, 2005:57).

Gregory (2000:576) discusses three aspects of informed consent. These are disclosure, competency, and voluntariness. 'Disclosure' is that risks, benefits and the release of reports are made available to the participant. This allows the participant to make an informed decision about participating. 'Competency' refers to the mental capacity of the examinee to provide consent. The standard of voluntariness implies that the choice to participate in the research is given freely and not based on subtle coercion.

In this particular research each participant would be informed of the intentions of the researcher, i.e. to have an in-depth interview with each participant in an effort to discover what kind of support would be most helpful when a learning disability is diagnosed. They would be made aware that the results would be printed in this dissertation, and that the school would have access to the information. Since the information is confidential participants' identity would not be disclosed to the school. In the dissertation participants would be referred to according to a coding system, and their names would be changed in the transcriptions. A letter of consent would also be obtained from the school giving permission to do the research (Appendix C).

3.7.2 Deception

Most qualitative researchers view deception as violating informed consent and privacy (McMillan & Schumacher, 2001:422). Alternative procedures which do not require deception should always be considered first. Intentional deception of subjects ought to be avoided at all costs (Breakwell, *et al.*, 1997:31). No deception will be employed in this research.

3.7.3 Debriefing subjects

In studies where participants are aware that they have participated in an investigation, any information that they might need or that they request concerning the study, after the data has been collected, should be made available to them. Any unintended or unanticipated effects of the research on the participants should be monitored through discussion with them (Breakwell, *et al.*, 1997:31). The nature of the in-depth interview in this dissertation almost serves as a debriefing process for the parents' experience at the time of the diagnosis of their child's learning disability, in that it gives them an opportunity to air their views in confidence. If, however, any further debriefing is required by participants the researcher would make herself available.

3.7.4 The subject's right to withdraw

The researcher would make it clear from the start that participants have the right to withdraw from the research at any stage. Participants would also be informed that they have the right to withdraw any consent to participate in the study which they may have given previously. The need to withdraw may be in the light of their experience of the investigation. According to Breakwell, *et al.* (1997:32) subjects also have the right to require that any data pertaining to themselves, including any recordings, be destroyed.

3.7.5 Confidentiality and anonymity

It is an ethical obligation in research that information given by the client must be kept confidential (Cohen & Swerdlik, 2005:1-5). When parents are asked to participate in this study they would want to know whether or not the information they give is confidential. It is important for them to be assured that all information obtained will remain confidential. As the information they give will be published in this dissertation a coding system will be used so that the parent is not identifiable by name. The names would be changed in the transcriptions.

3.8 Validity and reliability of the data

It is important to consider that the reliability and validity of the data may be affected by the subjectivity of the researcher (Gillham, 2005:6). The researcher should be aware of

this during the analysis of the data in an effort to maintain the reliability and validity of the information obtained. It is not only the subjectivity of the researcher that threatens the reliability and validity of the study, but also the probability that respondents may not give accurate and complete answers to questions. It is also possible that respondents may be motivated to lie - the truth may be embarrassing. Participants may dislike or distrust the researcher. It is also possible that even if they do not do any of the above they may, in fact, not remember the details of the subject under discussion, or they may not have understood the question (Breakwell, *et al.*, 1997:238). All these points would be taken into consideration when analysing the data in an effort to maintain the reliability and validity of this research. Credibility, transferability, dependability and confirmability will be discussed in the context of this. Experimenter and subject effects will also be discussed.

3.8.1 Credibility

It is important that the results of a study can be believed. This is known as the credibility of the study. If an in depth description of the setting and participants are given as well as the procedures used then the study might be more credible (De Vos, 2005:346). In this study the researcher interacted with ten participants, all mothers from the same school who had the experience of their children be diagnosed with a learning disability. Hour long interviews were held with them to get rich information about their experiences at this time. An example of an interview is included by the researcher.

3.8.2 Transferability

The transferability of a study can be referred to as the generalisability of a study. In other words are the results applicable to other settings. (De Vos, 2005:346). Because, as the researcher indicates, the participants are parents of learners with learning disabilities, in a setting that is universal (a school), it is possible that other parents in similar settings, with a similar concern about the diagnosis of their child's learning disability, might voice the same emotions and thoughts. Although qualitative research does not aim for generalization it is possible that the results of this research might be applicable to more than one school setting.

3.8.3 Dependability

The consistency of the findings of a study are referred to as the studies dependability (De Vos, 2005:346). To achieve this the researcher must describe the setting in detail, the requirements of selection of participants, how the data was collected and analysed. This is done in chapter three and four.

3.8.4 Confirmability

If other people agree with the findings of a study this is known as confirmability. (De Vos, 2005:347). Other people have not participated in this study, other than the researcher. However by interviewing ten participants it is possible to determine whether or not there is data saturation. Data saturation suggests confirmability.

3.8.5 Experimenter effects

Deliberate and unintentional influences that the researcher has on the participants are referred to as 'experimenter effects'. Experimenter effects may occur if the researcher treats participants differently, for example, by using a different tone of voice with different participants. The researcher may be more reassuring with one participant than with another, or may reinforce different forms of behaviour during the interview. Clothing, age, sex, educational level and the race of the experimenter can also affect the participant's responses (McMillan & Schumacher, 2001:191).

It is not possible to eliminate all experimenter effects but some steps can be taken to try to control them. One way is to have the same interviewer conduct all the interviews. In this research only one researcher would conduct all the interviews. The researcher would, no doubt, have an 'experimenter effect' on the participants, but it will be a uniform one.

Interviewer or researcher bias may also occur during interviews. A way to exclude interviewer bias is to use a tape recorder during the interview. This would enable anybody to listen to the recordings and to confirm the findings of a particular study more

objectively (Gillham, 2005:121). In this study each interview will be recorded on audio tape and transcribed.

3.8.6 Subject effects

The researcher should also be aware of subject effects. This refers to participant changes in behaviour initiated by the participants themselves, in response to the research situation. In most studies participants would want to present themselves in the most positive manner. This leads to positive self-representation, in a belief that certain responses are expected. This may affect the results of the research (McMillan & Schumacher, 2001:192). This particular research does not have the intention to judge participants, rather to listen to them attentively as they relate their story. Hopefully this lack of judgement during the research will limit possible subject effects.

Conclusion

This chapter provided information on the research design. In conducting research it is of the utmost importance that the various ethical issues are dealt with at the outset. These include confidentiality, informed consent, the possible use of deception, the debriefing of subjects and the subjects' right to withdraw. It is also important to consider the validity and reliability of the data and the possibility of experimenter and subject effects.

In this chapter it was also described how the sample would be obtained and the method that would be used to gather information, as well as the processing and analysis of data.

Chapter four will cover the research results.

CHAPTER 4

FINDINGS

4.1 Introduction

This chapter focuses on the findings from the in-depth interviews held with interviewees who were selected by means of purposeful sampling. The sample, the coding used in the content analysis, direct quotes from the interviews, comments on the quotes and a literature control are included.

4.2 Realisation of sampling

Ten mothers were selected from a list provided by the Learning Support Unit at the preparatory school that was chosen to obtain the sample from. All their learners had been diagnosed by the Learning Support Unit or outside professionals, as learners who had some form of learning disability, whether it be auditory or visual perceptual problems. All the learners were diagnosed with a learning disability while they attended this particular preparatory school. They do not necessarily still attend the school as some of the learners have moved to a local remedial school or other preparatory schools.

The first two interviews were held as a pilot study. The interview protocol was more restricted than the final one used, in that it asked too many specific questions with reference to the 'point' of diagnosis, and the kind of support that was needed at each stage. The researcher found that there was, in fact, not a 'point' of diagnosis; it is rather a process that the parents and the school go through until they finally determine that a child may have a learning disability. The questions seemed to interrupt the participants' flow of thought.

The following eight interviews were guided by a few main questions and allowed the mothers to talk more freely. There were two broad questions which were used as a guideline:

1. Explain how you discovered that your child had a learning disability. What process did the school follow?
2. What did you feel would have supported you most at the time?

If various areas of interest were not covered by these questions, then the interviewer asked more specific questions, e.g. "Did you, as a parent, feel that you were being listened to? Did you understand the terminology used? What was your husband's reaction compared to yours and could you support each other?" As each parent's experience was different, the researcher had to be 'open' to new information, thus being able to ascertain needs and support more accurately. When less questions were asked, participants had the opportunity to speak freely about their particular experiences. Much information about the participant's emotions and experience was obtained in this way. This is discussed below.

4.3 Coding

The interviews were transcribed and various categories were identified. This enabled the researcher to group themes from each interview in order to try to understand what most affects parents and where they would like support the most.

The coding of the content analysis is shown in the following table, table1.

Table 4.1: Coding

Category	Code	Category	Code
Emotion:		Parents approach teachers	PAT
Shock	EM Shock	Teachers approach parents	TAP
Denial	EM Denial	Terminology	Term
Anger	EM Anger	Communication	Comm
Desperation	EM Desper	Child's esteem	☺
Frustration	EM Frustr	Family stress	Fam Stress
Disheartenment	EM Disheart	A remedial school	F
Disbelief	EM Disbel	Knowledge	Knowl
Guilt	EM Guilt	More from school	↑School
Worry	EM Worry	Ritalin	R
Isolation/Alienation	EM isol/alien	Homework	H
Acceptance	EM Accept	Money	\$
Despair	EM Despa	Husband	Husband
Depressed	EM Depress	Therapy	Ther
Hope	EM Hope		

4.4 Overview of the findings

The findings indicated that mothers exhibit the emotions as described in the literature study related to grieving (see 2.7.1). In terms of support they seem to require more communication with teachers, earlier communication from the teachers in terms of a potential problem with their child, and support in the form of a support group to help them work through a situation they see as alienating, and leaving them feeling isolated from the school community.

The findings were sorted into various categories and these, in turn, have themes. Ten categories were identified. The first category is 'emotions' and the various themes related to the parents' emotions regarding the news that their child has a learning disability. These include denial, guilt, anger, sorrow, disappointment, desperation, frustration, disheartenment, worry, alienation, acceptance, hope and relief. This is followed by stress at home in the family, emotions relating to homework, and emotions experienced by the child. The next category is 'approaches', relating to whether the parents approached the school first with concern about their child or whether the school approached the parents first. This is important as it seems to affect the emotions of the parents during the time of diagnosis of a learning disability. The next category is

'reactions'. This includes the father's reaction to the news that their child has a learning disability. It also includes the parents' reactions to the school's recommendations. Another category is 'therapy', including fees for therapy; 'communication', which includes communication with the therapists and the terminology used by professionals. The expectations of the parents and support groups are also categorized. In the table below the various categories and themes used to provide an overview of the findings are summarised.

Table 4.2: Categories and themes

Category	Theme
1. Emotions	Emotions relating to the child having learning disabilities, including shock, denial, guilt, anger, sorrow, disappointment, desperation, frustration, disheartenment, worry, isolation, acceptance and relief
2. Emotions relating to stress at home and in the family	Emotions relating to homework; Emotions experienced by the child.
3. Diagnosis of a learning disability by the school or by the parents	Parents approach the school with concern The school approaches the parents with concern
4. Reactions	The father's reaction The parents' reaction to the school's recommendations The parents' reactions to recommendations that they move their child to a remedial school The parents' reaction to the recommendation of Ritalin
5. Therapy	Fees for therapy
6. Communication	Communication with therapists Parents' expectations of communications with the school Terminology used by professionals
7. Parents knowledge	
8. Terminology used by professionals	
9. Parents' expectations from the school.	
10. Support groups	

4.5 Discussion of the findings

A discussion of the various categories derived from the findings follows below. Many quotations are relevant to each category and theme. Only one or two that were obtained in the coding of the transcriptions will be discussed.

4.5.1 Category 1: The emotions of parents in relation to their child having a learning disability

There are many emotions that parents go through when they realise their child may have a learning disability. Many of the interviews conducted were rich with emotional descriptions. These thus form a large part of the content analysis.

As discussed in chapter two, section 2.7, parents' reaction to the diagnosis of a learning disability can include shock, denial, blame/guilt, anger and sorrow (see 2.7, McLoughlin, *et al.*, 1987:357; Oeckerman, 2001:3). The emotions expressed by the mothers will be included in more or less the above order. Moreover, feelings of desperation and frustration were expressed, as well as worry, and the feeling that they were isolated from the community. Some mothers expressed acceptance and hope, and some relief, at finally knowing what the problem was. A discussion of the various factors follows.

4.5.1.1 Shock

Some of the participants indicated that they were shocked when they were told that their child experienced learning problems. The shock also related to suddenly realising how far behind their child is in for example reading, in relation to the rest of the class. Even though they may have suspected some difficulty at school they did not realise it was so severe. One of them explained her experience as follows:

“Probably what upset us the most is that all of a sudden you realise you have this child of eight, nearly nine at the time, who can't read ... Yes, I think that was a big shock when they..., when she was young, she spoke so young, at 18 months, at two years she was talking, talking, so because they speak well you assume they are intelligent. She did all the normal things, so I actually thought she was quite bright. So, to find out she wasn't was quite a shock.”

This shock relates to the participant thinking that her child would have no difficulties with learning as she had spoken at such an early age, and the sudden realisation that at eight years she couldn't read.

