

**THE IMPACT ON THE FAMILY DYNAMIC
OF HAVING A CHILD AND SIBLING WITH
DOWN SYNDROME**

by

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DEDICATION

Peering into the bed of a child with Down syndrome
in the pre-dawn moonlight
can bring tears of unconditional love...
love that will not be based on report card performance,
scores as a star full-back
or outstanding successes as a life-saving surgeon.
This love is for *who* this person is...
for their qualities, their trials,
and for the inner strength they must develop to take their place.
It is *their* struggle...
we can only hope, help, pray, watch
...and love.

(Adapted from Orphan (2004: xi))

This dissertation is dedicated to
Peter, Courtney and Lauren
With gratitude and love...
... For the '*peers in the moonlight*' (*even if you think I do not see*)
For the sincere prayers (*when you think I do not hear*)
For the invisible hope
For the visible help
For the tears of unconditional love (*when you think I do not notice*)
For watching and waiting...
Faithfully by my side
...as our precious Hayley takes *her* place.

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Thank you, Heavenly Father, for gifting me, equipping and empowering me with Your continued blessing and grace beyond measure. Indeed, how *great* Thou art!

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To my three magnificent daughters Courtney, Lauren and Hayley: Thank you my darlings for being so brave, for often believing in me more than I do myself, for your understanding and patience and for filling my life with your light. As you grow and become the daughters I *want* you to be, you help me become the mother I *need* to be. You are, above all, the love of my life!

To Dr. A.J. Greyling for providing me with strong guidance, steadfast support and incredible motivation. I remain indebted to your belief in my ability and inspired by your enthusiasm for your subject. Thank you for the valuable lessons in juggling and for your constant reminder not to drop the crystal ball, especially as I cross the bridge that you provided... “The ideal teachers are those who use themselves as bridges over which they invite their students to cross, then having facilitated their crossing, joyfully collapse, encouraging them to create bridges of their own” (Buscaglia, 1983).

To Marina Ward at the NMMU library, thank your excellence, competence and efficiency. I sincerely appreciate your help.

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My sincere gratitude to the following institutions for awarding generous scholarships, thereby acknowledging my commitment to make a positive contribution to society: The Trustees of

the B, SM & HC Goldstein Bursary; The National Research Foundation; and the Department of Research and Capacity Development, NMMU Postgraduate Research.

I wish to thank my wonderful parents for inculcating an ethos of commitment and excellence, and for your ever present love and support of my efforts.

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My friend and mentor, Roche, who continues to enrich my life, expands my horizons and enthuses me with her calm sense of resolve. The tireless hours of discussion and contemplation have been etched on my above-and-beyond-friendship slate.

To the wonderful participants of this study: THANK YOU! As parents it is invaluable for us to have a map which will allow us to navigate a world that many before us have mastered. I commend those individuals, parents, brothers, sisters and family members, who have displayed generosity of spirit, unbending optimism and unflinching courage in their determination and commitment to their siblings and children with Down syndrome. There are many battles that have to be fought. Some we lose. But with so many to be fought in a lifetime it stands to reason that there will also be many wins. Claim your victory!

To the every awesome person I know with an extra chromosome, my friends with Down syndrome: I continue to be in awe of your enthusiasm for the ordinary, of your ability to find light in darkness and of your natural gift for loving. Listen to the passion of your soul, set the wings of your spirit free, and let not a single song go unsung!

FRIENDS DON'T COUNT CHROMOSOMES!

DECLARATION

I, Heidi Webber, hereby declare that this dissertation for Educationis Magister is my own work and that it has not previously been submitted for assessment to another University of for another qualification.

.....
HEIDI WEBBER

.....
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To whom it may concern

This letter should serve to verify that I did the language editing of Mrs. Heidi Webber's dissertation.

In support of my ability to do so I would like to state that I have been an educator for approximately twenty eight years as well as a principal for part of my career.

.....
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To whom it may concern

DISSERTATION FOR EDUCATIONIS MAGISTER: H WEBBER

This letter serves to confirm that I have critically read the dissertation of Mrs Webber, as well as discussed the content with her at length.

In my professional opinion, I have found the content, as well as the implications and recommendations to be valid and psychologically sound. I believe it was written with good insight into a complex problem, and I have no reservations in endorsing her recommendations for further research as well as for counselling for the concerned.

Yours sincerely



Roché Snyman

SUMMARY

The *raison d'être* of my research is simple: it's about tossing one more starfish back into the surf.

Down syndrome is not a disease, nor is it contagious or a death sentence (it only feels that way when you find out for the first time). At the moment of conception, the appearance of extra genetic material results in a total of 47 chromosomes in every cell. Usually each cell has only 46, thus making an individual with Down syndrome far more *like* others than *different* from them. Yet, this extra chromosome presents special circumstances regarding their ability to acquire new skills, be it academic or practical, encompassing a specific learning profile with typical characteristics, strengths and weaknesses.

Twenty-first century family life is simultaneously challenging and richly rewarding and the expectancy of most families are of a life lived on paved highways with well-marked signs, and rest stops never far apart. Adding an extra chromosome to the luggage sends the family travelling down a vastly different highway instead, not always knowing what is ahead. It's scary, but in reality even those on the wide smooth roads do not know the future. Echoing the feelings of many parents, Leonard (1992: 5) states, "The trouble is that we have few, if any maps to guide us on the journey or show us how to find the path..."

Assumptions from previous decades that used to increase stress associated with rearing a child with Down syndrome would negatively impact on individual family members and the family unit as such. This has made way for the growing consensus that it is not necessarily the norm. Whilst some families have trouble in adapting to the increased stress, other families adjust easier and even thrive. Successful adaptation seems more likely in resilient families who enjoy high levels of parental well-being and strong relationship bonds. Findings of this qualitative research study confirm that unresolved marital strains are more likely to result in divorce as opposed to the birth of their child with Down syndrome. Correspondingly, siblings of children with Down syndrome reported mostly positive impact than negated opportunities to participate in a normal childhood.

My motivation for this research was to explore the nature of challenges faced by modern families and to provide mechanisms to facilitate positive adaptation for the family and aid

inclusion of the child with Down syndrome into school and greater society. Recommendations are also presented for the medical professionals who, ironically, have proved to be the last people parents want to go for support, owing mostly to their decidedly objectionable treatment of parents; as well as the generally uninformed public, who seldom understand or support attempts of parents to include and expose their child to everyday experiences.

In conclusion, I summarize: Should it be that I may influence but *one* person to see persons with Down syndrome for the potential that they hold instead of the associated problems of their condition, this would afford me the satisfaction and contentment knowing that I have succeeded in making a positive contribution to their plight. I would have successfully portrayed the families for the ordinary people they are with anticipations, aspirations and anxieties, but later tasting the elation of being empowered, and the resultant enjoyment and pride of the achievements of their extraordinary “starfish” child. The simple story below explains it all.

A little boy was walking on the beach when he noticed scores of starfish washed onto the beach by the previous night’s high tide. He curiously watched as an old man bent down, came up slowly and tossed one starfish after the other into the surf. He went closer to investigate. “Excuse me, sir, what are you doing?” he enquired. The old man said: “I am throwing the starfish back into the ocean before they die, my boy...come, lend a hand”. The boy looked up and down the beach at the hundreds of starfish scattered along the shoreline. “But there’s too many...” said the boy, “it’ll make *no* difference!” The old man smiled, bent down, picked up another starfish, and carefully tossing it into the clear blue water, he replied, “...It makes a difference to *this* one...”

CHAPTER ONE

BACKGROUND, PROBLEM STATEMENT, RESEARCH DESIGN, RESEARCH PROCEDURES AND STUDY OUTLINE

1.1 INTRODUCTION AND BACKGROUND TO STUDY

“A period of nearly thirty years has enabled me to study not only the present but the future of such children, to make a forecast based on the experience and results, and to correct the notions of sanguine hopefulness. I can not recommend too strongly that caution should be used in giving a hopeful prognosis concerning children in this class”. Thus, in 1887, reports Dr. John Langdon Down, after whom Down syndrome was named (Ward, 2008: 118). Almost a century and a half later, this proclamation is mostly dispelled as persons *with* Down syndrome re-write the data *on* Down syndrome.

The family constitutes the nucleus that is the most constant, involved, selfless, closest and, for the longest time, intimately involved with the person with Down syndrome, hereafter referred to as DS. If the family functions properly, the person with DS makes progress. This study will investigate, elaborate and report on the needs, perceptions and experiences of this fundamental nucleus, and its contribution to the overall impact and effect of a differently abled child and sibling, specifically a child with DS, on the family dynamic within the South African context.

Amongst the list of supposed stress creators in modern lives, none compare in scope and magnitude to the life-altering event of becoming the parent of a differently-abled child. One is never quite so alone as the moments after you receive the diagnosis which changes your life, and that of all of your family members, forever. Where the thought of finding yourself a primary care giver to someone who potentially may have high, unrelenting and often totally exhausting special needs never crossed your mind, this is now your stark reality.

I was part of the “There-but-for-the-grace-of-God-go-I” and “How-do-they-manage-I-could-never-do-it” people. But the truth is that one *does* manage, not because of special skills or saintly infinite patience, but because you have no choice, and because you love your child and your whole family unit as much, or, indeed, more than any other parent. You find yourself on a

roller coaster from which you are unable to disembark. This ride affects the whole family including both spouse and siblings in the primary relationships. For some there is the hope that their child will attain some level of independent living, but for many there is the realization that there can be no retirement from this role of carer; a fact that alters their lives forever.

The topic for my research is inspired by the comprehension that destiny has allowed me to experience emotions beyond the normal range. Moments when I feel that my heart may just burst; moments when pain and exhaustion are transcended by something far greater, and the sheer joy of little steps of progress and triumph become a living testimony to the capacity we all have within ourselves to overcome the obstacles on the road of life.

Alvesson & Skoldberg (2009: 244) state that emotion is an inevitable and important part of a researcher's motivation and choice of orientation, and of the specific way in which the topic of the study is handled. This underpins why this research process was explicitly guided by my willingness to reflect upon and share my own feelings, without it becoming 'emotional research'. I agree with Alvesson & Skoldberg (2009: 244) that self-reflection and the critical self-analysis of feelings are an important part of the research process, particularly in qualitative research. This is not a question of emotional catharsis, but of interpreting and processing one's feelings before and during the empirical and theoretical work.

The experience for our family has, so far, been an overwhelmingly positive one: we have a 'good-news' story, but for many South African families such an outcome is not allotted. I have three daughters, the youngest of whom has DS. I did not choose this for her, I did not want this for her, but this is my family's reality.

God blessed me with equal amounts of grace and strength during the first few hours after the initial diagnosis. We dealt what we had to deal with, made our peace and promises, braced ourselves and embarked on the ride of our lives. Once the initial shock, apprehension and concern had dissipated, the need to know about and concentrate on this news became a driving force in my life. Through empowering myself with knowledge on the subject of DS via many hours of thorough research, by affiliating to supportive organizations, attending seminars, workshops and National and International conferences, I have gained information and insight into the phenomenon of DS. It soon became clear, that the more I learnt, the more there seemed to *be to* learn, rendering true meaning to a line which serendipitously, and almost prophetically, crossed my path during my pregnancy, *'Just when you think you have learned all*

there is to know in life, someone truly special comes along and shows you just how much more there is'. I often deliberate *why* I felt compelled to make a note of it at the time...

Twenty-first century family life is both a challenge and a richly rewarding experience, and when it includes a differently-abled child, the challenges are most certainly heightened, but so too are the rewards. Although the initial reaction of parents by and large include utter incredulity and shock, apprehension, fear, anger and all encompassing numbness, Antoine de Saint-Exupery (2010) reminds us that life teaches us that love does not consist of gazing at each other, but in looking *outward together in the same direction*. For families of a differently-abled child, such an attitude and expectation supports not only a positive outcome, but may also turn it into a richly rewarding experience.

Such an experience has, however, not always been the norm for most families, as our 'one-size-fits-all' society does not smile upon the 'labelled-differently', in many cases shunning the person with DS as well as the entire family. Until as recent as one hundred years ago, children born with DS were immediately removed from their parents and society and placed in institutions, where their life expectancy rarely exceeded more than nine or ten years.

Around the mid 1600's through 1850, places called "poorhouses" were established, which eventually grew to be called institutions, housing between ten and thirty people, although some of the larger buildings in Europe and the USA often held over 1000 people. The residents, albeit some almost prisoners, were a mix of the poor, the blind, the deaf, the mentally ill, and the developmentally disabled, or 'mentally retarded'. Men, women, and children were housed in the same facilities. In many of these places residents were treated poorly, many being shackled, living in filth and minimal or no effort was made to see to their personal or medical needs. Very few of these places were desirable for persons, especially children, with DS, as residents were rarely treated humanely and with kindness. Here these sensitive, loving, emotional children were left to fend for themselves under harsh circumstances amongst mostly adult psychotic, schizophrenic and profoundly disturbed adult patients. Around 1850 to 1899 institutions began to separate people with intellectual disabilities from the general poor and mentally challenged, and places were built specifically for them, housing men, women, and children in different buildings (De Bello, 2008).

However well-intentioned institutions professed to be, in DS history most of these were highly undesirable in terms of living conditions and suitable environments for growing up in due to

factors such as deprivation of love, affection and empathy; substantial amounts of verbal, physical and sexual abuse; emotional, physical and medical neglect and severe overcrowding. Children with DS are frequently born with congenital heart problems requiring surgery. Due to their particularly narrow upper respiratory tracts, they are predisposed to bronchitis and pneumonia, which in turn, not only affects their lungs but also their hearts. Their low muscle tone often require that they are physically taught the most basic of movements including sitting, crawling, walking, talking, eating and matters pertaining to personal hygiene (Ward, 2008: 29–36). Needless to say, intervention, in *any* of the above instances was mostly non-existent in institutions. Their short lives were hellishly crude and wasted.

One of the most infamous institutions was Willowbrook State School in Staten Island, New York, where, during the 1960's, healthy children were used in a controversial hepatitis study to establish the effects of a drug called gamma globulin. In the 1970's this institution was exposed for its extreme overcrowding, abuse and neglect, causing a public outcry that eventually lead to it being closed down in 1987 (Hevesi, 2010; DeBello, 2008).

Through the early 1900's, institutions became more school-like and instead of merely housing them, residents were being taught skills which would enable them to pursue outside employment. It was observed by some of the few caring staff that persons with DS could be taught, and were indeed educable. There are, however, in this day and age, still medical "*professionals*" who perpetuate the stigmatization of having a child with DS and who still advise parents against keeping their children at home with them, many strongly suggesting that the parents have another child as soon as possible to make up for the 'mistake' that had just occurred. Alderson's (2001: 628) qualitative study faulted the medical model's analysis, discovering that it is more a result of society's exclusion and neglect that erodes the health of persons with DS. Alderson (2001: 629) argued that many individuals withy DS are very capable of living a productive life, as well as contributing back to the community. Repeatedly cited is that the greatest impact on people with DS is not their disability, but rather society's attitude toward them (Alderson, 2001: 628).

Amongst many of the ethnic cultural groups, having a child with DS is often perceived as an ancestral curse. Due to the stigmatization of both child and family members these children are mostly hidden from society and are often subjected to very hard and harsh living circumstances. Only their most basic needs are met and they are often not viewed as human beings. In other cultures they may be accepted, but are hidden for fear of discrimination against the family members, or retaliation against them for bringing 'bad luck' to a tribe or

community (Gordon, 2008). Because many Black South African infants with DS are undiagnosed at birth, it is often only once the mother notices a marked developmental delay that she seeks medical advice, very often too late for effective early intervention. In many cultures, especially amongst poorer communities, the child with DS receives no early intervention and does not attend school. These children rarely learn to speak and are often left alone to fend for themselves during the day, and frequently at night. Due to their innate trust and childlike innocence, they are extremely vulnerable to physical, emotional and sexual abuse (Christianson, 1997: 995)

Parents have, from as early as the 1930's, attempted to fight for their children, including their children with DS. As these groups grew, each saw that if they united on a national level, much more could be accomplished. Their children were excluded from schools, discriminated against, and shunned by the general public. In 1952 the National Association for Retarded Children (now named The Arc) was established to improve the welfare of their children, and other organizations specifically for DS were created. In 1961 The National Association for Down syndrome was founded by a group of Chicago parents who refused to adhere to the advice of doctors and chose to keep their children and raise them at home. Parents discovered that support and resources available to parents of a child with DS were very limited, and as more groups and organizations were established, the value of parent support, early intervention, physical and occupational therapies, advocacy, scientific research and involvement in the political process were recognized and emphasized (National Down syndrome Society, 2008).

In most of the first world countries, children with DS are eligible for state funded crucial services to assist parents in helping their child reach his/her full potential. There are also adult services to assist in job training and placement, and help with where and how the individual with DS chooses to live. In South Africa, however, parents have to rely on non-profit parent support organizations such as, Down syndrome South Africa (DSSA) and its affiliated branches.

With the establishment and development of family support organizations, awareness campaigns, ground-breaking research, human-rights charters, advocacy causes, United Nations Convention and inclusive policies, ignorance has slowly but surely taken small steps toward understanding and embracing diversity (Down syndrome South Africa, 2010) .

Vast amounts of literature are available covering a wide variety of subjects in the field of DS and parents are able to make informed decisions concerning their children's future. The paradigm shift from the medical to the humanistic approach invites and supports parents,

siblings, extended family and society to gain knowledge and an understanding of the expectations and experiences of all the role players in the life of the person with the extra chromosome.

Despite conflicting opinions, it has become abundantly clear that the mental and spiritual health of the family, the nature of the marital relationship, coping strategies of each family member and the severity of resulting extra chromosomal material all intensely affect the functioning of the individuals and every member of the family unit. As diagnosis of this kind profoundly influences the entire family, it was my desire to research the impact that a differently-abled child and sibling, particularly a child with DS, has on the family dynamics, specifically within the South African context with its cultural and socio-economic diversity.

This specific study focuses solely on the perspectives of immediate family, i.e. parents and siblings and does not include the perspective of the individual with DS, except as complementary to the participants' experience. Encompassing vast terrain, I felt that the perspective of the individual with DS warrants a complete study of its own, covering aspects of early intervention, family involvement, education (inclusive and/or segregated), self-advocacy, independent living and human rights issues, to name but a few.

There are no perfect people, and since families are made up of people, there cannot be perfect families. As with every other family, families with differently-abled children, too, have their own idiosyncrasies, their own secrets, their own unique and sometimes odd ways of doing things. Strangely, however, there are those who hold an idealized view of the relationships within families with a differently-abled child. Thus the myth exists of instantaneous family bonding as a result of the child; or that the parents are more patient, smarter and more philosophical about life; or that siblings lavish constant attention on their 'special' sister or brother. This may be true in *some* cases *some* of the time, but there is certainly no guarantee that caring for a differently-abled child will automatically result in personal growth of this nature.

Having walked the road with many parents, especially mothers of children with DS, the pervasiveness of strained marital and familial relationships, as well as single-parent households, became alarmingly apparent. Upon subtle probing, the supposition arose that marriages, and therefore families, frequently do not withstand the challenges of raising a differently-abled child. I know that caring for a differently-abled child can be extremely stressful, often causing interpersonal relationships to suffer. Although the child, per se, may not

necessarily be the key factor in the decision for parents to separate, the additional strain of meeting the child's special needs often plays some part in marital breakdowns (Dowling, *et al.*, 2004: 124).

Many ancillary issues may influence the family dynamic. When a differently-abled child is born, it is natural that the family, especially the parents, 'grieve' the loss of the child which they expected. As no two people grieve or adjust to loss in the same way, this too, may cause conflict and misunderstanding, resulting in a highly emotional environment. Combine this dilemma with the very real and practical need of the parents to develop strategies and skills for the care of their child, and one has a situation unreceptive to the positive growth of family relationships.

Modern family life is challenged by rules and expectations in relation to behaviour and responsibilities. Understandably, this becomes ubiquitous once the child with special needs is born. Parents may interpret these quite differently and communicate differing expectations not only to each other, but also to their children, creating yet another source of conflict and stress. In some cases, the 'loss' of lifestyle and freedom may cause a further hurdle. Participation in social activities take a backseat to sheer exhaustion and often logistical difficulties, hobbies become neglected and friendships are foregone, whilst contact with other adults may become restricted to parents of other differently-abled children met through school or support groups (Dowling *et al.*, 2004: 125).

Being the sibling of a differently-abled child is probably as taxing as being a parent. Many additional burdens are placed on their shoulders, whilst their own needs are often neglected and seldom discussed. They too, experience loss and grief. Not only have they lost the possible playmate and friend they were eagerly awaiting, but they may have lost the extra attention from their parents, and in many cases the friendship of other children who now stay away through ignorance, fear or embarrassment. Frequently the siblings are required to take on extra responsibility, becoming virtual supplementary parents at a time in their lives when other children are relatively carefree, causing them to experience an even greater loss: the loss of childhood (Dowling *et al.*, 2004: 126).

The sibling issue is, of course, not all bad news and many siblings develop enormous empathy, patience and the ability to embrace diversity. There is, however, the distinct possibility of a sibling who may become jealous and bitter at the perceived disparity in attention given to

him/her compared to the differently-abled sibling. Displays of challenging public behaviours, demands on personal time and intrusion of personal space may further cause siblings to become embarrassed and frustrated by the brother/sister with DS.

How these specific issues are managed may dramatically influence the peace and harmony of family life. During my close association with families with children with DS, I have come to realize that it takes a very determined parent to maintain a sense of balance and normality in their life, but that the benefits of doing so are indeed enormous, as confirmed by Van Riper (2007: 117).

1.2 PROBLEM STATEMENT

Past research on parents, mainly mothers and siblings have mostly focused on the negative influences (Blacher & Hatton, 2001: 477), and only more recently have attitudes toward management of differently-abled children taken a more positive and inclusive position, with the majority of children remaining within the family. The latter may cause emotional as well as financial pressure on families that may already be vulnerable due to the aforementioned factors.

The unique developmental, health and educational concerns commonly associated with DS, cause families of children with DS to generally experience higher levels of stress than families with typically developing children (Baker, McIntyre, Blacher, Crnic, Edelbrock & Low, 2003: 223; Olsson & Hwang, 2003: 286; Lam & Mackenzie, 2002: 230). Challenges in families with children with DS are encountered more frequently than by parents of typically developing children. This may include time allocated to the differently-abled child and their therapies versus time spent with the siblings, as well as with a spouse.

These challenges may result in depletion of physical and emotional well-being, the ongoing educational battle, and both the short and long-term financial repercussions for the whole family. More often than not, it appears, marriages end in divorce. Continuous research into the impact on siblings and indeed every individual family member, and how this experience can be optimized, is therefore paramount to the well-being of each family member, as well the best possible outcome for every situation.

Based on this problematic scenario, the following research questions were formulated:

1.3 RESEARCH QUESTIONS

1.3.1 Primary Research Question

- *What is the impact on the family dynamic of having a child and sibling with Down syndrome?*

From the primary research question, the following secondary questions were derived:

1.3.2 Secondary Research Questions

- *In what way does having a child and sibling with Down syndrome influence familial bonds and relationships?*
- *What are the challenges parents face by simultaneous parenting of a child with Down syndrome and typically developing siblings?*
- *In which ways can families be empowered to address issues regarding Down syndrome?*

1.4 RESEARCH OBJECTIVES

In order to address the research questions, the following objectives were formulated to guide the researcher:

1.4.1 Primary Research Objective

The primary research objective has as task:

- *To determine the impact on the family dynamic of having a child and sibling with Down syndrome.*

1.4.2 Secondary Research Objectives

From the primary research objective, the following secondary research objectives were derived:

- *To determine in what way having a child and sibling with Down syndrome influence familial bonds and relationships.*

- *To ascertain the challenges parents face by simultaneous parenting of a child with Down syndrome and typically developing siblings.*
- *To recommend ways in which families can be empowered to address issues regarding Down syndrome.*

1.5 CONCEPT CLARIFICATION

- ***Down syndrome***

The accepted form of spelling in most countries is *Down* syndrome and not *Down's* syndrome. ***Down*** refers to the surname of Dr. John Langdon Down, who in 1886 recorded the characteristics that set a specific group of patients apart from others with a 'mental handicap' (intellectual impairment) (DSSA, 2010).

The term ***syndrome*** implies a collection of characteristics and symptoms "resulting from a common cause or appearing in combination, to present a clinical picture of a disease or inherited abnormality" (Mosby's Medical Dictionary, 2009). This term is used to refer to children who are born most commonly with 'Trisomy 21' (meaning three copies of chromosome 21). To a lesser extent, children are born with a translocation form of the extra chromosome, where the extra chromosome 21 is attached to one of a different chromosome pair. Small numbers of children have mosaic DS, where only some cells are trisomic and affected (DSSA, 2010).

DS is a genetic disorder that includes a combination of birth defects including some degree of intellectual impairment, characteristic facial features and, often, heart defects, visual and hearing impairment and other health problems. Severity of these problems varies greatly among affected individuals. It is one of the most common genetic birth defects, affecting approximately one in 800 babies worldwide. According to Down syndrome South Africa (DSSA), the prevalence of babies born with DS in South Africa is currently one in 550 live births (DSSA, 2010).

- ***Typically developing***

This is the most appropriate way to describe children who do not manifest special educational needs. In my opinion the term 'normal' is frankly offensive since it implies that a child with special needs is 'abnormal'. Typically developing refers to the many social, physical and cognitive aspects of development of children who do not have obvious difficulties and

challenges in the natural progress and process of the different phases of development. Thus it is often in contrast to 'typically developing' children that one can best describe the needs of children who face challenges in the abovementioned spheres (Webster, 2010).

- ***Differently-abled***

The terminology "disabled" is substituted by my own semantic conviction "differently abled", as I strongly believe that all individuals are indeed able, albeit in different ways. Furthermore, terminology such as "disabled" is unfortunately frequently, incorrectly and insensitively applied, constituting labelling with a negative connotation. I believe that ability is not in the eye of the beholder.

- ***Inclusive Education***

Inclusion is a philosophy of education based on the belief in every person's inherent right to fully participate in society. Inclusion is an educational process by which all students, including those with disabilities, are educated together for the majority of the school day. With sufficient support, students participate in age-appropriate, general education programs in their neighbourhood schools (National Down syndrome Society, 2008).

This practice of welcoming, valuing, empowering and supporting diverse academic and social learning among students of all abilities is called inclusive education. When inclusion is effectively implemented, research has demonstrated academic and social benefits for all learners: both those who have special needs as well as typically developing learners (Giorcelli, 2002: 55).

Friendships develop, typically developing students are more appreciative of differences and differently abled students with are more motivated. Inclusion implies acceptance of differences. It makes room for the person who would otherwise be excluded from the educational experiences that are fundamental to every student's development (National Down syndrome Society, 2008).

1.6 RESEARCH DESIGN

De Vos (2002: 15), McMillan & Schumacher (2001: 33) and Gay & Airasian (2000: 107) concur that a research design encompasses a general plan of study from inception to completion, thus incorporating the interrelated methodological assumptions which shape the rationale for a study and guides the researcher in selecting methods of data collection, analysis and interpretation.

Consistent with Mouton's (2003: 103) notion that **qualitative methods** are recommended to gain insight and understanding into the life of research participants, accordingly, a qualitative research paradigm was undertaken for this study. McMillan & Schumacher (2001: 226) hold the opinion that issues of 'how' and 'when' is exactly and directly addressed and answered by means of qualitative research, whilst affording the researcher direct access to the participants who constitute the primary source of information.

My interest in the richness of the information I generated from the study as opposed to the ability to generalize is supported by the feelings of Patton (2002: 127) on this subject. Thus, the research design took my intended exploration to a practical level by encompassing the action plan that involved 'getting from here to there', as stated by Yin (2009: 27).

Sinclair Bell (2002: 207) states that narrative inquiry rests on the epistemological assumption that we as human beings make sense of random experience by the imposition of story structures. That is, we select those elements of experience to which we will attend, and we pattern those chosen elements in ways that best reflect our experiences and perceptions. People's lives do matter, but much research looks at outcomes, discarding the impact of the experience itself. Narrative allows the researcher to get at information that people do not consciously know themselves. It also allows researchers to understand experience. And in this understanding lays the purpose of this study.

I further employed a narrative research approach, as I sought a richer understanding of the issues involved. In my case, such an approach highlighted the *unexpected* impact that is experienced by parents and siblings. This will ultimately equip me as an educator, to better understand the dynamic within the family with a child with DS, allowing me to render a more holistic teaching and learning experience, not only to the individual with DS, but also to the sibling. Having a better grasp of the functioning of families in this situation will further provide a sound base for comprehension and interpretation of situations, tolerant recognition and empathy of the nature and/or situation of the role players.

Being of reflective nature, this research method has required close collaboration with participants and their situation, illuminating the reality (lived experience) of the researcher as much as the participants. Throughout this study I have endeavored to impose meaning on the lived experience of the participants, and narratives allowed this researcher to present experiences holistically in all its complexity and richness. Although other research methods

would have captured understandings at certain points, my personal style of narrative expression was best accommodated by this method.

Qualitative research uses a **naturalistic (interpretive)** approach, which seeks to understand phenomena in context-specific settings without the researcher attempting to manipulate said phenomenon (Patton, 2002: 39). As this involves the opinions and experiences of people who are familiar with either their own, or the situations of others, I concede to the phenomenon of variable and multiple realities resulting from interpretation and assumption.

I found the interpretive approach suited to this study as it finds significance and substance in social action to which people attach meaning, as suggested by Neuman (2005: 69), thus this approach assists the researcher in evaluating both the behaviour (phenomena) and the understanding thereof. Struwig & Stead (2004: 12) reiterate that during qualitative research, emphasis is placed on the perspective of the participant in terms of beliefs, behaviours and description of events.

Adding to the above, Lichtman (2010: 79) refers to **phenomenology**, which, as an approach, is based on description and understanding of the lived experience of individuals, thus it expands the understanding of something into an interpretation of it, with the researcher being the interpreter of the data. Husserl (Lichtman, 2010: 80) coined the phrase 'lived experience', referring to 'life experiences' in which we are all involved.

Subscribing to this approach, as the researcher, I attempted to set aside my own thoughts on the topic, i.e. 'bracketing' it, suspended judgment and focused on inductively understanding the meaning of the experience as perceived by the participants in the study, despite my close connection to the topic of research.

As such, phenomenology can be viewed as either an approach or a philosophy and may range from conservative and traditional to broad interpretations and applications to the study of lived experiences. The purpose of my study, on a philosophical level, is to interpret specific situations. Furthermore, I would endeavour to provide answers to the possible emergent questions. These questions may cover how the nature of the participants' experience relate to a deeper level of their understanding and further, how certain individuals react to different situations and experiences - in this case *parenting* a child with DS, as well as *being the sibling of the child with DS*.

Neuman (2005: 74) also refers to the **critical approach**, which is appropriate to this study insofar as its main objective is to empower people. This objective is attained by helping people to change and improve their circumstances for themselves, i.e. emancipating them. Cresswell (2009: 169) reminds us that qualitative research provides a glimpse at the reasons behind a specific behaviour or reaction and emphasizes the significance that events have for those who experience them. Through critical study of each individual situation, the underlying aspects of each relationship becomes clear, which will allow me to evaluate the conduct and emotional activities of the participants, as well as the motive for its occurrence. The application of both the interpretive and critical approaches will therefore afford this study a qualitative and evaluative nature.

As I am part of this reality by direct association to the research topic, I will base knowledge on consensus as far as possible, considering that this may vary according to contextual, socio-economic and cultural factors, as explained by Guba & Lincoln (Struwig & Stead, 2004: 16).

Whilst it may be argued that a case study design, as used widely by researchers who endeavour to achieve an in-depth understanding of a particular phenomenon, would be suitable for a study such as this, I believe that a single case study would not have sufficed, as it would provide too narrow a perspective on a vastly complex phenomenon. Whilst studying six to eight cases may provide a slightly wider perspective, it is my opinion that, in order to include all cultural, socio-economic and ethnic groups and to allow comprehensive access, case studies would not be a suitable or recommended route to follow.

Patton (2002: 39) identifies the qualitative approach as ideal for investigating complex topics and for understanding continuity and change in family development. During my experiences in mentoring families, I have found the *why* and *how* aspects mostly neglected and unexplored, leaving parents and siblings vulnerable in many ways. Parents often place so much emphasis and time juggling the “balls” of physical, developmental and educational aspects, that the most important “crystal ball” of their *own* health, spiritual and physical needs, as well as those of their family and loved ones, end up precariously close to the ground, or often get shattered (Greyling, 2009).

In 1987 Kingsley (Friehe, Bloedow & Hesse, 2003: 220) based an essay, “*Welcome to Holland*” (see Addendum A) on her experience as a parent of a child with DS. She draws an analogy between a voyage to an unexpected destination and the birth of a child with an unexpected

diagnosis. As with planning a voyage, encompassing travel itineraries, shared roles of the family, and travel tips, so too, having children involve planning similar to that associated with an exciting voyage. All of this is 'revised' when the traveller realizes that the destination he has arrived at is not the one he/she had anticipated. Kingsley further describes the never-ending pain that accompanies this altered destination, especially as other travellers continue to talk about their 'trips to Italy' with their typically developing children.

My desire for this exploration and understanding was not to predict future outcomes, but more to explore the nature of challenges faced by modern families and to enable them to develop a resilient, self-supportive nucleus equipped with the 'map' they will need to make it through "Holland".

In conclusion I wish to share that I view research as a form of art. The researcher starts off with a blank canvas, but with an idea in mind – an idea of what the completed product *may* look like. But pre-conceived colours may not necessarily turn out the way the artists planned, and probable shapes may not necessarily fit the design. The canvas can only be *true* to life, if it is an actual reflection of the experiences of the participants. The researcher supplies the tools, the participants contribute the material. Sometimes the end result is dark, sometimes vivid; sometimes it contains blank spaces to be filled only by further exploration and research.

As researcher, my desire was to develop an understanding of *why* and *how* having a child and sibling with DS impacts on the family dynamic in general and this study, and not merely to become a yardstick to evaluate the dynamic in my own family.

1.7 RESEARCH METHODOLOGY

According to Johnson & Christensen (2008: 93) and Henning (2004: 15), research methodology refers to the specific actions planned by the researcher to meet the stated purpose of a study.

1.7.1 Sampling

According to Johnson & Christensen (2008: 222), *sampling* is the process of drawing a sample, selected from a larger group (the population) in order to study their characteristics. For the purpose of this study I applied a purposeful sampling strategy that involved recruiting desirable, willing information-rich participants who fit the criteria and would have an in-depth knowledge of

the phenomenon of interest in order to make constructive contributions, as suggested by Patton (2002: 127) and Merriam (1998: 84).

Merriam (1998: 62) and Glesne (1999: 29) suggest the 'snowball or network' sampling strategy as an initial means of gaining access to participants, which entails acquiring information via a source who may be aware of potential participants who may meet the research interest. For this study, however, this strategy was not required, as I have access to a vast database of potential participants due to involvement in DSSA, which is a supportive parenting organization.

Data was collected from families who had only one child with DS. Since the experience of siblings was also necessary for this study, to facilitate data collection, they had to be older than ten years of age. Sibling ages ranged between ten and thirty five years. The target group included:

- Single parent families
- Parents who have lost a child with DS
- Grandparents who have adopted the child with DS and have been the primary caregivers of this child
- Individuals from different ethnic and socio-economic groups.

In order to collect the data, different data collection instruments were considered as follows:

1.7.2 Data Collection

Succinctly stated, data collection is the procedure that a researcher uses to physically obtain relevant information from research participants. Selecting a suitable data collection strategy provides the researcher with rich information and description (Yin, 2009: 122) will best furnish the information sought for a study, and will, according to Dana & Yendol-Silva (2003: 84) assist in opening up aspects of the problem under investigation. For the purpose of this study, primary data was obtained from participant responses to open-ended questions (Bless, Higson-Smith & Kagee, 2000: 111).

- **Interview Guides/Self-Reports**

Although one-on-one interviews were initially planned, participants suggested the alternative use of an interview guide, affording them the opportunity to carefully contemplate and reflect

upon their experiences in order to provide quality responses, motivating the use of the self-report, a reflective, introspective method for collecting data.

Moreover, the opportunity to consider their response to the interview guide, elicits information from the participant that is not slanted toward what the *researcher* wants to hear or investigate, but rather to hear what the *participants* wants to say in their *own* words, in their *own* voice, with *their* narrative and language. Hence, the personal nature and subsequent need for elaboration on the topic deemed the interview guide as an appropriate method of data collection for this study.

Best & Kahn (2003: 256) compare the 'interview guide approach' to the semi-structured interview format. As such, the content and sequence of the predetermined questions allows the participants flexibility of response. This format also allows for systematic data collection, allowing for increased comprehensiveness.

Three interview guides were used: one for parents, and one each for siblings older and younger than eighteen years of age. In Chapter Three these are discussed in more detail (see Addendum D). Thus, primary qualitative data was gained from the understanding, insight, perceptions, experiences and ideas of the participants, as proposed by Fulcher & Scott (2003: 89).

Self-report evidence is necessary and valuable for inquiry about human experience, although it may not always be essentially a true reflection of an experience. Due to the nature and topic of this study, many participants had to revisit a place of anxiety and discomfort, which, in effect is a *reflection* on their experience and not automatically an *accurate* account thereof. Denzin & Lincoln (2008: 12) state: "Any gaze is always filtered through the lens of language, gender, social class, race, and ethnicity... Subjects or individuals are seldom able to give full explanations of their actions or intentions; all they can offer are accounts, or stories, about what they did and why". Polkinghorne (2005: 137) confirms that translating a reflective awareness into a written (or spoken) expression may be compromised as one may struggle to find the right word to accurately express a feeling, thought or experience.

Alvesson & Skoldberg (2009: 244) affirm the inevitability of emotion on the part of both researcher and participant, especially in topics of the nature of this study. They further maintain that self-reflection and the critical self-analysis of feelings are an important part of the research process, particularly in qualitative research. This is not a question of emotional

catharsis, but of interpreting and processing one's feelings before and during the empirical and theoretical work.

For the purpose of this study individuals who could provide relevant descriptions of their experiences were willing to participate, although the researcher included all contributions, whatever their command of the language proved to be. Multiple participants, some more able to articulate their experiences than others, provided accounts from different perspectives, which allowed the researcher to compare and contrast these perspectives. Thus, in a sense it served as a kind of triangulation of the experiences, not to verify a particular account, but rather it served to deepen the understanding of the investigated experience, as suggested by Polkinghorne (2005: 140).

1.8 DATA ANALYSIS AND INTERPRETATION

According to Mouton (2003: 108), "*analysis* involves breaking up the data into manageable themes, patterns, trends and relationships". I support the notion by Charmaz (2005: 514) that data are narrative *constructions* of the original experience itself.

Concerning analysis of data, Henning (2007: 101) proposes that the true test of a competent qualitative researcher comes in the analysis of the data and Wellington (2000: 147) affirms that data analysis requires thorough, systematic and meticulous organization of accumulated material. Gay & Airasian (2000: 240) support this, and adds that the researcher has to apply the aforementioned in order to make meaning of a large volume of information (Gay & Airasian, 2000: 240).

I agree with Lichtman (2010: 195) that qualitative analysis is an extremely complex aspect of conducting qualitative research, as each researcher makes sense of their data in a different way. Data interpretation furthermore refers to developing ideas about one's findings and relating them to the literature as well as to broadened concerns and concepts, as proposed by Willig (2001: 81). The latter argument supports that there is, therefore, not a *right*, *wrong* or *better* way to make interpretations.

The process of sifting, sorting, coding, organizing and extracting remains the prerogative of the researcher, who is closest to the topic and data. Documenting the procedure, however, is of paramount importance. Holloway & Wheeler (2002: 118) caution the researcher to 'bracket' his/her views during analysis in order to prevent confusion between the views of the researcher

and those of the participants. This is supported by Cresswell (2009: 15) that clarity and salient participant contribution (experiences and views) is reinforced hereby, any prejudice by the researcher is minimized, which results in sustained transparency throughout.

All original participant contributions will be saved on computer as well as in hard copy format, as Lichtman (2010: 59) reminds us, that data which is summarized becomes new data, which is why original raw data must remain available for perusal. The Content Analysis Steps as suggested by Colaizzi (1978: 48-67) will be used in this study to analyze the self reports.

Swann & Pratt (2003: 116) postulate that data analysis and interpretation necessitates more than merely providing answers to the research questions. It also assesses the trustworthiness of the data and the findings under the following criteria:

1.8.1 Validity and Trustworthiness of the study

- **Validity**

In any research the question of validity and reliability is imperative. I believe that one of the most controversial areas surrounding qualitative research is how to evaluate what you read. This presents a dichotomy in the arising question of *who* comprises the actual *expert* in this study: the academic community, the educational community, the medical community, or none of the above. Although therapists and medical practitioners do have particular expertise and experience to share, it is my firm belief that parents (and siblings) are the uncontested experts on their children. This is the community of persons who have indeed, 'walked the walk', more than qualifying their opinion and experience.

Many researchers have developed their own concepts of validity, and have either generated or adopted their own terminology of appropriate terms such as rigor, quality and trustworthiness according to Davies & Dodd (2002: 282) and Stenbacka (2001: 553).

So, too, there are many diverse opinions about validity and reliability in qualitative research. Lincoln & Guba (1985: 294) suggest that the researcher tests the adequate representation of multiple realities by using *credibility* as the test. McMillan & Schumacher (2001: 157) propose that it's equivalent, internal validity (truth value) traditionally describes how accurately reality is depicted in the findings. To increase the validity of the results of this study, a peer check will be done.

- **Trustworthiness**

Mertler (2006: 88) refers to trustworthiness in terms of accuracy and believability of the raw data compiled in the collection process, while Conrad & Serlin (2006: 410) argue that it fulfils a validating function. To substantiate this statement, Lichtman (2010: 224) supports that those studied in qualitative research are real people, with real feelings, ambitions, needs, fears and desires. Each setting, set of circumstances, experience and perception in this study is unique and cannot automatically describe another, although it may be possible to apply it to similar contexts (Cresswell, 2009: 182). Whilst the concept of consistency is encompassed in correlation with similar studies, it is important to remain aware of the individuality and uniqueness in a study involving personal human situations, such as this study.

1.9 ETHICAL CONSIDERATIONS

Struwig & Stead (2004: 66) view research as an ethical enterprise. During both the planning and execution of qualitative research, the researcher endorsed and adhered to ethical measures in a morally sound manner as described by Creswell (2003: 64-67), upholding the code of ethics pertaining to honesty, fairness and respect toward participants with no attempts at misleading or deceit of participants or readers of the study.

The rights and dignity of participants in relation to anonymity, privacy, confidentiality and autonomy were respected and it is my sincere desire that this research project benefit those participating in it, as suggested by Struwig & Stead (2004: 66).

According to the suggestions by Mouton (2003: 243) regarding rights of participants, the researcher adhered as follows: Participants were informed that participation was voluntary and they had every right to withdraw from the process at any time; written informed consent was requested prior to participation; information regarding the study and their involvement was provided beforehand; at all times the researcher was being mindful of cultural and individual differences among people, i.e. age, gender, race, ethnicity, religion, language and socio-economic status and avoided any knowing discrimination against participants on these grounds.

As honesty and integrity are characteristics that I hold in high esteem, I adhered to all the ethical rules and regulations as stipulated by Nelson Mandela Metropolitan University.

1.10 STUDY OUTLINE

This study consists of five chapters, divided as follows:

This study commences with the introduction and rationale in *Chapter One*. Incorporated in this chapter of the empirical study, is the background, problem statement, research design, research procedures and chapter outline. It includes the formulated research questions and objectives and in conclusion provides an outline of research methods to be implemented later.

Chapters Two and Three focus exclusively on information pertaining to DS per se. As the research topic called for a two-fold literature study – the etiology of DS on the one hand and the various facets of family dynamics on the other – the decision was taken to divide the literature study into two chapters. Chapter Two comprises solely of the etiology of DS, including aspects such as prevalence, incidence, characteristics, associated features and outcomes.

Chapter Three imparts the theoretical perspectives in a comprehensive literature study on the impact that a child and sibling with DS has on the family dynamic. Having a child with DS is likened to planning a trip to Italy, but being dropped off in Holland. Planning a voyage encompasses travel itineraries, shared roles of family members, and tips for successful travel. The never-ending pain that accompanies the altered itinerary is an adjustment that impacts the whole family dynamic. Are there *more* or *less* benefits in visiting Italy or Holland, and, more importantly, which outweighs which? Such “relocation” requires the family to learn new languages, establish new friendships and appreciate the value of their change in plans.

Chapter Three incorporates aspects of family dynamics such as intra-personal functioning of family members, inter-personal relationships and the process leading to acceptance, coping and function. It will further provide insight into the “sink-or-swim” scenario of families who have a member with DS and how they incorporate their ability to sink, use their life-jacket, or simply focus on the shore and swim. (*And anyway, Holland offers tulips, Rembrandts, succulent strawberries and care-free bicycle rides...*)

The research design and methodology undertaken in this study is provided in *Chapter Four*. Due to the comprehensiveness of the preceding two chapters, the decision was taken to start this chapter with an introduction that would place this study within a specific theoretical framework and philosophical paradigm before unpacking the research design and

methodology. Although I understand that this is not usual practice, I felt that this fitted better with the current chapter. Chapter Four, therefore, includes an in-depth description of the theoretical framework supporting the research design and methodology to answer the research questions, provides a discussion of the criteria of reliability and validity which govern research and incorporates the ethical considerations that shape this study. A qualitative research paradigm was undertaken, involving the opinions, experiences and perceptions of a selected purposeful participant sample in particular categories. Detailed information on the sampling determination and data collection concludes this chapter.

Chapter Five offers the data analysis and interpretation. The wide scope and nature of this narrative combined with the personal and intimate nature of this study necessitated a purposeful flow of literature, findings, interpretation and implication. Therefore certain aspects pertaining to implication may be detected in this chapter.

The recommendations of the findings are conveyed in *Chapter Six*. On a practical level, a “map” is provided to get parents and siblings from “here to there”. This chapter includes a brief outline of the limitations of the study. Further research topics, which might be studied in greater depth in future, are considered.

1.11 CONCLUSION

Chapter One provides the rationale for this study as well as the appropriate research design, procedures and overall study outline.

There has been growing recognition that the experience of parenting a differently-abled child is a paradox filled with conflicting emotions. Lam & Mackenzie (2002: 235) proffer that parents experience not only pain, despair, suffering and sorrow, but also joy, hope, happiness and optimism. Van Riper (2007: 117) concedes that the ability of a parent to embrace this paradox may ultimately enhance parental and family adaptation.

Not every juggler is equally adept at keeping the balls of life in the air at once, which is hardly surprising, given that parenting a differently abled child alongside typically developing siblings is a balancing act of the highest order. For some families mere survival is in itself a triumph. For people such as these, empowerment might simply be the ability to cope with today a little better than they did yesterday (Dowling *et al.*, 2004: 108).

Chapter Two will expound theoretical perspectives on DS to bring the reader to a better understanding of what DS is and how it affects individuals born with a specific extra chromosome.

CHAPTER TWO

THE ETIOLOGY OF DOWN SYNDROME

2.1 INTRODUCTION

The topic of this study revolves around the impact on the family dynamic of having a child and sibling with Down syndrome (DS), thus calling for a two-fold literature study: the etiology of DS on the one hand and the various facets of family dynamics on the other. I have therefore chosen to separate the literature study, focusing purely on the nature of DS in Chapter Two, whilst issues pertaining to family perspectives, family dynamics and coping related to DS will be covered in Chapter Three.

This chapter begins by exploring the historical development of DS, etiological factors and aspects such as incidence, prevalence, diagnosis, outcomes as well as general associated features and characteristics of persons with DS. The purpose of chapters two and three are to provide the reader with the contextual theoretical background and scientific research that informs the goals of this study and guides the exploration of the research problem outlined in chapter one. The understanding of the full complexity of DS and its profound impact on the individual, the family and the family dynamics motivated me to present this relevant information pertaining to DS as a separate literature study.

The birth of a child with DS has the potential to have many effects on the family. Conversely, the manner in which individual family members and the family as a whole respond to this situation has the capacity to have a profound impact each of the role players, not just with the diagnosis and/or birth of the child with DS, but throughout every stage and phase of development into adulthood and beyond. For the purpose of this study I have not demarcated a specific time-frame or age-span, and although reference is made to adulthood, the focus remains primarily on the childhood and the situation which involves simultaneous rearing of typically developing children and a sibling with DS.

Hodapp (2007: 279) verifies that much of the early research related to raising a child with a developmental disability focused predominantly upon pathology and dysfunction, with countless methodologies attempting to confirm 'maladjustment' and the notion that a family with a *child* who has a disability is a *family* with a disability. For the longest time researchers equated increased *demands* faced by these families with the *potential stress and strain* that these

demands may create, thus the persisting notion that most families with disabilities are not well-adjusted and/or risking collapse as a unit.

There was however a shift during the 1980's, as research findings suggested that couples who had children with developmental disabilities, such as DS, more often than not reported strong, mutually rewarding marriages, that they developed innovative ways to cope with higher caregiving demands, and that their typically developing children were generally well-adjusted (Abery, 2006: 18-19). Van Riper (2007: 117) verifies this gradual shift in recent research efforts from a focus on dysfunction to a focus on family strengths and resilience, with positive outcomes reported by many families of children with developmental disabilities, such as DS. Hodapp (2007: 280) concurs with this change in negative perception, confirming a definite move toward a stress-and-coping perspective.

Related to the aforementioned, I was intrigued by *why* some families seemed to come together and others appeared to fall apart. My involvement with families of children with DS has exposed me to a vastly diverse base of individuals, which strategically positioned me to observe unobtrusive tension within some marital relationships yet a strong sense of synergy in others. Being a mother, a supporter and an educator further compelled my natural curiosity to undertake family focused research on a subject close to my heart: Down syndrome.

DS is rather unique among the 750 to 1000 genetic-chromosomal disorders leading to intellectual disabilities. As alone among these disorders, DS features a research history that dates from the 1860's onward. Being the most common genetic cause of intellectual disability, this syndrome continues to serve in countless studies as the 'control' or 'contrast' group for those studying other disability conditions (Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney, 2009: 178).

In order to provide a better understanding of the syndrome, this chapter provides a comprehensive overview of the nature of DS, exploring etiological and related factors such as incidence, prevalence, diagnosis, characteristics, co-morbid disorders, life-expectancy and primary features.

Many great scientists and medical professionals daily dedicate their lives to research and development in the field of DS. Inevitably, every city in every country produces unsung heroes. Of the multitude of committed individuals who undauntedly pursue formidable tasks, at this juncture, further reference to any individual would be unjust. As a parent, I salute the many

men and women who tirelessly research and report on concerns ranging from genetics, medical intervention and health issues, to the vast spectrum of early intervention, communication, inclusive education, relationships and parenting issues.

Professor Lejeune and Dr. Langdon Down are regarded as the pre-eminent contributors to our present understanding of DS. Not only did their research involve much of their personal time and resources, but their indefatigable advocacy on behalf of individuals with DS and their families was my motivation to provide them with a worthy platform to enlighten and inform the reader of these pioneers and their research.

Generally little more than their names are known to most people, even those who deal with DS on a daily basis.

2.2 HISTORICAL BACKGROUND

- **The Role Of Dr. John Langdon Down (1828 – 1896)**

“In a remote part of the country on an alfresco picnic...driven by stress of weather into a cottage on the coast, I was brought into contact with a feeble minded girl, who waited on our party, and for whom the question haunted me – could nothing for her be done? I had then not entered on a medical student’s career, but even and anon the remembrance of that hapless girl presented itself to me and I longed to do something for her kind”. Thus recalls John Langdon Down in a public address 1879 (Ward, 2008: 10).

Little over a decade before, in 1866, John Langdon Down first identified a recognizable syndrome among people that we now refer to as having a learning disability, Down syndrome. His description of the syndrome as ‘Mongolian Idiocy’ was merely a reflection of the language used in Victorian England at the time. His observations regarding the physical characteristics of his patients and their similarity to the facial features of the people from the Mongolian race, led to the common use of the term ‘Mongol’ to describe the condition that we now refer to as ‘Down syndrome’.

Langdon Down, born in the village of Torpoint in Cornwall, was a brilliant man. He was taken out of school at age fourteen to help in his father’s grocery shop. At eighteen he had a personal experience which was to change his life (which he refers to in the introductory quote). A summer downpour drove the family to shelter in a cottage where they were politely offered

tea. The girl who served them had DS and this serendipitous meet inspired Langdon Down's resolve to make the care of similarly affected people his life's work.

As his father's shop also supplied pharmacy items, Langdon Down was sent to qualify as a pharmacist in order to expand that side of the business. A brilliant scholar, he was given a coveted position in the Pharmaceutical Society as laboratory assistant, and after his father's death, he went back to London to fulfil his ambition of becoming a doctor, maintaining academic excellence throughout his studies. His accelerated progress was a sign of his exceptional ability.

His life and career irrevocably changed in 1858 with his first big move to the Earlswood Asylum for Idiots where he was appointed medical superintendent (Ward, 2008: 33). Here he was appalled at the conditions of both staff and patients and he set about reorganizing and restructuring Earlswood in terms of staff recruitment, patient treatment, rules, meals and mealtimes, supervision, physical development, educational status, religious instruction, vocational training and on-site workshops. He endeavoured to prepare young people for life in the outside world.

At Earlswood he studied his patients carefully and noted what no-one had seen before. He believed passionately that people with learning disabilities had real potential and he realized that they were different from other patients with mental health problems. Langdon Down had served Earlswood well for twenty one years, but the Board objected to the work of his wife, Mary, who was running an independent disability outreach training program. This set in motion a life-altering journey for the Langdon Downs and many others as they set about creating an environment in which his patients could be educated and develop to the best of their abilities. These individuals were given dignity as the Langdon Downs cared for them and brought them into their family home at Normansfield (Ward, 2008: 109-114).

John and Mary produced four children. They lost their eldest son and only daughter, but his sons Reginald and Percival, and later a grandson and granddaughter carried on Langdon Down's work after his death. Reginald's main contribution to medical science was the identification of the abnormal palmer crease in persons with DS, although he also pursued the field of learning disability. Percival had two children, Norman and Molly (Ward, 2008).

Norman qualified in medicine, specializing in psychiatry and was later the last Langdon Down

Medical Superintendent of Normansfield. Molly also took up psychiatry and worked for Normansfield for over ten years (Ward, 2008).

John Langdon Down, whose driving force was his strong religious conviction, was a remarkable man, who freely gave of himself and his services to many medical charities. He was one of the outstanding doctors of his time and in due course became rich and famous, a figure of society. He was recognized as a sympathetic and empathetic man and clinical notes referred frequently to his being in attendance at the deathbed of patients (Ward, 2008).

In a fitting tribute, a family friend remarked, “Dr Down had not been able to make the blind see or the deaf hear, but he had been able to throw light upon slumbering intellects, and to bring forth from the darkness to which they seemed to be doomed, the lights of intelligence. That was no mean benefit to all humanity, because in doing that he had taught others to do the like, and from all parts of the world, most eminent members of his profession had come to learn how they could treat similar cases...” (Ward, 2008: 152).

John Langdon Down died in 1896. He was never to meet or know his namesake grandson, John, son of Reginald Langdon Down, a little boy *with an extra chromosome...* John Langdon Down, Jnr, by an ironic twist of fate, had Down syndrome.

- **The Contribution Of Professor Jerome Lejeune (1926 – 1994)**

*“The merciful quickly grasp the truth in their neighbours when their heart goes out to them with a love that unites them so closely that they feel the neighbours’ good and ill as if it were their own. With the weak they are weak, with the scandalized they are on fire. They ‘rejoice with those who rejoice and weep with those who weep’ (Romans 12:15). Their hearts are made more clear-sighted by love and they experience the delight of contemplating truth, not now in others but in itself, and for love of it they bear their neighbours’ sorrows” – St. Bernard of Clairvaux, *The Steps of Humility and Pride*, sums up Jerome Lejeune’s life-long work for those with disability (Bamberger, 2002).*

Jerome Lejeune became the youngest professor of medicine in France when in 1964, aged thirty eight; he assumed the country’s first professorship in fundamental genetics. His meteoric ascent was hastened by his discovery, in 1959, of the chromosomal basis for DS, ushering in the modern era of research into genetic disease, and abolishing the stigma of an illness that

had previously been attributed to syphilis. In an intimate memoir by a loving daughter, Clara Lejeune describes how the scientific genius of this merciful and loving family man, was rooted in his habits of “contemplation and wonder, seeking untiringly for the why and how” (Lejeune, 2001).

His love for the mentally and physically disabled patients inspired brilliant scientific research, but more importantly, it engendered an unwavering commitment to these “disinherited”, as he called them. “Disinherited because their genetic inheritance was not perfect. Disinherited because they were unloved members of this competitive, glamorous society” (Lejeune, 2001). When Lejeune became united with the disinherited, he found himself opposed to a society that valued perfection and convenience over the right of a person to live.

Lejeune’s scientific discoveries had, along with the newfound ability to perform amniocentesis, allowed physicians to diagnose DS in foetuses, which combined with legislation on abortion, paved the way for millions of foetuses to be selected and killed based on their disability. In 1972, Jerome Lejeune stood against this atrocity when, on the floor of the United Nations he publicly elaborated, for the first time in history, the genetic principals that confirm the completeness and integrity of human life from the moment of conception. His daughter writes, “He knew, and had proved it many a time, that in the first cell, from the very first day, the genetic patrimony is written in it entirely... Because every human being is unique, because he has an identity from the first day of his existence, because he is a member of our species, his life must be respected. The true physician does not have a choice” (Lejeune, 2001).

In the years following his affirmation, he was banned from society, shunned by his friends, humiliated, crucified by the press, and prevented from working for lack of funding. He did, however, find solace in a small league of sympathetic friends, and maintained his academic reputation and research support in the international community. He remained in his hostile homeland, driven by devotion to his patients, both born and unborn, and campaigned tirelessly for their protection under the law and throughout society. Lejeune established houses of hospitality for otherwise unsupported mothers, named Tom Thumb Houses, after the foetuses that he cared for so deeply (Lejeune, 2001).

In 1974, Pope John Paul II appointed Professor Lejeune to the Pontifical Academy of Sciences, and in 1994 made him the first president of the Pontifical Academy of Life, a position he held for only thirty-three days before succumbing to lung cancer on Easter morning in 1994 (Lejeune, 2001).

In the early 1950's new scientific methods were discovered that could depict chromosomes in modern ways, and so in 1956, the 46 chromosomes within each human cell were discovered. Lejeune and his colleagues first identified a chromosomal disorder, an additional 47th chromosome, which we know today as Down syndrome. His scientific findings brought about a new understanding of DS, providing opportunities to show that these individuals could indeed achieve despite their innate learning barriers and the disadvantage of the ignorance of others. Not only did his work result in a stronger move toward inclusion, but also the beginnings of a paradigm shift toward persons with DS and their abilities (Lejeune, 2001).

He pursued the truth without fear and maintained his course without hesitation. Throughout his life he fought tooth and nail, mind and heart, to alleviate the suffering of his patients, both as their physician and advocate. At the very end, in the clutches of death, he wrote to a friend, "Just when it is imperative to defend the embryos...I am out of breath. For the moment, faithful to the Roman legionary's motto, '*Et si fellitur de gnu pugnat,*' I write 'And if he should fall, he fights on his knees.'" Jerome Lejeune valiantly opposed a hostile society in pursuit of the truth, and "for love of it, he bore his neighbour's sorrows" (Lejeune, 2001).

2.3 THE ETIOLOGY OF DOWN SYNDROME

Scientific research in the field of genetics, contribute largely to our current understanding of DS. Defining the following terminology may assist in adequately explaining the role of genetics.

2.3.1 Clarification of Terms

- **DNA** (Deoxyribonucleic Acid)

Scientists refer to DNA as being one of the secrets to life itself. It is composed of nucleic acids linked with sugars, capable of forming very long chains. It has the ability to produce and replicate itself. It appears in human cells as a double stranded helix spiral, and is usually concentrated in the cell nucleus (National Library of Medicine, 2010)

- **Cell Division**

Every person inherits 23 chromosomes from each parent, which come from the egg and sperm cells. At conception they produce a cell with 46 chromosomes. Human cells divide in two ways, the first being ordinary cell division (mitosis), by which the body grows. In this method, one cell becomes two cells which have the exact same number and type of chromosomes as the parent cell. The second method of cell division occurs in the ovaries and testicles and is known as meiosis. It consists of one cell splitting into two, with the resulting cells having half the number of chromosomes of the parent cell. Numerous errors may occur during cell division. In meiosis, the pairs of chromosomes are supposed to split up and go to different spots in the dividing cell, which is known as "disjunction." However, occasionally one pair does not divide, and the whole pair locates in one spot. This means that in the resulting cells, one will have 24 chromosomes and the other will have 22 chromosomes, which is referred to as "nondisjunction." In the case of a sperm or egg with an abnormal number of chromosomes merging with a normal mate, the resulting fertilized egg will have an abnormal number of chromosomes. In Down syndrome, 95% of all cases are caused by this event: one cell has two 21st chromosomes instead of one, so the resulting fertilized egg has three 21st chromosomes. Hence the scientific name, trisomy 21 (Leshin, 2003).

- **Chromosomes**

Chromosomes are thread-like bodies in the nucleus (control centre) of the cell. Each chromosome is made up of two strands of DNA. Chromosomes are normally grouped together in 23 pairs, i.e. 46 in all. Half of these come from the father and half from the mother. A baby with DS has an extra number 21 chromosome, making 47 chromosomes in all (National Institute of Child Health and Human Development, 2010). (When explaining this concept to new parents, I usually say that our babies are children who *have* something extra, and therefore *need* something extra).

According to Webster's Medical Dictionary (2010), chromosomes contain the genetic code which controls and instructs cell division, growth, and function, and are the structures inside the nucleus of living cells that contain hereditary information.

- **Genes**

Chromosomes can be divided up into segments and these tiny units carry the materials of inheritance (DNA).

These determine the characteristics which we pass on to our children, i.e. height, intelligence, eye-colour, sex, blood group and so forth. Genes are thus part of the chromosomes (National Library of Medicine, 2010).

- **Karotype**

Karotyping means grouping chromosomes into pairs for examination and diagnosis. Although babies with DS have various physical characteristics which are recognizable at birth to the trained eye, the diagnosis should be confirmed by a blood sample or cell culture. This is known as a chromosome test or karotype analysis (National Library of Medicine, 2010).

2.4 WHAT IS DOWN SYNDROME?

DS is the most common genetic cause of significant intellectual disability in the human population. It is a chromosomal condition characterized by the presence of an extra copy of genetic material on the 21st chromosome, either in whole (trisomy 21) or part (such as due to translocations). To understand why DS occurs, the structure and function of the human chromosome must be understood. The human body is made of cells; all cells contain chromosomes, which are structures that transmit genetic information. Most cells of the human body contain 23 pairs of chromosomes, half of which are inherited from each parent. Only the human reproductive cells, the sperm cells in males and the ovum in females, have 23 *individual* chromosomes, not pairs. Scientists identify these chromosome pairs as the XX pair, present in females, and the XY pair, present in males, and number them 1 through 22 (Patterson, 2009).

When the reproductive cells, the sperm and ovum, combine at fertilization, the fertilized egg that results contains 23 chromosome pairs. A fertilized egg that will develop into a **female** contains chromosome pairs 1 through 22, and the XX pair. A fertilized egg that will develop into a **male** contains chromosome pairs 1 through 22, and the XY pair. When the fertilized egg contains extra material from chromosome number 21, this results in DS. Most people have normal cell structures, which are arranged in 23 chromosomal pairs, resulting in 46 chromosomes, but a person with DS has 47 chromosomes (Patterson, 2009).

All people with DS are individuals with individual talents and abilities. The effects of the extra copy vary greatly among persons with DS. The only thing they have in common is the syndrome itself. Much has been accomplished to overcome the medical conditions confronted by persons with DS, resulting in increased quality of life and life expectancy. Significant cognitive improvement has been achieved by enhancing the educational and social

opportunities of persons with DS, offering hope that additional progress is possible (Patterson, 2009).

The birth of any child is a happy and exciting occasion to be celebrated by the whole family. After the initial shock of the diagnosis, parents soon discover that the syndrome is completely secondary to the fact that their child is an individual, has exactly the same needs as every other child, and will bring them all the same joy and happiness in the world.

There is much misunderstanding about why a child may be born with DS. It is imperative that the parents understand that it is *not* the result of anything that they *did* or *did not* do. Most of the time, the occurrence of DS is due to a random event that occurred during formation of the reproductive cells, either ovum or sperm. DS is not attributed to any behavioural activity of the parents or environmental factors. It is no one's fault. DS knows no ethnic, social, socio-economic or cultural divide: it is simply a genetic chromosomal condition over which no one has any control. It is neither hereditary, nor is it a sickness or contagious, therefore it cannot be cured or controlled. The probability that another child with DS will be born in a subsequent pregnancy is about 1%, regardless of maternal age (Patterson, 2009).

Three genetic variations can cause DS as explained below:

2.4.1 The Three Types of Down syndrome

- **Trisomy 21**

About 95% of all people with DS have this particular form which is caused by the presence of an extra chromosome 21 in all cells of the person. The extra chromosome originates in the development of either the egg or sperm. Consequently, when the egg and sperm unite to form the fertilized egg, three (rather than two) chromosomes 21 are present. As the embryo develops, the extra chromosome is repeated in every cell. Parents will have normal chromosomes, but their baby has three number 21 chromosomes. This condition, in which three copies of chromosome 21 are present in all cells of the individual, is referred to as trisomy 21 (National Institute of Child Development and Health, 2010).

- **Translocation Down syndrome**

As the name suggests, this means 'movement to another location', where a segment of number 21 chromosome actually breaks off and attaches to another chromosome, (usually chromosome 14 or 15) either prior to or at conception. The person with translocation trisomy 21 will have only 46 chromosomes but will have the genetic material of 47 chromosomes. Because of the excess chromosome 21 material, the person will exhibit all the same characteristics as a person with standard trisomy 21. This type occurs in 2% to 3% of cases of DS. Translocation 21, unlike Trisomy 21, is usually inherited, and the translocated chromosome may be found in unaffected parents and siblings. In about one third of these children, either parent may carry a translocation but show no signs or symptoms, yet, karyotype analysis would show 45 chromosomes (Patterson, 2009).

- **Mosaic Down syndrome**

In 2 to 5% of people with DS, body cells have a mosaic pattern. This is the result of chromosomes having failed to split-up or separate properly. When division does not take place properly, one cell may contain 22 chromosomes and the other may contain 24 chromosomes, resulting in some cells containing 46 chromosomes and some 47. A person with mosaic DS may exhibit all, some or none of the characteristics of DS, depending on the percentage of cells carrying the extra chromosome and the tissues in which these cells are located (Patterson, 2009). It often happens that children with mosaic DS go undiagnosed at birth, since their features may be barely discernible. This may go undetected the child's whole life, which is 'first prize' for the child who has opportunity to lead an unlabelled life. Learning barriers may however occur during their academic career.

2.4.2 Developing Scientific Research

- **Scientific evidence in support of genetic influences**

According to Patterson (2009), the genetic mechanisms leading to the phenotype of DS are not yet known. Although the complete DNA sequence of most of chromosome 21 is known, scientists are still not familiar with all the protein producing genes on chromosome 21. In addition, recent advances in genetics indicate that regions of chromosome 21 that do not lead to production of proteins may be important for DS (Patterson, 2009).

Yet, due to its recognizable physical features and characteristics, DS continues to receive widespread attention in medical, educational and social research and literature.

The genetic influences that play a role in the etiology of DS are considered in the section below.

- **Scientific evidence in support of maternal age**

A number of researchers have attributed the incidence of DS to higher maternal age (Patterson, 2009; Malini & Ramachandra, 2006). However, of the total population, older mothers have fewer babies. It is estimated that about 75% of babies with DS are born to younger women because more often younger women than older women have babies. Only about 9% of total pregnancies occur in women 35 years or older each year, but about 25% of babies with DS are born to women in this age group (National Institute of Health, 2010).

