

**Parental Adaptation to the Cerebral-Palsied Child:
The Influence of Psychosocial Variables**

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Abstract

This study examined the degree of adaptation (operationalised by means of multiple measures, namely satisfaction with family life, stress and adjustment to the child) being attained by parents of a child with cerebral palsy. Drawing on the model of stress and coping of Lazarus and Folkman (1984), the outcome variable *adaptation* was held to be a function of the stressor (i.e. the exceptional child) and various mediating factors, namely demographics, coping mechanisms, perceived social support and locus of control.

A cross-sectional, correlational field survey was conducted in which seventy-nine parents, recruited via a school for children with cerebral palsy, completed a pencil and paper self-report questionnaire, generating both quantitative and qualitative data. Scales utilised in this study were the Family Adaptability and Cohesion Evaluation Scale III (FACES III; Olson, Portner & Lavee, 1985), the short form of the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg & Crnic, 1983), the Judson Scale (Judson & Burden, 1980), the Coping Orientations to Problems Experienced Scale (COPE; Carver, Scheier & Weintraub, 1989), the Family Support Scale (FSS; Dunst, Trivette & Jenkins, 1988) and the Pearlin Mastery Scale (Pearlin & Schooler, 1978). Qualitative data were solicited by means of four open-ended questions, the responses to which were content analysed on the basis of themes identified in the literature.

Univariate analyses of outcome variables were undertaken in order to ascertain the level of adaptation experienced by the parent sample. Thereafter, a thorough exploration of bivariate relationships between demographic and outcome variables utilising correlation, *t*-tests and ANOVA was undertaken. The independent variables coping, social support and control were examined, contrasted with norms where available, and their correlation with adaptation determined. Lastly, regression analyses were performed in respect of each of the measures of adaptation in order to identify the independent variables with the best predictive value. Maternal and paternal data were contrasted at each stage of the process.

Extremely high adaptation was reported for this sample via the quantitative measures, a finding that was not supported by the qualitative data. No significant differences in level of adaptation were reported between mothers and fathers. Home language was related to outcome in that Xhosa-speakers experienced more stress, and Afrikaans-speakers were better adjusted to their child than English-speakers. Income was related to adaptation for both parents. Child sex, age and position in the family was not related to adaptation.

Social support was not related to outcome for either parent. While considerable use was made of emotion-focused coping strategies, the best predictors of adaptation were locus of control and the degree of the child's disability for fathers and the less effective coping methods of mental and behavioural disengagement, together with locus of control and degree of disability for mothers. Above all this study demonstrated that successful adaptation was not contingent upon adherence to prescribed norms.

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Introduction

Samples from letters written to the editor of *Exceptional Parent: Parenting your child with a disability* (Psy-Ed Corporation, 1990; 1991) offer a glimpse into the life-world of those who form the focus of this study:

We are the proud parents of a beautiful two-year-old daughter, Sarah. She has cerebral palsy (spastic quadriplegic), microcephaly and a seizure disorder. All are due to unnecessary prolonged labour, lack of oxygen and meconium aspiration. Due to all this distress, she suffered ulcers, cerebral edema and was in a coma for the first six days of her little life. Sarah can sit with minimal support, but cannot walk, crawl or talk. She eats well by spoon. She's a very loving and happy baby. Her last MRI showed Sarah only had half of her brain left. The severely damaged parts deteriorated and have been replaced with fluid.

This is very hard for me to write and remember all the bad things that happened to our precious baby. Sarah also receives therapy (occupational, physical and is starting speech therapy in one week). Three times a week therapists come. Her daddy and I work with her constantly. I don't know any parents in our area and I feel very isolated and alone. I'd like to hear from other moms and dads who may have a similar situation.

K.M. & J.M.
Texas

(EXCEPTIONAL PARENT, July, 1991 pp.13-14).

We have an eight-year-old daughter and a five-year old son who both have physical and mental delays. The doctors are puzzled and can't group them with any one disability. Their symptoms are hypotonia, speech delay and gross and fine motor delays. Stephanie can walk and has moderate speech. However, she is behind by two to three years. Garrett still does not sit, walk or talk. Both children are very smart and can understand much more than they can express.

We're very eager to find parents of children with the same or similar disability.

J.S. & A.S.
Florida

(EXCEPTIONAL PARENT, October, 1990 pp. 12-13).

My five-and one-half-year-old son has cerebral palsy (spastic quadraparesis), developmental delay, chronic lung disease (bronchopulmonary dysplasia), Pierre-Robin syndrome and oxygen dependence. He has a tracheostomy and is on oxygen at 25 percent to 30 percent mist to the tracheostomy and gastrostomy. A home-bound teacher comes to the house four times a week, but he receives only 30 minutes of speech therapy a week. I feel that a computer would greatly enhance his learning, since he can already spell 50 words, understands the concept of communication and has been tested as being capable of using a computer.

I would like to correspond with anyone who has experience with any of these, or similar, disabilities, to compare notes on management of his educational and physical environment.

J.M.
Illinois

(EXCEPTIONAL PARENT, October, 1990 p38).

This study investigates the impact upon the parents of the presence within the family of a cerebral-palsied child. In particular it examines and seeks to explain the parents' reported level of adaptation as a function of demographics, personality factors and the perceived availability and use of psychosocial resources.

Parents such as those whose voices are reflected in the opening paragraphs, are uniquely qualified to bear the designation *exceptional*. In an indifferent and often alienating social climate, each has forged a path towards fulfillment of both their own and their exceptional child's otherwise unmet needs. The road has typically been replete with disappointments, yet rich with unexpected opportunities. For many an event initially deemed overwhelming has evolved into a valued source of growth and personal triumph.

The experiences of exceptional parents have been the focus of considerable investigation over the past fifty years. Researchers in England, the United States and Holland, for example, some of whom are not only academics and/or members of the helping professions, but also parents of children with disabilities themselves, have invested substantial energy in their attempts to understand the life-worlds of people for whom the experience of parenting is distinctly challenging. Far from being merely reactive, their efforts should be seen as a necessary prerequisite for prevention – something we expect from the technologically advanced society in which we are living. Aside from medically focused interventions – in the sense of genetic screening, antenatal and obstetric care, there is room for improvement on a psychological level in terms of distress reduction through greater understanding and information sharing.

International literature in the field of parental adaptation is voluminous. Virtually every aspect of the experience has been documented. The human element has however ensured that consensus has seldom been reached and many of the findings are equivocal. It is necessary therefore to consider a wide range of material in an attempt to fully appreciate the complexity of the topic. The following review incorporates studies in respect of disabling conditions other than that of cerebral palsy since the similarity of the parents' experience renders their inclusion valid. It is acknowledged, however that differences do

exist and that the injudicious application of findings across conditions may result in some erroneous conclusions. The findings have thus been interpreted with due caution.

Given the greater frequency of contact between children with special needs (exceptional children), their parents (exceptional parents) and medical practitioners, it is not surprising that the formation of attitudes towards people with disabilities has been directed to a large extent by the medical profession (Yom, 1998). Much of the early work in disability originated from medical researchers, who assumed a top-down, deficit approach, applying vituperative labels and locating the discussion firmly within a discourse of pathology. Despite attempts to counteract this impression by physicians who themselves have disabilities, misunderstandings and negative attitudes remain pervasive (Yom, 1998).

While it is not the intention of this study to minimize the considerable distress experienced by the exceptional child, his or her family and everyone concerned with their well-being, it is hoped that the means through which not merely functional but constructive, realistic, purposeful and fulfilling parental adaptation can be reached, will be brought to light in the course of this work.

Chapter One

Disability

1. 1 Political Issues

Before embarking on a study of this nature, a brief exploration of some of the central themes and political issues pertinent to the field is warranted. In a society in which the mythical 'normal healthy body' serves as the standard of reference, the concept of 'otherness' tends to be embedded in discourses on disability, through which the illusion of a dichotomy between disabled and non-disabled people is implicitly sanctioned. Boundaries are arbitrarily created - frequently on biomedical grounds - such that individuals with ailments deemed 'minor' may be granted admission to the mainstream, while those with specialized - and hence potentially inconvenient - needs are excluded by society's gatekeepers.

Historically, constructions of disability have tended to occupy either an individualist or a social constructivist position (Priestley, 1998). Within the former approach, disability is seen as a misfortune peculiar to the individual - the so-called "personal tragedy theory of disability" (Oliver, 1996 in Priestley, 1998 p75). Difficulties experienced in social living are seen to be caused by the physical limitations inherent in the (flawed) person, for which she or he should accept responsibility. Similarly disadvantaged individuals who have triumphed over 'their' limitations are offered as rôle-models - their feats to serve as a source of courage and inspiration (Watermeyer, 1994). Independence is encouraged, indeed rewarded, as are attempts to maintain (at least superficially) 'normal' modes of appearance and function (Mulderij, 1996; Watermeyer, 1994).

In seeking to promote conformity, biomedical reductionism permits no reference to the subjective experience of the individual. On the contrary, psychological and socio-cultural aspects of disability are considered secondary, sources of obfuscation impeding efforts to understand the true condition (Kleinman, 1987 in Watermeyer, 1994).

The social constructivist model, as the name suggests, views disability as a social construct, which has as its premise the concept of cultural relativism (Priestley, 1998). In terms of this understanding, the definition of disability varies in accordance with prevailing opinion, from which the individual acquires a certain social status, with rôle prescriptions and implications of a culture-specific nature (Mercer, 1973 in Lea, 1990; Priestley, 1998). Thus it is the relationship between society and the individual that is inherently disabling. A form of cultural imperialism is invoked in which the dominant (non-disabled) group establishes norms from which the disabled will axiomatically deviate, thereby legitimizing their categorization as 'other' (Young, 1990 in Priestley, 1998). In practical terms this translates into marginalisation in areas such as housing, schooling, employment and public transport (Oliver, 1996 in Kitchin, 1998). Hence the social model locates accountability for meeting the requirements of the disabled within the very society responsible for the labelling, stigmatization and ultimate exclusion of this group (Kitchin, 1998; Watermeyer, 1994).

Priestley (1998) contends that the individual-social dichotomy is simplistic and postulates the existence of four positions from within which disability can usefully be understood and examined. Together with the above debate, he engages the idealist – materialist polemic which, when placed in juxtaposition, produce four, albeit somewhat overlapping, approaches to disability theory.

Position 1 as identified by Priestley (1998), the individual-materialist position, is essentially akin to the 'medical model'. As the product of biological determinism, the malfunctioning body forms the object of empirical scrutiny. Areas of investigation falling within this paradigm are those involving active, sometimes radical intervention such as corrective surgery or drug treatment. Priestley cautions, however, that despite past evidence to the contrary, this position should not be summarily assumed to produce research that is oppressive.

In position 2, the individualist-idealist position, Priestley (1998) shifts the focus to the subjective cognitive and emotional experiences of individuals as they negotiate their social position and thereby their identity. Within this experiential approach, research

investigates and interprets attitudes and patterns of adjustment to disabling conditions displayed by individuals within the community. Essentially, the politics of personal experience and individual identity are acknowledged by means of this approach (Priestley, 1998).

Position 3 according to Priestley (1998), the socio-materialist position, encompasses the power-relations arising from oppressive political practices or philosophies. It is the approach within which activists have found a home and has informed the contributions of such leading analysts as Michael Oliver, amongst others (Priestley, 1998). Termed a social creationist standpoint, it monitors and seeks to expose politically generated forms of disability.

Position 4, identified by Priestley (1998) as the social-idealist position, concurs with the notion of social constructivism defined earlier. Within this view, language and discourse assume a prominent function, particularly with respect to labelling which is seen to operate as a primary force in the social construction of disability (Priestley, 1998).

It would seem, in light of the above typology, that this study allies itself most closely with Priestley's position 2, since it examines and holds as its focus individual's subjectively held views of the adaptation process.

Idealist motives notwithstanding, pragmatics dictate that this study will embrace existing structures, systems and ideologies that may be dissonant with the politically desirable. The ideals of inclusion and mainstreaming have not been realized nor yet the practices of segregation and labelling eradicated. Operation within these conventions is an artifact of their existence and should not be seen as signifying tacit approval of such practices or institutions.

1. 2. Definitions

This study is primarily concerned with the parents' experience of raising a child with the physical incapacitation that typically results from the (usually congenital) condition defined as cerebral palsy. Hence a few orienting definitions are provided for clarification.

1. 2. 1. The World Health Organization

During 1981, the International Year of Disabled Persons, the World Health Organization (WHO) Expert Committee on Disability Prevention and Rehabilitation held a conference with the specific aim of addressing these issues as they pertained to primary health care offered within community settings as well as state health care programmes and other sources of service. In an attempt to promote uniformity, delegates from WHO developed the following (now widely accepted) operational definitions:

- *Impairment*: In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.
- *Disability*: In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- *Handicap*: In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

(World Health Organization, 1981 p8)

1. 2. 2 The Human Sciences Research Council

In a project of the Human Sciences Research Council in which a standard nosology was designed for South African use, Hattingh, Harvey, Saayman and van Jaarsveldt (1987, in Lombard, 1992) applied the above distinctions, defining the physically disabled as "people who are born with a physical impairment or who have a physical limitation such as anatomical loss of major extremities, paralysis, physiological disorders or any other

conditions affecting important body systems, due to illness or injury. There is thus limited mobility as well as limitations of one or more life activities. The physical condition may continue indefinitely” (p101). Hence, it is in this context that the terms disability, handicap and impairment will be utilized as they refer to the cerebral-palsied child.

1. 3 Prevalence of Physical Disability

Advances in medical technology witnessed in the latter half of the twentieth century such as ultrasonography and amniocentesis, when used in combination with elective termination, have served to reduce the incidence of live births of infants with congenital abnormalities. Nonetheless, such costly screening and intervention is typically applied only to high-risk (Havermans & Eisler, 1991) or high-income mothers, leaving a significant proportion of cases undetected. The prevalence of childhood physical handicap world-wide is difficult to determine with a satisfactory level of accuracy. For example, Scheerenberger (1987, in McCallion & Toseland, 1993) has estimated that there are over six million developmentally disabled residents (including all types of disabilities in both adults and children) in the United States of America, representing some 2 percent of the population, whereas Weisenger-Ferris (1989, in Donald, 1994) suggests that the incidence of disability amongst first world communities is around 10% with underdeveloped communities experiencing double this amount.

Reliable estimates for this country are not available for a variety of reasons. The notorious pitfalls of statistical population monitoring in third world contexts (Donald, 1994) coupled with an historical indifference towards this and the issue of disability in general (Parekh & Jackson, 1997) - the latter being reflected in the fact that the majority of disabled South African citizens have been marginalised in respect of all major social services (*Government Gazette*, 1996), has precluded the maintenance by the state of comprehensive records. Epidemiological surveys, such as the one conducted in the Cape Peninsula by Disler and Jackler (1984, cited in Lombard, 1992) under the auspices of the Department of Community Health, University of Cape Town, were organized on an *ad hoc* basis and, while offering a good indication of differences in prevalence across

population groups for the three areas sampled, are not sufficient for the successful administration of a Department of National Health.

An opportunity to rectify this situation and source accurate information presented itself during 1996 when a national population census was undertaken. Attempts by service organizations to obtain much-needed data were thwarted when questions assessing disability - which could have provided information vital for lobbying and planning in both NGO and state-assisted programmes - were ultimately excluded from the questionnaire having been deemed discriminatory and vehemently opposed by representatives from within the disabled community (Viljoen, 1997 Personal communication).

Hence, prevalence figures for South Africa are, at best, speculative. Given the relatively poorer living conditions and lower levels of primary health care available in this country, leading not only to inadequate antenatal care but also to a greater frequency of illnesses and accidents causing permanent injury, it would seem likely that the incidence of various forms of childhood physical disability would exceed that of the developed western world (Donald, 1994). According to the National Council for the Physically Disabled in South Africa, the internationally accepted incidence of physical disability of any type (i.e. including minor ailments) amongst persons of all age groups is 12% whereas locally an estimated 8.5% of the population has a physically incapacitating condition of some sort. Severe motor disability is believed to occur in some 1.9% of the population, which translates into approximately 275 000 children (Viljoen, 1997 - Personal communication).

As this study focuses specifically on cerebral palsy, a common form of congenital physical impairment, the characteristics of this condition are described below.

1. 4 Cerebral Palsy

1. 4. 1 Definition

According to the Birth Defects Encyclopedia, a diagnosis of cerebral palsy can be reached when a child displays an “abnormality of movement or posture, present since early in life and not the result of recognized progressive disease” (Nelson, 1990 p300). This broad, overarching definition encompasses the many categories or clusters of physical symptoms associated with the condition. Multiple disabilities may be present as for example in a case cited by McNaughton (1991) in which a mother describes her daughter as having “a multidimensional neurological disorder resulting from a congenitally malformed brain, affecting the motor functioning of her trunk and limbs and with associated disabilities involving speech, hearing, vision and learning” (p33). Cases are widely disparate, and may include cognitive impairment, but a global assumption of mental retardation is unfounded (McNaughton, 1991).

The following major categories of cerebral palsy are identified by Nelson (1990):

- Spastic cerebral palsy, with hypertonia [excessive muscle tension] of the claspknife type. Anatomic subtypes existing within this category are:
 - (a) Hemiplegia - involving both limbs on one side of the body;
 - (b) Diplegia – involving the legs to a greater extent than the arms; and
 - (c) Quadriplegia – with involvement of all extremities, the arms more markedly than the legs
- Extrapyramidal cerebral palsy – with hypertonus tending to be of the rigid or leadpipe variety, with defects of posture and often with involuntary movements. These may appear in the form of:
 - (a) Athetosis – [a recurring series of abnormal movements of the hands and feet];
 - (b) Dystonia – [poor muscle tone]; and
 - (c) Ataxia – [failure of muscle coordination].
- Mixed types – incorporating any of the above features.