Another participant felt shocked when, after many years of different terminology being used in connection with her son, she was told he was dyslexic. She had never thought of it in that way: "... the day before she says to me, 'He is a full-blown dyslexic'. I said, 'What does that mean? How did you reach the conclusion that he is dyslexic?' But Dr Fox, in all these years, has never said he is dyslexic. She has never said to me ... , she just said, 'He is ADD.'" It is important for professionals not to skirt around issues and terminology.

The following participant's child had received much therapy and she thought that he was okay now, but the news from the teacher was not what she expected, "... because then you sit there you think everything is hunky-dory, and then you get hit with a fore-hammer against your head. My immediate reaction was shock, you know. Because I thought it was more or less sorted out."

Literature on the emotion of shock confirms that shock is a reaction on first hearing that one's child may have a learning disability. This might stem from the fact that a parent's expectations of his/her child are shattered on receipt of the news (see 2.7.1 Oeckerman, 2001:3). Quotations from the interviews indicate that a parent is also shocked when he/she finds out more about the severity of the disability.

4.5.1.2 Denial

Some parents were unable to accept the fact that their child might have a learning disability. Denial was expressed more strongly by the mothers who did not bring it to the school's attention that their child may be struggling. It was when the school approached the mother first that she expressed denial.

A mother indicated that she was not angry or sad, just that she did not want to accept it. She thought that it may be a phase that her child was going through: "You just find that you are not accepting it. That you are not really angry or sad. Just to find, ... I mean, how do you explain it that you didn't expect that it could happen to the kid?" "Maybe it is just a phase, ag man, maybe it is just a phase for now, maybe he's just not getting his feet on the ground. It will be over in six months' time, after six months it will be fine, or after that it will be fine. It is just something for now; maybe it is passing." This participant thought that there may be a misunderstanding at school because it cannot be possible that her child had a learning disability: "That's the first thing, because at home we did not observe any problem and at school he is having a problem, and as a parent you feel like, no, maybe somehow there is a misunderstanding or something. But normally you don't accept it, we didn't accept it at the beginning that maybe he is having a problem."

Denial is explained as a defense mechanism used by parents because they feel unable to cope with this new situation (Ho & Keiley, 2003:239) (see 2.7.1). Lessing and Strydom (2001:7) confirm that the denial can be in relation to refusing to recognise the child's disability (see 2.7.1).

4.5.1.3 Guilt

Participants expressed guilt relating to the responsibility they felt towards their children's disability. This is expressed in the following words: "You feel guilty and you think now, where did I go wrong? Did I not play with her enough as a baby? Did we not build bricks, did I not show her, and yet I have been one of those mums who has bought every educational toy possible."

Another mother said: "If you are confronted with a situation like that you feel as if you have failed in your responsibility to your child, but you didn't really know".

Parents feel guilty because they feel that perhaps their child's learning disability is their fault: "I think as a parent you obviously always feel guilty because you just assume it's

your fault. You know we've been working, we work in a business that takes us away from the house a lot. So you just assume ... , well, it's my fault because I am the one who has not been sitting and reading with her.”

They also expressed guilt for not having dealt with the disability earlier in the child's life: “When you finally do it in grade 3 you also blame yourself because you think, but why didn't I do this in grade 1?”

Guilt was also expressed in terms of the pressure they may be putting on their children to do well at school: “I am not the most patient person and I will be honest, but it's just, ja, to start a whole long battle, and then I feel guilty because they are happy children.”

Niedecken (2003:9) (see 2.7.1) describes it as guilt when parents feel responsible for their children who have learning disabilities. This is confirmed by Oeckerman (2003:3) (see 2.7.1) who also includes ‘guilt’ as a parent’s reaction to their child’s learning disability in terms of thinking that they may in some way be responsible for it.

4.5.1.4 Anger

Anger expressed by participants related to being told by the school that their child may have a learning disability. It relates more directly to the school not picking up the problem earlier, or waiting for a parent-teacher interview to tell the parents about their child's difficulties at school. This is expressed in the following words by a participant: “So and it's sort of like, ... it causes a certain amount of anger, you know, when all of a sudden only when there is a big problem, that you hear about it.” She felt angry that the school had waited for the problem to escalate, rather than approaching her when they first suspected there may be a problem. She expressed her anger in the form of an attack on the school, “And then if you are caught off guard your immediate reaction is attack which doesn't help anything as well because then the teacher is on the defense and who is going to fall through the cracks, the kid.”

Lerner and Kline (2006:153) (see 2.7.1) say anger occurs as the denial breaks down and the child's condition becomes more real and apparent. These expressions of anger by the participants seem to reflect their anger towards the school rather than a stage that follows denial.

4.5.1.5 Sorrow

One participant expressed their sorrow as heartbreaking. The heartbreak emanates from the struggle that she and her children have in trying to cope with a learning disability. She is sad that her children have to struggle with therapies, and she also finds it heartbreaking having two children who cannot read what they learnt the day before. She expressed her feelings in the following words, "And it's just been heartbreaking to see ... just grabbing at all kinds of straws, and here we are with the issue, and it's just heartbreaking. And the work from a mother's point of view is just ..., I mean, I have got enough going on in my life besides now doing reading with the child where from page to page there is just no recollection of words." "And also the heartbreak of therapy. They are going to these therapists left, right and centre". "The whole situation with the children has just ripped through my heart because it is heartbreaking."

In the following quotation the sorrow relates to the mother having to tell the child that he has a disability: "But I just find it difficult to actually sit down and tell him. Oh no, I'm going to cry. You know, to tell him what the problem is. He wants to be normal." This mother's sorrow relates to her son's difficulty in accepting that he may have a problem.

Literature explains this sorrow as grief. Kübler-Ross and Kessler (2005), (see 2.7.1), claim that grief "is a shattering of many conscious and unconscious beliefs about what our lives are supposed to look like". The mother who explains her experience as heartbreaking feels that her life "was not supposed to look like it does", and the child who expresses his sorrow does also not want his life to "look like it does".

4.5.1.6 Disappointment

Some of the mothers interviewed were disappointed because they had not expected a diagnosis of a learning disability. One mother expressed it in these words, “But yes, when you first find out ..., I think we all want our children to be clever, and then you realize ... but we weren't (clever) at school, so I don't know why I expected my poor daughter to be, but yes ... it's disappointing ... No, it is, none of us wants anything wrong with our children, so it is a bit disappointing when you find out.”

Disappointment can also be related to how the school handles the situation. One of the mothers was disappointed because her child had been promoted to grade 2 when she believes that the school knew she would not be able to cope in that grade. It is an expression of disappointment with the approach of the school. “And my disappointment is that at the end of grade 2, why did they put her through?”

In the following case the mother was disappointed because she had asked for a full educational assessment and didn't believe that that's what she got. Her disappointment is also related to the reaction of the school, “Of course I was very disappointed that I had not got the full educational assessment I was led to believe that I was getting.”

Literature from Tuttle and Paquette (1993:106, see 2.7.1) relates about the mother who was disappointed with the information on the evaluation of her child. They believe parents also need information on what evaluation is. They often do not know what it entails, nor what information will be obtained from it.

4.5.1.7 Desperation

It seems that as time goes by and mothers deal with their child's disability they may experience desperation, as expressed in the following cases:

“I think I am at my wits' end and we don't really know what to do ... And I seem to be grabbing at different straws ... And it's just that exasperating tiredness that you don't

know what to do.” She reflects desperation in terms of not knowing what to do, or how to cope with the situation.

Another mother feels desperate because her child cannot read: “For Nikki it is not easy to read, it's just things are not taking, I don't know why she isn't, she's getting there but some days, it's really ... , sometimes it is just shocking then you think ‘aah my word”.

Another type of desperation reflects wanting to find a solution to the problem and not being able to get any answers: “I think desperation ... , you do feel very desperate because you are wanting an answer because you want a solution to the problem, and you sort of start searching with people who are supposed to be in the know, and you are not getting a response from them. And then you start to feel that, am I making this up, am I being silly? Am I missing the point here?”

In relation to the last quotation indicating that a parent needs information and feels desperate from the lack of response to the queries, Quinn maintains in his study (2001:10) that parents want to be well-informed. This information decreases the desperation.

4.5.1.8 Frustration

Mothers expressed frustration with the school in that they may have been slow to pick up the problem and act on it. One of the participants asked, “... but why didn't they call me in and say we suggest that Emily maybe stay back now? But it was me the third year in a row going to them and saying, ‘I think there is a problem here, what are we going to do about it?’”

Many of the mothers expressed frustration with their child who does not seem to be able to remember what they have learnt from one day to the next, a frustration with homework. Parents and their children who struggle with learning are often exasperated by homework, as is reflected by one of the participants in the following words, “But just the one little exercise that she has to do, she ends up crying, I end up screaming,

because I just don't know how to explain something any simpler to her. And then you can see she has an absolute blank look, and you can see she is trying so hard to understand what it is that you are saying, and she's looking at those sweeties on the table, and it is not registering, but as a parent you just want to tear your hair out and say 'For God's sake, how hard can this be?'"

The frustration is coupled with disbelief as is expressed by the following participant, "I cannot believe how she can look at the page and there is no recognition of what she's actually seen. I have just done the word ... but every day I wake up and I say to my sister, I just keep hoping that maybe it was a dream that ..., that maybe today the children are just going to come right."

In a study done by Margolis (2005:5) it was found that parents and children find homework difficult, frustrating and laborious.

4.5.1.9 Disheartenment

As well as feeling frustrated mothers sometimes feel disheartened. One mother felt disheartened as she realised her second child also had a learning disability. She did not believe she would have to go through the same frustrations all over again. She expressed it in the following words: "I was just so disheartened to think, am I really going to have to go over this all over again?" "I just thought of the pressures and the hardships I have been through with Sam, to now we have this with Emily, we are just going back to square one."

Another mother felt disheartened when she left a meeting at the school. Although the school is positive she does not have the same outlook for her child, "... every time you talk to the school, sometimes you walk out feeling 'oh dear'. They are quite positive about it. But it's me and maybe we shouldn't be like that saying she's not fit for University, she shouldn't go to university. I don't feel that she will make university. I suppose that's awful to say, but yea." She feels disheartened about her child's future. Parents need information connected to their concerns and questions regarding what it

means for a learner with a learning disability to attend a tertiary institute. Counselors should be able to provide this information. They should anticipate the concerns and questions of parents (Milsom & Hartley, 2005:440).

4.5.1.10 Worry

The mothers interviewed seemed to be worried about how their children felt, that their child's esteem might be low, and they also worried about their child's future. The following mother was worried that her child could not care about her work anymore. She said the following, "Emily seemed to be at the stage where she says 'I don't care. I don't care', and that worries me."

Another mother was worried that her child's self-confidence would diminish if he stayed in mainstream schooling, "I was worried that his self-confidence would take a bigger knock if he stayed on at this school".

Her worry is supported by Bernard (2006:106) who writes that students with learning disabilities demonstrate lower academic self-concepts than do normally achieving students without disabilities.

Parents do not only worry about their children in terms of their self-esteem, they also worry about the future of their child with a learning disability. One mother expressed her concern in the following words, "I think also you worry about them. You worry because especially as she gets older she probably ..., I don't know whether she is getting worse ... but you worry about them, what are they going to do when ... she's always going to have to be protected because you always think, she isn't as bright as the average person, so we are always going to have to watch where she is and watch what she is doing." "I can't see Nikki going back into mainstream schooling, which is also a ..., that's also scary because you know... You are always worrying that she believes anything and everything. So it's always a worry that later on in life even as a young teenager she may just come across the wrong crowd of friends or the wrong boys or then she just ... ja ...

that's a worry. But I suppose it's something, you are just always going to watch her. What can you do?"

Tarleton and Ward (2005:73) confirm that parents are concerned about their child growing towards adulthood.

4.5.1.11 Alienation/ Isolation

All of the mothers interviewed expressed some sense of isolation or alienation. Some of the mothers felt that they were isolated at the school. They did not fit into the school environment and felt they were alone in their battle for their child.

Mothers do not only feel isolated from the school situation but also from their community. The following quotations reflect this isolation, "I feel like an outsider." "I'd drop off the kids and duck because I don't want to have to be seen, not to be seen by a teacher". "I am almost scared to become involved in the school. I've got mothers who come to me and say 'oh I hear your son did this, and your son was in detention for that.' I would rather not deal with that. I just drop and run. And it is not really what I wanted. I was so hoping it would be more of a family life. We go to the socials, you know, we try and fit in that way. But even Peter says, 'We're just out'. And ja, that's just how we feel."

"I feel like I am the only mum in this situation. And there have got to be other mothers out there ..."

"I was under the impression, as much as they were always very nice at the school, I was under the impression that it's fine you know all these extra therapists, and all of a sudden when the wheels fell off, they were very happy that I was taking her away. All of a sudden she wasn't an ... child, because she wasn't intelligent enough to be such a child. I found, I got that impression that they were quite pleased that I was moving her out".

“I just think they deal with the problem in a school environment without thinking about the family.” Sperry and Duffy’s contention (2002:431) is that a family counselor should be looking after the family as a whole as it makes decisions that impact on the whole family.

Research shows that the announcement of a learning disability is distressing and leaves parents feeling isolated from the process which will evolve to assist the child (Quinn, 2001:2). The above quotations reflect a feeling of isolation within the community rather than from the process.

4.5.1.12 Acceptance

One of the mothers interviewed expressed some form of acceptance. She said it in the following words, “I suppose at the same time it is just a learning disability, it can be overcome, it’s not anything physically wrong, so in that respect we feel pretty positive.”