Due to the rise in incidence of DS with increasing maternal age, many specialists recommend that women who become pregnant at age 35 (or older) undergo prenatal testing for DS. The likelihood of a woman under 30 having a baby with DS is less than 1 in 1,000, yet the odds increase to 1 in 400 for women who become pregnant at age 35. The likelihood of DS rises according to maternal age, thus by age 42, the chance is 1 in 60 to have a baby with DS, and by age 49, the chance is 1 in 12 (Patterson, 2009).

Female meiosis, much more than male meiosis, is error-prone and according to Garcia-Cruz, Roig & Garcia Caldes (2009: 128) this flaw increases exponentially with age. The increasing maternal age leads to an increase in the number of cells with an abnormal number of chromosomes, as the chiasmata formation reduces with age. Chiasmata refers to a point of contact between chromosomes during meiosis where two chromatids interchange, i.e. the actual break of the phosphodiester bond during crossing over. The larger the number of map units between the genes, the more crossing over occurs, enhancing the likelihood of genetic material to split off in an abnormal way (Carlson, 2004).

Despite this finding, approximately half the mothers who give birth to children with DS are younger than 35 years old. Personally, I can bear witness that most of the mothers whom I have met and mentored, have been younger than 35 years of age. Most of these women have, in fact, been under the age of 30.

A recent genetic study conducted in India, concluded that increasingly young mothers rather than older mothers are giving birth to children with DS. Results showed that young age mothers (18 – 29 years) born to their mothers at the age of 30 and older produced as much as 91.3% of the children born with DS. This suggests that the effect of the maternal grandmother has, as yet, been underestimated. Malini & Ramachandra (2006) hypothesize that for every year of advancement of the maternal grandmother, the odds of giving birth to a child with DS increases by 30%. Although this outcome is disconcerting, more research will have to be undertaken before conclusive results can be derived.

- **Scientific support of paternal age**

Although the effect of maternal age as a risk factor for DS is well known, the role of paternal age as a contributor of DS has not been clearly established due to limited scientific evidence. Christianson, Howson & Modell (2006) refer to research findings published in 1996 by The World Health Organization suggesting that the risk significantly increases with increasing paternal age (Dzurova & Pikhart, 2005). Christianson, *et al.*(2006) propose that age of the father is not as significant as the age of the mother, confirming that research has shown that in only 20 to 25% of all cases, do the fathers contribute the extra chromosome.

However, Warner (2003) informs us that older fathers contribute just as much as older mothers to the dramatic increase in DS risk faced by babies born to older couples. Warner (2003) refers to a new study that found older fathers to be responsible for up to 50% of the rise in DS risk when the mother was also over forty.

Fisch (Warner, 2003) confirms paternal age indeed has an effect on DS but only in cases of the mother being than thirty five years. No effect was recorded if the mother was younger. Warner (2003) verifies that there is only a modest increase in DS risk for women aged 35 to 39 compared with women aged 30 to 35 years old. Yet the dramatic increase in DS births among women aged 35 to 39 is largely due to the influence of older fathers as older women tend to have babies with older men. Although more research is needed to confirm these findings, researchers caution that the father's age should not be ignored in family planning.

2.4.3 Current Scientific Limitations on the Etiology of Down syndrome

Although DS is the genetic disorder which is most researched and widely documented, the

exact causes thereof still elude scientists and researchers. Medical scientists work tirelessly on the identification of the numerous genes, influences on these genes and the determination thereof. Developing theoretical discourses have come to the fore suggesting factors why some mothers conceive babies with DS and others do not.

The first of these discourses pertain to environmental factors, and the second is the discourse of inherent vulnerability factors and their possible prevention (DSSA, 2010).

- **The discourse of environmental factors**

Although DS is a genetic disorder which happens at the moment of conception, it stands to reason that environmental factors such as X-rays, chemicals and air-borne viruses may have an influence on chromosomes. Chromosomal abnormalities can involve the loss, gain, or exchange of genetic material from a chromosome pair. Such abnormalities often cause miscarriages, but may occasionally result in a baby with some kind of disability, such as DS.

Although the hazards of radiation are not fully understood, it is clear that radiation can have a wide range of effects on unborn children, including death, malformation, brain damage, increased susceptibility to certain forms of cancer, shortened life span, and various mutations. Radiation that occurs between the time of fertilization and the time when the ovum becomes implanted in the uterus is thought to destroy the fertilized ovum in almost every case. Although as yet unproven, men working in radiation exposing environments may suffer abnormalities of the first and second paternal meiotic division. Bearing in mind that the male body produces sperm throughout his life, this supposition may require further investigation in future to either support or oppose this hypothesis (Association for Health and Environmental Development, 2010: 43).

- **The discourse of inherent vulnerability factors and prevention thereof**

In an attempt to provide preventative measures for DS, scientists constantly search around the identification of genes. Christianson *et al.* (2006) believe that a decrease in DS of paternal origin would not be statistically significant in impacting the decrease in global incidence of DS cases. Genetic counselling, as the current only alternative in terms of effective prevention, is suggested by Christianson *et al.* (2006). Medical practitioners are in a position to render appropriate counselling and decision making tools for parents to better equip and prepare themselves if a pre-natal diagnosis of DS has been made.

The following section provides an understanding of the impact of DS.

2.5 INCIDENCE, PREVALENCE AND LIFE EXPECTANCY

The term 'incidence' refers to the number of live births and 'prevalence' refers to the number of babies surviving. Generally, a pregnancy involving an abnormal foetus will miscarry. A foetus showing a reduced number of chromosomes cannot survive, as the effect on the growing metabolism is too great (Patterson, 2009).

The effect of hyperploidy (too many) of the larger chromosomes also results in foetal elimination. Yet hyperploidy of the smaller chromosomes has a lesser effect and is compatible with survival. As chromosome 21 is one of the smallest chromosomes, the DS foetus has such a strong ability to survive. DS, as the commonest form of chromosome abnormality, is also the commonest recognizable form of intellectual disability (Patterson, 2009).

2.5.1 Incidence

Ascertaining accurate figures of DS are problematic, as not all cases are reported. Research in South Africa suggests that one in 550 children born has DS, while one in 750 to 800 is born worldwide (DSSA, 2004). March of Dimes Global Report names DS as the fourth of five most common serious birth defects of genetic origin in 2001, totalling 217 293 globally of an estimated 7.9 million children born annually (Christianson *et al.*, 2006). About 3.3 million children under the age of five die each year from birth defects (Christianson *et al.*, 2006). It is estimated that one in every 800 to 1000 live births in both the United States and the United Kingdom is a child with DS. The average figure is based on one in every 1000 live births in developed countries, and one in every 650 live births in developing countries (DSSA, 2010). South Africa is relatively high at 2.1 per 1000 live births, making its incidence approximately double that of high income countries such as the USA and UK (Christianson *et al.*, 2006).

2.5.2 Prevalence

Due to the inability and neglect in diagnosing DS in newborns in many hospitals, as well as the pervading stigmatization in many ethnic groups, it is difficult to accurately estimate the number of individuals with DS in South Africa, yet despite urging by DSSA, no studies have been undertaken in this regard (DSSA, 2010). An independent study conducted in the Limpopo

Province indicated that 65% of affected children died by age of two (Woods, 2004). Figures may be high in these areas due to lack of support and information, especially regarding serious health and cardiac issues, whilst it would possibly be lower in more developed areas (Woods, 2004).

Individuals with DS are from all races, religions, ethnic backgrounds and socio economic status. Researchers have attributed the prevalence of DS decrease in high resource countries to family planning, comprehensive information concerning age-related risks, antenatal screening, prenatal diagnosis and selective abortion (Christianson & Modell, 2004: 220). They found that DS is considered rare in middle and low income countries, especially in Africa, although this may be attributed to factors such as diagnostic oversight, ignorance of home-birth mothers, high mortality rate and low life expectancy, rather than low birth prevalence per se.

2.5.3 Life Expectancy

The life expectancy of persons with DS, as with anyone else, is related to factors including health issues, access and level of medical treatment, mental wellness, nutrition and lifestyle, level of physical activity, integration and interaction in their community. Izquierdo & Townsend (2003) reported accelerated aging and shortened life expectancy in their patients with DS, compared with that of the general population. Although they estimate the median age at 49 years, a number of their patients with DS have been older than 60 years. They further cite congenital heart disease as the major cause for early mortality in persons with DS, as well as an increased susceptibility to infections (including recurrent respiratory infections), epilepsy, intestinal obstruction, and acute myelocytic leukaemia. In previous decades, treatment for persons with DS who had congenital heart disease and digestive systems problems, was restricted, if at all available.

Despite this, research has shown that life expectancy for persons with DS has increased in recent decades from approximately 9 years in 1929, to approximately 50% of the population surviving up to 60 years and beyond in recent decades. Bittles & Glasson (2004: 282) further propose that DS is the sole genetic condition in which life-spans have doubled over the past 30 years.

Contributing to the improvement of the life and future of individuals with DS may include advances in medical knowledge and care, the prevalence of children with DS being raised at

home instead of in the institutions of past generations, changing attitudes and educational and social inclusion. Future early interventions, therapies and relevant treatments may further maximize the potential of individuals with DS, further enhancing their life and life expectancy. Research and personal experience have proven that the more normal the lifestyle of the developing child with DS, the more opportunities exist for societal success in all dimensions of functioning.

Permit me to share personal experience regarding life expectancy and outcomes. A number of years ago I 'adopted' four adult orphans with DS, resident in a local 'home' for individuals with physical and intellectual impairment in Port Elizabeth. The humble yet homely accommodation consists of free-standing units, each comprising a number of bedrooms (for single or double accommodation), two shared bathrooms, a kitchenette and communal lounge area. Larger communal TV rooms, recreation halls, diners and benched garden areas serve each cluster of units. Although personal touches to all areas provide individuality, it constitutes a 'segregated'-style living arrangement, complete with workshops, working farmyard and dairy on the premises. The sad reality for my wards is that this is the only home they have known since they were 'delivered' there (sometimes by parents, sometimes by strangers) from the school benches of the local special needs school. If not for the remarkable love and care of staff who took on the role of primary caregivers for these individuals, one shudders to think what their circumstances and life expectancy would have been.

My 'children' are respectively 52, 54, 55 and 67 years old. The precious 67 year old is as bright as a pin, always ready to tell a joke or go for a stroll. All of 1.3m tall in stature, she stands her ground in her size one health shoes. She has lived here on her own, with no visitors and intermittent contact with her only remaining relative (a sister who is a retired advocate in Cape Town and avoids contact as far as possible). This is where she was left, belongings in one hand, at the tender age of 18, with her bright blue eyes, quirky smile and sharp brain, she was born six decades too early. But she is seemingly content with her life and her living arrangements. This is what she knows. She belongs and she is loved. *This* is her life behind the cerise pink bougainvillea-thicket fence of social isolation.

The male in my group, an immaculate, bald gnome-like figure who, at 54, has never been taught to speak, is her 'special friend'. They sometimes hold hands when they walk; watch TV together; provide solace to each and share cake and laughs and napkins at tea-time. I can take my 'children' anywhere: they have impeccable table manners and an equally strong sense for

great chocolate cake and adventure! Their families placed a ceiling on their life expectations when they were left there. Yet they live 'full' lives within the boundaries of their situation and, undoubtedly, they have positively contributed to mine and my family's lives in ways they can never comprehend.

2.6 DIAGNOSIS OF DOWN SYNDROME

Although women at increased risk of giving birth to a child with DS have the option of prenatal screening (biochemical screening and ultrasound scanning), the choice to terminate the pregnancy remains their decision. Down syndrome South Africa's position on this highly controversial issue is to provide parents with neutral, balanced, accurate advice regarding DS, but to leave the decision up to them (DSSA, 2010). Herein, however, lays the dichotomy: is a neutral stance not, in fact, contradictory to the rights of children with DS? How can one fight for their right to be included in schools and society, yet be hesitant on their right to life? This remains a debatable question.

Research results show that African women are not generally familiar with DS and are therefore oblivious to the risks to women of advanced maternal age (AMA) having a baby with DS. Furthermore, many African women of AMA are not being offered genetic counselling and prenatal diagnosis (Schön, 2004). These findings illuminate the need for increased awareness of prenatal screening and diagnostic services, not only to prospective mothers, but also to the public in general. Genetic counselling for DS aims to inform individuals and families of the nature and cause of the syndrome, its prognosis and treatment and the probability of having children with DS in future pregnancies, with the option of available risk reduction and prevention.

Detecting DS in a foetus is a two-fold process, involving firstly a screening test for risk and secondly a diagnostic test to verify the prognosis.

2.6.1 Screening Methods and Diagnostic Tests

There are several ways of detecting high-risk pregnancies. Doctors either measure the mother's *blood levels* for certain proteins and hormones, or they use ultrasound. Since the 1980's, screening measures have become more accurate and safer through improved ultrasound definition according to Christianson & Modell (2004). Different symptoms of DS can

be detected by this scan, such as so-called nuchal translucency i.e. the thickness of a layer of fluid that forms near the neck of a developing foetus; incurved little fingers; particularly small feet with a larger than usual space between the first and second toe ('sandal-toe'); and congenital heart defects (DSSA, 2010).

- **Amniocentesis**

Cytogenic analysis, better known as *amniocentesis*, became the commonest test for DS in the mid 1960's. It involves the extraction of foetus cells from the amniotic fluid being analyzed for karyotyping. A positive result clearly shows the extra chromosome 21 (DSSA, 2010). This type of testing has to be done after the 12th and before the 17th to 18th week of gestation and although there is a small risk of foetal loss, the trauma to the foetus may be rather significant (DSSA, 2010).

As my conviction is pro life, it is my opinion that, unless the mother is convinced and determined to abort a foetus upon positive diagnosis, this test is unnecessarily traumatic for mother, father and baby. The waiting period for results is a gut-wrenching six weeks. I personally do not consider DS a reason for termination, as, in my experience, individuals with DS *can*, and *do* lead full and rewarding lives and make a valuable contribution to their families and society. However, basic human rights dictate that parents are entitled to make their decision, based on non-directive, accurate information that is right for them. It is recommended, though, that appropriate support be sought regardless of the resulting decisions taken.

- **Chorionic-villus sampling (CVS)**

This test, which involves the analysis of placental cells for chromosomal abnormality, is conducted at 9 to 11 weeks of gestation and the chorionic villi tissue sample is obtained through the mother's abdomen or cervix, carrying a 1 to 2% risk of miscarriage (National Institute of Child Health and Human Development, 2010).

- **Nuchal Translucency Test**

This test can be done from between eleven and fourteen weeks of gestation and involves an ultrasound measuring the space at the back of the foetus' neck for excessive fluid. The detection rate of this test is 80% (DSSA, 2010).

- **Percutaneous Umbilical Blood Sampling (PUBS)**

According to the National Institute of Child Health and Human Development (2010) this is the most accurate method and can be used to verify the results of CVS or amniocentesis. However, this test cannot be performed until later in the pregnancy (18th to 22nd weeks of gestation) and therefore carries the greatest risk of miscarriage.

2.6.2 Diagnostic Challenges

Combining results from both first and second trimester tests may be a more accurate method of identifying fetuses at high risk for DS. This would also reduce the number of invasive tests performed, thus minimizing the risk of miscarriage of a healthy fetus. The 'Holy Grail' for DS is a non-invasive diagnostic test that does not threaten the fetus (DSSA, 2010).

Given my AMA (I was aged 43 when my daughter was conceived), my gynaecologist suggested the relevant tests. When negative results returned, I opted not to undergo an amniocentesis. Apart from the risk factor, termination would never be an option. It does, however go to show that, despite its accuracy, tests are fallible.

In keeping with continuous research, researchers are currently investigating ways to locate and screen the limited number of foetal cells that float through the mother's blood stream. These cells are extremely rare, which impedes such facilitation. A new method of diagnosis, called pre-implantation diagnosis, which allows clinicians to detect chromosome imbalances before an embryo is implanted during in vitro fertilization is primarily used in couples who are at risk of passing on X-linked disorders or who have suffered repeated terminations. This allows the couple to begin their pregnancy knowing that the fetus is unaffected with the genetic disease of concern and provides an alternative to prenatal testing and termination in subsequent trimesters (National Institute of Child Health and Human Development, 2010).

In especially rural parts of developing countries, access to medical care, medical research and screening procedures are difficult, and frequently DS and other disorders go completely undetected, not just during gestation, but also after birth (Christianson & Modell, 2004: 260). This diagnostic failure prevents medical checks, treatments and care, resulting in minimal chance of survival, hence fewer adults with DS existing in developing countries (Christianson & Modell, 2004: 260).

2.7 PRIMARY FEATURES OF DOWN SYNDROME

A number of signs and symptoms may identify DS in a newborn infant to medical staff. Whilst the physical characteristics listed below are commonly seen in DS, it is important to bear the following in mind:

- the number of signs present or absent are no indication of a baby's mental ability;
- the baby who may not necessarily exhibit many physical signs (stigmata) will need every bit as much help as the baby whose appearance is more affected, and
- any of the physical features might appear in any other child, but it is only in DS that they occur with a degree of intellectual impairment (National Institute of Child Health and Human Development, 2010).

With advances and increased access to medical care, most of these problems are treatable and it must be understood that not all individuals with DS experience health problems. Moreover, none of these problems is unique to people with DS - they also occur in the rest of the population.

Primary features of DS are its physical and mental features. Most children with DS have some, but not all, of the following features according to National Institute of Child Health and Human Development (2010):

2.7.1 Physical Characteristics

- Reduced muscle tone which results in floppiness (hypotonia)
- A below average birth weight and length
- A flat facial profile, flat nasal bridge, small nose
- Small ears that may fold over a little at the top
- A short neck
- Small hands and feet
- Low muscle tone
- Short stature in childhood and adulthood
- Eyes that slant upwards and outwards, often with a fold of skin that runs vertically between the lids at the inner corner of the eye (epicanthic fold)
- A small mouth which may make the tongue seem slightly large
- A big space between the first and second toe (sandal gap)

- Broadish hands with short fingers and a little finger that curves inwards The palm may have only one crease across it (single palmer crease)

Many of these features are found in the general population. Therefore a chromosome test (karyotype) is needed to verify a positive diagnosis (DSSA, 2010).

2.7.2 The Cosmetic Surgery Question

In an attempt to ameliorate the crushing frustration for parents of high-functioning children with DS, they often consider 'corrective' cosmetic surgery in an attempt to enhance visual acceptability of their child. This focus on the importance of first impressions is often to protect their child from the societal stigma of not meeting subjective standards held by the ignorance of people concerning 'acceptable' appearance (Suzedelis, 2006: 538).

It is my opinion that this well-intentioned need to erase possible prompts of prejudice may stem from the parents' anxiety and possible denial of the condition of their child. Despite such a bold act of defiance against this life-sentencing label which is now the reality of their child, parents and often siblings, the jury is still out on any discernibly marked improvement per se that such surgery afford. It is further my personal, non-judgmental view that it may be that the parent who takes this decision, focuses too much on the possible consequence of first impressions. Will their child be less bullied, less vulnerable, treated more kindly? I think not. Discriminating, hypocritical bigots will always walk this earth alongside receptive, charitable, tolerant and insightful individuals, and that the latter, in actuality, uphold prevailing efforts to nurture societal acceptance for children with DS just as they are.

Parents, who place the burden of surgery upon a child before they are old enough to make an informed decision regarding alteration or enhancement of their physical appearance, place the burden on *themselves* of accommodating the discrimination of the ignorant and intolerant. However, as with any other person with a similar problem, orthodontic surgery often positively enhances not only the physical appearance, but also the intelligibility of speech of an individual with DS.

2.7.3 Intellectual Impairment

All people with DS will have some degree of intellectual impairment, ranging from mild (IQ: 50-70) to moderate (IQ: 35-50), and only occasionally to severe (IQ: 20-35). As stated previously,

there is no correlation between the physical features and the mental development, often referred to as cognitive development, of a person with DS (DSSA, 2010).

The Stanford School of Medicine (University of Stanford, California) is continuously researching the complex issue of cognition in persons with DS. Cognition involves the processing of the information we perceive, understanding and remembering the environment around us, and being aware of ourselves. Attention, learning, memory, and judgment are all part of what is referred to as cognition. Cognition requires the operation of a large number of specific brain circuits, each of which processes a certain type of information (The Stanford School of Medicine, 2010).

Evidence from studies of brain structure and function in persons with DS and DS mouse models, point to the hippocampus as the area of the brain that is selectively affected by this syndrome. Brain structure is essential for learning and memory. Research focuses largely on the hippocampus and its surrounding network of cells, as well as the synapses in order to better understand and treat impaired cognition in DS. Current research strategy involves identifying the genes responsible for cognitive deficits in DS, attempting an understanding of how these genes influence cognition, and then to find treatments that will reject or eliminate the activity of the extra gene(s), according to reports from The Stanford School of Medicine (2010).

Intellectual disability also affects present or adaptive functioning of the individual. Thus, the person's effectiveness is measured in terms of meeting the expected standards for his/her age by their cultural group in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety, with an onset before 18 years of age (NICHD, 2010).

There is a wide variation in ability in people with DS just as there is in the rest of the population. Children with DS do learn to walk, talk and be toilet trained but in general will meet these developmental milestones later than their typically developing peers. The exact age that these developmental milestones are achieved cannot be predicted. However, early intervention programs beginning in infancy can assist these children to achieve their developmental milestones sooner.

Early intervention programs which help in the development of all domains are essential for the child's development and can include speech therapy, physical therapy for gross motor skills development, occupational therapy for fine motor and other skills development, as well as

home teaching programs. Along with benefiting from early intervention and special education, many children are integrated into the regular classroom. Children with DS learn to read and write, and some graduate from high school and go on to post-secondary programs or college. Many children with DS participate in diverse childhood activities at school and in their neighbourhoods. Including children with DS in social activities with typically developing peers, not only enhance their social and communication skills, but they are often found to function much better in social situations than expected (Buckley, 2001).

Adults with DS frequently participate in workshop style programs although many adults also hold regular jobs. I have a number of young adult friends with DS who have excelled. A shining example is a most outstanding young lady from the Free State, who not only completed her high school career in mainstream education, but attended a tertiary college, and today teaches children with special needs. Coming from a traditionally Afrikaans background, she has taught herself to speak English and has become a sought-after motivational speaker at National and International functions. She has on numerous occasions been honoured for her remarkable achievements, yet has remained a proud and humble advocate for persons with DS. She is a beautiful human being who continues to inspire my efforts with my own daughter.

Similarly, a young man with DS from Natal, who was previously employed by a multi-national company as a packer for many years, recently purchased his own truck and currently does independent distribution for this company. Assisted by his now semi-retired father, this young man proudly contributes positively to his community and to society.

Another example is a 37-year old man from Port Elizabeth who has, with his own salary, purchased his third new car, which he drives via a rather tricky route, to work every day. This attractive, intelligent gentleman is an avid outdoor enthusiast who has completed many well-known trails, including the Otter Trail.

I have had the pleasure of hearing the positive message of an extraordinary young man. He is an accomplished professional musician and self-advocate with DS from New York, USA. He plays six musical instruments and in addition to his career he travels the World giving solo performances and leading self-advocacy workshops. He graduated from High School in 2001 with honours, and from the Berkshire Hills Music Academy, Massachusetts in 2003. He is the holder of ten coveted National and International awards for his music and self-advocacy and he lives a happy independent life in his apartment in Rome, New York. He has been the subject of documentaries, TV and international newspaper interviews, has been featured on The Oprah

Winfrey Show, 20/20 and Views as well as in the Wall Street Journal and Time Magazine. His sporting accolades include a second Dan black belt in Tae Kwan Do, being a “Sensei” martial arts teacher, and a number of awards for sport including a gold and silver medal for swimming at the 1999 Special Olympics World Summer Games. He got married in 2006 and the couple present workshops as a husband and wife team. He is featured in numerous websites on the internet (Down syndrome International, 2010).

I have met an incredible young woman with DS from the UK, who has a severe physical challenge, was encouraged to swim her whole life in order to keep up her strength and fitness. Some years ago she partook in the English Channel Relay and not only swam her own section, but also took the turn of a fellow competitor who was injured. She is a well-known International motivational speaker who has travelled the world, sharing her positive experiences.

I can list *countless* individuals with DS who have excelled in a variety of activities from ball-room dancing, as artists, as poets, as gymnasts, as motivational speakers, as actors or simply as dedicated, dependable employees. The bottom line is that many persons with DS are able to lead independent lives and contribute positively to their communities and to society as a whole. Today, an increasing number of adults with DS live semi-independently in community group homes where they take care of themselves, participate in household chores, develop friendships, partake in leisure activities and work in their communities. Children and adults with DS *can* and *do* continue to learn throughout their lives just like the rest of the population (Buckley, 2001).

2.7.4 Associated Features and Co-Morbid Disorders

The outlook for individuals with DS is brighter than it once was. Most of the health problems associated with the syndrome can be treated. Individuals with DS are more likely to have one or more of the following health conditions as outlined by the National Institute of Health (2010).

Heart defects: Almost 50% of babies with DS have congenital heart defects. Thus, it is important that all babies with DS are examined by a paediatric cardiologist shortly after birth or have an echocardiogram (ECG), a special ultrasound of the heart, within the first two months after birth in order to detect and subsequently treat heart defects. Some defects are minor and treatable with medication, while others require surgery.

Intestinal defects: About 12% of babies with DS are born with intestinal malformations that require surgery.

Vision problems: More than 60% of children with DS have vision problems, including crossed eyes (esotropia), near- or far-sightedness and cataracts. Spectacles, surgery or other treatments usually can improve vision. A child with DS should be examined by a paediatric ophthalmologist within the first six months of life and have regular vision assessments throughout their life.

Hearing loss: About 75% of children with DS have some hearing loss, which may be due to fluid in the middle ear (often temporary) and/or defects involving the middle or inner ear. Babies with DS should be screened for hearing loss at birth and again during the first months of life. Their very narrow ear canals make proper examination difficult, but regular hearing exams and timely treatment is necessary to avoid major hearing difficulties later as well as interference of language development.

Infections: Due to narrow upper respiratory tracts, children with DS are predisposed to colds, bronchitis and pneumonia. Obstructive airway disease is recognized as a significant problem for both children and adults with DS. Children with DS should receive all the standard childhood immunizations, which help prevent some of these infections. Auto-immune conditions are common in these individuals.

Thyroid problems: About 1% of babies with DS are born with congenital hypothyroidism, a thyroid hormone deficiency that can affect growth and brain development. Congenital hypothyroidism can be detected with routine newborn screening tests and treated with oral doses of thyroid hormone. Children with DS are at increased risk of acquiring thyroid problems and as such require annual testing.

Weight issues: Children with DS may have a tendency to become obese as they grow older. Besides its obvious negative social implications, this weight gain threatens the health and longevity of the individual. A supervised diet and exercise program may help reduce this problem.

Atlantoaxial Instability: Some individuals with DS may have this condition, which is a misalignment of the top two vertebrae of the neck, predisposing the person to injury if they participate in activities that overextend or flex the neck. Parents are usually urged to have their child examined by a physician to determine or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

Leukaemia: Although leukaemia is diagnosed more than other cancers in children with DS, fewer than 1 in 100 children are affected.

Oral-motor function difficulties: Infants with DS have been known to have difficulty feeding as a result of oral-motor function difficulties. This may also impede speech development and clarity. As this is mostly due to low muscle tone, physical and occupational therapies are helpful in this regard.

Developmental disorders: It was once thought that **Autistic Spectrum Disorders (ASD)** were not found in individuals with DS. This is now known to be incorrect, but the incidence of ASD in people with DS remains a matter of some debate. It has been estimated to affect some 3 to 7% of children and adults. Interestingly, the onset of ASD in children with DS may only develop during adolescence. The reason for this uncertainty is that there have been no large scale controlled studies of this issue and, more importantly, that the diagnosis of ASD is at this stage too uncertain to produce reliable data.

ASD is a spectrum disorder which covers a very wide range and there are many behavioural features which are associated with this group of conditions. However, many of these symptoms are non-specific in that they may be found in a large number of other disorders. The diagnosis of ASD is based on obtaining the developmental history of the individual and information about their behavioural patterns. At present there are no objective findings in ASD which are of diagnostic value.

Attention Deficit Hyperactivity Disorder (ADHD) is sometimes confused with ASD, especially if the child has severe learning disabilities. The level of intrinsic activity and liveliness in children vary enormously and the vast majority of young people with DS are normal boisterous youngsters. However, a small number are so overactive that their entire pattern of behaviour is disorganized. They are characterized by their short attention span, impulsiveness, 'silly' social behaviour, clumsiness and constant movement which are little affected by environmental influences (Buckley, 2006: 62).

Not much information is available on the particular dual diagnosis of DS and ADHD, and these provide widely differing estimates and interpretations of their findings. One reason for this could be the reluctance of paediatrician or child psychiatrists to make the diagnosis when a child already has a developmental disability. In addition, checklists may overestimate ADHD symptoms if the rater does not take account of the child's level of developmental delay.

However, this *can* happen and these children can be helped once a correct diagnosis and correct treatment has been established.

Buckley (2006: 61), a pioneer in the field of behaviour and education of children with DS confirms that children with DS and ADHD may develop difficult and sometimes aggressive behaviour, which can be very difficult to manage at home and at school, therefore suggesting the appropriate diagnosis for an unusually difficult child.

The management of this condition consists of a combination of behaviour modification and medication. Behavioural management strategies include praising 'good' behaviour. Medication would involve prescription drugs. There is an unfortunate anti-medication culture among many parents and others in a number of countries, which may deny children the benefits of drug treatment. This intervention may not necessarily have to be a long term arrangement. As with any medication, the only way to find out if a drug will help is to try it. Children who are unable to control their attention and behaviour are denied the social and learning opportunities essential to their development and educational experiences, according to Buckley (2006: 60).

Speech and language challenges: Speech intelligibility, language difficulty and delays are particularly prevalent among persons with DS. Comparisons across a variety of neuro-developmental syndromes provide evidence that DS puts individuals at particular risk for linguistic problems (Bray, 2007: 60).

Mental abilities such as talking, thinking, reasoning and remembering provide the foundation for intelligent behaviour or intelligence. Oates, Bard & Harris (2007: 46) note that it is the slow development of these functions, which assist individuals to meet demands and expectations of the world around them, that concerns the parents of children with DS most.

Bray (2007: 62), having documented the communication challenges in DS, including the assessment of communication skills, have found that progress in speech and language performance is linked to factors which include hearing status, speech motor function status, non-verbal cognitive level and chronological age. Language impairments appear to manifest mainly in phonological problems, and although parents can usually understand their children, strangers frequently find it hard to understand them. Low muscle tone of the facial muscles, of which the tongue is the largest, also contributes to this challenge. Individuals with DS are known to have much stronger receptive than expressive language skills (Buckley, 2001).

Buckley (2001) confirms that much research has gone into the promotion of cognitive development in recent years. This research suggests that reading instruction leads to useful levels of functional literacy for a majority of children, and also improves functional intelligence by improving speech, language and short term memory skills. Children with DS learn to read in the same way as typically developing children but they make use of their good visual memory skills to read and are slower to be able to use phonics. However, when they have reading skills in the 7 to 8 year level (based on norms for typically developing children), they begin to use their phonic skills independently to read and to spell, like other children.

As with typical developing children there are considerable individual differences in rates of literacy progress among children with DS, but if they have access to good teaching, their reading abilities are, on average, about two years behind their age in primary school, while language and number abilities are often more delayed. Buckley (2001) confirms that there is evidence to support the view that all children with DS will benefit from being fully involved in the pleasures of literacy and the imaginative world of stories, regardless of their independent reading abilities. There is also evidence to support the view that all children with DS should be in active and interesting literacy instruction from their pre-school years as it will help them to overcome some of their working memory and spoken language learning difficulties.

Memory loss: Individuals with DS are more likely than unaffected individuals to develop Alzheimer's disease, characterized by progressive memory loss, personality changes and other problems. Adults with DS tend to develop Alzheimer's disease at an earlier age than unaffected individuals. Studies suggest that about 25% of adults with DS over age 35 have symptoms of Alzheimer's disease.

Psycho-social issues: Having friends and being a friend defines us as human beings. Friends can play many roles in our lives, and without friends, life can become increasingly lonely. For young people, friends often take a counselling role in times of emotional stress, so loneliness or a life without friends who can understand the emotional contexts of friendships and "counsel" may affect a person's psychosocial quality of life. Staff of the DS Research Program LATCH-ON, at the University of Queensland developed a six-session program that was designed to better help young adults with DS understand friendships and the emotions associated with them. During the sessions, the students explored and discussed various types of friendships and the associated emotions (Jobling, Moni & Nolan, 2002: 235-245).

As children with DS have the same needs and emotions as typically developing children peers, Buckley & Sacks (2002) confirm that individuals with DS are people first, with the same rights and needs as everyone else. Their development is influenced by the quality of care, education and social experiences offered to them, just like all other people. Pertaining to adolescence, Buckley & Sacks (2002) informs us that the social understanding and interactive skills of adolescents with DS include the following:

- Most teenagers are socially sensitive and understand non-verbal cues to emotions, for example, facial expression, tone of voice, body posture etc.
- Many teenagers show good empathy and understanding of social behaviours but may not have the language ability to explain how they feel or to negotiate social situations.
- They can behave appropriately in showing concern, expressing emotion or becoming upset.
- Sensitivity can make teenagers with DS vulnerable as they will quickly pick up on negative emotions such as dislike, anger or rejection.
- As they are usually not able to explain how they feel, their distress will be expressed in behaviour.

As teenagers, young people with DS reach puberty at about the same age as other young people. As teenagers they develop typical leisure interests and awareness of sexuality, it is therefore important to recognize that the social and emotional needs of teenagers and adults are age-appropriate and that they learn as much as possible about the ways in which their bodies are changing and about taking care of their personal hygiene.

If individuals with DS are to be fully included in the community, as teenagers and as adults, it is important to recognize that their place in society will be linked to their chronological age, and that this is right and appropriate. Many young people with DS make significant progress during their teenage years, as they begin to take more responsibility, become more independent and apply learning to activities that they can see as meaningful in their everyday lives. The challenge for the teenager with DS, who may have limited speech, language and cognitive skills for his or her age, is to participate in life in an age-appropriate way.

Cuckle & Wilson (2002: 66) maintain that the social relationships and friendships among people with DS are an important part of interpersonal development, and are very dependent on opportunities created by families to facilitate their social life. These researchers based their findings on evidence that the development of peer groups in special schools allow real,

reciprocal, supportive relationships to flourish among peers with similar interests and abilities, especially if their interests, social life, emotional maturity, and communication skills were more equally matched. I agree with this hypothesis, as it is applicable to any circumstance where relationships are forged and developed.

Cuckle & Wilson (2002: 69) do however note in their findings that there were more obvious advantages for young people experiencing both groups of friends, i.e. friends with special needs and typically developing friends, since the social skills learned in an inclusive environment are considered valuable for increasingly independent living and development of a wider range of independent relationships.

Behavioural challenges: According to Cuskelly, Hauser-Cram & Van Riper (2008: 106) there is a definite association between behaviour problems and parental stress; however, children with DS generally exhibit fewer behavioural problems than children with different intellectual disabilities, although more than typical developing children and siblings. Research findings by Hauser-Cram, Warfield, Shonkoff & Krauss (2001: 66) reported that the increased stress levels of parents were related to increased child-related demands, which included behaviour challenges.

Persons with DS of all ages tend to talk to themselves and/or may have imaginary friends. In virtually all cases, this is perfectly normal. It is now generally accepted that self-talk is merely a form of thinking aloud and serves an adaptive function by helping to think about the various tasks and problems of daily life (DSSA, 2010).

It stands to reason that there would be a relationship between expressive communication skills, as explained in the previous section, and behaviour difficulties. The implication here is that at least some difficult behaviours are the teenager's way of communicating when he/she does not have the language to do so. In addition, certain behaviour may be the result of the frustration that arises when an individual is not understood. Schneider, Wedgewood, Lewellyn & McConnell (2006: 927) remind us of the challenges that coincide with the awareness of difference in their teenage years with resulting feelings of inadequacy and frustration when they are unable to keep up with their peers.

Many studies report a link between family stress and the level of difficult behaviours, often particularly affecting the mother (Hodapp, Ricci, Ty & Fidler, 2003: 137). Therefore, while only a minority of teenagers with DS can be described as difficult, it is important that the needs of

these young people and their families are recognized. Behaviour difficulties at any age can arise for a variety of reasons and will greatly affect the life of both the individuals with DS and those around them.

The majority of parents that I am involved with, describe the positive personalities of their teenagers, their social sensitivity, and how much they contributed to family life. As any teenager, difficult behaviours are at times exhibited, and sometimes they show some immature behaviour for their age (but probably not immature for their cognitive and communication abilities at this time). Most teenagers, typically developing and otherwise, will grow out of these behaviours by their late teens.

Many, if not most, difficult behaviour can be changed but not always easily or quickly. More persistent difficult behaviours will be more difficult to change and families (and teachers) will benefit from the support of professionals skilled in behaviour management.

Some individuals with DS may have a number of the afore-mentioned problems, while others may have none. The severity of these conditions varies greatly amongst individuals.

2.8 INCLUSION INTO SCHOOL AND SOCIETY

Literature tells us that the education of children with DS in developed countries has changed drastically over the past 50 years by 'integration initiatives' and in recent years by the international inclusion movement (Giorcelli, 2002: 55). Mainly driven by parents, social theorists and to a smaller degree by teachers, this inclusion movement has been an important change in traditional special educational services for learners with DS (Giorcelli, 2002: 55). Prior to this inclusion movement individuals with DS were regarded as uneducable and either stayed at home or were placed in training centres which offered day care and relief for parents instead of education for their children (Black, 2004).

Engelbrecht, Oswald, Swart, Kitching & Eloff (2005: 460) state that inclusive education involves the active meaningful participation in a mainstream classroom that moves beyond the mere physical placement of learners with diverse needs in the classroom. It extends beyond the quality and quantity of interactions between learners and teachers in the school, classroom and community context and involves the way in which individual educational and social needs are being met. In a truly inclusive setting there exists a sense of belonging in a classroom and school community where learner diversity is seen as an asset rather than a liability. Here all learners are appreciated as important members of the classroom and school community. This

is an environment where shared ownership among teachers, administrators, parents and learners prevail and which supports the shared responsibility for nurturing the development of all learners, making sure that all needs are met and that learners and teachers are supported in reaching their goals.

South Africa ratified both the United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol. On 3 April 2008 the twentieth county signed the Convention and on 3 May 2008 the Convention became an International Law. The purpose of the convention is to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities. It covers a number of key aspects such as accessibility, personal mobility, health, education, employment, habilitation and rehabilitation, participation in political life, equality and non-discrimination. This Convention is the first human rights treaty of the 21st century and marks a major shift in the way the world's 650 million persons with disabilities are treated (United Nations Convention Document, 2009).

The issue of inclusive education of children with DS is a minefield and the multitude of encompassing aspects justifiably constitutes numerous separate studies. However, for the purpose of this section of this study I will merely skim the top. Article 24 on Education states that persons with disabilities have the right to non-discriminatory, inclusive education at all levels in order to ultimately participate effectively in a free society. Although it states clearly that persons with disabilities are not to be excluded from the general education system but must have access to inclusive, quality and free education on an equal basis with others in the communities in which they live (UN Convention Document, 2009), this law is most frequently disregarded. The educational rights of children with DS are violated on a daily basis. Not only are they repeatedly denied access to schools on the most flimsy excuses, but often, when included by default, they are merely *accommodated* and not *taught*.

This basic shift in ideology from special-ed classrooms to educating all learners within an inclusive classroom caused some confusion in terminology. As children with labels enter the education system, the terms 'integrated' and 'included' are used to describe classroom settings they will experience. The fundamental difference is that the integration models (medical models) work under the premise that something is *wrong* with the child and needs to *be fixed*, whilst inclusion works under the premise (social model) that *all children are different and all children can learn*. Inclusion is an attitude, a value and belief system. All learners are encouraged to belong, thus nurturing everyone's self esteem. Learners are 'participating' in

school, as opposed to integration, where learners are 'going' to school. Inclusion is really a function of relationships and attitudes and the benefits for everyone is well documented. Integration simply accommodates and benefits no one.

In an ideal teaching situation the participation of all learners is encouraged in normal classroom activities. There will always be ones who 'get it' the first time and there will always be those who require a second explanation, a different strategy or a more practical technique before they grasp a concept. But herein lies the beauty of having a child with DS in the class – the *whole* class will benefit from a teacher who repeats something, simplifies the instruction, speaks slightly slower when explaining a new concept and explores new and exciting ways of garnering classroom participation of all learners. Every teacher knows that although the *content* of a lesson stays the same, she frequently has to *adapt* her planning, strategies and techniques to include every learner in the class, proving that in some cases, one size *can* fit all... if the teacher is skilled and willing to alter the cut!

Including a child with DS holds both academic and social benefits, and research has shown that children with DS do academically at least as well, if not better in inclusive settings rather than segregated settings. The teaching of traditional academic skills to children with DS has incited extensive debate in research since the late 1970's, with growing evidence that many children with intellectual impairment are indeed able to attain at least basic levels in these academic skills (Black, 2004).

Moreover, daily opportunities to mix with typically developing peers provide models for age-appropriate behaviour. This is also an important step towards preparing a child with different ability to become a full and contributing member of her community, and society as a whole benefits. Typically developing peers gain an understanding about different ability, how *able*, indeed, these children are; they learn *tolerance* and how to *support* those who are different from them. They learn and experience *that being different should make no difference*.

Persons with DS are life-long learners, and as a parent of a child with DS, it is important to me that my daughter early on perceives learning at school level as truly meaningful, on her own academic level but especially on interpersonal level. This can be achieved by learning together within the diversity of her own peer group, but at her own level of competence in different learning areas. I believe that *every* learner, as an individual, has special educational needs; not every learner understands maths in the same way, just as not every learner grasps phonics

in the same manner, or learns to read at the same pace. The emotional and environmental challenges most children face today profoundly influence their performance and learning, which supports my notion that, in effect, every learner today has special needs.

Personally, my desire, as that of most other parents, is that my daughter has the opportunity and equal chance to succeed in an environment where the expectations of her teachers match mine. Frequently many of the ceilings placed on the development of children are mostly not intrinsic, but imposed by others (teachers and parents). The benefits of early intervention, which involves supporting and promoting some of the complex developmental processes in children with DS, stand children in good stead when they enter an inclusive education situation. However, the high yet reasonable expectations of parents and teachers are always pivotal in the progress of our children. A successful outcome rests largely on the continued partnering efforts of school and parents, with a positive undertaking to meet the highs and the lows with equal expectation and understanding, building on strengths and supporting weaknesses in a positive way. I conclude this short section on inclusion with the analogy of the Good Samaritan and a question. (Actually two). The first question, which the priest and the Levite asked, was “If I stop to help this man, what will happen to *me*?” But the Good Samaritan reversed the question: “If I do *not* stop to help this man, *what* will happen to *him*?”

2.9 CONCLUSION

This chapter of the literature study has provided a comprehensive overview of the basic historicity and etiology of the syndrome. This chapter is summarized most accurately by the words of Peuschel (1999: 4) as follows:

“Individuals with Down syndrome let us know that they are able to learn, that they can have fun, be responsible, dependable, and can work hard. Persons with DS have feelings like other human beings and they have ups and downs. They will be happy when things go well, and they will be sad when they are offended or looked upon as second-class citizens. Persons with DS demonstrate that they do not have to be segregated, institutionalized, and shunned away, but can be active participants in community life. Displaying diversity in human abilities and functions, persons with DS make us aware of the fact that looking upon them with respect and dignity is of utmost importance”.

Chapter Three will address several factors regarding family perspectives and dynamics, as well as coping strategies of parents and siblings in a family with a child with DS.

CHAPTER THREE

DOWN SYNDROME: FAMILY PERSPECTIVES, FAMILY DYNAMICS AND COPING

3.1 INTRODUCTION

Chapter Three addresses numerous factors pertaining to family perspectives, commencing with a brief overview on historical perspectives on family research. A glimpse into the significance of family care paves the way to issues concerning family dynamics, including stress, adaptation, coping and the grieving experience.

Most parents aspire to having intelligent and able children who will achieve in relation to the expectations of a society in which intelligence is highly valued. Therefore, it is disquieting that people with intellectual impairment and their parents are at risk of being undervalued and stigmatized. I have found that many parents internalize these values and perceive themselves as somehow having failed, often believing that others share this view.

Children with intellectual impairment, their parents and siblings need to come to terms with their reality. They need, ideally, to adopt a different set of values, based on the inherent worth of every individual, focusing on strengths rather than weaknesses. This will result in individuals with intellectual impairment and their siblings, with the support of their parents, enjoying their childhood, growing up with good self-esteem and ultimately contributing positively to society. To some extent, this aspiration has already been accepted in many countries, being demonstrated through human rights legislation and policies of social inclusion such as the United Nations Convention on the Rights of Persons with Disabilities, of which South Africa has been a ratified signatory since 2008 (DSSA, 2010) .

The recognition by the family that their child is differently abled highlights the beginning of a journey that may bring both challenges and rewards. The family constitutes the nucleus that is the most constant, involved, selfless, closest and for the longest time by the side of the person with DS. If the family functions properly, the person with DS makes progress. Different stressors are met by families in different ways. Some families come together; others simply fall apart.

This chapter presents the reader with a comprehensive overview of research on the families and siblings of children with DS. It provides contextual theoretical background and scientific research that inform the goals of this study and guides the exploration of the research problem outlined in chapters one and four.

3.2 HISTORICAL PERSPECTIVES

Until the 1950s, the focus of research on families with a differently abled child was mainly on maternal reactions to the birth of the child. A contemporary quotation reflects the dominant narrative of despair: *“The permanent, day-by-day dependence of the child, the interminable frustrations resulting from the child's relative changelessness, the unaesthetic quality of mental defectiveness, the deep symbolism buried in the process of giving birth to a defective child, all these join together to produce the parent's chronic sorrow”* (Jacques, 2003: 1).

The birth of a child with a disability was seen as a tragedy for the family, without hope of resolution or adaptation. This view stigmatized the child, the mother and the family, thus, within this context institutional care was a way of preventing the child from further ‘disabling’ the family. Hodapp (2007: 280) affirms how almost every study for many years featured the negative nuance that having a child with a disability was bad, and the only real questions concentrated on which family members were adversely affected, in which ways, and by how much. Historically, studies were mostly aimed at families of persons with intellectual and developmental disabilities in general, with a shift over the past three decades becoming more focused on DS per se (hence the aged dates on some of the references cited in this study).

3.2.1 The Significance of Family Systems Theory

Family research moved away from models of individual pathology with the development of family systems theory, Bronfenbrenner (1989: 189) developed the eco-cultural model proposing that individuals and families do not exist in isolation. The family was seen as an interacting set of relationships between the members of the family and wider society, which prompted research to develop into areas such as stress, coping mechanisms, support networks, effects on siblings and the like. Research has since moved away from looking at family dysfunction, increasingly recognizing the successful, resourceful ways in which families adapt and provide care (Grant, Ramcharan, McGarth, Nolan & Keady, 1998: 58).

3.2.1.1 Accommodations

The eco-cultural model suggests that families create a meaningful and daily routine of family life, which involves various ways of responding to the often-conflicting pressures present. These responses are referred to as '**accommodations**'. The accommodations are elicited within the family as well as the wider social context. Therefore the family forms an eco-cultural 'niche'.

The significance of this concept is that it regards families' behaviour as adaptive. The process of accommodation is common to all families, and particular accommodation variables have been identified in relation to families of a person with intellectual disability. These are: family subsistence and financial base; access to health or educational services; home and community safety and convenience; domestic tasks and chore workload for the family; caring tasks; socialization; marital role relationships; social support; the father's role; and sources of information and advice (Jacques, 2003: 3).

Accommodations are made in different ways. For example, parents may change jobs and even move the family home to improve access to healthcare or schools for the differently abled child; families may leave old or develop new social-support networks as well as joining family support groups; siblings may start taking on domestic tasks.

The accommodations families make depend on the eco-cultural constraints and/or resources available to them (see Section 3.4.2).

The most pressing concern of a parent of a child with DS - or any disability - is without fail, *"What happens to my child when I am no longer here?"* This very real fear was identified by every participant in this study and appears to be, by far, the largest predictor of stress. The many accommodations that families make, altering in intensity and frequency over time, are often preparatory adaptations for future care-giving demands that may be placed on them.

Consistent with research findings of Seligman & Darling (1989: 114), participants in this study confirmed the occurrence of stability in family routines and a reduction in new accommodations as typically developing siblings in a family leave home and become independent. Often, at that time, accommodations are made by siblings, who, due to the aging and diminished ability of their parents, share, either practically or emotionally, the support given to both their parents and differently abled siblings.

3.2.1.2 Positive Findings

The 1980's brought about a shift in the negative perspectives. Hodapp (2007: 280) relates this to the increased sophistication of models used to understand family functioning; the move away from institutional models of care; the acknowledgement of the rights and value of people with disabilities within society; changes in family structure and the recognition of the importance of family care in providing support well into adulthood. Jacques (2003: 4-5) refers to the positive research findings of Stainton & Besser (in 1998) which recognized the rewards and benefits for the individual with DS and the family in the care-giving role. Interestingly, the recurrent core themes identified by their research, are concurrent with the findings emergent in this research study. These are:

- Source of joy and happiness
- Increased sense of purpose and priorities
- Expanded personal and social networks
- Increased spirituality
- Source of family unity and closeness
- Increased tolerance and understanding
- Personal growth and strength
- Positive impact on others/community

3.2.1.3 Down syndrome Advantage

A hallmark finding from studies focusing directly on DS involves the so-called *Down syndrome advantage* which relates to findings in numerous comparative studies that families of children with DS coped better, mothers experienced less stress and family relationships were closer, warmer and more harmonious (Hodapp, 2007: 280). In short, compared to other disabilities, most studies found that families which included a person with DS generally coped better than families which included a person with another disability (Hodapp, 2007: 280).

The reason for this phenomenon remains a mystery although, in one view, it is assumed to be related to the more sociable and cheerful personalities generally displayed by children with DS, as well as the absence of severe psychopathology in their demeanour. Another view, according to Hodapp (2007: 281), is the association of children with DS being born to mothers of advanced maternal age. The tendency of mothers to be slightly older, more mature and experienced, possibly also of higher average levels of socio-economic and education levels, may contribute to how they deal with and raise their child with DS. A further positive contributor

could be that DS is fairly well advocated, therefore more known to the general public and features several active National and International parent organizations.

Despite the so-called DS advantage, the normative and non-normative demands of a family with a child with DS can potentially create stressors and strains.

3.3 FAMILY STRESS

Glidden, Billings & Jobe (2006: 951) remind us that all child-rearing involves stress. However, parents of a child with intellectual impairment are likely to encounter challenges far more frequently than parents of typically developing children. This may include coming to terms with the child's condition and limitations, health and educational concerns, and planning for future caretaking. Whilst some families have trouble in adapting to the increased stress, other families adjust easier and even thrive (Flaherty & Gledden, 2000: 409). Although there has not been absolute constancy across studies conducted, the findings generally support that parents who use coping strategies focused on social support and problem-solving, reported more positive outcomes, whereas parents who have adopted strategies focused on escape, denial and avoidance of difficulties reported less positive outcomes (Stoneman & Gavidia-Payne, 2006: 12).

Van Riper (2007: 117), a family researcher interested in resilient families, contends that well-being in families is best understood by studying the natural capabilities of families to endure, survive, and even thrive in the face of crises. McCubbin & McCubbin (Van Riper, 2007: 117) defines resilience as the *positive behavioural patterns and functional competence* individuals and families demonstrate under stressful or adverse circumstances, determining the family's *ability to recover* by maintaining integrity as a unit while ensuring and, where necessary, *restoring* the well-being of the family members and the family as a unit.

3.3.1 Adjustment and Adaptation

According to Mandleco, Frost-Olsen, Dyches & Marshall (2003: 367) *adjustment* refers to the response of families to events not presenting major hardships, thus requiring only minor changes in current family functioning (or the initial response of the family to a major event) and *adaptation* refers to families' response to major transitions or hardships that require fundamental structural or systematic changes in family functioning (such as the many ongoing challenges associated with raising a child with DS).

Balance achieved between the needs of the child with DS, the needs of other family members, and the needs of the family as a unit, result in successful family adaptation (bona-adaptation). If not, unsuccessful family adaptation (maladaptation) occurs. High levels of parental well-being and overall family functioning suggest successful adaptation, whereas low levels of parental well-being and overall family functioning suggest unsuccessful adaptation (Mandleco *et al.*, 2003: 367).

When a child with DS joins a family, a process of adjustment and adaptation occurs over time. During the adjustment phase the family makes immediate short-term changes to cope effectively with the additional demands of rearing a differently-abled child. This may include practical aspects such as (extra/ full-time or sleep-in) domestic help, finding suitable therapists, joining a family support group, lift-clubs for siblings and gaining knowledge about the syndrome. A child with particular health needs would require specific adjustments in terms of time, duties, roles and immediate financial considerations. These adaptations are in response to the family's attempts to meet the demands it faces from both developmental and other unexpected stressors and strains.

3.3.2 Demands, Stressors and Strains

Abery (2006: 3) distinguishes between demands placed on the family, the strains and stressors that families endure, and the experience of stress:

- **Demands:** The external environment often creates a demand (or potential stressor) which may change over time. Demands resulting from *normative* sources (the expected changes and transitions over the course of the individual's life cycle) may include a child's initial entry into pre-school, elementary school, transition into adolescence, and entrance into employment situation. The *non-normative* (unexpected) demands may include relocating to another town, a divorce or the sudden death of a spouse. Abery suggests that, for parents of a child with DS, non-normative demands may include extensive participation in early intervention programmes, daily or weekly therapy, or the need to meet with professionals (teachers, school psychologists) regularly.

Abery (2006: 4) defines a *stressor* as a demand or event that has an impact on the family because it produces changes in the family system. These changes may be in any area,

including family boundaries and goals, family interaction, relationship quality, number or roles any one person needs to fulfil, and the values of individuals within the family.

- **Stress:** Family *stress* is defined as a state that arises from an actual or perceived imbalance between the demands placed on a family and the family's capability to meet these demands. One or more family members may experience stress if the family does not have the capacity to respond to additional demands or has to make significant changes (Abery, 2006: 6).
- **Strain:** *Strain*, according to Lazarus (2000: 665), refers to the actual negative effect on the person resulting from the stress. This unpleasant state most people seek to avoid or minimize. All individuals endure some amount of stress and strain, but over a lengthy period this can lead to both individual and family needs not being met.

To understand a family's response to rearing a child with DS, one need also consider the demands placed on the family unit as a whole. Parents still need to respond to the demands (physical and emotional) of their typically developing children as well, often requiring redefinition of roles within the family system.

Mothers are mostly the primary carer of children, but the child with DS, with its new set of demands in terms of therapists, possible health issues, etc, makes it impossible for the mother to cope without experiencing serious role overload. This is very likely to affect spousal relationships negatively and cause tension with siblings.

The demands associated with raising a family in general and a differently abled child in particular (and the strains and stressors associated with them) change continually. If they are not resolved, demands may pile up, placing the child and family at risk for poor outcomes.

3.4 FAMILY CAPACITIES

Numerous factors have been identified which is associated with successful adapting and coping when raising a child with DS, or any other disability. These factors, sometimes referred to as family capacities, according to Abery (2006: 6), include the following:

- The *meanings* which the individual members and the family as a whole attribute to the demands of the situation, and their capability to meet these demands;

- The available family *resources* or that which they are able to acquire;
- The *coping behaviours* the family uses in an attempt to achieve a balance between demands and resources.

3.4.1 Family Meanings

Antonofsky (Abery, 2006: 6) states that *how* family members think about *what* is happening to them as a group and as individuals, has a powerful effect on their success in adjusting and adapting to potential stressful events of all types (such as having a child or sibling with DS). The way the family defines and perceives the disability, as well as their capability to effectively cope with the demands it may impose, is incorporated into this thought paradigm. Their ability to develop positive, adaptive beliefs and meanings will increase the probability of a pro-active approach to life for each member of the family including the child with DS. Thus, finding meaning in what many may call negative events can, in fact, restore some order and purpose in their life.

The meaning a family attaches to having a child and sibling with DS is very important and it is subject to change over time. Perceiving the child as 'less than normal', 'sick' or 'less capable' may negatively affect family interactions. Abery (2006: 6) states that this negative meaning has been associated with more dependency on parents, lower levels of competence, and poorer developmental outcomes for the individual with DS, whereas positive meanings and attitudes toward the child with DS ("Our child is so much like other children", "Our child has drawn us together as a family") is a protective factor for families, helping them manage the situation, and at the same time minimizing stress and strain.

Attaching positive meaning to the different ability of their child and sibling with DS therefore influences both the family's ability as well as the child with DS to adapt. In turn, the meaning that the child comes to attach to being differently abled is therefore also likely to affect the family's adaptation.

Moreover, should a family choose to perceive the birth of their child with DS as having meaning or being a 'good thing', this family is less likely to develop resentment toward the child and will be more likely to provide the loving, nurturing environment that will facilitate the child's growth and development. Such a positive family atmosphere is likely to increase the overall

development of the child's skills, attitudes, and values, enhancing the probability of later independence, autonomy and a higher quality of life (Abery, 2006: 7).

The parents' frame of reference at the time of birth of their child with DS also plays a role in the meaning they attach to their situation. For some families the initial meaning may be quite negative, but may develop into a more positive meaning as they adjust and adapt to their child and their new circumstances. Conversely, if the family runs out of sufficient resources to deal with increasing demands (for example excessive medical costs); an initial positive or neutral meaning may become increasingly negative. It is often at this juncture where the strong opinions and influences of extended family members may be critical. It is then that the family should rely on the positive input and support from other families who have children with DS, and not rely too much on the opinions of persons who have never 'walked the walk'.

Viewing DS as a challenge rather than a catastrophe enables the family to assume a pro-active stance, whereas negative perceptions increase the probability that parents and extended family members will neglect to seek out resources that may provide extensive support and lessen demands. Families remain the best advocates for their child with DS. The meaning that the family attaches to having a child with this syndrome is likely to have a profound effect on the extent to which a family experiences a sense of empowerment and control, and is able to advocate effectively for their child.

3.4.2 Family Resources

Abery (2006: 8) defines *family resources* as the psychological, social, interpersonal, and material characteristics of the individual family members, the family unit and the community.

Existing resources are those already in place before the child with DS is born, and may include strong marital relationships, financial stability, and the health of family members. *New resources* are the resources the family and its members develop in response to the new or additional demands associated with rearing the child with DS, including making friends with other families who are in similar situations and may provide support, joining a family support group, and finding a suitable child-minder who is experienced in this field.

Families need to develop new resources continually as the demands and strains accumulate over time. It is therefore important that 'healthy families' are nurtured and maintained for the sake of the child with DS as well as the preservation of a healthy family life (see Section 3.5.2).

- **Personal resources/supports** include: *Physical health* (to meet increased care-giving demands); *psychological health* (to cope with frustration, intense care-giving, etc.); *level of education* (for financial stability, and to become more knowledgeable about DS); *spiritual beliefs* (to derive positive meaning and to maintain a positive, empowered outlook on life); *problem solving skills*(for capacity and ability to solve problems/remove barriers necessary to ensure provision of appropriate services; ability to minimize or effectively deal with conflict); *self-esteem and self-confidence* (for more persistence; greater likelihood of proactive approach to dealing with child-related issues; higher quality care-giving and support; higher level of marital and family satisfaction).

It is important that parents establish realistic expectations, avoiding blame of self or others for difficulties, and utilize formal and informal supports in order to maintain levels of self-esteem and self-confidence so that they are able to provide optimal support and care for all of their children (Abery, 2006: 9).

- **Family resources** encompass the following: *family interaction style* (conducive to higher level of family and marital satisfaction; better ability to provide interfamilial support; greater capacity to develop and maintain formal and informal support network; ability to provide support and nurturing to family members while fostering autonomy; ability to adapt to change); *marital relationship* (high levels of spousal support; agreement on roles, rules and responsibilities; shared care-giving); *informal support network* (for provision of emotional, informational, instrumental and companionship support) (Abery, 2006: 10).
- **Community support** presents a formal support network for the provision of emotional, informational and instrumental support, training or education, and the introduction to individuals who may become part of an informal support network (Abery, 2006: 14).

The past three decades have seen a considerable amount of research in an attempt to determine *how* families adjust and adapt to rearing differently abled children. Results point out that the *style* of family interaction has enormous impact on the ease and extent of family adjustment and adaptation, parenting competence, and child outcomes. In research directly relevant to the adjustment and adaptation of families with children with DS, Abery (2006: 10-11) shares his findings on family cohesion and family adaptability as follows.

3.4.3 Family Cohesion and Family Adaptability

Family cohesion refers to the emotional connectivity between family members. This ranges on a continuum from extreme connectedness (characterized by over-identification with the family) to extreme separateness (characterized by extremely low “sense of family”). Balanced levels of cohesion are viewed as functional, whereas continued functioning at either of these extremes is viewed as dysfunctional. The family needs to strike a balance between togetherness and separateness, allowing its members to deal more effectively with stressors and developmental change (Abery, 2006: 10).

Family adaptability refers to the family’s ability to change its power structure, role relationships, and relationship rules in response to developmental and situational changes Olson, Sprenkle & Russell (Abery, 2006: 10). The continuum of adaptability ranges from rigid (extremely low levels) to chaotic (extremely high levels).

Rigid families are characterized by authoritarian parents, stereotyped roles and rigid, strictly enforced rules. At the other extreme, in chaotic families there is little or no leadership, dramatic role shifts and reversals are the norm, and loose, arbitrarily enforced rules prevail. Moderate or balanced levels of adaptability (structured or flexible) are more functional and allows for a sense of stability, while it also provides room for change, i.e. rules, roles and power structure are flexible but not constantly changing or in turmoil.

Abery (2006: 10) found that families of children with DS displayed moderate levels of both cohesion (connected or separated) and adaptability (structured or flexible). These families showed more positive communication styles, reported lower levels of stress, were more satisfied with their marital relationships, had lower rates of divorce, and had children whose teachers rated them as having higher levels of social, academic, and behavioural competence than families who displayed extreme levels of cohesion and adaptability.

In practice I have witnessed excellent examples of styles and patterns of family interactions that facilitate the adaptation of individual families. These are families who function in a flexible separated manner (moderate cohesion; moderate adaptability) which allows enough autonomy for every member of the family, yet at the same time provides a profound sense of connectedness that encourages each person to feel that, if they needed support, it would quickly be provided. If a balance is struck with regards to family rules, roles and leadership so

that all family members feel that they are part of decision making, have well-defined roles and understand the basic rules under which the family functions, the needs of all the members of a family are met effectively, resulting in harmony and positive outcomes for everyone. It is all about give and take.

Little surprise then that one of the most important factors in successful adjustment and adaptation to rearing a differently abled child is *marital status and satisfaction*. I have seen in practice that single-parenting is one of the most powerful factors associated with stress and strain in families with differently abled children, as suggested by Beckman (Abery, 2006: 11).

The value of a supportive spouse as a resource in parenting a differently abled child is obvious and Giallo & Gavidia-Payne (2006: 938) note that parents who apply problem solving communication strategies reported higher parental function. Given the extra demands and challenges associated with caring for a child with DS, it is not surprising that the quantity and quality of spousal support is associated with both stress and child outcomes.

Interaction with people within their *social network* has certainly promoted adjustment and adaptation for the families that I have been involved with, as advocated by Abery (2006: 12). This interaction is supportive in a variety of ways, the most important being emotional, instrumental, informational, and companionship. To his end, research has shown that some forms of social networks are more beneficial than others to families.

Wikler (Abery, 2006: 14) suggests the establishment a network comprising of one or a few intimate friends with whom families have daily or semi-daily contact, rather than many acquaintances, none of whom are particularly close, as being more beneficial to families. Individuals within a support network who are able to provide a variety of types of support, protects the family from losing its sole source of support in a given area if an individual within the network should be unavailable for any reason. Related to DS, this would be advisable, as most mothers, by necessity, become rather skilled therapists and are able to advise new parents from breastfeeding to gross motor skill development and from early intervention to inclusive education options!

It is further advisable that parents become *contributing members* of such a support network, not only for the maintenance thereof but primarily also for the perpetuation of such a network. Reciprocating in such a manner will ensure continued support. Interestingly, it is often better

that all the individuals within the network do not know each other, as this eliminates the chance of losing all contributors to the network should problems arise between individual members.

3.5 COPING

According to Glidden *et al.* (2006: 951) coping refers to what the family *does* to achieve a balance between the demands on the family and the resources at their disposal. The simplest strategy to reduce demands is to redistribute them, for example, fathers who did not previously actively participate in household or childrearing chores may be roped in to do their share; older siblings may be assigned reasonable household tasks; overburdened families may obtain outside support from an informal support network.

Prioritizing and eliminating activities and roles that have low-level priority is another useful strategy. Related to families with a child with DS, it may involve limiting sibling participation to two leisure and recreational activities per week in order to reduce the demands on the parents' available time.

Glidden & Schoolcraft (2003: 253) maintain that coping mechanisms cluster into two main areas. **Problem-focused coping** relates to predominantly cognitive and behavioural strategies which will reduce or change the effect of the stressor event (the focus being the problem and not the person or emotion). **Emotion-focused coping** seeks to balance and regulate the feelings caused by a stressor event. Although both coping mechanisms may be required at times, families that predominantly use problem-focused coping have been found to have lower stress levels.

In its coping efforts, the family has to work at maximizing the resources available; applying them to the areas they are needed most, and also replenishing them continually. The demands of having a child with DS requires constant development of new resources, i.e. the skills needed to adapt to a baby are completely different from those required for an older child, an adolescent and later an adult with DS.

Family problems come in all shapes and sizes; some are short-lived and easily managed, while others are more chronic and difficult to handle. Stress points include events such as illness and injury, changing jobs, changing schools, moving and financial difficulties. A new addition to the family often causes stress, although this may diminish after a period of adjustment. However, if the baby is differently abled, the stress and adjustment period may very well be

prolonged, involving much more consideration, processing, contemplation and reflection. Each family develops its own ways of coping with these stresses, of which some work better than others. Having been married for almost thirty years, being a mother for half of that, and serving my community as teacher and mentor to families of children with DS, I have combined my academic background and personal experience gained from the school of life with theory to outline pertinent aspects of family coping in the following section.

3.5.1 Factors Contributing to Ineffective Coping

Poor coping can be recognized by a number of characteristics, including the following:

Poor communication: Family members either avoid talking with one another, or have not learned how to discern well what others are trying to say through their words, expressions or actions. A very common example is the scenario where the mother has spent endless hours with home stimulation intervention, ferrying the child from therapist to therapist over and above her normal domestic workload, and the husband may pass an insensitive comment about her poor time-management skills. Similarly, the husband may have been out working the whole day and comes home to an exhausted mother with frayed nerves who needs to unburden the horrors of her day on an understanding shoulder. The husband cuts her short at the door and heads straight for the television remote. He may be 'saying' to her, "I've had a terrible day, I need a few minutes to unwind before I take over from you", but she 'hears', "He doesn't appreciate me or my efforts..., we are not important."

I was involved with a family where the father had gone back to being a full-time student in pursuit of a life-long dream, while the wife had to deal with two teenagers (one with anorexia), a new business and a new baby with DS in a new town. She made it her mission to empower herself with knowledge on the syndrome and was burning the candle on both ends, whilst the addition of a differently abled child did not fit into the husband's egotistic profile, thus avoidance (of duties, communication and, in fact, of his family) became the norm. Fortunately in this case, the siblings did not take their cue from their father. On the contrary, they embraced their little brother and their situation, and this family has become superb advocates for DS. The marriage, however, remains on 'life-support' despite several attempts by the mother to alleviate the situation.

Unambiguous and effective communication is the foundation of healthy family dynamics, especially in a family with a differently abled child, as siblings need to be equipped with

communication skills and tools to use at school, on the playground and within their community. As illustrated by the abovementioned example, open and clear communication lines not only teach, equip and empower children to successfully communicate with peers, but sound communication between husband and wife is essential for modelling behaviour (Tanner Nelson, 2010).