(Nelson, 1990 p300)

1. 4. 2 Description

As is evident from the above definitions, the umbrella term 'cerebral palsy' is convenient, but potentially misleading for, while it is true that all persons with this disorder experience motor deficit, the severity thereof, and presence or absence of concomitant neurological or sensory disability, is subject to considerable individual variation. Even within a single case, the manner in which a difficulty presents may fluctuate over time, although a progressive deterioration is not usual (Nelson, 1990).

Most children with cerebral-palsy are slow to reach normal milestones and manifest abnormalities of muscle tone such as excessive stiffness combined with inappropriate reflexes in the legs, arms, neck or trunk (Nelson, 1990). Disparities occur with respect to concomitant difficulties such as mental retardation, which is present in approximately 50% of CP children, and seizure disorder, which appears in between a quarter and a third of all persons with CP (Nelson, 1990).

The pervasive muscular dysfunction impacts on sensory activity as well. Poor ocular muscle control leads to strabismus and/or refractive errors in half of all children with CP, while hearing deficits are found in 10-15% (Nelson, 1990). Furthermore, some children experience dental problems, speech and learning difficulties as well as social and emotional adjustment difficulties, the latter being particularly common during adolescence (Nelson, 1990).

Complications are possible, especially where severe mental retardation and quadriplegia are present. Conversely, the condition may be experienced in a very mild form. Ultimately, the outcome is determined by the interaction between difficulties within the individual - not only of a physical nature but also of emotional origin, resulting in part from the frustrations inherent in the lifestyle, and the environment in which he or she lives - conditions of care also contributing to quality and duration of life (Nelson, 1990).

1. 4. 3 Aetiology

Previously believed to result exclusively from birth trauma (Cape & Dobson, 1974), cerebral palsy is now recognized as having its genesis in a number of disparate sources. The majority of cases are now believed to be congenital - the result of intrauterine infection or maldevelopment of the nervous system, with only a small minority having their origin in perinatal causes such as birth asphyxia, or postnatal causes such as infection or injury (Nelson, 1990). Advances in obstetric and neonatal care aimed at eliminating these have failed to produce the expected decline in incidence. Recurrence in siblings and offspring is sufficiently low to exclude the possibility of hereditary factors (Nelson, 1990).

South African studies have identified socio-economic status (SES) as an interacting variable in the aetiology of cerebral palsy. In a comparative study of postnatally acquired cerebral palsy, Arens and Molteno (1989) observed a disproportionate representation of children from disadvantaged communities amongst those whose difficulty had resulted from preventable or treatable conditions. Contrasting with the estimated 10-12% of cases acquired after birth in developed countries (Nelson, 1990), the incidence in Cape Town ranged from 13.2% (high SES) to 36.1% (low SES) (Arens & Molteno, 1989). Low birth weight, a condition induced antenatally through maternal malnutrition and thus prevalent amongst low SES communities, has also been linked to spasticity (Richter & Griessel, 1994).

Ultimately, it would appear that the identification of aetiological factors is seldom achieved with certainty (Nelson, 1990) a factor known to exacerbate parental adaptation (Juvonen & Leskinen, 1994).

Chapter Two

Becoming an exceptional parent

2.1 Parenthood as transition

The transition to parenthood has long been viewed as a nodal point within the course of marriage. Reuben Hill's seminal publication *Families Under Stress* (1949 cited in Russell, 1974) in which new parenthood was framed as a period of crisis, together with Le Masters' subsequent landmark article *Parenthood as Crisis* (1957 cited in Russell, 1974) spawned a profusion of research and literature debating this issue during the following two decades, to such an extent that a backlash of works proclaiming the undoubted *gratifications* of becoming a parent was prompted (Russell, 1974). While the experience may encompass something of each of these two extremes for most individuals, a period of considerable personal psychological development is nonetheless likely to be stimulated. For many the advent of the additional responsibilities of parenthood serves as an unambiguous marker of the transition to adulthood (Gutmann, 1975 cited in Belsky & Rovine, 1984).

Consequently, despite cherished illusions to the contrary, the arrival of the first child may be experienced as an intrusion within the marital dyad (Benson & Gross, 1989), causing major disturbance to the established system. Mothers, physically tired from the strains of pregnancy, must adjust to the intensive demands of the neonate, while fathers, accustomed to an exclusive adult relationship, must accept that their position has been temporarily usurped. Such is the extent of the change in the lives of new parents, that this period has been rated amongst the top five percent of stressful life events according to a large scale study by Dohwrenwend, Krasnoff, Askenasy and Dohwrenwend (1978 in Belsky & Rovine, 1984). As a result couples tend to engage in more frequent contact with their families of origin as well as seeking additional support through the expansion of their social networks to include other similarly placed persons (Belsky & Rovine, 1984).

Given the disturbance surrounding the birth of a healthy child therefore, it becomes evident that the additional burden of handicap, contrasting sharply with their expectations (Bernier, 1990), places demands of an unprecedented magnitude on parents (Baxter, Cummins & Polak, 1995), heralding as it does a lifelong process of adaptation and redefinition of goals (Wikler, 1981; Kromberg, 1977), a prospect which some are unwilling (Weiss, 1997) or unable (Pollner & McDonald-Wikler, 1985) to countenance. No one anticipates that they will be robbed of a healthy child (Bernier, 1990; Cooley, 1994), on the contrary, the assurance provided by advances in antenatal and obstetric monitoring, lead modern parents to expect that the prospects of such an eventuality have been all but removed.

2.2 Disclosure

Where congenital abnormality is readily apparent, in that it involves a visible physical disfigurement, such as spina bifida, or immediately discernable genetic condition, such as Down's Syndrome, disclosure is likely to occur during the puerperium while mother and infant are still hospitalized (Herbert & Carpenter, 1994). Consequently, the responsibility for breaking the news usually rests with the attending medical specialists (Lonsdale, 1978; Quine & Pahl, 1986), some of whom may not have received training specific to this task (Turner & Sloper, 1992). Furthermore, those to whom patients have greatest accessibility, i.e. nurses, in an attempt to preserve the traditional confidentiality of the doctor-patient relationship, may appear evasive and unhelpful when questioned directly, thereby promoting anxiety, confusion, distrust and anger (Quine & Pahl, 1986). Yet the significance of the *mode* of disclosure cannot be overemphasized. This is believed to have far reaching repercussions – potentially affecting parents' sense of stress, long-term coping and adaptation to the child (Blacher, 1984; Cherry, 1989; Lonsdale, 1978; Voysey, 1975).

Investigators have frequently encountered grave dissatisfaction amongst parents in their recollections of the manner in which the diagnosis of disability was conveyed to them (Quine & Pahl, 1986; Sloper & Turner, 1993a). Information which was inadequate (Burden & Thomas, 1986; Lea, 1986; Mitchell, 1997; Quine & Pahl, 1986), ambiguous

or, worse still, inaccurate (Mullins, 1987) was offered too late (Lonsdale, 1978; Sloper & Turner, 1993a; Voysey, 1975) with an alarming lack of sensitivity (Burden & Thomas, 1986; Lea, 1986; Lonsdale, 1978; Mullins, 1987; Quine & Pahl, 1986), creating what was for some the single most stress-inducing life event (Baxter *et al.*, 1995).

Paediatricians' personal understanding and expectations regarding the impact of the news upon the parents and their consequent needs may influence both the substance and the tone of the disclosure as well as the extent to which parents are placed in contact with other appropriate services (O'Sullivan, Mahoney & Robinson, 1992; Sloper & Turner, 1991). Practitioners have recognized a deficiency in this aspect of their medical training (O'Sullivan *et al.*, 1992) and expressed a need for more specialized instruction in this area (Sloper & Turner, 1991; Turner & Sloper, 1992). In the absence thereof, the temptation to apply generalizations, such as the assumption that a deterioration in marital satisfaction is inevitable (Sloper & Turner, 1991) or that responses from parents will accord with existing stage models (Blacher, 1984) should be avoided. In short, notions of exceptional parents as members of a homogenous group should be discarded (Mitchell, 1997). Indeed, careful preparation for and management of this task in accordance with the needs of each unique case is paramount (Herbert & Carpenter, 1994; Sloper & Turner, 1993a). However, while allowing due deference for individual variation, consensus appears to have been reached in the literature in respect of those elements vital to the disclosure interview. It is widely held that:-

- Both parents should be present, together with the infant. It is believed that simultaneous disclosure to both parents has a unifying effect upon the marital dyad, providing an opportunity for mutual support (Cunningham, Morgan & McGucken, 1984; Murphy, 1990; Turner & Sloper, 1992). Additionally, it relieves the mother of the burden of informing the father and emphasizes their shared responsibility in the parental rôle (Murphy, 1990). Paediatricians with fewer years experience (i.e. more recently qualified) consider the presence of the child to be desirable (Turner & Sloper, 1992) as this promotes acceptance of the reality of his or her family membership.

- Parents should be informed at the earliest possible opportunity. Parents are unanimous in their desire for prompt disclosure (Lonsdale, 1978; McNaughton, 1991). Where the disability is not readily visible at birth, or where uncertainty exists as to the precise nature of the handicapping condition, attending medical personnel may be tempted to refrain from disrupting the 'bonding' process (Gath, 1972 in Quine & Pahl, 1986) by delaying disclosure until the accuracy of the diagnosis has been established conclusively (possibly years later), thus providing tacit confirmation of the baby's well-being (Quine & Pahl, 1986). Left to the inevitable realization that all is not well, through the insidious accumulation of subtle signs, such as failure to meet milestones timeously, parents withdraw from the child (Cox & Lambrenos, 1992), becoming embittered, angry and resentful towards medical professionals (Lonsdale, 1978). Turner and Sloper (1992) have found that, while it is understandable that paediatricians are reluctant to alarm parents unnecessarily, disclosure of *suspicion* of a handicapping condition is considered advisable. The honesty of this early communication is believed to promote the trusting relationship required for the continued cooperation between parents and professionals which will inevitably be necessitated as a result of the child's condition. Indeed where tests revealing an abnormality have been undertaken at the *instigation* of the parents, significantly higher levels of satisfaction with disclosure have been reported (Sloper & Turner, 1993a).
- Privacy should be ensured. Concomitant with the recommendations of Cunningham *et al.* (1984), the majority of parents (Quine & Pahl, 1986) and paediatricians (Turner & Sloper, 1992) consider adequate privacy to be a *sine qua non* for disclosure. It is believed that this could be promoted through the judicious choice of setting and range of participants. Use of a private room apart from the ward is advocated (McNaughton, 1991) although in practice inadequate facilities frequently force doctors to make the disclosure at the bedside regardless of ward occupancy (Turner & Sloper, 1992). Presence of additional personnel should be limited to those whose expertise is required for the provision of specialized information (Murphy, 1990) or support for the parents (Cunningham *et al.*, 1984). Confrontation by a 'panel of experts' can be overwhelming and should be avoided. Similarly, the

extent to which parents welcome the presence of a friend or member of the extended family should be ascertained prior to their inclusion at the disclosure interview (Murphy, 1990).

- Information that is adequate, understandable and inclusive should be communicated with compassion. One of the needs most frequently expressed by parents at all stages of their child's development is that of sufficient, appropriate information (Bailey, Blasco & Simeonsson, 1992; de Graaf & de Graaf-Posthumus, 1998; McNaughton, 1991; Wickham-Searl, 1992). The nature of the information provided at the initial session will vary not only with the child's condition but also with the parents' intellectual and emotional needs (Sloper & Turner, 1993a; Turner & Sloper, 1992). Considerable sensitivity and flexibility is required in this matter. For example, some may feel intimidated and excluded by the unfamiliar jargon exchanged with assurance between professionals, while others, undeterred, will demand to be apprised of every bit of available knowledge. Staff need to accommodate individual demands. As far as possible, information, such as a review of data or assessment results, should be linked to parents' existing beliefs – which may include stereotypes and/or superstitions – and allowance should be made for the fact that parents may have to *actively* modify significant concepts and attitudes (Murphy, 1990). It is important for professionals to respect parents as partners in the child's treatment by keeping them updated rather than pathologizing and alienating them (Johnson, Renaud, Schmidt & Stanek, 1998; Seligman & Darling, 1989). Doctors should seek to demystify the condition through the provision of examples which clearly demonstrate the meaning of any specialist terminology employed (Murphy, 1990), particularly where this may be associated with widely held misconceptions (Quine & Pahl, 1986). Parents appear to be reasonably satisfied with information provided in respect of their child's medical condition, but less so in respect of family centered issues - also deemed to be the province of the paediatrician. Researchers agree that level of satisfaction appears to correlate inversely with maternal educational level and SES (O'Sullivan *et. al.*, 1992; Sloper & Turner, 1993a) but dispute the influence of infant morbidity. O'Sullivan *et. al.* (1992) claim a negative relationship between

McNaughton, 1991; O'Sullivan *et al.*, 1992). Citizens of the United States of America are protected by law in this regard and consequently, parents have reported moderate satisfaction with this aspect of the service. However, further expectations that paediatricians would offer referrals in respect of family centred - i.e. *non-medical* - issues remain largely unmet, leaving parents dissatisfied with the level of helpfulness in this regard (Byrne & Cunningham, 1985; Johnson *et al.*, 1998; McNaughton, 1991; O'Sullivan *et al.*, 1992). Reports from the United Kingdom (Turner & Sloper, 1992) and Holland (de Graaf & de Graaf-Posthumus, 1998) have indicated that referrals to community organizations or parent support groups do not meet parents' expressed needs. Hence, ideally, doctors should liaise with such ancillary services as may exist in the vicinity in order to facilitate appropriate patient / agency contact.

Thus the paediatrician must lay the groundwork for future parent – professional co-operation by integrating the essential elements of the disclosure interview with the particular needs of each unique parent. Those in daily contact with illness and disability need to guard against desensitization by remaining ever mindful of the level of devastation unleashed as each set of parents receives the diagnosis (Cherry, 1986).

Chapter Three

Parental Reaction and Adaptation: an Overview of Theories

Images represented in the literature of parental reaction to disclosure have altered over the past few decades. Socio-political changes reflected, for example, in the growth of the human rights movement and the ensuing momentum created in respect of advocacy work for marginalised groups, the broader consciousness of - and subsequent objection to - pejorative constructions of disability resulting largely from the dominance of the medical model, together with concomitant developments in research practice – particularly the increasing use of qualitative methods in the social sciences – have all contributed to this shift.

While much has been written about the need and /or capacity for parental adaptation to a child with a disability, no definitive signification of the concept has emerged from the literature. Authors' liberal use of the term seems to have presumed a colloquial conceptualization implying simultaneously a *process* and an *end-state*. Consequently, adaptation has been operationalized variously in terms of prescribed developmental stages (see 3.2 below) or via different permutations of interacting measures such as maternal depressive symptoms, marital adjustment, maternal parenting environment (Bristol, 1987 in Bristol, Gallagher & Schopler, 1988), parental depression, marital adjustment, disruption of family routines and “observed parenting environment” (Bristol *et al.*, 1988 p 443), comprehensive measures of stress including subscales for attachment, depression, health, isolation, spousal relationship and parental experiences of life experience and satisfaction (Hanson & Hanline, 1990), emotional distress, physical health and social functioning (Wallander, Varni, Babani, DeHaan, Wilcox & Banis, 1989; Wallander, Pitt & Mellins, 1990) and mental health or psychosomatic symptoms, general satisfaction with life and acceptance of the child (Sloper & Turner, 1993b), any of which could serve as independent or dependent variable depending on the purpose of the investigation (Byrne & Cunningham, 1985).

It therefore seems pertinent to consider some of the major contributions in this field.

3.1 Early work

During the 1950's the topic of congenital handicap became the focus of considerable research interest (e.g. Blodgett, 1957 in Blacher, 1984; Evans & Carter, 1954 in Lombard, 1992; Holt, 1958 in Lombard, 1992; Kanner, 1953 in Blacher, 1984; Rosen, 1955 in Blacher, 1984; Schonell & Watts, 1957 in Lombard, 1992; Zuk, 1959 in Blacher, 1984) with much of the literature locating itself in a discourse of pathology. This culminated in the publication in 1959 of Farber's classic monograph in which he investigated and described parental and sibling reaction to the birth of a severely retarded child as a function of differing family organizations (Kazak, 1986; Lea, 1986). Over and above the adjustment typically necessitated by the addition of *any* new family member, Farber identified a period of "arrested family development" (Farber, 1959 in Kazak, 1986 p267) following disclosure - a disjuncture, with potentially deleterious sequelae in respect of the family system.

A number of publications followed during the early 1960's in which constructions of exceptional infants and their parents continued to be infused with pessimism (e.g. Farber, 1960; Jordan, 1962; Olshansky, 1962; Solnit & Stark, 1961). For example, drawing on his clinical experience, Olshansky (1962) claimed that the grief and sorrow which are re-experienced by parents at each of the points of transition in their child's life, such as entry into adolescence or adulthood, can never be fully resolved i.e. they are *chronic*. He therefore cautioned that, rather than expecting to induce a state of final acceptance, mental health workers should aim to assist parents in the ongoing *management* of feelings in respect of their disabled child. Solnit and Stark (1961) equated parents' experience of loss with that which occurs during bereavement, but without the opportunity for closure which death affords. Adopting a psychoanalytic perspective, they explored the problems that arise in the period during which parents struggle to reconcile accumulating evidence of their infant's deficiencies with cherished fantasies of the anticipated perfect child.

Throughout the 1960's and into the mid-1970's the family served as an object of curiosity (Goffman, 1963 in Lea, 1990) with opprobrious constructions of children with a disability and their parents continuing to appear in the literature. Young (1977 in

Blacher, 1984), for instance, compiled an overview of contemporary work on 'defective children'. The concept of the 'handicapped family' was introduced (Fotheringham & Creal, 1974; Goldie, 1966; McMichael, 1971 in Burden & Thomas, 1986) wherein it was held that the diagnosis of permanent disability within a child was a social and emotional setback of such magnitude that the family as a group could not be expected to recover.