Another mother, in her acceptance of her child's learning disability, decided to focus on her child's strengths, “I would like to spend it (our money) on the things that Rose can actually excel at rather than spending my money on things that she can't do, because I don't believe she ever is going to really become ... brilliant at reading. I don't think all those things are really going to help her in the big picture.”

Lerner and Kline (2006:154) believe acceptance is an important stage in order that parents can accept their child along with his/her special needs, while continuing to live a normal life.

4.5.1.13 Relief

In this research it was also found that parents often experienced relief, relief that is related to hearing what their child's problem may be. One of the participants said, “I felt ..., I think probably when I finally saw Renata, I think when I chatted to Renata, I actually think it was a relief. I think I was relieved because Renata was so nice, and then Nikki was going to the school where everyone was, or everyone was similar or

everyone had some sort of learning disability.” “In some ways, when the school finally said ‘Nikki is dyslexic’ it was ‘Oh that’s it, yes’. It actually was a relief. It was then ... in a way there is an excuse. You can say, thank goodness, there is something, she’s dyslexic. So, it was a reason why she was like this, because she’s dyslexic.”

Tuttle and Paquette (1993:8) include relief as an emotion when parents finally have their suspicions confirmed.

4.5.2 Category 2: Stress at home in the family

4.5.2.1 Emotional stress at home

Some of the participants spoke about the emotional stress at home being related to the learning disability in their child. One of the participants expressed it in the following way, “But as far as the friction in the house is concerned because of this learning disability, it is huge. Peter just hears the shouting and the tears, because I often land up in tears, because I cannot believe how I can turn a page and there is no recognition of what she’s actually seen.” “I am scared that I am making both of their schooling careers a bit of a nightmare. Because it is just nag and hound and it’s just ... but I mean this academic issue is just a cloud over our family. And it’s heartbreaking, it really is.” “It’s just a hard, hard, battle, that you have to come to terms with the fact that you’ve got two children, now every night there’s almost tears in the house because this one can’t do that. I’m not the most patient person, I will be honest, but it’s just the ..., to start a whole long battle, and then I feel guilty because they are happy children.” “And it is huge, it’s heavy, it infiltrates into every area of our life.”

Another participant related it to the school not being able to understand that the whole family is impacted by a learning disability. She said, “I just think, they deal with the problem in a school environment without thinking about the family.”

One of the mothers related the stress to sibling rivalry. Her youngest son always wants to do better than his older brother. She said, “He wants to do better than his brother, and the fact is that he is 16 months younger than his brother. He doesn’t cotton on to

the fact that he is supposed to lag behind a little but you know ... So it is complex when they are that close together and they both have learning disabilities.”

In relation to the above quotation Hallahan et al. (1999:166) claims that siblings of children with disabilities are at a greater risk of having problems in their relationships, than are siblings of children without disabilities.

Sperry and Duffy (2002:430) and Bender (2008:127) believe that there is added stress in the home-life of a family with a learning disabled child. Having children with a learning disability results in increased parental stress, which could negatively affect the parents' relationship with each other. This does not bring about an environment conducive to a learning disabled child's attempts to keep up with what is happening in mainstream.

4.5.2.2 Emotions relating to homework

All of the mothers interviewed expressed frustration with the homework situation. It is frustrating for the mothers to sit with their children who battle so much with reading. One participant said the following, “Mags Hunter said they must read for 20 minutes every day. And it is causing huge problems in my home, any homework situation is.”

A homework situation with children with a learning disability appears to be a challenge for the mother. She finds it difficult to remain patient with her children. Sometimes they end up doing the homework for their children: “It's a challenge for her to do the homework. And if you look at some of the worksheets, you think this is pretty simple, and here is my daughter, nearly 10 ... And at the end of the day the battle is because she can't read.” “It's very difficult to always stay patient with children like that. You know you sit down to do homework and you say ‘Okay, Nikki’ and in the end you end up reading it because you're so frustrated because she can't read. Then you think, ‘I shouldn't do that’”.

As well as getting frustrated with their children during homework sessions, parents are often not sure what they should work on, "I was working with Sarah in the afternoons, but I did not know what to work on."

Another participant found that her child was battling with her all the time, as well as with her homework. This made it particularly frustrating for the mother. "She was battling with reading, she was battling with her homework, and the therapy homework was huge, it was all in writing and words." "And that is where Rose was struggling, she fought me all the time. And I felt that for that entire year I didn't see Rose make much progress and she is still struggling terribly."

"I struggled to get Rose to understand things in her homework, you know. And I would like to have more support like ..., you know, how do I get her homework done?" "Rose can't work out 16 take away 2, let alone 360 take away 2, because she can't see whether it is 16 or 61 and she argues with me. Then we show with sweeties: 16 Jelly Tots, 61, 6 groups of 10 that is 61. You know she can't understand that, she just doesn't understand it. How do you ..., how as a parent do you teach that?" "Mary has been good in that she says she doesn't have to do all of it, but just the one little exercise that she has to do, she ends up crying. I end up screaming because I just don't know how to explain something any simpler to her. But as a parent you just want to tear your hair out and say, 'For God's sake, how hard can this be?'"

As well as being frustrated at home by the work, parents can be frustrated because their child does not write down the homework that they have to do "To find when he gets home he doesn't bring back the homework, I mean the diary, he doesn't even know what homework he has to do. I mean things like those, you find that it is sometimes frustrating for the parents."

In her work Margolis (2005:5) found that parents find homework difficult, frustrating and laborious.

4.5.2.3 Emotions experienced by the child

As well as a mother having various emotions as she tries to cope with their child's learning disability, the child himself/herself also experiences various emotions. It is important for parents to recognize their child's emotions in an effort to help them cope with a learning disability. Some children recognize the fact that they cannot keep up with the other children in the class. One mother said, "She has come to me quite a few times and said, 'Mum, I can't keep up, the children are all finishing their work and I'm being left behind. Please can you help me?' And it's the biggest nightmare to actually stay back a year ... And as I say ... my concern now is that she is getting to the stage where she says, 'I actually don't care.' She'll come home, she'll cry, say she's been left behind, she never finishes her work ... And the unfortunate thing with doing the therapies in the school is that the children come back more disappointed because Emily has missed music. And Emily says she misses all the fun lessons. So she didn't get a chance to sing at Idols which absolutely devastated her. Because she was now in therapy. She said she misses out on all the fun activities that all the other children do out of the classroom were Emily loves to be. And now she must go to therapy. So there is a resistance thing in that regard."

Not only is the child upset because she cannot finish her work in class, she is also removed from the classes that she enjoys because she has to go for therapy. Classes in which she might excel, such as art and music, have to be given up for language or occupational therapy.

Learners might cope for a while by copying from their friends, but they eventually become embarrassed because they realise they are falling behind. One mother said, "All of a sudden ..., I think at the beginning she was probably copying a bit from friends and such, that is how she was getting through, and then, all of a sudden, it was becoming more and more of an embarrassment because she couldn't read. And I think that's why her personality is so over the top. The one day, I think, the speech and language therapist phoned and said she was a bit concerned about Nikki. She was crying in the session saying that she is an idiot, saying she is stupid...Nikki hated

therapy at the school. She hated going, she hated the classes, she hated everything about it, maybe that's why she never progressed ... And at the moment (she is in another school) she is very confident because the classes are so small and you go to all this therapy on the side, which is just great.”

Even though this one child is anxious about his learning disability his mother finds it difficult to talk to him about it. She said, “But I just find it difficult to actually sit down and tell him. Oh no, I am going to cry. You know, to tell him what the problem is. He wants to be ‘normal.’” “But it is very hard for him, exceptionally, exceptionally hard for him, and you know what, we just do it one day at a time.”

Children are also teased at school because they cannot read as well as the other children. One mother said, “Because at that stage one of the other kids had picked up, and Joshua had picked up, that his reading was not up to scratch, there was this kid that started mocking him about it, and hammering him about it, and then, obviously, the emotional problem started and that is when the wheels came off ... But you know at that stage ..., I thought I would take him out of the situation where he was being bullied and rebuild his confidence ... It caused a lot of emotional turmoil with him, and it still has not gone away.”

Learners with learning disabilities often do not enjoy the therapy that they have to attend every week. “We found that Rose absolutely hated her therapy. She was battling with reading, she was battling with her homework, the therapy homework was huge, it was all in writing and words. And that is where Rose was struggling, and she fought me all the time ... And eventually I thought, you know what, this poor child thinks she is a nut case. She doesn't want to go to any of these things, she thinks she is stupid ... I might be wrong in all this, but as a parent I feel emotionally Rose was taking a real big knock. We know she is aware that she is different, and that she struggles with certain things, so that is it in a nutshell.”

In relation to the learners struggling in class, Wren (2006:271) believes that school is not necessarily the happiest of places for children with a learning disability. The results of a study done by Yu *et al.* (2005:239) suggest that children with learning disabilities report higher degrees of loneliness and lower levels of peer acceptance when compared to children who are not learning disabled.

Pickering (2002:7) argues that the parent should discuss the child's problem with him or her. The child has a right to know what causes his difficulties at school. He is usually quite relieved to know that he is not stupid or dumb. Kelly (2005:271) believes there exists a need for adults to allow children to communicate their views and experiences of their particular disability in a supportive environment.

4.5.3 Category 3: The diagnosis of a learning disability by the school or by the parents

In some of the cases in this research the parents had approached the school with concerns about their child's progress. This was often met with assurances that the situation was not so bad and that they were sure the child would catch up. This led to frustration in some cases where the parents felt the problem should have been picked up earlier. In other cases the school identified the problem before the parents did. Each scenario has its own implications for the relationship between the parents and teachers.

4.5.3.1 The parents approach the school with concern

Some mothers who suspected that their child might have a problem with learning felt that the teachers should have called them in earlier. These parents often approached the teachers first to say that they suspected their child has a problem. They were upset when, after having approached the teacher, many times their fears were placated, later to have been proved right. One mother said, "I approached the teacher and said I think there is a problem here. Her reading doesn't seem to be developing at any reasonable rate ... Well, she said to me that she actually hadn't noticed because she had been doing so much group-work, and I said, 'But have you actually heard her reading one on one?' and she said, 'Well, now that you mention it, she is a little bit jerky, she spells

every word phonetically.' But she actually hadn't picked up the problem ... And my concern is, why didn't they call me in? I know it's not reading related, but why didn't they call me in and say we suggest that Emily maybe stay back now? But it was I the third year in a row going to them and saying, 'I think there is a problem here, what are we going to do about it?'"

A mother said: "I picked up that there was a problem long before the school did, and I kept on asking, 'Is there a problem, is there a problem?' And they said, 'No, it's okay.' And then at the end of grade 2, at the last term parent interview they said, 'You know, there is a problem now.'"

It appears that sometimes the teachers do not take the parents' concerns seriously, or they believe that the child will catch up with the other children in the class. When the school finally acknowledges the problem the parents believe it would have been better to have acknowledged it earlier, so that early remediation could have benefited the child. These comments reflect frustration on the part of the mothers that they were not listened to from the beginning. Some mothers believe that the school should, at an earlier stage be able to determine whether a child has a learning disability or not.

4.5.3.2 The school approaches the parents with concerns

In some cases the teachers approached the parents to express their concerns that their child was not coping in class. The following quotations reflect this:

"What actually happened was in grade 0. Joy Banks said that he had a problem with the alphabet and with basic reading that they were doing at the time. He also was drifting around and wasn't paying attention. She suggested at the time that we do something about it. In grade 1 she told me that he was actually lagging behind the other kids and I could see when I got him home that he gets all anxious because he actually can't do it."

“Anne came to me, I think it was close to the end of the fourth term, and told me that Natalie is really battling; she needs to go to a remedial school ...They just said she is not going to pass grade 2 if she stays here; she must go.”

Sometimes parents would wait until the parent-teacher interview before they received any information on their concern about their child's progress. One participant said, “When we went there for parent-teacher interviews the teacher explained his progress to me and said he was a slow in class. After that we went to Anne Russel.”

If the parents themselves have not picked up a problem, there is probably more shock and denial. The two quotations in section 4.3.2.1 on ‘denial’ are from parents who have not picked up the problem before the school did.

4.5.4 Category 4: The reactions of the fathers

The mothers interviewed generally believed that their husbands’ reactions were different to their own. In one case the reaction relates to disappointment, as the following quotation states, “My husband was a lot more disappointed, I don't mean more disappointed with his child, but definitely a lot more upset about the whole situation. He doesn't have as much patience as me, but he was hurt. I think it affected him. He doesn't want anything to be wrong with his daughters; his daughters are perfect in his eyes.” “It has always been me who goes to the school. Henry (husband) never goes to the school. So it has always been me who does all that.”

One of the mothers believed her husband would not deal with it, that he has not accepted the diagnosis of a learning disability in his child. The husband does not want to be involved in meetings with the teachers. She says: “Chris finds it exceptionally difficult. You know, I just sat him down and I had all this for him to read and he still hasn't read it. From day one. He knows that he has a problem but he just chooses not to deal with it. He'll help me if I say, ‘Mike needs help.’ He still hasn't accepted it.” “I asked him this morning, ‘Please, will you come with me?’ and he said, ‘No, you do it.’” “But we need to know from a mother's perspective, how do we deal with this? How do I

deal with Chris?" In terms of support she would like to know how to deal with her husband.