Inability to resolve conflicts and disagreements: This usually occurs because family members *avoid* discussing problems or even *avoid admitting* that problems exist at all. In the case of a child with special needs in the family, this aspect is fundamental to family accord. If not, conflicts continue. Whilst conflict may cause some discomfort and unhappiness, it furthermore simultaneously *allows* the family to avoid what they see as the greater discomfort: that of *facing* the problem. Some families have either just not learned the skills of negotiating or, for some other reason, are unable to let go of bad or hurt feelings (Tanner Nelson, 2010).

Children are likely to pattern their behaviour after their parents' behaviour and may learn to refuse to talk about feelings and problems, thus also avoiding the issue of having a differently abled sibling. For example, a sibling who perceives his parents as spending all their time and attention on the child with DS does not always understand that the situation may be temporary, that his parents still love him just as much, and that they have only so much time that they need to share equally between two (or more) children. Parents may be exhausted and lack patience (with the child and with each other), which further reinforces the negative perception of the sibling's situation.

An example of possible contentious issues between mother and father could be related to the new baby's sleeping regime. The mother may insist, much to father's chagrin that baby sleeps in their bed. Similarly, the mother may, due to the baby's feeding routine, therapies or merely because she chooses not to leave her child with a minder, be unable to accompany her husband to as many social events as in the past. There are countless similar situations that could lead to conflict or disagreements. This may lead to frustration, and in time, even to social isolation. For the sibling it may result in withdrawal, under-achievement and behaviour problems at school.

Poor problem-solving: Conflict is a natural part of living together, but *how* conflict is resolved and problems are resolved, is important for the maintenance of healthy family dynamics. Poor problem-solving results in family members having trouble deciding *what* problems really exist or *who* is responsible. They are unable to agree on problem-solving *options* and how to apply or

implement these. If there is not agreement about what the priorities are within the family, this, too, may result in frustration, lack of family cohesion and a breakdown in communication, with negative results for the individual members of the family as well as the child with DS (Tanner Nelson, 2010).

Poor division of responsibilities: According to Schor (2009) families are often unclear on division of family responsibilities, leading to an overload for some, mostly the mother. In such cases family life can become chaotic, and many things remain unaccomplished. At the other extreme, some families are not flexible at all; not helping one another out or fairly assigning responsibilities as family circumstances change. Having a differently abled child in a family, by necessity, calls for reassignment of responsibilities, although parents should caution against consigning siblings to a 'substitute parenting' role or instilling any form of guilt in them. This could be detrimental to the sibling's own childhood experience and later recall thereof.

Insufficient emotional support: The most important source of emotional support for any person is the family. Salovey, Mayer, Caruso & Yoo (2009: 240) remind us that, especially children during the early and middle years, find it hard to obtain this emotional support outside the family and it is well-documented that children do not perform or develop well without it. Sufficient emotional support will strengthen the self-concept of other siblings as well as the child with DS within a family. The findings of a study undertaken by Giallo & Gavidia-Payne (2006: 938-939) on family factors as predictors of adjustment to children with disability, underpin what I frequently observe during my interaction with families: those who support each other emotionally, remain close, confident and optimistic about their ability to manage stressful times and they are able to employ effective coping strategies.

Intolerance of differences: Every person is unique and every individual has their own characteristics, especially the unique individual with an extra chromosome. Families function best when the individuality of each family member is acknowledged and appreciated. Even if the personal traits or characteristics of another member of the family are not necessarily valued by all, family members need to be tolerant and remain respectful of the individual.

Intolerance causes conflict, frustration and discord in families. It may even happen that family members withhold love from one another because of personal differences, but this, without fail, is to the detriment of interpersonal relationships. Children who may be subjected to such behaviour (from either parents or siblings) are likely to have a difficult time developing a healthy self-image. This results in low self-esteem and poor social skills (American Academy of Paediatrics, 2003).

Over-dependency on others: Children need to succeed in order to feel capable of successfully managing life's stresses and challenges. If they are taught or encouraged to depend on others (within the family or outside it) to solve their problems, they will develop low self-esteem and limited initiative and will have trouble succeeding in the world. The child with DS needs to be encouraged and supported to be as independent as possible in order to function successfully within society.

Making anyone, especially an individual with DS over-dependent on others will damage their self-confidence, compelling dependence on others for the rest of their life. My experience with especially older parents (with older children with DS) is confirmed by the assessment of Cunningham (1996: 93) of such a behavioural pattern. This has even been evident in cohesive families who have worked hard and positively for their child. They arrive at a juncture where they simply incorporate the young person into their own life-style. Sadly, this not only limits the experiences of the young adult, but it minimizes opportunities of age-appropriate socialization and exposure. Such a passive life-style is often a precursor to a passive personal coping style, which is referred to as learned helplessness.

The primary task of parents is to meet the multiple demands of family life with energy and creativity. By doing so, they enable their children to grow and develop in positive, healthy ways toward experiencing satisfaction and success.

Unfortunately, family dynamics are often viewed in the context of what makes a family *dysfunctional*. Within the context of a family with a differently abled sibling, outsiders often perceive this situation as catastrophic regarding the relationship of the parents and siblings as well as the financial situation of the family, their social relationships and their long-term commitment. From a personal perspective as well as my involvement with many families, I believe this to be a complete misconception and a supposition based on ignorance. Ignorance as in 'lack of knowledge about something' as well as ignorance stemming from preconceived prejudice.

Certainly there are those individuals and families who do not cope as well as others, but the general consensus is that family life with a differently abled child is, and can be, immensely rewarding, immeasurably joyful and extremely fulfilling for all the family members. It is all a matter of attitude toward the situation, the individual, and each other.

3.5.2 Factors Contributing to Effective Coping and Maintaining a 'Healthy' Family

Many parents agonize over whether theirs is a 'normal, healthy, functioning' family. There is no simple answer, since there are diverse definitions of the terms 'normal', 'healthy' and 'functioning'. There are, however, several characteristics generally identified with a well-functioning family. Some of these include support; love and caring for other family members; provision of security and a sense of belonging; open communication; and making each person within the family feel important, valued, respected and esteemed.

All the above are, and should be, part of satisfying, harmonious family functioning, whether it includes or excludes a differently abled family member. In fact, in families facing such challenges, these aspects require even more acquiescence to ensure positive outcomes. There are, however, also some other qualities to consider when evaluating how well a family is functioning. This would include positive responses to the following questions:

- Is there ample humour and fun within this family, despite the very real demands of their uniquely prevailing situation and daily life?
- Are there clearly stated, evenly applied, flexible rules that respond to new situations and changes in the family situation?
- Do family members have reasonable, realistic, mutually agreed upon expectations of each other and are they generally fulfilled?
- Are family members able to achieve most of their individual goals, and are their personal needs being met?
- Do parents and children have genuine respect for one another, demonstrating love, caring, trust, and concern, even when there are disagreements?
- Is the family mature enough to adapt to change without everyone getting upset or unhappy?

Bearing these questions in mind it is evident that much time, thought and energy need to be devoted to the following pivotal aspects which provide a supportive, emotionally healthy family environment.

Treating each child as an individual: Every child has a unique temperament, a unique view and their own way of interacting with the world around them. Although parents love their children equally, they inevitably have different relationships with each of them. Individualizing the relationship with each child, reinforcing their strengths and talents and avoiding unflattering comparisons to their siblings or friends, makes a child secure, within themselves and as a member of the family. Being treated as a *valued individual* has utmost significance in a

household where there are both typically developing siblings and a differently abled child. All children will thrive on having their individuality embraced and supported by family members, especially parents (Orphan, 2004: 49).

Maintaining regular routines: Families thrive on certain predictable day-to-day routines. Morning schedules, mealtimes and bedtimes are trouble-free for everyone when a pattern is followed. All children take pleasure in family rituals and traditions around birthdays, special occasions and family holidays and it is often only in retrospect that they truly come to appreciate the predictability (and dependability) of these events which provided and reinforced their sense of belonging and domestic stability. Children with DS function particularly well within well-structured routines and much of their security lays in the predictability of events (Fergus, 2009). This factor also supports why young adults with DS flourish in employment positions where the task at hand is manageable, predictable and routine.

Active participation in the extended family and the community: Families function better when they feel connected and supported by friends and relatives. This is especially true for families who have a differently abled child. Skilful utilization of family and friendship networks is associated with positive adjustments and outcomes in families of children with DS. Related to the aforementioned, Van Riper (2007: 118) further maintains that this is also supportive of enhanced parental subsystem functioning. Not only do friends and family take their cue from the behaviour of parents and siblings toward the child with DS, but continued close ties facilitate *their* expanded knowledge about the syndrome and practicalities thereof. They become empowered to construct a wider base of awareness about the specific challenges faced by families which include a differently abled child. Their increased knowledge and understanding, in turn, ripples out into an ever expanding circle of increased tolerance resulting in widely tolerance and acceptance of diversity in general.

It is supportive of parent and family functioning when parents make a concerted effort to get together socially with other families with similar circumstances, family support organizations and/or community projects. Involvement in society holds two-fold positive benefits: *awareness for the child* and *creating public awareness* (Orphan, 2004: 17-19).

For the family, there is the *freedom* of taking their child everywhere, thus exposing them to their community, society and the world. Secondly, because the behaviour of parents and siblings (especially with regards to their treatment of their child with DS) are constantly observed by others, their interaction with their child with DS is indicative to the public at large of how well adjusted families *can* be. This may be especially significant to members of the public who often

mistakenly perceive this situation as an intolerable burden. Thus, without much ado, the whole family group, almost effortlessly, accumulate and unobtrusively present most compelling advocacy for the inclusion of persons with DS.

During such informal, incidental observation of a child with DS, people are often amazed at the startling *similarity* between children with DS and their typically developing peers, once again dispelling preconceived notions regarding the syndrome. It is often within this context that society experiences first-hand indeed how *able* a differently abled individual can be.

Parents' realistic expectations of themselves and of other family members: The self-awareness, knowledge and skills of every individual within a family are constantly changing, sanctioning increased capabilities and expectations. In preparation, it is extremely important that parents equip themselves with knowledge on what should reasonably and realistically be expected of their children at each stage of development, whether it is their child with DS or a typically developing sibling.

A basic knowledge of DS and the realistically anticipated achievements of the child facilitate involvement of the entire family in the intervention, support and progress of the child with DS. Thus, every milestone successfully reached becomes the trophy of everyone in the family.

As children with DS are by nature copiers, their siblings are often their most adroit 'teachers' when it comes to day-to-day personal activities and household tasks or errands, socially acceptable behaviour, motor skills and communication skills. Since siblings seem to have a natural aptitude and talent for edutainment (my own word), parents tend to depend on them a great deal. Hence, the possibility of the real risk that siblings can be burdened with too much responsibility with regards to their brother/sister with DS under the guise of playing.

Parents should guard against placing the sibling under undue pressure and should always bear in mind that they are merely children themselves. It is often later in life that siblings admit to feeling overly responsible, often accompanied by pangs of resentment for having been obliged to accept responsibilities more appropriately assigned to an adult. It does, however, appear that as their insight develops with maturity, the siblings come to realize later that the tasks, responsibilities and sacrifices made for their sibling with DS realistically did actually not amount to much more than what would have been the case for any other younger sibling. Parents need to carefully manage and monitor such allotted responsibilities, bearing in mind that accountability should be age- and situation appropriate. The goal should be to maximize

enjoyment and effectiveness of sibling involvement and participation whilst at the same time minimizing possible stress for everyone involved.

Parents, too, have limitations on what they can accomplish, given the resources and the time available to them. Siblings need to help. It is that simple. It is fundamental for the well-being of the whole family that parents realize that there are no "super-parents," just individuals doing their best.

Ensuring that quality family time contributes to good relationships: Time is a valuable and scarce commodity. It should therefore be spent on something equally priceless: family togetherness. Time spent with children and a spouse should be relaxed, meaningful, fun and relatively conflict-free. Children take their cue from the union and harmony within their own homes and lessons learnt within the safety of the family fold is applied in the world outside their walls. Growing up within a cherished home environment reinforces the sense of security of all family members, strengthens familial bonds and reinvigorates the spirit of unity for each individual as well as for the family as a unit. The child with DS, who is by nature sensitive and a peace-keeper will not only derive much pleasure from seeing his/her family in a loving and close liaison, but his experience of security and happiness will be enriched.

Parents, single or as a couple, taking care of their own needs: This is often easier said than done for most parents. It is mostly the mother that bears the burden. The mother of a differently abled child often tends to lose herself completely in the constant maelstrom of personal needs, therapies, medical matters and time-consuming interventions and support required by her child. There is a saying, "if mother is happy, everyone is happy..." which supports the notion that a healthy personal life of especially the prime carer of the differently abled child, i.e. the mother, is vital for the mental and physical survival and progress of not only herself, but the entire family nucleus.

To this end, a healthy personal life includes proper, balanced diet, exercise, sufficient sleep, and setting aside (however brief) 'me'-time for something personally gratifying and enjoyable. Having strong emotional, supportive friendships may also stand the mother in good stead during tougher times.

Children thrive when the emotional needs of their parents are being met. They flourish when they are reared by parents who are in a harmonious relationship with each other. That being said, it often happens that the relationship between parents significantly change direction

following the birth of a differently abled child. This event has the potential to open a Pandora's box of potential negative issues pertaining to added financial pressures, less 'alone-time' (individual and as a couple), constant concerns about health, education and matters relating to the social and scholastic inclusion of their child, as well as possible anxieties concerning paternal 'tainted bloodline' issues, and concerns about the long-term commitment that comes with parenting a differently abled child. Parents are often also in turmoil about future reproductive choices and decisions.

Parents taking moral and social responsibility for their own lives: A parent is the most important role model for their child. They constantly demonstrate their value system through their actions, attitudes as well as their words. The children in a household will take their cue from their parents in terms of almost anything, and in this case, specifically *how* their sibling with DS is treated, spoken *to*, spoken *of*, and is included in the family (close and extended), the community and society as a whole. The position of parents toward diversity and dealing with situations, especially around the diversity within their family set-up, will also be indicative of future family functioning and the sustaining of a positive family dynamic. The example set by the parents in terms of a basis of sound moral and value systems will furthermore serve as a predictor for future outcomes for the children and the family system.

Family dynamics and the general functioning of the family are also influenced by a number of frequently-neglected alternative contributory factors. These may include the following:

Firstly, there is the consideration of the composition of a household. Restructured families with siblings from previous marriages are common nowadays and each of these individuals arrives with a *personal history* (involving perceptions, ideas, thoughts and experiences) from their original family, which is likely to add a new dimension to a family unit. Sometimes extended family members live together in a household. It stands to reason that age, maturity and relation to the child with DS will greatly influence a family member's perception and understanding of a family member who is differently abled. Obviously, a 78-year-old grandparent is going to experience family matters differently than an adolescent grandchild.

Secondly, it is the individuals in the family, personalities and family circumstances which determine the roles within a family. Next to roles, there are also rules within families. These rules usually govern behaviours and interactions within a family. The role-players, roles, rules and interaction of these shape the dynamics of a household. Some family rules are common knowledge, like cleaning up after yourself, and so forth. Other rules may be unintentional and

sub-conscious, like maybe *not* talking about your sibling's DS or associated conditions, or never discussing feelings and experiences with anyone outside the immediate family. Family secrets can cause ripples in the pool of family dynamics, but conversely, open, honest, positively oriented family communication promotes healthy family dynamics.

Part of coping entails dealing with a wide spectrum of emotions. As the parent of a differently abled child, you experience every emotion on the emotional continuum and every emotion is valid and justified. Van Riper (2007: 118) maintains that not only do parents experience pain, despair, suffering and sorrow, but also joy, hope, happiness and optimism, and the ability of a parent to embrace *this* paradox ultimately enhances parental and family adaptation. The growing recognition of the paradox of disability, which acknowledges that the task of parenting a differently abled child is, indeed, a paradox filled with conflicting emotions, motivated me to include a section on *grief*: the *one* emotion that *every* parent of a differently abled child experiences, yet many frequently disregard or actively hide.

3.6 GRIEVING 'WHAT MIGHT HAVE BEEN'

Nicoll (Dowling *et al.*, 2004: 11) defines *grief* as “a personal and emotional reaction to a significant loss; most commonly the death or involvement in unforeseen tragedy of a loved one”.

Grief comes to everyone at some stage of their life. All societies acknowledge this emotional state through ritual and ceremony, but *how* grief manifests itself when there has been *no death*, is the dilemma faced by the parents of a differently abled child. However, it is not necessarily only physical loss that brings about grieving, it can also flow from the loss of hopes, dreams, ideas and expectations – loss of ‘what might have been’ (Dowling *et al.*, 2004: 11).

The experience and expression of grief is as unique as the individual going through it. Not only does it affect each person in the family, but also the family as a unit.

In general, loss disrupts the natural coping strategies of a person, resulting in a process of grieving that is aimed at resolution (Friehe *et al.*, 2003: 211). The resolution: acceptance. It can therefore be said that grief is a dynamic, complex and psychosocial process produced by forced change (Friehe *et al.*, 2003: 212).

Grief is an emotion that involves several sub emotional stages. Some people go through the stages several times. Some may get stuck in one stage, or reach a stage of acceptance and then go back to one of the other stages when a different situation or milestone comes into their

life. Grief may be a long, ongoing process or a short, one time process. For some parents, the grief never stops; it just pauses now and then.

Because parents often feel that it is 'improper' to grieve when a child has just been born, I often encourage them to go through the motions by explaining that they have to grieve for the child they were expecting before they can accept the child they have. For the parent whose child is diagnosed with DS, it is no longer just the loss of what *could* have been or what *should* have been, but also grief and anguish about the future.

The five stages of grief were originally conceptualized by Swiss psychiatrist Dr. Elizabeth Kubler-Ross in her book "On Death and Dying". Although these stages originally focused on grief that occurs after death, they can also occur in response to other types of loss, such as having a differently abled child. Two terms for differentiating loss have emerged in literature: stage grief and episodic grief.

3.6.1 Stage Grief

Stage grief refers to loss in reaction to death or terminal illness. Despite its personal nature, there are a number of general stages that most people pass through on the road towards accepting significant loss. Dowling *et al.* (2004: 12) postulate that between three and seven stages (with significant emotions), occur during stage grief.

Shock is a stage often characterized by feelings of numbness, disbelief, sensations of being disconnected from the reality of the situation, confusion and bewilderment. Friehe *et al.* (2003: 213) define *denial* as the period which temporarily relieves painful feelings and provides time to regroup until the reality of the new situation is tolerable.

Anxiety, within this context, refers to the concern, fear and insecurity of the unknown. The significance in experiencing this emotion is that the discomfort forces redirection of energy to action that is more positive. It was my experience of this emotion which propelled me toward the need to be an expert on the disorder and the constant search for the best answer (Friehe *et al.*, 2003: 213).

Although *anger* appears to be an unhealthy emotion at face value, Nicoll (Dowling *et al.*, 2004: 12) considers it the beginning of healthy emotional healing, as it allows release of emotions, opens the door to acceptance and the individual can begin focusing on the present. Unless

anger is dealt with constructively, it may, however, heighten stress and interfere with constructive problem solving. Pining and reminiscence is part of this stage of grief, yet it is complicated to define in the case of parents experiencing grief at the diagnosis of a differently abled child, as the child is still with them, as opposed to having passed away.

Guilt feelings in the case of having a child with DS are likely to arise from a sense of failure and regret at the loss of previous expectations. Dwelling on what cannot be changed or controlled is of little, if any, value and may result in relationship problems. I have found that some parents attempt to compensate for this guilt by working tirelessly on their child's educational and therapeutic needs and by making their differently abled child the family's number one priority at all times. Ironically, this strident dedication could ultimately lead to more compound feelings of guilt as the parent realizes that the needs of the rest of the family are being neglected (Dowling *et al.*, 2004: 12).

Nicoll (Dowling *et al.*, 2004: 13), define *acceptance* as the acknowledgement of their child's diagnosis as reality. At this stage, people begin to re-organize their lives, re-focus their energies and get on with life.

For the parents of a child with DS, who face many demands after the diagnosis, a place of acceptance is not always clear cut. They are often so immersed in DS and their child's interventions that they may find themselves too busy to grieve. Such a delay in the grieving process may result in delayed attainment of acceptance.

3.6.2 Episodic Grief

Episodic grief refers to the loss experience of normal communication or ability in a family member. The episodic approach to loss is also referred to as *chronic sorrow*, *mobile mourning* or *recurrent sadness* (Friehe *et al.*, 2003: 214).

The primary difference between stage grief and episodic grief is that the latter is a prolonged process with no predictable end and perhaps no complete resolution, as it tends to be revisited at critical life junctures, according to Friehe *et al.* (2003: 214). Unlike stage grief, the parameters for episodic grief are less well defined, more pervasive, unanticipated, and cyclic. Because the source of their grief, in this case the child with DS, remains a tangible presence in their life, parents often find themselves returning to their grief. However, in some situations

they may not even associate these feelings with their child, as there has been no death. In such cases mourning is related to the ongoing *challenges presented*, and not the *person*. Friehe *et al.* (2003: 215) suggests that parents detach themselves not from the person, but from the syndrome which conducive to event-focused problem solving in the long term.

3.6.3 Dealing with Grief

The emotional pain experienced by parents may leave them with little energy to take care of themselves, their family or each other. Grief is an isolating emotion, and in the interest of forging strong familial bonds, it is important that family members talk to each other, share their feelings and fears, thus sharing their burden.

Emotional pain often entices people towards increased use of alcohol, cigarettes, tranquilizers and antidepressants as a means of helping them cope. Although this attempt to 'forget' their troubles for a while may bring temporary respite, it may further damage family relationships and confuse siblings. Friehe *et al.* (2003: 218) remind us that siblings and extended family members share the grief process. They, too, have had different expectations for their relative and for the interaction they would have with that person. To them there is also the prevailing sense of loss of anticipated experiences and relationships which may be replaced with confused perceptions of what they can readily expect as well as what is expected of them.

Despite the availability of information and support for families dealing with the death of a child, information and support for families dealing with the emotions related to having a differently abled child is sorely lacking. Dowling *et al.* (2004: 7) agrees that too often sentimentalizing the truth of raising a differently abled child demeans both parents and child, creating more stress for the parents who are still coming to terms with their child's diagnosis. Syrupy catchphrases, overtly sentimental mention of "being strong and counting blessings for the gift of a little angel" does not quite cut it for the parent who is going through very real emotions and the realization that the new set of circumstances is a frighteningly permanent arrangement. Often very little mention is made of sleepless nights, fear, frustration, many tears, or a life dominated by medical appointments, therapists, anxious hospital visits, battles with an unsupportive education system and the jarring insensitivity of a less-than-understanding prejudiced public in a less-than-accommodating world. This is how it *really* is for many parents of a differently abled child.

Parent support organizations usually have a designated person who meets with the parents, but sibling emotions are often neglected in this regard. Parents are often so overwhelmed that they are unable to deal with sibling questions and emotions in a rational, unemotional manner initially, leaving the siblings to deal with all of this turmoil by themselves. This creates confusion and anxiety for the sibling, which is very likely to affect their feelings about and reaction toward their new sibling.

According to Friehe *et al.* (2003: 217), mothers are more prone to episodic grief as they primarily assume the care-taking responsibility and time-management crises are mostly relegated to them. Friehe *et al.* (2003: 217) note that grief of fathers is often related to comparisons between their child and society's conception of a typically developing child.

Friehe *et al.* (2003: 216) maintain that episodic grief stems from the repeated modifications in family routines over time, such as experienced in families with a child with DS. Families make adjustments out of necessity in order to accommodate specific needs, locate additional financial resources, seek related services, make decisions based on the dynamics of the disorder and accommodate straining marital and family relationships.

Although families are frequently anxious about possible social isolation, Dowling *et al.* (2004: 128) remind us that it is indeed in times of crisis that you find out who your real friends are. Some parents find that the reason for their shrinking social circle after the birth of their child is because they themselves have become more selective and critical of whom they let into their lives, and not the other way around.

Social support systems change due to the ongoing nature of the challenge, cultural expectations and the comfort level of friends and family. This facet is discussed in the following section, with specific reference to a touching essay written by a parent of a child with DS (see Addendum A).

3.7 “WELCOME TO HOLLAND”

Each individual, with or without DS, has different capacities and needs, and so does each family. Each family will respond to the situation of having a child and sibling with DS in its own unique manner. Although some families cope extremely well with rearing a child with DS, other

families, for a variety of reasons, have considerably more difficulty. Many families do much better than cope; they thrive.

Having a differently abled child is not expected. It often necessitates a change in plans as the family members adjust their views of their own future, their future with their child, as well as how they will operate as a family.

In a poignant essay written by a parent of a son with DS, “Welcome to Holland” (see Addendum A); the mother draws an analogy between a voyage to an unexpected destination and the birth of a child with an unexpected disorder (Friehe *et al.*, 2003: 220). This analogy circumscribes the reactions of families of a child with DS perfectly. The author, Kingsley draws a parallel between having children and planning a voyage, both which involve excitement, planning, itineraries, shared roles of family members, and tips for successful travel. When the child is born differently abled, unexpected modifications of these plans and itineraries happen, as this ‘trip preparation’ hardly ever includes tips for coping with a disorder. Thus, the responsibilities and roles of the ‘travellers’ are altered and the final destination is changed.

Kingsley describes the never-ending pain that involves an altered itinerary involving a differently abled child, especially as fellow travellers continue to refer to and compare their fulfilled experiences in “Italy” with their typically developing children.

In response to Kingsley’s essay, another parent, Cathy Anthony (2003) describes her anguish at her relocation to ‘Holland’, which required family adaptation to a new territory, new language and new friendships, but moreover to appreciate the value of their change in plans (see Addendum A1). This does not just influence the parent or individuals in a family, but the entire dynamic of the family system is affected.

3.8 FAMILY DYNAMICS

Family dynamics refers to the ways in which family members relate to one another. This relationship is affected by many factors, not least being the extraordinary set of circumstances that come into play when a differently abled child becomes part of this equation. This brings about a complete change in how the family communicates, functions and reacts henceforth. Because humans are capable of change, and family members have individual perceptions and different experiences, the dynamics within a family never remain the same. Family dynamics

strongly influence the way people see themselves, others and the world, and exerts a powerful influence over their relationships, behaviours and their well-being. Therefore, an understanding of the dynamics of family functioning holds the key to identifying factors affecting family stability (Pretorius, 2005: 42-46).

This necessitates an initial understanding of the theory behind family dynamics and functioning (see Section 4.4.2), but as a backdrop for this chapter, the following concise clarification will suffice. Family systems theory views problems in an encompassing manner, using what is called a 'systemic perspective' (Jacques, 2003). Understanding problems requires the assessment of patterns of interactions, with an emphasis on *what* is happening, rather than *why*. This approach emphasizes the bi-directional nature of relationships, and moves away from blaming one person for the situation. Symptomatic behaviour is seen as arising out of the inter-related behaviour of all family members, therefore, in order to gain a better understanding of a person's situation, their behaviour is explored in the context of their family system, rather than in isolation.

Some of the many influences on family dynamics include:

- nature of parental relationship;
- parenting style – authoritarian (particularly strict), laissez faire (permissive and uninvolved) or absent parent;
- number of children in the family;
- personalities of family members;
- the configuration of family members living in the same household;
- level and type of influence from extended family or others;
- a chronically sick or disabled child within the family;
- events which may have affected family members, such as an extra-marital affair, divorce, trauma, death, unemployment, homelessness;
- other issues such as family violence, abuse, alcohol or other drug use, mental health difficulties, other disability;
- family values, culture and ethnicity, including beliefs about gender roles, parenting practices, power or status of family members;
- nature of attachments in family (i.e. secure/ insecure);
- dynamics of previous generations (families of parents and grandparents);
- communal systems (social, economic, political, including poverty).

Each person within a family unit has their own perception about what either supports harmony or causes conflict. Although every family member has their own theory/idea/perspective about a situation or incident, there is no requirement to reject one, but instead to see both as two sides of the one coin. There is an attempt to transcend 'either/or' dichotomies, and instead to embrace the idea of 'both/and'. One cannot exist without the other, and one gives meaning and contrast to the other. This meaning is the *personal truth* for someone, and not necessarily the true meaning.

Within the family system people take on different roles, which may be the result of the specific family dynamics, and not necessarily a result of conscious choice. Some of the more common roles that people (especially siblings or even the child with DS) take on in a family may include peace-keeper; 'black sheep' or the actual 'elephant-in-the-room' (the syndrome itself) may play a role. A child may unintentionally be playing the role of 'peace-keeper', mediating and reducing tension between conflicting parents. Their behaviour may be in response to their unconscious anxiety about family breakdown and this role may lead them to stay as a child in their family rather than to move towards age-appropriate independence. Sometimes a specific problem or challenge (for example drug use), may play a 'role' in the family system, distracting the family from other problems. In the case of DS, the parents may make the focal point all their attention the child with DS (or the syndrome itself) that they constantly avoid dealing with their own pain, grief, or unfulfilled emotional needs. Under a guise of superficial harmony there is often a complete disintegration of normal adult or spousal communication, with detrimental effect on their relationship, the family and sadly, the child(ren) that they so intently focused upon.

The attitudes of each family member toward each other, impacts not only each individual's self-identity and self-worth, but also the family dynamic per se. An example may be the very negative effect that ascribing labels to others within the family may have not only on the individual, but also on the functioning of the whole family dynamic. For example, in a family where emotional toughness is valued, a sibling may be called a 'sissy' for crying when the younger sibling with DS writes in his/her schoolbook or destroys a project. This may lead to certain responses by the individual, such as 'toughening up' or managing low self-worth in a destructive manner. To this end, parenting styles and parenting skills need a constant check, especially within a family where the dynamic may be influenced by the addition of a differently abled sibling. Warm parenting, as described by (Pretorius, 2005: 62) results in closeness of the I-you relationship between parent and child, which is regarded as the most important aspect of

child rearing. Acting lovingly, supportively and affectionately toward the child; encouraging, praising, showing interest and offering the child loving care and protection indicates the parents' acceptance of the child. Discussing plans with the child, setting realistic goals and offering wise advice will further support a strong relationship between parent and child.

Parents should further share the power in a family and support each other in decision-making surrounding their children, avoiding damaging alignments and hierarchies that may hamper optimal family functioning. Furthermore, parents can maintain positive family dynamics by identifying the strengths of each individual within the family and emphasizing the value of their attributes. An authoritative parenting style, which values and respects the opinion of each individual, will yield positive outcomes for the family with a differently abled member. Strong, sound family values, firm boundaries with appropriate discipline, attainable, realistic goals and positive, warm and supportive interaction between family members will promote sound family dynamics (Pretorius, 2005: 44-45).

3.9 SIBLINGS

Schuntermann (2007: 93) states that parents raising a child with significant developmental challenges are profoundly aware of the often sustained impact of that child's special needs upon their other children. However, Rossiter & Sharpe (2001: 66) confirm that whilst the majority of siblings are well adjusted there are a small number of siblings that may be at risk of developing significant adjustment difficulties. Such adjustment difficulties have mostly been associated with poor parent functioning, high family conflict, poor family cohesion and adaptability, and poor problem-solving communication (Fisman, Wolf, Ellison & Freeman, 2000: 372).

Schuntermann (2007: 97) postulates that siblings of differently abled children have a heightened sensitivity to family conflict whilst Dunn (2002: 23) concurs that the quality of marital relationships is linked to that of the relationships between siblings, suggesting that strong and positive marital relationships and parent-child relationships are correlated with satisfactory relationships among siblings. Dunn (2002: 13) cautions that sibling relationships are likely to be compromised when they perceive differential treatment which, according to Schuntermann (2007: 97), increases conflicted and hostile sibling relationships. Mackay (2003: 98) advises that families who remain close, confident and optimistic about their ability to manage stressful times have a higher capacity to employ effective coping strategies. To this end siblings are encouraged to learn problem-solving strategies within their families and to garner positive peer

relationships and good relationships within the family unit. Not only will this enhance self-worth and coping skills, but these are often seen as protective factors in psychosocial functioning (O'Dougherty, Wright & Masten, 2005: 17).

Sibling adjustment is further associated with family resilience factors, according to Giallo & Gavidia-Payne (2006: 945), Mandleco *et al.* (2003: 365) and Van Riper, 2002: 277). Resilience is not a trait that renders an individual invulnerable, rather it is tied in with demonstrating competence in the face of serious current or past adversity. Schuntermann (2007: 102) list family strengths that support resilience as follows: close family relationships, good boundaries, effective communication, and consistent, reasonable family rules (see Section 3.5.2). Some important individual resilient attributes include good judgment, social competence, self-agency, and intelligence. Communal behaviour, friendliness, and helpfulness (Yunger, Corby & Perry, 2005: 110), together with the capacity to reach out for support from friends, teachers, or extended family members, are qualities that further support coping and resilience (Schuntermann, 2007: 102).

According to Cuskelly & Gunn (2006: 924), having a sibling with DS does not appear to have a significantly negative impact on the typically developing sibling in terms of problem behaviours or self-perceptions of competence, and as such, it does not seem to penalize the opportunities of typically developing siblings to participate in a normal childhood. On the contrary, Cuskelly & Gunn (2006: 924) suggest that having a brother or sister with DS may indeed produce positive effects such as increased levels of empathy or appreciation for individual differences.

Recent research findings of Seltzer, Greenberg & Orsmond (2005: 354-359) indicate that brothers displayed more positive emotion (and less negative emotion and worry) in relation to their differently abled brother, whereas the emotional involvement of sisters was not affected by the gender of the differently abled sibling. Furthermore, sisters were found to be most involved, provided greater amounts of care-giving and companionship, and had a more positive effect on their sibling with DS.

It is thus logical to conclude that the relationship between the successful functioning of siblings with and without DS can expect a positive and mutually conducive outcome predominantly hinged on the strength and health of the family as a functioning unit. It would be safe to say that the positive attitudes and internal strength of the family is pivotal to the successful functioning

of the siblings during their experiences in the family unit as well as their achievements outside of the family where they have the opportunities to excel on their own.

3.10 FAMILY FUNCTIONING

Parenting can be a daunting challenge and all children are at times a source of frustration and exasperation, not to mention financial stress. Notwithstanding these challenges, these years are very likely to bring countless moments of joy, pride, laughter and closeness.

- **Potential Risk Factors**

Adolescence, and especially the teenage years, may mark be a daunting phase in any household with potential risk to harmonious family functioning. A comprehensive research study spanning several years yielded results regarding teenagers with DS as follows (Cunningham, 1996: 87): Mothers perceived the following: negative effects of the child with DS on the family; a decline in social support; the child with DS was placing greater restrictions on family life compared to a typically developing teenager; the teenager with DS had diminished social contacts and friendships; and increased levels of behaviour problems. In order to avoid duplication, a response to these concerns may be derived from the previous chapter which deals with associated features of DS, such as psycho-social issues, behavioural challenges and language challenges (see Section 2.7.3) discussed by Buckley & Sacks (2002). Strategies to address these issues will be supplied in Chapter Six as these concerns are consistent with this research study.

Although Cunningham's study outcomes reported that for the majority of families the management of the child became easier as they got older, which was associated with increased self-sufficiency and reduced behaviour problems, a study by Eisenhower, Baker & Blacher (Cuskelly *et al.*, 2008: 106) reported an increase in stress of mothers as the child became older. There are a number of variables that have been found to parental outcomes and a difference in response to the pressures of raising a child with DS was noted by mothers and fathers. Mothers reported higher stress levels associated to the parenting role and fathers reported more stress related to their attachment feelings to their child, which confirms the findings by Cunningham (1996: 90) who found that fathers of children who are low functioning and have moderate to severe cognitive difficulties (with or without behaviour problems), consistently reported lower satisfaction with life over the years. Although this appeared to be

more evident in cases where the child is a boy, these fathers further reported attachment issues as they battled to fulfil their parenting role while they were coming to terms with having a differently abled child.

Prolonged hospitalization and intense care-giving cases necessarily increase strain on a family and can also alter child management methods and expectations of child functioning. This may lead to increased over-protection by parents and increased dependency for the children. Should this behaviour occur in families with relationship problems, the effect will dramatically escalate. I have found that behaviour problems in children with DS and their siblings are found to be significantly associated with poor family relationship patterns (see Section 3.8) and not with any characteristics of the child with DS, confirming in practice, that family well-being is always identified as a central catalyst to adjustment and coping for parents and siblings.

Consistent with Cunningham's findings (1996: 101), wishful thinking as a coping strategy, is not effective, as it is unlikely to resolve the problem which remains as stressor. The mere 'hope' that things will improve, eventually gives way to 'acceptance', with the family increasingly adopting a routine of passive style of coping. Despite earlier interventions and much effort with the development of their child, some parents eventually adopt a "que sera sera" (whatever will be will be) attitude. This is often seen in families of young adults with DS, who, by sheer exhaustion after years of input, fighting the system and butting heads with bureaucracy, merely regress into less stressful, easy routines and the young adult is simply inculcated into the life-style of the parents. Sadly, in such cases the young adult is likely to adopt a passive personal coping style which is often referred to as learned helplessness.

- **Transformational Outcomes**

Over time, parents may experience changes in ways of seeing their child, themselves and the world. These new perspectives may encompass profound rewards, enrichments, and the appreciation of the positive contributions made by people who are differently abled (Nelson, 2002: 515).

Families cope by attributing positive meanings to their situations, defining them as manageable and making efforts to regain a sense of control. Hodapp (2007: 280-282) presents a wide range of positive changes of transformational outcomes that have been reported by parents of children with DS. These include the development of personal qualities such as compassion, tolerance, patience and love; improved relationships with family members and others; stronger

spiritual or religious beliefs; an ability to focus on the present; and a greater appreciation of the small and simple things in life.

It is evident in research that, with time and experience, parents of differently abled children may come to regain a sense of control over their circumstances and a sense of meaning in life by seeing the positive contributions of their children with respect to personal growth and learning what is important in life (Van Riper, 2007: 124).

- **A Change of Destination**

Mulroy, Robertson, Aiberti, Leonard & Bower (2007: 217) remind us that no matter how harmonious parents may want their family life to be, some disruptions and disturbances are inevitable, often stressful for every member of the family. The birth of a differently abled child disrupts the status quo of the course of family life, which can be unsettling for siblings who may not always understand. It is therefore imperative for continued optimal family functioning that siblings are included at every stage of the change in destination as families find themselves arriving and settling in 'Holland' (see Section 3.7).

Just as important as the home position is, so is the situation at school. The 'news' of the birth of the differently abled sibling will spread like wildfire and many opinions will fly around the school and playground. Research shows that the more family involvement with the school, the better that learner does in school (University of New Hampshire, 2008).

In our family experience, this situation was dealt with in a most sensitive, caring and nurturing way. We were of the fortunate ones. My daughters attended a Christian school. Their teachers visited us at home, bringing gifts, cards and prayers. Their foremost concern was the emotional well-being of my daughters and to this end, they had gained information about DS beforehand and sought my permission to discuss the topic in the classroom situation should this become necessary. During prayers, all the other children prayed for the new baby and the teachers took their cue from my daughters to discuss DS in class. This mostly transpired incidentally when my children did oral presentations in class featuring DS in one way or the other. The topic of DS has always been discussed openly and freely in our home and no-one, children or adults, were ever uncomfortable about the subject. Our experience was that people were curious, not callous.

- **Families Creating Positive Awareness**

Opportunities to create awareness present itself in many ways. When my daughter with DS was 6 weeks old, we were invited to the pre-school class of my middle daughter, who was doing 'families' that week. As the only family with a baby at that stage, we were an obvious choice. With the good weather in mind, I offered to give a bath demonstration, which was, needless to say, a spectacular success amongst the awe-struck four year old spectators, who also did not bat an eyelid when I breastfed the baby after her bath. I afforded the opportunity to explain in very simple terms that she was a little bit different, and they had the opportunity to see first-hand that, although she had an extra chromosome (and was a quarter of their size), this little girl was just like them. My daughters and I have used many similar opportunities since to create awareness of DS, and being ambassadors for DS is a family passion and commitment.

- **Spiritual Inspiration**

There is increasing evidence to suggest that it is a person's inner world of values, beliefs and inspiration that helps determine the process of coping (Do Rozario, 1997: 427). As evidenced in comments of participants to this study, spirituality and religion play a major role in many of their lives, reflecting a sense of strength gained from spiritual well-being. Pretorius (2005: 45) suggests that the basis of the child's views and experiences is laid in the family, and to guide the children in respect of faith, to realize a spiritual lifestyle and to practice joint religious activities is one of the core functions of the family.

Spiritual development impacts many other areas of family quality of life. Strength gained from faith and related activities provide a resource that enables family members to meet the challenges they face in everyday life. Challenges from other aspects of life, for example financial, health, emotional, social or daily life, can be ameliorated by the strength and sense of well-being gained through strong religious conviction and social support from members of their religious community. Personally, I drew much strength from a strong spiritual connection to my Heavenly Father and came to rely on this relationship and my faith more than ever before in my life.

- **Embracing the Change in Destination**

How parents deal with the change in family functioning once a baby with DS enters the family largely sets the tone and the pace for future family functioning. I can only first-hand relate to

our own experience: As a mature and more experienced mother, within hours of hearing that my daughter had DS, I realized that I may have to change everything I *thought* I knew about being a mother, and adapt my skills (and my head) to the newly presented set of circumstances. *Deciding* to make changes was the easy part. Despite still being 'cocooned' in the hospital, I instinctively realized that society would feature prominently as a future role player. This hurdle, I knew, would pose quite a challenge, as not every unobtrusive glance could be followed up with an enlightening lucid explanation. I knew I would not always be able to protect my daughter from prejudice, ignorance and thoughtless indifference. I found myself in scary uncharted waters and knew instinctively that I would have to initiate the change.

I knew without a doubt that people who crossed my daughter's path would take their cue from me, her mother. Change can be a wonderful gift, as indeed, it was. It was at that time the key that unlocked the doors to growth and excitement for myself and for many others, and most importantly, for the superb individuals who make up my family. As DS became a part of our world, it inspired our 'team' to get out of our comfort zones, and my duty now included constantly assuring them that even though we were on a new path, it was the right path for the right reasons. We simply had to embrace our new destination.

Underpinning the aforementioned reflection, Mackay (2003: 114) confirms the value of communication to help families deal with conflicts and problems that may arise (see Section 3.5.1) in order to maintain healthy family functioning. Regular and predictable roles, routines and activities established within the family will also stabilize healthy behavioural, social and academic outcomes in children according to Giallo & Gavidia-Payne (2006: 393).

As evidenced by the outcomes of the numerous studies undertaken regarding family function and DS, the picture appears more positive than negative. However, there are potential risks to sustained positive family dynamics. As is evident from the preceding section extolling the virtues of sound family coherence, it is to be noted and confirmed that expectations and predictions should be kept realistic and attainable based on the measure of healthy family situations with full apprehension and anticipation of potential risk factors which might present themselves.

3.11 CONCLUSION

Empirical evidence has produced positive and negative outcomes. As an individual, a parent and a member of a family unit with its own set of circumstances, situations and perceptions,

one has to consider the existence of multiple realities and of multiple truths. Variables within each sample and each study are significant. What may be true for one family may not necessarily be the reality for the next. Therefore, generalized assumptions that the family or individual members are necessarily 'at risk' for psychological problems just because one member has DS is dispelled as literature also provides support of harmonious, warm, cohesive family functioning, positive adaptation and the notion that the child with DS can positively contribute to the family. However, the intention is not to minimize the very real challenges faced by these families, as they indeed experience considerable trauma following the birth of their 'unexpected' child. Furthermore, in their roles as parents, relatives or siblings of a child with DS, they have the added challenge of developing new knowledge and skills and to reconstruct their ideas about themselves, their values and aspirations. This is done amidst little understanding and much prejudice.

Parents have to learn to deal with a wide range of professionals and bureaucracies and develop assertive negotiating skills in order to obtain the best resources for their child. They also have to develop practical problem solving strategies and maintain a positive expectant attitude for their child despite the many set-backs, discouragement and slow progress. The fact that so many families cope well is a testimony to their commitment to their child, and their adaptability and strengths, rather than a lack of problems.

Researching the literature on family perspectives and family dynamics, I was astounded at the wide scope encompassed by family functioning. Although I have constantly correlated with my research questions, volumes can be written about each facet of each issue. Although this is just the tip of the ice-berg, I have endeavoured to hone the relevant content to support and answer the research questions without compromising on substance.

This chapter provided a comprehensive overview of factors that influence family perspectives, family dynamics and coping. The overall impression of the families and children with DS is one of normality. The factors that influence their well being and that of the child are largely the same as those influencing any child and family, emphasizing the wide range of individual differences between and within the families and amongst the children.

Chapter Four will expound an in-depth description of the research design and methodology followed in this study to provide answers to the research question.

CHAPTER FOUR

RESEARCH DESIGN AND RESEARCH METHODOLOGY

4.1 INTRODUCTION

The core of this research rests in Down syndrome (DS). Although this chapter is dedicated to the research design and methodology, careful consideration from an academic research perspective motivated my decision to include the philosophical approach and theoretical framework on which this research is based, in this chapter.

Chapters Two and Three therefore exclusively focus on information pertaining to DS per se. As the research topic called for a two-fold literature study – the etiology of DS on the one hand and the various facets of family dynamics on the other – the decision was taken to divide the literature study into two chapters. Chapter Two comprise solely of the etiology of DS (including aspects such as prevalence, incidence, characteristics, associated features and outcomes) whilst Chapter Three incorporated aspects of family dynamics such as intra-personal functioning of family members, inter-personal relationships and the process leading to acceptance, coping and function.

Due to the comprehensiveness of the preceding two chapters, I have chosen to start Chapter Four with an introduction that would place my study within a specific theoretical framework and philosophical paradigm before unpacking the research design and methodology. Although I understand that this is not usual practice, I felt that it fits best here. This chapter further provides a discussion of the criteria of reliability and validity which govern research and incorporates the ethical considerations that shape this study.

4.2 BACKGROUND

Throughout our lives, we participate in and learn about the world around us. John Locke, a proponent of the philosophical doctrine of empiricism, stated in Johnson & Christensen (2008: 14), that, at birth, our mind is a *tabula rasa*, a proverbial blank slate ready to be written on. This most accurately describes my state of mind when, seven years ago, my daughter was born with DS. When it came to matters concerning DS, my mind was indeed a *tabula rasa*. To the ignorant, such as myself at the time, there always seems to be more reason to expect condolences rather than congratulations when a child with DS is born. This diagnosis had to be

rationalized in relation to my frame of reference, which, at that stage, was non-existent. Thus started my quest, as well as the writing on my “blank slate”.

What resulted was a study that would offer ‘autobiographical narratives’ - authentic, genuine and heartfelt realities of families of persons with DS, incorporating reflections on my own experience and how it has shaped me as an educator, a community leader and a human being.

Alvesson & Skoldberg (2009: 244) refer to emotion as an inevitable and important part of a researcher’s motivation and choice of orientation and of the specific way in which the topic studied is handled, motivating my narrative approach (including personal reflections) without it becoming ‘emotional research’. Although a highly emotive issue to those concerned, as researcher I remained neutral, interpreting and processing personal feelings before and during the empirical and theoretical work in order for this not to become a question of an emotional catharsis. However, many of the participants in this study perceived it as such.

Ultimately, the intention was to provide others with meaningful support. The focus of this research was never on problems. Rather, the emphasis was on *possibility* thinking. It is not only about seeing things as they are – it is a study of *what is* whilst exploring *what could be*. Parents and siblings needed to capture their own experiences, allow me, the researcher, to explore meaning, so that ultimately we could cause reflection to prequel change. Incremental change or a shift in the entire perception and experience of a family confronted with the diagnosis: Trisomy 21.

Within a qualitative research paradigm, narrative observations as well as normative guidelines from the researcher’s own life philosophy are introduced. The narrative is based on self-reflection on whom and where I am at present. This is a combination of what I observe, experience, and read, as well as that which I have extrapolated from participants in this study.

My personal reflection on any given situation is limited to where my child is now. As an academic, I am part of the community of parents of a child with DS and as such am part of the situation, even though my child is not yet being at that age and stage of development. Furthermore, being the mother of a typically developing adolescent sibling and an adopted pre-adolescent, affords me the ability to provide empathy and sympathy within an objective framework.

It is my deep love for my own children, particularly my child with DS, coupled with an innate burning desire to support and uplift those who need help, empowering them to indeed ultimately rise above their initially perceived limitations which has motivated and inspired me to undertake this study.

I learned very early on in my journey to “Holland” (see Addendum A), that, should I want to be an ambassador for “Holland”, I would have to empower *myself* with sound scientific knowledge or risk being perceived as just another emotional, neurotic mother. Standing up for the rights of the often voiceless takes more than courage. It requires an understanding of not only the clinical side of DS, but also the much more precariously balanced humanistic familial aspects. As parent and educator, it is my prerogative to investigate the preponderance of the good over the bad, despite the premise of misplaced premonition that so often is perceived by especially new parents. Now that my daughter is slightly older at age seven, it is more tolerable for me to remain objective whilst I explore, probe, frequently scrutinize and consider the material of a study as ‘close to home’ as this.

In order to sufficiently bracket my emotions and prevent any personal bias interfering with my analysis and interpretation, all data was produced in writing by the participants, and as such I could not influence their responses in any way. A peer check of the analysis and interpretation was conducted by a psychologist and the assistance of a critical reader was enlisted to further ensure objectivity.

As a predictor of intellectual impairment, many comprehensive studies have been undertaken in the field of DS and from a research perspective; each of the issues represents a potential legitimate research problem. However, my research idea arose from practical issues that required more guidance and direction, rather than a solution per se.

4.3 PROBLEM STATEMENT

The purpose of this study is to assess the impact on the family dynamic of having a child and a sibling with DS. Particular attention will be paid to resilience as prerequisite of the maintenance of the family dynamic per se.

Chapters Two and Three confirm that until the 1950’s research mostly focused on the negative aspects, reflecting that the birth of a differently abled child was mostly seen as a tragedy for the family, without hope of resolution or adaptation, a view that stigmatized both child and family;

however in the 1970's family research moved away from models of individual pathology with the development of family systems theory which allowed attitudes toward managing and parenting differently abled children to take a more positive and inclusive position (Jacques, 2003: 2).

Previous research has shown that the unique developmental, health and educational concerns commonly associated with DS cause families of children with DS to generally experience higher levels of stress than families with typically developing children (Baker, *et al.*, 2003: 223; Olsson & Hwang, 2003: 286; Lam & Mackenzie, 2002: 230), frequently, challenges are encountered in these families, often ending up in breakdown of marital relationships.

Based on this problematic scenario, the following research questions were formulated. Mertler (2006: 88) reminds us that a well-phrased research question is a key component to a successful research project.

4.3.1 RESEARCH QUESTIONS

4.3.1.1 Primary Research Question

What is the impact on the family dynamic of having a child and sibling with Down syndrome?

From the primary research question, the following secondary questions were derived:

4.3.1.2 Secondary Research Questions

- *In what way does having a child and sibling with Down syndrome influence familial bonds and relationships?*
- *What are the challenges parents face by simultaneous parenting of a child with Down syndrome and typically developing siblings?*
- *In which ways can families be empowered to address issues regarding Down syndrome?*

4.3.2 RESEARCH OBJECTIVES

In order to address the research questions, the following objectives were formulated to guide the researcher:

4.3.2.1 Primary Research Objective

The primary research objective has as task:

- *To determine the impact on the family dynamic of having a child and sibling with Down syndrome.*

4.3.2.2 Secondary Research Objectives

From the primary research objective, the following secondary research objectives were derived:

- *To determine in what way having a child and sibling with Down syndrome influence familial bonds and relationships.*
- *To ascertain the challenges parents face by simultaneous parenting of a child with Down syndrome and typically developing siblings.*
- *To recommend ways in which families can be empowered to address issues regarding Down syndrome.*

4.4 RESEARCH PARADIGM

Johnson & Christensen (2008: 33) explain a research paradigm simply as an approach to thinking about and doing research that will best help answer the research question.

Babbie & Mouton (2001: 78) view the qualitative research methods as most appropriate to the study of social processes. The researcher seeks a better understanding of the perspectives of those who have experienced a certain phenomenon (Leedy & Ormrod, 2005: 121). Mouton therefore (2003: 150) highly recommends qualitative methods as a means of gaining understanding and insight into the life world of research participants. Babbie & Mouton (2001: 80) propose that the interpretive approach (also known as the phenomenological approach), and the constructivist perspective, centres on the notion that all human beings are engaged in the process of making sense of their "life worlds". People are simultaneously shaped *by* and are active shapers *of* their social context, resulting in the occurrence of the interpretive, and therefore multiple truths (Babbie & Mouton (2001: 79). The multiple perspectives on the same situation facilitate a better understanding of the experiences of the insider's perspective, as stated by Leedy & Ormrod (2005: 121).

In order to rationalize the aforementioned, the theoretical foundation (systems theory) of this study needs to be clarified.

4.4.1 Theoretical Foundation

General Systems Theory (GST) was originally proposed by the Hungarian biologist Ludwig von Bertalanffy, a philosopher who, ahead of his time, in 1928, proposed that a system is characterized by the interactions of all its components, i.e. nothing exists or can be understood in isolation but must be seen as a part of a system. The term system is defined as a set of elements standing in interrelation among themselves and with the environment (Banathy, 2010). It can therefore be said that GST focuses on a specific phenomenon as a whole, the interrelation, structure and dynamics of their elements and not on the elements as separate parts. The basic premise of systems theory is the constant flow of cybernetic energy between all the subsystems, both internally and externally.

These subsystems interdependently influence each other, thus a change in one system causes the others to adapt. This is necessary in order for the system to survive and it can only survive if there is equilibrium within this system as a whole. It is therefore a holistic approach concerned with total-system performance. Relationships of sub-systems influence the overall performance of the system. The state of the system, at any given moment in time, is reliant on and influenced by these interdependent and interrelated relationships (Bateson, 1972: 441-446).

4.4.2 Family Systems Theory

Family systems theory, introduced by Dr. Murray Bowen, emphasizes the interrelatedness of family members, suggesting that individuals cannot be understood in isolation from one another. As families are systems of interconnected and interdependent individuals, i.e. an emotional unit, individuals as well as the family as a unit, cannot be understood in isolation from the system (Marshall, 1998).

In the 1970s, family research moved away from models of individual pathology with the development of family systems theory. The family was seen as an interacting set of relationships, both between the members of the family and with the wider society. This changed the focus to an inter-actional model of family functioning, and allowed for the development of ideas about family life-cycle in relation to disability and changes over time, as opposed to the previous static individual pathology model (Grant *et al.*, 1998: 58-71).

According to Bowen, a family is a system in which each member has a role to play and rules to respect. Members of the system are expected to respond to each other in a certain way according to their role, which is determined by relationship agreements.

Within the boundaries of the system, patterns develop as certain family member's behaviour is caused by and causes other family member's behaviours in predictable and circular ways. Maintaining the same circular pattern of behaviours within a system may lead to balance in the family system, but may also lead to dysfunction (Papp, 1983: 7-8). For example, if a husband is depressive and unable to pull himself together, the wife may need to take up more responsibilities to pick up the slack. The change in roles might maintain the stability in the relationship, but it may also push the family towards a different equilibrium. This new equilibrium may lead to dysfunction as the wife may not be able to maintain this overachieving role over a long period of time, or may cause a permanent shift toward a matriarchal family dynamic. This, in turn, causes the husband to be even more depressed and less able to adjust in a functional way.

The meta-theoretical integrated framework for this intervention is based on the eco-systemic paradigm. When an ecosystemic approach is used to understand family dynamics, it becomes clear that each sub-system requires support in order to promote optimal interactions between the various systems necessary for adequate development/ relationship interaction to take place. According to Harcombe (2001: 249) an ecosystemic approach does not merely focus on only one or two contributing factors to a situation. Rather it views the child holistically, i.e. as being affected by the context in which he/she functions, including home, school, society, and so forth, considering the child's genetics and how all of this interacts with contextual factors.

Urie Bronfenbrenner developed a theoretical paradigm to study human development which he labelled "the ecology of human development". He argued that individuals and families do not exist in isolation. Rather, like other organisms, humans exist in a context that can either promote or inhibit healthy development. According to Bronfenbrenner, family life and the development of children can be strengthened once there is an understanding and nourishing of the positive interactions among individuals, institutions and the broader social environment, while identifying and addressing the causes of negative influences (Babb, 1997: 775-777).

Bronfenbrenner (1979: 513) states that human development takes place through interactions between the individual and the environment (defined as persons, objects and symbols in the person's immediate environment. These interactions are two-way, i.e. the individual acts upon

the environment and vice versa. These include parental relationships, environmental relationships, social settings, cultural influences and economic factors. The four levels of environmental influences that influence a child's development are: the microsystem, the mesosystem, the exosystem, and the macrosystem, each nested within one another, representing degrees of intimate interactions (Jacques, 2003). These events are most effective over long consistent periods of time and he terms these interactions as proximal processes.

Oswalt (2008) refers to Bronfenbrenner's eco-cultural model proposing that individuals and families do not exist in isolation, but in the context of wider relationships within society. The functioning of an individual or family depends on how they relate to the wider context, which exerts influence upon them, and how they influence the wider context. This eco-cultural model suggests that families create a meaningful and daily routine of family life, which involves various ways of response to the often-conflicting pressures placed upon them. These responses are referred to as 'accommodations'. The accommodations are not only within the family but within the wider social context, the family forming an eco-cultural 'niche'. The importance of the concept is that it regards families' behaviour as adaptive. The process of accommodation is common to all families, and particular accommodation variables have been identified in relation to families of a person with intellectual disability:

- family sustenance and financial base
- access to health or educational services
- home and community safety and convenience
- domestic tasks and chore workload for the family
- caring tasks
- socialization
- marital role relationships
- social support
- father's role
- sources of information and advice.

4.4.3 Systems Theoretical Perspectives on the Family

In the systemic perspective on the family (Boscolo, Cecchin, Hoffman & Penn, 1987: 337), the family is considered to be a structure of inter-related parts in which the whole is greater than the sum of its parts. The structure is in a continuous process of evolution but will also resist changes during times of stress. Any action taken by one member will affect other members

and the structure as a whole. The family system comprises of a number of subsystems, for example individual, spousal, parental, and siblings, with alliances between said subsystems.

A crucial aspect of moving to the family level is to recognize that families are seen in terms of relationships which operate in terms of *mutual influence*. They are composed of individuals in an array of dyadic and triadic relationships, with each of these consisting of patterns of interaction that are continuing, recursive, mutually influencing patterns (reciprocal causality), according to Boscolo, *et al.* (1987: 10). Each of these relationships can be conceptualized both in terms of the individual experiences of each member and also in terms of the relationship between them.

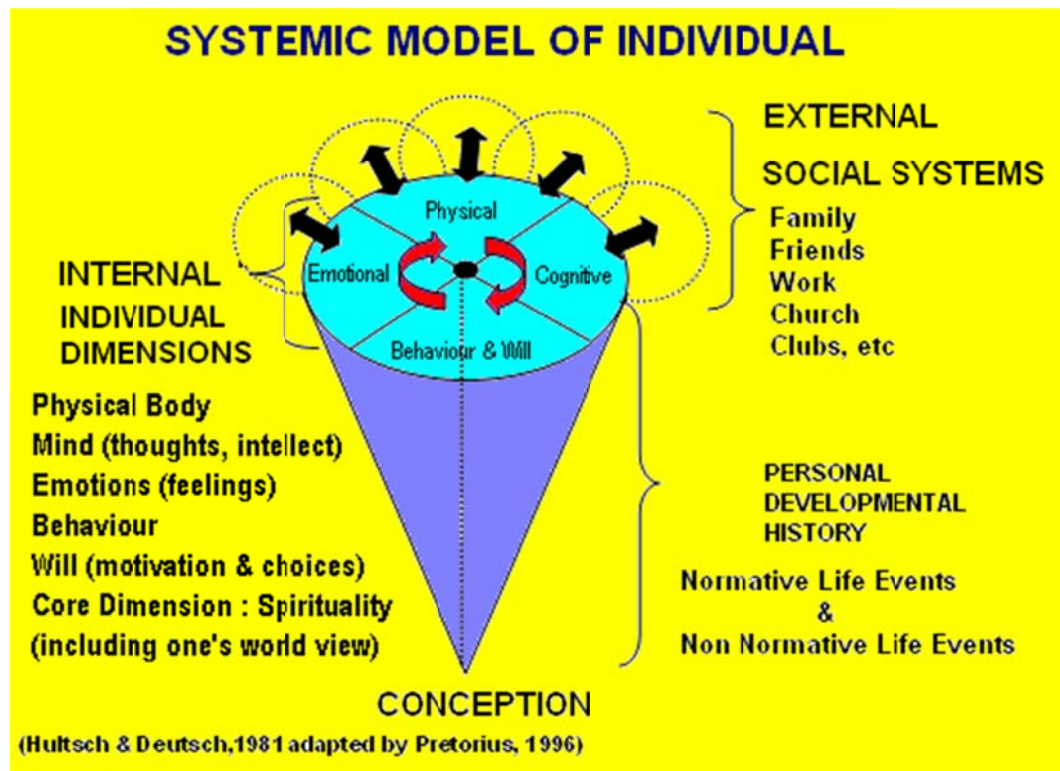
For example, some family systems may engender an inappropriate overlap in subsystems, with members participating in roles that are traditionally reserved for other members for example parent in childlike roles, and children in parental roles. Furthermore, in these families, boundaries can often be seen as distorted, confused or non-existent. Therefore, an ability to understand the uniqueness of each family and the function of the behaviours, roles, and processes of each family should facilitate the best practices for each family.

Interrelatedness: This refers to the dynamic of being mutually and physically responsible to, and sharing a common set of principles with others, yet not in a state of “dependence”, but all participants in an interdependent relationship that recognizes individual position and weaves them together (Vande Kemp, 1987: 230). It can further be defined as an interconnectedness and reliance on one another.

Interdependence: The concept of *interdependence* is implicit in the discussion of the organizational nature of family systems. Individual family members and the subsystems that comprise the family system are mutually influenced by and are mutually dependent upon one another. What happens to one family member, or what one family member does, influence the other family members. This is one of the primary concepts embedded in clinical models emerging from a systems perspective.

4.4.4 Systems Perspective on Individual Functioning

The following model was used in the analysis and interpretation of data. This model is based on general systems theory and the life time development perspective of Hultsch & Deutch (1981). The interrelatedness of the subsystems within the system is clear in the figure below which depicts the adapted version by Pretorius.



(Figure 1)

The point of the cone signifies conception/date of birth. The lilac section of the cone comprises the personal developmental history which includes normative events such as developmental milestones, going to school, going to university, getting married, and so forth. Any idiosyncratic events (non normative events) that occur during this stage influence the development of the individual, such as parents' divorce at age six, being involved in a motorcar accident during student years, having a child with DS, and so forth. All these events shape and influence the individual at their current age (the blue oval section at the top of the cone).

The blue section signifies the internal/ intra systems which include the following individual dimensions: physical body, cognitive dimension (mind, thoughts, and intellect), emotional

dimension (feelings), behaviour and will (motivation and choices). The core dimension is the spiritual (existential) dimension (meaning, purpose, world view, and so forth).

The 'loops' around the blue part of the cone signify the external systems. These include the social systems such as family, friends, work, clubs, church, etc. The directional arrows signify the basic premise of the systems theory: the constant flow of cybernetic energy between all the sub-systems, both internally and externally and to the system. There is an interdependent influence at all times, thus change in one sub-system causes the others to adapt, because this system has to survive and it can only survive if there is equilibrium within this system as a whole.

4.5 RESEARCH DESIGN

De Vos (2002: 15), McMillan & Schumacher (2001: 33) and Gay & Airasian (2000: 107) and concur that a research design encompasses a general plan of study from inception to completion. Fulcher & Scott (2003: 75) agree to the meticulous planning and translation of general ideas and concerns into specific and researchable questions prior to the commencement and execution of such a research study. Thus, to this end, the research design provided a logical plan of action regarding data collection, analysis and interpretation within the qualitative research design parameters as suggested by Gorard (2001: 8) and Terre Blanche & Durrheim (1999: 39).

4.5.1 Qualitative Research

Walsh (1996: 273) identifies the qualitative approach as ideal for investigating complex topics and for understanding continuity and change in family development, whilst Mouton (2003: 103) supports the notion that qualitative methods are recommended to gain insight and understanding into the life of research participants.

McMillan & Schumacher (2001: 226) propose that qualitative research directly address and answer the 'how' and 'when', enabling participants, as the primary source of information, to share their understanding, perceptions and ideas of the relevant issues. According to Gay & Airasian (2000: 19), the researcher is therefore directly involved and instrumental in creating new meaning by means of interpretive analysis.

By direct association (as participant in this reality) to the research topic, I chose to conduct an experience-centered narrative research. Unlike event-centered research, this kind of research includes meaningful 'stories' (narratives) of personal experience, is flexible about time and personal experience, and is defined by theme rather than structure, as suggested by Squire (Andrews, Squire & Tamboukou, 2008: 42). This decision was based on my preference to bring stories of personal experience into being by means of first person written narration of past, present or possible future experience.

Although I had initially planned to conduct face-to-face semi-structured interviews, interestingly, most of the participants requested the interview guide and self-report method of response in order to truly consider and reflect upon their responses. Due to the sensitive nature of the study, this preferred method of response (the interview guide), became the norm for data collection throughout. It must be understood that within the boundaries of this study, I did not conduct fully biographical accounts of participants' lives, but rather endeavoured to make meaning of the phenomena within a group of individuals who share certain commonalities.

Being a sensitive research topic, many participants were reluctant to participate, in accordance to the caution by Squire (Andrews *et al.*, 2008: 48). For some participants a return journey to a place of personal anguish and painful memories seemed too overwhelming to undertake, whilst others found the experience cathartic.

Lichtman (2010: 79) refers to phenomenology, which, as an approach, is based on description and understanding of the lived experience of individuals. Thus the understanding of something is stretched into an interpretation thereof, with the researcher being the interpreter of this data. Husserl (Lichtman, 2010: 80) coined the phrase 'lived experience', referring to 'life experiences' in which we are all involved. Subscribing to this approach, despite being part of this 'life experience', I suspended judgment and focused on trying to inductively gain understanding of the meaning of the perceived experiences of the participants in the study. The perceptions, beliefs and experiences of the participants about the phenomenon, were identified by means of narrative and descriptive data captured in their own words.

On a more philosophical level, the purpose of this study was to interpret specific situations, to formulate answers to possible emergent questions and to broaden my own reference framework. The questions covered how the nature of the participants' experience relate to a deeper level of their understanding and further, how certain individuals react to different situations and experiences. Firstly, in this case the parental perspective of simultaneously

rearing a child with DS as well as typically developing siblings, and secondly, the experience of siblings of children with DS. Factors surrounding the resilience and 'healthiness' of a family before and after having a child with DS was of particular interest to me as the outcome of this study would enable me to provide valuable support to new parents in terms of their own experiences, expectations and challenges.

"The position of the artist is humble. He is essentially a channel." Lichtman (2010: 43) refers to a researcher as an artist, further fuelling my desire to develop an understanding of *why* and *how* having a child and sibling with DS impacts on the family dynamic. During my experiences in mentoring families, I have found this aspect often neglected and unexplored, leaving parents and siblings vulnerable in many ways. My desire for this exploration and understanding was not to predict future outcomes, but rather to explore the nature of challenges faced by modern families and to enable them to develop a resilient, self-supportive nucleus equipped with the "map" they will need to make it through "Holland."

Neuman (2005: 74) refers to the 'critical approach', which, applicable to this study, would have as main objective, the empowering of people. Such an objective is attained by helping people to change and improve their circumstances for themselves through emancipation. Throughout this study, the underlying aspects of each relationship became clear in the critical study of each individual situation. This allowed me to evaluate the conduct and emotional activities of the participants, as well as the possible motive for its occurrence. In an *interpretive approach* significance and substance to which people attach meaning in social action, is found (Neuman, 2005: 69). Thus, application of both the interpretive and critical approaches afforded this study both qualitative and evaluative nature.

Whilst it may be argued that a case study design, as used widely by researchers who endeavour to achieve an in-depth understanding of a particular phenomenon, may have suited this study, I believe this would not have sufficed, due to its limitation of too narrow a perspective on a vastly complex phenomenon. It would have limited comprehensive access to a multi-cultural and broader socio-economic perspective, and thus, would not have been a suitable or recommended route to follow in this case.

Appropriate research methodology was planned in accordance to a qualitative research approach as follows.