The impact of labelling began to be investigated and it was acknowledged that, by virtue of their proximity to a disabled person, members of the immediate family acquired a "courtesy stigma" (Goffman, 1963 in Lea, 1990 p216). Parents were blamed for their children's problems and were accorded "guilt by association" (Darling, 1979 in Wright, Matlock & Matlock, 1985 p37) - such guilt having earlier been identified as the central organising dynamic and ultimate impediment to parental adjustment (Zuk, 1959 in Blacher, 1984). Criticism has been leveled at much of this work, not only for its disparaging nature, but also on the grounds that it offered no theoretical framework within which to promote understanding or develop intervention strategies (Byrne & Cunningham, 1985; Lea, 1986).

3.2 Stage Theories

The publication in 1969 of Kübler-Ross' landmark text *On Death and Dying* spawned a resurgence of interest in stage theories as a means of documenting, defining and thereby predicting the normal developmental sequence of the psychosocial aspects of close family members' reactions to a relative's chronic illness, disability or terminal disease. The book's bold treatment of the somewhat taboo subjects of bereavement and loss - issues central to exceptional parenting - provided the impetus for similar work in the field of neonatal handicap. A profusion of publications delineating stages of mourning and recovery pertaining specifically to the parents of children with a disability ensued. See, for example, Bristor (1984 in Bernier, 1990), Burden (1978 in Judson & Burden, 1980), Drotar, Baskiewicz, Irvin, Kennell and Klaus (1975 in Blacher, 1984), Emde and Brown (1978 in Bernier, 1990), Fortier and Wanless (1984 in Bernier, 1990), Gath (1985), Huberty (1974 in Shapiro, 1983), Huber, (1979, in Blacher, 1984), Jacobson (1979 in Shapiro, 1983), Kennedy (1970), Love (1973 in Blacher, 1984), Parks (1977 in Bernier, 1990), Shokeir (1979 in Shapiro, 1983) and Wright (1976).

From the foundation of Kübler-Ross' work, theorists frequently incorporated Bowlby's views on infant attachment and loss together with their own clinical observations in the formulation of their descriptive models. Consequently, despite an inevitable degree of variability, considerable coherence was evident across the majority of models – each of which outlined a sequence incorporating most of the following: an initial phase of grief and shock; a phase of disorganization incorporating denial, anger, guilt, shame, hopelessness, blame and anxiety; a bargaining phase in which alternative diagnoses are sought through 'doctor-shopping', hopes are raised and a period of 'anticipatory waiting' (for a more optimistic diagnosis) is experienced; a phase of depression and despair following confirmation of the original diagnosis; and a final stage of recovery including acceptance, resignation, reorganization and orientation towards the future (Bernier, 1990; Blacher, 1984; Shapiro, 1983).

The leading stage theories are summarized in Table 3.1.

Overview of Major Stage Theories: 1950 – 1980

Study	Stages	Data Source
Blodgett (1957)	<ol style="list-style-type: none"> 1. Rejecting the diagnosis <ol style="list-style-type: none"> a) overprotecting the child b) attempting to make the child normal 2. Accepting the diagnosis <ol style="list-style-type: none"> a) reacting with a rejecting attitude towards the child b) overprotecting the child 3. Accepting the diagnosis realistically. 	Parents (No details given) Not specifically stated. Appears to be based on experiences and observations with parents
Bowlby (1960)	<ol style="list-style-type: none"> 1. Thought and behaviour still directed toward the love object 2. Hostility 3. Appeals for help 4. Despair, withdrawal, regression and disorganization 5. Reorganization of the behaviour directed toward a new object 	Based on the work of others (e.g. Elliot, 1955; Lindemann, 1944; Marris, 1958; Shand, 1920) who have described common patterns of response to grief
Boyd (1951)	<ol style="list-style-type: none"> 1. Self-pity 2. Concern for child 3. Objectivity, resolution and acceptance 	Personal experience as parent.
Drotar, Baskiewicz, Irvin, Kennell & Klaus (1975)	<ol style="list-style-type: none"> 1. Shock 2. Denial 3. Sadness, anger and anxiety 4. Adaptation 5. Reorganization 	Mothers (N=20) Fathers (N=5) Open-ended interviews
Emde & Brown (1978)	<ol style="list-style-type: none"> 1. Denial 2. Mourning 3. Acceptance 	Mothers (N=6) Interviews and tests over six months
Farber (1960)	<ol style="list-style-type: none"> 1. Tragic crisis (initial crisis at time of diagnosis, resembling bereavement; anticipated life careers are frustrated and plans are demolished) 2. Crisis of role organization (inability to cope with the child over a long period of time) 	Mothers (N=not stated) Interview in the respondents home – oral section and written section
Huber (1979)	<ol style="list-style-type: none"> 1. Denial 2. Anger 3. Bargaining 4. Depression 5. Acceptance 	Parents (No details given) Based directly on Kübler-Ross (1969)
Jackson (1974)	<ol style="list-style-type: none"> 1. Shock and disbelief 2. Developing awareness 3. Restitution 	One young couple Applied Solnit & Stark (1961)
Kanner (1953)	<ol style="list-style-type: none"> 1. Complete inability to face reality 2. Disguises of reality 3. Mature acknowledgement of actuality 	Mothers (N=5) and Fathers (N=5) Case studies (based on author's experience with parents)

continued...

While allowance was made for some variation in the sequence within which stages were encountered, including revisiting of aspects previously negotiated, professionals were rigid in their view that the absence of a serial mourning process precluded healthy psychological adjustment. Wright (1976), for example, was adamant that the six stages which he identified must be worked through if the “host of fears” which consumed parents were to be overcome, and even predicted that for those who sought to resist this process “recovery w[ould] remain elusive, and guilt and shame and resentment w[ould] be their constant companions” (p 161).

Stage models served a useful purpose in that they furnished health service providers with a guideline for anticipating parental behaviour – thereby enabling them to render stage-appropriate support and intervention, as well as to discriminate pathological responses from the emotional lability that typically pervades the ‘normal’ adaptation process. Despite their intuitive appeal, however, stage models were limited in the sense that, while they may have given a detailed *description* of behaviour, they made no attempt to *explain* it (Shapiro, 1983) and hence provided no insight into the dynamics operating within and between family members.

Inevitably, with time - and social change, stage theories fell from favour. Authors challenged their validity on epistemological grounds. Blacher (1984), for instance, objected to the absence of “quantitative analyses of objectively gathered data” (p 64). She questioned the ontological merit of subjective measures - such as the use of clinical judgement based on observations and interviews with parents - in the derivation of stage theories. Theories thus formulated, it was argued, were *inferred* from parents’ (usually mothers’) cognitions about their child’s condition rather than being traced from actual records of their reactions. Furthermore, qualitative methods were deemed more susceptible to the influence of an accumulation of “popular wisdom” (Sieffert, 1978 in Blacher, 1984 p 65) and hence were viewed with skepticism.

Such empirical studies as were conducted revealed a broad variation in responses from individuals (e.g. Allen & Affleck, 1985; Silver & Wortman, 1980 both cited in Bernier, 1990) suggesting that the notion of a linear, sequential grief process satisfied

researchers' proclivity for order rather than reflecting objective reality. Consequently, professionals who attempted to force case material to fit the model, without due regard for the many mediating factors, may have been deemed to have rendered a grave disservice to their patients. A case in point was that of Lloyd S. Wright who, having been a vociferous champion of the stage model (Wright, 1976), subsequently berated himself for implicitly apportioning blame and perpetuating negative stereotypes of exceptional parents through his dogmatic approach (Wright, Matlock & Matlock, 1985). Similarly, Robert L. Burden shifted from slavish adherence to the dominant model of the era (Burden, 1978 in Judson & Burden, 1980) to an enlightened view, acknowledging a variety of potential influences and allowing for individual difference in parental reaction (Burden & Thomas, 1986).

3.2.1 The need for Alternate Models

Hence it has been recognized that, rather than being a discrete crisis from which parents effect a final recovery, the presence within the family of a child with disability constitutes a permanent stressor requiring ongoing adjustment and adaptation throughout the parents' lives (Sloper & Turner, 1993b). Besides diagnosis, certain transition periods such as school entry, adolescence and school leaving (when the discrepancy between socially prescribed norms and reality is particularly striking) are believed to be sites of renewed distress, activating earlier concerns, constellating anxiety and apprehension and potentially regenerating crises for the parents (Wikler, 1981). It has therefore become necessary to seek theoretical understandings which acknowledge the multifaceted, circumambulatory nature of the adjustment and adaptation process.

3.3 The Systems Approach

Systems theory, as conceptualized by von Bertalanffy (1968 in Bernier, 1990) has as its central tenet the notion that constituent parts are meaningful only when viewed in relationship to one another and to the whole. Originating in the natural sciences, this theory incorporates the concept of the closed system, which functions internally without reference to its surroundings, and the open system, which has a reciprocal relationship with the environment. It was recognition of the ready generalizability of the latter to

other disciplines - such as the human and behavioural sciences (von Bertalanffy & Rapoport, 1956 in Lombard, 1992) that led to the formulation of a 'general systems theory' as expounded by von Bertalanffy (1968 in Lombard, 1992).

Gregory Bateson (1971), a prominent contributor in the field of family relationships during the mid-twentieth century, defines a system as "any unit containing feedback structure and therefore competent to process information" (p243). Contrasting with von Bertalanffy's understanding of a system primarily in terms of mass and energy, Bateson employs an "epistemology based on cybernetics" (Tomm, 1984 p118) wherein he views a system in terms of its capacity to self-regulate on the basis of circulating data. He further contends that in order to understand a phenomenon, it must be considered "within the context of all completed circuits that are relevant to it" (Bateson, 1971 p244) i.e. in relation to any other system with which it comes into contact.

Extrapolating therefore, the individual (e.g. parent), as part of an open system (i.e. the family), cannot be understood in isolation but must be seen to function in mutual interaction with others inside (e.g. spouse, children) and outside (e.g. teachers, doctors, therapists, support groups) the system. Application of the systemic approach requires a holistic as opposed to a reductionistic understanding (Tomm, 1984) which recognizes the interdependence of system members upon each other and on other systems. Ideally, a system such as a family should experience evolution, yet maintain homeostasis i.e. a level of stability and internal integrity (Shapiro, 1983). Departures from this ideal are assessed in terms of the (circular) *effect* of family members' behaviour on the system, rather than their supposed *intentions* (linear causality) (Tomm, 1984).

3.3.1 Bronfenbrenner's Social Ecology

Similarly informed by Gestalt psychology, Bronfenbrenner (1979 in Thomas, 1992) adopts a social-ecological perspective within which he proposes a model for examining and understanding the developing child. Aside from the purpose for which it was originally conceptualized, this model lends itself to a broad range of applications including that of parental adaptation in the presence of multiple stressors (Kazak, 1986).

In his conceptualization of the relationship between contexts, Bronfenbrenner employs the metaphor of Russian dolls (Pellegrini, 1991), wherein each is embedded within a larger unit. He envisages a system of “nested concentric structures” (Kazak, 1986 p265) encompassing four levels, namely:

- i) The Microsystem. The innermost level comprising behaviour settings within which the individual assumes a certain rôle and performs activities via close interpersonal relationships. Membership of more than one microsystem is likely – even desirable. Examples include the family, work and social groups.
- ii) The Mesosystem. This level contains all of the microsystems and focuses on the reciprocal relationships that exist between them. Given that the individual holds a different rôle in each, analysis of his/her behaviour across diverse settings typically provides evidence of idiosyncratic or situation-specific behaviour. It is here that support for Bronfenbrenner’s thesis of human ecology is most striking.
- iii) The Exosystem. Operating beyond the mesosystem, this level is comprised of those groups or forces with whom the individual has no immediate contact, but with whom an indirect relationship of mutual influence exists. Structures for determining educational policy, for example, would exist in the exosystem.
- iv) The Macrosystem. Representing the outer layer of the model, the macrosystem incorporates the broader cultural, political, legal, economic i.e. *social* systems governing the environment, with the potential to influence or be influenced by the individual whose development (functioning) is being examined.

Despite its heuristic appeal, few researchers have employed this model in their investigations of the experiences of exceptional parents (Bernier, 1990) probably as a result of the methodological problems with which it is plagued. Operationalization of such a complex and dynamic framework is a challenging undertaking (Bradley, Rock, Whiteside, Caldwell & Brisby, 1991), making internal validity difficult to achieve (Oliveri & Reiss, 1984) – particularly when it is borne in mind that in terms of the “systems axiom of nonsummativity.....information obtained from isolated parts of the system cannot be summed to represent the whole system” (Keeney, 1979 p119). Accordingly therefore, the practice of deriving abstractions regarding *circular* family dynamics from

linear measures of individuals (Kazak, 1986; 1989; Keeney, 1979) represents an ecological fallacy, with axiomatic negation of inferences (Mouton & Marais, 1990) and should be avoided.

3. 4 The ABCX Model

In the aftermath of the Second World War, Reuben Hill studied the family's ability to adapt following stressors ranging in degree from hardship, such as loss of the breadwinner's income, to catastrophe, such as the sudden death, enemy capture or disablement of one of its members (Hill, 1949 in Cherry, 1989). In an attempt to recognize the dynamic nature of family groups and to accommodate the complex processes that constitute their interaction, Hill formulated the ABCX Model of family stress. Here, the initial *impact* of the stressor (identified as the degree of disturbance manifest within the family in the short term) was considered to be a function of:

- Factor A: the stressor *event* itself;
- Factor B: the perceived and/or actual *resources* at the family's disposal; and
- Factor C: family members' subjective *perception* of the stressor.

To the extent that the family system proved unable to withstand the disruption or restore its equilibrium, but instead experienced a persistent demand for change, *crisis* may be deemed to have resulted. This was signified as factor X (Cherry, 1989).

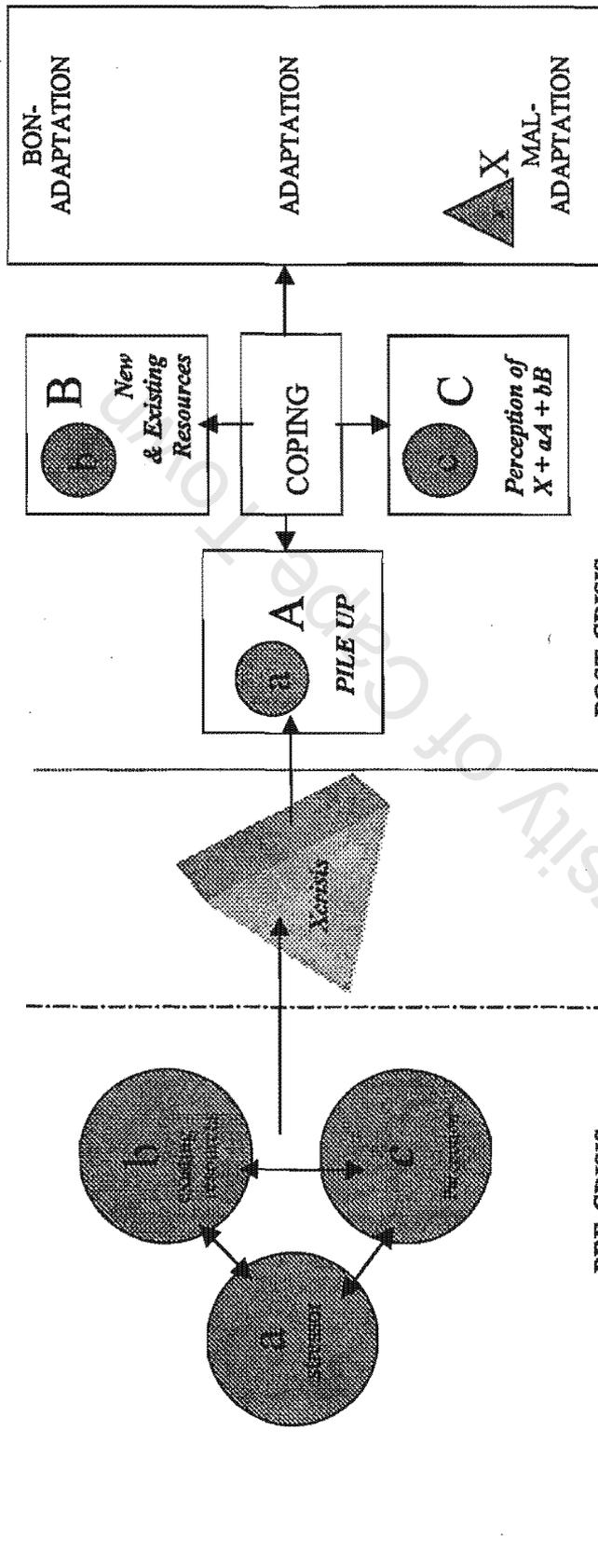
For Hill (1949 in Cherry, 1989) crisis served as the outcome of interest and it was left to subsequent researchers (M^c Cubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980 in Lombard, 1992) to describe the ensuing period of chaos, followed by recovery, leading ultimately to an enhanced level of organization, typically seen in families. Minnes (1980) noted that, where disruption had threatened to precipitate a crisis, the family's response would depend upon the source of the event, its effect on the configuration of the family, and whether the event was normative or non-normative.

Nonetheless, Hill's model, while not specifically designed with childhood incapacity in mind, proved useful in that it provided a framework for conceptualizing the interactive forces at work. Notably, he acknowledged the mediating rôle in the experience of crisis

of factors both internal (such as personality; previous experience of similar stressors) and external (e.g. social support; SES, extent of damage) to the family group (and its constituent members).

3. 4. 1 The Double ABCX Model

Working some four decades later, McCubbin and Patterson (1983 in Cherry, 1989) expanded Hill's original idea and developed what they termed the Double ABCX Model of Adaptation in which Hill's model was 'doubled' in the sense that a second, similar cycle was deemed to occur in the event that any crisis resulting from the first cycle had not been satisfactorily resolved. This took into account cumulative effects of the original stressor, particularly where this was chronic. See Figure 3.1.