Some husbands believe that their wives get too involved in their children's schoolwork. One mother said, "And Peter has now taken me, and knocked me on the knuckles and said, 'That's it. You back off now and you leave these children. I don't want to see you involved in their projects. If they are going to fail, they are going to fail.' So that's it. And as far as the school is concerned he said he's more of the opinion we are paying them the money, they must sort out the problem."

It seems that the mothers are more involved in their child's school-life. They have more communication with the teachers and the therapists who are involved with their children. It is possibly for this reason that the mothers' and fathers' reactions are different with regard to their child's learning disability. Mothers and fathers generally deal with the news that their child has a learning disability in a totally different way (Hastings, *et al.*, 2005:162).

4.5.4.1 The parents' reactions to the school's recommendations

In some cases the school may recommend therapy, they may recommend that the child be moved to a local remedial school. Sometimes they recommend Ritalin.

The school suggesting that the parents remove their child from mainstream schooling is discussed first. In some cases the school recommended that the child be put into a remedial school. There may be resistance to this suggestion, and to some parents it is a relief when they know their child will be put into a school situation that suits their learning style.

Some of the participants were frustrated by the suggestion that her child moves to a remedial school. One of the mothers expressed it in this way, "We've been speaking to the teacher, to the remedial staff and they have in no uncertain terms suggested that maybe a remedial school would be the best way to go with Emily. Having discussed

this with my husband, he doesn't want to do that. He just wants us to press on; he thinks it's a maturity thing ...They recommended that maybe a remedial school would be an option for me, so obviously they thought that was the best thing that they thought. But it's not what I wanted to hear.”

Another mother said in her reaction to the school recommending a remedial school that the school was not, in fact, taking on its responsibility, that they were passing on the problem. She said, “We had a meeting with the school, but then their whole approach was just, send him to a remedial school. They obviously ... there was very little support from the school's side. They sort of basically passed on the problem elsewhere. And it sort of ... causes a certain amount of anger, you know, when all of a sudden, only when there is a big problem, then you hear about it ...You know, they also put their hands up and said, 'Remedial school'. It is almost like passing the buck sort of thing for the school.”

A reason why mothers are reluctant to send their child to a remedial school is because the school that he/she is currently attending offers so much more in terms of afternoon activities and sport. Many of the children with learning disabilities excel in sport and other extra-mural activities, and the school provides them with the opportunities to excel in these areas. A mother said, “... because the school has so much more than just academics to offer her. There is the sport, and those are the things I had to look at as well, because although she is not incredibly sporty she does like the team and the effort. So, I don't think she will ever be the best at netball, but she enjoys that, she enjoys socialising with her friends, she enjoys the opportunity to try something else. I think the school is wonderful in that they offer the children something else besides the academics whereas a remedial school wouldn't.” “So I felt that Rose would be happy to stay here. Moving her to a remedial school was not the answer for her either.”

A collaborative approach between parents and teachers where parents are involved in all the decisions about their child, e.g. assessment, transition planning and intervention

programs will foster better relationships between parents and the school (Raver, 2005:11).

Secondly, the scenario when the school suggests that a child takes Ritalin is discussed. Some parents are against their children taking any kind of medication. They become angry when the school suggests that their child takes Ritalin or any other form of medication. This is revealed in the following excerpts:

“Ritalin is not an option for us. We had them on it, it definitely had adverse effects ... Peter (husband) said, ‘World War 111 will happen before that ever happens.’ He will never medicate children because he says this is how we start the drug problems and all the internet articles he has read in the past just closed those doors completely.”

Another mother said, “There is no way I'm going to put her on medication, not even on Ritalin, or anything. That is my personal opinion. And she was ..., I think she was upset about that. She felt that Sarah needed medication, and to me that was just pushing the problem away ... I think they felt medication ..., as I say, Anne Russel felt anti-depressants would then help, ... whatever. She felt, and then sort of diagnosed from her side, and said it was a home problem, and it is an emotional problem with Sarah. That's why her work is bad. I was quite upset about it and said, ‘No, I know there is an emotional problem, that is coming from the hearing’.”

The above quotation indicates that the mother does not believe the school is in a position to recommend medication. The following quotation supports this, “Because, from the school's side, that has often come up, ‘Put him on Ritalin, put him on Ritalin’, as if it is a magic cure. And they are not in a position to diagnose the problem, for starters, but prescribe what the remedy should be.”

“We do agree that teachers should not diagnose ADHD, however, being on the front lines with children, they collect information, raise the suspicion of ADHD, and bring the information to the attention of the parents, who then need to have a full evaluation

conducted outside the school” (Booth, Fellman, Greenbaum, Matten, Markel, Morris, Robin, Tzelepis, 2004:1).

4.5.5 Category 5: Therapy

The school has a Learning Support Unit which comprises of language therapists, Occupational therapists and remedial teachers. Many children who are diagnosed with a learning disability make use of this facility.

Some mothers believed that they were paying a lot of money for the various therapies but they weren't seeing any results. Moreover, they believed that perhaps it was a way for the school or therapists to make money rather than serve the purposes of helping with their child's learning disability. One participant said, “We're just paying a fortune in therapies and I don't see any result.” “With all the therapists on the premises, sometimes I feel they are just feeding the children to the therapists. It is almost like a ..., you know, not a money-making thing, but because the therapists are all there, it's just ... let's send all the children to therapy, you know.”

In some cases it was actually the rooms that were used for therapy that were criticized, “I think the only thing with the school and the therapy is the therapy rooms and everything. Nikki hated therapy at school. She hated going, she hated the classes, she hated everything about it, maybe that's why she never progressed. The classrooms in the school ..., one of the rooms was so small it was just awful.”

These quotations reflect tension between parents and the school's Learning Support Unit. This is important in terms of success in supporting parents with children with learning disabilities. A greater understanding of what the purposes of the therapies are and how they might help the child may bring about a better relationship between parents and the Learning Support Unit.

4.5.6 Category 6: Communication with therapists and the school

Parents would like to see effective communication between themselves and the therapists. This relates to homework that is required by the therapists, and also progress that the children are making during therapy. One parent was not satisfied with the work that she believed was being done in therapy: "Also, Lisa doesn't let us know from day to day. There is definitely no homework that comes. Or any additional work that comes. And when I ask Emily 'What did you do in class with Lisa?' she will say, 'No, we just played some games and we did this and we did that ...', but that's about it with regards to therapy." "... and even the therapists, they don't give you any information on how it is actually going."

"Good communication between professionals and parents is the key to successful programming for students with learning disabilities" (Hallahan et al., 1999:172).

Many of the parents interviewed would have liked earlier communication with the school. In other words, they did not want the teachers to wait for the parent-teacher interview. They wanted to be called in earlier and to discuss whatever problem they were having with the child. They often felt that by the time the parent-teacher interview came along it was later than the communication should have been. "I was hoping that they would, maybe after the first two weeks of the start of the year, have picked up the problem and said, ' Mrs Blake, could we see you ... let's monitor the progress over the next week, let's maybe see you more regularly, let's have meetings more regularly so we can see if there is any development.'"

Participants in the interviews indicated that more regular communication with the teachers would be beneficial. They would like to have an ongoing report on the progress of their child.

One of the participants was clearly frustrated by the lack of communication from a teacher: "The teacher should know. And I mean I e-mailed Susan Blaze, she hasn't even answered. And I go to her and she says, '... oh ya, I've got your e-mail'. I mean,

what the hell is the use of having e-mails? I mean where is the reply ...?. Do I actually have to come to get a reply? I love the school, he loves the school, but I just think that there are some communication problems which need to be addressed.” “I just find you have actually got to be there all the time, you can't do it once a term.” “There's just a few things that they are lacking, like getting back to parents, and giving feedback; there is no feedback. I shouldn't have to go there and say, “What is happening?” “Don't wait for the parent-teacher interviews. I mean, that doesn't help.”

It is not only communication between the parents and the teacher, but also among the teachers that presents problems. Some mothers feel the history of the child should be passed on from one class to the next. “I felt that every grade that Rose has been in, in the school, is like reinventing the wheel all the time. As a parent I had to come in, I have said, ‘Listen, these are the problems’. This mother would have liked the school to coordinate from year to year what would best suit her child.

A very positive comment relates to the school asking the parent what the school can do for her, “I think Lauren is the first one who called me into her office and who said, ‘Okay, what do you expect of the school in regards to your daughter?’ And that is the first time that anybody has ever said, ‘What can the school do to help you, and what are your expectations of us?’ And I felt this was very positive and I think she has been very good at putting together something. Mary can go to her for advice and there is beginning to be a more open communication between the Learning Support Unit, the teacher and parent. Because I did feel as a parent I was left in the dark.”

Parents' expectations of their children's progress at school need to be reassessed when they find out their children have a learning disability. A greater understanding about the origins and outcomes of parents' expectations concerning their child's education can provide information about opportunities available to help them achieve their goals, and in so doing improve relationships between home and school (Russel, 2005:119). Hopefully some of the above quotations can shed light on parents' expectations in terms of communication with the school and their child's progress.

4.5.7 Category 7: Terminology used by professionals during feedback sessions to parents

In terms of being well-informed it is important that parents understand the terminology used by professionals in their diagnosis of a child's learning disability. Many of the mothers found the terminology used by the professionals difficult to understand. Not only did they find the terminology difficult they also found the graphs used by therapists difficult to read and to interpret.

One of the participants said, "I don't understand everything." "But no, to be honest, those reports are a little bit above my head, and I see 'stanines' this ... and I just I want to see if the child's birth age is six years three months but the actual ability is five years and two months and just to see where they are above or below average." She carried on saying "We do get a comprehensive report at the beginning of the term. I don't understand everything that is on there as well. You get nice little graphs and they have progressed to this level and that ... and it is very nicely done, but I just want to see the results in the physical thing. That's my big thing."

Another participant said, "And a lot of all this is quite Chinese. You know, you get called in to these talks and at the end of the day all it comes down to is they say, 'O, with more therapy she will be fine.'" "And again we're stupid for not saying, 'Sorry, explain that to me.'"

It is important that parents and families are able to interpret the results of the assessment of their child, and to understand how these results will be used (Brink, 2002:254). The above quotations indicated the frustration of the parents who do not understand the reports and assessments.

4.5.8 Category 8: The parents' knowledge

The findings from the interviews indicate that parents need information related to learning disabilities, such as their child's potential, the effect of medication, as well as information about which assessments should be done. On talking about IQ as it relates

to learning disability, one of the mothers said, "It just shows you that as a mother I had no idea ... I was just thinking ..., she told me that their IQs are exceptional or very good, whatever ... And I'm thinking, well, how can you have a high IQ or be varsity material when you can't even read? And how do you know that about a seven year old child?"

Some mothers did not know how to handle the homework situation related to reading. "She said to me, 'Don't let him read out loud.' I said, 'Why didn't you tell me that?' I mean, how must I smell that he's got to read silently?"

The following participant spoke about her lack of knowledge of what assessments should be used. She said, "And I'm not a therapist, so you don't really know when you get all these papers what exactly has been tested and what hasn't."

Tuttle and Paquette (1993:106) confirm that parents also need information on what evaluation is. Parents often do not know what it entails, nor what information will be obtained from it. Quinn's study (2001:10) indicates that parents want to be well-informed. This confirms the needs of the parents described in the above quotations.

4.5.9 Category 9: The parents' expectations from the school

When parents send their children to a particular school they have various expectations of that school. When they find that their children have learning disabilities their expectations may change.

In the following quotation the expectation revolves around the school being able to keep her child in mainstream, and to accommodate his learning disabilities. The parents' expectation was that a solution could be found within the school rather than to move her child to another school. She said the following, "I was just hoping that they were going to create the solution and not just suggest that I take her out ... I think maybe the school should have suggested something a long time ago because I think, maybe they knew, they are the experts, maybe they knew."

There are also the expectations that the teachers keep in contact with the mothers regarding homework and keep them informed whether the teachers feel the child is coping in class or not. "But I don't expect the school to sort it out for me. I do expect from them, if at all possible, to keep him in mainstream, to sort of like accommodate him in a certain sense. You know, in a simple way, like letting me know if he's not doing his homework, and letting me know if he's constantly late, or if he is not coping with something. I do expect them to do that for me."

In order to communicate well one also has to listen well. The question asked was whether they felt that the school was listening to them. One respondent said, "No, I don't think they were listening to me, no not at all. I found Anne Russell to be a little bit condescending, almost, and that I was perhaps making a mountain out of a mole-hill. She would say, 'Oh yes, yes, she understands all these things', and said she would chat to the teacher, but she never really did." Even if teachers communicate verbally it is the actions of the teacher that also indicates adequate communication.

Another participant needed communication in terms of what assessments and testing needs to be done. She said, "I think to be given a clearer picture of what it is, which assessment and testing I needed to do."

Felber (1997:20) confirms that it is important that teachers and parents communicate their goals for and expectations of their children to one another. In this way they may create the best possible environment and facilitate the learning process.