4.6 RESEARCH METHODOLOGY

According to Creswell (2009: 179), Johnson & Christensen (2008: 93) and Henning (2004: 15), research methodology refers to the specific actions planned by the researcher to meet the stated purpose of a study, each of which require careful and thorough consideration before it is put to paper. Thus, according to Johnson & Christensen (2008: 93), the reader is informed of the researcher's plan and that it is the correct and best way of gathering the required information for obtaining an answer to the research question(s).

4.6.1 Sampling

According to Johnson & Christensen (2008: 222), *sampling* is the process of drawing a sample, selected from a larger group (the population) in order to study their characteristics. The basic unit selected from the population for this study is parents and siblings of individuals with DS. I started by constructing a *sampling frame* suited to my study, i.e. individuals who could shed optimal light on the research topic. *Intensity sampling* was applied. This involved the recruitment of desirable, willing, information-rich participants who fitted the criteria, who have an in-depth knowledge of the phenomenon of interest, and could offer constructive contributions (Merriam, 1998: 84; Patton, 2002: 127). This criterion-based selection which included a diversity of parents in terms of cultural, ethnic and socio-economic selection, was two-fold: parents of a child with DS (only child and/or with siblings) and siblings older than ten years of age of a person with DS. Interestingly, the *snowball* or *network sampling* strategy, as referred to by Merriam (1998: 62) and Glesne (1999: 29) occurred naturally as interested participants referred others. This further supported my proclivity that this was indeed a topic well worth researching.

4.7 RESEARCH PROCEDURES AND ETHICAL CONSIDERATIONS

Research procedure refers to how a study is executed from inception to completion. This involves a step-by-step account of both researcher and participants adequately communicating the procedure used to collect data to successfully answer the study's research question. The members of the sample were contacted personally, telephonically or by e-mail to introduce the researcher and explain the research topic and procedure. The following information documentation was given to potential participants:

- Invitational letter describing the nature and purpose of the study (see Addendum B)
- Information and consent forms (see Addendum C):
 - for parents
 - for siblings under 18
 - for siblings over 18
- Assent form for parents of siblings under 18 (see Addendum C)
- Interview guides (see Addendum D):
 - for parents
 - for siblings under 18
 - for siblings over 18

The information letters stated that the interview guides would provide participants with an opportunity to share their personal experiences, opinions and ideas about families of children with DS. Participants were asked to complete the assent forms and to return these to the researcher. Parental consent was required for participants under the age of eighteen years. In accordance with Henning (2004: 43), confidentiality regarding their identities and content of contribution as well as anonymity re their participation was explicitly reiterated. Participation was voluntary and participants were informed that they could withdraw at any stage.

According to Johnson & Christensen (2008: 101), ethics refer to the principles and guidelines that help us uphold the things we value. It is therefore logical to expect that a guiding set of principles be followed when it comes to researching human beings in relation to professional issues and the treatment of the research participants.

Professional issues include research misconduct, such as “the fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or reporting research results” (Johnson & Christensen, 2008: 103). They further remind us that the researcher may not deviate from the approved study design, which was upheld in this study.

Johnson & Christensen (2008: 105) furthermore caution against the potential physical and psychological harm in conducting research with humans. The treatment of research participants is therefore the most fundamental and important issue for a researcher. Struwig & Stead (2004: 66) agree that research is an ethical enterprise and in accordance, the researcher endorsed a code of ethics.

During this study great care was taken by the researcher to first and foremost at all times respect the rights and dignity of research participants in relation to privacy, confidentiality and autonomy. The researcher acted honestly, fairly and respectfully toward others with no attempts at misleading or deceit of participants or readers. Throughout, the researcher was mindful of cultural and individual differences among people, i.e. age, gender, race, ethnicity, religion, language and socio-economic status and avoided any knowing discrimination against people on these grounds.

As honesty and integrity are characteristics that I hold in high esteem, I adhered to all the ethical rules and regulations as stipulated by Nelson Mandela Metropolitan University.

4.7.1 Data Collection

Succinctly stated, data collection is the procedure that a researcher uses to physically obtain relevant information from research participants. This is supported by Yin (2009: 122) who refers to a “chain of evidence”, selecting those collection tools that may best furnish the information sought for a study, and which will assist in opening up aspects of the problem under investigation (Dana & Yendol-Silva, 2003: 84).

Lichtman (2010: 43) reminds us that the main focus of qualitative questions is on human beings and, pertaining to this study, how they see themselves and aspects of their environment. In accordance with Glesne (1999: 29) detailed information was extrapolated from knowledgeable individuals by means of a purposeful sampling procedure. Data was collected from families who had only one child with DS. Since the experience of siblings was also necessary for this study, to facilitate data collection, they had to be older than ten years of age. Sibling ages ranged between ten and thirty five years. The target group included:

- Single parent families
- Parents who have lost a child with DS
- Grandparents who have adopted the child with DS and have been the primary caregivers of this child
- Individuals from different ethnic and socio-economic groups.

For the purpose of this study, primary data was obtained from participants in response to open-ended questions (Bless *et al.*, 2000: 111) as detailed in the following section.

4.7.1.1 Interview Guides/Self-Reports

Johnson & Christensen (2008: 201) suggest that a good mix of research ingredients provides solid evidence for conclusions. The diversity of participants in this study provided rich information. Although data was predominantly going to be by personal interview, the alternative suggestion from the majority of participants was to respond by means of written self-reports. This option afforded them the opportunity to carefully contemplate and reflect upon their experiences in order to provide quality responses. This motivated the use of the self-report; a reflective, introspective method for collecting data. This method of response would further allow the participant the opportunity to say what *he* want to say in his own words, in his own voice and with his own narrative and language, rather than slant toward what he thinks the researcher wants to hear. Thus, because of the personal nature and subsequent need for elaboration on the topic, the interview guide and self-reports were deemed as an appropriate method for this study.

Best & Kahn (2003: 256) compare the 'interview guide approach' to the semi-structured interview format. As such, the content and sequence of the predetermined questions allows the participants flexibility of response. This format also allows for systematic data collection, and increased comprehensiveness.

Three interview guides were used: one for parents and one each for siblings older and younger than eighteen years of age (see Addendum D).

The interview guide for **parents** comprised four sections:

- Section A called for basic background information;

Sections B to D posed open-ended questions and emphasis was placed on encouraging the inclusion and elaboration of both positive and negative factors and contributors.

- Section B covered pre-birth and birth experiences;
- Section C dealt with the personal and marital relationship prior to the birth of the child with DS; and
- Section D provided the opportunity for the parents to elaborate on the personal, marital and familial relationship as well as the parallel emotional turmoil of elation and anxiety.

The interview guides for **siblings** also consisted of four sections.

- Section A of the interview guides required names and ages only.

- Sections B to D posed open-ended questions covering aspects of personal thoughts and feelings about growing up with a sibling with DS and how it influenced them personally, their family dynamic, relationships and social life. Siblings were invited to share advice to parents and other siblings of individuals with DS. *This* specific question was included to elicit *their* unique perception. Similar, albeit, simplified questions were posed in the interview guide for siblings under the age of eighteen.

Thus, primary qualitative data was gained from the understanding, insight, perceptions, experiences and ideas of the participants, as proposed by Fulcher & Scott (2003: 89).

4.7.1.2 Self-Reports and Self Reflection

Self-report evidence is necessary and valuable for inquiry about human experience, although it may not always be essentially a true reflection of an experience. Due to the nature and topic of this study, many participants had to revisit a place of anxiety and discomfort, which, in effect is a *reflection* on their experience and not automatically an *accurate* account thereof. Denzin & Lincoln (2008: 12) state that “any gaze is always filtered through the lens of language, gender, social class, race, and ethnicity... Subjects or individuals are seldom able to give full explanations of their actions or intentions; all they can offer are accounts, or stories, about what they did and why”. Polkinghorne (2005: 137) confirms that translating a reflective awareness into a written (or spoken) expression may be compromised as one may struggle to find the right word to accurately express a feeling, thought or experience.

It was evident in this study that participants often found their experience more complex and nuanced than could be expressed in literal language. Yet, despite this, they expressed their feelings, perceptions and experiences into language, which is, after all, a researcher’s primary access to the experiences of others.

Alvesson & Skoldberg (2009: 244) affirm the inevitability of emotion on the part of both researcher and participant, especially in topics of the nature of this study. They further maintain that self-reflection and the critical self-analysis of feelings are an important part of the research process, particularly in qualitative research. This is not a question of emotional catharsis, but of interpreting and processing one’s feelings before and during the empirical and theoretical work.

For the purpose of this study individuals who could provide relevant descriptions of their experiences were willing to participate, although the researcher included all contributions, whatever their command of the language proved to be. Multiple participants, some more able to articulate their experiences than others, provided accounts from different perspectives, which allowed the researcher to compare and contrast these perspectives. Thus, in a sense it served as a kind of triangulation of the experiences, not to verify a particular account, but rather it served to deepen the understanding of the investigated experience (Polkinghorne, 2005: 140).

4.8 DATA ANALYSIS AND INTERPRETATION

Gay & Airasian (2000: 237) endorse the importance of having all completed data collected and available prior to commencement of data analysis. In support of Henning's (2007: 101) statement that the true test of a competent qualitative researcher comes in the analysis of the data, Wellington (2000: 147) affirms that data analysis requires thorough, systematic and meticulous organization of accumulated material by the researcher in order to make meaning of a large volume of information (Gay & Airasian, 2000: 240).

I agree with Lichtman (2010: 195) that qualitative analysis is an extremely complex aspect of conducting qualitative research, as each researcher makes sense of their data in a different way. Therefore, there is not a *right*, *wrong* or *better* way to make interpretations. The process of sifting, sorting, coding, organizing and extracting remains the prerogative of the researcher, who is closest to the topic and data. It is therefore important to document the procedure followed.

For this study the Content Analysis Steps as suggested by Colaizzi (1978: 48 - 67) were used to analyze self-reports as follows below:

- Initial reading of all the self-reports to become familiarized with the content and to get the general feeling of them;
- Secondly, significant phrases/sentences that directly pertained to the research topic (investigated phenomenon) were extracted;
- Thereafter meaning of each significant statement was formulated (level 2 coding);
- All the above protocols were repeated for each contribution.
- Aggregate meanings were then formulated into clusters of themes;
- Then the results were integrated into a comprehensive description of the research topic;

- The core was extracted, i.e. identification of the fundamental structure of the phenomenon in the abovementioned description.
- Colaizzi's last step required verification of the themes by returning to the participants. Due to the level of this qualification (Masters' degree) and the escalation in the scope of the research, should this step be added, I decided not to return to the participants at this juncture.

It is evident that *qualitative data analysis* requires organizing the data, breaking it down into manageable units, synthesizing these and searching for patterns, whilst *data interpretation* involves explaining and framing one's ideas in relation to theory and research, showing why your findings are important and then stating them in meaningful units. Wiersma (1995: 227) suggests that data interpretation revolves around developing ideas about one's findings and relating them to the literature as well as to broadened concerns and concepts whilst Swann & Pratt (2003: 116) remind us that the analysis and interpretation also assesses the trustworthiness of the data under the following criteria:

4.8.1 Validity

In any research the question of validity and reliability is imperative. One of the most controversial areas surrounding qualitative research is how to evaluate what is read. This presents a dichotomy in the arising question of *who* is the actual *expert* in this study: the academic community, the educational community, the medical community, or none of the above? The experts, in my opinion, are the community of persons who have, especially in this case, indeed, 'walked the walk', more than qualifying their opinion and experience: the parents and siblings of persons with DS.

The concept of validity is described by a wide range of terms in qualitative studies and although some qualitative researchers have argued that the term validity is not applicable to qualitative research, they realize the need for some kind of measure for their research. Cresswell & Miller (2000: 124) suggest that the validity is affected by the researcher's perception of validity as well as choice of paradigm assumption. As a result, many researchers have developed their own concepts of validity, and have either generated or adopted their own terminology of appropriate terms such as rigor, quality and trustworthiness (Davies & Dodd, 2002: 282 and Stenbacka, 2001: 553).

There are many diverse opinions about validity and reliability in qualitative research. Lincoln & Guba (1985: 294) suggest that the researcher tests the adequate representation of multiple realities by using *credibility* as the test. McMillan & Schumacher (2001: 157) propose that it's equivalent, internal validity (truth value) traditionally describes how accurately reality is depicted in the findings. However Krefting (1991: 214-222) argues that credibility is much more dependent on the analytical ability of the researcher and on the complexity of the gathered information, than it is on the size of the group being studied. In this study forty participants were used. Their responses were not compared per se, rather only correlated to establish emergent themes.

All original participant contributions were saved on computer as well as in hard copy format, as Lichtman (2010: 59) reminds us, that data which is summarized becomes new data, which is why original raw data must remain available for perusal. As the critical reader remarked during a discussion, data becomes information when assimilated, which in turn provides the valued intelligence that will bring clarity to field of study.

4.8.2 Peer Check

To increase the validity of the results of this study, a peer check was done. To this end, two knowledgeable critical readers were selected. One is a psychologist, currently doing her doctorate, and both are familiar with qualitative research. The peer check involved the analysis of four different, unmarked participant self-reports in each participating category. They were requested to draw a diagram depicting the factors for classification into identified themes. This was implemented as a guide to check against my own diagram and the core differences were analyzed afterwards. Interestingly the results were analogous and only semantic disparity differentiated the outcome. This noted similarity to my own analysis further confirmed my objectivity as researcher.

4.8.3 Trustworthiness

Mertler (2006: 88) refers to trustworthiness in terms of accuracy and credibility of the raw data compiled in the collection process, while Conrad & Serlin (2006: 410) argue that it fulfils a validating function. To substantiate this statement, Lichtman (2010: 224) supports that those studied in qualitative research are real people, with real feelings, ambitions, needs, fears and desires. Each setting, set of circumstances, experience and perception in this study is unique and cannot automatically describe another, although it may be possible to apply it to similar

contexts (Cresswell, 2009: 182). Whilst the concept of consistency is encompassed in correlation with similar studies, it is important to remain aware of the individuality and uniqueness in a study involving personal human situations, such as this study.

4.8.4 Neutrality

Neutrality, as in any valid study, refers to freedom from bias in research and research procedures, and excludes any contamination by prejudice, motivation, agenda and personal perspectives of the researcher. The researcher agrees with Holloway & Wheeler (2002: 118) who suggest that researchers 'bracket' their views when writing reports. In light of my personal closeness to the topic, I support this argument with the intention to prevent confusion between my views and personal experiences and those of the participants. Creswell (2009: 15) agrees that when the researcher is able to harness his personal perceptions, the experiences and views of the participants become more clear and salient, suggesting transparency and an avoidance of prejudice by the researcher.

It stands to reason that the findings need to be meaningful in light of the questions asked. Lichtman (2010: 224-232) refers to the following criteria for evaluating qualitative research:

- **The researcher's role: revealing the *self* and *other* connection.** Lichtman (2010: 224) contends that an understanding of the *other* (those who are studied) does not come about without an understanding of the self and how the self and the other connect. I agree that each is transformed through this research process.
- **Convincing arguments: what was studied and what was found.** This concept is critical in an assessment of the worth of a qualitative research study, and although it is difficult to get at its essence, if the researcher does their best, the reader will be convinced that the topic is an important one to consider and fits into a larger context.
- **Rich in detail: how the study was done.** The information about how the study was conducted is indicative of the quality of the study and will provide clear and concise explanations of concepts, approaches, rationale and sufficient, well-researched literature information. Detailed descriptions of how the study was done, and clear explanations of new concepts will also be evident.
- **Communication: the reader must be convinced by the presentation.** This includes an engaging opening; personal reflections; writing style reflective of thoughtfulness and scholarship; integration between research and own insights; rich detail; using the voices of

others; justification; and writing reflecting new connections, interpretations or insights based on the research.

4.9 CONCLUSION

This chapter proffered the philosophical approach and theoretical framework on which this research is based as well as a discussion of the research paradigm in which this study is situated. The research design and research methodology was presented, including the rationale for choosing methods of sampling, as well as a description of the way in which the research data was produced, approached and analyzed. Aspects of reliability and validity were included. The intricate working relationship between these research sections and their relevance to the quality of the study was also briefly explored. This chapter concluded with a discussion of data analysis and aspects of trustworthiness. Ethical considerations in social research were discussed.

In Chapter Five a detailed discussion on the results of the study will be presented.

CHAPTER FIVE

ANALYSIS, INTERPRETATION AND DISCUSSION OF FINDINGS

5.1 INTRODUCTION

Qualitative data analysis required organizing the data into manageable units and synthesizing these into themes, whilst data interpretation involves explaining and framing of the researcher's ideas in relation to theory and literature. As a point of departure, systems theory (see Section 4.4.2 & 4.4.3) was implemented as a theoretical foundational paradigm to explore the impact on the family dynamic of having a child and sibling with Down syndrome (DS).

The primary question of this research was: *What is the impact on the family dynamic of having a child and sibling with Down syndrome?* Data collection was by means of written participant self reports in response to interview guides (see Section 4.7.1.1). These contributions, indicated throughout this chapter in a smaller, italicized text, are original and no semantic or spelling errors whatsoever have been corrected.

To provide valid substance to the interpretation and discussion of the findings, the researcher, in addition to the literature, drew on supportive relevant knowledge extrapolated from several National and International Conferences and seminars attended, numerous conversations and mentoring sessions with other parents, and from life experiences gained from the researcher's own simultaneous parenting of typically developing children and a child with DS.

A family is made up of individuals. It therefore necessitates the examination of the intra-psychic influences of the occurrence of DS on each of the individuals in the family system i.e. mother, father, child with DS and siblings. According to general systems theory, all subsystems are interrelated and interdependent. It can therefore be deduced that the incidence of DS in a family will affect each individual uniquely, and each individual will in turn affect the other members in the family in some way, depending on their intra-psychic adaptation to the incidence of DS in the family.

In order to answer the research question with any measure of success and comprehensiveness, it necessitated the dissection of *who* constitutes a family, *what* constitutes family dynamic and the breakdown of *how* each individual within this assembly feels, functions

within and fits into the family dynamic. As this broadens the scope of this study considerably, an in-depth discussion of each aspect did not prove practical.

The nature of this narrative, combined with the personal and intimate nature of this study, necessitated a purposeful flow of literature, findings, interpretation and implication. To facilitate ease of reading and 'staying in the moment of the experience', I have chosen to integrate and weave the findings, interpretation and implication in a logical manner throughout this analysis. I trust that this will aid (rather than distract from) the full conceptualization of this study.

For the purpose of analysis, findings were categorized into the following themes (systems):

THEME ONE: INTRA-PSYCHIC FUNCTIONING

- Intra-psychic functioning of the mother
- Intra-psychic functioning of the father

The following subsystems are addressed: emotional, cognitive, physical and behavioural subsystems

THEME TWO: INTRA FAMILY FUNCTIONING

- Marriage system
- Sibling system
- Parent-sibling relationship

THEME THREE: EXTERNAL SYSTEMS

- Extended family
- Social systems
- School and education systems
- Medical fraternity
- Occupational systems
- General public

5.2 THEME ONE: INTRA-PSYCHIC FUNCTIONING

The Intra-psychic system of the individual can be divided into the following subsystems, which influence each other reciprocally:

- The emotional subsystem
- The cognitive subsystem
- The physical subsystem
- The behavioural subsystem
- The spiritual subsystem

5.2.1 INTRA-PSYCHIC FUNCTIONING OF THE MOTHER

In Kingsley's analogy she metaphorically tells of one planning a trip to a desired destination (Italy), only to find out that the plane had headed for another destination all together (Holland). The explanation of how this forced change in direction influences one's perceptions of what is desirable, one's dreams and loss thereof, as well as practical issues of having learnt the wrong language and having bought the wrong map, is only too familiar to parents with children with DS. However, also familiar to these parents, it also tells of acceptance. How, after a while, one comes to realize the positives of the new destination, and adapts to its unique systems, possibilities and other realities.

In this study, it was found that, to a parent, and maybe especially the mother, this forced change in direction has a profound impact not only on her emotions, but also on her thought paradigms, behaviour and physical system. On a physical level she needs to make accommodations in terms of more demands placed on her time (time for herself, her spouse, other children, social activities, community work, and so forth), she may feel physically and mentally overwhelmed by the challenges brought about by her new circumstances, thus leading to stress and strain in all subsystems.

Such a shift in cognitive paradigm often also implies a new shift in personal direction, be it values, spirituality and, on a far more practical point, an occupational shift. She may have to give up her career, take a part-time position resulting in reduced income or she may entirely cease all career and entrepreneurial pursuits in order to fulfil her new role as primary care giver to her child with DS syndrome. Such physical accommodations may influence her behavioural and cognitive functioning, leading to feelings of resentment, loneliness and discontent. She may further experience loss in terms of personal independence, leaving her feeling resentful and withdrawing from others even more. These emotions may affect her interactions with her entire support structure, namely family, spouse, extended family and friends.

5.2.1.1 Emotional Subsystem

Prior to the birth of the baby, mothers often experience pre-natal anxiety in terms of the general health and well-being of their baby. Because older mothers are subconsciously aware of a possible higher risk of complications, they are often torn between undergoing the amniocentesis and having their fears either dispelled or confirmed, and *not* doing the amnio. On a subconscious level the latter supports the expression that 'ignorance is bliss'. However, once a child with DS is born, a variety of mixed emotions are experienced. All of those discussed below have been reported in different degrees.

- **Shock and denial**

The initial reaction, reported by all, is always shock. Literature confirms that upon postnatal diagnosis, the parents feel shocked, angry, devastated, overwhelmed, depressed, stunned and helpless (Skotko, 2005: 72). Shock, as experienced by all mothers when they hear the diagnosis, may manifest in denial or may propel them forward into action of some sort.

Most mothers in this study reported shock characterized by feelings of numbness, disbelief, sensations of being disconnected from the reality of their situation, confusion and bewilderment (Skotko, 2005: 74). This confirms the view of Friehe *et al.* (2003: 212) who refer to this denial stage as 'nature's anaesthetic' as it numbs the senses, prevents being entirely overwhelmed by the situation, thus cushions the blow.

Some mothers blocked out the truth and went into denial, which Friehe *et al.* (2003: 213) define as the initial refusal to accept the diagnosis. The value in experiencing this emotion is that it temporarily relieves painful feelings and provides time to regroup until the reality is tolerable.

There is definite value in experiencing denial, as the discomfort of this emotion forces redirection of energy to action that is more positive. From personal experience, this emotion propelled me toward making every effort to become knowledgeable on DS and constantly search for the best answer. It is often the more emotionally resilient mother who assumes the more pro-active stance. Her attitude is more positive and she approaches her new set of circumstances in a rational and logical manner from the very beginning.

How and *when* the mother finds out that her baby has DS, may be a precursor to her initial reaction and acceptance of her child. One such mother, whose husband was under extreme

work pressure and whose own terminally ill mother was staying with her, relates her feelings after hearing baby's diagnosis immediately after the birth.

Dit was 'n geweldige skok...geweldig...die grootste skok ooit...ons kon of wou dit nie aanvaar nie. (M/1/D)

...not a planned pregnancy – lots of emotional turmoil in beginning of pregnancy (3months) lots of denial all from my side... (M/22/B)

Other mothers share similar emotions.

...morning after he was born the Dr said he would like to do a chromosome test as he thinks he may have DS. I was alone at the time and this was a huge shock! I was unable to talk to my husband about it as the family arrived just minutes after he did at visiting. When we left the hospital the Dr said he was really not sure if he has DS or not, "if he has he is the most normal looking baby he has ever seen". We had a 2 week wait for the results and were told at his 2 week check up. Devastated!! (M/9/B)

... I remember looking at [the doctor] without blinking once, I was so scared that I would miss a word, and with a heartbeat of 120 beats per minute waiting for his next words to come out of his mouth...Your baby girl was diagnosed with Down- Syndrome...I cannot begin to tell anybody what I felt at that very moment. I could not even think anything. It felt like I was having a very bad dream and that I was gone wake up any moment... I didn't even know at that stage what Down syndrome was. It felt as if my entire world stopped... tears...uncontrollably...scared and I felt unexplainable alone and helpless. (Mother aged 19) (M/10/B)

...routine blood tests at 16 weeks...few days later I read an article about DS children in a baby magazine...put the book down thinking that if God were to give me a child with THAT,so be it...phone call from gynaecologist... instantly knew something was wrong. The dr. told us that I had a 1 in 20 chance of having a DS child, I was shocked but I was somehow calm...have an Amnio test to confirm that our baby would have DS. I was given the option to have an abortion if the Amnio was positive. The amnio test was nerve wrecking but all went well and the test results showed that 83% of the cells were positive... My parents supported our decision but my sister advised me to have an abortion as she read all the doom and gloom on the internet. (M/16/B)

- **Shame and guilt**

Mothers reported feelings of guilt. Sometimes these feelings of guilt are on such a subliminal level, that mothers do not even identify it. Although the mother knows that the child having DS was by none of her doing, she subliminally may harbour feelings of guilt that *somehow* she may be responsible for the circumstances of her child. Alternatively, she may feel guilty that she is unable to *make it better* (which is, after all, what mom's do!)

One baby was only diagnosed when he was twenty four days old. The mother was devastated and blamed herself. Her husband was not with her when she was told and she was filled with fear and shame to tell him.

...the results came... [the doctor] explained everything...I cried, confused blaming God why he did that to me. Mind you, my husband had told me that he doesn't want a baby now...how I am going to tell him that the results came and it was proven that I gave birth to a child with disability...I was the one who was crying looking for answers, blaming God, blaming myself. If I had listened to him, and waited, none of this could have happened. (M/3/B)

This shame often extends further than the mother herself.

...hard for me to tell my friends...no one knows...I'm still waiting for the right time...I do have fear than my secrete one day will come out. (M/3/B) (This baby is already one year old and the mother has still told no-one that he has Down syndrome.)

...ander mense het geen inkling van hoe dit is nie...hulle reken ons laat dit dan so maklik lyk, maar dit was soms absolute hel... (M/1/D)

A lot of parents with Down syndrome children hide their children and are shy... (M/10/D)

A mother shared her feelings of guilt for spending more time with the child with DS. This is often related to therapies, research and intervention.

Now that we have another child, I realize how it has taken over our lives and I am finding it difficult to try and get my life a little back to normal so that my [typically developing] daughter can experience a bit of normal life, that's not right! (M/9/D)

Most new mothers are faced with an occupational dilemma upon accepting the role of motherhood. The time that an occupation takes them away from their children is a point of much guilt and discontent for mothers, yet the commercial world expects mothers to see their job as first priority. For mothers with a differently abled child the career consequences are even more significant – mainly as a result of their child needing so much more intensive mothering.

It was thus not surprising to see that there were definite career consequences for mothers in this study. Some mothers could not/ would not pursue a career and stayed at home to look after her child with DS, whilst others changed direction.

...moeder werk eers toe [son with DS] 17 jaar oud is. (M/1/A)

If I didn't have [daughter with DS] ...would have been...busy career woman...I was in software development for 13 years and could have been earning megabucks! (M/2/D)

On a work level I went through a bit of a wobble after...I was busy with a PhD when he came into the world, and I felt such an enormous responsibility for focusing on what he needed in those first years (window time for development) that I cancelled my studies and focused on DS and helping...to develop. I even considered switching to doctoral studies in a DS related theme. I have however since then returned to a greater level of work stability. I realize that running an organizational psychology practice is where my talents lie. I have however started a special needs class for early intervention in conjunction with other parents, to help give... as much stimulation as possible before he needs to attend school. (M/12/D)

- **Fear**

Fear is said to be the opposite of trust, and often the mother's equilibrium is so unbalanced upon diagnosis, that she cannot see the wood for the trees. Especially a fear for the future of her child is often a strong emotion of the mother immediately after the birth, being almost too much to comprehend, let alone bear. This fear manifests as a physical pain, bending her double, aching in her chest and preventing her from breathing deeply. Mothers fear for the physical, emotional and future well-being of their child, but moreover, she fears her own possible limitations in both preparing and supporting this child for the road ahead.

A mother felt anxious, concerned and insecure of the unknown, and she experienced feelings of being alone and totally responsible for all decisions.

...I have felt that I was dealing with DS and my husband was dealing with his son... (M/9/D)

Fear, however, has a way of siphoning through the thickest screen of resilience and if not for her immediate situation, then certainly for the future of her child. The following was reported regarding fear for the child's physical and emotional well-being:

...baie vrese...bang hy kry seer, bang hy word ernstig siek... (M/8/D)

...and also the fear that [son with DS] would not live long... (M/12/C)

I don't want him to be lonely or depressed or rejected... (M/7/D)

I am acutely aware the day will come when a cruel remark will be uttered that [daughter with DS] will completely comprehend and therefore be wounded by it. (M/20/D)

Some mothers had fears surrounding their own inadequacy and limitations.

Ek het sommer gehuil want ek het gedink hoe deel ek met 'n gestremde kind. (M/18/B)

...fears around how to deal with the challenges of DS... (M/12/C)

...who's going to guide me in when is the right time to introduce a next word etc I am not a teacher... causes ... anxiety. (M/22/D)

All mothers fear for their child's future.

My huge fear is that my child might not do well at school because of his difficult in learning...every parent has a dream and the future for their children. (M/3/D)

I do worry about [child with DS] future prospects and happiness... will [he] be happy in his 40's? (M/7/D)

Ek is ook bang vir wat die toekoms inhou vir hom. Gaan hy gelukkig wees, gaan hy iets betekenisvol doen, wie gaan na hom omsien as ons oud word? (M/8/D)

My grootste vrese is dat sy moet in 'n normale skool wees en dat sy sal kan aanpas...wonder somtyds gaan ek die voorreg het om haar te sien in haar volwassewording. (M/18/D)

Will he be able to get a job and be semi-self-sufficient? What if we fall away? (M/12/D)

...really concerned...future...who will look after him if we are not around? Would he be ok? Is he ever going to talk or eat properly? (M/19/D)

Social isolation is often an issue for parents and parents fear not only for their own social isolation, but also that their child may be shunned. These initial fears are often dispelled.

We were so scared of being shunned by all our friends that we never realized that everyone would be so good to us and so helpful and understanding. (M/6/D)

...[before] free to follow our own hobbies and interests... went out to eat a lot...everything changed when he was born, the fact that he has DS is more relevant now I feel than when he was a baby. We were easy going, now we have to keep to a strict timetable. (M/9/C)

Our social life, what's that? We find it difficult to go to a lot of places as our son is so very active and an explorer that we end up not being able to have a proper conversation as we are always looking out for him. Child friendly is not always parent friendly! (M/9/D)

...socially not difficult as a baby, but definitely a challenge to take...out now! (M/19/D)

- **Loss**

Some mothers confirmed that their initial shock was not primarily caused by the thoughts of the possible burdens lying ahead, but rather provoked by the difference between the *wanted* child and the *real* child. Mothers welcome the child that arrives, yet at the same time they have to let go of the child they were expecting, along with the plans, hopes and dreams they had for that child. A profound sense of loss is often a strong emotion. Some mothers reported diverse experiences of their own loss of independence and the impact it has had on their lives.

It has had a huge influence on my life! What I would like is to have a little bit of my life back, yip that's it!! I fear that I will never get time again...I feel that I don't know who I am anymore (M/9/D)

...most frustration is [son with DS] dependency on us is greater... (M/5/D)

...hy is nou 19mnde daar en kom gereeld huistoe. Ek het lank aan bomskok gelei toe hy soontoe is... vir die eerste keer in ons lewe, kan ek en my man, sommer alleen uitgaan en iets doen. (M/1/D)

The loss of dreams for their child's future, cause many mothers much emotional trauma and pain:

...wanting so much more for her and wishing for her sake that she had not been born with DS...heart aches for her when she refers to being married one day and having children of her own. (M/4/D)

...ek kan sien dat sy hartseer is met haar sussies se troues...breek my hart. Daar is niemand wat ons ken wat regtig by haar pas en so sterk is soos sy nie. (M/15/D)

...I didn't do well at school...I have a dream that I will make my effort for my babies to study more...that is my negative attitude towards my son. (M/3/D)

...all she wants is to be like others her age... (M/2/D)

When I held him properly for the first time, 4 hours after he was born, I looked at him and said "you will never know how much I love you until you hold your baby in your arms one day". To hear that they are unable to father children killed me, I just thought 'he will never know just how much I love him.' (M/9/B)

- **Pain**

Some mothers experience deep pain, not *because* of their child, but *for* their child.

Pain...when I see him between a group of "normal" toddlers of the same age, I feel the pain of him being marginalized/ignored/ for not communicating in the same way. Also that he would not have the opportunities in life that they have. (M/12/D)

...painful to think of all the many things he will probably never achieve. (M/19/D)

- **Cycles of grief and joy: paradox of disability**

Consistent with the literature (Dowling *et al.*, 2004: 11), mothers confirmed their feelings of grief as a personal and emotional reaction to the significant loss of the child they had expected. This flows from the loss of hopes, dreams, ideas and expectations – loss of 'what might have been', as commonly associated with the birth of a differently abled child or later discovery of a disabling condition. For the parent whose child is diagnosed with DS, it is no longer just the loss of what could have been or should have been, but also grief about the future – for the child, for themselves and for their entire family unit.

Friehe *et al.*, (2003: 211) reminds us that this loss disrupts the natural coping strategies, which necessitates devising new coping mechanisms to deal with a grieving process aimed at resolution, as experienced by many mothers. It can therefore be said that grief is a dynamic, complex and psychosocial process produced by forced change. Mothers concur with the findings of Schneider (Friehe *et al.*, 2003: 212) who describes grief as holistic as it involves cognitive, behavioural, emotional, spiritual and physical dimensions. Numerous symptoms from these dimensions may coincide, which places further stress on the individual and family as well as further complicating the resolution process.

The findings of this study are consistent with the opinion of Van Riper (2007: 118) regarding the experience of parenting a child with DS being a paradox filled with conflicting emotions: these being despair, anxiety and pain, but also intense joy, hope, optimism and happiness. It is indeed the ability of a parent to embrace this paradox which ultimately enhances family and parental adaptation. Parents and siblings attested to experiencing periods of great happiness, humour, pride and contentment, despite experiencing incidents of grief for the years to come. Some mothers report periodic cycles of alternatively grief and mourning and gratitude and joy, as is clear from the following remarks:

I go through cycles of mourning and grief...sadness that the world is tough for people like her...The cycle then moves to thankfulness and joy that she is in fact very capable of looking after herself. (M/2/D)

My heart had been broken, and I think there will always be a little crack in it forever... (M/9/B)

I cried at least once a week about what I felt (at that stage) was a loss to my boy. I felt very heartbroken for him for the adversities that he would have to face in his life. (M/12/C)

Haar hartseer breek my hart... (M/15/D)

We were very sad and cried together. The moment that other people rejoice in at the arrival of their first baby was one of the saddest moments of our lives... (M/19/B)

Feelings of profound joy and happiness, inspired by their child with DS, were shared by most mothers.

Her beautiful; giving and loving nature gives us unbound happiness; joy and pride every day. (M/4/D)

...baie positiewe oomblikke...sy blydskap as hy ons sien na 'n dag by die skool of as hy iets lekker eet!... dat hy besef wat liefde is en drukkies en soentjies gee! (M/8/D)

My biggest joy is how my little boy is growing, learning, exploring and exceeding expectations every day!!!! (M/13/D)

Om te sien hoe almal wat haar sien met verwondering na haar kyk is heerlik, en deesdae gesels almal met haar en vertel haar dat hulle al van haar gelees of haar op TV gesien het. Sy blom dan. Wat my die gelukkigste maak is wanneer sy regtig gelukkig is, maak nie saak waaroor nie. (M/15/D)

Wat my baie gelukkig gemaak het...sy haar eie treetjies kon neem...die feit dat sy soos 'n normale kind reageer. (M/16/D)

Episodic recurrent sadness (see Section 3.6.2) is characteristic of the sense of loss mothers feel. This often revisits when one least expects it: in the dead of the night, during the applause at the prize-giving, at the sight of your child on the top of the slide, or simply when he/she has succumbed to the blissful, peaceful sleep after a tiring day at school. Consistent with literature, it tends to be revisited at critical life junctures according to Williams (Friehe *et al.*, 2003: 214), for example honours evenings, the graduation or the wedding of an older sibling.

This type of grief is, however, related to the ongoing challenges presented, and not the person. Powers & Singer (Friehe *et al.*, 2003: 214) observe that on a cognitive level, this grieving is more conducive to event-focused problem solving, as it often does not result in emotional detachment from the *person* with DS, but rather in detachment from the *syndrome* per se.

There is not a single mother I have ever come across that does not identify with the Kingsley's analogy, "Welcome to Holland". Mothers have an acute understanding of and insight into the never-ending pain that involves an altered itinerary that comes along when one has a differently abled child. The respite of the experience of 'Holland' versus 'Italy', lays in the *paradox of disability*: the episodic see-saw effect of sadness and grief and joy and happiness.

The pain that you do sometimes feel means that you can feel, and at this stage it is way exceeded by the delight and joy she brings to us every... (M/20/D)

This made us really gravitate towards each other, rather than apart.... (M/12/C)

...frail health...final catalyst in cementing our relationship...fragile condition (she was in heart failure from 4 weeks) drove us together and gave us a focus away from ourselves... We both reached times when we buckled under the pressure and took it out on each other but in a painful way it made our relationship stronger. (M/20/D)

...[son with DS and multiple challenges] brings us joy and happiness everyday. (M/19/D)

- **Pride**

Probably because there is such an expectancy of delay and failure due to the characteristics manifestations of DS, mothers are enormously proud of the achievements of their children with DS. Sometimes, after months of therapy toward a milestone, *nothing* can compare with the sheer elation, pride and joy when her child achieves a breakthrough!

I am super proud of any little task he learns to master, the other day he did the shape sorting turtle on his own and that was fantastic we even took it to OT to show her! (M/9/D)

I am proud of him just because he is my son. I am happy to hear his normal child-like belly laughter – signaling to me that he is a happy little boy. I am so proud of him practicing every word diligently, and for building a puzzle on his own. Every little milestone makes me as proud as a parent can possibly be. (M/12/D)

Wanneer sy haar motiverinstoesprake lewer en die mense se trane loop, kan ek sien sy beteken vir gewone mense iets, dis lekker. Die pad wat sy geloop het en die deursettingsvermoë wat sy getoon het, spreek tot baie mense. Sy beteken iets in die samelewing!!!! Dis vir my wonderlik. (M/15/D)

Wat my gelukkig maak is die feit dat baie mense nie kan glo die dat sy 'n DS is nie, want sy is soos 'n normale kleuter...doen alles soos bv. dans, sing, maar op haar tune... (M/18/D)

Every accomplishment she makes and every breath she takes fills me with pride and joy... she is the most awesome human being and there are not many parents who get to have profound respect for their 3 year old who never gives up and slowly slowly achieves what al her peers can do. (M/20/D)

Some mothers reflected on the sense of gratitude and blessing they felt to have their child with DS in their lives.

When I look at my boy today, I cannot begin to describe the deep gratitude that I have for having him in my life! The thought that we might have aborted this unique and truly wonderful little person is too much to bear. (M/12/B)

We are so thankful to have him in our lives. (M/19/D)

- **Frustration and depression**

Many mothers relate most of their feelings of frustration to the abilities/inabilities of their child with DS. The disequilibrium that occurs as a person shifts from one way of knowing to a more complex way of knowing can be painful, frustrating and depressing.

The mother may feel frustrated by internal or external circumstances. Internal frustration may leave her feeling emotionally isolated and unable to cope, whereas external circumstances may leave her feeling inadequate on many levels. This inadequacy is often related to her frustration

with the child's (dis)abilities and she feels directly responsible for the lack of or slow progress of her child. Numerous mothers reported that they felt ill-prepared for the long haul of therapy and its accompanying rollercoaster ride.

...taking much longer to do anything – he only sat at a year old and I was starting to think it was never going to happen. (M/6/D)

Wat frustrasie betref is kommunikasie met [son with DS] no 1. (M/8/D)

The most frustrating thing is him not talking... (M/9/D)

Die feit dat sy 'n hart problem het dat ek nie altyd weet wat om te doen wanneer sy siek is nie...en wanneer en nie kan uitmaak wat sy probeer se nie." (M/18/D)

...most frustration and pain is not knowing what [daughter with DS] is thinking or what she is feeling. This is actually hurting more than I can put words to. (This child, aged 11, is non-verbal). (M/10/D)

...the most frustrating is schools, people and anxiety for future due to my age!" (This grandmother at age 56, adopted her granddaughter at birth because her daughter did not want a child with DS. She is now 79 years old and her daughter with DS is 20 years old.) (M/11/C)

...the slow process of learning. (M/12/D)

As sy haar kop neersit op iets is dit baie moeilik om haar anders te laat dink. Sy vat baie ooredings-vermoë en tyd om haar van iets te oortuig waarmee sy nie saamstem nie. (M/15/D)

An emergent factor that often causes frustration and pain is the ignorance of others.

My biggest frustration/pain is other people's misconceptions (particularly family and friends) about DS even after you have explained things. And the more you explain the more it sounds like you are trying to justify your child's existence. It's incredibly frustrating when people attribute everything he does to DS. (M/13/D)

I've learnt to just smile and walk on as people stare at [daughter with DS]...some people would stop me and ask me to pray for my child...some people would say we are chosen...cliché...nothing special about us...or that she will grow out of it... (M/16/D)

Die feit dat baie mense my aanstaar maak my baie frustreer voel as ek en my dogter saamloop... (M/18/D)

- **Emotional isolation**

Some mothers reported that they felt alone in dealing with their child with DS, i.e. as if they are bearing the 'burden' by themselves.

...not sharing...interaction within family...it's up to me to spend time with [daughter with DS]. (M/2/D)

I have felt that I was dealing with DS and my husband was dealing with his son... I was the one taking him to all his therapy, sitting while he cried for 45mins at a time at physio... I had to harden myself and I suppose I have hardened myself to everything in my life. I did feel like I was carrying the heavy load of DS alone. (M/9/D)

- **Anger**

Anger arises primarily out of anxiety. Anger often neutralizes the anxiety coupled with helplessness and feelings of being overwhelmed. It has the ability to restore some semblance of power and authority for a while, thus in the short term, it offers some protection from emotional trauma (Dowling *et al.*, 2004: 46). Not many mothers reported feelings of anger. Their anger was mostly directed at the failure of a supportive system, for example unprofessional conduct of medical staff, inefficient support structures in terms of intervention and support and tactlessness and thoughtlessness of society as a whole.

We all have demons to face. I really thought I have dealt with this anger and now I think I am just shelving it. I am not good at speaking about my feelings. (M/22/D)

Part of the cycle is also anger that you have to fight all the way for special people like...schooling...sport... disability grants...income tax returns...place for her to live as a semi-independent adult.(M/2/D)

I was VERY ANGRY with my doctor. Specifically asked to be sterilized at the birth of my second child. This was not done I believe because of GREED from the doctor's side. I totally still blame the Dr for his manipulation of my life. (M/22/B)

I was just so angry at everyone and overcome by complete sadness... I kept asking why the hell me. I was fighting with God as I completely trusted him when He gave me this child. And I knew He was taking care of us but then He allowed this to happen. (M/22/D) (This child was sexually violated at a pre-school).

- **Emotional responsibility**

A mother's retrospective reflection on her challenging journey with her son (now aged twenty) was brutally honest yet insightful of the magnitude of the responsibility, both emotionally and physically, which she had borne during this journey.

Als is water onder die brug, maar in retrospek, sal ek dit definitief nie oorkies nie. Dit was net te swaar en weet jy wat? Ek dink [her son] is al een op hierdie aardbol, wat my rerig verstaan en als beseef, so in sy vertraagdheid. (M/1/D)

One of the mothers is in fact the grandmother who adopted her granddaughter after the biological mother, her daughter, wanted to place the baby with DS in a children's home. Although the biological mother has moved on and has other children, the teenager with DS is oblivious of her history. She believes her birthmother to be her sister and this matter is a "family secret", never to be discussed. The grandmother/'mother' took on an enormous physical and emotional responsibility, and although she did not elaborate too much in her written response, she has often spoken to me and reflected on her wonderful journey.

...Legally adopted granddaughter at birth when I was 56 years old...as far as family is concerned this is a closed book...husband died when child had 3rd birthday. (M/11/D)

The thought paradigms and thinking patterns that are characteristic of the individual fall under the following subsystem.

5.2.1.2 Cognitive Subsystem

This includes how the individual thinks about and makes sense of his/her situation cognitively. It also includes the individual's value system, beliefs and attitudes, which influence decision-making and eventual behaviour.

Mothers that I have met who did not have prior knowledge of their child's diagnosis, were content with not having known beforehand, as they felt they had no alternative but to deal with the diagnosis, accept the baby, love it and mother it once the child was born. However, some mothers felt that they would have preferred to have known beforehand in order to mentally and cognitively prepare for the baby. They mostly felt that the shock would not have been as acute and they would have had time to do some research, allowing them time for adjustment and mental preparation.

Diagnosis of DS was confirmed to a participant during an advanced stage of her pregnancy, and the couple worked through the shock in their own time. During her stork-tea she shared the doctor's suspicion with friends and family. This garnered her much support during the last days of pregnancy and particularly once baby was born. As there was no additional trauma once baby was born, it was also easier on the sibling.

However, other mothers who did not know beforehand were in agreement that it allowed them to enjoy their pregnancy without the added stress of knowing that the baby may have DS and other health problems.

...was eers baie onseker oor wat die toekoms met 'n gestremde kind sou inhou, het baie probeer lees daaroor. .. het gehelp dat ek as sielkundige reeds met Down sindroom kindertjies in kontak gekom het...op praktiese vlak was my grootste bang...legio moontlike verwante siektes sou he... In ons wagtyd, waarin ons met elke sonar nog meer "sagte tekens" van Down sindroom moes aanhoor en aanskou, en waarin slegs 'n amniosintese vir ons finale sekerheid kon gee oor die diagnose, moes ons telkens herbesin oor wat dit beteken om te glo. Ons het besef dat onsekerheid, alhoewel dit met tye amper ondraaglik was, tog ook die geestelike vrug van geduld kweek – op 'n manier soos nog nooit tevore nie! (M/12/D)

...if the tests came back positive for Down syndrome I don't know what would have happened...I didn't want to know about the baby having complications... (M/10/B)

...I had a very good pregnancy...I knew there was something was different...it was a relief only to know then that my initial motherly instinct was correct... (M/13/B)

- **Cognitive reasoning and decision-making**

The fears described above are often unsubstantiated as initial shock makes way for rational thought and one realizes that you are not dealing with a diagnosis, but with a child. A child presenting with a challenge affecting one in many different ways, certainly, but first and foremost, it is a child.

...I was sad for the baby...but not devastated...na 'n dag se hartseer het ek weer geglimlag...ek was so bly dat ek 'n babatjie het en dat die wereld haar aanvaar en veral dat haar pappa mal is oor haar. (M/5/B)

...it's fantastic...we are blessed... I don't even see him as a child with DS...my son can do anything he needs time and patients...(M/3/D)

To a mother her child is perfect in every sense, despite obvious challenges such as unmet milestones for example, yet the sheer enormity and uncertainty of the future causes many mothers to doubt their ability to survive at being 'mother', let alone wife and partner.

At some point during their pregnancy, most mothers actively discussed issues surrounding the likelihood of giving birth to a differently abled child, and what their response should be. No mothers reported considering abortion.

...husband had not been married before...no children of his own...had discussed risks and agreed that if baby was born with a disability... we would accept it and love /take care of our child, regardless. (M/4/B)

...my telling vir DS was baie hoog...ons het daarteen besluit omdat al rede vir die toets sou 'n aborsie beteken...ons het voortgegaan met die swangerskap...ons het op die beste gehoop...al het ons geweet daar is 'n kans op DS het dit nie saak gemaak nie...mekaar ondersteun...skok was groot toe ons meegedeel was dat hy DS is. (M/8/D)

My husband was there for me 100% all the time...loved me...cared about me so much more, always making sure that I was feeling ok. He attended every doctor's visit and ultra sound, he was in it with me all the way. (M/16/B)

...test...was only a confirmation of what we already knew. I was sad for the baby and afraid that I would not know what to do, but not devastated and the sadness soon changed to complete trust in the Lord and then happiness for every day with this little angel. (M/15/B)

There was a measure of regret acknowledged by a mother that they did not have conclusive evidence in either direction after refusing the amniocentesis. This was a decision she and her husband took together.

...in some ways it would have been nice to have definite results to work on. We did lots of reading and talking and praying at this time and continued the long wait...although we had some preparation we had almost convinced ourselves that everything was going to be ok... (M/19/B)

A mother shared a serious decision which she had to take behalf of her child.

Due to ongoing monthly medical problems (menstruation) and on the advice of her doctor to avoid future medical complications; it was necessary for her to have a hysterectomy at age 12 years. She does not as yet fully understand the implications hereof and this is a 'mountain' that still needs to be climbed and explained to her, when she is at an age of suitable/full understanding. (M/4/D)

- **Acceptance**

Acceptance is reached once the parents can acknowledge that the diagnosis of their child is indeed their new reality. This is the stage when mothers start to regain equilibrium in all subsystems and they are able to begin to re-organize their lives and families, re-focus their energies and get on with life.

For the mother of a child with DS, reaching a point of acceptance is probably somewhat of a journey, as the immense emotional and physical demands often placed on her after the diagnosis envelopes her time so completely that she may find herself too busy to actually go through the process of grieving. Such a delay in the grieving process may make acceptance harder to attain and maintain, as noted by Nicholl (Dowling *et al.*, 2004: 13). At each stage of moving toward complete acceptance, the mother may experience turmoil in each of her subsystems, and concerted cognitive engagement will support her movement toward full acceptance.

For most mothers the decision to accept the child fully for what he or she represents brought some peace.

Ek aanvaar my kind soos hy is... 'n mens wonder tog hoekom dit so moet wees... (M/8/D)

Na...se geboorte het ek na 'n dag se hartseer weer geglimlag, ek was so bly dat ek 'n babatjie het en dat die wêreld haar aanvaar en veral dat haar pappa mal is oor haar. (M/15/B)

She is my miracle, I loved her since the first moment I found out that I was pregnant and even more so when I was told that she would have DS. I made peace with God, with [daughter with DS] and myself. Loving and accepting her is the best thing I can do. (M/16/B)

Ek het ook besluit dat as enige van my volgende kinders ook 'n Downs sou wees, sou ek die swangerskap behou. Downs was vir my fine en so ook vir my man, die familie en al die vriende. (M/15/D)

My persoonlike lewe was soos 'n proses van lering want dit was die eerste toepasing in ons familie...die belangrikste is om positief te bly en nie hoop op te gee nie... (M/18/D)

Had a 3D scan done at 5 months and saw for myself on the monitor and the picture that was printed for me. Acceptance was instantaneous even before the dr confirmed. (M/22/B)

My kind se skeppingsdoel is om God se oorweldigende liefde te demonstreeer op 'n opregte en kinderlike wyse, sonder die inhibisies van hierdie wêreld. En daarvoor glo ek moes hy 'n Down sindroom seuntjie wees – dit sit hom in 'n baie unieke posisie van opportunity! En dan is hy mos PERFEEK! (M/12/D)

For others acceptance did not come easy.

...dit was moeilik om dit te aanvaar... (M/16/B) (This was the eighth child in this socio-economically challenged family).

...was difficult for my husband who was trying hard to accept [baby with DS] and move on. (M/19/D)

- **Recognition of differences in reaction to the situation**

We did not grieve in the same way, as we are very different personalities...{my husband] knows that I need to have time to work things through on an emotional level, and to talk about it. He gave me the space to do this. At the same time I know that he is much more simplistic in his coping mechanisms - he focuses mainly on the present and where we are at today. (M/12/C)

- **Increasing one's knowledge about Down syndrome**

Pro-active mothers felt urged to empower themselves with information and help which facilitated both their understanding and acceptance.

For the first two years...it was as if DS became the script of our family's life. There was not one day that I did not think about it and ponder some issue around it. Most of my conversations with friends, family and with my husband would include a theme around DS. I read and researched the syndrome extensively to try and get a handle on what I was supposed to know and do...sometimes made me anxious as I did not feel adequately skilled to give ... what he needed. I resorted to experts in the different fields to help me with what I needed. (M/12/D)

...B Sc gewot en in Genetika het ons DS bestudeer...amper alles daarvan geweet, maar dadelik weer begin oplees uit mediese boeke...Ek wou nie net die mooi stories weet nie, daarom het ek 6 mediese boeke gelees...volwasse Downs gaan besoek...met hulle ouers gaan praat..Ek was akademies en emosioneel voorbereid op enige gebeurlikheid tov Downs. Ek wou my beste gee, maar nie meer as wat ek ook vir my volgende kinders sou gee nie. (M/15/C)

- **Values**

The incidence of having a baby with DS inevitably brings with it either a confirmation of existing values, or a significant value shift on a cognitive level.

I would have been fairly selfish...My values were shifted from the material to that which really matters – health, relationships, community and looking beyond my own circumstances to the needs of others. (M/2/D)

I came to realize that life is a gift, that we have so much to be grateful for, that everything that happens in life, happens for a reason and that I am not in control of my life. I now understand that God looks at the bigger picture and that I must just trust and know that he bought me to this and He will help me through it. (M/10/D)

...he has helped me to see people's true colours... (M/19/D)

Mothers recount the incalculable ways in which their child with DS has positively influenced their thinking, values and consequently their behaviour. These are related as *lessons* from their child and include: patience, loving, forgiveness, affection, less shy, understanding, perseverance, compassion

...teaches us lessons everyday of how to be more patient; loving and forgiving. If anything, her influence in our lives has taught us both to be more giving and tolerant of others. (M/9/D)

...extra time pressures involved in raising a child with DS... has taught me to slow down not that I always get it right. (M/5/D)

...having a child with DS has made me a less shy person and has forced me to do things I thought I would never do. It has made me stronger than I have ever been before... brought new ppl and friends into my life. (M/6/D)

Having ... in our lives has made [husband] and I into more real people... (M20/D)

It has been a very positive experience for me personally. It teaches you so many things – perseverance, compassion & understanding and that you truly cannot judge a book by its cover. (M/13/D)

- **Acknowledgement of individuality**

Once these mothers reached the place of insight that the child is a unique individual, and not a diagnosis, they were able to move on.

...has a wonderful sense of humour and that gladdens my heart, she is also a very caring person and helpful, she has lots of courage to try new things. (M/2/D)

Slowly the pain receded as we realized that our boy was not just a subject in a medical book... (M/7/B)

- **Thought paradigms around parental responsibility**

Whilst acknowledging the challenge, these mothers did not feel that parenting a child with DS was much different to parenting any other child.

Having children changes your life considerably and influences your marriage, friendships, social life etc. I haven't found that having a child with DS is any different to having a regular child – it is still a big responsibility. Children are a huge responsibility for any parent irrespective of their needs. (M/13/D)

- **Positive view to the future**

Development, growth and support of the social skills and self-concept of the child is often a motivator for mothers to have a positive view to the future.

...very capable of looking after herself, speaks well, has housekeeping skills, is attending a tertiary college, will most probably work as a nursery school assistant and her health is generally good. (M/2/D)

- **Expectations**

Some mothers reported that having realistic expectations of herself, her husband, her child with DS and other siblings, yielded more positive outcomes. All mothers have limitations regarding what they are able to accomplish within the constraints of their resources and the time available. It is important to have high yet realistic expectations of her child with DS as reported by the following mothers:

...bring [son with DS] up in as normal a way as possible. I did not make any real adjustments around his development at home – but would treat him and expect of him exactly what I expected from his older sister. I only take into account that his development is delayed when he can't deliver! (M/12/D)

... she has 2 siblings...we have a very normal family dynamic and have high expectations of [daughter with DS]...encourage her to be the big sister with all it entails and we have been rewarded with a self-sufficient, talking, eating, potty trained, self-dressing beautiful human being. (M/20/D)

5.2.1.3 Physical Subsystem

This subsystem refers to the physical challenges and experiences of the individual, as influenced by other intra-psychic dimensions, as well as by external demands by the individual's supra systems.

- **Physical challenges**

Mothers, as primary care-givers, commented about the physical toll of having a child that remains at each stage of development for longer, thus requiring more time and effort to help to reach the next stage. This does, however, become better as the child grows toward independence.

....need extra care and attention...baby stage lasted a lot longer as the milestones are delayed...responsibilities were shared...gets older the responsibilities became more mine...more independent by the day. (M/5/D)

Feelings of being tired and physically overwhelmed with demands were reported.

...marriage took strain in beginning...everything was about [son with DS]...being at home, going to DS and therapists was very tiring and overwhelming for me. (M/19/D)

...dit was 'n geweldige stremming...dit het my soms so depressief gelaat... (M/1/D)

...I have to work hard... (M/3/D)

Having a child with DS has been and is challenging as they need extra care... (M/5/D)

...reached times when we buckled under the pressure... (M/20/D)

- **Stress and concerns**

Inevitably, the concern over what will become of their child once they are no longer there is a major stressor for parents. This affects the mother on an emotional and cognitive level, and the family as a whole on a physical level, as not only do financial accommodations need to be made, but frequently siblings feel that they need to assume responsibility for the individual with DS once their parents are no longer able to do so (see Theme Two).

I fear that he will not have independence and I have fear for his future when we are no longer around. (M/9/D)

Maar dis my grootste vrees...dat niemand so goed na haar kan kyk soos ek nie. Dat sy ongelukkig sal wees en te veel na my sal verlang. (M/15/D)

Another area of concern and worry is the tendency of children with DS to wander off.

...[son with DS] loves to wonder away so that's draining...major concern/fear is that he gets lost in one of his attempts to run away. He has no fear on the unknown...inquisitive mind. (M/5/D)

5.2.1.4 Behavioural Subsystem

The behavioural subsystem refers to the individual's will and choices, which leads to his/her behaviour in the situation. It is influenced by the individual's cognitive paradigms and emotions on the issue, as well as by the physical demands and external influences of supra systems.

- **Pre-natal tests and procedures**

One of the most significant behavioural functions centres around whether to have pre-natal tests, and eventually an abortion on confirmation of a diagnosis of DS. The only definitive in-vitro test for DS is by means of an amniocentesis, but many mothers reported having declined this option as it carries a risk for the baby. Most mothers rarely risk any behaviour or procedure that could in any way harm the life she is carrying, hence the reluctance of many to undergo the amniocentesis. It is a mother's natural instinct to protect her baby and herself. Abortion is a term much easier used when one is not pregnant, however not everyone is equally prepared for the enormity such a decision in the light of having a child with DS.

...hard time falling pregnant...refused amnio-thesis test as risks attached of losing baby too great to take. (M/4/B).

Had a blood test done at 12 weeks and it came back high risk but chose not to go ahead with amnio because had had 2 previous miscarriages and didn't want to take a chance of having another one. (M/13/B)

...devastated but hopeful when we were told...something wrong...high result for Down syndrome...offered an amnio but I was adamant...if any risk at all to baby we would not do it. Went to number of diagnostic scans...all the things that could have maybe indicated Down syndrome were not there. (M/19/B)

A history of infertility was the prequel to a successful IVF (in vitro fertilization) for one mother. A traumatic pregnancy ensued. Despite being hospitalized, the mother would tell no one of her pregnancy until all was confirmed as well. After the Nuchal Fold scan she was deeply concerned about her baby and requested further testing, despite her husband's disapproval.

...despite sonographers positive attitude I continued to be pessimistic, something my husband found very difficult to tolerate. I requested that further testing be done but was discouraged by medical staff as all invasive procedures obviously carry a risk and the blood tests combined with my nuchal fold scan put me in a relatively low risk category (that of a 25 year old). (M/20/D)

Mothers offered diverse opinions about abortion. Only one mother, aged 33 when she had her last child, a son with DS, said that she would have terminated the pregnancy had she known at the time. She was clear about her position.

As ons voor...geboorte geweet het van sy Down Sindroomheid, sou ek definitief 'n aborsie gehad het...maar gelukkig het ons nie geweet nie. (M/1/D)

Some mothers who were told that their babies would have DS plus possible other related health issues, were given the option to terminate well into the gestation period. Their opinions were as follows:

Both my husband and myself rejected this idea and supported each other. He was a gift from God and we would love him no matter what. Whether he died in womb, at birth, at 3 months or forever how long he lived we would love and treasure him for the gift that he is. (M/5/B)

...from this sonar, in addition to the blood tests, it was estimated that I had a 1:4 chance to have a baby with DS...recommended that I have an amnio...We declined, having decided not to abort...husband supported my decision not to have the amnio...and at the 7mth check-up the sonar showed a possible heart defect...put me into an emotional spin. I knew intuitively that my boy had DS, but I was not prepared for the emotions around possible additional health issues...pray day in and day out that he would be healthy and strong in all other aspects. (M/12/B)

...we would not have terminated the pregnancy if we had found out then that he had DS. (M/13/B)

- **Overprotection**

Although overprotection stems from a cognitive paradigm surrounding the child's abilities/disabilities, the emotions are influenced to such an extent (for example feeling sorry for the child) that the behaviour of the parents is modified. The child then experiences not only physical overprotection (for example not being allowed to climb a tree, or ride a horse, and so forth) but also emotional overprotection (for example molly-coddling, which prevents the child from fighting his own battles, or standing his own ground). Cognitive overprotection is also prevalent, i.e. parents not expecting the differently abled child to think for himself, to take own decisions and preventing the child from learning new things. Mothers may assume that the child will want to stay with her forever and not want to leave the nest. Not only does this stunt

the child's development into adulthood but leads the child/young adult to believe that she is not capable of independent living.

Mothers often overprotect their children by taking decisions on their behalf. This presents a moral dilemma: does the mother infringe on the human right of the child by taking certain decisions on behalf of a minor, or does she wait until the child is of an age where he/she can make his own decisions or at least have insight into the long-term effect. This is in specific reference to parents who have had to take tough decisions on invasive procedures, i.e. sterilizations, hysterectomies and cosmetic procedures. Undoubtedly these are decisions not easily reached. In this regard, the researcher takes a neutral, non-judgmental position, understanding full well that the personal impact of such decisions. As these decisions may involve submitting their pre-adolescent or teenage child to painful and invasive procedures (many with long-term or permanent effect), must most certainly yield severe and extreme mental anguish for a mother. It stands to reason that such decisions must cause turmoil in every subsystem and require supreme effort to eventually stabilize the equilibrium.

...wanting to protect her from harm/hurt and for her future if and when we are no longer alive to take care of her...she will always be my baby and with me, and will not want to leave the 'nest' one day... (M/4/D)

...concern is being too overprotective of [son with DS]...therefore inadvertently "shutting out" [younger sibling of child with DS] – which will be detrimental to each of them and their development. (M/13/D)

- **Personal growth**

A mother reported how the reaction of others to her daughter with DS has encouraged her personal growth.

This is not an easy thing to go through, but I have learned that the more these things happen, the easier it gets because the next time something happen, you know how to handle it." (M/10/C)

5.2.1.5 Spiritual Subsystem

Mothers experience their journey on a spiritual level and often depend on God for grace and help, at all stages of their journey (see Section 3.10).

- **At diagnosis**

...we both decided that if the baby had DS, we would not see it as a tragedy, but as something God allowed for a reason...(M/12/B)

Ons is albei gelowig...het gou besef...pick up the pieces and go on as best we can. (M/1/D)

God was in control...protected me by keeping all kinds of tests away from me...if they had tested me in the beginning stages of my pregnancy and the test results came back positive for Down syndrome, I don't know what would have happened...someone might have convinced me not to have my baby... very young... (M/10/B).

We both sensed a great peace ...felt that God was present and that he said that it will all be ok. (M/12/B)

- **During their journey**

Ek dank God net vir sy bystand en krag elke dag. (M/1/D)

...pray daily that God will spare me to take care of her for as long as possible. (M/4/D)

Ek dank die Here vir dit wat Hy my geleer het deur ... Ek waardeer klein dingetjies meer, ek sien die lewe in veel meer vlakke en ek is so bevoorreg!!!! (M/15/D)

...nou voel ek dat die Here 'n rede gehad het met die kind...ongeag wat die here vir jou gee...aanvaar dit want hy weet alleen jy is bekwaam om die taak te kan doen... (M/16/D)

...daar was so baie se goed ek het amper moet verloor maar ek het aanhou glo en vertrou op die Here. (M/18/D)

...ons maar altyd eers moet hoor wat op God se agenda is – anders is daar baie keer soveel teleurstelling en geestelike wonde wat mense opdoen!...self by die Here gaan vra, wat beteken sy PERFEEK vir ons in hierdie situasie? Die antwoord was nie die lekker een nie... maar tog ook 'n ongelooflike vertroosting waaraan ek selfs nou, drie jaar later steeds vashou wanneer ek hartseer wil word oor my[son with DS]se uitdagings. Dat ons Perfek is wanneer ons ons skeppingsdoel uitleef. En dat ons skeppingsdoel nie gemeet kan word aan die "normale definisie" van 'n prestasiegedrewe, intellektueel-gefokusde wereld nie... (M/12/D)

- **Premonition**

Some mothers reported having a sense of *knowing* before the time.

Only diagnosed 10 days after birth...I was worried about the baby and the birth – I knew something big and life changing was coming and I was anxious. (M/7/B)

There was a 1-6 chance that she has DS but we still hoped. I on the otherhand “knew” that I was gonna have a disabled child. (M/22/B)

...after the Nuchal Fold scan...I took one look at the foetus and knew beyond a shadow of a doubt that something was 'wrong'... Deep inside I felt the baby had Down syndrome but I was not able to speak these words yet...following 2 trimesters...relatively uneventful...largely characterized by my constant worrying...I finally found my voice a week before she was delivered...said to my husband I believed our baby girl had Down syndrome and that we must be prepared... (M/20/B)

Who you are as an individual, what your coping mechanisms are and what your attitude is, plays a huge part in how you deal with firstly yourself and then your child and family once you have a child with DS. One cannot pre-empt every variable of every situation.

As one mother reported, *“I was positive about my baby and when people asked me what if things go wrong, I told them that “I will handle problems as they arise, and not before the time”.* (M/15/B)

Balance of needs and time stem from a physical paradigm, yet the emotions and behaviour of the mother become unbalanced if there is no equilibrium within this subsystem. All the mothers agreed that concerted effort, however difficult, to attain balance between the needs of the child with DS, the needs of other family members, and the needs of the family as a unit, resulted in successful family adaptation.

This is often easier said than done for most parents, especially mothers. Mothers of typically developing children, but particularly mothers of a child with special needs, completely lose themselves in the constant stream of personal needs, therapies, medical concerns and time-consuming support rendered to a differently abled child. The mental and physical health of the mother is vital for adjustment and ultimate ‘survival’ and adaptation of not only the mother, but the entire family nucleus.

5.2.2 INTRA-PSYCHIC FUNCTIONING OF THE FATHER

Parents, and probably more so fathers, who are excitedly awaiting the precious new addition to the family, never really believe that *this* can happen to them. Afterwards, they often justify why they don't *deserve* it, why it *couldn't* be the hand that they were dealt, and that it seems

completely incredible and incomprehensible that such a thing should happen to *them*. Although this materializes within the emotional realm, it is strongly influenced by the cognitive subsystem in its rationalization of the *possibility* and indeed *probability* that it can happen to *anyone*. This study confirmed the knowledge and literature that DS undeniably knows no status, age, colour, creed or socio-economics. It is simply the fall of the dice.

There was a marked reluctance of participation amongst especially black and coloured men. This could be attributed to their cultural belief of keeping personal and family matters private, along with their general disinclination to discuss matters pertaining to emotions and feelings. The personal nature of this topic probably further enforced their innate protection of private family matters, as demonstrated by the poor response rate from this group. Although the researcher approached ten black and coloured fathers to participate in the study, only three responded.

What was established during this study is that fathers similarly share the process of grief, manifesting similarly to that of mothers in the subsystem disequilibrium of cognition and behaviour.

Although not experienced by participants of this study, it is possible for an individual to turn to alcohol as a means to anaesthetize shock and inability to cope with an unacceptable or unbearable situation. Inevitably, such diversion to denial serves no purpose aside from possible relationship and personal problems. This could be a manifestation of feelings of utter helplessness and despair at not being able to '*fix*' things for their child (or their family, for that matter), traditionally perceived by fathers as a significant role of the protector and provider of the family.

Intra-psychic variables related to the experience of fathers of children with DS were identified as follows.