The Double ABCX Model of Adjustment and Adaptation
 McCubbin & Patterson (1983 in Cherry, 1989)

Figure 3. 1

In the above figure, the a, b, C and X in the *pre-crisis* phase on the left of the diagram, correspond to the four factors of the original ABCX model.

Factors in the *post-crisis* cycle on the right of the diagram may be understood as follows:

- aA represents the increased demands on the family resulting from the cumulative effect of hardships compounding over time, particularly if a (the stressor) is chronic;
- bB refers to enhanced coping skills which the family may have acquired through reading, therapy or training, together with increased social support which may have been developed through contact with support groups, greater involvement with the extended family or cultivation of an explicit, shared belief system amongst intimate family members, especially parents;
- CC refers to the altered perspective that evolves within the family on the basis of advancing insight derived from clarification of and familiarity with germane issues. Such redefinition of the stressor depotentiates the emotional burden, thereby facilitating coping. It is here that professional intervention has the greatest potential for success;
- XX signifies the level of adaptation resulting from the interaction between the aA, bB and CC factors. Rather than reflecting pressure for change, this double X factor represents the altered dynamics of a more permanent nature into which the family has settled *post crisis*.

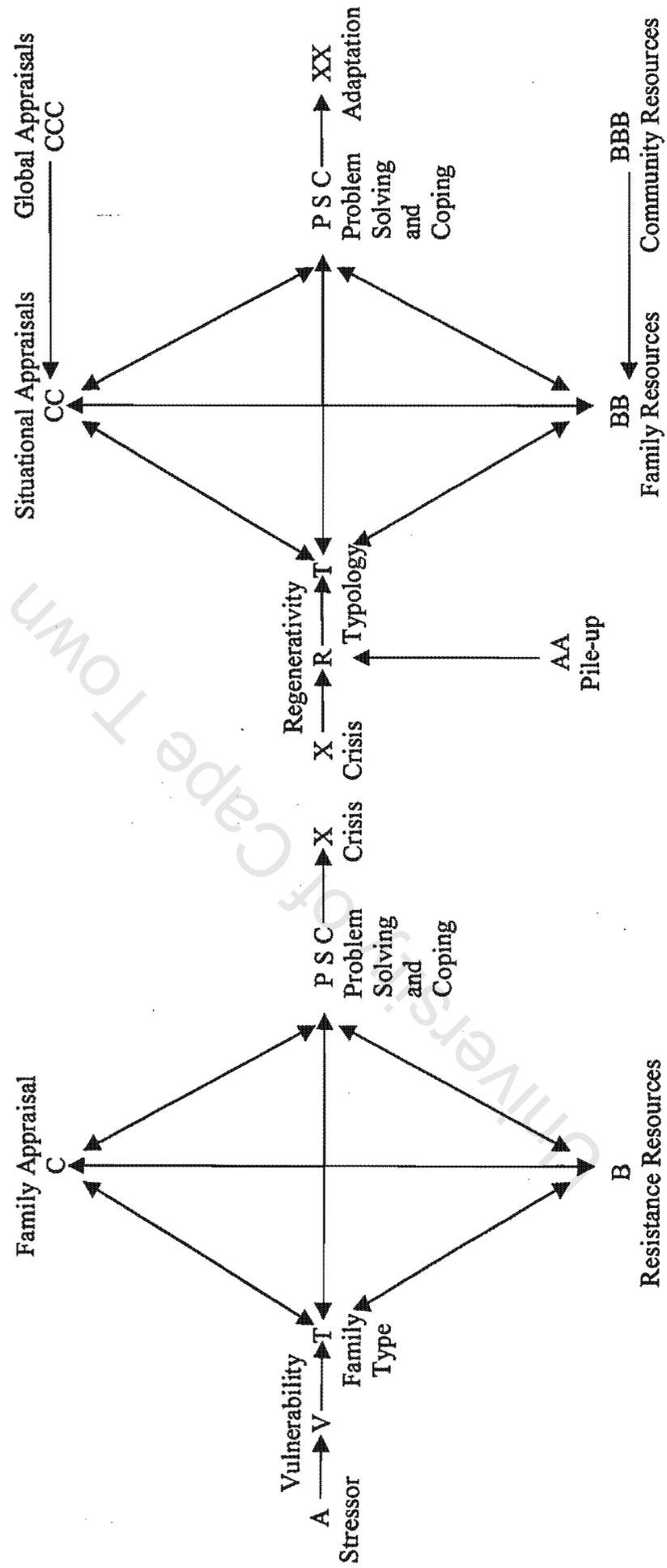
The expanded model of McCubbin & Patterson (1983 in Cherry, 1989) provides a convenient matrix within which clinicians and researchers may conceptualize dynamic forces operating inside the family. Its generic form renders it universally applicable, irrespective of the nature of the stressor. That it is particularly suited to the family with a chronically ill or disabled child has been cogently argued by Cherry (1989).

3. 4. 2 The T-Double ABCX Model

Further developments in the field led to the evolution of the T-Double ABCX Model of Adaptation (McCubbin and McCubbin, 1987 in Reddon, McDonald & Kysela, 1992), also known as the Typology Model of Adjustment and Adaptation (Lombard, 1992). As before, pre-crisis and post-crisis phases of reaction to extraordinary stress are outlined. These are now known as the adjustment and the adaptation phases. Where this model differs from the former is that it places emphasis on family *types* and incorporates a broader range of potential influences. See Figure 3.2.

University of Cape Town

Outline of the Adjustment Phase of the T-Double ABCX Model Outline of the Adaptation Phase of the T-Double ABCX Model



Adapted from McCubbin and McCubbin (1987 in Reddon, McDonald & Kysela, 1992)

Figure 3. 2

3.4.2.1 The Adjustment Phase

This is the pre-crisis phase during which the stressor is introduced into the family system, interacts with and is countered by mechanisms in its existing repertoire. If sufficient, this may lead to positive adjustment, if not crisis may be precipitated.

The factors which constitute this phase are:

- **A Stressor**

This factor corresponds with the A factor in Hill's ABCX Model as well as the a Factor in the Double ABCX Model of McCubbin and McCubbin (1983 in Cherry, 1989). It represents a transition point or stressful life-event (such as, for example, the birth of a child with physical handicap) which places demands on the family system of sufficient capacity to warrant constitutional change. To the extent that the balance within the family is threatened or disrupted in the process, so the severity of the stressor is gauged.

- **V Vulnerability**

This refers to demands acting upon and within the family system concurrently with the new stressor, which may occur as a function of the particular stage in the life-cycle at which the family finds itself and its concomitant resources.

- **T Family Type**

Family typology refers to the classification of families according to criteria such as organization, behaviour and balance – particularly with respect to adaptability (i.e. capacity to effect structural change in response to stress (Lee, 1988)). Recognising these characteristic variations within families, McCubbin and McCubbin (1987 in Lombard, 1992) have incorporated typology as a factor in their model, distinguishing it in this respect from its predecessors. Differing family types are predisposed to crisis to a greater or lesser degree. The type best equipped to avert a crisis is the balanced family i.e. the family that can maintain equilibrium despite undergoing major internal reorganization in respect of power and rôle relationships (Lee, 1988) - such as may be required of the family with a cerebral-palsied child.

- **B Resistance Resources**

This corresponds with the eponymous factor from the ABCX and Double ABCX Models outlined above. It refers to existing strengths and resources within the family which serve to facilitate resilience, ward off crises and promote adjustment in the face of potentially destabilizing hardships or stressors. Degree and sufficiency of organization - reflected in the family's level of cohesion, interdependence, affection and adaptability - is positively correlated with resistance.

- **C Family Appraisal**

As before, this factor designates family members' subjective perception of the stressor and its likely effect on their lives. Views are informed by individuals' past experience of similar events, leading to idiosyncratic variations within families – a potentially destabilizing influence. The unifying effect of shared family values may serve to overcome this to some extent, however.

- **PSC Problem Solving and Coping**

In interaction with all the foregoing, the family's existing problem-solving skills and coping mechanisms will determine whether or not the stressor event is sufficient to precipitate crisis.

- **X Crisis**

Crisis results where persistent demands for change exceed the family's capacity to assimilate them. A state of disorganization prevails, negation of which can only be achieved through major restructuring in respect of rules, boundaries and behaviour patterns.

3.4.2.2 The Adaptation Phase

Given that the adjustment strategies employed within the family have proved insufficient to prevent crisis, advancement into the adaptation phase becomes inevitable. Here the focus is on those positive aspects of family functioning that can be activated, stimulated and drawn into service in order to promote satisfactory negotiation of the prevailing exigency. Where minor adjustment was anticipated for the restoration of homeostasis in the previous phase, the necessity for radical reorganization is implicit with entry into this phase. Characteristics both internal and external to the family group and its individual

members are deemed to operate conjointly in determining the degree of adaptation attained, the ultimate goal always being to “achieve a new balance and fit at both the individual-to-family and family-to-community levels of functioning” (McCubbin & McCubbin, 1987 in Reddon *et al.*, 1992 p2).

This phase comprises the following factors:

- **R Regenerativity**

Corresponding with the vulnerability factor in the adjustment phase, regenerativity refers to the capacity of family members, having accepted that crisis has indeed developed, to marshal the resources necessary to meet the escalating demands with which they are faced. The question of how well the family is situated to undergo major reorganization is raised and this, in turn, is informed by factor **AA**.

- **AA Pile-up**

Aside from the initial demands placed on family resources, new sources of strain arise in the aftermath of a major stressor, even when this comprises a single event. Clearly a chronic or prolonged stressor such as permanent disability introduces additional hardships that potentially *pile-up* i.e. compound over time, depleting existing resources and impairing the family’s usual level of functioning in regard to other, incidental matters. Exacerbating factors include negative emotions resulting from previous, unsuccessful attempts to adjust and escalating ambiguity with regard to intrafamilial as well as social roles.

- **T Typology**

This factor was introduced into the model on the basis of the conviction that adaptation evolves, not only from the tension between demands and resources, but also as a function of differing family types.

- **BB Family Resources**

This refers to the redoubled effort that must be made - both individually and collectively - to process the demands of the stressor constructively. These may include skills acquired in the course of the pre-crisis phase and will be enhanced by judicious use of **BBB** factors.

- **BBB Community Resources**

Located externally, these complement the family's internal resources and may provide support of a practical nature, such as access to specialized equipment, or of a psychological nature, such as membership of focus groups.

- **CC Situational Appraisals**

This refers to members' subjective assessment of the family's current situation with respect to the stressor. To the extent that available resources (factors BB and BBB) and restorative measures (factor PSC) are deemed propitious, a reasonably positive, adaptation-promoting outlook can be achieved.

- **CCC Global Appraisals**

Beyond the immediate concerns generated by the stressor, lie concerns regarding the family's capacity to preserve its integrity with regard to internal functioning, as well as to maintain a position in the broader community in keeping with previously held schemata. While life-stage appropriate evolution of such schemata is to be expected, radical deviation from desired status can seriously threaten the family's equilibrium.

- **PSC Problem - Solving and Coping**

Despite earlier failure in this regard, past experience should inform the present situation. Coping, as constituted by pro-active attempts to alleviate stress and tension, is essential. The ability to implement suitable solutions in response to unique demands is crucial to successful adaptation.

- **XX Adaptation**

The ultimate outcome measure, this is directly dependant on the previous (PSC) factor, and indicates to what extent balance has been restored following the major reorganization necessitated by crisis. This reflects both internal family dynamics and the family-community relationship.

Clearly, of all the models, the T-Double ABCX model offers the most comprehensive framework within which to evaluate the forces interacting to promote or hinder the adaptation process.

3. 5 The Stress Model

Another conceptual model which has provided the basis for the study of parental adaptation is that derived from the cognitively oriented theory of stress and coping of Lazarus and colleagues (Folkman & Lazarus, 1985; Folkman, Lazarus, Gruen & DeLongis, 1986; Lazarus, 1993; Lazarus & Folkman, 1984). As early as 1952, while still operating in the shadow of the behaviourist movement, Lazarus and colleagues recognized that a simple stimulus-response model was insufficient to explain the effects of stress and argued that the characteristic contribution of intervening variables had to be acknowledged (Lazarus, 1993). A considerable volume of research on the subject culminated in the publication with Susan Folkman in 1984, of the oft-cited tome *Stress, Appraisal and Coping* in which their explication of the relationship between these concepts was set forth.

In terms of their theory, stress is explained as a function of the person-environment relationship, wherein it is held that the degree of stress experienced can neither be predicted nor measured from the precipitating event alone. Rather, stress is construed as a subjective process evolving from the interaction between i) the individual's *perception* (appraisal) of an event and ii) the availability of resources - such as social support network and coping strategies - with which to countermand any potentially harmful effects.

Appraisal, as conceptualized by Lazarus, refers to the cognitive aspect of the equation. Operating on two levels - reflecting personal investment and coping options (Folkman *et al.*, 1986), it is a type of monitoring process, believed to function continuously in humans (and animals) (Lazarus, 1993) in the interests of self-preservation. It performs a mediating function between the individual's values and belief system and the demands, limitations and contributions of the environment in which s/he exists and as such is responsible for individual differences (Lazarus & Folkman, 1984).

The model recognizes the dynamic nature of the constituent elements and consequently of their interrelationship (Folkman & Lazarus, 1985). Demands perceived to outweigh resources, prompt negative appraisal, leading to ineffective coping and increased stress.

Success wrought from renewed efforts to cope permits favourable appraisal and a consequent decline in stress. Fluctuation in any one factor affects the other two. Thus stress, appraisal and coping are bound in a recursive pattern.

A number of researchers have applied the stress model to good effect in their investigation of the adjustment and adaptation process (e.g. Dunst, Trivette & Cross, 1986; Frey, Greenberg & Fewell, 1989; Gallagher, Beckman & Cross, 1983; Minnes, 1988; Peterson, 1984 in Bernier, 1990; Sloper, Knussen, Turner & Cunningham, 1991; Sloper & Turner, 1993b; Wallander & Venters, 1995). Viewing the birth of the child as the event, and coping and available sources of social support as mediating factors, adaptation (which may incorporate a measure of stress) is held to be a product of the person-environment relationship.

From this brief review of early work in the field, stage theories, the application of systems theory and the stress model, it is evident that the question of parental adaptation to a child with a disability has been reasonably thoroughly investigated. Each approach has attempted to reflect the complexity of the interacting forces – each has succeeded to a greater or lesser degree, for as Bernier (1990) has so astutely observed “no single theory adequately describes, much less predicts, the course of a parent’s adaptation” (p595).

Chapter Four

On being an exceptional parent: Factors influencing adaptation.

In raising a differently-abled child, parents are faced with a range of challenges and opportunities extending far beyond anything they may have anticipated or for which they could possibly have been prepared (Paul & Beckman-Bell, 1981). For instance, in seeking merely to secure services aimed at fostering their child's development, they may find themselves having to assume the rôle of advocate (McAnaney, 1990). In South Africa, as elsewhere – see for example, Lehmann and Roberto (1996), attempts at mainstreaming have been largely unsuccessful in that teachers have been ill-equipped to accommodate children with special needs (Donald, 1994), particularly those with severe physical disability (McDonald & Howie, 1992), and thus parents have frequently found themselves at variance with these and other service-providers. With the child's continued progress, new areas of resistance are likely to be encountered (Mittler, 1990) - especially from established institutions (Mullins, 1987) - and hence parents are forced to empower themselves (de Graaf & de Graaf-Posthumus, 1998), to cultivate the capacity to confront social convention (McNaughton, 1991) and to contest rigidly held biases in order to sustain their child and best promote his/her interests. While this may be a daunting prospect for some, for others it can bring fulfillment in that it provides the impetus for a lifetime of lobbying, activism and advocacy work with repercussions extending far beyond the original objective, namely to satisfy the needs of their own children (cf. Wickham-Searl, 1992).

Contingencies of such a formidable nature are not limited to the public domain. Accommodation - in the sense of necessary, practical changes or "functional responses" (Gallimore, Coots, Weisner, Garnier & Guthrie, 1996 p216) - within the home and parental subsystem must also be achieved. These may include such perfunctory measures as adjusting the daily routine in order to allow travelling time to distant facilities (Crowe, 1993; Korn, Chess & Fernandez, 1980 in Kazak, 1986) or making structural alterations to the building in order to provide wheelchair access (Hewett, Hewett & Newson, 1970 in Kazak, 1986), or measures of a more profound nature such

as redistribution of roles within the family (Kazak & Marvin, 1984), or reduction in outside employment leading to restriction of career aspirations for one or both partners (Barnett & Boyce, 1995) due to extra demands for childcare. In some cases the proximity of a school or health-care facility may dictate residential as well as occupational/employment options.

Accommodation will also incorporate financial considerations. In addition to the reduction in earnings resulting from curtailed employment, frequent medical consultations and therapeutic interventions such as speech therapy, occupational therapy or physiotherapy, the need for operations, specialized equipment, nursing and day-care can present the parents with a considerable financial burden. The potential for ongoing expenditure, even beyond the parents' death, needs to be acknowledged with appropriate practical and financial arrangements being made where necessary (Hallum & Krumboltz, 1993). Failure to meet any of these or other obligations causes an accumulation of demands and serves only to heighten the degree and intensity with which their satisfaction is solicited.

From this glimpse of the practical implications inherent in caring for an exceptional child, the significance of the psychological aspects, the psychosocial variables and personality factors, involved in parental adjustment and adaptation becomes evident. Mothers' and fathers' individual perspectives will now be examined whereafter their joint experiences will be considered.