4.5.10 Category 10: Support groups

The last question during the interview related to the need for support groups. The findings from the interviews indicate a very big need. Parents of children with learning disabilities who indicated that they felt alienated or isolated said that belonging to a support group would put them into contact with people in a similar situation as themselves, whereby normalising their own situation. The following excerpts from the interviews indicate their attitudes regarding support networks:

This participant believed that a support group would fulfill her emotional needs. She said the following, "Yes. Now that would be a great idea. Very much so. I think from an emotional point of view that's fantastic." "And where it is not actually a homework thing, it's just more the day to day life, how it is affecting our family, and how everything is tying up together. But to be in a group situation where I am actually with other mothers, because, to be honest, I feel like I am the only mum in this situation ... And I just wish I could see another mother who was dealing with what I'm dealing with ... I feel like it is almost an embarrassing situation. It is terrible, and ... um, I think the group thing would be fantastic, because it is just the idea, if you know you are not the only one in the situation. And there have got to be other mothers out there ... But I think to have a person in your position as well, I think that would ..., where one can actually just unload, where it doesn't just have to be academic based. That you are actually interested in how it is affecting me as a person, how it is affecting my family life, my relationship with the children, my relationship with my husband. I think that is a huge burden off one's shoulder as a mother." For this participant emotional support which would include a facilitator would be the most beneficial.

Other mums would like the support of having someone to talk to, to discuss how they cope with their children's homework, and how their children behave. One said, "I think it is nice to speak to other mothers. Ja, I know Shannay quite well and it's nice to talk to her, to other mums that are in the same situation, not only, ... maybe just to relate to certain problems. 'Oh, they act like that! Well, so does mine'. It is a bit of a relief to think, well mine is also battling with reading. 'Oh well, okay, yeah'. It's ..., you don't feel as bad if there is someone else with maybe a 10 year old that can't read. So yeah, I think it would be nice."

One participant felt that the school deals with the problem purely from an academic point of view without considering the needs of the family. She feels she needs support related to her husband's lack of involvement, and various other issues that might affect the child, such as bullying. She remarked, "I think it would be awesome. We had a whole group of mums, and it worked so well and you know that you are not the only one

in the boat...I just think they deal with the problem in a school environment without thinking about the family. They need to, like you say that the support group ... They don't need to have speakers. Even if it is just tea and we say, 'Listen, today we are talking about bullying'." "But we need to know from a mother's perspective, how do we deal with this, how do I deal with Chris (her husband)?"

One of the participants prefers to deal with the situation on her own: "Ag, you know I am not a groupie type, so for me personally, that would not have made a difference. I find my comfort in getting the knowledge and then making a decision, once I have done that, I am fine. But I think a lot of mothers would like that support. It is just me, I'm probably odd as far as that is concerned."

Hastings and Beck (2004:1340) confirmed that professionals who facilitate supporting networks for parents of children with learning disabilities might be creating effective support for parents.

4.6 Conclusion

Starting with the intensity of emotions that parents experience when they are confronted with a child with a learning disability, the chapter continued with further stresses that occur. These include stress at home and in the family, stress with homework, and emotions that the child himself/herself could experience. The difference in the reactions of the mothers and the fathers was also discussed. Communication with the school and the therapists and the expectations of the parents were raised as important issues. Support groups as an additional type of support for mothers were looked at.

A summary of the literature and the empirical study, the conclusions, limitations and implications of the study, and recommendations for further study will be explicated in chapter 5.

CHAPTER 5

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 Introduction

In this final chapter the literature study as well as the empirical study of this research will be summarised. Also included will be a discussion of the conclusions made by the researcher. The limitations of the study will be followed by implications, and then recommendations for further research.

5.2 Summary of the literature study

The aim of the literature study was, amongst others, to try to obtain an overall view of the world of learning disabilities. Various aspects of learning disabilities had to be covered to achieve this. An obvious starting point was to define and discuss the nature of learning disabilities. Different definitions may accentuate different aspects of learning disabilities, but essentially they all agree (see 2.2). Because of a learning disability the learner has difficulty in understanding or using language, spoken or written, and as a result, may not be able to listen, think, speak, read, write, or spell or do mathematical calculations. All of these difficulties impact on the learner's ability to cope at school, which is a cause of great emotion for the parents involved (see 2.7).

It is important to understand how these disabilities impact on the learner, and therefore, on their performance in the classroom. These difficulties include aspects such as academic skills, fine-motor skills, long- and short-term memory, including attention-, sensory-, integration-, and organizational skills, the making and keeping of friends, and a low self-esteem. The causes of learning disabilities include, amongst others, the structure of the brain, genetic inheritance, the environment, and medical factors (see 2.3).

An important debate revolves around the diagnosis of learning disabilities. Traditionally, the discrepancy model was used, and it still is (see 2.4). Professionals are advocating a new system, called dynamic assessment.

Various types of learning disabilities were defined in detail. Those are: phonological and orthographical dyslexia, dysgraphia, dyscalculia, and dyspraxia (see 2.5).

Of great concern in this dissertation is the impact a learning disability may have on the child, the family and most importantly, on the parents, and what support they may need from the school.

To understand what support parents might need it is important to understand what the parents' reactions may be to the diagnosis of a learning disability in their child. The literature covers the various stages that a parent may go through on receiving this news (see 2.7). They include: denial, shock, anger, sadness and depression, bargaining and finally, acceptance. The literature covers the intense emotions a parent may feel. It puts into perspective the importance of support for parents of children with learning disabilities. Mothers and fathers react differently to the news that their child has a learning disability, and this has to be taken into consideration.

The impact on family life, difficulties with homework, and the extra financial burden are also important issues, as is the effect that behaviour problems have on the relationships among siblings. Handling discipline at home and the importance of positive support from parents were highlighted (see 2.8).

Interaction and communication with the school is an essential aspect of support to parents whose children have learning disabilities (see 2.9). Parents have different expectations of the school, and these expectations change when they realize their child has a learning disability. The relationships between parents and teachers are equally important.

Parents suddenly come into contact with a number of professionals when they start to unravel what type of learning disability their child might have. In giving feedback to parents, professionals have to be sure that parents understand the terminology they use. Parents who truly understand what difficulties their child is experiencing are better able to support their child with his/her disability (see 2.10).

This dissertation covers the support to parents when they first have to deal with the knowledge that their child has a learning disability. It is, however, often a lifelong concern for parents, and it is important that professionals and others who provide support to parents are aware of the fact that at each stage of the child's life parents may have new questions and may need new and different support systems (see 2.11).

Finally, a short section was devoted to the feelings of the learner about his or her disability, and what information the learner himself would like. Any support program for parents, without taking the learner's view into account, would ultimately fall short of providing adequate support (see 2.12).

5.3 Summary of the empirical study

As stated in chapter 1 the research was guided by an anti-positivist approach. This emphasizes the understanding and interpretation of phenomena, and making meaning of the process. In the following summary, the researcher tries to obtain meaning from the interviews and the mothers' emotions and experiences. In obtaining meaning a number of guidelines are provided which this particular school, and maybe others, might find useful in their handling of parents when their child is diagnosed with a learning disability. Phenomenology, a school of thought within anti-positivism believes an individuals' behaviour is determined by their experience (Dash, 2005:3). The behaviour of the mothers, for example, not getting involved in school activities because they feel alienated, or they do not want to discuss their children's problems with other parents, might be determined by their experience with the school at the time of diagnosis. The guidelines provided might create an experience that is different to the one they have

experienced and thus foster a behaviour that is constructive for the positive development of their child.

Ten interviews were held with mothers of children who attend a particular school in White River, Mpumalanga. Purposeful sampling was used, which means they were intentionally chosen from a list of parents whose children had been diagnosed with a learning disability while attending the school. Two pilot interviews revealed that too many specific questions interrupted the flow of the interview. The interview subsequently started with one general question asking the mothers how they found out that their child had a learning disability and what process the school followed to inform them. This question was followed by another asking what they felt would have supported them most at the time. Mothers spoke readily and easily about the emotions they felt at the time, about their communication with the school, and what kind of support they would have liked from the school.

The first section of the empirical study covers the emotions experienced by the mothers whose children have been diagnosed with learning disabilities. These were varied, and some parents felt them more intensely than others. The emotions that they revealed were shock, denial, guilt, anger, acceptance, and also disappointment, desperation, frustration, disheartenment, worry, alienation, hope and relief.

Some of the mothers described their shock on hearing the actual reading age of their child compared to that of children of a similar age. Another mother who heard the term 'dyslexic' being used to describe her child, was deeply shocked. She knew her child was struggling, but had never heard the term before (see 4.5.1.1).

Some of the mothers interviewed expressed denial that their children may have a problem, which makes it very difficult to assist the parent or the child in an effort to alleviate learning disabilities at school.

Most of the mothers expressed some form of guilt, most of them feeling that in some way it might be their fault that their child has a learning disability. They also wished that they had picked up the learning disability earlier. And if they didn't pick up the problem themselves they could not believe that they didn't notice it. It was a strong emotion expressed by most of the mothers interviewed. This is an important factor in supporting parents. If mothers understand the possible causes of learning disabilities they may be alleviated of their feelings of guilt and begin to work constructively towards the acceptance and remediation of the problem (see 4.5.1.3).

Some mothers expressed anger, anger towards the school in the sense that they only heard of the problem when it became a big one. They would have preferred earlier warning signs from the school (see 4.5.1.4).

The sorrow expressed by mothers related to their own heartbreak at seeing their children struggling so much at school, not being able to learn to read, and having to attend so many therapies during their school day. It also related to having to tell their children that they, in fact, had a learning disability, and experiencing the disappointment of their child (see 4.5.1.5)

Disappointment in the mothers concerned the school taking so long to confirm that there may be a learning disability, and in the fact that their child was not coping as well as they had assumed he/she would. The mothers expressed their disappointment in not being made fully aware of what assessments would be required and why (see 4.5.1.6).

Mothers also felt desperate. They felt desperately tired, being at their wits' end when it came to coping with homework and behavioural problems at school; desperate because they so badly wanted an answer or a solution to the problem. They felt desperate about the fact that their children probably would not be able to cope with the schoolwork (see 4.5.1.7).

Frustration was expressed when mothers had on occasion been to the school to ask if their child was coping well, as they themselves had suspected a difficulty with learning. They felt frustrated when the school only called them in a year or two later, saying, "Yes, there is a problem." There existed a sense of wasted time. Mothers experience frustrations with the children when they cannot remember what they have learnt from one day to the next, when they can't seem to teach their children to read (see 4.5.1.8).

The interviews also revealed that mothers, at a stage, begin to feel disheartened. One of the mothers felt this way when she found out her second child also had learning difficulties. Another mother was disheartened when she talked about her child's future, how she would always have to take care of him. Mothers worried about their children's confidence, about their apparent apathy towards their work after so many battles, and worried that the pace that the school works at would leave their child lagging behind (see 4.5.1.9).

A strong emotion revealed in the interviews was one of alienation or isolation. As one mother said, "I felt like an outsider." When their children display behavioural difficulties in the classroom, and other mothers comment on it, the mothers feel alienated. They cannot talk to mothers whose children are doing well because they don't know how to say, "Well, actually, my child is just not coping". They felt alienated in the sense that as soon as the school determined that there was a disability, they no longer felt welcome at the school. The impression they had was that the school would be much happier if the parents 'removed' their child from the school. This section was poignant and full of emotion. Another mother said "I think they just deal with the school environment without thinking about the family". This indicates the depth of understanding the school needs in terms of the impact that a learning disability has on a family, in order to create guidelines for support. A sense of loneliness and isolation was prevalent in all the interviews (see 4.5.1.11).

Some of the mothers expressed acceptance of the disability. This acceptance seemed to create a situation where one mother started to focus on the strengths of the child.

She remarked that her child had never felt happier at school, as a result of her change of attitude (see 4.5.1.12).

Some mothers also expressed feelings of relief when they finally knew what their child was faced with. Things started to make sense, and they now had something to work at. A diagnosis of a learning disability gives mothers information to give to teachers in terms of their child's needs in the classroom (see 4.5.1.13).

Emotions relating to stress at home were expressed. Mothers indicated that they were often at loggerheads with their husbands in terms of how to deal with the situation. Some mothers would accept that their child should take Ritalin, or other medication, but the fathers refused this option. Mothers often end up crying during a homework session, which causes tension in the home when fathers get back from work. In many ways the stress was related to homework. Mothers often do not know exactly what to work on, nor the best way to go about it. Also, they experience the frustration of teaching their child to read the one day, and having to start from scratch again the next day. The organization and planning of homework and homework diaries are also sources of frustration and stress for mothers (see 4.5.2.1).

On asking the mother how her child felt, it is important to note that often the response was that the children who are taken out of class for remedial therapy have to go during the lessons that they, in fact, enjoy and really excel in, like music, sport, or art. This is done so that the child does not miss out on any academic work. It, however, does not allow these learners to excel in any field where they would have liked to. Often other children tease them because they can't read and this damages their self-concept. Children hate the therapy, because in therapy they have to do what they can't do and what they hate doing (see 4.5.2.3).

An important aspect in an effort to support parents pertains to the very beginning when there is a suspicion that there may be a learning disability in the child. In some cases the school would approach the parents and mention that they suspect a learning

disability. In most of the cases the parents approached the teachers and asked if everything was fine, as the mothers suspected a learning disability. The scenarios are different. When the school approaches the parent first the parents are more shocked. When the parents approach the school and the school tells the parents not to worry there is a sense of frustration that the problem was not picked up earlier, that the school did not listen to the parents' concern (see 4.5.5.1).

The mothers briefly discussed their husband's reactions to their child's learning disability. In all the interviews it was the mothers who had more communication with the school, and they had to deal with the day to day reality of the problem. Most fathers were supportive, but from a more distant perspective, and some mothers felt they needed support in terms of how to deal with their husbands' lack of support (see 4.5.3).