5.2.2.1 Emotional Subsystem

Although fathers and mothers experienced many similar emotions around their child with DS, it was evident that there was also a range of emotions unique to the fathers. These were centered on the wellbeing of the spouse and of the baby, as fathers naturally assume the role of protector of their families.

- **Fear**

Fathers in this study feared for the well-being of both mother and baby in vitro and rarely considered the amniocentesis test for DS, due to the risk for baby and mother. Termination of the pregnancy was not an option considered by any of the fathers.

...no chance we would have considered... an amnio because of the risk of miscarriage...would not have terminated...should the test prove DS anyway. (F/1/B)

...test results ... 80% chance that our baby could be down-syndrome. ...don't know what to expect and fears were very real in that stage. We went for the testing of the amniotic fluid, a very nerve wrecking and frightening experience!.(F/3/B)

... had I been told during the pregnancy that my child is going to suffer from Downs Syndrome...well to be honest I don't know what I would have done. I will say this, I thank the Lord I never knew, I will never forget holding my little girl, that same day I found out. I wouldn't let her go I kept looking at her... (F/6/B)

Some fathers shared their fears surrounding their own limitations and feelings of inadequacy, toward the mother and the child, and their inability to always be there to always protect their child.

I knew very little about DS... had no idea how we were going to manage...(F/1/D)

The fear of the unknown also plays a prominent part in my daily thought. (F/2/D)

Not being able to "soften" the "blow" for my wife, to help reduce her pain, anxiety, frustration, exhaustion. (F/8/D)

...the fear of them getting teased and ostracized at school and by their peers... (F/2/D)

...the thing that has the worst affect on me is when [my daughter with DS] is sick or hurting and she cannot tell me about it. I remember when she got abused at school here in JHB; she could not tell me she was hurt. I remember the marks I could only imagine the pain she was put through. (F/6/D)

The primary emotional stressor for all of the fathers participating in this study is the future of their child with DS once they are no longer here.

... lack of support and infrastructure in South Africa for disabled people. Obvious primary concern is the long-term wellbeing and care for our child. Having invested heavily both emotionally and financially to try

and give her the best possible chance of operating as a fully functional, contributing member of mainstream society, we are extremely concerned that should she not continue to have this kind of support for the rest of her life, there would be significant regression and loss of quality of life for her. (F/8/D)

My primary fear is who will look after [son with DS] once we are no longer here. (F/2/D)

...we didn't know what his capabilities were going to be or what his prospects in life were going to be. (F/1/D)

- **Shock**

Just like the mothers, many of the fathers shared their feelings of shock.

...there were no tests done for Down's syndrome as we were a young couple so the day I was told, it came as shock as it was never expected. (F/6/B) (In this case the father was 23 and the mother 19 years old.)

...The diagnosis hit me like a freight train...I was in total shock for about 3 weeks...(F/1/D)

Ek was eers baie geskok want dit was die eerste keer in my familie wat ons so 'n kind het... (F/11/B)

... it was a shock to know that we are having a child with DS... (F/10/C)

- **Pain, anger and frustration**

Many fathers reported feelings of pain related to comparisons between their child and society's conception of a typically developing child.

...Painful is when family and friends etc say things like "I wonder where this thing comes from?, I wonder how you guys cope" such statements are painful and can cause you to become angry. (F/5/D)

...Having a DS child is devastating... (F/2/D)

...D/S is so much work and one can never get away or forget about it so the stress will be always on ones shoulders. (F/4/D)

...Concerns and anxiety are when there is a heart condition, cataract etc. these are concerning as a parent. (F/5/D)

Frustration is often caused by internal and external factors as some fathers reported:

...most frustrating... people's well meaning but insensitive comments and looks eg: they are such lovely children and you must be very special parents or my amnio results came back all clear etc etc...general lack of knowledge and awareness of DS.... society's view that DS is a "problem"... (F/1/D)

...frustration...development of her speech is quite slow in relation to her normal development... (F/3/D)

A father shared his experience of pain which manifested in anger.

My reaction was that of anger the whole thing about WHY ME ????? WHY MY GIRL ??????. I then found myself outside the hospital beating up the phone booth on the pavement. My mom managed to calm me down... told me that I have a wife up stairs and daughter who is wanting to meet her father. In the beginning it was hard, I had to go for therapy for my anger towards people. No one could even look at my girl and they were flat on their back. This happened many times. (F/6/B)

- **Loss**

The loss of dreams was shared by a father.

...I did not really think that he would have DS. I imagined my son to be a good mix between his mom and I...already thought about schools...hobbies...interests he may have. I imagined what we would do together... (F/1/B)

The possibility of losing a child with DS is always present. This father lost his son at age two due to complications following cardiac surgery.

Having a child with DS has really strengthened me and feel that although we were told that it would be very difficult it has been a true blessing for me... melted the hearts of all those that he came into contact with (family and friends) To have a DS baby is a Blessing as you grow in every aspect of your life. Our family has really grown by the experience. Our children have adapted well to help grow Josh up but sadly we have lost him. (F/5/D)

- **Gratitude and pride**

Similarly to mothers, many fathers were grateful for their child with DS and proud of what their child was achieving.

I feel privileged to have a child with DS in my life...taught me a lot about myself, my wife, my family and life. (F/2/D)

...exceeds my expectations on a daily basis ... I have learnt compassion and patience as a result of having him. (F/1/D)

...to see her grow up in a family that supports her and understand her short comings...most rewarding...makes us happy...see her progress although slowly gives us immense pride and joy. (F/3/D)

Small progress in him was very huge for us as we could see it wasn't very easy as it would normally be. (F/5/D)

Wat ons trots maak op haar is die feit dat sy baie sterk was self met haar operasie het sy geveg. (F/11/C)

- **Happiness and joy**

As her farther the thing that brings me the most happiness and joy is the fact that [daughter with DS] is not letting life get the better of her she has taken part in the special Olympics and won medals for running. (F/6/D)

*Seeing how our child can grow/learn/love unconditionally...brings us most happiness/joy/pride. (F/8/D)
Even though we've lost our little angel we talk about him very often, we miss him very dearly as he was always a joy to be with. (F/5/D) (This little boy died due to complications after cardiac surgery.)*

- **Unmet emotional needs**

This aspect is revisited in Theme Two under the Marriage System (see Section 6.3.2.1). Although a number of the intra-psychic factors of mothers and fathers are directly related to the Marriage System, they also need mention under the individual subsystems as these were emergent in this study.

A number of fathers shared their feelings on unmet emotional needs.

...more lonely ... don't have any sympathy for other's plight... your own challenges to deal with. (F/1/D)

...no time for each other and only for kids...I feel I live with the mother of my kids and not my wife. (F/4/D)

...there are times when you as a person feel lonely. (F/2/D)

In many ways it has brought us closer together and in others it has placed different stresses and strains on our relationship... (F/8/D)

5.2.2.2 Cognitive Subsystem

It was evident that there was increased confidence of some fathers to competently raise their child with DS as they expanded their knowledge and insight regarding the syndrome as well as the potential and capabilities of their child. This went hand in hand with the cognitive decisions around acceptance of their child.

...we slowly started to learn more about down-syndrome and became more confident that we will be capable of raising our daughter. (F/3/B)

Ek het haar aanvaar so sy is... Sy is 'n normale kind net soos my ander kinders. (F/11/B) (This father is a 47 year old 'stay-at-home-parent' whose daughter aged 3, is his 8th child).

...we supported each other and reassured each other...big difference in our confidence... (F/3/B)

It has at times been a HUGE emotional burden on all of the family, but having weathered it, it has made us all stronger. (F/8/D)

- **Recognition of positive influence**

...dramatically influenced our lives, as individuals as well as a family... made us more aware of the challenges faced by people with disabilities and the impact on the balance of the family by having a member that has disabilities. We have experienced that LOVE is not just a word in the dictionary, but is something that we experience and that we live it in our family. (F/7/D)

...I have become more affectionate and caring towards others and respecting of one's ability ... The DS has taught me a lot about life. (F/4/D)

...feel more positive now than ever. (F/2/D)

- **Thought paradigms around parenting decisions**

Some fathers related their view on parenting as joint efforts.

...we both agree on the basics when it comes to parenting decisions so it hasn't lead to any conflicts in our relationship. I don't think that having a child with DS has made too much difference. The issue here is having a child ... (F/1/D)

... we have experienced that a lot of the arguments between us, husband and wife, have been about [son with DS] in specific the upbringing and discipline of him. Mother has the softer input and I as a father had a stricter methodology and procedures. (F/7/D)

5.2.2.3 Physical Subsystem

On a concrete physical level a stressor for fathers in this study seemed to be the financial implications of having a child with special needs.

- **Stress**

...affects any relationship, whether one has a kid with or without DS. Stress and unknown plays a huge roll so one is tested at all times. (F/4/B)

Fathers recognized the physical strain that mothers were taking.

...wife has permanent stress on keeping my kid with d/s on top of things e.g. schooling, extra classes and therapy's... (F/4/D)

Although the costs of therapies and interventions may cause financial strains, only one father mentioned financial considerations. It is my opinion that parents often do not mention financial constraints as they are wary of the negative perception it may create with. Parents often say nothing as they do not want to sound resentful for having to spend large amounts on expensive therapies. It is often only other parents in similar situations who fully understand the financial burden.

...There has also been a significant financial burden too. (F/8/D)

5.2.2.4 Behavioural Subsystem

Mothers and fathers who are pro-life or have strong beliefs about abortion usually do not opt for any test that carries a risk to the baby, even if it enables detection of abnormality in the fetus. People have their own reasons for the decisions they take, and this decision, as stressor, exceeds all others in terms of apprehension and anxiety (before, during and after the procedure, waiting period, and prognosis), as attested by fathers. In cases where parents have a history of conception problems and/or miscarriages, it is unlikely for either to consent to tests that carry a risk for mother or baby. None of the fathers considered termination.

... no chance we would have considered... an amnio because of the risk of miscarriage...would not have terminated...should the test prove DS anyway. (F/1/B)

Similar to mothers in this study, the fathers exhibited a propensity towards overprotecting their special needs child. Also significant is the role that fathers take in the community to advocate for their children. This correlated with their personal growth experiences as indicated below:

...The only negative is that I feel very overprotective of [son with DS]...could be detrimental to his development. (F/1/D)

A father felt empowered and emotionally strong and shared his desire to assume the role of ambassador and to support other parents in a similar situation.

I really want to make a difference not only in his life but potentially other couples or families who have children with DS. (F/2/D)

Having grown and evolved as a human being were feelings shared by many fathers.

...I am now able to “see” children with special needs. I used to be that insensitive and condescending person who now irritates me... I am much more compassionate, patient, caring and tolerant of others, especially those with a disability I am able to approach people with disabilities with an open heart and have a genuine interest in them and their challenges. (F/1/D)

...challenged us as individuals, made us stronger personally and also as a family...aware of the struggles that most families face with down-syndrome...humbled us to know that we have a healthy down-syndrome child. (F/3/D)

It has caused me to be able to complete my PhD in Theological Counseling with special focus on parents with Down Syndrome children. (F/7/C)

It has made us mature and grow in ways we probably never would have, had we not had a child with DS. It has opened our eyes to things many others are NEVER aware of, or simply choose to ignore or could not be bothered to try and understand. (F/8/D)

5.2.2.5 Spiritual Subsystem

Fathers seemed to rely on God to help them with this challenge, and many reported spiritual growth as a direct result of having a child with DS.

Going to church with our little family has given me the strength to look at...diagnosis with renewed vigor and I feel more positive now than ever. (F/2/D)

Having the Down Syndrome child has also given us the opportunity to grow not only in maturity, personality, but most important, in our spiritual lives and growing close to Lord God. (F/7/C)

The only way I can explain this is having her in our lives as a family it has brought us closer and taught us how to love and be more patient, through her we met God. (F/6/D)

... but we pulled through with the support of my family AND the help of God. (F/10/C).

5.3 THEME TWO: INTRA-FAMILY FUNCTIONING

The following systems are influenced in the case of a family with a child with DS:

- Marriage system
- Sibling system
- Parent-sibling relationships

5.3.1 MARRIAGE SYSTEM

Having a child with special needs unavoidably puts a high strain on the marriage relationship. The two people in the marriage, each with their individual intra-psychic systems, together create a “we”. This can be seen as a joint intra-psychic system, containing all the subsystems i.e. cognitive, emotional, physical, behavioural, and spiritual, and influenced by the history and development of said system. Related to the eco-systemic theory (see Section 4.4.2) the children, and in this case the child with special needs, represents a supra-system of the marriage – and thus influences the latter in all its subsystems.

The following characteristics of the marriages of parents, as related to this study, will be discussed:

- **Emotional Manifestation**

As previously mentioned the emotions of the parents can range from being volatile, to extreme pain to the peace and joy that characterizes acceptance. The parents in a family may not always be experiencing the same emotions, and because they are individuals, they also do not

experience the same emotions at the same time. This “out-of-sync” emotional experience could influence their joint emotional subsystem and result in anger with each other, disappointment at their difference and reduced intimacy. There is often also irritation as a result of mere fatigue in having to cope with the special circumstances. The following example is a case in point:

Daar was n tyd wat ek die hele gesin wou los en weghardloop want my man het sy werk gehad waaragter hy geskuil het, hy was bitter selde tuis en dan was hy moeg en geirriteerd. My man het wel sy support gegee as hy die odd keer oor n naweek af was. (M/1/D)

Neither of us were in a particularly good space...father had committed suicide...business was very demanding, and I was struggling to integrate into a new city and marriage with a man I loved but who was clearly depressed and not always able to give the support I craved. Enduring fertility treatment and the demands it makes of you and what it 'does' to your wife often came close to driving us apart for good and this culminating in a pregnancy which did not deliver the 'joy' we expected very nearly ended our marriage. (M/20/D)

On the positive side, the couple who manages to share their emotional pain, and support each other, often report increased intimacy.

...we are closer as a result of this special boy we share...make time for regular date nights... normalized it for ourselves as just a phase that we have to get through... We have much more grace for each other that before! (M/12/D)

It is often only much later when parents feel physically, emotionally and cognitively more equipped to re-establish their equilibrium. Parents may initially experience negative emotional outcomes, but these adjustments soon abate or decrease in time to make place for positive outcomes such as psychological well-being, improved relations with others, personal growth, changes in philosophical or spiritual values, and satisfaction with parenting (Van Riper, 2007: 118). Certainly the majority of parents indicated increased enrichment and meaning in their lives due to their experiences with their child with DS.

- **Spousal Support**

Reciprocal emotional support within the marriage cornerstones a healthy marriage. High emotional spousal support reinforces the emotional subsystem, positively influencing cognitive and behaviour domains.

Mothers need a great deal of understanding and affirmation at this time, yet fathers often divert to their primordial instinct to 'bring home the bacon'. Consciously or subconsciously they are able to put everyone and everything second to financially provide in order for their wife and children to have the best according to his ability. Men often have a mindset that financial support will suffice. Nothing could be further from the truth. Mothers who do not enjoy sufficient spousal emotional support may be prone to postpartum depression, which includes a wide range of emotions (anxiety, sadness, increased sensitivity and vulnerability) which may further be exacerbated by having a baby with special needs.

Even though the quality of the partnership is important to the mother's adjustment to both pregnancy and motherhood, there has been little research on the psychosocial adjustment of the fathers preceding and following the birth. The pain of having a child with DS is not diminished just because the father is necessarily less involved in the daily care-giving functions and therapies than the mother. His every level of functioning and being is affected by the hand his family has been dealt, despite him being possibly less verbal and outwardly emotional about it.

As mother often becomes immersed in her role as primary carer, therapist and student (as there is so much to learn and to know about DS), the father may inadvertently withdraw, which causes a physical and behaviour subsystem imbalance. The mother may grow to harbour feelings of resentment for having to carry the load by herself, perpetuating further relationship problems and marital conflict. It therefore stands to reason that his emotional, cognitive, behavioural and possibly physical subsystems would all be influenced.

Some mothers reported low levels of marital relationship, both before and after the birth of the child with DS.

The next day my husband left for a week on a prior commitment he could not get out of. That was hard as we never got the chance to talk about anything! (M/9/B)

...my man...min tuis...iewers in die agtergrond...wat medies betref...hy het al die kontakte en knowhow...hoe selfsugtig en bisar dit ook al mag klink (M/1/D)

Many couples reported a positive repositioning of their relationship as a result of high support. *[my husband] and I seem to be closer since the birth of...tend to share our fears and feelings with each other. (M/5/D)*

...drifting apart and had no empathy for one another...[baby with DS] brought us closer ...we seem more loving and caring to each other...marriage and relationship is better...responsibilities still more on moms shoulders but [dad] does a good share and is irreplaceable. (M/7/D)

My husband... immediately said that it is fine with him to have a son with DS, that all we need to do is just love him, and that it would be easy to do that in our family... my husband is a very loving father, and he has an extremely soft spot for those who have special challenges...(M/12/B) (His sister's daughter has minimal brain dysfunction, and he had a very special relationship with her throughout her childhood and into early adulthood – she is 21 now).

[my husband] and I felt very united in our upcoming challenge – make no mistake we were overwhelmed and scared but felt lucky to have each other and both to feel the same way. (M/13/B)

...my man het altyd my moet ingepaat. Hy het altyd gese sy is pragtig en daar is niks fout nie... (M/18/B)

...one thing is for sure, you have both got to make a concerted effort to make time for each other and your relationship. In my experience I think you shouldn't leave it too late either. (F/1/D)

Despite what had been a very difficult time in our marriage he hugged me and said we would love our baby no matter what. I do believe that it was this very brief moment in time that carried me through the first few difficult weeks of coming to terms with our little girl and her 'diagnosis'. My husband had vowed to love her and so I knew he would. To me this had an enormously significant effect on allowing me to bond with our little baby safe in the knowledge that I had his support. Had he rejected our baby I believe I would have found myself in a situation that I would not have been able to handle. (M/20/B)

- **Financial Concerns**

Despite financial concerns being mentioned by one father only, some mothers shared their feelings about the matter.

*I worry about the financial burden constantly...heart operation... cost us over R280,000.00...we spend all of our money on medical bills and never seem to be able to put any money aside for ...future. (M/6/D)
....money and supplements debate. (M/7/D) (This mother found that the high costs of alternative supplements for her child caused some contention).*

- **Commitment to the Family**

...Our absolute commitment to her brings us through the trying times together. (M/20/D)

...limited time and exhaustion influence your intimate relationship especially when your children are still little. The key is to try not to develop bad habits that could potentially become problems later. (M/13/D)

In fact we are enjoying the family at the moment, and put family time before relationship time. (M/12/C)

Our love for her has made our love for each other grow. It has not taken away the turbulent times only given us a common cause that is so much bigger than our combined egos. (M/20/D)

- **Communication and Understanding**

Most women feel the need to contemplate, analyze and assimilate related information regarding a given situation. Similarly, they try to make sense of their new role as mother of a child with DS. It is often very difficult for them to fathom the feelings and opinions of the male partner in the relationship due to the predominantly mechanical thinking of the typical male (sees the situation, speculates the cause, immediately tries to figure out the possible way forward).

This innate difference in approach may cause mothers to have feelings of extreme loneliness. Not only does her husband, partner and father of her child not seem to 'understand' her need to talk this situation through constantly, but he does not seem to 'grasp' how hard it is for her to deal with the pressure of having to be the 'perfect' mother in an 'un-perfect' situation. Some mothers may feel that, whereas she is totally committed, the father is merely involved. Open and honest communication was identified as unifying strategies.

The birth of...brought us closer together than before... we are the only two people that will ever be able to share mostly the same emotions toward our child, the loss of dreams we had for him, the fear of him having to fend for himself when we fall away etc. We have discussed it and both cognitively decided to not stress about it, do what we can to have special time, but realize that it is a season in our lives – one that we cherish. (M/12/C & D)

...very good relationship...based on a long and solid friendship... open and honest relationship... Things don't always run smoothly and we have our ups and downs like any other couple but fortunately we seem to be able to communicate quite well and so to date we have always been able to resolve any issues. (M/13/C)

We do however discuss openly with each other about how we yearn for the good old times and touch and tenderness have had to be a substitute. We definitely treasure moments together more than we used to and our fist dinner out together (alone) in years was so exciting it felt like a first date. (M/20/D)

Despite the obvious stressors, understanding the physical and emotional needs of partners was eminent in consolidating a good relationship and marriage.

Enduring fertility treatment and the demands it makes on you and what it 'does' to your wife often came close to driving us apart for good and this culminating in a pregnancy which did not deliver the 'joy' we expected very nearly ended our marriage...[daughter with DS] arrival, 1 month early, did a strange thing in that it united us, we both recognised that we would not cope without the other... (M/20/C)

A mother felt that her husband did not understand the demands placed on her concerning early intervention, causing resentment and feelings of fighting this battle alone.

I feel [husband] doesn't understand why things has to be done in a certain way or repeated all the time...he is at work while I have to deal with the therapy... (M/16/D)

- **Relationships and Intimacy**

In the cases of marital strife prior to the birth of the child with DS, these problems were often exacerbated by the added stress of having a child with special needs and everything that it encompasses. In the case of children with serious health issues which required constant medical attention and care, the pressure and responsibility often falls on the shoulders of the mother as primary care giver, and can lead to a breakdown in communication and interpersonal relationships. Sheer exhaustion of the mother, feelings of her emotional and physical needs not being met, and feelings of being in this alone further cause her to isolate herself emotionally from her spouse. She may further harbour a measure of resentment toward her spouse for having the opportunity to pursue a career, have some 'alone-time' (even if it is at work), engage in activities and people outside of her restrictive cocoon of care, or simply get out of the house and be a part of the 'regular' world for a while.

Despite the abovementioned scenario, not all mothers attributed spousal relationship problems to DS.

...speel nie so 'n groot rol in my en my man se verhouding nie...As ons sou skei, sou ons..ons geval sal ek eerder se dat...die behoudende factor was. Hy was die een wat my weerhou het van tye wat ek wou waai. Suiwer omdat ek nie kans gesien het vir al die stress op my alleen nie. (M/1/D)

Lack of time and energy are identified as stressors related to reduced intimacy.

Our intimate relationship has changed a bit – not enough time with each other but any child does that to a relationship. (M/5/D)

...the constant demands for attention that a DS child puts on the parents results in exhaustion and feeling that your whole family life has become one big DS laboratory. (M/12/D)

...overwhelmed with all the responsibilities, tired...less time together...have to do things separately because of having [child with DS]...we have had to set aside more time together and really had to work on our marriage.. (M/19/D)

...its exhausting work and that kind of fatigue is always going to impact on the amount of energy you have left for other aspects of your life. (F/1/D)

...not leave too much time for our relationship, and we are definitely not as in tune with each other as before...sometimes feel as though we are just handing the baton to the other one in the run! If we do go out together, we mostly talk about the kids! (M/12/D)

Our marriage has suffered, as I have put everything I have into helping [toddler with DS] to be the best he can be. Taking him to therapy sections, stimulation classes, anything that may help! That I have had very little left to give. (M/9/D)

...tyd wat ons saam spandeer...heelwat minder...slaaptyd...raak een van ons of albei aan die slaap by die kinders...gaan aande verby dat ons nie in een bed slaap nie (M/8/D)

We don't have time for each other...Our intimate relationship is nonexistent! I feel it has been so long that I don't know him anymore, I feel we should start from scratch with dating then move on from there.(M/9/D)

[toddler with DS]...slaap ook in dieselfde kamer as ons... (M/8/D)

Our intimate relationship has suffered as stress does not encourage passion. (M/20/D)

...your intimate part of your relationship has fallen apart... main reason is stress or control of stress. I find woman handle stress in different ways to men. A woman needs affection to feel loved. And a man need love to feel affection. (F/4/D)

There were however reports of increased intimacy.

...intimate relationship has changed for the better...marital relationship is stronger... (F/3/D)

Our intimate relationship has changed maybe reaching a more mature level. (F/5/D)

- **Relationship Shift**

The spousal relationship prior to the birth of the child with DS is often a predictor of the relationship and any shift in family dynamic after the birth of the child with special needs.

Fathers reflected as follows:

We have a very strong relationship and marriage... close friends...very open and honest...very good communication...Has influenced all aspects of our life but I don't think any more so than having a "standard" child. (F/1/B/D)

Initially it brought us closer together very quickly, we felt united in a time of crises ... both worked towards a common goal of nurturing a child with special needs... (F/1/D)

...we were sort of still on honeymoon...only married for... 2 years. Since [son with DS] came into our lives and marriage, we have certainly grown closer and with a more mature relationship. (F/7/C)

Ons persoonlike lewe was 'n proses van lering en dit was 'n nuwe aanpassing vir my. Maar net deur my vrou se self vertrou het my ook die moed gegee om dit te aanvaar. (F/11/C)

- **Additional Siblings and Division of Responsibilities**

The addition of a sibling for the child with DS often adds a new dimension to the family dynamic. This was reported as significant in the adjustment of a family setup.

Ironically, having our 2nd child (without DS) has caused the family dynamic to change. When it was just the 1st child we were united in our roles as parents and did everything together but when the 2nd one came along we were pulled in different directions ie: one deals with eldest while the other deals with the youngest and vice versa and it feels as though you are not united or connected in your role as parents anymore...no longer possible for me and [husband] to do everything together. (M/13/D)

...the arrival of... 2 siblings also did not help things as sheer exhaustion and sleep deprivation are also not aphrodisiacs. (M/20/D)

...Now with a second child I have nothing left, not for me or anyone else!! I am exhausted everyday. Enough said. (M/9/D)

Parents found that sharing responsibilities was imperative to their personal well-being and continued positive relationship development.

We focus more on sharing responsibilities...I as the father had to do more than I normally did, that created an opportunity for me to be more involved for and with the family. (F/3/D)

...when our second came along things became really tough. We were united in our efforts to provide for the first child but with the second its each one for their own. I watch one and [my wife] watches the other – it's actually more lonely this way and you generally don't have any sympathy for the others plight because you have your own challenges to deal with. (F/1/D)

My husband was very supportive and pro-active right from when we heard the news. (M/2/C)

We focus on supporting each other, making turns, giving each other some space and "me-time". We constantly say to each other that we do not know how single parents of DS children do it. (M/12/D)

...deel graag take wat die kinders en huishouding betref... (M/8/D)

...haar papa was die beste...wanneer niemand haar aan die slaap kon kry nie, het hy haar gevat, vir haar gesing, haar op sy bors neergesit en later sy hand op haar lyfie gesit en dan het sy saggies aan die slaap geraak. Sy geduld met haar het nooit opgeraak nie. (M/15/B)

As ons praat van verantwoordelikheid het ons altwee dit gedoen veral met die mediekasie, sy dokter moet gaan spreek of as sy in die hospital beland was ons altwee daar. (M/18/D)

- **Divorce**

There is no question that having a differently abled child can be a tremendous source of stress for a couple. A once carefree romantic relationship can turn into a painful, confusing, emotional rollercoaster for a while, and should one partner decide he or she wants off the ride, this may leave a tremendous burden on the spouse left behind.

To understand a family's response to rearing a child with DS, one need consider the demands placed on the family unit as a whole. Parents still need to respond to the demands (physical and emotional) of their typically developing infants as well, often requiring redefinition of roles within the family system. Mothers are mostly the primary carer of children, but the new baby,

with its new set of demands in terms of therapists, possible health issues, etc, mostly makes it impossible for the mother to cope without experiencing serious role overload. This may negatively affect spousal relationships and cause tension in siblings.

The demands associated with rearing a family in general and a differently abled child in particular (and the strains and stressors associated herewith), change continually. If they are not resolved, demands may pile up, placing the child and family at risk for poor outcomes.

The findings in this study was consistent with the findings of recent research conducted at the Vanderbilt Kennedy Centre showing that divorce rates were, contrary to popular belief, indeed lower among parents of children with DS than national averages (Hodapp, 2007: 284). This is assumed to be attributed in part to what is referred to as the *Down syndrome advantage*, which refers to the advantage that parents with a child with DS supposedly have over parents raising children with other disabilities. It refers to children with DS having a more amicable personality and less challenging behaviour, as well as the supposition that parents of children with DS are mostly older, have more parenting and life experience, are probably more settled, more educated, and are in most cases in fairly stable marriages at that stage of their lives.

The researcher reserves judgment on the claim that children with DS are *mostly* born to older mothers. Although forty three when my daughter was born, the number of younger parents of children with DS by far outweigh the older group that I have met over the world during travels to World Conferences on DS. In fact, I would go as far to say that out of an estimated group of three hundred women that I have met personally, maybe twenty would have been mothers my age. In my experience with families with children with DS, most mothers were under 35 years of age.

It is further my opinion that the divorce rate is lower in parents of children with DS for the simple reason that parents who opt to keep their babies rather than abort them, would generally have a mindset, attitude and approach to life that is positive and resilient. Thus they would refuse prenatal testing because the outcome is of no consequence to them: they choose *life* for their child, knowing that together, as a couple and a family, they could possibly be entering a season of challenges. Their attitude toward raising a child would probably mirror a similar attitude to marital commitment, positively influencing both.

I would imagine that when divorce did occur in families with DS, it was more likely to occur within the first two years after the child's birth. Having been there and having discussed this very challenging stage with many mothers and fathers, it is understandably the time when

mothers are still reeling from the initial feelings of being overwhelmed. During the first two years most mothers would have had to take serious career decisions (in most cases placing family above career). On a physical level heels are replaced by sneakers, suits by tracksuits, hair-do's by hair bands, acrylics (nails) by Aqueous (cream) and frivolities and fun are substituted by their child's physios and physicians. Meetings make way for milestones and social life starts revolving around chromosomes. As one mother accurately remarked, "the first two years our life became a DS Lab!"

Whilst this is the most important time in terms of development and therapies, it is also the time during which the most relationship crises germinate. In a caring, supportive and mature relationship this will most probably be treated and handled as a passing season, but in an unstable and immature relationship, this may fuel discontent and resentment affecting cognitive and especially behaviour subsystems. Along the way self-concepts suffer irreparable damage if lines of communication close down. The emotional domain is mostly in turmoil, yet other subsystems are equally unbalanced and in constant survival mode to regain equilibrium.

My involvement with families often exposes me to a number of marriages which may require 'life-support'. One such couple who opted not to participate in the study due to personal reasons, are parents both in their forties when their child with DS was born. The father, an insecure and image conscious individual, battled to come to terms with the 'negatives' of DS. Although several reconciliations have been attempted, divorce is imminent. Knowing the background, it is my opinion that it is not the DS as such which will finally break the camel's back, but simply the culmination of a number of serious character flaws and unresolved past issues, which, sadly becomes a valid statistic for DS divorce rates.

On a positive note, research findings by Abery (2006: 15-17) suggest that couples who have children with developmental disabilities, such as DS, more often than not reported strong, mutually rewarding marriages. This is consistent with the findings of this study as most of the participants attested to strengthened spousal relationships.

For the longest time, researchers (see Chapter Three) have equated increased *demands* faced by families with children with developmental disabilities, with the *potential stress and strain* these demands may create, hence the persisting notion that most families with disabilities are not well-adjusted and/or risking collapse as a unit.

It stands to reason that the normative and non-normative demands of a family with a child with DS can potentially create stressors and strains. Despite participants in this study mostly

agreeing on the stressors, not one family indicated that they would get divorced because of DS per se.

Although there were cases of divorce (or previous divorces), no direct connection to DS was reported. A mother of three divorced her husband when her daughter with DS was six years old. She shared her thoughts as follows:

... stress and pressures of life in general...cause the divorce... I never for one split second thought that maybe there could have been a connection, because we both love our three daughters so much... means the world to both of us and we promised the day of the divorce that we will both be very active in their lives and we both are...talk on a regular basis regarding the children, making decisions surrounding the girls together and we really try our best to be the best parents we can be. (M/10/C)

The father, who gained custody of his three daughters (aged six – with DS, three and one at the time), commented on this rather unique shift in family dynamic as follows:

After my divorce it was just me and the three girls. It was only in this situation that I could see just how blessed I was and still am. M helped her two younger sisters as well as my self to get into a routine, from when we woke up till we got into bed again. The three of them are very close like sisters should be. We spend a good part of 4 years alone and it has brought us closer than we ever were as whole family with there mother. (F/6/D)

A couple who had one child got divorced. They remarried and had another child, who has DS. They shared their individual perceptions on the positive experience of parenting a child with DS.

...married from 1996 to 2003...remarried in 2006...our personal relationship has improved one hundred fold and that's the reason for having more children. With the birth of [child with DS] our relationship grew even stronger. Having a child with down-syndrome has strengthened our marriage and challenged our personal relationship with each other but in a good way. (F/3/D) (Father's perspective)

...relationship has grown and matured...we do have occational fights like any other couples...most certainly not about [daughter] having DS. We have more understanding and love for one another. (M/16/C) (Mother's perspective)

Most mothers indicated that divorce was never a consideration.

...been through some tough times, but divorce...never something we would consider. (M/2/C)

*Egskeiding was nie eens 'n oorweeg saak nie. Ons verhouding was net sterker as ooit van te vore.
(M/17/C)*

*...ons sou... nooit aan 'n egskeiding blootstel nie, ons ander twee ook nie...so dit was nooit 'n oorweging
nie. (M/15/D)*

*Daar was geen sprake van 'n egskeiding my man het haar aanvaar en gese sy is 'n geskenk van God af.
(M/18/D)*

*...both threatened each other with divorce...we have come to realise that this is a cry for help when one
of us is feeling overwhelmed and under supported. When we discuss things during 'sane' moments it is
not an option that either of us could consider. The demands that [daughter with DS] Down Syndrome
and feeding issues have placed on us have without a doubt put pressure on our relationship that a
regular kid does not exert on their parents marriage. Our absolute commitment to her brings us through
the trying times together. (M/20/D)*

Parents mostly attributed marital discontent to other factors, and not to parenting a child with
DS per se.

*...personally I have not considered divorce...the stuff that leads to discontent in the relationship is the
normal day to day frustrations...has nothing to do with down-syndrome issues... (F/3/D)*

*... my marriage was already on the rocks yes having a child with DS put extra stress on us as a couple...
our marriage ended not because [daughter with DS] was born, things had happened and we could not go
on with our marriage. (F/6/C)*

*We have both threatened each other with divorce but i think we have come to realise that this is a cry for
help when one of us is feeling overwhelmed and under supported. When we discuss things during 'sane'
moments it is not an option that either of us could consider. (M/20/D)*

...No, not as a direct result of the child [with DS]. (F/8/D)

*We have never ever considered divorce or separation because we stil love each other and the Down
Syndrome in our house has more than strengthen our love rather than broke it down. (F/7/D)*

*...many people look to external factors to justify/blame their actions on...people are not prepared to take
responsibility for their action/decisions. To blame the breakdown of a relationship on a child/money/ etc.
etc. is merely an excuse for weak character. ANY relationship is made or broken based on the quality of
the communication between, and the integrity of the individuals in that relationship. (F/8/D)*

5.3.2 SIBLING SYSTEM

According to Mosby's Medical Dictionary (2009), family dynamics is defined as the forces at work within a family that produce particular behaviours or symptoms. It is the way in which a family lives and interacts with one another that creates the dynamic. And this dynamic, whether good or bad, changes who people are, it burrows into their psyche, ultimately influencing how they view and interact with the world outside of their family.

The birth of a differently abled child, or the discovery that a child is differently abled, has a profound effect on a family (Glidden *et al.*, 2006: 949). The arrival of any new baby necessitates a change in family dynamics. Add an extra chromosome and the funfair machines crank into motion! Parents and siblings are hoisted onto a roller coaster ride that they don't choose to get on, and that they cannot get off. Siblings suddenly need to adjust to a brother or sister who, because of their condition, may require a large portion of family time, attention, money and psychological support. Often the parents are still reeling from the shock and have not had time to deal with the impact or the shift in family dynamic.

It is, however, vital to the family functioning and sustained family dynamic that the typically developing child adjusts to his/her sibling, as this reaction can affect the overall adjustment and development of self-esteem in both children.

No matter how harmonious parents may want their family life to be, some disruptions and disturbances are inevitable. When they occur, they can be stressful for every member of the family. The unexpected addition of a sibling with DS can interfere with the normal course of family life and such a disruption becomes more unsettling for the child if parents are vague about their new sibling's condition or do not offer support to help the sibling deal with his/her questions relating to the situation.

Senel (Cuskelly & Gunn, 2006: 924) states that children with a differently abled sibling may feel that they hold more responsibility and may further feel that they are neglected by their parents. Although this was not the perception of all the siblings who participated in this study, there were siblings who had this notion when they were younger. As they grew up and matured, they came to the realization that this was what was required at a certain time in their lives, but no participants harboured any resentment toward either their parents or their sibling with DS.

The following dynamics in the sibling system, with the remarks from participating siblings in this study are important to explore:

- **Spiritual Meaning**

Being the sibling of a child with DS can result in spiritual meaning and purpose.

...om [sussie met DS] in my lewe te he is een van die grootste seeninge wat God op my pad gestuur het. (YS/2/C)

... Sy laat my altyd dink aan die gelykenis van die muntstukke, waar God verduidelik dat ons nie almal dieselfde hoeveelheid talente gekry het nie, maar dis wat ons daarmee maak wat belangrik is. [my sussie met DS] het miskien net 1 muntstuk gekry in vergelyking met my 5, maar sy's besig om hare in veelvoude vir God terug te gee, en het ek myne selfs eers verdubbel? Ek twyfel sterk!!! (YS/2/D)

...now i care and have more respect 2 them and understand that they got the right to live. My behaviour has completly changed 2 them I see the will of god. (OS/9/D)

...Ek weet dit was 'n seen van God en het veroorsaak dat ons gesin baie naby aan mekaar is. (OS/5/D)

- **Impact on Family Relationships**

In this study parental acceptance and attitude was shown to be a strong predictor of positive sibling adjustment, which is consistent with research indicating that parent functioning is a major determinant of child adjustment outcomes (Amato & Fowler, 2002: 704). Most siblings, like their parents, in this study felt that their lives did not drastically change after the birth of the child with DS.

This has not influenced our lives in anyway and we have continued to live our lives normally and treat her as any other normal child. (M/1/D)

Ons kon ons sosiale lewe ook geniet want 'n problem was sy nie...was altyd iemand wat ons haar by kon los het as ons uitgaan...geen klagtes nie. (M/18/D)

Ons gesins dinamika was en is fantasties...hegte gesin...normale sosiale omgang...Ons het nooit onttrek nie, maar net heerlike normale aktiwiteite beoefen...Niks het verander na [daughter with DS] se geboorte nie...was nou net deel van als...sy het ingeval en aangepas en ons as gesin was soooo gelukkig. Dit was so 'n lekker huis, met sing, huisgodsdien, gaan stap en piekniek hou op die gras of iewers." (The father died tragically when the child with DS was a teenager). Na [dad]se dood het

baie verander...bes probeer om twee ouers se rol vol te staan... Ons gesin is nie begrawe nie, 'n nuwe gesinstruktuur het ontwikkel en ons is weer gelukkig en die gees in die huis is vol harmonie en liefde en baie humor. As ons 4 wat oor is bymekaar is, is daar lag, huil, sing, terg en speel. (The mother remarried 4 years ago). Na my troue het almal ook aangepas... die huis is so lekker en almal is so gemaklik bymekaar. (M/15/D)

However, another mother felt that her whole life had been influenced by DS, and this was impacting negatively on her other child.

I am finding it difficult to try and get my life a little back to normal so that my daughter can experience a bit of normal life, that's not right! (M/9/D) (Due to numerous seemingly unresolved issues, this mother is not coping well, which is exacerbated by her son having DS).

In any family, each sibling, and each relationship that siblings have, is unique, important, and special. Brothers and sisters influence each other and play important roles in each other's lives. It is indeed sibling relationships that make up a child's first social network and are the basis for his or her interactions with people outside the family. Brothers and sisters are playmates first and as they mature, they take on new roles with each other.

They may, over the years, be many things to each other: teacher, friend, companion, follower, protector, enemy, competitor, confidant, role model. When this relationship is affected by a sibling's different ability the long-term benefits of the relationship may be altered. This is often why there is such a close relationship between the typically developing and differently abled sibling, as the latter may have limited opportunities to interact with other children outside the family; thus, social interaction between the siblings often takes on increasing importance.

As siblings grow up and mature, the subsequent step is often that they assume responsibility for their differently abled sibling.

... [sister with DS] was deur die jare 'n stukkie gom wat ons as gesin altyd ekstra naby aan mekaar gehou het...ons was regtig 'n gelukkige gesin, maar daar is niks wat ons almal saam so trots en opgewonde kan maak soos as... iets bereik nie. Dis regtig die 'ultimate'!! (YS/2/D)

... Ons was en is steeds 'n baie hegte gesin en ek glo dat my ouers verantwoordelik was vir hierdie band. (YS/4/D)

- **Family Adaptation and Coping Skills**

...Busy happy home. This little family comes first not work or other family. (M/7/D)

Literature studies indicate that families cope by attributing positive meanings to their situations, defining them as manageable and making efforts to regain a sense of control (Clarke, 2009). Over time, parents may experience changes in ways of seeing their child, themselves and the world. These new perspectives may encompass profound reward, enrichments, and the appreciation of the positive contributions made by people who are differently abled (Clarke, 2009).

- **Initial Introduction to Sibling**

The initial introduction between the siblings and the world of DS is often a predictor of the future sibling relationship.

[My suster met DS] is my ousus en vandat ek klein was, het sy haar rol... baie ernstig opgeneem. Ek glo ook dat die Here vir ons 'n ekstra "blessing" gestuur het. (YS/4/A)

[My suster met DS]se eerste tree was na die 'cot' waar ek gele en slaap het...daardie 'eerste ontmoeting'... som nogal ons verhouding baie goed op... (YS/2/B)

As i was young i didn't know that my brother is DS i was plying with him everyday but not knowing that he got DS. (S/9/D)

This often leads to an early recognition and understanding of the individuality of the sibling with DS. The parental guidance in this respect is an important factor in the understanding of the sibling.

Ek moes op 'n baie vroeë ouderdom alreeds besef en verstaan dat [my sussie met DS] anders is as ek en dat sy moeiliker deur die lewe gaan as ek. Ek kan natuurlik glad nie onthou wanneer ek dit agtergekom het nie, vir my was dit altyd net 'n gegewe. My ma het vandat ons baie klein was altyd vir ons verduidelik dat... anders is, dat sy spesiaal is omdat sy 'n ekstra kromosoom het, en ek het dit so aanvaar. (YS/2/B3)

In one case the parents had no idea what DS was and their first attempt to get their son into a school was unsuccessful. This caused pain for the sibling who felt that he was unable to help as he was still at school himself.

...i remember... when my mother take him to school principal didn't accept him she said we have to take him to special school,that's were i feel pain and by that tym i was @ school nt working didn't know what to do... (S/9/D)

- **Positive Emotions**

On an emotional level, siblings reported mostly a positive effect in their relationship with their brother/sister with DS, with a positive spin-off regarding their own self-concept. Consistent with the view of Cuskelly & Gunn (2006: 917) siblings revealed positive effects such as increased levels of empathy and appreciation for individual differences

...and happy that she is who she is because without her I would not have been who I am. (YS/1/D)

...taught us all to have patience with each other, to love unconditionally and to accept the fact that none of us are perfect in this world. (FS/6/D)

...so 'n groot passie in my lewe, ek kan maklik weghardloop met stories oor haar, juis omdat ek dit so positief ervaar. (OS/1/D)

Ons het regtig soos 'n 2ling funksioneer. Maar soos 'n 2ling waar daar 1 swakker lid is van die span wat heelyd deur die ander lid opgelig en vasgehou word. Ek bedoel dit glad nie negatief nie – dit was een van die positiefste ervarings van my lewe. (YS/2/B)

Mens raak so maklik ingesluk met die lewe se materialistiese dinge, en met [my broer met DS] bring dit mens af aarde toe. (OS/3/D)

...het my goed gedoen om so onselfsugtig te wees ...sedert ek baie jonk was geleer dat die lewe nie net om my draai nie en dat 'n mens mense om jou help orals waar jy kan. Ek kom agter dat ek vandag nog 'n instink het om altyd te kyk of almal rondom my regkom en bybly en of hulle dalk hulp nodig het...ek doen dit outomaties... ander se behoeftes voor myne te stel...geduldig te wees met ander mense se tekortkominge... (YS/2/C)

They have also been motivated and inspired by their sibling with DS.

...as ek lui was en nie lus om te leer nie...net na haar kyk en besef dat ek nie anders kan as om my deel ook te doen nie... Ek is vandag waar ek is a.g.v [my sussie met DS]...sy het my aangemoedig en gemotiveer om my akademie en studies ernstig op te neem...as gevolg daarvan het ek goeie matriekuitslae behaal... goeie kursus kon gaan studeer... vandag in 'n goeie werk kan staan. (YS/2/C)

This study is testament to the saying that 'love conquers all', as parents and siblings generally reported a profound love and acceptance for the individual with DS. For some it undoubtedly evolved as the child grew up and for others it was merely always an attitude and a way of life.

Vandag is... ons allergrootste vreugde en die hele gesin stel hom boaan ons favourite mense in die wereld. (M/1/D)

... She is my daughter and I Love her. (F/6/D)

... Sy is 'n geskenk van God. (F/11/C)

We have experienced that LOVE is not just a word in the dictionary, but is something that we experience and that we live it in our family. (F/7/D)

...die liefde wat ek vir hom gevoel het en nou voel is onbeskryflik... (OS/5/B)

Ek het met die jare al hoe liefwer vir [brother with DS] geraak en sien hom amper as my eie kind. (OS/3/C)

...so lief was vir haar en haar nie jammer gekry het nie... (YS/4/C)

...was en is nog altyd ongelooflik lief vir hom. Hy laat ons altyd glimlag en ek kan nie my lewe sonder hom indink nie! (OS/3/D)

Empathy, reciprocal love and support between typically developing siblings and their brother/sister with DS facilitates understanding and acceptance.

Ek het ouer geword en kon sien dat dit vir haar sleg was dat ek dinge makliker en vinniger as sy kon doen omdat sy tog my ousus is. Maar nou kan ek sien dat dit vir haar lekker is as ek haar help. Ek dink sy as mensie het ook so baie in haarself gegroei en vrede met haarself gemaak. ...het my nog ALTYD in ALLES ondersteun en sy gun vir my die wereld. Dit beteken vir 'n sussie so baie. Sy bid vir my en gee regtig om! (YS/4/D)

...sou enige iets vir my doen – en ek weet vir 'n feit dat sy vandag nog steeds so voel! (YS/2/B)

...sometimes I feel sorry for her because she is different... (OS/8/B)

All the siblings take great pride in the accomplishments of their sibling with DS.

Sy is die hardwerkendste mensie wat ek ken. NIEMAND anders wat ek ken het al so hard gewerk om te kom waar hulle vandag is nie...kan so hard leer en soveel ure agter boeke spandeer net om 'n vak agter haar naam te skryf nie. (YS/2/C)

...oomblikke wat vir my uitstaan...die dag toe sy oor die verhoog gestap het... met daardie klein togatjie... (YS/4/D)

...hoe vinnig hy vriende maak... (OS/5/D)

....as sy haar kop op 'n ding neersit, sal sy dit doen!!! (YS/4/D)

...ek is die trotste kleinsus wat daar op hierdie aarde is. Van al die mense wat ek ken, het niemand eers naastenby uitgerig of bereik wat sy het nie. (YS/2/D)

...daar is niks wat ons almal saam so trots en opgewonde kan maak soos as...iets bereik nie. Dis regtig die 'ultimate'!! Ek was nog nooit so trots...soos...dag wat sy haar diploma by die college ontvang het nie. Dit was een van die hoogtepunte van my lewe!! (YS/2/D)

I'm proud of all she can and does do. (YS/1/D)

Siblings were honest about their strong protective feelings toward their brother/sister with DS.

...Ekt so beskermend oor hom geraak dat ek nie bereid is om uit kaap te trek(die poste vir my man se werk kom op in Gauteng)maar ek wil nie sover van my boetie wees nie veral oor hy nou in Sunfield(n tehuis)in Wellington is(hy is nie vreeslik gelukkig daar nie en sal verkies om by my ouers te woon maar verstaanbaar is dit nie moontlik nie. (OS/3/B)

...Ek weet wel ek was nog altyd baie erg en berskermend oor hom. (OS/3/B)

...As kinders of tieners hom spot of giggel of so iets, dan verloor ek dit heeltemal en sit hul gou gou op hulle plek....ek het kwaad geword as mens van "mongool" of "korkie" gepraat het as kind. (OS/5/B)

A message of unconditional acceptance came to the fore.

...die kinders her haar aanvaar so 'n normale kind en suster. (M/18/B)

...I'm happy that she is who she is... (YS/1/D)

Ek het nooit gevoel ek wil graag he sy moet normaal wees nie...nooit nie!! (YS/4/D)

...although some look at her like a rag cloth...I am not shy to spend time with her...I jus play with her theres nothing to be ashamed of. (OS/8/B)

...on the whole most people are not phased by her being DS and don't treat me any differently for it. (YS/1/D)

- **Negative Emotions**

Siblings were candid in their opinions regarding their experiences with a brother or sister with DS and they reported on their negative emotions including frustration, embarrassment as follows:

... frustrates me that she does everything so slowly... (YS/1/D)

A younger sibling was wary of possible embarrassment.

... I sometimes feel that people is going to tease me... (OS/8/B)

This usually changes as they grow up and mature.

...as kind... het my glad nie gepla nie, daar was seker 'n stadium in 'n tiener wees wat mens bietjie skaam was, maar dit was seker meer tiener druk..my persepsie was seker dat hy bietjie stadiger was... (OS/5/C)

Having taken a positive cue from her parents, one sibling felt that this was never an issue.

...my ouers so lief was vir haar...nie jammer gekry het of vir haar skaam was nie, was ek as sussie ook glad nie skaam vir haar nie. (YS/4/D)

A sibling shared his feelings of embarrassment due to the perceptions of others in the rural village in the Limpopo where he grew up as a young boy.

When i was young i didn't know about disability,in the village were i grow up when we see people with disability it was a joke 2 us,not kwning that they didn't choose 2 b in that way and their family. Because of his physical appearence and speachless i was so shy to go out with him to twn and other busy places... (OS/9/D)

As he grew older he came to the realization that acceptance and support from his community would be cue'd by his behaviour.

... but when i grow up started 2 more responsible i understood that he also need the support that i also need from people around,started nt 2 take no care of what people say about me and my brother now can go wherever with him and people appreciate what im doing. (OS/9/D)

Typically developing siblings did not display feelings of resentment towards their brothers/sisters with DS, even though it was understood that their demands and needs relied heavily on the resources of both parents and siblings.

... My persepsie was seker dat hy bietjie stadiger was maar die liefde wat ek vir hom gevoel het en nou voel is onbeskryflik, al moes ek hom aan die slaap sing tot 'n latere ouderdom, terwyl my nefies kom kuier het. (OS/5/B)

Invariably my folks end up spending more time focusing on her and what she needs to learn or do, she tends to require more attention than I do in many areas, but I understand and it mostly doesn't bother me. (YS/1/B)

...it does not make our family feel any different in a bad way...but that will never break our family apart i hope. (OS/8/C)

- **Sadness**

Some siblings voiced their concern for the future and shared their feelings of sadness for their sibling with DS.

...i would of liked to know how things were going to be like... (OS/8/D)

It saddens me that she'll never be able to be completely independent like she so desperately wants to be...(YS/1/D)

Ek is so lief vir haar en dit maak my baie bang as ek dink dat Downsies nie so lank lewe soos normale mense nie. (YS/4/D)

- **Personal Growth**

Siblings often only recognize a little later in life how their lives have been enriched by the experience of having a sibling with DS and this awareness enhances their life experience in terms of understanding diversity.

As klein dogtertjie...nie besef watter invloed sy op my lewe het nie. Ek het nie toe besef hoe 'n 'blessing' dit is dat ek gewoon kon raak aan mense met gestremdhede nie...Sy het my lewe verryk en my oë oopgemaak in die wereld van gestremdheid. (YS/4/C)

I think it's made me realize I have to be responsible at all times and therefore made me grow up sooner than other kids my age. (YS/1/D)

Dis hoe my ma ons grootgemaak het [my sussie met DS] is nie iemand om oor skaam te wees nie, sy' iemand om oor te 'brag'. Ek het geleer om onselfsugtig te wees en ander mense se behoeftes bo my eie te stel...geduldig te wees met ander mense se tekortkominge... waste ongelooflike voorreg dit is om 'n gesonde verstand te he, 'n liggaam sonder enige gebreke. Dit het my aangemoedig om altyd die beste te doen met wat God vir my gegee het, want ek het gesien dat 'n gesonde verstand nie 'n reg is nie, maar 'n ongelooflike voorreg... (YS/2/C)

...when he sees us we always get a huge hug... (FS/7/D)

As daai liefde jou nie gryp nie, is daar sekerlik iets fout of jou ego is te afhanklik van wat mense dink of se...Dit help my om kleiner dingetjies raak te sien en te waardeer. (OS/5/C)

Hy laat ons altyd glimlag en ek kan nie my lewe sonder hom indink nie! Ek is dankbaar dat ek so boetie het, dit hou mens nederig. (OS/3/D)

He is a good example of Dance as if no one is watching you... (FS/7/D)

... without her I would not have been who I am. (YS/1/D)

...taught me the meaning of not being prejudice to people who are not the same as us. (FS/6/C)

...elke gestremdheid is anders...ook so elke persoon met Down's...eie persoonlikhede nes ons... (YS/2/D)

- **Inclusion Into Their Own Friendships**

The sibling with DS often perceives the friends of siblings as their own. To some siblings this is irrelevant...

...all my friends don't have a problem with...but some people will ask what in the world is DS but when you explain what it is they ownt tease me. (OS/8/C)

But not all siblings feel that way...

Sometimes it's been hard when I'm going out and she wants to come with and I don't really want her there but she thinks my friends are her friends too and therefore wants to join us... (YS/1/D)

- **Siblings will be Siblings...**

For most, having a sibling with DS was no big issue and they perceived it as regular sibling relationships.

I don't mind having a sibling with Down syndrome... It's just like having any other sibling...sometimes you like them, sometimes you don't but you always love them! (YS/1/B)

Selfs na [my jongste sussie] se geboorte was ons die twee 'ouer sussies' en daarom was ons altyd 'n span wat saamgewerk het. Ons het alles saamgedoen... saam pop gespeel... huisies gebou... stout gewees... saam verrassings vir ons ouers beplan... (YS/2/B)

...hy het ons ringe in die kerk ingedra toe ek en my man trou... (OS/3/C)

...ons dieselfde behandel ... ook dieselfde aangetrek... ...sy was net 'n kind soos die res van ons...sy is nooit verskillend behandel nie...dieselfde reels gehad... (YS/2/D)

Ons kon as gesin lekker vir haar lag as sy snaaks was. Ek het haar geterg... geirretee... en met haar gespeel (wat ek maar met almal in die huis ook gedoen het). Ek het nooit gevoel ek wil graag he sy moet normal wees nie... nooit nie!! (YS/4/C)

...alles wat ek gedoen het saam met my gedoen...ballet...swemlesse...musiekwaarderingsklassies. (YS/2/B)

...we treat her like we do everyone else so...It's not that big a factor. (YS/1/B)

...dieselfde stel reels...het ook vir haar gegeld. (YS/2/D)

...in the end she is just a normal sister to me. (OS/8/B)

One family fostered a toddler with DS from aged three. At that stage the siblings, all girls, were seventeen, fifteen and twelve irrespectively. They shared their perceptions as follows:

...it was easy to welcome him into our home...had lost his best friend...lived in a place tht none of us would have wanted to live in...we took him everywhere...was easier for us as "foster" family to accept the DS than for a family who is traumatized by the birth of a child with DS...my two sons have grown up with the knowledge of accepting people...knowing their limits but also expecting the best for them...very

protective of their “uncle” and grateful for all they’ve learnt from him...he has amazing memory, unconditional love and the most amazing confidence..he is a gentleman...very positive influence on our lives...he has been a gift...thank him for everything he has taught us...we love you dearly. (FS/7/D)

...taught me the meaning of not being prejudice to people who are not the same as us...he sees the good in all people...always fitted into our family...bringing him home when he was small was a family decision...our parents included us in that decision...don’t think any of us have ever regretted it... (FS/6/D)

- **Career Inspiration**

Although not unique to DS per se, siblings of differently abled individuals frequently pursue a career related to their situation or circumstances to render future support to the differently abled. One such participant was inspired by his brother with DS to pursue a career in the field of physical well-being, recently completing a masters’ thesis on the impact of physical activity on the longevity of persons with DS.

Ek het my Meesters tesis aan hom “dedicate” en ek is baie lief vir hom. (OS/5/B)

Another sibling has become an outreach coordinator in a rural area in Limpopo.

... this is something that we can not leave it like that...people around me know that im DS co-ordinator because every were I advise people who got DS people @ hme 2 take a good care...i tell families with DS that god have purpose with their family they hv 2 accept what god gave 2 them. (OS/9/D)

- **Relationship with Sibling Spouse**

There are often extremely close sibling ties between the typically developing child and the sibling with DS. This emotional bond often extends to the spouse of the typically developing sibling. The extended family member’s acceptance of and love for the sibling with DS serves as a wonderful support for the typically developing sibling.

...toe toe ek en my man begin praat het oor trou, moes ek dit vir hom baie duidelik maak dat ... deel is van my lewe en altyd sal wees... impak kan hê op 'n gesin, aangesien sy net MY sussie is en nie my man s'n nie. Dis ook nie soos nog 'n kind in die huis nie, dis nog 'n volwasse persoon wat in ag geneem sal moet word en 'n hele gesinsdinamika sal moet aanpas om hierdie persoon in ag te neem...by my geen twyfel dat dit is hoe dit sal werk nie, maar my man moes baie mooi verstaan wat die implikasies daarvan is voor hy besluit het of hy met my wil trou of nie. Hy't natuurlik nooit vir 1 oomblik getwyfel daaroor nie en dadelik gesê dat dit reg is met hom, maar ek dink nie enige van ons besef ...wanneer dit

later kan gebeur nie. [Sister with DS] my keuse van 'n lewensmaat beïnvloed... moes iemand wees wat met haar oor die weg kom! Dis egter nie 'n slegte ding nie, dis 'n goeie ding, want daar is niemand wat karakter so vinnig toets soos... nie!!! (OS/1/D)

Ek was baie gelukkig in dat my man so wonderlik met my boetie is...voor ek getroud was...altd my nommer 1 en ekt geweet dat my man hom sou moes lief he...sou verstaan...baie meer as n boetie vir my is en dat daar n moontlikheid sou wees dat hy dalk eendag by ons sou woon as daar nie n ander uitweg was nie.EK is baie dankbaar dat dinge met my man en...uitgewerk het anders sou ek my keuse moes maak en nog 'single' gewees het. (OS/3/C)

A mother reported on her daughter's close relationship with her brother with DS.

[My daughter] het 'n abnormal close band met [child with DS] en beskerm hom soos 'n tierwyfie en sy meng soms so in asof dit haar kind is.Sy het ook aan haar man, waarmee sy vroeer vanjaar getroud is, gese, dat ... haar eerste prioriteit Altd sal wees, bo syne. Gelukkig is ...net so erg oor ...en bel hom elke dag. (M/1/D)

Overall, it appears that being the sibling of a child with DS does *not* have a negative impact on either problem behaviours or self-perceptions or competence and the brothers and sisters of a child with DS do not seem to be penalized in their opportunities to participate in a normal childhood (Cuskelly & Gunn, 2006: 924).

5.3.3 PARENT-SIBLING RELATIONSHIP

Invariably the relationship between parents and the typically developing sibling is affected when a child with DS enters the family. However, this does not always have to be negative effect. It is safe to assume that siblings of differently abled children have special needs themselves, and therefore the parents have to pay special attention to each child in the family system's individual needs.

The differently abled child will for example definitely get more attention than the typically developing children, and too often the family script is cantered on the DS theme. Feelings that siblings might have at different times could be quite conflicting. According to Boyse (2009) the siblings may feel:

- worried about their sibling
- jealous of the attention their brother/sister receives

- scared that they will lose their sibling
- angry that no one pays attention to them
- resentful of having to explain, support, and/or take care of their brother/sister
- resentful that they are unable to do things or go places because of their sibling
- embarrassed about their sibling's differences
- pressure to be or do what their sibling cannot
- guilty for negative feelings they have toward their sibling or guilty for not having the same problems.

Boyse (2009) however also mentions that with the challenges of having a differently abled sibling also come opportunities to develop many good qualities, including:

- patience
- kindness and supportiveness
- acceptance of differences
- compassion and helpfulness
- empathy for others and insight into coping with challenges
- dependability and loyalty that may come from standing up for their brother or sister.

Essentially, parents, other adult family members, and professionals should realize that typically developing siblings need special understanding, attention, support and recognition of their unique contributions to the family system (Clarke, 2009).

- **Equal Attention versus Favouritism**

Parents may love their children equally, but naturally will have different sorts of relationships with each of them. Individualizing the relationship with each child, reinforcing their strengths and talents and avoiding making unflattering comparisons to their siblings or friends, would make the child secure, not only in him/herself, but also within their family. A mother reports:

Vir my was en is al 3 my kinders ewe spesiaal...[daughter with DS] is net meer by my en het my meer nodig. Hulle behoeftes is vir my net so belangrik ...maar hulle behoeftes is bietjie anders...sy was nooit meer spesiaal as die ander 2 nie. Elkeen was ewe spesiaal, al was elkeen anders. (M/15/D)

- **Adequate Sibling Preparation**

How parents prepare the typically developing siblings to receive a sibling with special needs into the family system can have a profound influence on their attitude towards the latter in the

future. Children usually have a better attitude about special needs than most adults do. To a child a baby is just a baby, regardless whether he has a deformed limb, has medical problems requiring a great deal of attention or has unusual facial features. Children are mostly very excited about their new sibling who brings the prospect of a friend and playmate. Feelings of disappointment and constant anguish of the parents, may cognitively impact the attitude of the siblings, further extending into their behaviour subsystem. Constant anxiety over the much-anticipated baby (if the mother knows beforehand) or once the baby is there, will overshadow the joy of having a new baby, whereas children who witness their parents handling the news/new situation reasonably well and with a positive attitude are more likely to be relaxed and rational about most aspects pertaining to a sibling requiring special needs.

...it was difficult at first...brother and sister were not allowed to go into NICU to see him. ...recovered well...discharged and then we could enjoy him...gathered as much information as possible...started teaching our children and ourselves how to interact, teach and stimulate [baby with DS]. (F/5/C)

Ek was 8 jaar oud. My ma het gebel en gese dat ons boetie gebore was en dat hy 'n spesiale kind is... My boetie is my lewe en ek kannie 'n lewe sonder hom verbeel nie. Hy is vir my belangriker as enige iets anders in die wereld. (OS/5/A)

Ek was 6 jaar oud... en vir die eerste paar jaar het ek nie besef dat hy anders was nie. Ek weet wel ek was nog altyd baie erg en beskermend oor hom. (OS/3/B)

- **Realistic Parental Expectations of Siblings**

Some typically developing siblings acknowledged that, on a subliminal level, they felt obligated to compensate for their differently abled sibling to make up for that child's limitations. Siblings reported assuming a surrogate role, taking on more responsibility than would be usual in the case of another typically developing sibling.

...Al wat ek sou wou verander...toe ek baie jonger was is dat my ouers nie besef het dat ek self n kind was en nie reg was vir die verantwoordelikheid wat n ander kind en dan nog n Down sindrom ook nie.My niggies en nefies sou ure speel toe ons jonk was en ek sou [bother with DS] aan die slaap moes sus.Dit was n gereelde ding om te baby sit en was baie hard op my. (OS/3/D)

...My ouers was baie sosiale mense en ek moes gereeld na hom kyk. Dit was vir my swaar op skool as my vriende uitgaan in aand en ek moet 'baby sit' oor my ouers uitgeggaan het maar ekt [brother with DS] nooit blameer,hy was onskuldig en jonk maar daar was effe kwaad gevoel van my teenoor my ouers op

tye,ekt nooit iets vir hul gese daaroor en hul weet tot vandag toe nie dat ek soms so gevoel het nie...
(OS/3/B)

...moes ek hom aan die slaap sing tot n latere ouderdom, terwyl my nefies kom kuier het. (OS/5/B)

...Sometimes it's hard when you have to be responsible for two people constantly when you're out together without your parents and there have been occasions where the experiences were not pleasant, but I've learnt that to be embarrassed or whatever doesn't help the situation, you just need to stay calm and rational. (YS/1/B)

Some parents felt that siblings do not always have an understanding of the magnitude of the challenges faced by their sibling with DS. I do believe that this has to be viewed in relation to the age of the sibling, the period of time that the sibling was an only child as well as *how* the parents have prepared and explained the situation of the sibling with DS in terms of abilities, delays and challenges related to DS. All children play up at some stage or another, which is acceptable childish behaviour, but that it remains age-appropriate and *managed* by the parent, is important.

It is sometimes difficult for his sister... as she does not always understand that her brother is not capable of doing what a 4year old can do. She sometimes feel that it is unfair that the same is not expected from him as from her. (M/12/D)

Teaching a sibling responsibility does not necessarily mean that parents always expects the sibling to assume responsibility for the child with DS.

... she is the older sister and he is a toddler. She has to take on more responsibilities. We are super sensitive to not make her feel that she is always to take responsibility for her brother. (M/12/D)

...sister (4)...takes care of [daughter with DS(3)], protecting her, talking on her behalf...doing things for ...that she can't do herself like pouring colddrink, helping her on the jungle gym and trampoline. We all try to help where ever we can and that makes life a lot easier. (M/16/C)

A mother realizes her mistake in placing undue pressure on a sibling.

...I always remind my other daughter of her "DUTY" towards her sister and I'm not sure that this is fair practice from my side. (M/20/D)

The thought pattern here is often motivated by the mother's innate fear that no-one else will be as capable as she. "Be alert, be aware, be trained... then you will be able to step into my shoes," thus 'training' the sibling for future duties. Mothers all step into that trap. In this case, however, mothers often forget that the sibling themselves are just children and that they should be allowed to do things and think things and experience things as *children* and not as *trainees*. Many mothers have found themselves wracked by guilt for this exact reason. Fortunately some mothers realize the error of their ways and are able to apologize, even if it is much later in life.

Daar was veral baie druk van my kant af op ...,[son with DS's sister] en ek het op haar gesteun en het later jare aan haar om verkoning gevra. (M/1/D)

- **Time and Attention as Stressors**

Parents recognize that interpersonal problems between themselves and siblings may arise from too much time and attention assigned to the child with DS.

Our younger daughter accused me of not being interested in her...has a close relationship with her father. I...often feel that the two of them...not sharing the responsibility for interaction with [daughter with DS]...and it's up to me to spend time with [her]. (M/2/D)

...has affected our older son quite a bit as he sees it that I love [son with DS] more because I have had to spend more time...[older son] has become very demanding on me and my time expecting me to help him with getting dressed ect even though he is able to do so. (M/5/D)

...the older sister understands...needs therapy...can't do all the extra mural activities that she would like...not always funds for that, but she shows understanding and consideration for this. (M/16/C)

...time is tried to be spent equally with both kids but not always possible as d/s needs more time... (F/4/D)

Invariably my folks end up spending more time focusing on her and what she needs to learn or do, she tends to require more attention than I do in many areas, but I understand and it mostly doesn't bother me. (YS/1/B)

Typically developing siblings may resent the time their parents give to the differently abled sibling and perceive it as rejection. They may start to wonder what is wrong with them and why their parents love their differently abled sibling more. This is mostly far from the truth.

Frequently, the sibling is still too young to fully comprehend that much of the time spent revolves around early intervention, which in itself, is extremely time consuming. But experience and practice shows that at some stage, the child with DS, too, becomes self sufficient and does not require such intensive ongoing assistance or attention. Communication is the cornerstone of managing such situations.