4. 1 The Exceptional Mother

By far the greatest number of studies investigating the impact of the exceptional child on the parents have concentrated on the mother as the chief respondent. See for example, Atkinson, Scott, Chisholm, Blackwell, Dickens, Tam & Goldberg (1995); Boyce, Behl, Mortensen & Akers (1991); Bradshaw & Lawton (1978); Chen & Tang (1997); Crowe (1993); Donovan (1988); Erickson & Upshur (1989); Fagan & Schor (1993); Friedrich (1979); Friedrich & Friedrich (1981); Fuller & Rankin (1994); Hanson & Hanline (1990); Harris & McHale (1989); Havermans & Eiser (1991); Henderson & Vandenberg (1992);

Lehmann & Roberto (1996); O'Sullivan, Mahoney & Robinson (1992); Quine & Pahl (1985); Quittner, Glueckauf & Jackson (1990); Ryde-Brandt (1991); Singer & Farkas (1989); Sloper & Turner (1991); Walker, Van Slyke & Newbrough (1992); Wallander & Noojin (1995); Wallander, Pitt & Mellins (1990); Wallander, Varni, Babani, DeHaan, Wilcox & Banis (1989); Wallander & Venters (1995); Warfield & Hauser-Cram (1996) and Wickham-Searl (1992). Indeed, this practice is so widely accepted that some researchers have generalised their findings to the *family* on the basis of maternal data alone (e.g. Boyce *et al.* 1991; Bradshaw & Lawton, 1978; Henderson & Vandenberg, 1992; Quine & Pahl, 1985; Walker *et al.*, 1992).

Compared with parents of healthy children, it appears that even amongst formerly egalitarian couples, parents of developmentally disabled children tend to adopt more traditional sex rôles (Schilling, Schinke & Kirkham, 1985), with the burden of primary care-giving typically being borne by the biological mother (Bristol, Gallagher & Schopler, 1988; Byrne & Cunningham, 1985; Gallagher *et al.*, 1983; Hallum & Krumboltz, 1993; Harris & McHale, 1989; Romans-Clarkson *et al.*, 1986). This may precipitate a shift in priorities between paid work (or study) and child care (Barnett & Boyce, 1995; Singer & Farkas, 1989), with low SES mothers being particularly hard hit (Breslau, Salkever & Staruch, 1982a in Wallander & Venters, 1995). In some instances, rather than simply availing themselves of maternity benefits (where available), mothers engaged in careers opt, or feel compelled, to defer such pursuits in favour of a full-time commitment to the parental rôle.

For example, findings of a large mail survey by Lie, Börjeson, Lagerkvist, Rasmussen, Hagelsteen and Lagergren (1994) conducted in Denmark, Finland, Norway and Sweden on mothers of children with myelomeningocele (MMC, a type of spina-bifida), indicated that 83 percent of women experienced vocational disruption (proportional to the degree of disability) as a direct consequence of their child's birth. While this is not unknown amongst mothers of children *without* special needs, it is significant that those who ultimately resume their careers tend to delay their return to permanent employment for longer (Freedman, Litchfield & Warfield, 1995) or compromise by electing to work part-time, in order to accommodate the particular needs of their exceptional children. This may be accounted for,

in part, by the considerable difficulty likely to be encountered by mothers, in locating a suitable, affordable day-care facility (Freedman, *et al.*, 1995; Lie, Börjeson, Lagerkvist *et al.* 1994), such difficulty escalating in proportion to the child's impairment (Warfield & Hauser-Cram, 1996).

Clearly then, the individual attention required by developmentally disabled children is characteristically more demanding than that of their able age-mates and this, in turn, translates into additional time constraints for the mother as primary care-giver (Harris & McHale, 1989; Schilling *et al.*, 1985; Tavormina, Boll, Dunn, Luscomb & Taylor, 1981). In order to investigate this, Crowe (1993) undertook a study of time use amongst three groups of mothers, one each of typically developing children, children with Down syndrome and multiply disabled children. It was found amongst the latter group that 63.34% of their waking hours were spent in homemaking and child-care, as opposed to 57.93% for mothers of children with Down syndrome and 45.56% for mothers of typically developing children. The disparity of approximately 40% reported between mothers of multiply disabled and mothers of well children concurs in general with other research in the area (e.g. Barnett & Boyce, 1995; Beckman, 1983; Bradshaw & Lawton, 1978; Harris & McHale, 1989). Similarly, in the aforementioned study by Lie, Börjeson, Lagerkvist *et al.* (1994), care-load was perceived to be extremely (21%), much more (42%) and somewhat more (29%) time-consuming than was the case for healthy children. Only 8% of mothers in the study reported no significant increase in care-load.

Variations of the above are found in studies by Erikson and Upshur (1989) where mothers of children with Down syndrome reported greater involvement in child-care than any of three other comparison groups, including the mothers of children with motor impairments, and Breslau (1983 in Barnett & Boyce, 1995) who reported an increase in housework but not in child-care for married mothers of children with physical disabilities. General consensus, nonetheless suggests that, for mothers of exceptional children, a significantly greater proportion of time is diverted from leisure/career activities to domestic/child-care work than is the case for mothers of typically developing children.

Consequent upon their reduced opportunities for professional and recreational pursuits, exceptional mothers have been known to feel thwarted (Holroyd, 1970 in Kazak, 1986), to find themselves accepting “deflated personal aspirations” (Wallander, Pitt & Mellins, 1990 p 818) and, in forgoing advancement, to bear high “opportunity costs” (Baldwin & Gerard, 1990 in Lie, Börjeson, Lagerkvist *et al.*, 1994 p1006). Where the nature of the child’s condition implies life-long dependence, this may become an ongoing problem affecting major life choices for mothers (Hallum & Krumboltz, 1993), well beyond the typical period of child-rearing.

The pessimism thus engendered is clearly not without justification. Maternal prospects for personal growth and career development are undoubtedly diminished. Breslau *et al.* (1982a in Wallander & Venters, 1995) coined the term “perceived rôle restriction” (p621) specifically to describe the feeling of having to curtail ones’ own interests as a direct result of the responsibilities inherent in the care of a physically disabled child, and it was this subjective aspect that Wallander and Venters (1995) ventured to explore. In their study of 50 mothers of children with either spina bifida or cerebral palsy, Wallander and Venters (1995) found that mothers’ *subjective perceptions* of being restricted served as a far better correlate of adaptation than any objectively derived measure of the level of disability or presence / absence of problem behaviours. Likewise, mothers’ subjective sense of the strength of their social support network predicted their perceived rôle restriction. As Wallander & Venters point out, perceived rôle restriction is inextricably linked to women’s goals and values which, in turn are influenced by the prevailing social and cultural context. Women from cultures in which the domestic rôle is viewed as primary feel less restricted than those for whom outside employment is encouraged. Not surprisingly, compared with men, for whom the rôle of breadwinner is virtually universal, the latter report a significantly greater sense of rôle restriction (Reddon *et al.*, 1992).

Accordingly, negative mood states are disproportionately high amongst mothers of children with disabilities. Disappointment and grief are recurrent (Bruce & Schultz, 1994). In their study comparing 54 mothers of children with various congenital handicaps (including 13 with cerebral palsy) with 184 control mothers, Romans-Clarkson *et al.* (1986) reported a significantly greater degree of psychiatric morbidity amongst the former group. Items such

as 'not feeling full of energy' and 'getting edgy and bad tempered' were most frequently endorsed by this group on the general health questionnaire (Goldberg, 1978 in Romans-Clarkson *et al.*, 1986). Significance remained even after social class and employment state had been controlled for.

Incidence of depression has been investigated by several authors. In a comparison of 31 mothers of developmentally disabled pre-school boys with 25 mothers of non-disabled boys of similar age, twice as many at-risk mothers (39% versus 20%) were identified in the disabled group (Bristol *et al.*, 1988). Chi-square tests failed to reveal significance, however. Similarly, work by Ryde-Brandt (1991) comparing 13 mothers of children with Down syndrome, 18 mothers of psychotic children, 18 mothers of children with motor handicap and 13 'supporting mothers' found that, while borderline depression scores were recorded for seven mothers of psychotic children and three mothers of children with down syndrome, statistically significant differences were not achieved. Notably, none of the mothers of children with motor disability had high depression scores.

Ryde-Brandt (1991) did, however, identify guilt feelings amongst mothers of children with mental retardation. These pertained mostly to their desire to spend time alone, away from the child. Compared with controls, discussion of family problems within this group was less extensive, seemingly due to the guilt-inducing capacity of this activity. In keeping with their hypothesis, Finnish researchers Juvonen and Leskinen (1994) found a correlation between guilt and a perception of having caused the child's condition. This was found to decrease mothers' acceptance of the disability. Conversely, the perception of responsibility for relieving the child's condition was correlated with hope and a concomitant increase in child involvement and acceptance (Juvonen & Leskinen, 1994). Amongst Chinese societies, congenital disabilities are viewed as a form of retribution for transgressions against Confucian teachings, in respect of which mothers deserve no assistance or reprieve (Chen & Tang, 1997).

The association between child-related characteristics and maternal adaptation has been reasonably thoroughly investigated. A number of researchers have reported an inverse relationship between the severity of the child's disability and the mother's well-being and

capacity to adjust (e.g. Bradley, Rock, Whiteside, Caldwell & Brisby, 1991; Havermans & Eiser, 1991; Lie, Börjeson, Lagerkvist *et al.*, 1994; Sloper, Knussen, Turner & Cunningham, 1991; Sloper & Turner, 1993b; Tew & Lawrence, 1975 in Kazak, 1986). Communication difficulties, in particular, are cited amongst the sources of greatest hardship for mothers (Donovan, 1988; Frey, Greenberg & Fewell, 1989; Quine & Pahl, 1989; Sloper & Turner, 1993b; Wallander & Noojin, 1995) as are the practical problems which characterise diminished functional independence, such as urinary and bowel incontinence (Hewett *et al.*, 1970 in Kazak, 1986) and the lifting and carrying of non-ambulatory children (Tew & Lawrence, 1975 in Kazak, 1986). A weaker association has been found for other factors such as child's sex (Friedrich, 1979; Tavormina *et al.*, 1981) and age (McAndrew, 1976 in Kazak, 1986).

By contrast, a number of authors have disputed the significance of 'degree of disability' as a precipitating factor in poor maternal adaptation (e.g. Kolin, Scherzer, New & Garfield, 1971 in Kazak, 1986; Trute & Hauch, 1988; Wallander, Pitt & Mellins, 1990; Wallander, Varni, Babani *et al.*, 1989; Wallander & Venters, 1995). In a variety of studies involving mothers of children with cerebral palsy, spina bifida, hearing problems and developmental delays (not specified), none of the variance in adaptation has been attributable to changes in the child's level of physical functioning. It would seem pertinent to conclude, therefore, that findings in this area remain equivocal (Beckman, 1983; Kazak & Clark, 1986).

There are those for whom, what may initially have seemed a setback, evolves, via an uncharted journey, into an opportunity for phenomenal personal growth and development. Mothers have been known to abandon established careers in order to immerse themselves in the helping rôle – some even returning to tertiary institutions to gain the necessary vocational qualifications (Freedman, *et al.*, 1995). Wickham-Searl (1992) examined the careers of fourteen mothers who, drawing on personal experience of adversity and discrimination endured in the battle to promote their own children's health and welfare, worked to establish advocacy and support groups intended to sustain new parents in their encounters with indifferent service systems and apathetic professionals. Frustrated by the absence or inappropriateness of educational and social services for their children, as well as a lack of social support for themselves, these

mothers campaigned, privately at first, but later offering their experience and advice to others as a community service. In a series of case studies, Wickham-Searl documents the remarkable metamorphoses which these women underwent, from a state of ignorance and bewilderment through frustration, anger and indignation to empowerment and advocacy in their dealings with medical personnel, educational institutions, 'support services' and all forms of bureaucracy.

4. 2 The Exceptional Father

Inasmuch as the mother has been the focus of scholarly investigation, so the father has been neglected. Prior to the 1970s, academic literature on fatherhood in general was sparse (Greenberg, & Morris, 1973; Hanson & Bozett, 1987) probably due to the fact that, while the father's contribution to the sex-rôle and moral development of later childhood was acknowledged, it was widely theorized that his rôle in infant social development was minimal (Lamb, 1975). In the wake of the women's movement, however, fathers began to re-examine their position in the family - and in society - thereby prompting a surge of interest from social scientists (Young & Roopnarine, 1994). Nevertheless, in comparison with that of the mother, the father's experience has attracted scant research interest.

Predictably, this bias is reflected in the literature on fathers of children with special needs. It may be due in part to the belief that, despite the widely acknowledged increase in active involvement of fathers of healthy children (McBride & Darragh, 1995), fathers of children with disabilities still tend to assume a secondary or supportive parenting rôle (Herbert & Carpenter, 1994; May, 1992a). This has been exacerbated by fathers' reticence regarding participation in research undertakings such that investigators have lamented their frequent absence (Fagan & Schor, 1993) or inaccessibility (Lonsdale, 1978; Meyer, 1986 in Herbert & Carpenter, 1994). Mothers' experiences have been considered paramount, with findings summarily generalised to fathers (Meyer, 1986 in Herbert & Carpenter, 1994). In a study by Byrne, Cunningham and Sloper (1988 in Sloper *et al.*, 1991) in which maternal ratings of father-child relationships were compared with paternal self-report measures, the poor validity of such practices was

demonstrated. Recognizing the complementary aspect of the father's parenting rôle (May, 1992a; 1992b), responsible researchers have highlighted the necessity for obtaining first-hand information rather than relying on maternal reports when seeking an understanding of paternal experiences (Sloper *et al.*, 1991; Young & Roopnarine, 1994).

Understandably, the degree of father involvement in child-care activities differs somewhat from that of mothers. Historically, the primary task of the father was considered to be that of provider and protector (May, 1992a). While the modern father has not relinquished that rôle entirely, he no longer carries the sole responsibility as the bread-winner. The shift towards egalitarianism amongst couples in the last thirty years in which wives/mothers have assumed a growing accountability in respect of the family's material stability has been well documented. While a concomitant shift towards the domestic rôle on the part of husbands/fathers may have been anticipated by some (e.g. Cummings, 1976), it has not materialised with commensurate vigour (Hirsch & Rapkin, 1986; Hochschild, 1989). Hence child-care is still asymmetrically distributed, even amongst dual-income couples.

Amongst parents of children with special needs this is particularly pronounced. Given that, as stated in 4.1 above, exceptional parents do indeed adopt more traditional rôles, in which the father is seen as "provider first and parent second" (Schilling *et al.*, 1985 p858), matters of finance are once more deemed to be his primary concern (Howard, 1980 in Kazak, 1986; Sloper *et al.*, 1991) with childrearing assuming a subordinate place. As recently as 1995, a study by Willoughby and Glidden of 48 married couples to whom a developmentally disabled child had been born, reported that in all but 10 percent of cases, the father was the primary bread-winner. While this may be an onerous duty, it does have positive side-effects for, as Schilling *et al.* (1985) point out, early parenthood usually coincides with an expanding social network and a growing sense of career importance for men. In direct contrast with mothers, fathers do not experience limitations on their careers as a consequence of their child's disability (Sloper & Turner, 1993b).

Fathers' interactions with children are likely to be both quantitatively and qualitatively different from those of mothers, or fathers of typically developing children, although studies in this area have been equivocal. Barnett and Boyce (1995) found that, in comparison with fathers of healthy children, exceptional fathers devoted more time to child-care and less to social activities. In a study of 23 two-parent, middle income families with a pre-school age child with a disability (Young & Roopnarine, 1994), fathers estimated the amount of time they spent in primary caregiving to be about 36 percent of that of their spouses. This was virtually identical to that of fathers of non-disabled children (35 percent) and concurred reasonably well with mothers' impressions (of fathers' contributions) in both cases (30 and 38 percent respectively) (Young & Roopnarine, 1994). A similarly disproportionate level of involvement amongst fathers of disabled children was reported by Bristol *et al.* (1988) yet, in the same study, fathers of non-disabled children reported child-care involvement that was almost equal to mothers. Bristol *et al.* (1988) attributed this disparity to the greater rate of employment amongst mothers of non-disabled children, a theory that was not upheld by Shelton (1990 in Willoughby & Glidden, 1995) who found no increment in fathers' domestic or child-care involvement concomitant with mothers' increasing employment. On the whole, father-child interactions have a socializing rather than a nurturing emphasis. Hence their involvement tends to centre around recreation and informal play (Frey *et al.*, 1989) with some general helping activities rather than the intimate exchanges of feeding and cleansing (Willoughby & Glidden, 1995) which form the focal point of much mother-child interaction.

The extent to which factors inherent to the child influence the nature of the father-child relationship has been a source of some controversy amongst researchers. For instance, the sex of the offspring has been held to affect the father's capacity to accept her or his limitations, with greater difficulty typically being ascribed to fathers of sons (Frey *et al.*, 1989; Goetting, 1986 in Sloper & Turner, 1993b; Leyser & Dekel, 1991; Schilling *et al.*, 1985; Sloper *et al.*, 1991; Tavormina *et al.*, 1981). Yet some authors have reported contradictory findings in this regard (Sloper & Turner, 1993b) or disputed any contribution of child sex towards paternal adaptation (Cummings, 1976). The child's age has also been regarded as a source of variation influencing the father's parenting

experience, but conflicting views have obscured the direction of this association. An inverse relationship between age and degree of positive adjustment has been claimed by some (Bristol & Schopler, 1984 in Krauss, 1993; Gallagher *et al.*, 1983; Hallum & Krumboltz, 1993; Sloper *et al.*, 1991), a matter questioned in the work of another (Cummings, 1976), and for which indeterminate results lead to ambivalence on the part of a third (Krauss, 1993).

Dispute has also arisen over the relative contribution of the nature and/or severity of the child's incapacitation to the fathers' acceptance of and adjustment to the child. While some studies have reported a decline in paternal adjustment concomitant with increasing morbidity (Sloper & Turner, 1993b; Frey *et al.*, 1989), it has also been suggested that due to his reduced care-taking function and lower level of physical involvement with the child (as described above), the father is likely to be less negatively influenced by the degree or diagnostic category of the child's disability (Schilling *et al.*, 1985; Shapiro, 1983; Sloper *et al.*, 1991; Young & Roopnarine, 1994). After an extensive review of the subject, Minnes (1988) declared findings in this regard to be equivocal.