When the school recommended that the parents move their child to a remedial school, this was met with mixed feelings. Some parents were absolutely against it, and others felt it was a relief that their child would at last receive the kind of teaching that would best benefit him/her. Many mothers believed that the more all-round activities of a mainstream school benefited their child more. They did not want their child to attend a school where there would be very little focus on sport and other extra-mural activities. When the school recommended that their child be moved to a remedial school some parents felt that their child just wasn't good enough for the school anymore (see 4.5.4.2).

In some cases the school may recommend that it would be beneficial for the learner to take some form of medication such as Ritalin to help them to concentrate in class. Some mothers believe that Ritalin is not an option for their children. It makes some parents angry that the school should recommend Ritalin when they are not qualified to make that recommendation (see 4.5.4.3).

The school where the research was undertaken offers various forms of therapy, such as occupational, language and remedial therapy. Some of the mothers interviewed

believed that this was just a money-making racket. They thought that because the school had therapists available they had to 'feed' the children to them. Some commented on the poor facilities for therapy. Others mentioned that they could not afford it to continue the therapy. In an effort to support parents, it would be important for them to understand the value of the therapy for their child, and also, when they see the child's progress, for them to be supportive of the therapy (see 4.5.5).

Communication with therapists is important in respect of the terminology that they use, and also in terms of the feedback they give on the child's progress, the work to be done at home and the reason for it. It seems that parents often do not understand what the reports mean, and do not see their child's progress. They also do not understand what the work that their child is doing in therapy is about and how it is helping them to improve their ability to learn. This is a very important point concerning the information parents have and how they use it (see 4.5.6).

In terms of support, communication with teachers was a very important aspect. The parents of children with learning disabilities feel they need more frequent communication with teachers. They are upset when the first information they receive regarding a problem is at the parent-teacher meeting at the end of the term. They feel that if the teacher thinks there is a problem they would have liked it to be addressed earlier. Sometimes, even though their child has passed his/her grades year after year, the teachers need to be told anew every time that the child has a learning disability. Parents' expectations of the school change when they learn that their child has a learning disability. They seem to expect more communication from the school and more support for their child in the classroom in relation to the particular learning disability (see 4.5.6).

To alleviate the sense of isolation and alienation from the school and the community, support groups were considered to be of great value. For some mothers support groups would be a situation where they can voice their emotions of coping from day to day with a child with learning disabilities. For others it would be a place to receive information, or

a place where they could learn how to cope with their husbands' lack of support. All the mothers, except one, who said she preferred to read about the problem and find her own information, embraced support groups as a wonderful idea (see 4.5.10).

This researcher believes that the pain parents feel when they are informed of their child's learning disability is real and profound. Enough attention is not given to this feeling of sadness and desolation when parents are called in to a meeting to hear the news about their child. Group support for such parents would be highly beneficial. It may also be prudent to recommend that these parents receive counseling to help them to work through this emotional process and come to terms with their own issues so that they can focus on their child's needs. It seems to be a natural process of grieving that they go through, but they are not thoroughly prepared for the extent of it. The intensity of their emotions does not seem to be recognized, and therefore inadequate support is given to them. The school needs to understand these emotions and their impact on the family to be able to adequately provide support.

5.4 Conclusions

One can safely conclude from the literature study and the stories of the mothers interviewed that there is an emotional ordeal to bear when one has a child with a learning disability. The emotions suffered at the loss of your anticipated dreams for your child, and frustrations at home relating to homework, inter-familial stress, and inadequate support from fathers can be compared to the grief suffered when losing a loved one. Communication with teachers and therapists are important in terms of support for the parents of children with learning difficulties.

At the school where the research was done the first form of support would come by means of the teachers listening to the parents when they voice a concern about their child's possible difficulties with learning. In some cases it may be that a mother is being overly concerned and protective. On the other hand, an early diagnosis and reaction on the part of the school can benefit the child, the parents and the teachers as they determine what the child needs to facilitate his difficulty. If the school takes a parent's

concern seriously from the first alarm bells by the mother, she may be pacified by the efforts the school makes to either confirm her suspicions or to be able to acquiesce them after a professional person has made an investigation.

Whether the school asks for an assessment or the parents do, it would facilitate the progress and understanding of the process if the parents were brought to understand the details of comprehensive testing and what the benefits of it would be. Parents should understand the possible outcomes of the testing before it occurs so that they are more prepared for the results.

Professionals and therapists need to ensure that parents understand the terminology that they use in relation to learning disabilities. If therapy is required by an occupational or language therapist, parents would like to understand what work the therapists will be doing with their children, why they will be doing it, and how it will lead to progress. Parents also need to know what homework has to be done and how they should approach the homework situation with their children. This would remove the impression that the school is trying to make money, 'pushing' children through the various therapies.

Parents often felt that the news that their child was struggling in class came too late. To tell parents at the teacher-parent interview at the end of the term that their child is struggling in class, is leaving it a bit late. A parent whose child has been diagnosed with a learning disability would like to be informed as early as possible that their child is struggling, to be able to take the necessary measures to try and remediate the situation. Close communication with teachers in terms of the child's needs is required by the parents.

A strong issue that emerged during the interviews was the feeling of isolation or alienation. Parents often felt alienated from the school when their child was diagnosed with a learning disability. They believed that the school would be happy if they removed their child and that the problem would then no longer be the problem of the school. At

the same time they felt isolated from the community as they felt they could not speak freely to other mothers about their child's difficulties. The general consensus from the interviews was that the formation of a support group for mothers whose children have learning disabilities would be valuable. It would offer them an opportunity to talk about their loneliness, the problems with their child's homework, and their child's behaviour in class. It would also allow them to feel part of a community, a smaller community which would help mothers realise that they are not the only ones struggling with a child's learning disability. Most significant would be an understanding and acceptance of the emotions that parents experience when they learn their child has a learning disability. The emotions expressed, such as anger, which is often anger directed at the school, can be seen as a natural process of grieving, rather than a vindictive attack on the school. The full spectrum of emotions can be dealt with through counseling or group-work.

In conclusion to the question: "How can parents be best supported when their child has been diagnosed with a learning disability?" the following broad outlines can be used:

- A full understanding by the school of the emotions and sense of isolation that parents feel would help the school in its consideration of what support is required.
- When a mother expresses concern about her child's progress it should be incumbent upon the teacher to take the mother's concern seriously. The teacher could organise a more formal time to have a meeting, possibly including the Learning Support Unit. During the meeting the various issues and possible relevant assessments could be discussed.
- When professionals, such as Educational Psychologists, Occupational therapists and Language therapists talk to the parents, they should use terminology that parents understand, and link their feedback to how it helps the child in class.
- Therapists should be clear about what homework and what progress they expect from the child. They should also explain their reports to parents so that they are fully understood.
- The school should consider in which fields children with learning disabilities excel and the children should not be deprived from attending these classes. This would

support parents in the sense that their children's strengths are accentuated, and this would lead to a happier child.

- Parents would like closer communication with teachers and more frequent meetings to ensure that their child does not fall 'between the cracks'.
- A support group should be formed. Its needs can be dictated by the parents.

5.5 Limitations of the study

The following limitations were identified:

- Interviews were conducted with the mothers only. Although they expressed their opinions on the father's reactions to their child's learning disability, first-hand information was not obtained. Mothers might want them to join a support group but the fathers themselves might not find this necessary. They may require other means of support that the interviewer is not aware of.
- Only eight mothers were interviewed. Though much of the information overlapped, there are many more mothers at the school who may have had other opinions in terms of the support that they require.
- The eight mothers interviewed all come from the same school. The results may thus not be transferable to other school situations.

5.6 Recommendations for further study

The following recommendations for further study are made:

- The benefit of including the entire family for support if they have a child or children who have been diagnosed with a learning disability.
- The respect in which a father's need for support may be different from a mother's when they have a child who has been diagnosed with a learning disability.
- How the child with a learning disability perceives therapy, and how he/she sees, or does not see the benefits.
- How teachers can be equipped to be alert to possible learning disabilities in learners at a very young age.

- What strategies a teacher can best employ to assist a learning disabled child in a mainstream school.

5.7 A final word

“We may not know very much, but we do know something; and while we must always be prepared to change our minds, we must act as best we can in the light of what we know” (Auden 2002 in Forness, 2005:311).

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APPENDIX A: Letter of consent to the school

PO BOX 2805
White River
1240
2008.05.12

PO BOX 244
White River
1240

ATT: MR.

Subject: Dissertation: Support to parents whose children have been diagnosed with a learning disability.

Dear Sir

I am conducting research on the above-mentioned topic for a Masters degree in Educational Psychology. In order to fulfill the requirements for the degree I will be interviewing 10 mothers whose children attended your school at the time of diagnosis of the child's learning disability. The aim of the interview is to try to understand how best to support them when their child is diagnosed with a learning disability. Although the information obtained from the interviews will be used in the dissertation, all participants will remain anonymous. Participants are also aware that they may excuse themselves from the research at any point, and debriefing will be provided by myself should the need arise.

If you agree I will use the school's name in the dissertation unless you prefer the school to remain anonymous.

Thank you for your continued support. Please indicate that you are comfortable with the above information.

I would like the school to remain anonymous: yes/no.

Signed:.....Date:.....
Head Master

APPENDIX B: Letter of consent to the participants

I am currently undertaking research on the topic **Support to parents whose children have been diagnosed with a learning disability.**

I will obtain the information necessary for the research by means of interviews with the mothers of children who have been diagnosed with a learning disability. Although the interview will be audio-taped and transcribed for the purposes of analysis, all information obtained will remain confidential. The information obtained will be used in the dissertation without disclosure of the participants' identity.

You as a participant are entitled to withdraw from the research programme at any time without any prejudice towards you. The interviewer will make herself available for debriefing, should this be required.

Further clarity may be necessary during data analysis. Further contact will be made with you.

If you consent to participate in the study, please sign below.

Signature of participant:.....

Date:.....

Signature of researcher:.....

APPENDIX C : PILOT INTERVIEW

Support to parents whose children have been diagnosed with a learning disability

Biographical details:

Date:

Name	
Contact number	
Child's name	
Child's age at time of diagnosis	
Child's age now	
Parents' age	
Parents' level of education:	
Father	
Mother	
Language	
Place of Interview	
Other siblings	

An in-depth Interview.

1. Were you aware that there may be any learning problem, or that your child was struggling at school before the school approached you?
2. If so, what made you think there may be a problem?
3. If not, who brought the problem to your attention? Who first approached you?
4. How did that person go about informing you?
5. How did you feel at that time?
6. What was your reaction?

7. Who did you talk to about what you had been told?
8. If you approached somebody first, what was that person's reaction?
9. How did you feel?
10. What steps were taken next?
11. Who took them?
12. What information did you have, if any?
13. Was your child assessed by an Educational Psychologist?
14. How were the results of the assessment conveyed to you?
15. Did you understand what was being told to you?
16. How did you feel at the time?
17. Were you referred to other therapists?
18. How was this handled and how did you feel about it?
19. Was your husband involved in this whole process?
20. What was his reaction?
21. How did you deal with each other's reactions?
22. What would you have liked to have been put in place at this time?
23. What would you have liked to have been done differently?
24. What kind of support did you feel you needed?
25. Whom would you have liked it to come from?
26. Did you actually get any support?
27. Were you aware of what your child was feeling?
28. Was any attention paid to his feelings?
29. What do you think the overall impact was on you?
30. Any other comments?

APPENDIX D: The final interview

Notes for the interviewer.

The three main areas to be covered are:

1. An explanation of how the parents discovered that their child had a learning disability and what process the school followed.
2. What did you feel would have supported you at the time?

The following details are important. The researcher will ask specifically about them if they are not covered in the initial answers.

Can you tell me from the beginning what happened? (i.e. were you concerned about your child, or did the school bring the problem to your attention?)

Did you feel you as a parent were being listened to?

Did you understand the terminology used?

Did you feel the school was working with you as a team or did you feel they tried to take over without giving you enough information?

Did you feel the school gave you credit for being the person who knows your child the best?

What was your husband's reaction compared to yours? What support did you receive from him? Could you support each other?

Which of you, father or mother, was more willing to accept the diagnosis?

What support would you have liked from the school?

What procedures do you think would have suited you and made it all an easier experience?

APPENDIX E: TRANSCRIPTION SAMPLE

Dissertation: Support to parents whose children have been diagnosed with a learning disability.

Interview 1: 001

Date: 12.05.2007

Place: White River

Interviewer: Veronica Rörich

V: Please tell me how everything came about.

001: Okay, I think being exposed to some of the problems that Sam, my son, had, the tell-tale signs were there. I picked them up pretty quickly, in grade one. I approached the teacher and said, "I think there is a problem here. Her reading doesn't seem to be developing at a reasonable rate and there are words there that she sees once, I turn the page and she gets to the same word and it's as if she has never seen the word before." Definite signs of reversals, dyslexia, when she writes the 'b's' and the 'd's' that are backwards. I know a lot of it's developmental. It will come over time with maturity, but Emily was showing definite signs of reading just not making sense to her; she just wasn't seeing the words. And that's where I became concerned. I approached the teacher, we had assessments done, it has gone from bad to worse, to be honest. We've been speaking to the teacher, to the remedial staff and they have in no uncertain terms suggested that maybe Flamboyant would be the way to go with Emily. Having discussed this with my husband, he doesn't want to do that. He just wants us to press on; he thinks it's a maturity thing. But very evidently, there were problems.