Parents have noted that in some cases, especially during the early years, the typically developing sibling either mimics the physical or behavioural actions of the child with DS or regresses in behavioural development. More prevalent with older siblings is the manifestation of becoming prone to extremes of behaviour such as "acting out" or becoming the "perfect" child. A case of the latter was reported as follows:

...op 'n vroeë ouderdom alreeds op 'n sielkundige vlak 'n impak op my gemaak...ouers my later vertel het hoe my kleuterskooljuffrou my ma ingeroep het om te hoor hoekom my ouers my so 'druk' om te presteer...ma was natuurlik stomgeslaan...juffrou het verduidelik dat ek om een of ander rede 'n dryf het om altyd dubbeld soveel te doen as my klasmaats...klas 1 prentjie teken, moes ek altyd 2 teken...So het hulle agtergekom, dat ek OF namens [sister with DS] ekstra hard werk, of probeer opmaak vir dit wat sy nie kan doen nie. Tot vandag toe kan ek nie sê of dit is wat in my kop aangegaan het nie, ek weet egter wel dat haar deelwees van my lewe definitief een of ander impak gehad het. (YS/2/C)

- **Early Maturity of Siblings**

Parents and siblings reported perceptions of earlier maturation than their peers of the typically developing siblings.

I think it's made me realize I have to be responsible at all times and therefore made me grow up sooner than other kids my age. (YS/1/D)

... two sisters really love her a lot and they are very protective...so much more mature than their friends, they are more responsible, they are very caring about other people's feelings, they are more considered but they do get frustrated with... (M/10/D)

Her younger sibling has been forced to be the "Big Sister" almost from the moment she was able to walk/talk. This has caused the sibling to mature and grow up in a very different way to many of her peers. (F/8/D)

All parents share the desire for a measure of independence for their differently abled child, yet perhaps the most challenging issue that families face is, on the one hand, encouraging and fostering the independence and self-determination of their child with DS and, on the other hand,

facing the reality that, at some level, assistance may be necessary. Herein lay the dichotomy for parents: How much responsibility and commitment can I expect from my typically developing child/adolescent/adult and how much is the sibling, in fairness, honesty and reality prepared and able to assume.

Although parents all shared their concern for the future of their child with DS, some parents reported that they did not wish their child with DS to be a 'burden' to the typically developing sibling once they are no longer here.

Die kinders sê hulle sal kyk...Ek sal nie graag wil hê dat sy impakteer op my ander kinders se huwelike nie. (M/15/D)

As typically developing siblings grow up and move on to their own lives (and often families), they often face unusual, additional responsibilities because of their unique relationship with their differently abled brother or sister. The amount of responsibility that siblings assume for their differently abled adult sibling varies amongst individuals and circumstances. It is often dictated by a consideration of family, career responsibilities and/or personal choice.

- **Anxiety Surrounding the Typically Developing Sibling**

A mother related her unnatural fears surrounding her daughter, her second child, who does not have DS.

I have a huge fear that something will happen to my daughter!!!! This is a fear I have never felt, I am so afraid that something will happen and she will not be "normal", this haunts me at times! (M/9/D)

- **Stubborn Behaviour**

It is interesting how many parents of children with DS talk about their child's stubborn behaviour as if it is part and parcel of having a cognitive delay. I see stubborn behaviour as a direct result of lacking the skills and/or language to negotiate a position. A child with a cognitive delay, such as DS, will continue to do things in a specific way because it is safe, it is known and it has worked in the past. When new things are introduced, their 'safe place' is threatened. People with DS are not always able to persuade people to their view due to lack in language skills, the cognitive flexibility needed in verbal discourse and the large world view to win many verbal arguments and thus are easily labelled as stubborn (Johnson, 1998: 77).

The parent of a toddler reported manipulative behaviour patterns of her son with DS.

...extremely stubborn and strong willed...He has learnt to use his DS to manipulate people because they all have the “ag shame” attitude when we choose to discipline him. (M/5/D)

A mother reported how stubborn behaviour as reaction to punishment from the father is affecting her relationship with her husband.

My husband says she is stubborn and I say she is not. He speaks to her firmly and I speak to her nicely... he will say “..., I said go pack away your toys! You again don’t want to listen. Must I take my belt off” SHE BLATANTLY IGNORES HIM THEN and I don’t blame her. I will say ...-girl please can you be a good girl and pack up your toys now sweetheart. Give her a hug and off she goes and does what she was asked. My husband cannot see the difference and it angers him that the child will listen to me and not him. So this is what is putting a strain on our relationship – not DS I think. (M/20/D)

Evident throughout this study are the many different factors (or combinations thereof) that can alter the family dynamic, for better or for worse, beginning with the relationship between the parents. Influences may include parenting practices, the number of children a family has, an absent parent, death, socio-economic status, unemployment, divorce, family values and of course, in this case a family member with DS.

Just as in any other situation where people are expected to coexist, family members, most especially children, begin to take on particular roles within the family. These roles could very well be the due result of their family dynamics, and have little to do with conscious choice. Depending upon their position within the family, including their birth order, the roles quickly become an indelible part of the given dynamic. In all families one finds the perennial peace-keeper, the scapegoat/ irresponsible child, the family hero/the responsible child, the care-taker and the mascot. Each role has a very specific duty to its family, and it is nearly impossible for a child to separate himself from it.

Evident in this study is that, with time and experience, parents of differently abled children may come to regain a sense of control over their circumstances and a sense of meaning in life by seeing the positive contributions of their children with respect to personal growth and learning what is important in life.

5.4 THEME THREE: EXTERNAL SYSTEMS

According to eco-systemic theory, the individual and family system is an open system. Thus communication flows to external systems, and is also taken in from external systems. This circular flow of energy is needed for the system to adapt to stressors and remain in a state of

equilibrium, ensuring the survival of the system. The following external societal systems influence the family system of a child with DS and will be discussed:

- Extended family
- School and educational systems
- Medical fraternity
- General public

5.4.1 EXTENDED FAMILY

Active participation in the extended family and the community is imperative for the healthy adjustment of the family with a child with DS. All families work better when they feel connected and supported by friends and relatives. This is especially true for families who have a differently abled child. Not only will friends and family take their cue from the behaviour of parents and siblings toward the differently abled child, but it will also empower them to create a wider awareness about the specific challenges faced by the affected family (Orphan, 2004: 26).

The following was reported on the social subsystem:

- **Family Support**

Although evidence of mostly high support from the extended family was reported, there was also evidence of the opposite and of relationship changes as a direct result of the family having a child with DS.

...Our families are 100% supportive and if anything, over protective of her. (M/4/D)

...families are very supportive ...help as much as they can – my mom and aunt are speech therapists and so very supportive with regards to speech....I have become closer to one of my brothers... (M/6/D)

...My dad found me in tears and very confused...My father just held me close... asked me why I was weeping so deeply. He then said something to me that I will never ever forget.: “Can’t you see? God really must think so much of you to give you a Down syndrome child? Do you know how privilege you are? This child is God send so please don’t cry, everything is gone be okay”. (M/8/B)

Unfortunately there were also reports of low family support and some relationship changes within extended family circles were noted.

...Sadly my own family, I am one of 8 children, did not support us very much at all. (M/2/B)

...my sister advised me to have an abortion... (M/16/B).

... It is painful to see how difficult it is for even some close family members to bond with him. (M/19/D)

My relationship with my older brother took some strain when...was born as he doesn't know how to talk about DS with me. He tends to try and joke with me to make things lighter and I don't really take well to this. (M/6/D)

My sisters admit to being scared of taking care of [daughter with DS] as they wouldn't know how to deal with her...has damaged our relationship to a great extent. (M/16/D)

Support from friends and other social systems ranged from very low to significantly high, depending on the relationships. Parents reported that a network network of friends and supportive persons (friends, clubs, organizations, church) who understand are invaluable to especially the mothers.

My redding was my geloof, goeie vriendinne en 'n inwoonbediende. (M/1/D)

...wonderful support systems in place i.e. live in nanny...continued to lead a normal and healthy life and include her in all family/shopping outings. (M/4/D)

Family and friends were very supportive. (F/1/D)

Our families through their non stop dedicated love and support have been phenomenal and I doubt we would be where we are emotionally as a family if it wasn't for them. (F/2/D)

Selfs my ouers was baie ondersteunend en my selfs gemotiveer om aan te gaan nie nie moet op te gee nie. (F/11/C)

...joined the DS association which was very helpful and encouraging. (F/5/C)

...relationships with friends have strengthened and everyone seems to care more than we ever thought... social life has only gotten busier since [baby with DS] was born and our circle of friends has just grown. I was very lonely before and meeting other women with children with DS has made me a lot happier. (M/6/D)

On a social level not much has changed...take [son with DS] absolutely everywhere we take our older child...very active in our church, go to home cell once a week, and have many friends with whom we

visit. I have made one adjustment though in sometimes inviting friends to rather come to my house for a visit, rather than go to their not-[son with DS]-proof homes where I have to run after my intensely curious little boy! (M/12/D)

The social life of some parents slowed down. This is often only significant in the younger years and as the child becomes more self-sufficient and independent, friendships are often restored.

...sosiale lewe ongelukkig heelwat afgeneem...ons vriende nog nie kinders het nie en omdat ons kinders so woelig is...bang om [son with DS] na vreemde omgewings te neem...breuk iets of kry seer... (M/8/D)

...Social life...hampered in the early years... (M/2/D)

Many parents merely contribute this turn of events to the joys of having small children, which in itself can be restrictive in a socializing context.

...social life has been limited due to the fact that we have two young children...not because we have a down-syndrome child...friendships suffered...restraint of having two small children...no longer attend all social events. (F/3/D)

We have also experienced that at first people are very scared to talk to us about the disability, but later when we have showed them that we can talk about it without fear or resentment, they would also start asking more probing questions. Some of our friends and even family have rejected the fact that [our son] is different until such time that he grown older and they could see that he is definitely different. For me a major issue with interpersonal relationships is that we have also experienced rejection but some friends and the stigma that we have a non-normal child was just too much for them. They did not appreciate the fact that we took [our son with DS] with were-ever we went and we were not shy of his and tried to hide him from public-eye. (F/7/D) (This young man with DS is currently twenty eight years old, he lives with his parents and is employed full-time).

As the child grows up, it appears that social support either strengthens or wanes.

[son is currently 20 and moved away from home]...Tot van ons vriende bel hom gereeld. (M/1/D)

...social life – not much time for that...friendships most have become stronger and more valuable some have faded. (M/7/D)

One specific family perceived their situation as “abnormal” and felt that their son having DS negatively influenced their social life as well as their support on social level.

[Son with DS] se DS het ons hele lewe beïnvloed, waar ons moes gaan woon, wat ons waar doen, wie ons vreinde is, wat, hoe laat, by wie ens ens ens. Dit was 'n geweldige stremming, ons kon hom nooit by iemand los nie, niemand het kans gesien nie. Dit het my soms so depressief gelaat, veral as hy siek was. (M/1/D)

Parents and siblings bear witness to the positive effect that the child with DS has on extended family and friends.

... an absolute blessing in our lives and that of our extended family, friends and community. We have all been influenced in a positive way. (M/5/D)

...with the help of my friends, 3 brothers and 2 sisters and their childrens help...[daughter with DS] is the healthy and loveable angel she is today...can't imagine life without her. (M/21/C)

5.4.2 SCHOOL AND EDUCATION SYSTEMS

Although every child differs in their ability and pace of learning, a child with DS, just like any other child, has the potential to learn (Guerin & Male, 2006: 1). Despite South Africa being a ratified signatory of the United Nations Convention on the rights of persons with disabilities, which states clearly in Article 24 that persons with disabilities are not to be excluded from the general education system but must have access to inclusive, quality and free education on an equal basis with others in the communities in which they live (United Nations Convention Document, 2007), this law is most frequently disregarded and the educational rights of children with DS are violated on a daily basis (see Section 2.8). Not only are they repeatedly denied access to schools on the most flimsy excuses, but often, when included by default, they are merely *accommodated* and not *taught*.

Successful inclusion does not happen automatically. One of the most important ingredients in successfully implementing inclusion for a child with DS is simply the *will* to make it succeed. For the parents, who are mostly ignorant about their rights and the rights of their children, the option of a special school is often the path of less resistance. Research has proven that children with DS do better academically and socially if they are included in a mainstream environment (Buckley, 2001). However, often, as the children with labels enter the education system, teachers are not accommodating and make it difficult for the child and the family to continue this important journey.

Inclusion is an attitude, a value and belief system. It does not only happen in school, but should also reach beyond the school gate. Although there are many adults who are gainfully employed, many parents feel that their child may be exploited in a working environment. This belief often stems from their educational experiences and has long term effects on the individual with DS. Inclusion, in both school and society, is therefore really a function of relationships and attitudes and the benefits for everyone is well documented.

This study shows that parents all want their children with DS to have the opportunity and equal chance to succeed in an environment where the expectations of their teachers match their own. Unfortunately parents are often not adequately empowered to take a firm stand with regard to the education education of their children, which makes it easier for schools and society to further marginalize persons with DS.

The following factors regarding the educational support of the differently abled child were identified:

- **Low Acceptance in Schools**

This is a major stressor, often causing the family members extreme anxiety, especially with a view to the future of their child with DS.

Schooling is the greatest concern. We are constantly having to assess how and where we can send him for schooling. The systems of inclusive education in SA is an area for great concern. (M/12/D)

Die skool het op 'n stadium ook nie vir hom kans gesien nie... (M/1/D)

Concern = Schooling is the greatest concern. We are constantly having to assess how and where we can send him for schooling. The system of inclusive education in SA is an area for great concern. Also concern for his future. (M/13/D)

The academic road is often hard and unsupportive.

Just nursery school was ideal...acceptance from all teachers, parents, children...second and third nursery schools – disgusting...not accepted...fourth nursery school – Montessori absolutely wonderful...Testing to go to 'Real School' done by education Dept dreadful...said never go to school – sandpit the only place! Went to school for 1 year...loved and accepted...won prize for reading...teachers so impressed...next was lady of retirement age...impossible so removed from school. Tried 2 more special schools...parents not happy as if child had measles and was catching. Put in another special

school...very happy. Moved towns and only one school available...totally impossible, only 2 or 3 teachers quite good...left at 16...should have removed before... (M/11/D)

The plight of the child with DS's educational experience is mostly high-lighted, yet the typically developing sibling is often forgotten in this equation.

...when children and adults will want to focus on her differentness and not her sameness to themselves...cruel remark will be uttered...will completely comprehend and therefore be wounded by it. (M/20/D)

- **Abuse**

Instances of **abuse** in school were reported.

...was in a special school in Gauteng and the one day she came home from school with bruises all over her small little body. I thought I was going to lose my mind. I felt uncontrollably helpless... who on earth can do such a thing to her...till this day, we don't know what happened...person never came forth. We never took ...back to the school. (M/10/D) (This child is nonverbal and was unable to communicate to her parents what had happened. She was too terrified to point out the perpetrator at school. The case remains unsolved).

Her safety at school...major concern to me as she was violated (sexually) when she was 5yrs old (at school). This has totally messed me up emotionally and I am still not over it. Thank God it hasn't affected her although I often wonder and worry that she is suppressing it. (M/22/D)

- **Low Support: Government and Social Systems**

Low societal support continues to be a source of concern for parents.

Part of the cycle is also anger that you have to fight all the way for special people like ...from schooling to sport, to disability grants and income tax returns, to a place for her to live as a semi-independent adult. (M/2/D)

...she is in a special need school...personally... not prepared to take the risk of inclusive education and worry sometimes, that this may be unfair to her in the long run but to us, we do not want her hurt or frustrated with the lack of infrastructures in place in S.A...worry about her future... when we are no longer alive... lack of suitable facilities/workshops etc. available in S.A. (M/4/D)

She spells and recognizes her own name and this is NOT thanks to her teacher but thanks to the home circle and DS Support. This makes me ask questions around what she does at school all day. It took her

just 15 min to learn to spell her name out loud without looking at it written down. Now who's going to guide me in when is the right time to introduce a next word etc I am not a teacher...causes concern and anxiety. (M/22/D)

The differently abled remain marginalized in this country where the Government systems are more obstructive than supportive. Mentionable here is the paltry disability grant, reluctantly paid out only to those in the most dire income bracket. Persons with DS and their families certainly did not choose their circumstances, yet what should be the most basic of 'birth-rights' (meagre pay-out for their 'life-sentence') is balanced on extreme poverty.

Any semblance of therapy, financial support or independence (at whatever stage of their lives) is out of the question for these persons as the amount can barely sustain life. In the case of families with low combined incomes, this grant is withheld, thus placing the betterment of their child's situation completely out of their reach as well. The slightly advanced socio-economical group does not qualify at all, and expensive, ongoing therapy to sustain development of their child, becomes a financial burden, impacting negatively on the family income, the family as a whole and worst of all, the person with DS. Current tax laws allow a certain deduction percentage, but to qualify, a multitude of nonsensical tests and absurd documentation completion by 'professionals' can cost up to R5000.00 (five thousand rand) to obtain. To many parents this is unattainable.

Many culturally diverse families and their young children with disabilities or delays are not provided appropriate early intervention/early childhood special education services, especially not in a culturally sensitive and meaningful context. Families with diverse backgrounds often feel helpless and stressed because their concerns are not identified, and therefore their needs are not met due to the lack of support from appropriate resources. At most, family organizations such as DSSA and affiliated National branches are able to fill a small gap in this ongoing battle of marginalization.

5.4.3 MEDICAL FRATERNITY

A most distressing aspect, frequently discussed and mostly experienced by parents of all walks of life, has been confirmed by this study. It revolves around the decidedly objectionable treatment of parents, especially mothers, at both the diagnosis and actual conveyance of the devastating news that the child they had just given birth to has DS.

Most medical staff, which includes nursing staff, gynaecologists, paediatricians and general practitioners, are completely oblivious of the destructive effect their behaviour, attitude and thoughtless utterances have on a parent who has just had their world turned upside 'down'. It is discouraging that this dismal state of affairs perpetuates on a daily basis. The irony is that the very people who should be most qualified to allay initial anxieties and fears, are often the very people who wound and harm most in the eye of the storm.

The following emerged in this study:

- **Low Medical Support:**

Tactless and callous bedside manner of medical professionals, especially at the critical juncture of informing parents of the diagnosis is the cause of extreme emotional trauma for parents. Often the mother is informed without her spouse or another supportive individual being present.

...after the birth, the pediatrician told me (without my husband being called to be present), that...most probably has DS. I was struggling to be a mother, shocked by the diagnosis... (M/2/B)

The attending professionals at and probably prior to birth (we did not know till after birth), play a MASSIVELY significant role in how the couple and family with handle the introduction of a baby with DS. Unfortunately the pediatrician that informed my wife the morning after my daughter was born, had zero empathy and zero bedside manner/ability. This individual's actions have had a significant and long term impact on my wife's mental and emotional state. I am convinced that had he handled the situation with the smallest dose of humanity the journey for our family would have been very different. (F/8/D)

...told...had Down Syndrome about 2 hours after birth. As parents, we were not told together...told separately – father first and then mother. (M/6/B)

...paediatrician saw [baby with DS] and immediately said DS you have a problem...gave us an awful photocopy from a medical book to read. We went to a room next door and cried and cried. Waited for blood test hoping he was wrong. (M/7/B)

...3 weeks...took her for overall check-up...his pesice words "Do you know that your child is DS"...That was the first time I heard the word. He further explained that she'll be a vegetable I must send her to a instution as they any way die at 10 years or before... (M/21/B)

The aforementioned single mother, aged twenty two at the time, was a teacher and the primary carer of her physically disabled mother. Today, at age sixty two, she sings the praises of ‘*the vegetable*’ she took home on that fateful day. Her lovely daughter with DS recently turned thirty seven. Her mother reports:

... she takes care of me and is my best friend, daughter. She was in my class (adaptation) and can read, write cook and does the most beautiful needle work...she changed my life for the better...I most certainly can't imagine my life without her... (M/21/D)

A mother who had requested a sterilisation after the birth of her previous child launched a scathing attack on the medical profession.

...I was VERY ANGRY with my doctor. Specifically asked to be sterilized at the birth of my second child. This was not done I believe because of GREED from the doctor's side. I totally still blame the Dr for his manipulation of my life. Went back to him with this pregnancy (can't figure out this madness)...at 5 months offered to do an amnio... Refused the amnio....The same DAMNED Dr delivered her...pediatrician confirmed the possibility and ordered the blood tests. The medical profession sucks in the support department even in the private sector. No one came to me to discuss my child's condition. On discharge I was given some written material. The nurse said "This is the first DS birth at our hospital since it's been reopened" WTF!!! I would have preferred to know about her low muscle tone and her floppy head. (Imagine the damage I could have inflicted on my child) The medical profession (private practice) again fails in not setting up a plan of action for the well being of my child. No speech therapy referrals. No occupational therapy referrals. Nothing. No interventions nothing. I had to figure it all out myself and do what I thought was right from the materials supplied by DS Support. (M/22/B)

This traumatized mother wrote an authentic and heart-wrenching poem that mirrors the helpless anguish that she felt in the aftermath of her experience. I have chosen to include it at the end of this chapter.

- **Poor Medical Guidance**

First time mothers are often not well-informed about medical procedures and tests during pregnancy.

A lot of DR. does recommend an abortion when something like this happen and the mother and father are very young and they are not financially stable. It is a very sad reality. (M/10/B)

...no tests were done to see...Down Syndrome or not...were not told of any tests that were supposed to have been done...did have the translucency test and were told that our child did not have Down Syndrome... did not have the triple test, Amnio nor the 3D scan. (M/6/B)

Because I was so young when I fell pregnant, the doctors never tested me during my pregnancy for Down syndrome. (M/10/B)

It was not easy to them [parents] because they were not expecting him like way he came "DS",it was a challenge to my parents because by the time they were told about my brother they didn't get any advise from doctors how to take care of him. (S/9/D)

Die kliniek het nie uitgevind nie...na 3 maande het ek uitgevind sy was 'n DS. Ek het onmiddelik gesien daar was iets nie reg nie...dokter toe... (M/17/B) (This mother attended a township clinic).

- **Poor Professional Support**

Parents reported mostly negative experiences from professionals. Rather it is compassionate individuals in positions of support who are most knowledgeable and helpful.

[upon diagnosis]...we were told that we would see a psychologist and a member of staff from Pathcare. We did not find the psychologist helpful at all but [person] from Pathcare was unbelievable. (M/6/B)

Had I known the importance of early intervention and the benefits thereof. I had to search and find my own resources until DS Support came into my life after I phoned them to make contact. Thank goodness I had the sense to do it early in my child's life. (M/22/D)

We met many exceptional people as a result of... but none of them fulfill a social need and are largely in a supportive role as therapists. (M/20/D)

Insensitivity to the needs of the person with DS and the parents are often displayed by medical professionals.

The birth did put some strain into the marriage relationship in the early weeks as my wife battled to accept the situation. I believe this was primarily due to very bad handling of the notification of her condition by the attending pediatrician. (F/8/B)

...hy is op medikasie gesit wat sy testosteroon onderdruk het en hy soos 'n vet slapende zombie was. Ek as moeder het teen almal se wens hom na 'n paar jaar van daardie aaklige goed afgehaal... (M/1/D)

Although one has to believe that the intentions are well meaning, one cannot but wonder what in the world goes through the minds of medical professionals when they are dealing with parents of children with DS. Are they truly sorry for these children? Do they believe that they cannot have hopes and dreams? How is it possible that someone who takes the Hippocratic Oath seriously can expect parents not to raise their children without any expectation for greatness?

Ironically, the medical profession has turned out to be the last place parents want to go for support. Parents experience too often that their children are no longer regarded as people, they are seen as a diagnosis and the medical profession is so good about giving you the worst case scenario. Often nothing helpful is said, and nonsensical drivel such as "...just love her as a *normal child*" (*like they wouldn't anyway?*), "... they are always happy and smiling" and the *classic*, as relayed by many a young couple: "Of all the different birth defects, if you had to choose one, DS is one of the better one" is often passed off as valuable input and advice by medical professionals. Often customary sympathy rather than support is offered, which is terrifying for especially new parents.

Parents become aware of the many challenges that their children will face, and educationists carry on where health care providers have left off, small wonder that their stress coping mechanisms function at all!

"Parental coping" is not a new concept, there have *always* been parents who have coped, but few have been brave enough to face the world squarely in the eye and say "No more! Life is *not* one size fits all! My child certainly will *not* fit any societal imposed mould, but that's just *too bad!*" Parents who take this route less travelled almost always yield positive results. Their courage to expose their child to an inclusive life style, expecting of society to accept him/her, in the end proves to stand them in good stead.

Sadly, a society that cannot tolerate and embrace its vulnerable can never 'see' ability. They are too busy searching for dysfunction and disability to notice...

5.4.4 GENERAL PUBLIC

An uninformed society does not understand, and seldom supports the attempts of mothers to include and expose their child to everyday experiences. This causes much emotional trauma for mothers and fathers. The global move towards valuing diversity has proven a positive move

for differently abled children and their families. Today it is much more natural and acceptable for parents to include their child with in regular ('normal') life and to expect of their communities and society at large to accept and include, even *value* their child for his/her unique contribution.

In this study both positive and negative experiences were reported:

Coldness and reservation of society has an impact on the family and social life.

Some people have no problem relating to her and including her, others don't even bother to make an effort. (M/2/D)

Most people don't know why [daughter with DS] looks diverent. They stare, some laugh, some will come up to me and ask questions. (M/10/D)

Some people just avoid you because they think it is some kind of disease...others ask what I did wrong during pregnancy... (M/16/D)

The first thing that I did was google DS on the internet and that is probably the worst thing to do in hindsight as I was met by a barrage of "retard" comments etc. The DSSA forum was offline because someone had posted insensitive comments. To this day the biggest hurdle we face is dealing with the general population's ill informed attitudes towards DS. (F/1/D)

...placed different stresses and strains on our relationships, both internally in the family and with others in our wider social/family circles. It brought in sharp focus for me the lack of understanding and lack knowledge about people with disabilities, that exists in "mainstream" society. (F/8/D)

Parents often experience high levels of frustration due to the thoughtless, unkind and inconsiderate behaviour of others toward their child (both juvenile and adult) with DS.

Normal people think they are never wrong when they work with disability and their approach on the matter...people in general are ignorant about disability and would rather deny that here is something different with the Down Syndrome...people pity him as a Down Syndrome, and then he does not really understand that he is different from others..."normal" people take advantage of his disability and abuse his human rights. (F/7/D)

Despite the negatives, a parent reported her experience of acceptance and tolerance from the general public.

We have also found that in going out to public places, her nature /disposition is always well received by the public and results in such warm and loving response...a source of joy and pride to us. (M/4/D)

5.5 CONCLUSION

From the findings it became clear that, consistent with findings from other studies, negative consequences are not inevitable outcomes of parenting a child with DS. Understandably, however, more vulnerable families may encounter more negative outcomes. As researcher, avid supporter of this community of people and as participant in this reality, I am at liberty to proclaim that many families of children with DS are *indeed* able to function in a healthy way, and, as the outcome of my study predicted, a significant number of families have found their lives *enriched* by what was originally considered to be a catastrophe. This is consistent with the view of Van Riper (2007: 119) that “while the birth of a child with DS a “change of plans” for families it does not have to be a negative experience. In fact, for many families, it is a positive, growth-producing experience”.

Further endorsing this view, the mother of a delightful, remarkably accomplished young woman with DS wrote:

Ons gesin, familie, vriendekring en almal wat ons ken sou geestelik armer gewees het as...nie daar was nie. Ek dank die Here vir dit wat Hy my geleer het deur ..., maar ook dat Hy haar geseën het om haar ideale te bereik, al het dit langer geneem as vir ander. Ek waardeer klein dingetjies meer, ek waardeer mense liefde vir ... en my ander kinders, ek waardeer mense se geduld met ander wat swaarkry, ek sien die lewe in veel meer vlakke en ek is so bevoorreg!! (M/14/D)

This sentiment was echoed by another parent, whose life has been touched in an inimitably constructive and positive way by her toddler son with DS:

I am much more focused on living in the present. Because it is so difficult to predict his future, I live for today. When [son with DS] is happy today and he has learnt something today, I feel that is enough. As we continue on the road, I believe I will have enough light to make the right decisions for that day. I have more faith in God's providence, and also in his unconditional love for us. I believe that ...is as perfect as can be in God's eyes. I also have acquired much more patience – there is no other way – [son with DS] has his own tempo of living and I have to accept that! (M/12/D)

Findings from this study provide support for the argument that many families are able to function as ‘regular’ families, regardless of the challenge of raising a child with DS or the simultaneous parenting of typically developing siblings *and* a child with DS. Not only did

parents and siblings respond positively, but many also included descriptions of individual and family accomplishments. Warm and heartfelt descriptions of how the experience of raising their child with DS had resulted in positive consequences for individual family members and the family unit.

Understanding and embracing the paradox of disability is a compromise between acceptance and denial. This is pivotal for the psychological well-being of parents of children with DS, as it allows them for hope, renewed energy, positive a positive view to the future, optimism and personal growth.

Parents are often reluctant to verbalize their negative emotions or feelings of disappointment and frustrations in case they sound insensitive or are perceived not to be coping. As a parent of a child with DS, I am constantly acutely aware that my family functions within a fish-bowl. We are always on display. People seem to watch every move you make closely and relate it to “the syndrome”. What you say is often evaluated and taken to be significant of the “special circumstances” that you have, instead of just being part of normalcy. This results in unrealistic pressure (often self-inflicted) on parents, who feel that they are constantly performing in front of a pavilion of critically evaluating spectators. I have witnessed the exasperation of many parents who feel that others don’t consider that their child has only *one* extra chromosome...along with all the other forty six normal ones! How quick we forget that it is so much easier to grant each one his measure of sunshine, and that it would be *much less complicated* to live together in peace that surpasses all understanding.

In the end it is all about acceptance, love, and the understanding that one size does *not* always *have* to fit all.

As a mother so poignantly stated: ...*“want sy is soos ‘n normale kleuter...doen alles soos... dans, sing... maar op haar tune...”* (M/18/D)

In Chapter Five, the researcher offered the analysis and interpretation of the data collected by means of self report responses to the question guides posed to participants. There are different role players who ultimately constitute the subsystems in families. How these are affected by being a parent and sibling of a person with DS, were discussed. Chapter Six presents the implications, recommendations and conclusions of this study.

In conclusion to this chapter I share the following narrative which was presented as a part of the participant's response. It is included with the permission of the participant.

The background: This working mother had two children aged fifteen and four. After the birth of her last child, she requested to be sterilized; this direct instruction was ignored by her gynaecologist, although the mother believed that the procedure had been done. At age thirty nine this mother gave birth to a third child: a little girl with Down syndrome.

She recalls:

“ I wrote the poem I think 2yrs ago. I remember feeling very down at the time. I was having to fight with the Dept of Educ and the schools close to home. They refused my child entry because of her having DS. I was angry at [the Pre-school she attended] for failing my child the worstway possible (she was violated in their care) I was really hoping she could stay at that school for a long time as she was so settled in and doing so well. I was just so angry at everyone and overcome by complete sadness. I kept asking why the hell me. I was fighting with God as I completely trusted him when He gave me this child. And I knew He was taking care of us but then He allowed this to happen.” (M/22)

(POEM FOLLOWS ON NEXT PAGE)

I DENIED IT...

I denied it. For weeks I denied it. "I'm sick" I said I think "I have the flu".
I'm in denial man.....The mind can think askew!!!
"I AM IN CHARGE".....
You're pregnant the Dr said.....WTF it can't be.....no! Am I? No I can't be.....but how LOL
I only have the flu man.....
I cried, I cried, I cried and I cried. I already have 2
"I AM IN CHARGE".....
The Gynae confirmed 4 months alongbut wait.....I need to run some tests.
Don't be alarmed it's normal... at your age(39).....Ja right
I waited, I waited, I waited
Dr said....one in six chance....Down Syndrome! but you have options..... WTF
You denied me my option for sterilization 2yrs ago.....#@\$ *&^ ^%\$ No Amnio No thanks I know the risks.
"WHO'S IN CHARGE?".....
Scan pic confirmed for me at least, it's 3D after all. Hope Pray Hope some more. Pray Some more
She'll be OK. She'll be healthy I just know.....Denial again?
It's that damn Dr's fault. I told him to sterilize me at no 2
HE THINKS HE'S IN CHARGE damn fool!!!!!!
"She's the first baby born with DS at our new revamped unit" the nurses said
.....HOOORAY!!! Does that make me feel better?
No support. No sympathy. No advice. NOTHING.
She's beautiful. What shall I call her. She's beautiful. Oh She's sooo beautiful.
"I AM IN CHARGE"

My father wants to know how, why. What do I tell him. I don't know. No one told me anything.
People come to see. Some ask, some leave in a hurry, no one advises.
Mom I think it's easier if we just say "Come meet our Georgia, She has Down Syndrome" but she healthy and she's beautiful.
"I AM IN CHARGE".....

Yes God YOU ARE IN CHARGE OK I get it now. You have a bigger plan.....Now give me patience until
You reveal your plan.....and Thank You for Georgia.....She's beautiful.....Thank You Lord

CHAPTER SIX

IMPLICATIONS, RECOMMENDATIONS AND CONCLUSIONS

6.1 INTRODUCTION

The aim and purpose of this study was to ascertain the impact of a child and sibling with Down syndrome (DS) on their family dynamic. This was done by means of a qualitative study which focused purely on the perspectives of the immediate family, but excluded the perspective of the person with DS.

The preceding chapters offered the background to the research study, the problem statement, the intention of the research aim, clarification of concepts, research design, methodology, and research plan. The theoretical perspectives which underpin this study and a comprehensive literature study on DS as well as family perspectives were provided. Chapter Five offered an analysis of the research findings. As the final stage of this study, the implications, practical recommendations and conclusions are provided and limitations of this study and possible areas for future research are suggested. In keeping with the individual style of narrative expression, the researcher concludes this study with a personal reflection.

Throughout this study the researcher found the participants' level of honesty reassuring and in only one case was embellishment suspected, as previously both parties had, albeit on different occasions, been met by the researcher. In order to protect the identities of the particular participants, it will suffice to say that having the background it was not difficult to assess the sincerity and authenticity of their written responses, yet the researcher remained neutral and unprejudiced during analysis of said contributions.

Throughout the research, and especially in the analysis, it was interesting and compelling to note how participants presented (and sometimes justified) their actions and or reactions, especially in cases where the researcher had been involved with different family members at different times. This merely adds force to the researcher's argument that people are desperate for support and understanding, which regrettably, is mostly restricted to parents who have already *worn those shoes*.

Even those participants who presented with a language (or literacy) barrier, made an attempt to tell their story. Although there was an expected measure of reluctance from certain invited participants, the researcher was delighted at the spontaneity of many of the contributors. One

such example of commitment is a specific participant who walked several miles to the house of a family whom she knew also had a child with DS. Here she interpreted the question guide, acted as scribe for the illiterate mother and father, and took two taxis to meet the researcher on the outskirts of the township to hand over her 'work'. These contributions were enormously significant to the researcher owing to the modest and sincere attempt to make a difference. Despite the clear reserve and fairly low standard of these particular contributions, the researcher was however still able to use the data. Their opinion mattered; their voices were heard; they contributed when many far more eloquent and capable preferred to evade feelings reflective of reality and of real people. Instead they opted for silence, stifling not only their own voice, but in effect the voice of the voiceless they could be advocating for.

The recommendations that follow are aimed at a wider audience than an examiner or moderator. The earnest intention of the researcher all along has been to provide insight, assistance and support to all the relevant role players. At closer inspection this audience is enormous. What was originally perceived to be a study directed at the immediate family, has, by virtue of its outcomes, encompassed extended family, friends, community members, educators, medical practitioners, in fact, glaringly obvious, is that *most* human beings need some measure of help in order to reach even a slight understanding of what it means to be fully human. The researcher believes that an individual who is fully human seeks knowledge and understanding, will ask instead of avoid, and abides by tolerance rather than bigotry; will embrace diversity rather than be repulsed by it; and will look with eyes that reflect acknowledgement and acceptance, which is, after all, what we all seek. In a nutshell, allowing a wider range of help and providing the strategies was the ultimate goal of this exercise.

To attempt to cover the entire life-span of an individual with regard to implications and recommendations would be unrealistic, as those would change at every age and stage of development of every family member, dependent upon variables and situations. The focus is therefore more on the general rather than the specific. Each individual has a unique way of functioning and these recommendations may not suit everyone or every situation, rather it may provide a stage-set on which everyone can place their own prop.

As I am part of the participants' community (although not an active participant in this study), supporter, an educator, a wife and a mother, the recommendations comprise the careful convergence of experience, observation and contemplation coupled with practice, understanding and familiarity with the subject. The foundation, however, lays in the literature,

which is extensive beyond belief in its scope, accessibility and content. Nonetheless, it was crucial to the length of the study that I self-imposed certain boundaries within the range of relevant recommendations. Although I endeavoured to present an accurate, relevant and holistic study, these implications and recommendations are merely a tip of the iceberg.

The nature of certain of the themes necessitated a measure of interpretation interwoven into the implication as evident below.

6.2 THEME ONE: INTRA-PSYCHIC FUNCTIONING

Although many similarities were found in the intra-psychic functioning of the mother and the father, these will be discussed separately. However, the recommendations are often applicable to both. The implications and recommendations refer to the different subsystems of the intra-psychic system (i.e. emotional, cognitive, physical, behavioural and spiritual subsystems). The components which comprise each subsystem are mostly interrelated which is why, for this exercise, they were consolidated, as the recommendations mostly transcend these components. It is therefore not a simple case of 'stating the problem' and making a recommendation. A measure of elaboration was therefore required in order to place the implication into perspective. To facilitate ease of referencing, key aspects have been printed in bold.

6.2.1 INTRA-PSYCHIC FUNCTIONING OF THE MOTHER

6.2.1.1 EMOTIONAL SUBSYSTEM

Although emotional experiences are unique to an individual, all parents in this study shared the range of feelings upon getting a diagnosis of DS (pre- or postnatal). The magnitude and turmoil of which is often so intense that they are only able to express these years later; hence, the withdrawal of many mothers who had committed to participating in this study. Orphan (2004: 98) confirms that equating the intense and painful feelings to those felt when someone close to you dies, may provide some understanding of the chaos and turmoil of these feelings. Although the feelings are acute in the early days, they dissipate with time, yet revisit at different junctures throughout the journey with your child with DS.

➤ Implications

Being common responses to traumatic events in life, it was not surprising that most mothers identified with feelings of **shock and disbelief** when their child was diagnosed with DS. Most mothers in this study experienced that only a part of their mind accepts this shock whilst, in order to protect themselves from feeling overwhelmed, another part of their mind goes into denial. It was also my experience that, although the information could be processed mentally, it took some time to process it emotionally. Such denial further implies the actual denial of the feelings that have been caused: it denies that the message (diagnosis) has caused extreme distress or that it may indeed change your life (Orphan, 2004: 98).

In my experience mothers are often desperate to prove to everyone how well they are coping and how positive they are about the whole situation, yet beneath the smile they often hide an array of emotions that cause turmoil and confusion. Many mothers who participated in this study shared afterwards their feelings of a strange disconnectedness with reality (dissociation as associated with trauma) and **emotional dissociation**. As a result a mother will find herself merely going through the motions, more than *experiencing* the here and now; a feeling as if her life had become a movie, playing off around her, but she is no longer part of the cast. This emotional disconnectedness is a form of denial, accurately defined by Orphan (2004: 98) as the refusal to believe what is happening, which buys them time to discover the inner strength to handle the problem. I personally experienced this exact emotion acutely a number of hours after the diagnosis once everyone had left. I was fortunate that it only lasted for a few hours before sleep brought oblivion; yet, dawn brought renewed peace, fervour and the anticipation of new motherhood.

Fear is one of the first thoughts and a major stressor for any new mother who is suddenly, without her having a choice in the matter, connected to a 'life-long sentence' of probable stigmatization, social and educational stereotyping and possible long-term dependence on others of her child. These feelings of fear were shared by many mothers in this study. A typical implication of fear is **denial** of the full truth and reality of the situation. This may lead to feelings of uncertainty about the future, which causes many mothers to doubt their ability to survive at being 'mother', let alone wife and partner.

On the other end of this spectrum, fear can be debilitating, often resulting in dysfunctional denial coping mechanisms that hamper constructive dealing with reality. The mother, who is

driven to high levels of anxiety as a result of fear, may find it so stressful that she lapses into clinical **depression** – rendering her incapable of handling the demands placed on her by the situation. According to Orphan (2004: 101), at the very least, dysfunctional fear can result in a level of inertia and denial ('mental paralysis'), which could result in the parent not really accepting the full implication of the diagnosis, and thus not giving the child the necessary care (such as, for example therapeutic interventions necessary for his/her optimum development and so forth). I have met many mothers that have teetered on the brink, but with help and support they have managed to pull through.

The implication of the sense of **loss and grief** a mother experiences, is a complex issue, because when considering that the origin of this emotion is likened to bereavement, there is one crucial difference: the person she grieves is still alive. This carries intricate emotional implications, as few people around her know or understand that she might be grieving, yet in herself she may actually feel **guilty** for feeling this way at all. So why do mothers feel sad? The root of this sadness is the profound sense of loss. As mothers welcome their child with DS into the world, they also bid farewell to the child they *dreamed* and *expected* to meet (Dowling *et al.*, 2004: 11). They have to say goodbye to the plans, hopes, dreams expectations and aspirations they had for the child they were expecting. For the parent whose child is diagnosed with DS, it is no longer just the loss of what could have been or should have been, but also grief about the future – for the child, for themselves and for their entire family unit (Dowling *et al.*, 2004: 12). This profound sense of loss was identified in the findings by both mothers and fathers.

Apart from the initial grief emotions felt at the diagnosis there is a day-to-day sadness and grief that parents of typically developing children do not experience. One of the mothers has even developed an unnatural fear of something happening to her typically developing daughter as a result of not dealing with this combination of sadness and fear. The findings of this study clearly showed that parents experience sporadic sadness for the unjust and unfair way in which society treats their child, as confirmed by Orphan (2004: 102).

Findings showed that most mothers find themselves moving through the cycles of mourning in much the same way as someone having lost a loved one. She *has* in fact lost a loved one, and in his/her place she has been given an "alien", albeit a very cute one! The implication is that she needs to mourn the child she did not have, before she can be fully ready to accept the child she got.

It is evident in the findings that the mother's manifestation of **loss** affects not only herself, but also each person in the family, as well as the overall family dynamic. The implication hereof is often negative for the marital relationship and siblings and the child with DS is often subjected to over-protection as a results. Behaviour such as withdrawal and communication problems in the marriage was found in this study, which obviously affects the family as a whole (Dowling *et al.*, 2004: 11). Findings showed that this emotional 'dysfunction' also has implications for the father (who feels helpless and guilty that he is unable to ease her pain), and for the siblings, who may equally be feeling guilty for being 'normal' and even angry at the sibling with DS for causing their mother so much heartache. A culmination of the aforementioned could result in further mental and emotional stress for the mother, which impedes her need to attain a level of acceptance and resilience.

(Orphan, 2004: 102) reminds us that **shame** is a hidden feeling and it is an emotion that often makes the mother feel terrible, as was evident in this study. The implication of shame is that it makes one want to hide; you feel exposed and you want to cover up (Orphan, 2004: 102). I have often found that mothers do not want to tell others how they really feel and this has serious implications for how she is *actually* coping (or not) and whether there is *actually* acceptance of her child, the diagnosis and the situation she now finds herself in (or not). Although only one mother pertinently shared her feelings of shame by denial and withdrawal, shame manifests in different ways, depending on the personality of the person: some may pretend that everything is well; some may attack others; some may choose to withdraw from everyone and everything else; and, most destructive, others condemn themselves, as confirmed by Orphan (2004: 103).

Most mothers reported feelings of **guilt**, whether it was about their typically developing children, their child with DS, their husbands or simply circumstances beyond their control. Orphan (2004: 101) reminds us of the many cultures who have a view that 'bad things happen to bad people', which was why one mother thought it was her fault that her child had DS. The implication of these feelings is simply a perpetuation of further guilt which may result in feelings of inadequacy, withdrawal and relationship problems, as was classically reportedly experienced by this mother. Although this mother was brave enough to equate her feelings regarding the diagnosis as her 'punishment', I have often come across such a mindset amongst specific cultural groups.

The implication of such an approach is far-reaching for the mother who lives, functions and has to raise her child in a community who maintains such a negative and judgmental attitude. The mother's feelings of shame and guilt are likely to arise from a sense of failure for not having produced a healthy child that is "acceptable" in a normal society. Sometimes the mother is also made to feel guilty for having decided against an abortion, and in so doing not having thought of the child's best interests (as some medical professionals often vocalize) or by placing a burden on society to care for an individual with special needs. Fascinatingly, this particular mother thought that having a child with DS was her punishment for falling pregnant when her husband had said that he was not yet ready to start a family.

The implications of feeling shameful and guilty would be most evident in the mother's behaviour, often isolating herself and/or the child with DS from society, effectively cutting them off from the support which they so sorely need from their community. This could, in turn, potentially lead to emotional problems like depression, loneliness, anger, resentment, as well as a perpetuating the cycle of shame and guilt – even for the rest of the family members who then have to make excuses for the absence of a mother and sibling from normal societal functioning.

On a conscious cognitive level the implication may be that the mother often attempts to compensate for this guilt by working tirelessly on her child's educational and therapeutic needs and by making the differently abled child the family's number one priority at all times. Ironically, this strident dedication may in fact ultimately lead to even more feelings of guilt, as the parent realizes that the needs of the rest of the family, including her spouse, are being neglected (Dowling, 2004: 12). The implication of the latter is often shattered relationships and even divorce, as confirmed by the findings of this study and the reality of a number of mothers who chose not to participate.

In the findings, some mothers voiced their feelings of **anger and frustration** resulting from internal and external circumstances. Externally this was directed toward the unfair society we live in, the medical fraternity, their spouse, or simply toward the universe for allowing *this* to happen, whilst internally mothers were angry at themselves for not coping, not knowing enough, not spending enough time, not doing enough and so forth. There is no end to the times a mother can stab herself with the same dagger. This inadequacy is often related to her frustration with the child's (dis)abilities and she feels directly responsible for the lack of or slow progress of her child. The implication of this anger is that it can be very isolating. The mother

feels that she cannot vent her fears, concerns or frustrations for fear that she will be perceived to not be coping. This may cause relationship, physical and behavioural problems. Orphan (2004: 100) cautions that it is not the anger itself, but getting stuck in a spiral of negative feelings and thoughts, which is the real danger here. Based on the findings, the following recommendations are suggested to support the emotional well-being of the mother (also applicable to the father).

➤ **Recommendations**

- ✓ **Facing your feelings:** It is suggested that, as a starting place, the mother try to look at it from a matter-of-factly level (as if she is an outsider trying to create order) and realize that in order for her to get on with her life, she needs to face, feel and express her feelings. To switch off or bottle up feelings expends too much energy which could be put to better use in order to deal with the situation and with life in a constructive way (Orphan, 2004: 106).
- ✓ **Let out your feelings:** Tears are extremely therapeutic and a good cry releases pent up emotions (So too does a good scream! However, use a pillow or take a drive and let it out in the open). Some people find emotional release in physical activity such as cycling, running or cleaning; whatever the mother needs to do, this should be a priority. Feelings need to go somewhere and if they are not expressed they will manifest in physical symptoms such as being run down, anxious and stressed, ill, blood pressure conditions, sleep disturbances and so forth (Orphan, 2004: 107). Listening to the distress calls of one's body is important in order to understand how to deal with it, for example most people know when they are becoming anxious or angry by onset of specific symptoms. To this end, relaxation techniques, yoga or a form of exercise which combines relaxation, non-strenuous exercise and tension release may prove beneficial.
- ✓ **Trauma counselling:** It is advisable for the mother to have some trauma counselling in the early weeks after the birth of the baby with DS to prevent dissociation to escalate into mental health problems. The help of counsellors at hospitals is invaluable and should be non-negotiable. It is fundamental to the mother's emotional health to help her deal with stress effectively, and to recognize the link between stress and fear, anxiety, and depression. There are many techniques and tools to combat stress that can be taught to the mother by a professional counsellor, including internal relaxation exercises, the importance of facing one's fears and monitoring it, and to monitor one's own fear and anxiety in order to manage it effectively - including having a prevention plan for relapse

(Nejad & Volny, 2008: 18). For the mother debilitated by fear, anxiety and/or depression, being treated by a professional psychologist may be required. This would help her deal with the demands of the situation by acquiring better coping mechanisms, by eliminating non-useful ones, by effectively managing her stress levels and by handling fear and anxiety to prevent relapse.

- ✓ **Deal with grief:** Working through the grief process is something only the mother can do for herself and her husband, members of the family and community needs to allow her to do so. This will take time and could be marked by periods of great sadness and heart-wrenching grief, as well as anger at herself, doctors, God, her spouse or any other person she feels that has let her down. It would be preferable to solicit the services of a trained counsellor to gently help her through the stages of grief. Once the mother has reached acceptance, the counsellor could guide her to reframe the situation on a cognitive level in order for her to have hope and develop strategies to make the best of the situation. This is needed for her to reach an acceptable level of quality of life, both for herself and for the DS child, as well as the rest of the family.

The mother who gets stuck in the grief process will find herself in a deep depression from which she would seemingly be unable to find her way out. Should this happen, it is imperative that professional counselling and medication are enlisted to help her reach a state of equilibrium again. This could also include cognitive behavioural therapy to help her to change her negative self-talk and her unhelpful thought processes around the situation.

- ✓ **Find someone to listen:** It is valuable for the mother's emotional stability to find some caring, sensitive and gentle people to be with. A mother does not necessarily need advice, clichés or people who problem solve without listening to her feelings first. Thus, she should best avoid persons who start their sentences with "Cheer up, everything will work out...", "I hear these kids..." or "If I were you..." Other strategies to help her cope would include a support group and for the mother to stay in touch with her friends for continuous emotional support.
- ✓ **Accept feelings as natural:** It is suggested that the mother allows herself the time to feel what she is feeling. Holding back the feelings will merely prolong the process of coming to terms with a situation. It is important to respect one's feelings as valuable and important. Orphan (2004: 107) accurately states that the feelings are reminders of the difficult events that we have been through. Accepting feelings as natural and managing their own

emotions will also teach the children in a household about emotional intelligence, and as with everything else about DS, yet again children will take their cue from their mother (or parents). In turn, parents can take a leaf out of the book of the child by showing others how they feel, albeit by using words, behaviour or sounds, and also by their easy-forgiving natures.

- ✓ **Look after yourself:** It is suggested that the mother give herself some 'me'-time every day, and taking some time for herself once a week. This time should involve something enjoyable, whether it is sitting alone in a cinema, a pampering session at a spa, laughing with friends, or simply relaxing in the back garden with a book. Scheduling me-time will allow the mother some 'time-out' without feeling guilty (Orphan, 2004: 107). A good friend reminded me once that life is a juggling act with many different balls. Some get dropped and they bounce back, but the most precious balls are the crystal ones of health, family and self, and if one of these should fall, they shatter, and the act is over. Some things are almost impossible to mend, of which a crystal ball is one.

6.2.1.2 COGNITIVE SUBSYSTEM

➤ Implications

Orphan (2004: 10) cautions us that parents are often their own worst enemies. Especially mothers often impose extreme expectations on themselves, being a harsh and constant critic of herself, as again confirmed in the findings. The implication of **unrealistic expectations** is that she loses perspective. For most parents this is a time of crisis in their life and as Orphan (2004: 10) reminds us, people do not 'perform' in a crisis; they get through it and survive. It is important for the well-being of the whole family that the mother realizes that she does not have to be a "super-mom," and that all mothers in her given situation are all merely normal individuals doing their best. This requires a conscious mind-shift, which, if unaddressed causes great anxiety for the mother as well as the other family members. Should such a mindset not prevail, the emotional, behaviour and especially physical subsystem of the mother will remain in turmoil as she struggles and strives to do the impossible.

The findings confirmed that it is only the mother who can give the first step towards **acceptance and a positive view to the future**, no one else can do this for her. It is a cognitive decision that may require her to adapt her thought paradigms around parental responsibility. Friehe *et al.* (2003: 212) advise us that acceptance starts with the acknowledgement of the diagnosis as a

personal reality. The findings confirmed that once the mother has worked through the emotions characteristic of the mourning process, she naturally gets to a stage of acceptance. Only then is she able to find equilibrium in all her subsystems, which will enable her to re-organize her life and manage her situation.

➤ **Recommendations**

- ✓ **Have realistic expectations:** For most mothers this will be their first experience with disability, so not only will she have to rethink her own expectations of herself, but also those of the other family members and society, in addition to the expectation she has of her child with DS. It is imperative for the mother to learn behavioural strategies that would assist her in healthy coping. She needs to realize this knowledge on a cognitive level first, in order for her to behave with balance and equilibrium. To this end counselling will help the overcompensating mother to reframe her expectations of herself and her child with DS so that she is not constantly putting everyone at risk of stress burn-out.
- ✓ **Rethink disability:** It will be significant for the mother to change her thoughts around disability now that it is also part of her reality. By adopting a view of seeing her child for what he/she *can* do rather than what they *can't* do, as someone of value who has something to offer, and as someone who has different gifts and abilities that can be applied to make a contribution to society, will increase the mother's positivity. The mother may benefit from talking to other mothers who have had positive experiences in order to come to a better understanding of the child as a unique individual. The mother needs to reach an understanding that she and the immediate family (not forgetting the child himself once he/she is older) is the expert, and not the professionals. The persons closest to the child know the child's strengths and needs and actually understand what the experience of disability is like for the child. Reaching such an understanding will further empower the mother to see the child in a different way and will allow her to build up support for herself, her child and the other members of her family (Orphan, 2004: 10).
- ✓ **Move toward a positive view of the future:** The mother needs time to get to a stage of acceptance, and should not be forced on any emotional level. However, there should be a good deal of progression through the stages to ensure that she does not get stuck in mourning. The counsellor could play a vital role in helping her acquire some positive coping mechanisms – of which reframing to include a positive view of the future would be the most important. The mother needs to see that there is a future for her family and child with DS,

and that it is not a life sentence of misery for everyone concerned. To this end 'good news' stories and successes of persons with DS and their families will be helpful. Information and evidence of other DS adults living full and contented lives – albeit with some measure of support – should be presented to the mother to help her visualize a positive future. This is valuable for her to gain a sense of hope, which in turn would mobilize her into constructive action towards managing her situation. Managing her situation amounts to healthy adaptation to a life crisis, as described by Moos (2002: 67-88). The role of organisations and support groups, as well as DS literature in this regard is vital. In a sense they present life as “normal” for the new DS family. The mother should concentrate on literature which provides positive information that focused on adaptation, instead of endless medical information and reports on what could possibly go wrong in future.

- ✓ **Remain focussed:** A mother is often required to multi-task yet remain focussed. Anyone can only do one thing properly at one time. Mothers do not always understand this. What she needs to remember, however, is that this is a journey that can only be undertaken one step at a time. It is therefore recommended that she focuses on remaining focussed. This may require her to apply her organizational skills, her time-management skills and her people skills. In order to remain focussed, it would be beneficial to draw up a roster of all the children's activities (sport, leisure, therapies and so forth) as well as her and her husband's activities. This is where the help of family, friends and grandparents also come in handy. Setting out a daily routine not only helps the mother to plan her life, but to gain a perspective of whether everyone is getting equal attention and time. This may further help the mother to also focus on siblings and not just give in to her own grief or over-protection and over involvement with the child with DS.
- ✓ **Increase knowledge:** It may be beneficial for the mother to provide as scheduled time allocation for 'DS Research' as the internet has a sneaky way of swallowing up many hours. This has two-fold benefit: not only will she be actively increasing her knowledge on DS, but she will also become more empowered to deal with matters in an informed and knowledgeable way. This may support not only the cognitive subsystem, but also the physical, behavioural and emotional subsystem.
- ✓ **Include laughter:** Including a good measure of laughter in daily activities will stand the mother in good stead. Dowling *et al.* (2004: 188) reminds us that laughter is the most natural of cathartic processes and this tends to reflect a sense of wellbeing in times of stress and the ability to separate oneself from stressful events. The fact that a child has DS

does not mean that parents and family members are not allowed to find them funny as well. It is necessary to see the child as a real person and not in terms of the possible limitations of his/her diagnosis. Not only does laughter make a person feel better, but it reduces stress and (according to researchers, also has health benefits (Dowling *et al.*, 2004: 188). Laughter also enables the parents to experience the more difficult aspects of parenting in a lighter way and often alleviates the tension when they share their difficult experiences with others. Therefore including a good measure of laughter in daily activities will not only bring immediate respite of a sometimes potential stressful happening, but may enhance the experiences of the individual and the family in order to facilitate a more positive view to the future.

- ✓ **Become flexible:** The key to dealing with different ability, as with everything else in life, is to accept the limitations of oneself and of those around you and to have the wisdom to know that you cannot control what others do or say. In anticipation of the possibility of unpredictability, a parent should be flexible enough change direction and move forward without regret. There must be a willingness and flexibility to let something go if it is not beneficial to or supportive of their attitude, convictions and/or efforts. For example, the child with DS practices for the school concert for months on end, and on the evening of the much-anticipated event, front row packed with family and friends, video camera rolling, the child refuses to come out onto the stage. Everyone will react differently to this situation and recognizing and accepting the differences in reaction will require flexibility of cognitive thinking patterns.

To illustrate this point I relate to a story told by Beck (2010) of a programme she saw on Discovery Channel. When confronted by a predator, some animals fight, others run while a few hide, hoping not to be noticed. The pebble toad of Venezuela does something altogether different. Once, a particular little toad finally reached the top of a tiresome and long climb. He peaked over the edge of the rock only to find a *huge* tarantula right there. And literally, in a hundredth of a second the little frog pulled in his arms and his legs and became a pebble and bounced back down the hill, landing in a puddle. No worse for where he pulled himself up and (*probably*) thought, “*Okay, what do I do next?*” He gave up on his plan fast when something changed. Relating to thought (and behaviour) processes, this does not mean that a mother should not have hopes and aspirations; she should also have the flexibility when something different or unexpected happens, to take a deep breath and say, “Well, how could this be better?” For the sake of sanity it would be worthwhile for the mother to learn flexibility and an acceptance of present reality.

6.2.1.3 PHYSICAL SUBSYSTEM

➤ Implications

Stress is defined by Nejad & Volny (2008: 8) as a state of tension that occurs when the mother perceives that there are too many demands in her environment, or when she experiences a situation that is perceived as threatening, unpleasant, or unfamiliar. This was confirmed in the findings. Stress has a major physical effect on one's body, as well as on the other subsystems i.e. cognitions, emotions and behaviours. The implication of stress experienced with this life crisis is that mothers experience a level of anxiety and depressive symptoms at varying stages of dealing with their situation. In turn, this results in a negative cycle of thinking, which ultimately affects her self-care behaviour. Findings confirmed that, often due to a lack of time, some mothers tended to neglect themselves. Typical self-neglect manifests in her not nurturing herself adequately for example not eating nutritious meals, not exercising enough, not taking needed medication regularly (including supplements), and not taking enough time out to focus on her own mental health. Add to this the inevitable decrease in quality sleep that new mothers experience, as well as the social isolation typical of the early stages of motherhood, and the mother becomes a prime candidate for a major depression. This may have a negative implication for every role player as a mother suffering from major depression or burn-out is unlikely to be capable of taking care of herself, or the rest of her family.

➤ Recommendations

- ✓ **Rely on support:** Support for the new mother with a child with DS is vital. She needs assistance so that she will be assured of sufficient sleep, good nutritious meals, and especially some time alone in order to gather her own thoughts and spend some leisure time on something of interest to her. This will go a long way in combating the all too common occurrence of her losing part of her identity and becoming a "DS mother". She needs to be encouraged to see the bigger picture on a cognitive level and then to take good care of herself on a physical level.
- ✓ **De-stressing techniques:** It is recommended that the mother enlist the help of someone who is able to teach her good stress management techniques like relaxation, reframing, facing her fears, managing her anxiety levels, and developing strategies to combat relapse. To this end a psychologist or life-coach may be helpful. On a physical level she may find help at a reflexologist, chiro-practitioner, physiotherapist and masseuse. There are

numerous relaxation therapies available at health spas and a trip to a day spa would certainly give the mother a new lease on life.

- ✓ **Accept offers of help:** Help does not always have to mean physical help and most mothers often do not know what to ask for when an offer of help is extended. Accepting such offers free her time and hands just enough to allow for extra breathing space. A simple arrangement like a regular scheduled play-date or outing for a sibling, allowing a friend to collect siblings from the school one afternoon per week, helps mother and sibling. Similarly a competent baby-sitter or child-minder is of great value to a mother.
- ✓ **Monitor the marriage:** Mothers who reported high spousal support and understanding regain equilibrium in all their subsystem with relative ease. It is thus essential that the mother monitors her marital relationship and opts for counselling should she lack support from her husband.

6.2.1.4 BEHAVIOURAL SUBSYSTEM

➤ **Implication**

As findings confirmed that mothers may tend toward over-protection of their child with DS, the following recommendations are made.

➤ **Recommendations**

- ✓ **Rethink parenting skills:** The manner in which the mother was raised and was treated as a child will most likely become the model for how she parents her children, and will also influence the way she interacts with her spouse during parenting (especially if she has had no other training) according to Cremer-Vogel & Richards (2008: 223). It is therefore imperative that parents examine their own past and clean out the closets of childhood, dealing with unfinished business and moving forward. Although many people vow never to parent like their own parents did, the sad reality is that, unless they do a thorough examination of themselves, find compassion in their hearts for the struggles of their parents and *choose* to learn alternative ways, they will surely repeat some of the behaviours (and mistakes) of their parents. Parenting is not for the feint-hearted. Parents must be well trained and guided with precise knowledge. If parents follow these guidelines it may enable them to not only accept, but ultimately embrace their challenge. In their book, "What every adoptive parent needs to know", Richards & Cremer-Vogel (2008: 221-232), share their

discovery and use of “the therapeutic parenting approach”, upon which I have based a number of my recommendations.

➤ **Implications**

The findings were consistent with the overwhelming sense of uncertainty of what-to-do-next when the mother receives the diagnosis of DS. Prospective parents may not be able to imagine that their child could have extraordinary needs, let alone be prepared for what it might take to meet such needs. Logistically speaking not all bases can be covered, but setting a firm base of preparation, may rule out many of the potential challenges. Thus, the following parenting guidelines could be a helpful guide to the mother, not only with dealing with the diagnosis, but also for the future.

➤ **Recommendations**

- ✓ **Be prepared:** If the mother knows the diagnosis before the baby’s birth, it is recommended that she read and learn all she can about DS, focusing on newer publications and valid, supportive and reliable information on recognized websites. Parent organizations are a valuable source of support specifically helpful in understanding the range of physical and developmental challenges, as well as the realities of raising a child with DS. The interaction with parents who are still ‘ascending the mountain’ may prove to be helpful and inspiring. Consulting with a therapist who specializes in helping and supporting families with a child with DS may further provide helpful and practical information on the day-to-day and milestone-to-milestone essential information.

- ✓ **Prepare family members:** As stated several times throughout this study, family members take their cue from the mother. It will minimize future embarrassment and uncomfortable situations if ‘rules’ are laid down regarding terminology. Not everyone knows that certain terminology is hurtful to the parents and family members (a list of preferred terminology follows as a last recommendation) therefore addressing the elephant in the room beforehand minimizes hurt (see Section 6.4.1). Using different terminology for adults and children, the mother can explain in simple terms what DS is and what it is not. It is suggested that the mother arrange a family gathering and break the news gently to all the role players in the child’s life. At this time it would be beneficial to focus more on the positives and similarities than the differences. If the mother has reached a place of understanding at this time, it would be valuable if she is able to guide others to see that the

idea of a differently abled child could be a preferred cognitive paradigm instead of viewing DS as a disability.

If the mother is feeling emotionally fragile, it she could ask someone who has had a child with DS to support her and to do the talking and to answer questions. This meeting may be pivotal to her acceptance as well as that of her family of the new situation. Such a meeting would have great value as the honest and open would set the tone and level of acceptance of the new baby into the family. Furthermore, by the time the baby arrives, the key persons in the child's life would already have had the time to work through many of the emotions, may already be at a place of acceptance of the situation, and be ready to embrace the diversity/challenge.

- ✓ **Come to terms with the “loss”:** It is perfectly normal for the mother to go through the different stages of loss. These would include shock and numbness (dissociation), sadness, anger and acceptance. It is important that the mother mourns separately and with her spouse. The gravity of the future and the parenting of the child must not be underestimated and therefore the parents should make sure that communication between them is effective so that there is clarity on the position of both mother and father on the issue of raising a child with special needs. If there are significant grief and loss issues, it would be advisable to consult with a therapist/ psychologist to help reach a resolve in order for this not to negatively affect the parenting experience for either parent, or their relationship in the long run.

- ✓ **Closely examine expectations:** It is advised that mother and father, separately and together, write down exactly what they are expecting from this new experience. Are the hopes realistic? Do they focus on the child's needs? Are they achievable? What personal, couple, family and community issues need to be addressed? What are the best and worst-case scenarios that could happen? What if the worst-case scenario comes to pass? This should be kept, periodically viewed and expectations adjusted as time passes. (This exercise would be extremely valuable as a bonding exercise for parents and typically developing sibling too). A number of very important things need to be kept in mind: Mothers are cautioned not to compare their child to others, but to keep abreast of what the next milestone is for typically developing children, supporting their child through therapies, home exercises, occupational therapy (if necessary) and a double helping of mother-love to reach the milestone. Never give up. Never think it will not happen. Never lose heart. The

mother should look into the eyes of her child and see the love and expectation that his/her mommy is proud.

- ✓ **Identify resources and supports:** It is suggested that mothers enquire about possible support groups and specialist organizations in their area. For ongoing support, she may find value in local parenting support groups, joining on-line forums, and attending conferences and seminars arranged by nationally renowned organizations and professionals. Down syndrome South Africa is the umbrella parenting organization for DS and has twelve branches nationally. Many informal support groups exist and they are often steered by parents who have some experience in the field. The mother may consider making contact with someone who has had a positive experience to counsel the family and to help them to understand and prepare for what is to come. Usually experienced parents are helpful in recommending reliable therapists. Rally friends, family, community and church for support. Locate and befriend other parents who have 'walked the walk', ask for help and ask often, even if it just for little things. Mothers who establish a small core support group of their own with two or three families with children of similar ages have found this type of support networking extremely beneficial and constructive and have come to rely on the friendship, understanding and the constant flow of new information and advice found in such a liaison.
- ✓ **Secure the financial situation:** Not all medical aids cover the variety of therapies that the child may require and this could become a costly exercise. Mothers should inquire beforehand what is covered by their medical aid and about chronic benefits such as physiotherapy and so forth. This information is especially significant if the child has congenital heart problem. It would be worthwhile for the mother to familiarize herself with the terms and conditions of the government financial grant.

It is recommended that parents take out a policy for their child and that they write their will, bearing in mind that they will not be around forever. With this in mind, it is important to remember that god-parents are there to spoil a child, but guardians have a huge responsibility and commitment long-term. Parents should discuss the appointment of guardians in depth and have an open and honest meeting with the prospective guardians. The ensuing arrangements must be stated very clearly in a last will and testament. More often than not adults with DS are placed in 'institutionalized care' because parents have neglected to secure long-term living and life-style choices and funding to support such. All too often, the guardians are taken by surprise and are unprepared both financially and

physically for the problems that arise after the death of parents of a person with DS. On this topic, parents should remember to emotionally prepare the older child for the day that they may not be there. Such preparation may ease the child's transition should something unforeseen happen. The child must always know who his/her guardians are and what their role in his/her life will be. Forging strong emotional and supportive bonds with the guardians will facilitate such a transition with minimal stress. Should such a situation transpire, the person with DS must be allowed to take familiar personal items for along for comfort.

✓ **Practice positive parenting:** The following guidelines should be helpful in parenting a child with DS:

- Remember that all the traits of effective traditional parenting such as providing a stable home, instilling good core values, modelling caring behaviour and so forth also applies to raising a child with DS.
- Disciplining children with DS in a loving and nurturing way is just as essential, if not more, than with typically developing children.
- Children with DS are without malice, but like other children, may push the boundaries. This should be addressed immediately bearing in mind that the child with DS child will not always be three years old and have the benefit of the "cute" factor.
- No matter how small, notice and celebrate the successes and only if absolutely necessary mention weaknesses (Orphan, 2004: 84).
- Comment on the child's bravery when there is success after previously failed attempts.
- Set up the child to succeed and not to fail; encourage the child to do things he/she is good at (remember that every child has some talent just waiting to be noticed and be aware of activities where he/she might shine) (Orphan, 2004: 84).
- Discipline and rules should be obeyed and the child must understand the concept of action and consequence. Be enthusiastic and excited when the child remembers rules and obeys.
- Be patient and consistent with boundaries, rules and consequences for unacceptable behaviour.
- Be especially consistent with discipline. Children with DS need much more consistency as they do take longer to learn.
- Also remember that in order for the child with DS to be integrated and accepted, the mother has to teach her child to be part of society which also involves the ability to follow acceptable societal norms and rules.