Nevertheless, certain child characteristics are known to have a particularly deleterious effect on the father's capacity to adapt. In keeping with mothers, poor communication skills are a source of considerable distress (Frey *et al.*, 1989) as are difficulties with feeding (Sloper & Turner, 1993b), disrupted sleeping patterns (Tavormina *et al.* 1981), the origin of the child's disability (i.e. whether or not it is congenital) (Sloper & Turner, 1993b) – which serves to exacerbate distress where liability is traced to the father (May, 1992a) - and the child's position in the family (Price-Bonham & Addison, 1978 in Kazak, 1986). Although fathers are reportedly also affected by the degree of visibility of the child's impairment (Bradbury & Hewison, 1994; Meyer, 1985 in Sloper *et al.*, 1991), for many it is not the child's physical characteristics that generate the greatest concern but rather the quality of the emotional relationship that they enjoy with their son or daughter (Krauss, 1993).

May (1992b) contends that, in a success-oriented society, exceptional fathers experience “universal feelings of failure and guilt” (p39) which may be exacerbated by particular

social or cultural expectations. In orthodox Jewish families, for example, the knowledge that a son with a disability will not be capable of fulfilling the many functions and religious duties expected of men serves to heighten feelings of shame and frustration (Leyser & Dekel, 1991). Whereas the mother is likely to receive emotional social support to a greater or lesser degree, the father's needs in this regard are seldom acknowledged, much less met (Herbert & Carpenter, 1994; May, 1992a). Most early intervention programmes are designed for mothers - assumed to be the primary caregivers - and are frequently offered during working hours, making them inaccessible to the majority of fathers (May, 1992b). Contact with medical personnel occurs mainly via the mother (Herbert & Carpenter, 1994) who is seen to become an 'expert' in the child's condition while the father's knowledge remains limited (May, 1992b). The resultant feelings of frustration and alienation may drive the father to invest renewed efforts into his vocation (Bailey *et al.*, 1992) wherein he may find compensating feelings of accomplishment and success.

In a systematic study of published accounts of fathers' experiences of parenting a child with special needs, Hornby (1992) provides an illuminating exploration of the practical and emotional challenges with which these eight men were faced. Drawing numerous quotations from the original authors, some of whom are writers and academics, Hornby creates a vivid image of the parents' experiences ranging from anger and dismay, through torment and despair to resignation and acceptance (or in some cases, inability to accept and subsequent institutionalization of the child). The havoc created in their marriages, personal and working lives is conveyed with immediacy as are the conflicts, bitterness, resentment, disappointment, pain, joy and ambivalence that constitute their daily lives. For most men the most striking change occurred in respect of personal values, where social goals replaced those based on competition.

4. 3. Sources of Parental Stress

While some observers have questioned the validity of the concept of stress, viewing it as an artifact of the late twentieth century (Pollock, 1988), a large body of medical and social science research has continued to be generated on the topic (Coyne & Holroyd,

1982; DeLongis, Folkman & Lazarus, 1988; Lazarus, 1993) through which supporting evidence of its authenticity has been provided. Nevertheless, attempts to define stress have been plagued with confusion (Baum, 1990), the preferred method typically reflecting the perspective or bias of its originator.

Emphasizing the environmental aspect in his work with families, Hill (1956 in Gallagher *et al.*, 1983) identified a *stressor* as “a crisis-provoking event or situation for which the family has little or no preparation” (p11). Extrapolating from both the biological/physiological approach and the social/ psychological approach, researchers developed the concept of stress into a more complex, biopsychosocial construct, the effects of which may be immediate or delayed (Rabkin & Streuning, 1976 in Gallagher *et al.*, 1983).

Stress, as a facet of adaptation, is conceptualized in this study in accordance with the transactional perspective. This is the approach employed by Lazarus and colleagues in which stress is understood in terms of the reciprocal relationship between the individual and the event. Informed by this early work, Coyne and Holroyd (1982) defined stress as “neither an environmental condition nor a response but rather as a person-environment relationship in which demands tax or exceed the resources of the person” (p104). Lazarus and colleagues emphasized the mediating rôle of appraisal and coping in the experience of stress, concluding that it is better understood as “a dynamic, unfolding process, not as a static, unitary event” (Folkman & Lazarus, 1985 p150). (See section 3.5 for details of the work of Lazarus).

An abundance of literature attests to the stressful nature of the exceptional-parenting rôle (e.g. Atkinson *et al.*, 1995; Baxter *et al.*, 1995; Beckman, 1983; Boyce *et al.*, 1991; Bradshaw & Lawton, 1978; Chen & Tang, 1997; Cherry, 1989; Donovan, 1988; Frey *et al.*, 1989; Friedrich & Friedrich, 1981; Gallagher *et al.*, 1983; Holroyd & McArthur, 1976; Kazak & Clark, 1986; Kazak & Marvin, 1984; Krauss, 1993; Lea, 1986; Leyser & Dekel, 1991; Lombard, 1992; Minnes, 1988; Noh, Dumas, Wolf & Fisman, 1989; Quine & Pahl, 1985; Quittner *et al.*, 1990; Reddon *et al.*, 1992; Rousey, Best & Blacher, 1992; Singer & Farkas, 1989; Sloper *et al.*, 1991; van Rooyen, 1989; Walker *et al.*, 1992;

Wallander & Noojin, 1995; Wallander *et al.*, 1990). Various factors located within the child, the parents, the siblings, grandparents and service institutions have been associated with raised stress levels in parents (Gallagher *et al.*, 1983).

Factors intrinsic to the child such as age, sex, diagnostic category and degree of physical incapacitation have been explored in sections 4.1 and 4.2 above, to which the reader is referred. A further child-centered factor with potent stress-inducing capacity is that of behaviour problems. In a study of primary care-givers of mentally handicapped children, Quine and Pahl (1985) identified practices such as biting, screaming, being destructive and the enactment of temper tantrums as the leading sources of stress amongst this group.

Stress may also be elevated as a consequence of characteristics inherent in the parents themselves. Several factors believed to contribute in this manner have been identified. These include age, occupation, income, socioeconomic status, intelligence, personality traits, past experience (Rabkin & Streuning, 1976 in Gallagher *et al.*, 1983), marital status (Beckman-Bell, 1980 in Gallagher *et al.*, 1983) and the parent's perception of his or her culpability (Juvonen & Leskinen, 1994). However, findings in this respect are frequently inconclusive.

For example, in their study of 82 religious Israeli families, most of whom were experiencing financial hardships and social isolation, Leyser and Dekel (1991) found that increased maternal age was associated with higher stress levels in the family. This was ascribed to the cumulative effect of extraordinary demands placed on the mother over an extended time period. Conversely, in their study of 479 middle class American mothers from intact families, Boyce *et al.* (1991) found a significant decline in maternal stress with increasing age.

The relationship between socioeconomic status and stress is also unclear, probably due to the dearth of class-linked studies in this field (Schilling *et al.*, 1985). Early work by Farber and Grossman suggested that the birth of a child with a disability would provoke greater distress amongst low SES families than typically seen in middle- or upper-class

families (Schilling *et al.*, 1985), a finding for which Bradshaw and Lawton (1978) and Donovan (1988) found little evidence of support. Turnbull and Turnbull (1986 in Leyser & Dekel, 1991) on the other hand ascribed fewer adjustment difficulties to low SES parents as did Lea (1986), who postulated that the level of alienation, stigmatization and chaotic living already endured by low SES parents would negate the threat of further stigmata, thereby promoting acceptance of the child amongst this group.

Parental beliefs regarding the aetiology of the disorder have been shown to affect their capacity to relate to the child. A conviction that they are somehow responsible for the child's disorder has been seen to adversely influence the nature and intensity of parent-child interactions (Lavelle & Keogh, 1980 in Gallagher *et al.*, 1983; Zuk, 1959 in Blacher, 1984), in addition to promoting stress. Conversely, a belief that they could be effective in reducing their child's difficulties or somehow improving his or her condition has prompted greater acceptance of and adaptation to the child (Juvonen & Leskinen, 1994).

Financial pressure, such as may be experienced in the event of paternal unemployment, has been identified as a factor contributing to maternal stress (Sloper *et al.*, 1991). Indeed, lack of financial or material resources is a frequent source of distress to both parents (Quine & Pahl, 1985), but one that can be ameliorated by appropriate support such as, for example, instrumental support (money) from grandparents (Sandler, Warren & Raver, 1995).

Factors affecting stress levels which are external to parents, but with which they must nevertheless contend, include prolonged uncertainty about the diagnosis (see section 2.2), the necessity for repeated explanations to others and the attitude of the extended family. Grandparents who reject the child, deny the existence of any limitation, apportion blame or demonstrate a lack of understanding in some way are believed to increase the stress experienced by the parents and thereby impede the process of adaptation (Sandler *et al.*, 1995).

The view of exceptional parenting as inevitably stressful may be simplistic. Hence it is more appropriate to investigate the stressful impact of the presence of a child with disabilities in light of environmental contexts and the coping resources at the parents' disposal (Boyce *et al.*, 1991) together with the nature and quality of the social support available to them.

4.3 Marital Satisfaction

The topic of marital satisfaction has enjoyed considerable research interest in recent years despite some difficulties of a conceptual and methodological nature (Fowers & Applegate, 1996). Self-report measures have been found to provide a reliable indication of the state of the marriage, with a strong correlation manifesting between spouses' assessments – particularly at the extremes of high or low satisfaction (Fowers & Applegate, 1996).

Numerous studies have employed this means to examine the impact on the marital dyad of a child with special needs, but results have been equivocal. Evidence indicating elevated marital discord has been offset by claims of increased cohesion amongst exceptional parents. The possibility of a simultaneously positive and negative effect has even been suggested (Benson & Gross, 1989).

As some researchers are of the opinion that dissolution of the marriage is a likely consequence of the handicapped child's birth (Featherstone, 1980 in Mullins, 1987; Wright *et al.*, 1985), particularly where non-acceptance is high (Sloper & Turner, 1993b), incidence of divorce and separation amongst exceptional parents have been closely monitored. Significantly increased levels of marital breakup have been found in comparison with parents of typically developing children in some cases (Tew, Lawrence, Payne & Rawnsley, 1977 in Benson & Gross, 1989), particularly where mutual support between parents is lacking (Samit, Nash & Meyers, 1980), yet little difference from the population divorce rate has been reported in others (Begleiter, Burry & Harris, 1976 in Benson & Gross, 1989).

Intact marriages have also formed a focus of research interest. Attempts to gauge parents' level of marital satisfaction have seemed appropriate given the drain placed by the child on their resources not only of time and money, but also of health and energy leaving them little to invest in the marital relationship (Benson & Gross, 1989). Fathers seem to have a particular difficulty (Bristol *et al.*, 1988) although increased active involvement in parenting activities on their part has been found to improve satisfaction for both partners (Willoughby & Glidden, 1995). Even amongst couples who do not divorce, a marked increase in marital conflict has been reported by some observers (Friedrich & Freidrich, 1981; Gallagher *et al.*, 1983; Sabbath & Leventhal, 1984 in Romans-Clarkson *et al.*, 1986). Mothers are believed to exacerbate their feelings of isolation by forming a very close, enmeshed relationship with the child, to the exclusion of fathers (Shapiro, 1983) who then retaliate by engaging in "emotional divorce" (Tavormina *et al.*, 1981 p130).

Some researchers have adopted a more optimistic approach and have tried to understand the dynamics of those relationships which are strengthened by the challenge of raising an exceptional child. Donovan (1988) claimed that a good marital relationship was 'insulated' from the stresses of exceptional parenting. In a study of parents of children with difficulties necessitating a high degree of practical care and personal involvement, Taanila, Kokkonen and Järvelin (1996) found that more than two-thirds of their sample (70%) claimed that their relationship had been unaffected by the child's birth. A further 25% believed that their marriage had, in fact, improved as a result of this experience, a factor that was associated with a lower level of education, adequate information about the disorder and its implications and sufficient time for hobbies (Taanila *et al.*, 1996). Financial status was seen to affect the marital relationship by Willoughby and Glidden (1995) who measured greater satisfaction amongst couples who were not experiencing financial hardship, a finding that was not supported by Taanila *et al.* (1996). Fagan and Schor (1993) found that whether or not the couple were legally married, the presence in the home of a significant adult companion improved maternal well-being.

Ultimately, no assessment of marital functioning in respect of exceptional parents is complete without some indication of the nature and quality of the pre-existing

relationship (Farber, 1959 in Byrne & Cunningham, 1985; Gath, 1985) i.e. prior to the child's intrusion into the marital dyad. Attempts to derive an association between the presence of the child and changes in the marital relationship will be misleading without some base-line or point of reference that pre-dates the child's arrival (Martin, 1975 in Sloper & Turner, 1993b).

4. 5 Coping

As in the case of stress, the complexity of the concept has precluded the development of a unified approach to the study of coping (Fleming, Baum & Singer, 1984). Lack of consensus over the conceptualization and measurement of coping strategies has characterized work in the field (Aldwin & Revenson, 1987). Granted that coping is subject to multiple influences both internal and external to the subject and as such constitutes a multifaceted construct (Billings & Moos, 1981), attempts at quantification have seldom captured the full spectrum of influences, but have typically favoured the theoretical standpoint of the author (Aldwin & Revenson, 1987).

Pearlin and Schooler (1974) defined coping succinctly as "the things that people do to avoid being harmed by life-strains" (p2) by which they assumed an active response to the threat of impinging stimuli. Lazarus and Folkman (1984) articulated this somewhat more adroitly as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p141). Advantages of this definition, according to the authors, were that it emphasized the process aspect of coping, it provided a distinction between coping and reflex reaction and it obviated the confounding of coping and the outcome of any coping behaviours.

Coping is believed to fulfill a mediating function between stressful events and both somatic health and psychological symptoms (Folkman *et al.*, 1986), although consensus has not been reached in respect of the nature of this relationship. Individual variation in health status as a function of degree of stress prompted speculation as to the relative efficacy of differing coping styles (DeLongis *et al.*, 1988).

Lazarus and Folkman (1984) distinguished two major functions of coping namely to change or manage the stress-inducing problem and to contain the resultant emotion. Termed problem-focused coping and emotion-focused coping respectively (Folkman & Lazarus, 1986; Lazarus, 1993; Lazarus & Folkman, 1984), they correspond with the categories of approach and avoidance coping subsequently employed by Holahan and Moos (1985).

Problem-focused or approach coping is similar to problem-solving in that it entails definition of the problem, generation and weighting of alternatives, selection and action (Lazarus & Folkman, 1984). It also involves direct confrontation of the problem and deliberate counter-action on both a behavioural and cognitive level (Fleming *et al.*, 1984; Holahan & Moos, 1985). Strategies may be instrumental i.e. directed outwards, towards the environment or palliative i.e. directed inwards, towards the self (Lazarus & Folkman, 1984).

When it is apparent that the stressor cannot be removed or eliminated, the individual is more likely to engage in emotion-focused or avoidant coping strategies (Lazarus & Folkman, 1984) aimed primarily at regulating emotion and concomitant physiological arousal (Coyne & Holroyd, 1982). This may entail altering the subjective meaning of a situation (while the objective reality remains the same), a practice termed cognitive reappraisal. Alternately, it may simply involve strategies of avoidance such as directing attention towards other tasks or screening out undesirable aspects of a situation (Lazarus & Folkman, 1984), methods for which a negative association with psychological adjustment has been empirically demonstrated (Vaillant, 1977 in Holahan & Moos, 1985). Approaches of this nature employed in the context of marriage or parenting in particular, have been seen to exacerbate stress (Pearlin & Schooler, 1978).

Appraisal plays a pivotal rôle in the model of stress and coping proposed by Lazarus and colleagues. Initial evaluation of the potential risks, threats, demands and losses posed by a transaction - a process shaped by existing beliefs - is known as primary appraisal (Coyne & Holroyd, 1982; Folkman, 1984). Where the transaction is adjudged to

represent a serious hazard to the individual's continued wellbeing, secondary appraisal is invoked. Secondary appraisal refers to the individual's constant re-evaluations of available coping options, their cost and likelihood of success (Coyne & Holroyd, 1982), together with the long-term implications of each (Folkman, 1984). The two are distinct more in theory than in practice, sharing as they do considerable mutual interdependence. For example, a given situation may be appraised as benign on the basis of past successes coupled with plentiful resources, whereas the absence of either of these may prompt the reverse (Coyne & Holroyd, 1982). Depending on the outcome of these appraisals, one or more coping responses is executed.

While acknowledging the contribution of Lazarus, Folkman and others to the field, Carver, Scheier and Weintraub (1989) argued that their dualistic division of coping strategies was simplistic in that it overlooked a number of widely divergent factors with potentially different implications for success. Both problem- and emotion-focused coping were believed to subsume conceptually distinct – at times, inversely correlated – mechanisms which, according to Carver *et al.*, merited individual assessment. Drawing on theory and a body of research findings, the latter devised an instrument incorporating measurement of a comprehensive range of coping strategies of greater or lesser efficacy. The fourteen categories are described in Table 6.2. Carver *et al.* (1989) warned against glib endorsement or condemnation of a particular method in the absence of contextual information.

4. 5. 1 The Parents' Experience of Coping

Featherstone (1980 in Schilling, Gilchrist & Schinke, 1984) believed that parents of developmentally delayed children inevitably understood themselves to be carrying a 'private burden' for which enhanced personal coping skills were required. Societal expectations of acceptance, altruism and engagement with the adjustment process (Denhoff & Holden, 1971 in Shapiro, 1983; Fairfield, 1983) served to reinforce this view. These and other behaviours that promoted family values, disciplining of children, religious adherence to demanding therapy schedules and trust in professionals were regarded as indices of 'good coping' (Daniels & Berg, 1967 in Shapiro, 1983).