V: So you approached the teacher. What was the teacher's reaction?

001: Well, she said to me that she actually hadn't noticed because they had been doing so much group-work and I said, "But have you actually heard her reading one on one?" And she said, "Well, now that you mention it, she is a little bit jerky, she spells every word phonetically." But she actually hadn't picked up the problem. This was probably in the second term of grade 2. You know, initially in grade 1 we thought it was just going to be a beginning thing. In grade 2 the problem was definitely picked up and by grade 3 we just weren't getting anywhere, I mean she is still reading baby books, still battling immensely. And I spoke to Mrs Pointer this year also in the second term, hoping things would right themselves, but she said to me, "No, there is a definite problem here." And that's when all the teachers were called in. Lauren White was called in and said, "Let's discuss what the best thing is for Emily." And in no uncertain terms it was suggested that she is Flamboyant material. Afterwards we saw Audrie Theron, who assessed Emily and said this is definitely not a Flamboyant child. So we were confused, and.....

Veronica: When was she assessed by Audrie?

001: I think it was in March of last year.

V: So after your concern you took her to Audrie?

001: So I took her to Audrie and said we're just coming to ask you, "Are the children at the right school or should they be on medication?" And it was Audrie who said she doesn't believe Emily should be at Flamboyant but she did think that we were not going to escape the route of Ritalin. She says Emily is definitely ADD and she has some learning disabilities.

V: The school didn't actually really listen to you in grade 2, if I understand you correctly?

001: That's actually really what it is and my disappointment is that at the end of grade 2, why did they let her pass?. That we've now got to grade 3 where it's not a....., you know reading is not a joke any more. Now they have to read in order to do their work. And that's been the problem: she never finishes her work because she can't read it. She can't do any of her math work because she can't read any of the sums. You know this is what I said to them, "Why wasn't the actual disability or the problem brought up?" And they said, "Well, you know we've got big classes, and she just seemed to move below the radar." And I said, "But have you heard her one on one?" And it was Cathy Kleet who has also taken Emily for remedial reading who said, no, she had picked up a problem but was hoping it would right itself. But to this day it hasn't. She's still battling immensely. But I wouldn't say that the school picked it up at all. Not to say the wrong thing about the school. But it definitely wasn't. And even in grade 1, I went to Karen and said, "You know, Karen, this is a little bit scratchy the way things are going." She said, "No, it's grade 1 you know. " And we had a very good understanding. And I thought, well that's how it goes. And then in grade 2, she had Mrs Aloe. And I approached Mrs Aloe and said, "Listen things aren't right here." And then Mrs Pointer in grade 3. And my concern is why didn't they call me in? I know it's not reading related, but why didn't they call me in and say we suggest that Emily maybe stay back now? But it was me the third year in a row going to them and saying I think there is a problem here, what are we going to do about it?

V: Then they finally listened. Now in grade 3 they are listening to you because they realize there is a big problem What happened, did they call you in, or was it you saying "Help, help,or..?"

001: I think it would have probably been a bit of a battle, because you know my husband and I we are not in favour of Ritalin, so I think they were probably a little bit nervous to call us in and say, now that child number two was having problems, not after the background with Sam. I said to Lauren, "I think there's a problem we need to sort out." Lauren was very good at organizing a meeting and we had Mrs Pointer there and Cathy Kleet and then the therapist, and we sat down and we discussed it. They just

made it very clear that Emily is battling immensely. And their recommendation was to remove her from the situation to a smaller group of children to really address the problems that this child is having. They have been very good about it, you know, Mrs Pointer has asked to see me again just to give me an update. But since this meeting we made the decision not to send them to Flamboyant and now Emily is receiving occupational therapy, they both go to Mags Hunter here in town for speech therapy. And Veronica, I'll be honest with you, we're just paying a fortune in therapies and I don't see any result. I mean that occupational therapy, I asked Emily what she did, and maybe there is something theoretical that's happening in the brain, but when she says she colours pictures, and she draws this and she draws from line to line... it's costing us a fortune. We've got both children in occupational therapy, remedial therapy, Sam is in supervised prep and that and I just, I think I am at my wits end we don't really know what to do. We had a meeting at Flamboyant. I really liked what I saw there and my concern there was that Emily was going to be in a class of five, with four boys and Emily. She was quite at ease to go, because she has come to me quite a few times and said "Mom, I can't keep up, the children are all finishing their work and I'm being left behind. Please can you help me. " And it's her biggest nightmare to actually stay back a year. And I said, "Well, what about Flamboyant?" and she said, "Anything that will just help me." And she was a bit disheartened when she heard there were only five in the class and they were all little boys. So she was worried about her friends, she's a very social child. So, but it's just a case of not knowing. They recommended that Flamboyant is an option, may be an answer, but its not really what we want to do with the children. Ritalin is not an option for us. We had them on it, it definitely had adverse effects. She just cried the whole time. It was just not the right thing for her. And I am just trying, but I don't know besides reading, and now unfortunately I think they have a bit of a rebellion against it because it's almost like a punishment when I make them read. Mags Hunter has said they must read for twenty minutes every day. And it's causing huge problems in my home. Any homework situation. That's why we have taken Sam now to prep guidance. That's actually done at school. But even that. You know we are paying a lot of money. And I will be honest, the work isn't done really well. Emily I now fetch an hour earlier so I can spend an hour with her one on one and try and get through. But as I say

there are days when she will see a word, and they are the basic sight words that we have done since grade 1, and it's as if it has not even registered. And I know it is just so imperative that they read. But now there is friction in the house because of this learning disability; it's huge. Peter just hears the shouting and the tears, because I often land up in tears, because I cannot believe how I can flip a page and there's no recognition of what she's actually seen. I have just done the word. I'll do spelling words with her on Monday. Twenty spelling words and blow me down on Tuesday morning she doesn't recognize one of them. So I'm not stupid, I know there is a definite problem. And I seem to be grabbing all different straws. I thought really what we should do, and this is really lateral thinking, is take them to a place like White River Primary, where they'll just be, not lost in the masses. But surely there's going to be kids there that are weaker than Emily. I know they've got some African children because I have had an interview there as well to see their situation, and I thought, maybe if she wasn't the weakest in the class, she would fit in. I'm scared that I am making both of their schooling careers a bit of a nightmare because it is just nag and hound and it's just And as I say, I do not see any progress, that is a thing that I am finding disheartening, with both of them. They are maturing beautifully socially, they have got good relations with people, you know they are polite children, but I mean this academic issue is just a cloud over our family. And its heart-breaking, it really is.

V: Tell me how you felt at the time of Emily's diagnosis?

001: I think the biggest thing with Emily is that as she was growing up she seemed to be so competent. She had her pen in her hand from an early age, and everything. You know, it just seemed as if everything would fall into place. She reached all her milestones at the right time. I think having had the hardships of Sam I thought Emily was going to sail through. I had visions of Emily almost, Sam probably staying back, and Emily probably being a year, these were my concerns that Emily was going to be just behind Sam and probably reading his works and reading his books, because she's so gifted. Because she showed these signs. And I think as the realization came of this, of Emily's learning disability, I was just so disheartened to think I am really going to

have to go over this all over again. I have one child who has a definite issue, although I think Sam's issue may definitely be a behavioral issue more so. And I just thought am I going back to stage one with Emily now? And it's just been heartbreaking to see. And then you've got to say, where does this problem come from? Why have I got two out of two? Everyone says there's usually one, usually it's the boy, and now I've got the little girl whose tenfold worse, and I just thought the pressures and the hardships I have been through with Sam, to now have this with Emily, we are just going back to square one. And as I say, you go back and you think, is this a gene problem where my husband was not a good reader, and maybe I wasn't such a good reader at school? But our attitudes were so different. You know we were hardworking. Emily seems to be at a stage where she says, I don't care, and that worries me. You know, because she has to care. But I think it's just that whole down-feeling of knowing you are battling in square one with disabilities, therapies, the whole lot. I mean, we have had so many assessments that we've been to Susan Brown, to people in Johannesburg, just grabbing at all kinds of straws and here we are with an issue and its just heart-breaking. And the work from a mother's point of view is just , I mean, I have got enough going on in my life, besides now doing reading with a child where from page to page there is just no recollection of words. And yet I marvel because some days it seems to come to her. And then I get so excited because then I start thinking maybe it is something in the brain that snaps, its going to come right, and the next day we will be just back to square one. And as I say my concern now is that she is getting to a stage when she says, 'I actually don't care'. She'll come home, she'll cry, she'll say she has been left behind, she never finishes her work. You know the teacher now, and this is a concern, they will get twenty spelling words and the teacher will say that Emily only has to learn five words. I don't want Emily to be separated, and things like that. She's very lenient; Emily is very untidy and she says 'continues to write good work'. Maybe she sees Emily as an individual and she is more encouraging, but I mean her work is bad. You know the spelling is completely wrong. So, ja, Veronica , it's just a hard hard battle, that you have to come to terms with the fact that you've got two children now that every night there's almost tears in the house because this one can't do that. I'm not the most patient person, I will be honest, but its just ja, to start a whole long battle and then I feel guilty because they are

happy children, but every day I wake up and I say to my sister I just keep hoping that maybe it was a dream that, that maybe today the children are just going to come right. Because every other area in my life, touch wood is going so well. You know we've got a good business, we've got a good marriage, we've got a good family life, but we've got, just the burden of schoolwork. And its huge, its heavy, it infiltrates into every area of your life.

V: Your emotional reaction, if you sum it up, it's heartbreaking?

001: Heartbreaking, yes it is and its,....you feel guilty and you think now, where did I go wrong? Did I not play with her enough as a baby? Did we not build bricks, did I not show her? And yet I have been one of those moms who has bought them everything educational possible. I've got more books than the average school library. I've got scrabble games, I've got board games, I've got block games, anything that I've tried to try and stimulate, and then I'm saying but why didn't this work? Its seems that you have spoilt them so much you have over-stimulated and now where's the balance? So it's the confusion of not knowing where I have gone wrong. I'll be honest now, there is a huge issue between my husband and myself. I see it one way, he sees it another way. You know, Peter is very much "They'll get through it, leave them, don't help them, they will work their way through it. If they fail they fail". To me to fail is catastrophic. In my life, I just know what children can be like, I don't like to fail, and I am just imagining these children when I hear about them at school and they say "O, that one stayed behind, and that one stayed behind'. I don't want my children to go through it. So these are the kinds of emotions, besides the guilt, the conviction that I've done something wrong somewhere. And then just that exasperating tiredness that you don't know what to do. And also the heartbreak of therapy. They are going to these therapists left right and center; we are really paying a lot of money. I don't see anything and, ja, and so there's the confusion and I'll be honest, the social embarrassment. Because you know, moms will say, and I mean the children, there are clever kids in Emily's class. And the moms will say, o, their child did well in this, and did well in that and how did Emily do? And I've got to say just, you know 'Emily is just not at that stage'. She is still on the grade 1 and

grade 2 books. And it's a thing that mothers do talk about, and I have chosen to just withdraw because I think having been through it with Sam I just didn't want to go through it again. Socially it is a nightmare.

V: What most do you feel would have made a difference to your emotional reaction at the time? I think what I am trying to say is, what support would you have liked at Uplands School that might have made it easier for you to bear this news? Now you were hoping Emily would be fine, and suddenly it wasn't fine. What kind of support do you think...?

001: You know I'll be quite honest, their support, while Anne Russel was there I was very in tune with the situation. That was more Sam's era. And then Lauren came along. I don't know, I was hoping...as I say the meeting we had with them, they recommended that maybe Flamboyant would be an option for me, so obviously they thought that was the best thing. But it's not what I wanted to hear. You know, I want to be able to find a solution to Emily's problems. But the classes are big, but I can't expect more than they have actually given me. I must be honest. But as I say, my initial concern was that I actually brought up the problem with them. You know, I said, "Listen, this child has got a problem." So, as far as picking up the problem is concerned, they didn't pick it up. And Mrs Pointer was very honest. She said, "Brigitte, I'll be honest, they have been reading in a group so I actually haven't heard." And this is in the second term, you know at the end of the first term. And she said, "I haven't actually picked up that Emily's battling." And so I said, "Well please, the next week just listen to her." And then she did. And that's when we had the emergency meeting. And they said, no, there is a definite problem here. But Mrs Pointer has been fantastic. She has even said that she will come in earlier. She will read with Emily for a few minutes before school. She'll do the reading in the afternoons with her. And I see she writes 'well done', 'keep trying' and things like that in Emily's book. But there isn't progress. But Mrs Pointer has been fantastic. Lauren, she is very in tune with keeping me updated and things like that. I can't expect them to be...., you know, trying to build me up, hoping that the problem is just going to go away. Emotionally I think it's a thing you have to deal with in

your family. You've got to accept things and you've got to eventually take the right road, and if Flamboyant is going to be that then we must do that. But as far as the support from the school is concerned, it is very good. I know if I've got a problem I can bring it up. Frank is very aware of the problem, and, um, no I couldn't expect anything more. I think their support structure is really good. I just think the actual finding of the problems, and then the other thing is that, and this is also a personal opinion, with all the therapists on the premises, I sometimes feel they are just feeding the children to the therapists. It's almost like a, you know, not a money making thing, but because the therapists are all there, it's just: let's send all the children to therapy, you know. That's a little bit disappointing but, my biggest concern is that there are all these therapies, and I am not seeing any difference. And that's a thing. And that's what Peter says. He says, "Look at this, you know we are paying this and we don't see any results." And maybe it's meant to be a long term thing, it will kick in eventually but the emotions are pretty difficult when you have to deal with something like this.