- Spend time with the child talking about the nature of his condition so that, as much as possible, they understand why there may be difficulties.
- Every mother has her own way of affirming her child's desirable behaviour. To this end I have found '**time-out**' on their own, to be an effective behaviour-shaping tool. This simply involves that the child sits alone, with the door closed in preferably a guest bathroom where there is minimal distraction and not anything else to do. I have found time-out to be effective only if I apply the following rules which I have devised. Once the child has had one warning that time-out is imminent the next transgression has to be punished as warned. Before I take my daughter to time-out (never send her on her own), at her eye-level, I explain in an unthreatening tone that she had been warned and still chose to be disobedient and therefore has to have time-out. I have always used the same terminology and my daughter has been familiar with terms such as 'disobedient', 'disobey', 'disappoint', 'consequence' and 'apologize' from age two. I walk her to the bathroom, sit her down and explain in simple terms what she has done to deserve time-out. I then tell her that she is going to sit there and think about what she had done (be specific so that they know what they did; it also provides them with specific words to use in their apology), that I will close the door, and she is not allowed to touch anything, do anything, talk or call until I open the door to let her out (the child needs to know exactly what is expected and what is to be expected of her).

The duration of time-out equals child's age in minutes). If she calls, I ignore her. If she opens the door to come out I take her back, explain the rules again and the time starts over. Once the time is up, I go in (always smiling and no anger), take her hands and ask her why she was in time-out (help her with specific terminology). I ask her to apologize (she must use specific terms. I repeat and, adding the words "disobedient" and "consequence" so that she understands why she was punished. We hug, I walk her out and it is over. Time-out can happen anywhere anytime. Because children often play up in restaurants and shops, I have taken her to time-out in public places such as the changing room in a shop, or in the parking lot on a bench. Interestingly the success of this punishment lays in the 'isolation' (although I remain in very close proximity there is no eye contact and no words exchanged)) and exclusion from activity. Time-out is never used as a humiliating experience; rather it is a behaviour modification strategy. For us, the first few times were challenging, with much calling, howling and fuss. I ignored her calls but let her know that I was there. When she ignored the rules the first few times, I gently took her back, explained them again and stood silently outside the

door with pounding heart and tears in my eyes for three excruciating minutes! I know that it is an effective method as I just need to say the word 'time-out' to ensure compliant behaviour.

- ✓ **Find a gentle, mutually-rewarding parenting style:** Like any other, the child with DS will benefit from being raised in a nurturing, caring and positive environment, where his needs for self-actualization, esteem building, social needs, safety and security needs are met (Pretorius, 2005: 27), thus, a warm parenting style (see Section 3.8).
 - Family mealtimes are valuable bonding and communication times and harmony at this time makes this an excellent teaching and learning environment. This is a good time for everyone to share the day's experiences and it also creates an opportunity for the child with DS to share stories and learn from the experiences of siblings and parents. Bedtime could provide another opportunity for the child who may take longer to verbalize his experiences of the day to enjoy the undivided attention of the mother.
 - It is important that the mother understands the child's behaviour and knows the trigger points. A child with DS is generally disturbed by loud noises and loud sounds and this may cause distress.
 - Due to the child's language barriers, he may be unable to verbally express his anger and resort to physical means of getting his message across. Explain to the child that there is a difference between being angry and hitting. It is essential for the child to know that his emotions are valid and heard, thus it is crucial to teach the child (and show by example) about emotional restraint.
 - Because verbal communication may be a challenge it is suggested that simple questions are used (who, what, where) and that questions are phrased to elicit choice of two responses. If the mother does not understand a response she should encourage the child to explain by saying, "Show me..." or "Can you tell me in a different way?"
 - It is important that the mother prepare the child for any life change for example changes in school or home environment.
 - The child with DS will display a range of behaviours that may be indicators of stress and teaching the child strategies to deal with this would be beneficial to calm himself down. For example, when provoked, teaching a phrase or word ("Keep cool" or "Relax"); self organizing problem solving ideas, for example teach the child a phrase that will serve as prompt to start asset of actions such as "Now let's see where do I begin?", which may be followed by "Okay, that's done, what do I do next?". Teaching the child to have a

- more positive image of himself by changing negative ideas (“I’m stupid”) into positive self-talk, such as “I can do it if I try”.
- Rewards are important but should be kept simple, although this should never replace praise, encouragement and enthusiasm (Orphan, 2004: 76). Rewards should not always be material, but can also be special time with the mother, a simple outing like a nice long walk or a baking/ creativity activity of their choice.
 - The child with DS will thrive on routines and rituals and clear consistent rules.
 - Anger and shouting will terrify the child and lose-lose situations benefit no-one.
 - The list of parenting strategies are endless and parents can find valuable ideas on the internet or in the wide selection of parenting books available commercially. However, it is most important to remember that ultimately you are dealing with a child, so be gentle and do not harm, remembering the words of Goethe who said, “If you treat an individual as he is, he will stay as he is; but if you treat him as if he were what he ought to be and could be, he will become what he ought to be and could be.”

6.2.1.5 SPIRITUAL SUBSYSTEM

➤ Implications

Consistent with the findings, mothers experience their journey on a spiritual level and often depend on God for grace and help, at all stages of their journey. The implication is that mothers who do manage to find some spiritual meaning and peace with their situation, are often more resilient with more hope in dealing with future challenges.

Experiencing a life changing event such as having a child with DS inevitably brings existential questions to the fore such as “Why did this happen?”, “Why me?”, “Why was I chosen for this task?”, “Did I do something wrong, am I being punished by God?”, or for the more spiritually inclined – “What does this say about my purpose as ordained by God?”. These questions can potentially drive a mother to the point of insanity, as there are no concrete answers to be found. An implication of this could be that she breaks connection with her faith, or turns her back on God in anger. On the other side of the spectrum she could also spiritualize everything to the extent of not dealing with the reality of the situation effectively.

➤ Recommendations

- ✓ **Seek pastoral counselling:** Finding meaning and purpose in the situation is essential for a person to move on and accept the reality of their situation. With a child with DS, a mother needs to be guided in finding some personal meaning in mothering this special child. This will facilitate a level of peace and acceptance needed to deal with her reality in a functional way. It brings hope and comfort for the person to realize that what is happening is part of God's greater plan. As one of the mothers in the study aptly remarked, "DS is part of my son's life purpose for now, but there will be no DS in the afterlife".

6.2.2 INTRA-PSYCHIC FUNCTIONING OF THE FATHER

Many parallels were found in the intra-psychic functioning of the mothers and fathers in this study, with the consequent implications also being related. Subsequently the recommendations in the previous section (see Recommendations in Section 6.2.1) pertain to both parents. However, factors pertaining to the intra-psychic functioning emergent in this study as unique to the experience of the fathers will be expounded in terms of implication and recommendation in the following section.

6.2.2.1 EMOTIONAL SUBSYSTEM

➤ Implications

A number of fathers in the study voiced fears around their **own limitations**. These included their limited knowledge of DS; their inability to "*soften the blow for my wife to help reduce her pain, anxiety, frustration, exhaustion*", and a fear of not always being around to protect their child. The implication hereof is feelings of inadequacy, which may impact the father's self-concept and may subsequently also lead to relationship problems in the marriage and, as noted in the findings, unmet emotional needs.

Many fathers are reluctant to firstly, admit that they *need* help, and secondly, to then actively *seek* help, as this further enforces their belief in their inadequacy. It is this constant reinforcement of negative self perceptions that may have long-term implications on how the father sees himself in his parenting role, as well as in his role as provider, protector and emotional supporter of his family, with resulting negative implication for his relationship as both father and husband. Such denial of own feelings may cause the father to remain stuck in the

denial phase to protect himself and to mask his own feelings of inadequacy and helplessness. If nothing is wrong there is nothing to fix, which is, after all, what fathers do.

Although one of the fathers in the study who realized that he had serious **anger** issues went for anger-management therapy, not all fathers are able to recognize the impact and the implication that their anger may have on multiple levels of their functioning. Suppressed anger may have negative implication for the parenting role (of the child with DS as well as siblings), the spousal relationship as well as the father's behaviour in society and in his work place. Bearing in mind the findings surrounding the emotional functioning of the fathers, the following recommendations are offered:

➤ **Recommendations**

- ✓ **Seek counselling:** Denial may buy the father some time to come to terms with the diagnosis (or later challenges faced by an older child) on an emotional and cognitive level. However, counselling which will help him deal with his grief process as well as his anxieties surrounding the future of his child may be a constructive step toward acceptance of his own limitations and those of his child with DS. This will further help the father to reach a level of peace and acceptance, so that she can deal with the challenge effectively.
- ✓ **Do not dwell on what cannot be changed or controlled:** This is of no value and may result in relationship problems. No guarantee of a smooth ride is delivered with the extra chromosome. I would urge a father to adopt an attitude of 'whatever it takes' in his attitude toward himself, his child with DS and his child's future.
- ✓ **Talk to someone:** There is no shame in seeking emotional support from a wife, a friend, a pastor or someone who is in similar situation. Ideally a trained professional will be best suited to help him work through any guilt, shame or anger issues and assist in reframing the situation on a cognitive level.
- ✓ **Deal with the 'elephant in the room':** Counselling will enable the father see that there are no real absolutes around the terms "normal" and "intelligence", and that his special child could be just as "normal" as others in many aspects of his/her life, and have special "intelligences" that others might lack. Some grief counselling sessions will help the parents with the inevitable grieving process for the "normal" child that they have "lost", and will help them to work on a positive plan for dealing with their special future together, further strengthening the marital relationship.

- ✓ **Deal with anger:** Some sessions with a therapist trained to deal with anger management may be helpful in: guiding the father to face his feelings of anger instead of repressing them; expressing his anger in healthy ways; and guiding him towards forgiveness of himself and others in order to find acceptance. Not dealing with anger may result in depression. To some fathers anger is part of the process of coming to terms with a situation and he should not be made to feel guilty about his feelings of anger toward anyone, even if it is unrealistic.

6.2.2.2 COGNITIVE SUBSYSTEM

➤ **Implication**

Findings showed that increased knowledge about DS resulted in the **increased confidence** of fathers to feel confident and competent to raise their child with DS.

➤ **Recommendation**

- ✓ **Build own knowledge about DS and parenting issues:** Fathers often rely on the mother to find and share information on DS and related matters, yet it will be of significant value to them to do some research in this field themselves (see specific parenting recommendations Section 6.2.1), not only to expand their knowledge but to build their confidence which will naturally result from an increased understanding of DS. Fathers who feel empowered and emotionally strong about DS and have a sound knowledge base on the topic feel more confident to take a role in the community to advocate for their children, with a positive spin-off for the child with DS and the maintained resilience of the family unit.

6.2.2.3 PHYSICAL SUBSYSTEM

➤ **Implications**

Due to the stress that fathers experience, as noted in the findings, it is important that they maintain their physical health. Insufficient physical activity could have far reaching implications for the father as well as his family. It may lead to health related problems which in turn may have financial implications for the family, i.e. maybe the father is unfit and overweight (due to stress related over-eating) which could cause a heart attack, stroke, blood pressure related

health problems or diabetes. Should the father lose his ability as provider, the whole family (and especially the child with DS's future) may be in jeopardy. The following are recommended for fathers.

➤ **Recommendations**

- ✓ **Become active:** The benefits of a healthy body are immeasurable. Just as with mothers, the physical activity level of the father will help him to cope better with emotional matters. This could also be a good bonding time for the father and the child with DS (and all of his children) as they can practice a sport together, cycle, jog or simply go for a brisk walk together and everyone will benefit from the physical exercise.

- ✓ **Secure financial position:** This recommendation was discussed under the section for mothers, but it is such a salient point that it has to be emphasized again. Traditionally, as provider of his family, the father needs to make long-term financial provision for especially his child with DS and his wife (as primary carer of the child). It does, however happen that the father may work from home and be in a position to spend more hands-on time with the child, which is. Still, securing sensible policies and sound investments are crucial. It may be advisable to invest in property to provide a passive income in future. The services of a financial planner may be enlisted to help in this regard.

6.2.2.4 BEHAVIOURAL SUBSYSTEM

➤ **Implications**

Just like mothers, the findings showed that some fathers also exhibit a propensity towards **overprotecting** their child with DS, which has implications for both father and child: the father dis-empowers the child to function independently and take independent decisions and the father, on the other hand overburdens himself with having to take all decisions for the child (especially during adolescence and adulthood). This can cause a breakdown in their relationship, feelings of insecurity for the child and frustration for the father. This could further typically lead to a shift in the father's parenting style, self-imposing a more authoritative and autocratic way of raising his child, which may, in the long run have negative implications for the marital relationship. The following recommendations are offered in this regard:

➤ **Recommendations**

- ✓ **Practice flexibility:** Flexibility will provide latitude for both father and child and may create an environment where issues are discussed and informed choices are made. The child with DS already has limited choices, and the father should not limit them further by taking away the child's involvement in making decisions pertaining to those choices. Sometimes situations change and they are not always controllable (see Section 6.2.1).

- ✓ **Avoid overcompensation:** Self-imposed need for societal compliance can lead to social isolation, which is why situations such as the following examples should be avoided by a father. For example, a previously active sportsman suddenly feels compelled to stay home in support of his 'terrified-to-venture-out-with-her-'imperfect'-child' wife. He gives up his sport as an outward show of support, but inwardly resents having to do this (and possible later resentment of the wife and child too). On the other side of the spectrum the father starts spending more and more time away from home, in avoidance of this new domestic situation. The father engulfs himself in work as an escape from his overwhelming new reality, which he has come to perceive as a 'burden'.

6.2.2.5 SPIRITUAL SUBSYSTEM

➤ **Implications**

Findings of this study showed that fathers rely on God to help them with this challenge. Because the spiritual equilibrium in a household is so important, the following may provide food for thought and inspiration for fathers.

The wife and mother in a home is like a thermometer, sensing and reflecting the home's temperature, but the father and husband is like the home's thermostat, which determines and regulates the temperature. The equilibrium of the father's spiritual subsystem will have an implication on his 'thermostat settings' to set the right temperature in the marriage and his family.

➤ **Recommendations**

- ✓ **Be a courageous parent:** It takes courage to stand by your spiritual convictions in times of strife and turmoil.

- ✓ **Acknowledge your child:** Fathers who follow the Christian faith know that the Gospel of Matthew, 3: 16-17 says: “As soon as Jesus was baptized, he went up out of the water. At that moment heaven was opened, and he saw the Spirit of God descending like a dove and lighting on him. And a voice from heaven said, ‘This is my Son, whom I love; with him I am well pleased.’ At closer inspection we see what God the Father did for his son Jesus. First, he claimed Jesus as his own, saying, “This is my son.” Next, God the Father said the words every child needs to hear directly from his own father’s lips: “I love you.” And finally, God the Father affirmed his son Jesus, saying, “I am well pleased” (The Parenting Bible, New International Version, 1994: 984)

- ✓ **Love your child:** When a child accomplishes something a father will often proudly claim, “That’s my boy! /that’s my girl!” Fatherly pride enables him to say it out loud in the presence of strangers or friends, yet often he forgets to say these words to the very person who needs to hear it most and most often. God sets the example and in His departing command, He urges us to remember what He had done, remember the example He had set and to do the same. Telling your child that you love him is not a choice. It is an order from the High Commander Himself.

- ✓ **Be proud of the person your child is, and you will be proud of the person he will become:** God the Father publicly declared his pleasure in Jesus as a person even before he began his public ministry. This was not was not based on his performance. God’s love for his son was unconditional. I urge fathers not to wait for their child with DS (or any of his children) to bring home report cards, merit certificates, team jerseys or even a clean room, but to tell them every day that they are pleased with them just because they are who they are. The example is set, when, in the final act of his blessing, God the Father affirms Jesus, stating, “With him I am well pleased.”

- ✓ **Forgive your father:** Men often struggle to say the words “I love you” to those they cherish most, and this burden, common to men, is passed from generation to generation. It may be time that fathers forgive their own father for giving them this burden. In order to move forward, it may be significant for a father to find the inner strength to tell his child with DS often how much he/she is loved.

- ✓ **Practice what you preach:** A father who follows the biblical principles provides the security to the mother and his children that he is absolutely committed to them. It is suggested that fathers not only teach the child physical, academic and emotional skills, but

to instil spiritual and moral values as well. The child, who sees his /her father living a life that is exemplary, will want to follow that model.

6.3 THEME TWO: INTRA-FAMILY FUNCTIONING

Family systems theory suggests that individuals cannot be understood in isolation from one another, but rather as a part of their family, as the family is an emotional unit. Families are systems of interconnected and interdependent individuals, none of whom can be understood in isolation from the system. The marriage system forms a subsystem of the family unit, and can have a deciding influence on whether the family will weather the storm of having a child with special needs.

6.3.1 MARRIAGE SYSTEM

➤ Implications

There is no conclusive research about how a child with DS affects a couple's relationship, yet like any other stressful event it can either bring people together or drive them apart. The findings of this study support this statement. Encouragingly, couples reported finding connections they did not know were there and their findings showed an increased closeness and strength which developed in many of the relationships. Couples reported that working through things brought a deeper understanding and an increased respect for the other person as they both cope with what is obviously enormous pressure.

However, the findings also showed that some marriages were challenged, especially in the early days. The early stages soon after the diagnosis, when grief emotions run high, are often the most dangerous and the reality is that some relationships break down at this time as there may be differences about therapies, parenting, time management and sometimes just a breakdown of communication between husband and wife due to the immense emotional strain they are both under, which often, they feel unable to share with each other. The implication may be misunderstandings, conflict or complete withdrawal. Relationships which were unstable before the birth of the child are at risk at this stage and may not survive.

Findings were consistent with the reality that if the child with DS becomes the focus of everything, time and demands may swamp the relationship and if all the time, energy and love are channelled towards the child, often too little is left to maintain a relationship. Because the

mother is the primary care-giver and therapies and appointments happen during the day, the father may feel excluded, resulting in him feeling that his emotional needs are not met. The result: communication, relationship and marriage failure.

Although recommendations in this regard (and each aspect thereof) could fill volumes, the decision was taken to address only the most general issues by applying experience and some ideas from Orphan (2004: 120).

➤ **Recommendations**

- ✓ **Put the relationship first:** This is much easier said than done. Yet, the most important contributor to such an effort would be a committed attitude of ‘...no matter what’, which will help the couple to focus on their commitment toward each other and the undertaking to spend time together. Sometimes it may be a quick coffee other times a long, meaningful conversation, but it is suggested that they remain constantly aware that, apart from the needs of the child with DS (and siblings), there is a relationship on the line which also needs nurturing.
- ✓ **Talk to each other about how you feel:** It is often crises that set the wheels of communication in motion, and the way to find a deeper understanding and a connection is simply to communicate one’s feelings, needs, anxieties and concerns. By talking through issues, sound and joint decisions can be taken.
- ✓ **Be kind:** Acknowledge that you are both under stress and agree not to take it out on each other. Avoid hurtful criticism. Do not demean what the other person is feeling or doing. Avoid negativity.
- ✓ **Make time for ‘dating’:** It is suggested that the couple schedule ‘dates’ occasionally, which is a strictly non-parent occasion (no conversation about DS or children, and if the conversation runs out – as it inevitably does – discuss random, crazy ideas, dreams, fantasy holiday destinations and so forth). These occasions should be marked by fun and laughter. (As this is also my reality, my husband and I have set up a roster with twelve dates, one for every month, and we each get to decide on six ‘compulsory’ dates, ranging from theatre to exotic new restaurants with at least two of those dates being a weekend away).

- ✓ **Share hands-on parenting:** It is suggested that parents both be actively involved in the parenting of their child with DS. This has worked wonderfully in our family and everyone is involved and in touch with what everyone else is doing. This has also brought our family much closer.
- ✓ **Rethink communication:** It is said that women are from Venus and men are from Mars, which is mostly evident in their means and skills of communication and expressing themselves. Husbands and wives do not become mind-readers by default just because they share a life, bonds and insurances, which is why it should never be assumed that one party automatically knows what the other is thinking. The margin for misunderstanding and arguments is often too wide due to the pressures and often subliminal stresses created by their specific circumstances, which is why open and honest communication and a healthy dose of understanding are vital.
- ✓ **Verbalize your grief:** Do not be reluctant to share your grief emotions as this may be isolating and harmful to your spousal and familial relationships. Sharing the feelings shares the burden. It is important to realize that time *does* lessen the pain, even if it does not heal all wounds.
- ✓ **Let go of fear:** Younger parents, whose first child is born with DS, are often burdened by inexplicable loads of personal guilt about their child's diagnosis, and may find it extremely painful to communicate their personal fears and anxieties to their partner. The excruciating fear about the uncertain future of their child can be devastating to new parents and unless they discover a common place of understanding and acceptance, their relationship and marriage may suffer critical consequences.
- ✓ **Seek professional help:** A couple that feels overwhelmed with problems, or experience a breakdown in relationships need to seek outside help to restore the balance and harmony. Marriage guidance counsellors, psychologists and life-coaches may be helpful for individual and couples therapy.

There are many applicable models for couples therapy, but all with a shared goal of improved relationship functioning. These therapy sessions would also be a time to work with the couple on cognitive and emotional coping strategies, as well as educating them on how they can support each other through empathic, validating and non-judgmental listening techniques for example the Imago "couple's dialogue" communication strategy (Hendrix, 2001: 142-153). Teaching them to deal with the inevitable anger and frustrations that they

will experience by using a strategy like Hendrix's "container transaction", may provide useful tools for the couple to use in difficult days to come (Hendrix, 2001: 275).

- ✓ **Target your therapy:** Couples seek help from therapists for many reasons, ranging from difficulty communicating and dissatisfaction with their emotional relationship to problems in co-parenting or wanting to prevent divorce or separation. Couples may come to therapy for any issue that they need to face together, be it individual problems or family problems related to sibling or parenting issues. The role of the therapist is to help them cope with these difficulties together, and guide them to an understanding and acceptance, even if no solution can be found.

6.3.2 SIBLING SYSTEM

Siblings of a child with DS fulfil a huge role: they bring normality to a family experiencing abnormal events, they make the family less isolated by forcing the family to do normal activities, they are fantastic teachers, therapists and role models, and they are patient and sensitive playmates for the child with DS.

➤ Implications

Consistent with the findings, positive implications of being actively involved in the life of their sibling with DS, typically developing siblings often have a strong sense of belonging and of contributing positively to someone's life. A further positive spin-off is enhanced self-concept and increased ability to cope.

However, there are also negative implications. It is a common fact that a child, who does not have the whole story, inevitably completes it (often) to his own detriment. Because siblings are sometimes accidentally overlooked by overwhelmed parents after the diagnosis process, they are often confused by the situation. They need to be included and informed on their level of understanding. Negative feelings that the siblings may have may cause damage to the self-concept of siblings. Although findings were mostly positive, siblings did share some negative implications which included embarrassment (because they are always on display in public); shame (feelings that the family becomes 'marked'); guilt (for being 'okay', yet not always feeling okay about the situation); fear (that parents aren't coping/ for family/ for sibling with DS/ for own coping); and, resentment (too little attention/ too much sibling-related responsibilities). Due to the wide range of ages of the participating siblings, the following recommendations pertain to

younger and older siblings and encompass a positive parent-sibling relationship.

➤ **Recommendations**

- ✓ **Keep siblings informed and involved:** A sustained positive family dynamic depends on the involvement of the whole family with each other and with the child with DS. Explain the diagnosis in understandable terminology and allow siblings to ask questions. They may ask the same question many times but that is part of the processing of the new information and situation. Good clear communication between parents and siblings with information about their brother/sister with DS will reduce fears, anger and anxiety, and will assist them in putting the disability into perspective. Parents need to explain how they are planning to deal with the situation and reaffirm the importance and the stability of the family. This will also help siblings to not assume the 'parental child' role, as they will see the parent is in charge, has the answers, and is constructively taking action.
- ✓ **Realistic expectations of siblings:** A younger sibling needs a measure of older sibling assistance although parents should guard against unrealistic expectations of the sibling's time. It is perfectly typical behaviour for siblings to feel hard-done-by whenever required to lend a hand, especially when their agenda is a different agenda. However, this is an acceptable part of learning and developing and also serves to strengthen familial bonds and relationships. It further instils empathy and aids the sibling's understanding of what it may be like to *not* be able to do different things.
- ✓ **Encourage siblings to express their feelings:** It is important to allow them to express negative feelings, to be reassured that these feelings are normal and acceptable, and to help them to deal with such feelings. Internalized feelings complicate sibling relationships. It may be worthwhile for the parents to sometimes verbalize their own feelings, for example, "Her behaviour is sometimes embarrassing for me", as this reflects reality and validates the sibling's feelings. Allow enough latitude for siblings to work out their own conflicts.
- ✓ **Encourage laughter:** Teasing, as in any family, within reason, is acceptable. Children with DS are often comical and laughter and humour will play an important part in balancing the fun and the serious in a family. It is important to laugh *with* the child and not *at* the child. Siblings must be allowed to have spontaneous fun, which is, after all, what being a child is about.
- ✓ **Alone time with siblings:** It is important that parents spend time alone with siblings that do not involve the child with DS or even conversation about DS. It may be practical to

schedule 'dates', just as with husband and wife, to ensure that sufficient individual time is allocated to siblings. This time does not necessarily have to involve an outing. It may be a fun activity at home, but must exclude the child with DS. Carefully scheduling this to correspond with the father's alone-time with the child DS or a play-date at a friend's house may provide a practical solution for all concerned.

- ✓ **Give siblings their space:** Parents should caution against making the sibling the primary entertainment provider of the child with DS as this may lead to resentment. Giving teenagers their space is important. They do not always have to be included in a juvenile activity. Recognize the sibling as an individual.
- ✓ **Clear communication:** Clear communication between parents and siblings positively affect the family dynamic, promoting stability, security, and togetherness during difficult times. Parents are advised to teach siblings effective communication skills to use on the playground, with peers, and in their community. Sound communication between father and mother sets an important example to children and essential for this situation.
- ✓ **Stay positive:** Siblings will always take their cue from the parents. Empathy, love and support are copied by siblings. Siblings often only recognize a little later in life how their lives have been enriched by the experience of having a sibling with DS and this awareness enhances their life experience in terms of understanding diversity.
- ✓ **Advice to others who have siblings with Down syndrome:** One of the questions included in the question guide for siblings, was what advice they would offer to other siblings of persons with DS. The following are their verbatim responses (no spelling or semantic corrections were made):
 - ✓ *...just stay courages and never hide your little sibling from your friends trust me all real friends wont tease you because only spoiled and backstabbing friends will tease you don't worry just be happy. (OS/8/D)*
 - ✓ *...Ek sal ook vir vir ander raad gee om 'n DS boetie of sussie, so onafhanklik as moontlik te groot te maak. Ek sal hom/haar van n sekere ouderdom alleen by die huis los, kafee toe stuur, huis en tuin takies gee, musiek instrument laat speel, sport aktiwiteite laat deelneem. Hy/sy moet voel hul is in staat omverantwoordelik te wees en om 'n bydrae tot die gemeenskap te lewer. Ek sal ook van 'n vroeë ouderdom 'n fisiese aktiewe leefstyl prober inkorporeer, wat hul in staat sal stel om meer funksioneel, gesond, en aktief te wees. Meeste DS individue het vetsug, wat 'n aktiewe leefstyl inhibeer want die persepsie word dan "ek kan dit nie doen nie, of ek is te moeg". (OS/5/C)*

- ✓ *Sometimes it's harder, sometimes it's easier. Don't feel sorry for yourself, it's not a burden, and remember to be patient! (YS/1/D)*
- ✓ *Ek kan net se dat hulle onvoorwaardelik lief moet wees vir hulle boetie of sussie en dankbaar wees vir hom/haar en hulleself oopmaak om te leer by die mensie. (YS/4/D)*
- ✓ *...elkeen hulle eie persoonlikhede...waardeer jou boetie / sussie vir die mens wie hulle is. Wees geduldig, moenie van hulle verwag om die onmoontlike te doen nie, sien raak wanneer hulle hulle potensiaal bereik en moedig hulle altyd aan om die beste te doen / wees as wat hulle kan wees. (YS/2/D)*

6.3.3 PARENT-SIBLING RELATIONSHIP

Consistent with the findings, a strong sense of belonging and family cohesion is pivotal to the well-being of every individual as well as the over-all resilience and optimal functioning of the family. The recommendations in this regard encompass more than just the parent-sibling relationship; as a vantage point, it offers recommendations focused toward building family resilience and building (and maintaining) relationships. It is therefore of value to every family member. The characteristics of each aspect provide a framework which allows each family to adapt and apply their own strategies best suited to their unique family configuration, situation and way of functioning. Headings provide demarcation of different aspects which are: building family resilience; teenage DS and relationships; and, understanding and dealing with the behaviour of the child with DS and his/her siblings.

- **Building family resilience:**

- **Implications**

The findings of this study confirm that families are much more than groups of individuals. As a unit, they have their own goals and aspirations. It is also the place where every child and adult should feel that they are special and where everyone's individuality is permitted to flourish. Families become resilient by developing their strengths, learning to meet daily pressures and by managing life's changes and challenges; the implication of which would be a strong sense of cohesion and belonging.

Findings of families participating in this study confirmed that life with a sibling with DS can at the same time be rewarding and challenging, and although most families indicated that they generally have the capacity to survive stress and grow stronger, support and reinforcement in

this regard just affirms their ability to cope. Within a family the individual members must also develop their own personality, self-esteem, and potential. Developing their personal strengths will assist families to solve problems and adapt to change. However, it is more important for families to move toward these strengths than to try to achieve all strengths simultaneously. As improved harmonious family functioning is the cornerstone of increased growth and development of individuals and the family unit, the following recommendations offer constructive steps toward building family resilience:

➤ **Recommendations**

• **Commitment**

- Commitment is the expectation that the family will be together forever, in good times and when problems arise.
- Committed families feel a sense of trust, belonging, and unity; solving problems together and looking toward the future gives the family purpose and direction.
- Time and energy is spent every day on developing family interests.
- In a committed family the needs of all are recognized; the family does not overtake the individual; all family members are encouraged to grow and develop individual identities; and, they affirm and appreciate positive qualities, and encourage and support each other.

• **Family wellness**

- Family wellness means that all family members have a healthy lifestyle that includes proper nutrition, regular exercise, adequate rest, and relaxation.
- It goes beyond just physical health - it is a holistic way of living that nurtures and develops the body, mind, and spirit which further ensures that the family as a unit is able to deal with problems that may arise.
- The spiritual aspect of family wellness means looking outside the self and tuning in to the feelings, needs, and welfare of others. It means going beyond the self and becoming part of something larger in the world, such as nature or a spiritual presence.
- A family's spiritual strength comes from sharing similar values and finding a guiding force.

• **Communication**

- The implication of effective family communication is that it maintains positive, healthy relationships, helps solve problems, and lowers stress.

- Effective communication means listening to words **and** nonverbal messages. The siblings and the child with DS are frequently reluctant to talk about specific incidents (for example something which may have happened at school), therefore creating an emotionally safe place at home will encourage them to share disappointments, hurts, anxieties or concerns. Rephrasing a question and providing verbal prompts will help especially the child with DS and younger siblings to verbalize their thoughts.

- **Positive speaking**

- Positive speaking means being kind and encouraging to the other person, addressing them in a respectful way in a tone of voice that says 'I care about you and your feelings'.
- It involves sharing your own feelings, thoughts and experiences, showing them that you value their input and their involvement in your activities and life. Honesty is a part of this, but it is never brutal.

- **Dealing with conflict**

- Conflict happens in every household and it is usually an emotionally-charged disagreement or an attempt to force another person to change either their view or behaviour.
- Strong families deal with conflict quickly and directly by using effective communication and problem solving skills which help them reach an amicable agreement without hurt feelings or resentments afterwards.
- To deal with conflict in a constructive way it is important to remember that both parties should benefit; a win-win situation is conducive to strong family cohesion and building mutual trust; it teaches children valuable negotiation skills to apply in peer groups or at school.
- In dealing with conflict, focus on one thing at a time and to seek solutions in small steps.
- During conflict, avoid focusing on the person; rather stick to the issue (problem). Bullying tactics benefit no one and will break down all communication, resulting in a frustrating lose-lose situation.
- Because conflict is emotionally charged it is normal to feel angry, then fatigued, by the intensity of emotions. Try to quickly get beyond arguing to negotiation.
- An activity to get adolescents interested and involved in positive conflict resolution may be to ask them to search for problem-solving strategies on the net. As a family building activity, these may be discussed and evaluated (but not during a conflict situation). In normal family life there will be many opportunities to put theory into practice! This will also

build individual and family resilience. Teach simple conflict resolution skills to the child with DS to apply with peers, at school or in possible public situations.

- Problem-solving skills must be used to negotiate a solution. An attitude of 'because-I-said-so' will not teach the child anything except that his opinion is of no value, negatively impacting his self concept and possible future interaction with peers, the work-place and even in his own family in future.
- An *agreement* is reached when the discussion can be summarized, the outcome acknowledged by everyone concerned, and everyone agrees to share the changes, on whatever level.
- Everyone should be included in a conflict resolution situation, and everyone should get a turn to respond. If not, it is merely another 'sermon' to enforce compliance.

- **Appreciation**

- A caring attitude brings family members together.
- Appreciation can be shown in a number of ways which include: pointing out the good qualities of others, congratulating family members on their accomplishments and speaking about each other in a positive way.
- Caring is also shown through hugs, a kind or encouraging touch or goodwill gestures (such as leaving a note of encouragement or love in a briefcase, on the bathroom mirror or (as I often do), in a lunchbox).
- It is important to acknowledge and accept the appreciation sent by other family members. Although accepting appreciation may make some people feel uncomfortable, it is important in establishing trust and goodwill between people and it also builds self-esteem.

- **Family time together**

- Spending meaningful time together gives the family an identity and a sense of unity. This nurtures positive self-identity in the individuals who make up a family and it reduces feelings of isolation often felt by families with a differently abled child.
- Strong and resilient families eat, play, work, and share outside activities together. They celebrate special days and occasions which enrich family life and build memories for the future.

- **Dealing with stress**

- Aside from normal stresses, families of children with DS have to deal with a much wider scope of stress than other families, often marked by uncertainty and anxiety.
- Support from caring and understanding friends, relatives, neighbours, and others in the community will support families dealing with stress.
- A combination of positive attitude with a view to a positive future and a plan to work together to overcome difficulties are pivotal to dealing with family stress.
- When dealing with stress and crises it is important to remember the following: keep a perspective on things; you are not alone in feeling stress; things will get better; develop and use humour (laughter helps reduce tension and keeps things in positive perspective (see Section 6.2.1.2).
- Set priorities and simplify things, especially in terms extra-mural activities or over involvement outside of the family. Learn to manage time by prioritizing activities and choose carefully how to spend time. It is a valuable commodity and its use should be considered carefully.
- Take one day at a time. Make your boat of life light and make a concerted effort to let go of worries. Make time to relax. Learn relaxation techniques and get physical exercise. Spend time outdoors.
- Develop friendships, help others, and practice your spiritual beliefs. Get outside yourself.
- Stay flexible. Strong families are resilient and can adjust to many changes. Survival depends on being flexible and adjustable.
- Should it become necessary, families should seek outside help. A few sessions of individual and family therapy may be helpful to all concerned. Pulling together and drawing on spiritual resources is the cornerstone of dealing with a crisis, all the while remembering to maintain open and honest lines of communication.
- It is important to remember that parenting a differently abled child is a long, long journey of discovery and rediscovery, of setting and resetting goals.
- Every member of the family will benefit from relieving themselves of their burden of guilt and frustration and allow themselves to glimpse peace with their situation.

- **Teenage Down syndrome and relationships:**

- **Implications**

It became apparent in the findings that the teenage stage also presents its own complexities. It is during this stage that young people with DS become aware of their difference, develop

feelings of inadequacy or become frustrated when they are unable to keep up with their peers. This is often exacerbated by being stigmatized, teased or rejected by peers. Whilst adolescence usually heralds greater independence for typical developing individuals at this stage, this may not be the reality for all teens with DS. As evident in the findings, this makes it harder for parents to fulfil all the social needs and to control or discipline their child. If this period coincides with the midlife transitions of mothers who may also be grappling with identity issues and experiencing difficult emotional, physical and social changes, this could lead to major disruption in family relationships and dynamics.

The following recommendations are also related to the possible types of demands that may be placed on the family.

➤ **Recommendations**

- ✓ **Caretaking demands** - these concern the level of personal self-sufficiency in the child such as feeding, dressing, bathing, toileting, ill health, mobility. The extent to which the family copes with such demands depends largely on their utilitarian resources, practical social support and health/energy resources. In some families these demands will be influenced by belief systems such as the extent to which they encourage self-sufficiency in the child and practical problem solving ability in seeking help and advice. As with any child, encouraging efficacy and independence from a young age will yield positive results in the teenage years.
- ✓ **Supervisory demands** - such as length of time the child can be left alone, whether the child can be trusted in the home, with friends or when out on excursions. These are related to the child's behaviour and ease of management. For parents, programmes which support their confidence in their parenting skills would be of great value. As with any teenager, the basic rules of social interaction, behaviour, safety and trust apply. This process happens gradually and should initially involve shorter, supervised activities with trustworthy, reliable friends. Youth activities at church may be a sensible choice, and as the child with DS becomes more confident and involved, parents and siblings are released to pursue their own entertainment for increased periods. Non-negotiable logistics rules (such as collection times and remaining at the venue) should be in place.
- ✓ **Affective demands** – Parents and siblings who experience possible low feelings of fulfilment may find pastoral counselling or family therapy helpful to restore positive feelings toward the adolescent with DS. This need not be a long-term arrangement and may serve

to affirm positive relationships between siblings and parents, and will be beneficial in learning how to observe their child and understand and interpret the child's behaviour and development. It is important that parents and siblings reflect on their feelings about disability, relationships and role shifting and how these are likely to change and fluctuate as the child and the emerging person is observed. Support should therefore be focused on individual needs, but nested within an understanding of the family. Including the adolescent with DS in honest and frank discussions with teenage siblings will be of great value to establish a base of understanding. Although siblings are often expected to include the child with DS in their social activities, these arrangements should be limited and the teenager with DS should expand his/her own group of friends.

➤ **Implications**

It was apparent in the findings that parents and siblings enjoyed more positive experiences with their child and sibling with DS. Parents who are able to balance the needs of all of their children reported positive outcomes for everyone. The inevitable change in relationship between parents and the typically developing sibling (upon arrival of a child with DS), requires special time and attention, as every child has their own special needs, which, if unfulfilled, may lead to resentment, feelings of rejection, sibling rivalry and/ or behaviour problems (which may in time also manifest in learning problems). The following recommendations may offer a broad guide for parents in this regard.

➤ **Recommendations**

- ✓ **The power of positivity:** A positive approach by the parents will be one of the greatest contributing factors to the successful assimilation of the anticipated scenario.
- ✓ **Realize and acknowledge individual needs of siblings:** Parents should be mindful not to allow the family script to centre on the DS theme. Acknowledge and respect the fact that siblings need special understanding, attention, support and recognition of their unique contributions to the family system.
- ✓ **Equal attention vs. favouritism:** Parents are urged to guard against possible undue prejudice in favour of the child with DS. Provide clear guidance and explanation to assure siblings that there great care will be taken not to deny them their due attention and that there will be actively guarded against favouritism. They should be made to understand that all of them will still be loved equally although much attention may be initially needed to

stabilize the family dynamic. It is imperative that parents make time to attend to the physical and emotional needs of all siblings as the need and intensity requires. This will assure all siblings of their worth and role as well as confirm their importance to the family.

- ✓ **Prepare but do not scare:** Parents should regard sibling preparation as priority. They need more than holding the new baby. Explain, on their level of understanding, the implications of having a differently abled sibling with the greatest of circumspection and diplomacy. Do not overload. Provide them with opportunity to ask questions and draw conclusions whilst constantly monitoring their reactions as the full implication of having a differently abled sibling becomes more apparent to them. It is recommended that the opportunity and platform should be created where their attention will be focused and where they feel most at ease, for example around a table without any interrupters (television, phones or radio). Parents would be wise to remain positive, pro-active and calm during this session. Not only will it help a great deal to inform the siblings adequately, but active awareness of remaining positive and calm will alleviate much of the internal stress of the parents at this time.
- ✓ **Maintain realistic expectations of siblings:** Sibling involvement with the child with DS should be gender and age related and being specific about the role of the sibling will facilitate successful integration and acceptance of the child.
- ✓ **Siblings are not surrogates:** Parents are advised against imposing too much responsibility and should be mindful of possible self-imposed behaviours and responsibilities of siblings and manage these situations as they arise. Some typically developing siblings in this study acknowledged that, on a subliminal level, they felt obligated to compensate for their differently abled sibling to make up for this child's limitations. Especially mothers must be constantly aware not to step into the trap of 'training' and 'preparing' the sibling for future duties regarding responsibility toward the child with DS when the mother is no longer there. Parent should frequently discuss the boundaries of sibling vs. surrogate so that siblings are reminded constantly that they are themselves just children. Siblings should therefore be allowed to do things and think things and experience things as children and not as trainees.
- ✓ **Divide time fairly:** It must be mentioned that siblings often resent the time their parents give to the child with DS and perceive it as rejection. They may even start to wonder what is wrong with them and why their parents love their differently abled sibling more. This is mostly far from the truth. Open and honest communication is the basis of managing such

situations. Parents are advised to carefully plan division of duties to include quality time with siblings, both together and individually. These times do not always have to include the child with DS. Time is often perceived as an expression of love and appreciation and as such will most definitely afford each member of the family the surety of their importance and belonging to the family.

- **Understanding and dealing with possible stubborn behaviour of the child with DS:**

Participants in the study commented on stubborn behaviour of the child with DS. In order to maintain harmonious family relationships, it would benefit parents and siblings to have some insight into possible behaviour triggers in order to maintain balance in family functioning.

Understanding the behaviour of a child with DS is not always easy. A possible explanation of stubborn behaviour may be as follows: A child, deeply involved in something, may want to continue or complete an activity despite being asked to end it. In order to continue, he avoids eye-contact or any acknowledgement of the request, causing his behaviour to be seen as stubborn. A possible unpleasant scene may develop, resulting in punishment for non-compliance. Because the child is now punished or censured as a result of *perceived* stubborn and uncooperative behaviour, this may actually provoke future uncooperative behaviour. This could be the child's response to people who enforce something that he/she does not necessarily want to do, maybe does not understand or does not agree with. This behaviour is then seen as non-compliance or a problem. His previous attempts to manipulate matters in his favour worked, and he resorts to the familiar (such as avoiding eye contact, ignoring, lying down on the floor, making a fuss and so forth). If parents and siblings condone such behaviour, it perpetuates, often getting out of hand if not controlled and managed effectively.

Such a cycle of resistance may develop 'under the radar' if parents and siblings do not have an understanding of the possible connection between communication challenges faced by the child with DS and his/her behaviour. It is often the lack of mastery of sufficient language skills to negotiate an outcome which leaves the child with DS feeling that the other party does not care about his/her view. His inability to effectively verbalize his take on the situation may then manifest in a physical way, often being perceived as obstructive stubbornness.

➤ Implications

As stubborn the stubborn behaviour was noted in the findings to cause relationship problems between parents, it may be valuable to heed the following recommendations regarding such behaviour. It may also negatively impact the relationship between parent and siblings, who often lament the amount of latitude afforded the child with DS, with all soon forgiven once they act all innocent. It is interesting how many parents of children with DS refer to their child's stubborn behaviour as if it is caused by cognitive delay. I see most stubborn behaviour as a direct result of lacking the skills and/or language to negotiate a position. A child with a cognitive delay, such as DS, will continue to do things in a specific way because it is safe, it is known and it has worked in the past. When new things are introduced, their comfort zone is threatened. It is often the lack of language skills and cognitive flexibility needed in verbal discourse which is the underlying cause of perceived stubborn behaviour.

➤ Recommendations

- ✓ **Manage and control behaviour:** Deviant behaviour (such as manipulation of situations to get their way) is often more prevalent in younger children and should be managed. Parents should inculcate acceptable behaviour patterns as young as possible to avoid behaviour problems manifesting later.
- ✓ **Playing parents off:** A mother reported how her child's stubborn behaviour as reaction to punishment from the father, is affecting her relationship with her husband. Such an example would be the child ignoring instructions from the father and continuing what she is doing. However, when the mother makes the request in a playful manner, offers to help the child to pack up, and praises the child for her obedience and helpfulness, the child is happy to comply. The father feels the child has defied his authority and the mother feels the father's request came across too harshly. Bearing this scenario in mind, it would be beneficial if the parents had candid and frank discussions (afterwards) about possible triggers that could result in non-compliant behaviour. These may include, for example, a specific tone of voice or a specific action which would normally trigger the child to ignore or avoid eye-contact with him, thus ignoring his request or command. Parents should commit themselves to modifying these triggers and also to make the other aware when they detect the onset of a potentially trigger situation.
- ✓ **Understand the root of stubborn behaviour:** Parents will benefit from understanding why a child with DS may act in a certain way. Is it for attention, power, showing

helplessness or wanting revenge? Re-assessment of the situation is necessary in order to gain the child's cooperation. However, a vigilant parent will quickly pick up on manipulative behaviour and should deal with it purposefully and immediately.

- ✓ **Keep instructions clear:** It is advisable to keep instructions simple and clear and to not overwhelm the child.

- ✓ **Positives rather than coercion:** Parents can be enthusiastic about the 'packing-up' activity, turning this into an activity of its own. Sometimes what appears to be a transgression is just a way to get some extra time and attention from the parents, even if it is something simple like packing away pencils and putting away toys. It is strongly that parents remain consistent about what behaviour is allowed and what behaviour is not negotiable. Inconsistency may lead to problems with boundaries later.

- ✓ **Step back:** Laugh. Walk. Count to ten. Relax. Release the tension and try again in a different way. Use positive reinforcement in order to make the child feel successful and capable. This will also encourage the child toward independence and simple problem solving (i.e. the simplest way to gather all the cars strewn all over the floor, how to fit all the blocks back onto the box, and so forth) and reinforce his self-esteem. The child with DS needs to be taught to be as independent as possible in order to function optimally within society. Making the child with DS over-dependent on others will damage his self-confidence and keep him dependent on others for the rest of his/her life.

6.4 THEME THREE: EXTERNAL SYSTEMS

6.4.1 EXTENDED FAMILY

The emotional and physical support provided by the extended family is invaluable for the family as it may provide an emotionally safe place of understanding and nurturing. However, for most people, this will be a first experience with DS or any disability and although they may *want* to say and do the right thing, they may not necessarily know how or what, even those closest to the mother and father.

➤ Implications

Findings indicated positive and negative feedback from extended family. The implication being hurt feelings, further anxiety for the parents and feelings of rejection which may lead to family

feuds and broken relationships. Insensitivity and ignorance is a poor combination, hence the following recommendations.

➤ **Recommendations**

- ✓ **Do it right from the beginning:** If the mother knows the diagnosis of DS beforehand, drawing up a simple information note with added do's and don'ts for family and friends may be helpful all around. If she only finds out after the birth, such a letter may still be helpful and it can be forwarded to friends and family prior to the 'meet-and-greet' tea (or distributed at the function). If the mother feels emotionally vulnerable she may ask someone who has been through a similar situation for help in this regard or even to speak on her behalf at the gathering. This will also provide an opportunity for questions and fears to be allayed.
- ✓ **Everyone will always take their cue from the mother:** If she is tearful and emotional (which may be expected), that will set the tone, but if she is emotional (which is right and expected) yet positive and proud of her new baby, that will create a completely different atmosphere.
- ✓ "He doesn't look like he has DS". DS is not just a look, it is a chromosomal abnormality. The baby looks like a baby, but the extra chromosome is still there.
- ✓ "Maybe the doctor is wrong" demonstrates a lack of knowledge about DS and genetics.
Some "don'ts": Some of the following well-meaning statements can unintentionally annoy and hurt parents and are best avoided.
 - Don't say "I'm sorry" or relate any other form of pity. New parents do not need or want it; they need love and acceptance of their new baby.
 - Avoid statements like "God gives special parents special children" or "There's a special place in heaven for people like you", or any variation, as the parents do not feel very special and may even be a little angry at God. Also, why do people assume this to be an absolute?
 - "They're such loving children" is a stereotype, which only demonstrates that the person saying it really knows nothing about DS.
 - "How serious is it?", again proves lack of knowledge and may provoke an angry response like "Every single cell in his body has an extra chromosome...is that serious enough?"
 - "You are handling this better than I could". Firstly the person does not really know how the parent is handling it and such a statement puts the focus on the speaker instead of on the new parent and baby.

- “Maybe he just has a little DS” which falls in the same category as being a little pregnant.
- “Didn’t they think this could happen at your age?”, “Why didn’t the doctor check?”, “Didn’t you have the test?” Such mindless questions are not worthy of discussing; the responses to which would anyway be limited to intimate friendships. The baby was born with DS by no doing of anyone which does not make him inferior or a mistake. He simply has an extra chromosome.
- ✓ **Congratulate the family:** In a loving way, show your support and acceptance of the lovely newcomer by congratulating the parents on their new arrival in the same terms as you would anyone else. After all, they’ve just had a baby! Flowers, champagne, gifts and cards are a good idea.
- ✓ **Remark on the baby’s likeness to his family:** All babies look like someone in their family and as this baby has the genes of his family, naturally he resemble someone in the family.
- ✓ **Show thoughtfulness:** Show love and concern for the baby and family by doing something valuable and personal, like reading about DS on the internet or copying an interesting article or buying a book with article on DS.
- ✓ **Offer to baby-sit:** By doing this in a natural way the person dispels the fear of parents that the baby will not be accepted. This gesture will be a relief to them as it shows a willingness to be part of the baby’s life.
- ✓ **Say something supportive and positive:** Statements like “He/she will do fine” or “We will all learn from him/her”, shows a positive attitude. Being a close friend and extended family member comes with the responsibility of support and acceptance and often the first line of defence in terms of providing information and guidance if the parents are fragile and overwhelmed.
- ✓ **Help without offering:** Providing meals, ferrying siblings, stopping by to make the new mom some tea or just talk, dropping off a magazine, offering to accompany her to the first check-up, and offers to bath baby or take feed turns will not only help the mother but also forge strong relationships of trust.
- ✓ **Remember dads and siblings:** Be mindful to include fathers and siblings in activities. Arrange play-dates. Arrange a get-together of the father’s friends. Remember that the whole family is involved.

- ✓ **Best advice given to me:** In the early days a friend gave me advice related to her experience with her mother who was blind. Being out in public with a person with a disability constantly places you in a fishbowl, as people look and make assumptions. Her advice was to always 'look the part'. My daughter naturally attracts attention, so ensuring that she, and everyone with her, is always clean, well-groomed and immaculate. (Still today carrying an extra outfit and toiletries along has become second nature). For future reference, I have also taken a leaf out of the book of someone I much admire, who ensures that her lovely adult daughter is always immaculately groomed from head to toe and stylishly dressed. Mother and daughter (with DS) make an outing of going for treatments, having nails done, visiting the hairdresser, and so forth.

6.4.2 SCHOOL AND EDUCATION SYSTEMS

Inclusion is not an education system. It is an attitude, a value and belief system which often gets lost between prejudice and potential.

➤ Implications

Findings indicated that most parents have a negative perception and experience with the school and education system when it comes to their child with DS.

An inclusive education setting for a child with DS may have positive and negative implications, although experience and research concur that the positives by far outweigh the negatives. Positive implications include raising a positive awareness regarding the abilities of persons with DS (in the school and in the wider community), the child's increased social skills, increased vocabulary and communication skills, exposure to a broader academic curriculum and educational experience than offered by special schools, providing a model for appropriate and acceptable social behaviour, and smoother transition into society and the work force. Thus, it enhances the child's development, full potential, self-esteem, independence, and future opportunities. However, if inclusion is not handled effectively negative implications may ensue, such as not meeting the child's emotional (poor self-concept and feelings of inadequacy), social (for example no spontaneous reciprocal friendships or exclusion from sport and competitive activities) and academic (barriers due by cognitive and communication challenges or educational needs).

There are numerous ways to support the inclusion of children with DS, and although there are countless suggestions in this regard, the following should suffice.

➤ **Recommendations**

- ✓ **Active parental involvement:** It is suggested that parents take an active role in creating positive awareness at their child's school as well as all schools in the area as a general awareness campaign (preferably before their child attends the school). To this end sound knowledge of inclusive education, the education system, perseverance, strong motivation and a positive attitude are prime requisites. It is suggested that parents empower themselves with knowledge regarding the educational needs of their child with DS by attending National and International conferences and seminars and joining interest groups. It is advised that parents remain involved in the academic progress and continuously challenge, probe, question and confront. Providing a teaching assistant would be valuable.

- ✓ **Involvement of the Department of Education should ideally include the following:**
 - Provision of proactive actions to bridge any discrepancy between the ideology of the South African inclusive education policy in theory and the reality of its implementation.
 - Provision of support to schools, principals and educators in order to facilitate the inclusive education process of learners with DS by conducting audits at school to assess areas of difficulty and making subsequent revisions to the inclusive education policy which will align with the reality of the situations in schools. This should include budget adaptation, training of educators, provision of information, raising awareness, guidance, offering seminars and workshops to principals and educators and allocating further learner support to educators across all districts.
 - Adequate and targeted training of teaching assistants.
 - Creating permanent positions for multidisciplinary teams within schools to include inclusive education coordinators, speech-language pathologists, physiotherapists, occupational therapists, educational psychologists, remedial therapists and social workers.
 - Assessment of the child by a multidisciplinary team of professionals **ONLY** for the purpose of curriculum adaptation and provision of an individual learning programme and not for decision on placement. Accepting the child is mandatory. This assessment needs to be done from time to time to determine changes and improvements to the child's IEP. Therapies necessary for the progress of this child should be provided in school as part of the child's regular school day.
 - Provision of an inclusive education co-coordinator to lead the team of professionals and liaise between all the role players on a continued basis in order to facilitate a smooth transition between grades. This co-coordinator should also be involved in continued

- awareness activities for staff and learners. A further function would be to continuously assess the efficacy of the inclusive education efforts by correlating theory and practice, and to provide practical feedback to the Department of Education in order to revise and improve the process and the policy.
- The Department of Education should get involved on a practical level by sending out teams to observe and to subsequently provide practical support to schools regarding the implementation and practice of inclusive education.
 - Provision to educators of updated information and material regarding curriculum adaptations which should include comprehensive, practical information on inclusive education, its philosophy and rationale, and the learning styles/profiles of children with DS. Practical strategies on how to assist the child to overcome barriers and challenges and guidance on how to adapt and perform the necessary curriculum and teaching adaptations is vital. This should be supplemented with practical interactive workshops, to which end the Department of Education may enlist the help of DSSA and their base of experts.
 - Running awareness campaigns, organizing road shows and involving the media in ongoing awareness specifically targeted at DS. Many such campaigns have drastically improved the general awareness of DS worldwide.
- ✓ **Tertiary Institutions:** Relevant, updated, practical course material on a variety of disabilities, but specific to those most commonly found in inclusive education settings should be mandatory in all the areas of the Humanity studies. Aspirant educators should receive training specifically aimed at inclusive education practices, which should include a variety of practical strategies and tools. These should not only be targeted at the academic performance, but also at areas such as informing the other learners in the class, strategies to enhance empathy, helpfulness and inclusion of all people in a variety of settings. The underlying message should be “Being different makes no difference”. There is a great need for targeted teacher assistants and tertiary institutions could offer these short courses using the same material. These courses could even be presented by post graduate students.
- ✓ **DSSA:** At the heart of this family support movement is the concept of family empowerment. DSSA should continue to play an active part in advocacy and liaising with the Department of Education regarding inclusive education. Their continued efforts to provide parent and educator support should be better advertised in schools and an annual DS inclusive education workshop should be mandatory at schools as far as logistically and practically possible, especially for schools that already include learners with DS.

- ✓ **The School:** Adopting an ethos and philosophy of inclusion, acceptance and positive attitudes should be the cornerstone of every school, as no two learners in any school are the same. Each one is inherently different – in looks, circumstances, learning style and way of coping, thus schools are already exposed to huge diversity and in a sense already practice inclusion by accommodating learners from different races, cultures, religious convictions, family configurations, behavioural patterns and learning styles. The principal as leader and visionary of the school should take a proactive role to facilitate this culture and positive attitude amongst his staff members, learners and their parents. His insight, knowledge and awareness should lead the way for inclusivity in his school and as such, he should take the lead in organizing workshops and awareness programmes which include best practices and strategies to attain those. Diversity should be embraced in schools, but it can only happen on the watch of someone who is truly supportive thereof.

- ✓ **Teachers:** It is suggested that teachers continuously empower themselves with current information and teaching skills to include the learner with DS, whether the child with DS is in their class or not. A willing and positive attitude toward the learner with DS is crucial. Attendance of workshops and seminars are valuable and networking with teachers from other schools who include children with DS will be an excellent source of information and practical advice. It is suggested that teachers maintain open, honest and clear communication with the parents. Teachers should ascertain beforehand what the parents' expectations of the child and of the inclusive experience are. It will be beneficial to teacher and learner if flexibility and creativity are demonstrated in adapting the curriculum to be more accessible to the learner with DS.

The teacher can be sensitive to the emotional needs of the child and help him/her to settle in with ease by including him/her in small general errands, such as sending the child with a message to a colleague. It would be beneficial to make use of a rotating 'buddy system' to ensure that the child with DS has someone to show him around and guide between classes and lessons, thus also opening a door for the typically developing peer to communicate and become involved with the child with DS. It is strongly recommended that the teacher be a positive role model for the typically developing learners in the class in terms of attitude toward acceptance and inclusion of the learner with DS into the classroom.

- ✓ **Early Intervention:** This is the most significant base for the development and later educational experience is of the child with DS and should be started as early as possible. My daughter was seven days old when we started with basic neuro developmental

physiotherapy exercises. Neuro developmental physiotherapy is vital in terms of development and reaching milestones. In most first world countries a multidisciplinary team meets the parents at hospital (or at home) shortly after the child's diagnosis and they follow an integrated programme of intervention to ensure optimal development and stimulation. The coordination of such teams in South Africa would be extremely helpful to especially new parents who are overwhelmed and unaware of the possible therapies and their eventual value in terms of the child's development. Early intervention would include neuro developmental physiotherapy, occupational therapy, speech and articulation therapy and could include a variety of alternative therapies and developmental support therapies such as aqua therapy, equine therapy, mother-and-child early stimulation groups, music therapy and so forth. Any form of early developmental stimulation whatsoever would be beneficial to the child with DS.

- ✓ **My plan of action regarding my daughter's inclusive education experience:** I have always maintained very close relationships with the principal and staff members of the school my daughter attends. Going out of your way as involved parent to assist in any way makes you a visible and valuable parent. This often ensures that, in a reciprocal relationship, there are always extra hands and eyes on your child with DS. (The term 'bending over backwards' springs to mind). To create an awareness and explain what DS is, I have always found it constructive and valuable to take a turn at presenting an assembly at schools (at my own child's school and schools in the area, bearing in mind that sport and other activities often involve surrounding schools). During these assemblies I focus on positives and similarities and integrate the topic of DS into an interesting presentation which ends off with a slide-show of my daughter.

A few minutes during the first parents' meeting for the year also provide a good opportunity to inform parents about DS and to respond to questions they may have. An informal presentation to the group (or grade) of my daughter provides opportunity to speak to the little ones on their level and to explain DS in simplified terms to them, and also to answer their questions. In preparation of the teacher of my child, I have drawn up a comprehensive document (entitled "Dear Teacher of a very precious little girl" (See Addendum E) which provides her with general guidelines, tips and strategies to better understand my child in order to successfully include her in class.

The principal of the current school that all three my daughters attend invited me to visit the classes of the prospective teachers for my daughter beforehand in order to confirm his

decision of the most suitable teacher for my child. I was also invited to address the entire staff and the board members during a special staff meeting. Afterwards I handed out copies of the comprehensive document which I used as a guide, which included additional material for their further reference (see Addendum F). The principal also invited me to address the parent-teachers' evening and the learners of the school (different phases) during assembly. These pro-active acts of kindness were strong indicators of the positive attitude and commitment of the principal and his staff's support toward inclusion of my daughter. Once the year is underway, a teacher assistant and tutor are employed, although the teacher remains the primary educator and the assistant focuses solely on my child's needs. Showing appreciation for the immense task of the teacher is very important and occasionally showing appreciation in a visible way to the person who takes care of your most valuable asset is essential.

- ✓ **Remember the siblings:** It is important for educators to be sensitive to the feelings and needs of the typically developing siblings. In a perfect world, a caring teacher will gain information about DS, sharing this in a sensitive way during an appropriate lesson. Alternatively, the parents can draw up an information sheet to send to the class. In the interest of the sibling's academic and social well-being, the school could include DS as topic for an awareness campaign in an appropriate learning area, thus providing factual information and possibly a human-interest guest speaker to enlighten both pupils and teachers about the syndrome, the *ability* and *capability* of individuals with DS.

Educators can do much to promote positive sibling interactions as well as acceptance of different abilities in all children. During especially the early years, teachers can help to promote sibling awareness and interaction by providing opportunities for siblings to learn about the differently abled and their abilities vs. their disabilities. For example, conducting a "sibling day" (held on a school day or over a weekend) or a sibling workshop can be an excellent way of introducing siblings (and their peers) to a variety of disabilities.

Information puts fears into perspective. In most instances, simply knowing the facts about DS takes away the sting of embarrassment, as well as uncertainty and fear. While embarrassment can and does occur in many situations over the years, knowledge can help siblings cope and it promotes understanding and tolerance amongst peers. To this end the sibling's educational experience is not compromised, resulting in healthy, supportive relationship between siblings and also sibling and parent.

- ✓ **Recommendation ‘from the horse’s mouth’:** A former South African Minister of Education, Professor Kader Asmal, offered the best recommendation for all the role players in inclusive education within the South African context when he said, “Let us work together to nurture our people with disabilities so that they also experience the full excitement and joy of learning, and to provide them, and our nation, with a solid foundation for lifelong learning and development. I acknowledge that building an inclusive education and training system will not be easy. What will be required of us all are persistence, commitment, co-ordination, support, monitoring, evaluation, follow-up and leadership.” (Department of Education, 2001: 6)

6.4.3 MEDICAL FRATERNITY

➤ Implications

The findings of this study indicated very poor medical support and a prevailing sense of general apathy amongst health care providers.

The time has come for health care providers to acknowledge that DS does *not* stand for ‘death sentence’. Findings confirm that far too often the health care fraternity offer sympathy rather than support, terrifying especially first time (or young) parents with their negativity and/or insensitivity.

To fully comprehend the implication of the unaccommodating behaviour and attitude of the medical fraternity, it is necessary to have some understanding of the ‘paradox of disability’ as described by Larson (Myers, Mackintosh & Goin-Kochel, 2009: 682). The paradox of disability is a compromise between acceptance and denial. Understanding and embracing this is pivotal for the psychological well-being of parents of children with DS, as it allows them for hope, renewed energy, a positive view to the future, optimism and personal growth. Doctors and nurses, as the first ‘experts’ the parents encounter, are therefore perfectly positioned to play a key role in helping parents embrace the paradox of their child’s different ability. They are able to provide parents with a safe, supportive environment to verbalize their conflicting emotions, share their fears and have their questions answered. However, it is recurrently *this* fraternity, with the potential to make or break the experience for parents, who *in reality* mostly *cause* or *contribute* to the turmoil.

The findings confirm the 'multitude of sins' committed by this fraternity, often bordering on nothing short of immoral. Parents reported the uncaring and callous way in which many of them were told the devastating news – often alone without the other being present for support); the use of tactless, overtly negative medical jargon (leaving the parents shattered and confused about their child's condition; by evasion (often avoiding the parents after the initial indifferent breaking of the news); or, as too often reported by parents, patronizing the already terrified parents with insensitive and soul destroying remarks regarding burdening society with their less-than-perfect child. Findings in this study remained largely devoid of considerate or thoughtful gestures from the medical fraternity. The following recommendations would be directed at health care workers.

➤ **Recommendations**

- ✓ **Congratulate the parents:** It is suggested that especially doctors avoid lapsing into medical jargon to mask their own discomfort with the situation. Congratulate the parents and calm the waters before jumping in. Create an atmosphere of nurturing, caring and partnering, as the parents will rely on their doctor and his guidance for a long time.
- ✓ **Avoid sympathy:** If the doctors or nursing medical personnel offer sympathy, the parents go into emotional, physical, behavioural and spiritual 'mourning' immediately. When offered sympathy, the parents think they have heard a death sentence. It is therefore recommended that health workers and especially the doctor steer clear of using impersonal pessimistic terminology in a morbid tone of voice.
- ✓ **Meet the parents prepared:** Parents will want answers, which is why the paediatrician, gynaecologist and senior maternity and paediatric nursing staff need to be knowledgeable on DS. As it is beneficial for parents to speak to someone who has been in a similar situation soon after they have been told, it is suggested that a 'menu' of suitable support persons and organizations are kept at hand. The senior nurse should inform the parents in a gentle way that she can arrange for someone who understands and has been in this situation to come and speak to them. This should be pre-arranged with the parents first. In my case I was not informed beforehand and had no idea who these random visitors were. The attitude of one of these people was reserved and positive, but the other person's experience was rather negative. Fortunately at this time my own mindset was already one of optimism and confidence that I would do my best for my daughter. I knew without a doubt that I would be the best mother for this most welcome precious addition to our family.

To me she was just a baby. The extra chromosome and the implications thereof were completely secondary to this.

I have on a number of occasions been the first knowledgeable person of similar experience to meet the parents (and sometimes the whole family) after the birth of their baby. Being the first voice of reason in an emotional tsunami, it is rewarding and enlightening to witness how the burden literally lifts as new parents become empowered by positive input and they are able to see their baby as a treasured human being first, and not as a diagnosis or genetic statistic.

- ✓ **Caring treatment by hospital staff:** It is recommended that all staff in the maternity section of every hospital receive some training to equip them to deal with the mother in a sensitive, caring, respectful and knowledgeable way. However, in reality this does not happen. One mother shared her experience of being in hospital for an entire week when her son with DS was born. Not one person said the word DS. Even the outcome of the test was given over the phone a week after they left the hospital. Most mothers reported horror stories of nursing staff manipulating patients with guilt about their “irresponsible” behaviour in stead of being respectful of the mother’s choices in deciding to not abort a baby with potential DS.
- ✓ **Avoid clichés and blame:** The shocking and patronizing statements which are often made clearly reflect a poor combination of lack of compassion and ignorance. These range from (actual statements reported by some of my support group parents) “Shame on you”, “Look what you’ve done”, “This one is a mistake, you should try to have another one”, to “Your baby is retarded but I hear they’re not too much trouble”, “They are always very happy kids”, “Of all the disabilities this is the best one” and so forth. Even if only one child is born in their facility or during their watch, it is reason enough for health workers (nursing staff and doctors) to pre-formulate an accurate, positive response from actual current data available which they can adapt and apply to different situations rather than inflict damage of this extent.
- ✓ **Continued education of peers and co-workers:** It is essential that paediatricians, gynaecologists and maternity and paediatric staff familiarize themselves with DS and keep up to date with current information, focusing on the positives (most of the books and internet sites offer the negatives anyway) in order to supply the parents with answers and advice which they inevitably seek immediately after diagnosis.