Parents displaying these behaviours were rewarded for 'coping well' while others attempting to vent negative emotions were sternly discouraged (Fairfield, 1983). As a result, strategies such as denial and positive reinterpretation of events were tacitly encouraged. Fairfield (1983) contends that these practices may become so ingrained that parents' true feelings remain unconscious unless accessed via indirect, projective methods for the purpose of healing.

Women, who are typically socialized into subservient rôles in which the needs of others are placed ahead of their own (Schilling *et al.*, 1985), may be particularly susceptible to these coping practices. Whereas men favour cognitive coping strategies, women utilize both cognitive and interpersonal methods in response to stress (Schilling *et al.*, 1985), i.e. they consider the effect that their coping response will have on others. Yet Schilling *et al.* contend that it is fathers who are more inclined to use denial in connection with their developmentally delayed children. In general, mothers are inclined to demonstrate greater acceptance with respect to their offspring (Tavormina *et al.*, 1981).

Fathers' level of acceptance is influenced substantially by the attitude of their parents and family (Sandler, *et al.*, 1995; Waisbren, 1980 in Schilling *et al.*, 1985) i.e. their degree of emotional social support. Mothers and fathers of children with cerebral palsy have been found to have similar ways of coping. Practical aspects, such as providing medical treatments at home as well as emotion-focused methods such as maintaining the equilibrium in the family are common to both. However, mothers are more inclined to seek emotional social support than fathers (McCubbin *et al.*, 1983 in Schilling *et al.*, 1985) and to demonstrate improved coping when this is forthcoming from within the marriage (Friedrich, Cohen & Wilturner, 1987).

More recently, Atkinson *et al.* (1995) attempted to demonstrate that a diverse collection of coping scales were all, in fact, measures of cognitive approach and avoidance. They argued that, in the case of the exceptional mother, both of these approaches would be detrimental to affect. Their data supported this hypothesis. Approach appeared to be more distressing than avoidance, probably due to the immutable nature of the stressor.

In general parents display considerable versatility, exhibiting a variety of coping behaviours which are most often situation-specific (Sloper & Turner, 1992). Coping should not be understood in the narrow sense of managing without assistance, but rather the decision to call upon available social services should be viewed as an active coping behaviour (Sloper & Turner, 1992).

Indeed, it is difficult to separate coping styles, availability and use of social supports and the ultimate experience of stress and capacity to adapt as these factors seem to be inextricably linked within the individual (Schilling, *et al.*, 1984). As Dunkel-Schetter, Folkman & Lazarus (1987 p79) have determined “coping behaviours elicit and direct support efforts; supportive actions, in turn, influence and modify the way an individual copes”.

4. 6 Social Support

The concept of social support has received widespread attention in the academic and research literature in the last twenty years, probably as a result of increasing appreciation of its relevance in both basic and applied research contexts (Dunkel-Schetter, *et al.*, 1987). Burgeoning interest has seen a proliferation of definitions and measuring instruments in current use (Cohen & Wills, 1985), such that the notion of social support has become conceptually diffuse. According to Cohen, Mermelstein, Karmack & Hoberman (1985), researchers have not achieved consensus with regard to the topic, each preferring to devise his/her own instrument without due regard to its suitability or psychometric properties. In so doing, issues of network structure and function have been employed indiscriminately, rendering resultant indices conceptually meaningless (Cohen *et al.*, 1985).

Lin (1986 in Zimet, Dahlem, Zimet & Farley, 1988) defines social support as “perceived or actual instrumental and/or expressive provisions supplied by the community, social networks, and confiding partners” (p31). Alternately, Sarason, Levine, Basham & Sarason (1983) suggest simply “the existence or availability of people on whom we can

rely, people who let us know that they care about, value and love us” (p127) as a means to the same end. Regardless of the manner in which it is conceptualized, it appears that two elements constitute the core of social support, namely the *perception* of the existence of an adequate network and a modicum of *satisfaction* therewith (Sarason *et al.*, 1983), the balance between these two being determined by personality factors intrinsic to the recipient.

The efficacy of social support as a health promoting agent has been firmly established (Dunst *et al.*, 1986; Lieberman, 1982), but the mechanism by which it works remains a matter for debate. Two competing theories have enjoyed prominence, namely the ‘buffering hypothesis’ and the ‘main-effect model’ (Cohen & Wills, 1985). In terms of the latter, the existence (or perception) of a satisfactory support network engenders a feeling of health and prosperity which is generally beneficial, regardless of the presence or absence of stress (Cohen & Wills, 1985). By contrast, the buffering hypothesis contends that social support serves to protect people from harm solely in the event that their continued wellbeing is placed under threat i.e. it has relevance only in times of stress (Cohen & Wills, 1985). A study conducted in Norway by Dalgard, Bjørk and Tambs (1995) in which these two hypotheses were put to the test, produced support for the buffering hypothesis. An interaction was found between negative life events, social support and control with respect to mental health risk, particularly depression – but only for those with an external locus of control (Dalgard *et al.*, 1995).

4. 6. 1 The Parents’ Experience of Social Support

Sources of social support available to parents may be categorized into two groups, namely formal sources such as medical professionals, therapists, support groups, welfare agencies or schools and informal sources such as spouse, parents, friends, neighbours and the extended family. Lea (1986) distinguished these in terms of ‘public’ and ‘intimate’ support respectively.

Formal Support

Caplan and Killilea (1976 in Kazak & Marvin, 1984 p69) capture the essence of formal support in their description of it as “attachments among individuals or between individuals and groups that serve to improve adaptive competence in dealing with short-term crises and life transitions as well as long-term challenges, stresses and privations”. Clearly then, the value of formal services lies in their capacity to serve as moderators of stress (Folkman *et al.*, 1986). Yet, while parents and their exceptional children have been found to avail themselves of medical and other social services at least to the same extent as parents of typically developing children, they have tended not to seek assistance at a level that is consistent with their (presumably increased) needs (Unger & Powell, 1980 in Kazak, 1986; Waisbren, 1980 in Kazak & Marvin, 1984).

Reluctance on the part of parents to become involved with formal agencies may stem from ignorance, denial (Schilling, Gilchrist & Schinke, 1984), “passive optimism” (Sloper & Turner, 1992 p277), fear of stigmatization (Chen & Tang, 1997) or simply reflect the dissatisfaction so often voiced with (usually state-run) service organizations (Knoll, 1990). An important determinant of this relationship is the extent to which the support on offer matches the parents’ needs and serves to sustain their strengths and abilities (Cooley, 1994; Dunst, Trivette & Cross, 1986), a matter which, it is held, is likely to improve with increased involvement at a developmental level on the part of the intended recipients (Cooley, 1994; King, Rosenbaum & King, 1996; Knoll, 1990; Lonsdale, 1978).

Parents may also be deterred from enlisting support from formal organizations by the subtle inference of incompetence implicit in so doing. In the acute crisis phase, help from a variety of sources may be welcomed. However, once the stressor has been established as chronic, outside help may cause offence, being viewed as intrusive or indicative of some presumed deficiency on the part of the parents (Quittner *et al.*, 1990).

Informal Support

Social support from the immediate family can be crucial to exceptional parents (Bradbury & Hewison, 1994; McCubbin *et al.*, 1980 in Frey *et al.*, 1989). The arrival of

a new family member typically elicits a warm response, but when a congenital abnormality is found, a support system that was perceived, indeed assumed, to exist, may disintegrate (Mullins, 1987), leaving bewildered parents to fend off accusations of blame and irresponsibility.

Members of the extended family also play a valuable rôle in support of the parents (Hewett, Newson & Newson, 1970 in Kazak & Marvin, 1984). The familiarity of these relationships is believed to provide a climate of emotional safety conducive to much-needed self-revelation for fathers (Herbert & Carpenter, 1994). Grandparents have been identified as the most significant sources of both emotional and instrumental support (Beresford, 1994 in Bradbury & Hewison, 1994; Sandler *et al.*, 1995), particularly in the case of fathers (Schilling *et al.*, 1985) for whom a positive correlation has been found between the degree of adaptation and the level of parental support and acceptance (Sandler *et al.*, 1995).

Network size i.e. the number of people to whom one can turn for help, and density i.e. the extent to which network members are acquainted with each other, have been examined for their relationship with parental health (Kazak & Marvin, 1984). Generally speaking, larger networks are considered advantageous. Networks of high density may prove beneficial, serving to promote a sense of belonging. Conversely, the uniformity expected of such a group may become counterproductive, particularly given the exceptional circumstances likely to prevail (Kazak & Marvin, 1984). Parents of children with special needs have (or perceive themselves to have) social networks of less than optimal size (Kazak & Wilcox, 1984 in Kazak, 1986; Kazak, 1987).

Irrespective of the constitution of the support system, fathers seem to be vulnerable to a heightened sense of isolation from the wider community, especially during periods of elevated stress (Reddon *et al.*, 1992). Conversely, under similar circumstances, mothers appear to derive increased emotional support from the broader social network, possibly due to their greater inclination to pursue assistance in this manner, should their usual resources prove insufficient (Reddon *et al.*, 1992). Certainly mothers perceive their receipt of support in this way to exceed that of fathers (Young & Roopnarine, 1994).

Neighbours and friends are sometimes reticent in their approach to the family, with offers of help generally being directed at the other (healthy) children (Kazak, 1986). Yet feelings of alienation and isolation from friends and family frequently reported by parents of non-disabled infants (McAndrew, 1976 in Kazak, 1986), render the assumption that this derives from the child's difficulty equivocal.

Clearly, with the child's advancing age, a concomitant shift in requisite parental support will occur (Eiser & Havermans, 1992). The informal sources so urgently sought upon diagnosis, make way for the structured interventions of helping professionals such as teachers, lawyers and investment advisors. With hindsight parents have reported that the support which proved to be of the greatest value was that which most closely addressed their situation-specific needs (Baxter, Cummins & Polak, 1995).

4.7 Control

The concept of locus of control as advanced by Julian Rotter (1966 in Folkman, 1984) refers to an individual's beliefs regarding his or her capacity to influence outcomes by means of deliberate actions. Persons considered internally orientated tend to take responsibility for their own deeds, believing themselves to have control over (i.e. the power to influence) their own life-chances. In other words they experience a sense of mastery (Folkman & Lazarus, 1985; Pearlin & Schooler, 1978). Conversely, those who are externally orientated display a more passive, fatalistic approach to life, attributing success or failure to forces beyond their control.

Cognitive appraisal, as understood within the aforementioned model of stress and coping in which it serves to assess and depotentiate the harmful effects of stressors, is markedly influenced by the individual's perception of control (Folkman, 1984). Decisions reached in respect of the two forms of appraisal identified earlier (see section 4.5) are shaped by the individual's sense of mastery, which according to Felsten (1991) may be distinguished into two broad categories, namely generalised and situation-specific.

For instance, with respect to primary appraisal, the evaluation of a transaction as harmless is contingent upon the subjective sense of power one has with respect to one's capacity to deal with threats or challenges of a general nature i.e. confidence in one's efficacy as an agent of change. According to Rotter (1966 in Folkman, 1984) individuals draw upon their generalized expectations of control to the greatest extent when confronted with threats of an ambiguous nature.

In the case of secondary appraisal however, decisions regarding the level of threat or challenge will be specific to the particular stressor and will derive from one's evaluation of relevant past experiences together with currently available resources (Folsten, 1991; Folkman, 1984). Reserves of a social, psychological, physical and material nature will be assessed and enlisted for coping purposes (Folkman, 1984). It is a cycle of such secondary appraisals within which the exceptional parent may be seen to operate.

4. 7. 1 The Parents' Experience of Control

Cooley (1994) maintains that the diagnosis of disability robs the parents of their sense of personal mastery. Faced with the inevitability of the situation, parents are rendered powerless, regardless of their generalised sense of control. Anticipated feelings of pride and accomplishment in respect of the child's (typical) development are no longer appropriate and the parents are forced to redefine progress in terms of their offspring's limitations. Under such circumstances locus of control has not been found to have any association with parents' satisfaction with this event (Sloper & Turner, 1993a).

Gender differences in respect of locus of control are evident in that mothers are more inclined to be externally orientated, while fathers display more internal characteristics. For instance, mothers have been found to be more willing than fathers to place control over their child's development in the hands of professionals (Krauss, 1993).

Mothers' subjective sense of control can also be seen to affect the extent to which they are able to adapt to the demands of exceptional parenting when the question of 'perceived rôle restriction' (discussed in 4.1 above) is considered. The two are, in

essence, inverse measures of the same construct. To the extent that the mother *perceives* herself to be restricted, she can be seen to experience a lack of control or an external locus of control. Both perceived rôle restriction and an external locus of control result from an individual's belief that he or she must comply with some societally imposed expectation. Should the mother freely elect to devote herself to full-time childcare, she would not need to feel restricted, or should she have an internal locus of control, she would be (or at least perceive herself to be) able to arrange relief child-care thus eliminating her feelings of restriction.

In light of the above, Wallander and Venters (1995) hypothesised that, as a subjective index of the impact of the child's disability on the mother, perceived rôle restriction would explain more variance in the mother's adjustment than would objective factors such as the degree of the child's physical incapacitation or behaviour problems. Indeed, their research supported this view. Wallander and Venters (1995) further postulated that the effects of perceived rôle restriction would also be seen to influence mothers' general sense of life satisfaction in that less restriction would be associated with a pervasive sense of well-being which would influence mothers' capacity to function in other areas.

Certainly, locus of control is held to affect the individual's experience and use of a number of psychosocial variables and thereby to moderate stress (Lefcourt, 1983 in Henderson & Vandenberg, 1992). For instance, a positive link or interaction has been postulated to exist between the perception of control and social support (Dalgard *et al.*, 1995; Lefcourt, Martin & Saleh, 1984). The belief that one can increase one's network size at will permits the perception that it is adequate – and thus a sense of support is maintained. This, in turn, has a reinforcing effect, especially for mothers in that, the perception of an adequate support network, diminishes the subjective sense of rôle restriction - with concomitant benefits (Wallander & Venters, 1995).

Coping efficacy has also been linked to the subjective perception of control (Pearlin & Schooler, 1978). In their multidimensional study of parents of young, developmentally disabled children, of whom 16.5% had cerebral palsy and 60% had Down syndrome, Frey *et al.* (1992) found that a strong internal locus of control was associated with

favourable outcomes on measures of stress, adjustment and psychological adjustment for fathers. High levels of distress, as measured by the Brief Symptom Inventory (Derogatis, 1975 in Frey *et al.*, 1992) - indicative of ineffectual coping - were associated with poor perceptions of control (i.e. an external locus of control) for mothers (Frey *et al.*, 1992).

Notwithstanding the above, a number of researchers, and parents, have cautioned against the glib assumption on the part of health professionals that the demands of caring for a child with special needs axiomatically exceed the parents' capacity to meet them. Some documentary evidence has been found to suggest that parents can and do adapt to the unique demands with which they are faced without serious impairment (e.g. Carr, 1984; Darling, 1983 both cited in Trute & Hauch, 1988).

The pessimistic prognosis assumed by professionals may result from the absence of well-adjusted family members from consulting rooms and clinics, leading to the erroneous impression that all families with a handicapped member experience adaptation problems (Trute & Hauch, 1988). Certainly parents have objected to the fatalistic outlook adopted by members of the medical profession (Sloper & Turner, 1991) from whom a more positive approach, adopted in conjunction with parents, could improve children's social and vocational prospects (Gilbride, 1993).

In a deliberate attempt to address this issue and to explore the means by which successful adaptation was achieved, Trute and Hauch (1988) interviewed 36 parental couples deemed by the local health authority to be satisfactorily adjusted to their child with a disability. No relationship was found between the severity of the impairment, behavioural difficulties or income level and parental adaptation. Factors which favoured successful adaptation were intact marriages and limited family size. Marital satisfaction and judicious use of an adequate informal social support network proved most beneficial (Trute & Hauch, 1988).

Chapter Five

Review Summary and Study Objectives

Clearly, as compared with their non-disabled counterparts, the parents of children with a disability are faced with numerous additional pressures and duties. The manner in which these tasks are approached and executed is determined by a multiplicity of variables of both an internal and external nature. Factors intrinsic to the child have been seen to exacerbate or moderate the process, while those of parental origin can be similarly influential. Even events surrounding the time of disclosure have shown themselves to impact on the long-term relationship between parent and child.

A range of theoretical explanations of adaptation has been identified. Sequential processing models as well as systemic and transactional approaches have been examined - the shortcomings and advantages of each being duly considered.

The overwhelming demands facing exceptional parents have been enumerated. A wide variety of stressors originating both in the environment and in the parents have been recognised. Most notable has been the many inconsistencies that have emerged from the literature. For almost every variable under consideration, contradictory findings have been reported. The need for clarity in this regard is evident. A most striking feature has been the emanation of evidence of an inextricable link between the psychosocial resources of coping, social support and control and their ameliorating effect on stress.

Much of the existing work on exceptional parents has focused on perceived deficiencies and shortcomings in the parenting process, with meagre attempts being made to discover the means by which parents accept, accommodate and adjust to their exceptional offspring. Consequently, parents have frequently expressed dissatisfaction with the attitude and recommendations of health professionals. Greater understanding in this regard is called for.

Study Objectives

Based on the stress model of Lazarus and colleagues and informed by the work of Bristol *et al.* (1988), Frey *et al.* (1989), Hanson & Hanline (1990), Sloper & Turner (1993b), Wallander, Varni, Babani *et al.* (1989) and Wallander *et al.* (1990), this study explored the concept of parental adaptation as follows:

- The exceptional child was viewed as a permanent *stressor*, demanding change in the lives of the parents;
- Coping mechanisms, perceived social support and locus of control were viewed as factors mediating the effects of the stressor;
- Parental adaptation was viewed as the capacity of the parents to achieve a balance between the demands of the exceptional child and their own and other family members' needs. This was operationalised by means of three factors, namely: satisfaction with family life, stress and adjustment to the child.