V: The support therapists, the occupational therapists and people like that, do they give you feedback regularly enough to tell you what progress has been made?

001: Well we get a report at the end of the term but nothing during the term. Not at all. And the unfortunate thing with doing the therapies in the school is that the children come back more disappointed because Emily has missed music. And Emily says she misses all the fun lessons. So she didn't get a chance to sing at Idols, which absolutely devastated her. Because she was now in therapy. She said she misses out on all the fun activities that all the other children do out of the classroom where Emily loves to be. And now she must go to therapy. So there's a resistance in that regard. And also Lisa doesn't let us know from day to day. There is definitely no homework. Or any additional work. And when I say to Emily, "What did you do in class with Lisa?" she will say, "No, we just played some games and we did this and we did that...", but that's about it with regards to the therapy.

V: There are some points that I have to make sure that we have covered. In the beginning you didn't think you were being listened to as a parent. Or did you feel you were being listened to as a parent by the school?

001: You know, as I say, it's such a personal thing there because I almost think our reputation as a family is a bit tainted because of Sam. I will be honest with you, Veronica, I drop the kids off and I duck because I don't want to have to be seen, not to be seen by a teacher, but even with Frank. I know he's got problems with Sam in the school. He has called us in a few times to talk about that, and I just don't feel that....., how can I say, I feel like an outsider. And maybe this is self-imposed because I know of the problems we've got, I don't want to get too involved with the school and that. But I just feel that Uplands would be a better place, I don't know how to say it, that Uplands would almost be a better place if we took the children out. I don't have anything against Frank. I had a meeting with Frank when he said it has been recommended that we take Emily out and maybe go to Flamboyant, and then he said and what about Sam? I said, "Well, do you maybe think it would be a good thing to take Sam out?" and he said he thinks it would be a good thing to take Sam out at the same time. Which, you know, it was heartbreaking to hear. And I just feel that we are a bit of a thorn in his side. Sam does have his character traits which aren't conducive to Uplands life, and that. He does antagonize children. But it's just a case where I feel we should be removed from the situation. But as I say, Peter says that it tends to be self-inflicted on me. You know I feel like that. But I think it's also from the children, you know. I go to fetch them and they are hiding behind a school wall and then they will sprint to the car because they don't want a teacher to see them or to ask them something. It's just a case of cat and mouse hiding all the time and it's sad because the reason we moved to White River was to become more involved in the school. But I am almost scared to become involved in the school. I have mothers who come to me and say, "Oo, I hear your son did this and your son was in detention for that". I would rather not deal with that. I just drop and run. And it's really not what I wanted. I was so hoping it would be more of a family life. We go to the socials, you know, we try and fit in that way. But even Peter says, we just are out. And ja, that's just how we feel.

V: When they, when Audrie or whoever, gave you a report and explained it to you did you understand the terminology that they used?

001: No, I think I just kind of scan the basics to look for ADD or, you know, I have seen it so many times. Ritalin, the need for this, learning disability. I don't understand everything. I look more for deeper things in the report like the family life. And, is it because the dad was absent when the kids were growing up?, and things like that. But as far as the graphs are concerned, that theoretical educational stuff, I don't really know what is happening.

V: If they say something about visual perception and auditory perception and all of that, has anybody...?

001: I've got a basic understanding but I can't say that like really... I'm just looking more for the surface things that I said about the children. I know it's got to have an effect, all that perception kind of thing. But I don't take that too much to heart. But those are the underlying issues that are not right and I'm seeing the results of those things. But no, to be honest, those reports are a little bit above my head, and I just I want to see if the child's birth age is 6 years 3 months but their actual ability is 5 yrs and 2mnths, and just to see whether they are above average or below average. And I understood a lot when Audrie spoke to me and she said both of their verbal abilities are high but there are academic things, so they compensate by being so verbal, it doesn't look like there is too much of a problem. But there are underlying issues deep down... And not that I know much about IQ's, but I know Audrie said to me these two children should both be at university level because both have exceptional IQ's. And I think that's also been a bad thing because it's always at the back of my mind. I don't know what the ranges are but at 117..... And I am told this is good. And yet I am not seeing. How can you get that and you don't see any results?

V: IQ doesn't really relate to learning disability.

001: It just shows you, that as a mother I had no idea. I was just thinking, she told me that their IQ's are exceptional or very good, whatever. And I'm thinking well how can you have an IQ or be varsity material when you can't even read? And how do you deduce that from a seven year old child?

V: Ja, carry on, it's fine. Did you feel the school was working with you as a team or did you feel they were trying to take over without giving you enough information?

001: No, I would say they were very good. I mean the ladies who came into the meeting were very thorough with me and very open. And I know a few of them on a social level, Cathy Kleet and the likes, and I think they all just looked at me and said, "Listen, we just want the best for Emily." Which I appreciate as a mother. You know you really do. But I just feel I was hoping that more would be done to help Emily. And I don't know how much more you can do. If you are doing remedial reading, you are reading for half an hour with Cathy Kleet, plus remedial reading. You pay your fee for that, and I'm wondering now why isn't she getting better? Why isn't the word 'and' becoming a natural word for her that she is seeing the whole time? And Cathy said she took almost a week getting 'and' in Emily's brain. And she said, "Brigitte, I'll be honest, there's a definite problem, and why not take Emily.....?" And they were very good, they sounded like real teachers that had the child's interest at heart. Which were, remove her from the situation, the pressure is too much, the kids are moving at a fast rate, she is getting left behind in everything, and I just think there might very well be another school that would help her. But I wanted the help from the school. And we are paying a lot of money. Sort the problems out, you know. But I understand the situation where you've got 26 kids in a class. You've got to get through a syllabus. If there is one child holding you back, they've got to move on you know. And I think the easiest way to deal with that is just to suggest possibly moving the weaker child. I definitely believe that Emily's interests are at heart. And as I say, I was just hoping that they were going to create the solution and not just suggest that I take her out.

V: Do you feel the school gave you credit for being the person who knows your child best?

001: No, I wouldn't say that, no. Um, I think they are with her most of the time during the academic situation but I mean, in the light of that question, why was I then the one who brought this issue up with them? It was I who said, "Listen, what is going on, you can see this child can't read? and for a teacher to say, "Well, I actually hadn't noticed" by grade 3, and I said, "But we picked up these signs in grade 1, and grade 2, why does she keep going through?" And then they say, "Ja, she is very social and she's got lots of friends. " And you know that often covers up a lot of what was happening with her. And I said, "That's not the problem. When the kid comes home to do schoolwork she can't read a math sum." And they said, "Ja well, you know, she does prep with the other children so she copies. We can't actually pick up that there is a problem. So, as far as giving me credit for the one that found the problem, discovered the situation I can't say anything was credited to me there. Definitely.

V: What was your husband's reaction compared to yours?

001: Okay, I'm just far more emotional. This whole situation with the children has just ripped through my heart because its heartbreaking. I think coming from a background where my dad was a teacher, for us to perform has always been of paramount importance. Peter comes from a very laidback background. You do your best, if you fail, you fail, you will do it again. He's very much of the opinion that you grow as a person the more you fail. And I just can't deal with failing and I can't deal with my children failing. And I can't deal with the children being the weakest in the class. So when a project is given I will help Sam, I will help Emily. I'll literally write their speeches and I'll train them so that when they stand up there they are actually really good. Because in that way they can compensate for the other pieces that I can't help with in the class. And Peter has now taken me, knocked me on the knuckles and said that's it. You back off now and you leave these children. I don't want to see you involved in their projects. If they are going to fail they are going to fail. So that's it. And as far as the

school is concerned, he said, he's more of the opinion we are paying them the money, they must sort out the problem. And I must stop trying to run from the problem. They are not going to Flamboyant, they are not going to White River Primary, we pay Uplands the fees they must sort the problems out. But the problems aren't being sorted out. And it's a huge issue between the two of us on how to deal with it. But there are certain things which will not be discussed. The option of Ritalin. And I'm not, I am against Ritalin, but the more I see Emily's behaviour, I would say she is truly a candidate of ADD, 100%. She doesn't sit still, she talks from the minute she wakes up. And if ever I have seen a child that I would say needed medication to calm her down to keep her concentrating, it would be Emily, but Peter said World War 3 will happen before that ever happens. He will never medicate the children because he says this is how we start the drug problems and all the internet articles he has read in the past just close those doors completely. So we have very different opinions of what is happening, but the instruction to date is that I am to butt out and to leave them. If their work looks like a dog's breakfast, then that's how it goes to school. If there's ten spelling mistakes in twelve words that's how it goes. So I feel like I am not really doing my bit. But he has told me to back off completely because the more I fix up their mistakes and send their work to school looking perfect the more the teachers don't realize there is actually a problem. I can see his point but I just don't want the children to hand in work and get 0 out of 10 because its just that failure, that issue of failure, and they are going through enough as it is. So we see things very differently.

V: In an ideal world how would you have liked it to be handled by the school?

001: In an ideal world I wouldn't have been in this situation, but what I think they've got to do, I was hoping that they would have, maybe after the first two weeks of the start of the year, they would have picked up the problem and said, "Mrs Blake, could we see you?" I would have said I'd come in and they would say they've picked up problems with Emily, let's monitor the progress over the next week. Let's maybe see you more regularly, let's have meetings more regularly so we can see if there is any development. Because even if there is a 2% development, then I'd say there is progress. But now we

see each other sporadically, you know, once a term, we sit down at the end of the term when we have our parent interview meetings. You know, her report looks fine, it's all threes and fours and there's no 1's, so she thinks she's doing fantastic at school. But it only seems so on the surface. Those kinds of things. Okay, it has a lot to do with appearance and manners, and things like that. But I don't believe they get truly deep down and honest with you and say, listen, we have a major learning disability here; we need to sort this out. It was definitely a case when I was saying to them, "Are we seeing the same things?" and they said, "Well, now that you've mentioned it". So I think it would have been better to be on more of a even, on a weekly basis where I could see them, even if it is only for 5 minutes when they can say Emily has had a good week, we are seeing some progress here. Maybe at home you can work on this and this area. How's it going with the therapist? And even the therapist doesn't give you any information about how it is actually going. And there has been the issue with occupational therapy: we took them out too soon. They were both at occupational therapy for two terms, and then Susan Brown said Emily definitely does not need occupational therapy. So I'm thinking "Well, why is she there?" So we take her out. And then at the meeting now at the end of the first term they said Emily needs occupational therapy urgently, and we took her out so soon. So we didn't see any development, and occupational therapy is a long-term process. So, maybe it hasn't been ideal that we have put her in, taken her out, put her in and that. But here is certainly no feedback as far as that is concerned. We do get a comprehensive report at the beginning of the term. I don't understand everything that is on there as well. You get nice little graphs and they have progressed to this level and that, and it is very nicely done but I just want to see the results. That's my issue.

V: Would you have liked emotional support from the school or from somebody?

Would you have liked group support, like if you had meetings with other parents who have the same problems, who are in the same situation?

001: Yes. Now that would be a great idea. Very much so. I think from an emotional point of view that's fantastic. And that's why I enjoyed those sessions with you last

year. Just to get things off my chest about how it was actually going at home. And where it is not actually a homework thing, it's just more the day to day life, how it's affecting our family, and how everything is tying up together. But to be in a group situation would have been fine, where I am actually with other mothers, because to be honest, I feel like I am the only mom in this situation. I'm looking around to see, and I even asked Emily, "Emily, is there anyone in your class who reads worse than you do?" and she said, "No, I'm the worst." And I just wish I could see another mother that was dealing with what I'm dealing with. You know, besides going to a teacher and saying, "Who are the five weakest ones in the class? Who are the mothers and let me go talk to them." But I think, I feel like it is almost an embarrassing situation. It's terrible, and um....., I think a group thing would be fantastic, because it's just the idea,.... if you know you are not the only one in the situation. And there have got to be other mothers out there. And I am getting so desperate I am beginning to think it is all the black children who don't speak English. That Emily is in that kind of category. And I look at them at school, and she comes home and she's got some very bright friends, but she just comes home and she says, no they do her homework for her, they are helping her with this and that. So I think we are also getting a wrong impression of what her capabilities are. She'll bring her homework home and there will be things there where she actually doesn't know how she got it. And that's when I pick up that a lot obviously happens in the class, where the children help her quickly so she can go out and play. But we are not seeing any progress. But with regards to support, I think a group situation would be good, because it's almost like the AA, you talk and you help one another, and to know that you are not in it alone. It's not your fault and I think that is the biggest thing. And that I haven't, I have got to believe in my heart of hearts, it is not something I have done wrong. It's just the way things have turned out. And that's the biggest thing. But a support group would be wonderful. Very nice.

V: Is there anything else around that that you would like to mention?

001: No, I think that would be a great idea. I wonder if there is any way.....

V: Ja, no we could structure one.

001: Ja that would be good. But I think to have a person in your position as well, I think that would be fine, where one can actually just unload. Where it doesn't just have to be academic based. That you are actually interested in how it is affecting me as a person, how it's affecting my family life, my relationship with the children, my relationship with my husband. I think that is a huge burden off one's shoulder as a mother. And if there are four or five others who are in the same situation I think a close bond could develop between mothers like that. Because you are compassionate to women who are going through the same thing. Very much so.

Debriefing took place from here.