- ✓ **Provide positive input:** When speaking to the parents always bear in mind that the child is *differently* abled, i.e. focus on what the child will be *able* to do vs. what he/she will be *unable* to do. An affirmative attitude from health workers may be pivotal in the positive paradigm shift of parents.
- ✓ **Include the father:** It is important that the father is treated with equal importance at meetings. Although the mother often leads the questions and therefore becomes the focus for responses, the role of the father must not be underestimated, remembering, too, that his shock and feelings of anxiety may be even more heightened at this stage.
- ✓ **Make a courtesy call:** Very few doctors ever phone the parents afterwards, yet it is extremely valuable to the mother to know that she is not alone and that her doctor cares about her well-being and that of the baby.
- ✓ **Allow sufficient bonding time:** Nursing staff should guard against wanting to do everything for the baby in order to let the mother rest. Rather suggest that the baby stay with the mother as close physical contact will encourage bonding. Remark about how beautiful and healthy the baby is. Be helpful and positive about breastfeeding (often babies with DS have a problem with breastfeeding due to low muscle-tone, or they are very lethargic, which could indicate a heart problem).
- ✓ **Advise mothers on early intervention:** Medical personnel should offer some guidance on early intervention strategies and supports, and sharing some early intervention hints regarding newborns with DS may empower the mother to feel a bit more in control of the situation once she gets home. Even in private hospitals such advice is sorely lacking. Liaise with parent support organizations and arrange that a knowledgeable person speaks to the staff and leave printed material for parents and family. A database with information and contact details of relevant therapists in the area will be helpful to parents as they often do not know where to start in their search for suitable therapists. DSSA has a family pack which offers information and advice.

6.4.4 GENERAL PUBLIC

Awareness on every level of society is instrumental in the encouragement of tolerance and acceptance of diversity.

➤ Implications

Based on the findings of this study, it has become abundantly apparent that the general public are blissfully unaware of the full ramifications of raising a child or being the sibling of a child with DS. By creating a constant awareness that we live in a diverse country and a diverse world, society may begin to understand the coping strengths required by families and acknowledge the positive contributions of persons with DS. Therefore, creating and maintaining positive awareness would produce positive implications for societal change regarding common misconceptions about disability in general. Awareness of the rights of persons with DS in society will also greatly contribute to mothers not having to hide their children from their communities, but will instead grant them the freedom to expect full support and acceptance.

➤ Recommendations

- ✓ **Attitude change required:** The general societal attitude of apathy toward the differently abled needs to be addressed, as it is often not the syndrome itself but the way it is interpreted that impacts on the individuals with DS and their families. Parents don't need sanctification; they are just ordinary people with extraordinary circumstances. What they need is acceptance of their fallibility as parents, the evident diversity of their family and the acceptance of their child as a human being capable of making a positive contribution to society if given the chance. In South Africa, a country rife with adversity (as indeed also all over the world), there should be no place for social judgment and stigma, yet it is alive and well and living in our backyard.
- ✓ **Give them a chance:** For young adults with DS the end of school does not mean the end of the road or the end of learning. Further education colleges should be accessed or organizations that work specifically with people with DS such as DSSA, 'Employability' or 'Living Link' ('Living Link' provides further training whereas DSSA and 'Employability' do not). Some of the DSSA branches such as Gauteng provide assistance to access employment using the supported employment model. Accessing employment in the open labour market leads to improved quality of life, increased self-concept, self-esteem and increased social interaction with persons who are not differently abled. It also offers financial relief to the individual and the family and reduces the stress of the family in terms of the family having to take care of them. The benefits therefore far outweigh the costs involved.

- ✓ **Self-advocacy:** Young adults can join self advocacy groups that add pressure to Government to ensure service delivery as well as the alignment of local policies with the United Nations Convention on the Rights of Persons with Disabilities.
- ✓ **Awareness begins at home:** Creating a positive awareness of DS within the extended family circle and community brings about a better understanding of the syndrome, the individual with DS, thus encouraging tolerance toward general diversity. Usually such relationships require that parents make an active effort to get together with others socially or for community projects. The positive spin-off is that the more the individual with DS is exposed to society, the wider the acknowledgement of differently abled individuals within the community and broader society will become. It is often in this context that society experiences first-hand indeed how *able* a differently abled individual can be.

By the time my daughter was seven months old, and I had caught my breath, I was approached to write an article about DS for our community bulletin. After much thought, I decided to write it in the first person from her perspective, offering palatable portions of DS, some Hayley-talk and some inspiration. This was so well received that it became a regular feature for three years. She was absolutely accepted as just another little girl in the community. The ripple effect of these articles were returned from far and wide as people contacted me inquiring about Hayley and wishing me success on my obvious quest to find out more about DS.

- ✓ **Awareness campaigns:** The goal of awareness campaigns should always be to get more people to see beyond the disabilities of persons living with DS and to celebrate their accomplishments. By educating people about the syndrome it may help everyone to accept others for who they are and not to avoid them because they are different. In any awareness campaign the focus should always be on success. One such global initiative by the National Down syndrome Society commenced in 2008 and will be running through the end of 2011 and maybe longer. This campaign, with the central theme of, "My Great Story", publishes posters and stories worldwide on a variety of forums by using various media to celebrate the accomplishments of persons with DS. Such awareness material (posters) could be published in newspapers, magazines (national publications and in-house commercial publications), the internet, advertising boards, large billboards and on television depicting the individual with DS portraying his accomplishment, for example someone who has won several medals at ballroom dancing, someone who has a particular artistic talent, someone driving a motorcar and many more.

The Japanese Down syndrome Network currently runs an awareness campaign depicting simplistic graphics of persons with DS doing normal activities and it is in the simplicity of presentation that the power of the message is captured. For a national campaign on local ground such a campaign could include the following: A young man with DS on a game drive (caption: *I enjoy the outdoors. I have Down syndrome*); a young girl with DS doing shopping (caption: *I am a fashion junkie. I have Down syndrome*); a child at a school desk (caption: *I am learning new things every day. I have Down syndrome*); a young man seated at his computer (caption: *I have 82 friends on facebook. I have Down syndrome*), and so forth. Another example for such a campaign could be a photograph of a diverse group of people (ages, uniforms, someone in a wheelchair) and featured prominently, a person with DS. The caption could read: *Anyone can change the world.*

Three of the most powerful awareness campaign posters I have seen have been Canadian initiatives on an inclusive education and a UK initiative on employment. The first featured a photo of young girl with DS in a classroom, her hand held up high along with all the other children, her face beaming with anticipation. The caption reads: *"My name is Jessica. I'm in grade 5. People say I'm disruptive in class. People say that I hold the other kids back. People say that I take up all the teacher's time. None of these people are in my classroom."* The second was a close-up of the face of an attractive young man with DS. The caption reads: *"You have been looking at me for longer than any employee ever will."* The last featured a most poignant black and white photo of two boys playing, one has DS. The caption reads: *"My friend does karate. My friend can swim fast. My friend likes reading books. My friend helps me climb to the top of the jungle gym. My friend has Down syndrome."*

There are many other ways of creating awareness such as organizing buddy walks, involving local schools; presenting talks at schools, libraries and women's tea's; poster and photographic presentations permanently exhibited at libraries, doctors' rooms and shopping centres. DSSA and its national branches celebrate national DS day on 21 March every year. This date is significant as '21' signifies chromosome 21 and March is the third month of the year, i.e. trisomy 21 (three chromosomes on number twenty one chromosome). October 20th is annually celebrated as international DS day. Specific awareness programmes are generally arranged to commemorate these days. DSSA publishes an annual magazine which creates national awareness as it features topical articles as well as information and photographs about branch activities.

Awareness in any form is worthwhile if it is able to take people forward without prejudice and fear of the unknown. I believe that creating awareness is therefore a bridge to understanding, tolerance and acceptance. Buscaglia (1983: 113) once asked his niece “What is a bridge?” The simple response of a five-year-old aligns most accurately what I perceive awareness to be when she said: “A bridge (*awareness*) is when the ground falls out under you, and you build something to connect the cracks.”

6.5 LIMITATIONS OF THIS RESEARCH STUDY

Although every effort was made to conduct a thorough research, the following limitations were noted:

Due to the personal and emotive nature of this study, many participants who initially indicated an interest, declined to participate.

The study included a total of forty participants (some young and some not-so-young men, women and children of South Africa) who represented amongst others, the Northern Sotho, Coloured, Xhosa, Muslim, Christian, English, Jewish, Afrikaans, Dutch, and Portuguese communities. They ranged from professionals to stay-at-home moms, from artists to artisans, from early graders to graduates, from first-time parents to widowed grandmothers, whilst their children (and siblings) with DS spanned from thirty seven weeks to thirty seven years of age. However, what the sample may have lacked in *quantity*, it exhibited in *quality* which, by implication, confirmed the validity of the research findings for the researcher.

Although participants were from diverse cultural and socio-economic backgrounds, the coloured and African communities were poorly represented, resulting in the findings being more reflective of the Caucasian BC-income group. Subsequently the implications and recommendations are specific to these findings. The researcher realizes that the experience, and therefore the implication for the socio-economically challenged parents and siblings would be completely different to many reported by the participants. Cultural values concerning family functioning and family dynamics also differ vastly, which further limited the generalization capacity of this study’s findings. It may have been suited to this research topic to have considered a cross-cultural comparative study of the experiences of parents and siblings of a child with DS with specific reference to challenging socio-economic circumstances.

Although some may argue the use of self reports, the researcher found this to be an effective way of gaining the valuable data to substantiate this inquiry about human experience. According to Polkinghorne (2005: 139), the capacity to recollect one's experiences is intrinsically limited as was evident in the incapacity of some participants to recall exactly what their emotions, feelings and reactions were at a specific time. Also, in light of the emotional journey required during responses, some participants were reluctant to delve too deep, resulting in the superficiality of some responses. However I do not believe that the limitation was in the manner of data collection (I believe face to face interviews would have inhibited candid responses even more), but more the personal and emotive topic of research. This was primarily noted in the responses of fathers. I do however believe that sufficient quality data was supplied in order to fulfil the research aim.

I found that the coloured and African participants were challenged by the experience of accessing profound feelings and verbalizing them (even in written form). With hindsight, these participants should have had the option to respond verbally in their mother tongue and have their transcripts translated.

The biggest limitation to this study was the extremely wide scope encompassed by the topic. Being more explicit in terms of a very specific relationship or family dynamic would have been a more sensible alternative, for example, the impact that a son with DS has on the father-son dynamic in rural South Africa: a case study of three diverse cultures.

To present such a broad topic in a coherent yet concise manner proved to be somewhat challenging. In order to remain focused on the chosen brief it became abundantly clear that I would be obliged to select specific elements of this vast field of study and apply set perimeters to my research in an effort to do justice to the insight that I wished to impart through this study. This was also done in order to support my chosen research questions and to present a comprehensive dissertation.

Numerous personal challenges contributed to the predicament of being a full-time distance student a thousand kilometres removed from her tertiary institution.

Despite the above-mentioned factors, I am satisfied that I have achieved the goals of this research study, which was to determine the impact on the family dynamic of having a child and sibling with DS and I trust that the information will be relevant to families with children with DS as well as to educators who may in future teach a child with DS. If a single person benefits

from this study and as a result makes a positive contribution to the life of only one person with DS, I would have achieved my goal.

6.6 SUGGESTIONS FOR FUTURE RESEARCH

Although research is ongoing in the field of DS, the following areas for further research has been identified by the researcher.

Siblings:

Future studies regarding sibling experiences could focus on the following:

- The psychological adjustment of those who receive the extra familial responsibilities, i.e. the siblings, as also suggested by Quintero & McIntyre (2010: 37);
- Gender and age related coping skills for siblings, i.e. tools to use in the different situations at home, in public and at school;
- A gender and age related support programme for siblings, also including siblings who have lost a brother or sister with DS;
- A study on how siblings successfully adapt to living with a sibling with DS over the course of their own development (or as an alternative, over the course of the development of the sibling with DS);
- A study on the coping skills required by siblings to deal with their uniquely stressful experiences and also with their unique opportunities for learning and emotional growth, as also proposed by Schunterman (2007: 93).

Fathers:

Cuskelly *et al.* (2008: 110) report on the increase in the number of studies that include fathers, however there seems to be much we do not know about the experiences of fathers in their parenting role. Future studies may shed light on the mother-father differences and issues related to paternal employment, health, time use, and friendship patterns, which remain almost unexplored.

As it is evident in literature that fathers have more stress related to the child's low social acceptability, it is clear that we need to learn more about fathers' experiences of parenting a child with DS and to examine the father's contribution to family life in ways that move beyond the limited possibilities of providers of economic and spousal support. Cuskelly *et al.* (2008: 110) agree that a deeper knowledge of the father's contribution to family functioning would provide a more complete picture of the influences on other family members.

Family dynamics:

In support of optimal family functioning, more research is needed into the development of teenagers with DS and/or the issues which affect their progress. Knowledge of these issues would support maintenance of optimal family functioning.

An interesting and I believe extremely beneficial study would be a study of best practices involving case studies of families of highly successful individuals with DS - how *this* became their reality and ways in which other parents can adapt these strategies to attain positive and high outcomes for their own children. I believe that research on the etiology of DS is important, but pivotal to positive outcomes, is continued research in the field of family functioning focused on the positive rather than the negative (as is so often undertaken).

Societal Awareness:

An investigation could be undertaken to establish the positive contributions of people with DS to their families and to society as a whole. Empirical evidence of positive value will go a long way toward strengthening the value that all persons are worthy and valuable human beings.

Culture specific studies:

For my study, I sourced participants from different cultural and ethnic groups in order to gain rich information from a variety of perspectives. Yet, it became abundantly clear that a study on the shared attitudes, values, norms, beliefs, practices, patterns of interaction, perspectives and experiences pertaining to DS, of especially rural Black South Africans, needs to be undertaken. Due to logistical constraints, it was impossible to fully include and account the many challenges faced by this specific group of people when a differently abled child is born into their family and/or community. What is clear, however, is that multiple challenges related to superstitions and preconceived ideas pervades within this set. Hence my firm recommendation for further research into this concern, as also supported by Cuskelly *et al.* (2008: 110).

Inclusive education:

There are many areas of inclusive education that would benefit from further research. Related to similar suggestions by Klompas (2007: 186) these could include:

- The attitudes and reactions of typically developing learners, family members and the community at ordinary Government schools towards inclusion of learners with DS.

- A comparative study of the personal experiences of learners with DS in mainstream settings vs. learners with DS attending special needs schools.
- A study focused on the speech and language development and academic attainment of learners with DS who attend school where the medium of instruction differs from their home language.

6.7 CONCLUSION

Chapter Six provided the reader with further insight into the impact on the family who has a child and a sibling with DS. Relevant recommendations were made, especially with regard to more effective building and strengthening of resilient families. Limitations of this study, as found by the researcher, as well as suggestions for relevant future studies were indicated.

In conclusion to this chapter, and in keeping with the reflective style of presenting this study, I share my thoughts of my DS experience as follows:

Some families have trouble coping with life's inevitable crises. In these families, even relatively simple problems are not resolved, but take on the appearance and feel of major dilemmas. Thus, due to their lack of successful coping skills, these families create additional problems for themselves and go from crisis to crisis, with little relief and little pleasure from life or from one another.

Although we all strive for perfection, there is no such thing as a perfect family. Each family has its own strengths and weaknesses, assets and liabilities, challenges and solutions. It is, however, important that these aspects are recognized and addressed timeously in order to restore balance and harmony. The family as a system needs to function optimally, especially if this family includes a child with special needs.

There is no shame in having a child who is different. There is no shame in having a sibling who is different. There is no shame in whole-heartedly accepting the package marked "*For your attention...Down syndrome*". On the contrary, there is only pride, love and a whole lot to be learnt, and to teach to others who have yet to overcome their ignorance and prejudice.

On any journey, travellers will discover strikingly beautiful scenery that stay imprinted in their memories forever, just as simply as they may encounter roadblocks, potholes and detours. This is a given and is to be expected on our journey through life. Sometimes these are transitory encounters and at other times, we just have to endure while the storms of life blow

themselves out. What sustains our survival, however, is the amazing power of persistence and resilience, and the simple suggestion of Leo Buscaglia (1983: xiii) to “stop doing all the things you know you can do so well and try something new.”

Do I love her more than my other children, as they so often imply? I believe a mother does not love one child more than another. The child who needs you most at any given time is the child you love the most at that time. It is natural for a parent to love a child, but it is instinct to hold the bird with the damaged wing a little closer.

The question arises: What have I learnt on my journey with my child with DS? Of the immeasurable lessons, I share but a few as follows: I have learned that *laughter* is higher than *all* pain; that it takes one little-girl's almond-shaped smiling eyes to melt away untold hurt inflicted by the well-meaning ignorant; that all mothers wear guilt under their make-up; that navigating the school system is not for the feint-hearted; that it's okay to overestimate the 'experts', they don't have a clue anyway; that the criticism of others is nothing compared to the criticism a mother inflicts upon herself; that nothing happens and no-one crosses your path by chance. I have learnt that sibling rivalry is alive and well and living comfortably in every home; that it is *not cool* for the little sister with DS to hug *all* her sister's senior friends at school assembly; that individual attention to siblings means '*time-absolutely-alone-without-the-little-sister-with-DS*'; that projects destroyed by an 'artistic' DS sibling takes the mother *much* longer to repair and reconstruct than they originally took to do; that it's harder to be a sibling of a child with special needs than you'd like to confess but at the same time there's *no* joy that compares to the spontaneous adoration this little person shows openly, honestly and without reservation *every day* of her life – anywhere and everywhere.

I have learnt that the ache fathers hide in their chest about their little girl's future sometimes wake them up in the middle of the night; that no man will ever love my little girl more than her father does; and that no one basks more in pride at her accomplishments than her daddy. I have learnt that perfection is in the eye of the beholder.

I have learnt to look for, and find, the best in others. I have learnt to stop anguishing over the small issues. I have learnt that the real world functions perfectly within the grey area. I have learnt to look the way God looks: through eyes reflecting unconditional love and acceptance. Possibly the most important thing I have learnt is that God is indeed Love. That we are all loved, and the sole purpose of our existence is to love and be loved, no matter how many chromosomes we have.

If I should ask anyone what they wish for most in life, most would answer: to be happy. Without diminishing the very real challenges that we face as a family, I can boldly state that I am. Despite moments of private anguish and at times anger at large and small inhumanities, every time I look into my little girl's trusting eyes, I see the person I want to be, and I am truly happy. And grateful. Above all, I am grateful for the precious gift I never thought to ask for.

I consider myself to have been *blessed with a burden* and I am not oblivious of the long haul ahead. But like so many courageous parents before me, I have come to realize that the only way to climb this mountain is one step at a time. As the lyrics of a popular song goes: it's not about how fast we get there, it's not about what's waiting on the other side: it's all about the *climb*.

I anticipate the rest of this journey with excitement, and I know that this journey will still require much courage. Amongst the many lessons I have learnt while living in 'Holland', is that courage does not always roar. Sometimes it is a quiet voice at the end of the day, saying, "I will try again tomorrow".

“DO NOT FEAR, FOR I AM WITH YOU,
I WILL STRENGTHEN YOU AND HELP YOU;
I WILL UPHOLD YOU
WITH MY RIGHTEOUS RIGHT HAND.”

- Isaiah 41: 10-

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ADDENDUM A

WELCOME TO HOLLAND

(Emily Pearl Kingsley)

I am often asked to describe the experience of raising a child with a different ability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...



When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum, the Michelangelo David, the Gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "*Welcome to Holland.*"

"*Holland?!?*" you exclaim. "What do you mean *Holland??* I signed up for *Italy!* I'm *supposed* to be in Italy. All my life I've dreamed of going to Italy!" But there's been a change in the flight plan. They've landed in Holland, and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a *different* place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you never would have met.

It's just a DIFFERENT place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... Holland has tulips... Holland even has Rembrandts. But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. For the rest of your life, you will say, "*Yes. That's where I was supposed to go. That's what I had planned.*"

And the pain of that will never, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you *didn't* get to Italy, you may never be free to enjoy the *very* special, the *very* lovely things... about Holland.



ADDENDUM A 1

Celebrating Holland - I'm Home

**A follow up to Welcome to Holland, by Cathy Anthony
a parent, advocate and Executive Director of The Family Support Institute in
Vancouver**

"I have been in Holland for over a decade now and it has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned. I reflect back on when I first landed in Holland. I remember clearly my shock, my fear, my anger, and the pain and uncertainty. In those first few years I tried to get back to Italy, my planned destination, but Holland was where I was to stay. Today, I can say how far I've come on this unexpected journey. I have learned so much more, but this too has been a journey of time.

I worked hard; I bought new guidebooks; I learned a new language, and I slowly found my way around this new land. I have met others whose plans changed, like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travellers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many encouraged me; many taught me to open my eyes to the wonder and gifts to behold in this new land. I discovered a community of caring - Holland wasn't so bad!

I think that Holland is used to wayward travellers like me and grew to become a land of hospitality, reaching out to welcome, assist and support newcomers. Over the years, I have wondered what life would have been like if I had landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and, at times, I would (and still do) stomp my feet and cry out in frustration and protest. Yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too, and look closer at things with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts. I have come to love Holland and call it Home.

I have become a world traveller and discovered that it doesn't matter where you land; what is more important is what you make of your journey and how you see and enjoy the very special, the very lovely things that Holland, or any land, has to offer. Yes, over a decade ago I landed in a place I hadn't planned yet I'm thankful, for this destination has been richer than I ever could have imagined!"

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ADDENDUM B

2 August 2010

Dear Participant (Parents of child with Down syndrome)

THE IMPACT ON THE FAMILY DYNAMIC OF HAVING A CHILD AND SIBLING WITH DOWN SYNDROME

My name is Heidi Webber and I am currently studying towards a Magister Educationis (Masters' Degree) at the Nelson Mandela Metropolitan University. As part of the requirements of the degree, I am required to complete a research thesis. My study aims to ascertain the impact on the family dynamic of having a child and a sibling with Down syndrome, and to ultimately provide tools for the family to become more resilient as they deal with the challenges that their circumstances necessarily bring.

In order for the study to be a success, I require parents and siblings of persons with Down syndrome to participate in the research. I would be grateful if you would consent to participating in my study.

If you choose to participate in this research, you will be invited to respond, in writing to questions in an interview guide aimed at your perception and experience of having a child with Down syndrome and how it has affected your life personally, and within the family context. Although I initially planned face-to-face in-depth interviews, most of my participants requested to put their thoughts in writing in order to give them more time to reflect and order their thoughts. Questions are open-ended, allowing participants to expand as much as they like.

Responses are confidential and will not be discussed with other family members unless the participant has given permission to a parent to read it before forwarding it to me. Participants can contact me directly to collect their responses or to make postage or faxing arrangements. Participation is completely voluntary. **Confidentiality and anonymity** will be maintained at all times and in the analysis of the data and the completion of the Magister Educationis. A summary report of the findings will be made available to the participants.

If you would like any further information or are unclear about anything, please feel free to contact me via e-mail: heidwebber@mweb.co.za or telephonically on 083 442 5069. In case of participation kindly complete form below and fax to: (011) 768-8385.

Your cooperation and participation is valued and appreciated.

Kind regards

HEIDI WEBBER
Researcher

DR. A.J. GREYLING
Supervisor

2 July 2010

Dear Participant (Sibling older than 18 years of individual with Down syndrome)

THE IMPACT ON THE FAMILY DYNAMIC OF HAVING A CHILD AND SIBLING WITH DOWN SYNDROME

My name is Heidi Webber and I am currently studying towards a Magister Educationis (Masters' Degree) at the Nelson Mandela Metropolitan University. As part of the requirements of the degree, I am required to complete a research thesis. My study aims to ascertain the impact on the family dynamic of having a child and a sibling with Down syndrome, and to ultimately provide tools for the family to become more resilient as they deal with the challenges that their circumstances necessarily bring.

In order for the study to be a success, I require parents and siblings of persons with Down syndrome to participate in the research. I would be grateful if you would consent to participating in my study.

If you choose to participate in this research, you will be invited to respond, in writing, to questions in an interview guide. Your response would focus on your perception and experience of having a brother/sister with Down syndrome and how it has affected your life personally, and within the family context.

Participation is completely voluntary. **Confidentiality and anonymity** will be maintained at all times and in the analysis of the data and the completion of the Magister Educationis. A summary report of the findings will be made available to the participants.

If you would like any further information or are unclear about anything, please feel free to contact me via e-mail: heidwebber@mweb.co.za or telephonically on 083 442 5069.

Your cooperation and participation is valued and appreciated.

Kind regards

HEIDI WEBBER
Researcher

DR. A.J. GREYLING
Supervisor

ASSENT FORM FOR CHILD PARTICIPANTS (Sibling under 18)

TITLE: THE IMPACT ON THE FAMILY DYNAMIC OF HAVING A CHILD AND A SIBLING WITH DOWN SYNDROME

14 JULY 2010

Explanation of the Study (What will happen to me in this study?)

Before a baby arrives, every parent has certain expectations for this new little person and mostly they take for granted that their children will do what every other child does. However, this does not always happen. Sometimes, instead of the perfect, healthy baby they expected, they find themselves with a baby with special needs, such as Down syndrome. This is when parents realize how little they know and how little other people know about having a child that is differently abled. We never say 'disabled', because every person on this earth is able of doing something, learning something, sharing something and contributing something, but everyone on earth does this in a different way.

My little girl, Hayley, has Down syndrome. It is important for me to teach people about Down syndrome. The research I am doing is to find out how it affects a family when a child with Down syndrome is born, and how it affects the brothers and sisters when this new little person in their family suddenly needs a lot more time, attention and effort to raise.

For some families it is more difficult than for others, and not every family has a good experience. Parents and siblings often do not understand how to deal with different situations and my study will help new parents to understand their situation a bit better.

Your part in the study will be important and all you will have to do is to write down, in your own words, your own thoughts about your experiences regarding your life with your brother/sister with Down syndrome and how it affects your life. I am allowing you to write your thoughts down so that you can think about what you what to say for a bit.

Risks or Discomforts of Participating in the Study (Can anything bad happen to me?)

Nothing bad can happen to you. You will write down your thoughts and your parents may help you, but only if you want them to. But I need your own ideas and thoughts please.

Benefits of Participating in the Study (Can anything good happen to me?)

Your participation is very important and valuable for my study and will help many other brothers and sisters of children with Down syndrome in future. You can make a big difference to the lives of others. Thank you for helping me, I really appreciate it.

Confidentiality (Will anyone know I am in the study?)

Only you and I will know what you wrote, unless you have asked a parent for guidance, so you need not worry that your answer is right or wrong! I will not be using your name anywhere so no one will know what you said and whom you spoke about. The only person that will know that you helped me will be your parents and my (supervisor) teacher at University, but she will not discuss it with anyone.

Contact Information (Who can I talk to about the study?)

If you would like to talk to anyone about this study, you may contact my supervisor at the University, Dr. Greyling on (041) 504-4564.

Voluntary Participation (What if I do not want to do this?)

If you do not want to do this, you are welcome to tell me. You will not get into any trouble if this is what you decide.

Do you understand this study and are you willing to participate?

YES

NO

Signature of Child

Date

2 July 2010

Dear Parent of participant

THE IMPACT ON THE FAMILY DYNAMIC OF HAVING A CHILD AND SIBLING WITH DOWN SYNDROME

My name is Heidi Webber and I am currently studying towards a Magister Educationis (Masters' Degree) at the Nelson Mandela Metropolitan University. As part of the requirements of the degree, I am required to complete a research thesis. My study aims to ascertain the impact on the family dynamic of having a child and a sibling with Down syndrome, and to ultimately provide tools for the family to become more resilient as they deal with the challenges that their circumstances necessarily bring.

In order for the study to be a success, I require parents and siblings of persons with Down syndrome to participate in the research. I would be grateful if you would consent to your son/daughter participating in my study.

If you choose to allow your son/daughter to participate in this research, he/she will be invited to respond to questions in an interview guide. This will be done in writing in order to afford the participants time to reflect upon their thoughts and formulate their responses in their own time. The questions are aimed at his/her perception and experience of having a brother/sister with Down syndrome and how it has affected his/her life personally and in the family context. Participation is completely voluntary. Confidentiality and anonymity will be maintained at all times and in the analysis of the data and the completion of the Magister Educationis.

A summary report of the findings will be made available to the participants.

If you would like any further information or are unclear about anything, please feel free to contact me via e-mail: heidwebber@mweb.co.za or telephonically on 083 442 5069.

Your cooperation and your son/daughter's participation is valued and appreciated.

Kind regards

HEIDI WEBBER
Researcher

DR. A.J. GREYLING
Supervisor

ADDENDUM C

DECLARATION BY PARTICIPANT

I _____ (I.D. number _____)
hereby confirm as follows:

(Please initial
against each
paragraph)

1 I was invited to participate in the above mentioned research project, which is being undertaken by Heidi Webber of the Department of Education in the Faculty of Education, Nelson Mandela Metropolitan University.

2 This research aims to ascertain the impact on the family dynamic of having a child and sibling with Down syndrome. The information will be used as part of the requirements for Magister Educationis. The results of the study may be presented at scientific conferences or in specific publications.

3 I understand that I will need to complete the consent form and return it to the researcher on completion. In addition, I will be required to complete an interview guide.

4 My identity will not be revealed in any discussion, description or scientific publication by the researcher.

5 My participation is voluntary. My decision whether or not to participate, will in no way affect my present or future career or lifestyle.

6 No pressure was exerted on me to consent to my participation and I understand that I may withdraw at any stage without penalization.

7 Participation in this study will not result in any cost to myself.

I CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT.
Signed at _____ on _____ 2010.
Signature of participant: _____

DECLARATION BY PARTICIPANT

I _____ (I.D. number _____)
hereby confirm as follows:

(Please initial
against each
paragraph)

1 I was invited to participate in the above mentioned research project, which is being undertaken by Heidi Webber of the Department of Education in the Faculty of Education, Nelson Mandela Metropolitan University. This research aims to ascertain the impact on the family dynamic of having a child and sibling with Down syndrome. The information will be used as part of the requirements for Magister Educationis. The results of the study may be presented at scientific conferences or in specific publications.

2 I understand that I will need to complete the consent form and return it to the researcher on completion. In addition, I will be required to respond in writing to an interview guide.

3 My identity will not be revealed in any discussion, description or scientific publication by the researcher.

4 My participation is voluntary. My decision whether or not to participate, will in no way affect my present or future career or lifestyle.

5 No pressure was exerted on me to consent to my participation and I understand that I may withdraw at any stage without penalization.

6 Participation in this study will not result in any cost to myself.

I CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT.
Signed at _____ on _____ 2010.
Signature of participant: _____

DECLARATION BY PARENT OF PARTICIPANT

I, _____ (I.D. number _____)
in the capacity of parent/guardian of
_____ (I.D. number _____)
hereby confirm as follows:

(Please initial
against each
paragraph)

- 1 My child was invited to participate in the above mentioned research project, which is being undertaken by Heidi Webber of the Department of Education in the Faculty of Education, Nelson Mandela Metropolitan University. _____
- 2 This research aims to ascertain the impact on the family dynamic of having a child and sibling with Down syndrome. The information will be used as part of the requirements for Magister Educationis. The results of the study may be presented at scientific conferences or in specific publications. _____
- 3 I understand that I will need to complete the consent form and return it to the researcher on completion. In addition, my child will be required to participate by responding, in writing, to a question guide. _____
- 4 My child's identity will not be revealed in any discussion, description or scientific publication by the researcher. _____
- 5 My child's participation is voluntary. My decision whether or not to allow my child to participate, or my child's decision whether or not to participate, will in no way affect his/her present or future school career or lifestyle. _____
- 6 No pressure was exerted on me to consent to my child's participation and I understand that I may withdraw my child, or he/she may withdraw at any stage without penalization. _____
- 7 Participation in this study will not result in any cost to my child or myself. _____

I CONSENT VOLUNTARILY TO ALLOW MY CHILD TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT.

Signed at _____ on _____ 2010.

Signature of parent or guardian of participant: _____

ADDENDUM D

THE IMPACT ON THE FAMILY DYNAMIC OF HAVING A CHILD AND SIBLING WITH DOWN SYNDROME

Thank you for your participation. All information is **confidential** and will not be published. Please use this as a guide to your response:

SECTION A:

1. Your name
2. Your age
3. Marital status and number of years married (if applicable – mention 1st marriage, etc)
4. Age at birth of child with DS
5. Position in family of child with DS e.g. 1st child/ Only child/ 2nd child etc
6. Current age of child with DS
7. Ages of siblings: current and when the child with DS was born
8. Employment: working parent/ stay-at-home parent (2 line detail info unless you want to go into more detail)

SECTION B:

Short overview of pregnancy, diagnosis & birth. Please consider details pertaining to tests, stage of diagnosis, spousal support during pregnancy & diagnosis, thoughts about your baby prior to birth, etc.

SECTION C:

Information regarding your marital and personal relationship prior to birth of child with DS. This is important detail as I am trying to establish a correlation between DS and divorce.

SECTION D:

How has having a child with DS influenced your personal life (marriage, relationship, sharing of responsibilities, social life, friendships, fears, concerns, etc).

After having a child with DS: Have you ever considered divorce? Has your spouse? What are the issues leading to spousal/ relationship discontent? Has your intimate relationship changed (how and why)?

What has the impact on the family dynamic in your home been of having a child with DS?

Within context of having a child with DS: What causes you most frustration/ pain/ concern & anxiety? What brings you most happiness/ joy/ pride?

How has having a child with DS influenced you as a person & your family? (*Positive & negative*)

PLEASE FEEL FREE TO ADD ANY INFORMATION YOU DEEM APPLICABLE

THANK YOU FOR YOUR TIME AND VALUABLE CONTRIBUTION

Heidi Webber – Researcher (heidwebber@mweb.co.za)

THE IMPACT ON THE FAMILY DYNAMIC OF HAVING A CHILD AND SIBLING WITH DOWN SYNDROME

SIBLING OVER 18 YEARS: Thank you for your participation. All information is **confidential** and will not be published. Please use this as a guide to your response:

SECTION A:

1. Your name, current age and your age when your sibling with Down syndrome was born.

SECTION B:

Share with me: (*Please share **positive and negative** experiences*)

- Your thoughts on how *you* feel it influenced (and still influences) *YOU PERSONALLY* to have a sibling with Down syndrome? (Not how you think *others* want/wanted you to feel).
- Some of your experiences of growing up with a sibling with DS in terms of time spent with your parent(s), attention to yourself and the sibling with DS, responsibilities, family discontent/harmony, etc.
- How did it influence your family life to have a child and sibling with DS?
- What would you have changed/ liked to have done differently growing up with a sibling with DS? How could you have accomplished this?
- What would you have liked your parents to have done differently? How could they have accomplished this?

SECTION C:

- How has having a sibling with DS affected your friendships and relationships outside of your family? Consider social life, school experiences, sport, etc in this response please.
- If you are married or in a relationship, what role does your sibling with DS play in this relationship and what would you change about this?

SECTION D:

- What advice would you give parents with children with DS?
- What advice would you give a sibling of someone with DS?
- What advice do you wish someone had given you as a sibling of someone with DS?
- Within the context of having a sibling with DS: What causes you most frustration/ pain/ concern & anxiety? What brings you most happiness/ joy/ pride?
- In a nutshell, what has the impact of having a sibling with DS had on your life?

PLEASE FEEL FREE TO ADD **ANY** INFORMATION YOU DEEM APPLICABLE

THANK YOU FOR YOUR TIME AND EXTREMELY VALUABLE CONTRIBUTION

Heidi Webber – Researcher (heidwebber@mweb.co.za)

THE IMPACT ON THE FAMILY DYNAMIC OF HAVING A CHILD AND SIBLING WITH DOWN SYNDROME

SIBLING UNDER 18 YEARS: Thank you for your participation. All information is **confidential** (for my eyes only and will not be published). Please think about the following questions and answer them honestly:

SECTION A:

1. Your name, your current age and your age when your sibling with Down syndrome was born.

SECTION B: *Remember: There is no right or wrong answer! Please tell me the good and bad (positive and negative) things in your own words:*

- How do *you* feel about having a sibling (brother or sister) with Down syndrome? (Not how you think *others* would want you to feel).
- Tell me about some of your experiences of growing up with a sibling with DS in terms of time spent with your parent(s), attention to yourself and the sibling with DS, responsibilities, and so on?
- How do you think it influences your family life to have a sibling with DS?
- What would you change (or liked to have done differently) growing up with a sibling with DS?
- What would you like (or have liked) your parents to have done differently? How do you think they could do (or have done) this?

SECTION C:

- How has having a sibling with DS affected your friendships and relationships outside of your family? Think about your social life, school experiences, sport, etc when you answer this question please.

SECTION D:

- What would you like parents of children with DS to know that you would like to tell them?
- What do you wish someone had told you about having a sibling with DS?
- What would you tell someone if they tell you they have a sibling with DS or that their mom is having a baby with DS?
- If you think about your brother/sister with DS: What makes you sad/ hurts you/ makes you anxious/makes you cross or frustrated? What makes you happy and proud?
- One last question: what is it like having a sibling with DS and how has this affected you (had an impact on your life)?
- Is there anything else you would like to tell me or add?

YOU ARE A STAR! THANK YOU SO MUCH FOR YOUR HELP AND EXTREMELY VALUABLE CONTRIBUTION! Heidi Webber – Researcher (heidwebber@mweb.co.za)

ADDENDUM E

Dear Teacher of a very precious little girl



"There is always one moment in childhood when the door opens and lets the future in"
(Graham Greene)

Thank you for teaching my daughter this year. Please allow me to share with you a few things that may help you along the 'path less traveled'...

"All kids need is a little help, a little hope and somebody to believe in them."
(Magic Johnson)

- I appreciate that the unknown can be frightening, but I know that, armed with some appropriate information, any initial apprehension will quickly dwindle once you get to know my daughter and realize that she is far more *like* other children than *different* from them. Thank you for always bearing in mind that she is a little girl first, and that she has Down syndrome second.
- There is a huge amount of literature on Down syndrome and their academic support, which I can provide, as you require it, but thank you for remembering that your best resource will always be us, her family, who know her best.
- Her previous teachers are only too happy to supply any additional information, so feel free to get relevant names and phone numbers from me.
- Just as with typically developing children, there is a wide variation in intellectual abilities, behavior and developmental progress in individuals with Down syndrome.

- Because of the range of ability in children with Down syndrome, it is important for us, her family, and her educators (especially her primary teacher) to place few limitations on her potential capabilities. *Expect her to do well, and she will.*
- Allow her to live up the expectations placed on her.
- The benefit of my little girl, as other children with DS, being included in a mainstream setting has proven significant gain of language and social skills as they observe in their typically developing peers. They flourish with exposure to the rich language and play experiences they witness around them.
- Having a child with special needs as a peer is also beneficial to the other children. It has been proven that they develop their nurturing skills while learning not to smother, and most importantly, they learn to accept differences by this early exposure. Many caregivers give testimony to the joy a child with DS brings to a group, maintaining that the child with DS is usually not 'difficult' and are mostly very popular members of their class.

*"A good heart and a good heart are always a formidable combination."
(Nelson Mandela)*

- Like any typically developing child, my child may sometimes misbehave, become distracted or shut down to hide her difficulty with a given task. Academic strategies from your 'basket of tricks' may solve the problem better than disciplinary ones.
- My child may be embarrassed or shy to ask for help. Please help her get it in a way that is not socially stigmatizing.

- Teaching strategies intended for children with learning disabilities will help my child learn better and make her easier for you to deal with.
- She is a visual learner and will learn better through demonstration rather than through mere verbal instruction. Information presented together (visual and verbal) will give her a better chance of picking up the information and acting on it.
- Children with DS are very skilled in copying demonstrated actions. Thank you for remembering this when a complex action is shown, as she may need to be shown this a few more times than her typically-developing peers are. Once the action is learned, she will usually not forget the skill and will take great pride in the achievement.
- As she imitates well, unfortunately, she may also easily pick up unhelpful or negative behaviors by observation of adults and peers and these can and should be corrected. Not only actions, but also especially speech patterns and words. Thank you for keeping an eye on this and for gently correcting and guiding her to more positive behavior and actions.
- As all children, my daughter likes to be praised and will work hard to please her teacher. Thank you for encouraging positive behavior by giving her your attention, letting her know that her behavior is acceptable. You need not say a word; your mere presence near her is a reward in itself. You may, however, make your attention more powerful by talking to her and making eye contact. Specific praise is the most effective. Instead of saying "well done", say "good tidying up" or "good sitting still". This ensures that she knows exactly what you are pleased with, thereby increasing the chances that the behavior will be repeated.

- She will be able to work well independently. Please help her if needed and then allow her to continue by herself. Once she has acquired a skill, please encourage her to perform it without assistance and then without teacher even nearby. Initially recognition of independence can be given, e.g. "Great! You cut that out all by yourself! Well done!"

"Children allowed to develop at their own speed will usually win the race of life"
(F.O. Bosman)

- Though my child has some areas of weakness, she also has areas of great strength. Please use these to give her experiences of success.
- My child is an individual, not a diagnosis - thank you for being alert and receptive to things that make her unique and special.
- As with all little ones, teaching tasks in a step-by-step manner with frequent reinforcement and consistent feedback has been proven successful in teaching children with Down syndrome.
- Breaking tasks into smaller steps, repeating words and instructions, and re-phrasing instructions and/or questions, the use of more graphic explanations will benefit not only my child, but everyone else in the class too.
- Allowing my child a few extra minutes to complete a task or to formulate an answer will boost her confidence and give her the opportunity to achieve feelings of success. Thank you for being sensitive to her need to participate.



"Just when you think you have learned what you need to know in life, someone truly special comes into it and shows you just how much more there is".

- Thank you for dealing with Down syndrome in a positive way with my child's classmates. There are *so* many learning opportunities and possibilities with the inclusion of Hayley in their group.
- Please keep the lines of communication open between our home and the school. My child needs all the adults in her life working together.
- Thank you for taking the time to listen carefully when she speaks. It will not take you long to recognize her individual edited manner of speaking. Simply ask her to repeat herself if you do not understand her the first time (she is very used to us doing it at home e.g. "I beg your pardon, Hayley?" or "I am not sure what you are saying/ asking me, can you tell me/ ask me in a different way?"
- Bear in mind that her receptive language skills are greater than her expressive skills, which means, as with all children with DS, she understands language better than she is able to speak it. Sadly this aspect often results in underestimating the cognitive skills of children with DS.
- This speech and language problem often means that children actually receive fewer opportunities to engage in language and conversation, and it is more difficult for them to ask for information or help. Adults tend to ask closed questions or finish a sentence off for the child without giving them much needed time or help to do it themselves. Thank you for being aware of this.

"Sometimes in the winds of change we find our true direction."

PRACTICAL IDEAS FOR SUPPORTING AND INTEGRATING A CHILD WITH
DOWN SYNDROME INTO A PRESCHOOL ENVIRONMENT:

- **Expect her to behave in the same way as the other children.** Enforce rules. Do not allow her to monopolize your attention. Remember what age-appropriate behavior should be e.g. hair-pulling. All children do the same things at the same age. Bear in mind that behavior may be the result of an underlying cause, e.g. communication difficulties due to speech delay or 'under the radar' bullying. 'Naughtiness' always has a cause.
- **Answer other children's questions honestly.** Answering a child's questions as honestly as possible provides them with the information they need to adapt to their environment. If a child asks why a child with DS keeps sticking her tongue out, or is not speaking clearly, he/she is simply trying to make sense of what he/she sees. When the teacher then gives a factual non-emotive account in clear language, the child simply accepts it, e.g. "The muscles in her mouth are not as strong as yours yet. In the meantime, we'll just keep helping her to remember to close her mouth." Vague answers and patronizing tones create mystery and intrigue and the questions turn into an issue. ***You are welcome to call on me to visit your class and explain what DS is in very simple and understandable terms. This may provide a wonderful learning experience.***
- **Please stop peer over-assistance.** A healthy relationship will have positive benefits for both children, but please keep an eye on the typical 'caretaker' friend who wants to assume too much responsibility and offer too much assistance to the child with DS. Thank you for reminding the class that my daughter can take off her own jacket or retrieve her lunch box herself. Positive statements such as "Thank you Emma, but Hayley can do that for

herself" can be a real confidence booster for Hayley and Emma will delight in her achievement.

- **Adapt materials to suit her**, e.g. giving her 'chunkier' materials to work with if her fine motor skills are still developing. If she is not succeeding in a task, please look at how you could adapt the materials to make it work for her. Achieving success is such an important part of learning. Thank you for supporting my child to realize that she "can" by being a creative and observant teacher. Consider the layout of the room and make it easy for all children to work independently.
- **Encourage interaction with peers and friendships.** This is always difficult if there is a language delay as the child becomes very frustrated when he/she cannot communicate with others. Try to discover what is trying to be communicated and think of inventive ways in which the child can gesture or say to others what it is he/she wants or wants to do. Amazingly, peers are mostly quite perceptive and work out soon enough what is being said.
- **Buddy system.** A buddy system works well, whereby each child is paired with a buddy for 10 to 15 minutes of free play time each day. During this time, the buddies stay together, talk and play together. This expands the social and language skills of all children in the class and ensures no one is left out. Buddies are reassigned on a daily basis so that over time each child will get to be a buddy with another child in the class. Laminated photocopies of everyone in the class paired on a board show them clearly who their buddy is for the day. You can also encourage socialization by teaching my daughter simple play routines which she may not be familiar with. This simple action ensures that she is in the middle of the action and increases the chance of inclusion in a game.

- **Make language accessible.** Children with DS understand more language than they use. Although Hayley communicates clearly, there may in future, be a child in your class who relies more on signing. Finding unique sign and teaching it to the whole class will be helpful to all. Once the correct word is learned, the sign will automatically fall away. For a very shy child who does not speak at all, making a scrapbook with pictures may be helpful, will allow him/her to indicate their needs, and will extend communication.
- **Children with DS respond best to clear routines.** Having a clear routine for the order of the day and how activities are performed will help to support a child with DS. Displaying a picture schedule for the activities of the day will further support her keeping to the daily routine. Taking photos of items in their environment and making display picture strips work well, e.g. a picture strip of washing and drying hands displayed above the basin. Giving her a "job" will further reinforce transition between tasks, e.g. before snack time ask her to carry the cups to the table (this reminds her that snack time is the next activity), or allow her to ring the bell to indicate that break is over. If a child finds it hard to transition from one activity to another, try giving a five-minute warning that an activity will end. In this way, he/she prepares to finish one activity and knows that something else happens next.
- **Step away when the child learns a task.** A child with a learning disability may require more assistance in learning tasks, but once you recognize that she is able to perform it on her own, physically walk away from her while she works at this task. This will teach her that she *can* do something on her own. Thank you for encouraging her confidence in this way. Thank you also for recognizing and praising independence.

COMMUNICATION WITH HOME:

- Thank you for reminding me when a **new song** is being learned, so that we can **practice at home**. Thank you for singing a bit slower in class until she is familiar with all the words and comfortable with participating.
- Thank you for letting me know when you are starting a **new topic** so that we can introduce key words at home and ensure that not everything is new and strange. This will help her attend better and make more sense of what is happening in the class.
- If you have a **show-and-tell** or a sharing-news period in class, please let me know so that we can draw or paste a picture on paper that she can show and use as a memory prompt when it is her turn to participate.
- **Communication book:** Thank you for writing down important details of specific difficulties she may encounter in class. Practicing at home gives her confidence to participate in class and is another step toward successful integration. Thank you for not just writing notes about the negative, but for also noting her major achievements, particular interests and special friends. Positive feedback is so important for parents as we truly desire to partner with the school and teacher to ensure our child's progress and happiness.

Our desire for Hayley at school:

- to be loved and valued for the individual that she is
- that her many good points are praised and enjoyed e.g. sharing, helpfulness, caring, loving and concerned nature, her sense of fun and humor, her absolute unreserved honesty
- for the attitude of the people around her not to add to the barriers created by the condition of Down syndrome

- to be spontaneously included in her school activities and schooling "community"
- a stable & safe learning environment
- the positive attitude of her educators
- to experience encouragement, to grow in confidence and to experience success
- a caring & affectionate environment

How does Hayley learn?

- by **seeing & doing** (visual aids are VERY important - also cue cards)
- abstract thoughts are difficult - **concrete concepts** and aids work best
- keep her part of routine i.e. doing **same activity as others** (if not finished, allow later or during "free time")
- do not exclude her in **any** way i.e. allowing her to do something else while the rest of the group do a different activity, e.g. she plays clay while others listen to story
- EVERY LESSON IS A **LANGUAGE** LESSON - please **encourage** her to use full sentences and to speak clearly. She may become a lazy speaker if allowed to get away with it!
- Using **shorter sentences** or breaking down sentences will benefit my child **as well as the other children** in the class whose first language is not English
- Keep **instructions short and repeat** them again at the table if she is unsure of how to begin a given task - it is often more a case of confidence than skill
- **Make learning fun!** Learning occurs best when a child (and teacher) enjoys the teaching situation. Use what the child enjoys doing and join in, pointing out what you want to teach her. E.g., if you want to teach colors and you see

she is playing with a tea-set, you could describe what she is doing and say: "You are pouring the tea into the blue cup." Then pick up another cup and say: "I like my tea in a red cup." Try not to over-direct her play in order to teach something. When we start demanding actions from a child, play becomes work and therefore less interesting. Remaining playful and undemanding makes the child take more notice of what is being demonstrated.

- Whatever you want to teach, **take one step at a time**. Many tasks are made up of a number of smaller tasks e.g. in lacing beads. This would involve holding the lace properly, holding the bead properly, putting the end of the lace through the hole, etc. Presenting the whole task in one go may be overwhelming and too hard to remember. The teaching situation would be far more effective if only one step is practiced and then, when the task is mastered, you move on to the next step. Oddly, the best technique for teaching littlies with DS is in a backward order. Motivation stems from how to pull the bead down the lace first, as they consequently get the reward of seeing the bead on the string.
- **Motivation** is important for all children and they need to see the 'point' of learning something to really apply themselves (like all children!) Teaching counting, for example, may be far more successful if she is asked to count the cups put out for a snack, or the crayons in the box, rather than counters placed on a tabletop. Generally, the child with DS responds better to using **real objects in a real context**.
- Teaching **functional skills** and goals are more beneficial during the early years than pure academic knowledge. There is little point of knowing all the colors and animal names if the child is sitting on her own and unable to communicate

simple requests. Helping her to develop social skills will help her so much more. Few simple learning targets for each term are a good idea.

- **Teach, don't test.** She will stay motivated and progress if the teacher is not an examiner who constantly demands her to answer questions, e.g. "What's this? What's this? What's this?" Simply take off the pressure by showing a picture or object and tell her what it is. After a while, you can show her the picture and pause briefly to allow her time to respond. If she does not respond after a few seconds or gives an incorrect response, simply give her the correct answer. This is called '**errorless learning**', a teaching method that maximizes success while reducing failure and pressure to perform. If children learn that the teacher is not focusing on errors then they learn a greater lesson. They learn that they can try their best without fear of failure.
- **Please don't overdo it.** Although it may be tempting to compensate for a learning disability by spending more time drilling for longer periods, this may not work with her. A child with DS will probably need more time to learn certain tasks, but put it in context to her developmental age, for example, a typically-developing 4-year old is not expected to spend 30 minutes naming flashcards, so this should not be expected from a 4-year old with DS.
- **Play** is the best way for a 3-year old to learn, so also apply this technique to teaching a child with DS. All young children like to play and the child with DS is no different. Exposing her to many different types of play situations helps to facilitate working knowledge in different areas. The following types of play experiences are highly recommended for a child with a learning disability: **Home corner; Quiet area; Construction area; Arts and Crafts; Sand & water play; Small World play (e.g. doll house/ car with car mat/ animals/ farmyard.); Group times (small group times and whole group times).** Apart

from the wonderful social, emotional, cognitive and language opportunities provided by these rich play experiences, exposure to different sounds and textures are stimulating for littlies with DS.

- **Make eye contact** - if necessary, bend down to her level, cup face in hands and repeat what you said.
- **Use simple and clear instructions**
- **Repeat word or phrases** (beneficial to the entire group - promotes reinforcement)
- **Practical material & hands-on activities**
- In an ideal teaching situation the **participation** of all learners is encouraged in normal classroom activities. There will always be ones who 'get it' the first time and there will always be those who require a second explanation, a different strategy or a more practical technique before they grasp a concept. But herein lies the beauty of having a child with DS in the class - the **whole class** will benefit from a teacher who repeats something, simplifies the instruction, speaks slightly slower when explaining a new concept and explores new and exciting ways of garnering classroom participation of all learners. Every teacher knows that although the *context* of a lesson stays the same, she frequently has to *adapt* her planning, strategies and techniques to include every learner in the class. So yes in some cases, one size *can* fit all... if the teacher is skilled and willing to alter the sizes!

"Education is a social process. Education is growth. Education is not a preparation for life, education is life itself."

(John Dewey)

- Including my child holds both **academic and social benefits**, and research has shown that children with DS do at least as well, if not better, academically in inclusive settings rather than segregated settings.
- Daily opportunities to mix with typically developing peers provide models for age-appropriate behaviour. Thank you for keeping an eye on behaviour of especially the boys toward my child, as little boys of this age often tend to be rough, resulting in bullying (frequently occurring 'under the radar').
- Every day is an important step towards preparing my child with a different ability to become a full and contributing member of her community. Including her at this age has benefits for her immediate group, the larger school community, as well as society as a whole. Typically developing peers gain an understanding about different ability, and learn first-hand how *able* indeed differently abled children are; they learn tolerance and empathy (how to support and understand) those who are different from them. These typically developing peers share their experiences and perceptions with *their* families, who now, through the experience of their child, have the opportunity to gain and impart knowledge of a unique situation that is such an integral part of growth toward being fully human. Thank you for being instrumental in allowing them to learn and experience the concept that *being different makes no difference*.

The first question, which the priest and the Levite asked, was "If I stop to help this man, what will happen to me?" But the Good Samaritan reversed the question:

"If I do *not* stop to help this man, *what* will happen to *him*?"

(Martin Luther King)

Have a wonderful year, and enjoy teaching my daughter. She a little girl *first*, and has Down syndrome *second*. John Lubock reminds us that *what we see depends mainly on what we look for*. Look for the sunshine, it is *all around you!*

With respect and kind regards

A mommy,

Heidi



"Ideal teachers are those who use themselves as bridges over which they invite their students to cross, then having facilitated their crossing, joyfully collapse, encouraging them to create bridges of their own."

ADDENDUM F

PRESENTATION TO THE STAFF AND PRINCIPAL: THE KINGS' SCHOOL WEST RAND

"Children allowed to develop at their own speed will usually win the race of life"

- F.O. Bosman -

Down syndrome is not a disease, it is not contagious and is not a death sentence (it only feels like it when the doctor tells you for the first time!) It happens at the moment of conception, is not hereditary and as it is not an illness, cannot be 'treated', 'reversed' or 'fixed'. The name Down comes from Dr John Langdon Down who first described the syndrome in 1866. Syndrome means a collection of signs/characteristics. In 1959 a French geneticist Prof Jerome Lejeune discovered that DS was caused by an extra copy of chromosome 21, hence the medical diagnostic term Trisomy 21. Instead of the usual 46 chromosomes, a person with DS has 47.

Down syndrome is the most common form of learning disability affecting, in SA, about 1 in every 550 live births a year. All children with DS will have *some* degree of learning difficulty, although this ranges from individual to individual. Although DS is due to genetic factors, as with any child, environmental factors play an important part in development. Children with DS vary as widely in their development and progress as typically developing children and there is, like any other child, no way of predicting the level of ability by merely looking at the physical characteristics of the child. The extra chromosome means that children with DS reach their milestones slightly later and will have mild to moderate developmental and intellectual delay, but most children with DS do learn to walk, talk, ride a bike, read and write, in fact, do most of the things other children do. Like everyone else, they have an individual learning style, learn at different paces and, just like other people; they have different interests, hopes and dreams. It is pure fiction that people with DS are always happy, they have the same feelings and moods as everyone else. People with DS are perfectly capable of forming all types of relationships with people they encounter in their lives, be it friendship, love or a dislike of someone. Generally speaking children with DS develop more slowly than their peers, arriving at each stage of development at a later age and staying there for a little longer.

So what do we do in Kings' with little girl who looks a bit different? Simple: treat her like any other child. She is not 'special'. She has a special set of circumstances regarding her ability to acquire new skills, albeit academic or otherwise. As with anyone else, treat a person with DS with dignity and respect. She is a little girl first. She has DS second. As with anyone else, if you do not understand what she is saying, ask her to repeat and wait for her to reply. Treat her and address her in an age-appropriate manner, just like any other child. Remember, she has only one extra chromosome, thus she is far more *like other children than she is different from them*. Terminology: please do not ever refer to a person with DS as a Mongol (it is an outdated medical term, offensive and unnecessarily hurtful to both the individual and parents/family). The correct terminology is a person *with* DS. We do not refer to the person as *a down*s (just as you would not refer to someone as *a cancer*), say: Hayley is a little girl who *has* DS or *with* DS. Definite no-no's are: retarded, mentally handicapped, handicapped, backward, etc. The correct word, if you would have to describe the syndrome, is a learning disability. Intellectual impairment would refer to the intellectual level of functioning.

If you want to know something, please ask. Knowledge empowers us and leads to understanding and understanding brings tolerance and acceptance. Let us endeavor to make our school and community one where being different makes no difference. In this world we want to be like everyone else, we want to fit in. People are afraid of different because what is different stands out. Everyone wants to be perfect and everything needs to be perfect – slaves to perfection. Let us strive toward tolerance and acceptance of *that which is different*. Hayley is just a different kind of perfect. I also dreamed one Hayley... then another one arrived, infinity in my arms, fresh from heaven. But different... She lay there all soft and pink and when she opened her almond shaped eyes, she looked straight into love. And this is the love that that teaches her and shows her that she, too, is fearfully and wonderfully made and that her heavenly Father's fingerprints are also all over her. Just like you, your child and grandchild...

As parents, and I suppose teachers, we expect our life with our children to be lived on paved highways with well-marked signs, the rest stops never far away from one another. However, in my case, our Hayley is taking our family down a different highway, a blue highway instead. It is scary not to know what is ahead, but no one, even on the wide smooth roads, know the future. Dis duidelik geen toeval dat in die Bybel daar 365 keer staan "Wees nie bevrees nie"; dalk een keer vir elke dag?

Know that I entrust my Hayley to *every* teacher and staff member of this school, and I know that you may feel anxious, scared, or under-equipped to teach her at some point, but *know* that you *do* have the skills to *understand* the individual needs of a learner with DS. There are many simple strategies for teachers (and peers) that can be implemented in every phase of learning and I have compiled a comprehensive supportive 'toolkit' for every phase for her teachers. I will also collaborate with the teacher on every issue and aspect as we progress along this road. Most of the strategies are actually good teaching and education practices anyway – plus a good dose of common sense! I think it may be over-ambitious and premature to try and cover every variable spanning the entire school career at this point, but know that lack of support will not be an issue. On a lighter note I can tell you that having a child with DS and teaching a child with DS is not a crisis: in contrast with a typically developing child, they come with *many manuals!!!* and research and development is ongoing worldwide. Strong organizations like DownsEd make matters a lot easier as well.

I understand why some teachers may struggle to include children with different abilities into the mainstream curriculum, and very often the child is present, but left on the perimeter of the teaching and learning experience. This is unacceptable in any circumstance, and no committed, resourceful teacher will allow this to happen in her class. However, there *are* other learners in class, and *everyone's* needs require attention. Thus, with permission, I will offer my resources in assisting the teacher in *any* way possible. (The term: 'bend over backwards' springs to mind!) I will become as involved as the school requires me to, without overstepping the boundaries, in order to avoid a situation where Hayley's assistance beyond the normal teacher/learner interaction distracts from the regular teaching practise. Should a part time tutor or teacher's assistant be required, this can be arranged once such a need is established. Logistics will be thoroughly considered with the class teacher and she will remain the primary teacher and educator of my child.

Children with DS, as with many typically developing children, have a specific learning profile with characteristic strengths and weaknesses. Being aware of the factors that facilitate and inhibit learning allows the teacher to plan and implement meaningful and relevant activities and possibly differentiated activities (which is where the involved parent/support person/tutor slots in). Not all children with DS exhibit all the needs and variations within that profile. Factors that facilitate learning would be the following:

- strong visual awareness and visual learning skills
- ability to learn and use the written word
- tendency to model behaviour and attitudes from peers and adults
- ability to learn from practical material, hands-on activities and demonstration
- keen to communicate and socialise with others

Factors that may inhibit learning would include:

- auditory and visual impairment (Hayley wears specs for classroom activities)
- delayed motor skills (fine and gross – Hayley did not attend OT this year, but may continue next year to sustain her positive development)
- speech and language development (her receptive language skills outweigh her expressive skills at this stage, but this is an ongoing learning process and as she socialises and is exposed to situations more, so her language will develop. Although not always in clear full sentences, she is quite capable of communicating needs, wants and ideas. Being in an inclusive setting promotes clearer speech as the child needs to make herself understood by peers and teachers. Often a child with a speech delay is initially not fully understood by the unaccustomed listener, although they 'tune in' quickly. Hayley continues to go to speech lessons, and articulation tutoring will follow. The language delay is caused by a combination of factors, some of which are physical and some due more to perceptual and cognitive problems. It is as a result of this delay in learning to understand and use language, that cognitive delays are experienced. The level of knowledge and understanding and thus the ability to access the curriculum will inevitably be affected. However, receptive skills are greater than expressive skills, which means that children with DS understand language better than they are able to speak it. As a result, their cognitive skills are often underestimated. These speech and language problems often mean children actually receive fewer opportunities to engage in language and conversation, and it is more difficult for them to ask for information or help. Adults tend to ask closed questions or finish a sentence off for the child without giving them much needed time or help to do it themselves.

There are no behaviour problems *unique* to children with DS, however, as with any other child, their behaviour will be related to their level of development. So when problems occur, they are generally similar to those seen in typically developing children of a slightly younger age. In addition, children with DS have to cope with more difficulties than many of their peers, as much of what they are expected to do in their everyday lives will have been much harder to accomplish due to challenges of speech and language, auditory and working memory, motor-coordination, shorter concentration span and learning difficulties. Trigger thresholds may therefore be lower than in their typically developing peers, i.e. they are likely to feel anxious or insecure and become frustrated more easily, therefore vulnerable.

As in the case of every individual, some people with DS master their life better than others, and a nurturing supportive school environment will go a long way to Hayley's optimal development, participation in, and contribution to life as we know it. Sadly, no matter how much the word 'diversity' is tossed around, the world does not look kindly on difference. It takes more than this thing we call self esteem to manage to live well in a world that doesn't want you to live at all.

It is my firm belief that all children deserve to be welcomed in the school of their choice, whatever the reason for this choice. The United Nations, of which SA is a ratified signatory, stated in March 2007 that inclusive education was a right of all people. This basic shift in ideology from special ed classrooms to educating all learners within an inclusive classroom caused some confusion in terminology. As children with labels enter the education system, the terms 'integrated' and 'included' are used to describe classroom settings they will experience. The fundamental difference is that the integration models (medical models) work under the premise that something is *wrong* with the child and needs to *be fixed*, whilst inclusion works under the premise (social model) that *all children are different and all children can learn*. Inclusion is an attitude, a value and belief system. All learners are encouraged to belong, thus nurturing everyone's self esteem. In inclusion, learners are 'participating' in school, as opposed to integration, where learners are 'going' to school. Inclusion is really a function of relationships and attitudes and the benefits for everyone is well documented. Integration simply accommodates and benefits no one.

In an ideal teaching situation the participation of all learners is encouraged in normal classroom activities. There will always be ones who 'get it' the first time and there will always be those who require a second explanation, a different strategy or a more practical technique before they grasp a concept. But herein lies the beauty of having a child with DS in the class – the *whole* class will benefit from a teacher who repeats something, simplifies the instruction, speaks slightly slower when explaining a new concept and explores new and exciting ways of garnering classroom participation of all learners. Every teacher knows that although the *context* of a lesson stays the same, she frequently has to *adapt* her planning, strategies and techniques to include every learner in the class. So yes in some cases, one size *can* fit all... if the teacher is skilled and willing to alter the sizes!

Our history with Christian education has proven that educators, their teaching approach and the curriculum which is in line with a Christian ethos promotes personal and individual growth which builds on the *strength* of the individual (whilst supporting the weakness) to excell in many diverse ways. The reciprocal influence that a relationship between a typically developing child and a child with DS can have, may profoundly affect how our children, the future parents and leaders of our society, view/ treat/ perceive persons who are differently abled. How *better* to teach the fundamental concepts of empathy, caring and support than creating an opportunity for hands-on first hand experience? I can think of *few* better ways in which many children will begin to *own* what they are taught.

Including a child with DS holds both academic and social benefits, and research has shown that children with DS do academically at least as well, if not better in inclusive settings rather than segregated settings. Daily opportunities to mix with typically developing peers provide models for age-appropriate behaviour. This is also an important step towards preparing a child with different

ability to become a full and contributing member of her community, and society as a whole benefits. Typically developing peers gain an understanding about different ability, how *able* indeed these children are; they learn *tolerance* and how to *support* those who are different from them. They learn and experience *that being different should make no difference*.

Furthermore, Hayley has a little spirit that needs nurturing – where better than in the embrace of an understanding community of Christian teachers, parents and peers, where people go way beyond the confines of curriculum and have a strong support structure such as right here? It is widely recognised and documented that people with DS are not only capable of socialization and education but also of spiritual development. To us as a family, it is not just about mainstreaming Hayley, to us it is about the journey of inclusion into society – albeit a long and hard journey. To us a school like Kings’embodies a truly committed node of caring in providing education that stretches beyond the normal learning and teaching. The first two months of this year, our last in PE, Hayley attended Harvest Christian school with my other daughters –a school with which our family had very close ties. Hayley grew up on the lawns and swings of that primary school, and she was embraced as a little girl first, and a child with DS second. *That* is what I want for my child at school. That *she* may benefit, but also that *you* may benefit. And benefit you will, in ways I cannot begin to describe... I am not asking you to consider *every* variable today (of which there may be many in future) or try to nitpick and solve every possible future challenge. I *am* asking you to give a little girl a chance. Let us partner in making a difference to the life of *this* child – one step at a time, one day at a time.

Persons with DS are life-long learners, and it is important to us that Hayley perceive learning at school level as truly meaningful, on her own academic level but especially on interpersonal level. This can be achieved by learning together within the diversity of her own peer group, but at her own level of competence in different learning areas. I believe that every learner, as an individual, has special educational needs; not every learner understands maths in the same way, just as not every learner grasps phonics in the same manner, or learns to read at the same pace. Nobody knows better than *you* how profoundly the emotional and environmental challenges our children face today influence their performance and learning, so in effect *every* learner today has special needs.

We want Hayley to have the opportunity and equal chance to succeed in an environment where the expectations of her teachers match ours. Any ceilings placed on her development will be ours, not hers. Hayley has benefited from early intervention, which has involved supporting and promoting some of the complex developmental processes in children with DS, and she has proven herself to be an excellent candidate for inclusive education. For the previous three years she was a much-loved pupil of Little Eagles School pre-school, spent the first two months of this year at Harvest Christian School in PE is currently at Alma Mater Academy. The high, yet reasonable expectations of her teachers have always proven pivotal in her progress.

The education of children is an awesome task that requires close partnership of parents and teachers in raising children to walk in God’s ways. Giving is a way of living and I employ you to give Hayley the chance of a lifetime. Graham Greene said “There is always one moment when the door opens and lets the future in.” Thank you for your willingness to open the door.

Thank you Ken, Erika and the foundation phase teachers for availing yourselves the privilege of teaching Hayley the love of her Heavenly Father and to also share His love amongst others around her. Thank you for considering this step in a spirit of unity and purpose. I trust, too, that your decision will be supported by your teachers, the people who pour out *their* lives into the lives of the children they teach. No doubt Hayley, as my other girls, will benefit from people who truly walk the talk by way of your purposefully committed staff who, I believe, approach their calling in a very special way.

Moreover, as we, school and parent, partner in this endeavor, let us undertake to meet the highs and the lows with equal expectation and understanding, building on strengths and supporting weaknesses in a positive, Godly way. I close with the analogy of the Good Samaritan and a question. Actually two. The first question, which the priest and the Levite asked, was "If I stop to help this man, what will happen to *me*?" But the Good Samaritan reversed the question: "If I do *not* stop to help this man, *what* will happen to *him*?"

I thank you for your time and the opportunity to speak to you.

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