The specific aims of the study were:

- i) to examine the level of adaptation to a child with cerebral palsy experienced by South African parents;
- ii) to contrast maternal and paternal levels of adaptation;
- iii) to investigate the association between parent characteristics such as age, marital status, home language, education, employment, income and parental adaptation;
- iv) to investigate the association between child characteristics such as age, sex, birth order, degree of disability and parental adaptation;
- v) to contrast maternal and paternal coping styles, perceived level of social support and locus of control;
- vi) to determine which of the aforementioned variables contributed significantly to optimal parental adaptation;
- vii) to provide a means through which pertinent issues from parents' experience could be brought to light.

Chapter Six

Method

6.1 Participants

To be eligible for participation in the study, individuals had to parent a child who had been diagnosed with Cerebral Palsy. The participants in this study were all parents of children attending a school that caters specifically for pupils with this condition.

6.1.1 Response Rate

Of the 472 questionnaires delivered to the school, 123 (26.1%) were returned of which 14 (11.4%) were spoiled (incorrectly completed) and 30 (24.4%) were incomplete (i.e. they contained insufficient information to make their inclusion in the study viable). Thus the final sample consisted of 79 participants, representing some 16.7% of the original target group. Notwithstanding the fact that a poor response rate is generally acknowledged to be one of the hazards of mail surveys (Kerlinger, 1986), a word of explanation is due here. While pupil enrolment was known to be 236, and the study aimed to survey both parents, the actual accessibility of respondents could not be guaranteed. Absence due to death, divorce or desertion could not be ruled out and hence the actual response rate may have been higher than the intended sampling frame suggests.

6.1.2 Demographic details

The sample comprised 55 mothers and 24 fathers of 38 girls and 41 boys. See Figure 6.1

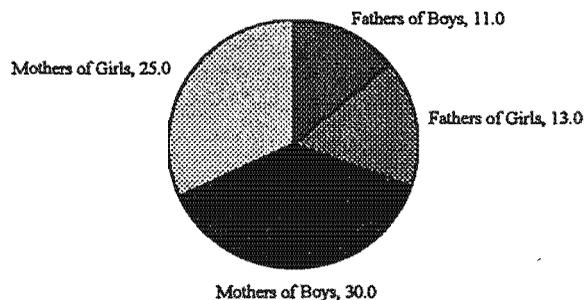


Figure 6.1

PARENT - CHILD DISTRIBUTION (N = 79)

6.1.2.1 Age

Parents' ages ranged from 22 to 70 years, with a mean of $M = 38.3$ years. Fathers ranged in age from 22 to 70 years with a mean of $M = 42$ years while mothers' age range extended from 24 to 54 years with a mean of $M = 36.5$ years. See Figure 6.2.

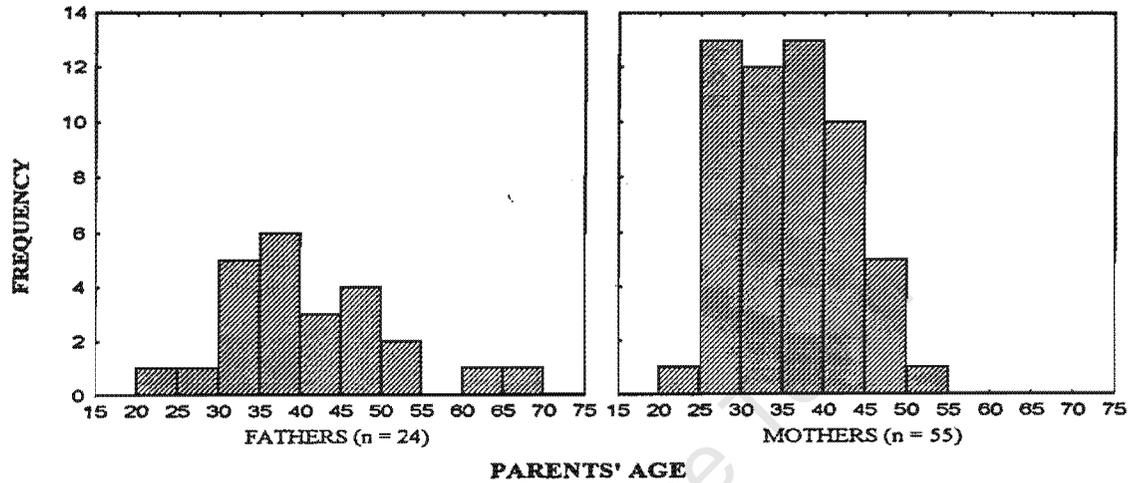


Figure 6.2

6.1.2.2 Marital Status

The majority of parents in the sample were married (62%). The remainder consisted of 19% single parents, 4% parents who were permanently separated from their partners, 10% divorcees, and 5% widowed persons. Figure 6.3 illustrates the distribution for fathers and mothers separately.

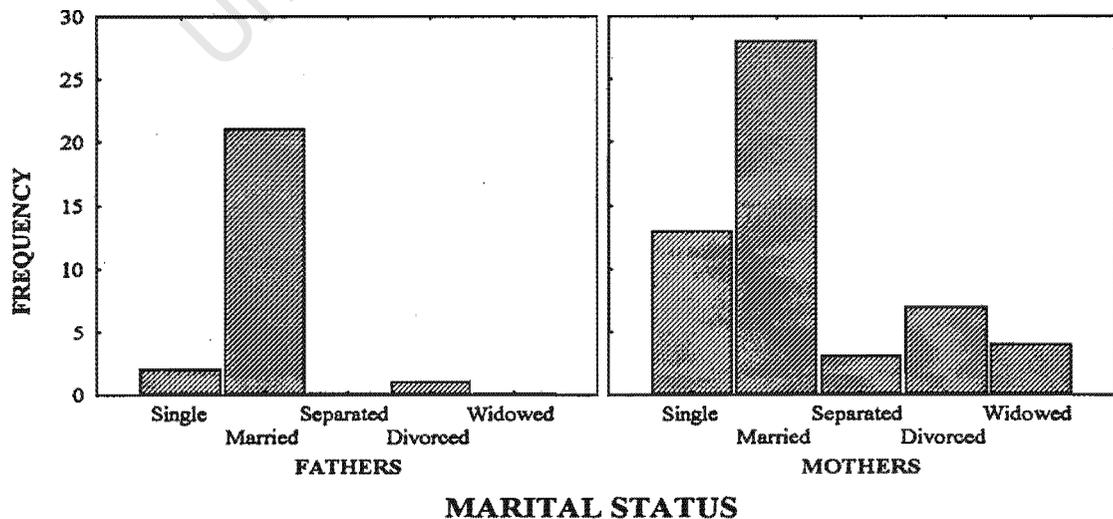


Figure 6.3

6.1.2.3 Home Language

With regard to home language, parents in the study were predominantly Afrikaans-speaking (53%), with 34% English-speaking, 9% both Afrikaans- and English-speaking and 4% Xhosa-speaking. No other language groups were represented. Figure 6.4 presents the language distribution for mothers and fathers separately.

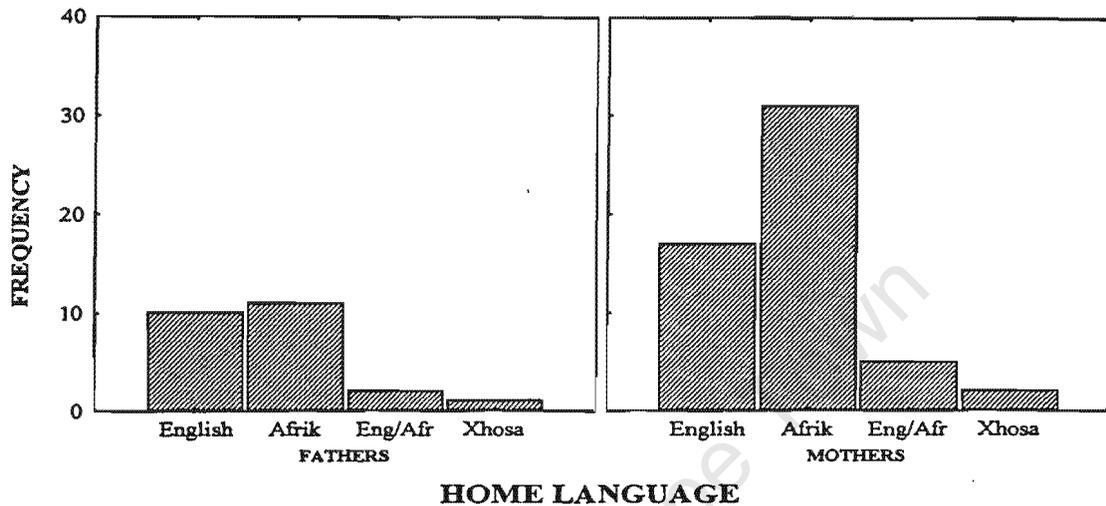


Figure 6.4

6.1.2.4 Education

Parents' level of education ranged between the two extremes from none to postgraduate degree. The majority of parents (50%) reported some high schooling, while 18% had some primary schooling and 18% were matriculated. Three percent of parents reported no schooling, 4% had a tertiary diploma and 7% had one or more degrees. See Figure 6.5

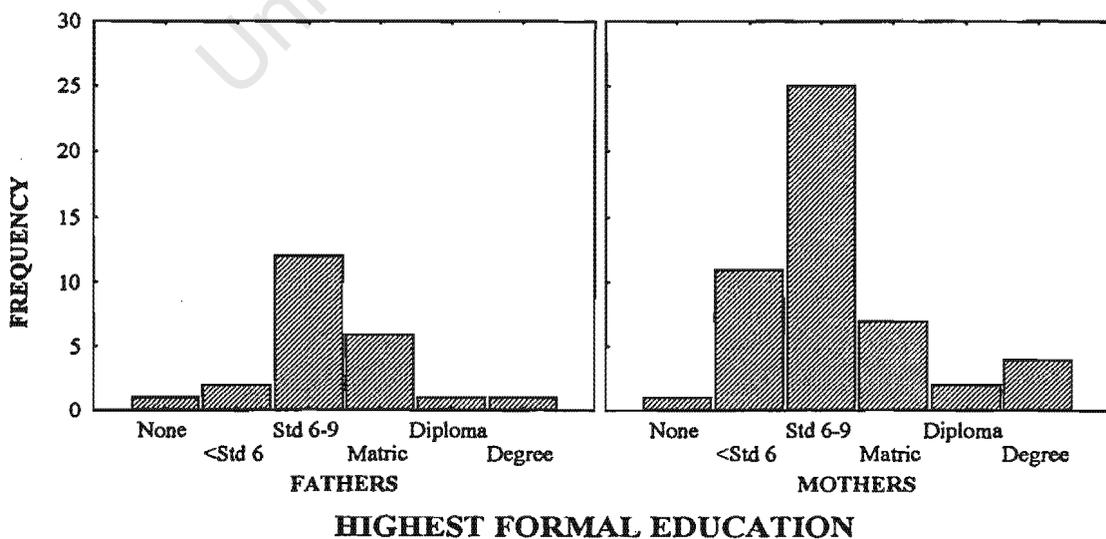


Figure 6.5

6.1.2.5 Employment

Parents were asked to indicate the nature of their employment. Consistent with their level of education, most parents occupied positions of service requiring semi-skilled labour. In the interests of parsimony it was decided to simply examine the extent of parents' employment rather than their occupational category. See Figure 6.6.

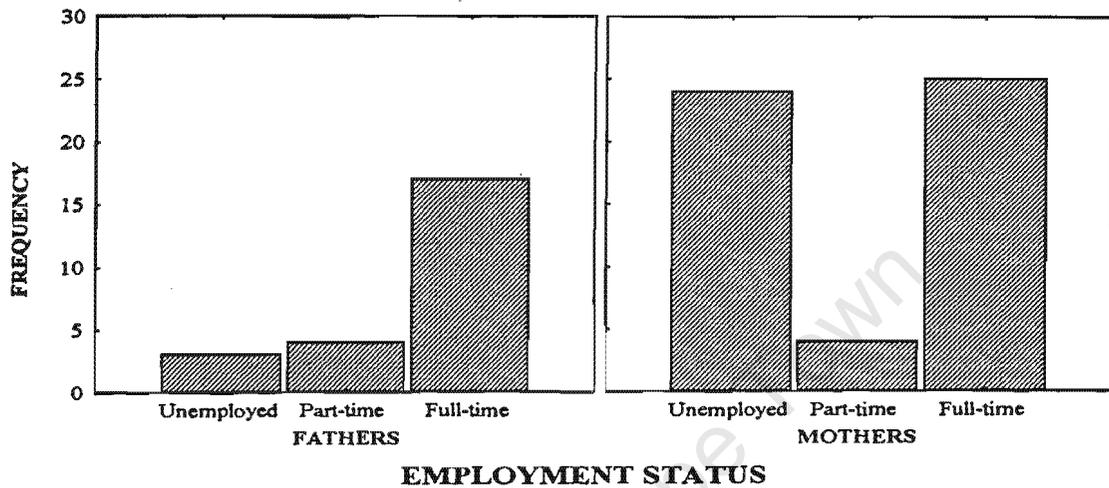


Figure 6.6

6.1.2.6 Income

Of those respondents who indicated their income, 21% had none, 51% earned less than R2500 per month, 15% earned more than R2500 but less than R5000 per month, 10.5% earned between R5000 and R7500 per month and 2.5% earned between R10000 and R12500 per month. Five respondents failed to report their income. This positively skewed distribution is illustrated in Figure 6.7.

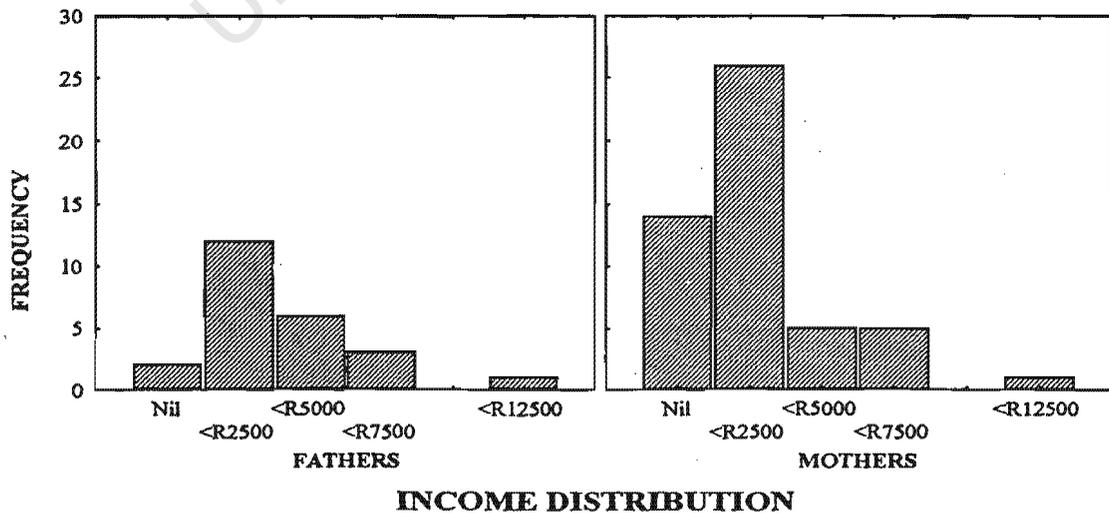


Figure 6.7

6.2 Research Design

It has been customary for the term 'research design' to be employed only in respect of experimental studies in which active independent variables are manipulated, over which the researcher maintains full and complete control (Kiess & Bloomquist, 1985; Mouton & Marais, 1990). More recently, however, it has become acceptable to apply the term indiscriminately to a variety of systematic investigations of a scholarly nature, both theoretical and empirical (Mouton, 1996). Hence the present *ex post facto* study may be defined as a descriptive field survey having a cross-sectional, correlational research design. Accordingly, the data was collected retrospectively by means of self-report questionnaires, from participants who were self-selected by virtue of the attribute variable 'parent of a child with cerebral palsy'. This design was deemed appropriate, as it is clearly neither feasible nor ethical to conduct research of an experimental nature in this area. Furthermore, the degree of anonymity that this method affords was considered important due to the personal nature of the required information.

6.3 The Research Instrument

The research instrument consisted of

- i) A demographic data sheet
- ii) Six standardised scales (one check list, one graphic scale and four numerical character rating scales)
- iii) Four open ended questions

Questionnaires were identical in all respects other than the designation of the intended respondent i.e. Mother or Father. A sample questionnaire appears as Appendix B.

6.3.1 The Demographic Data Sheet

Respondents were requested to furnish information regarding their age, home language, marital status, education, occupation and income. In addition they were asked to provide details in respect of their child with special needs, namely child's age, sex and position in the family.

Coding of demographic information thus obtained was dictated by the nature of the information itself. Sex of parent and sex of child were classified as dichotomous variables. Discrete variables with more than two possible (nominal) responses were home language, marital status and employment status. Ordinal variables included education and child's position in the family. Due to the forced choice format, income was coded on an interval scale, while data in respect of age of parent and age of child were entered as given and as such constituted continuous (ratio) variables.

6.3.2 The Standardised Measuring Instrument

The six rating scales, four numerical, one dichotomous and one graphic, constituted the bulk of the research instrument. Informed by past research in which the concept of adaptation, as it refers to exceptional parents, has typically been assessed by means of multiple measures incorporating mental health or stress, satisfaction with life and adjustment to the child amongst others (e.g. Bristol *et al.*, 1988; Frey *et al.*, 1989; Hanson & Hanline, 1990; Sloper & Turner, 1993b; Wallander, Varni, Babani *et al.*, 1989; Wallander *et al.*, 1990), this study employed three separate scales by means of which to operationalize the variable *adaptation*.

Firstly, the Family Adaptability and Cohesion Evaluation Scale III (Olson, Portner & Lavee, 1985) was used to measure satisfaction with family life (although measures of parents' subjective assessment of family cohesion and adaptability, while not the central focus of this study, were also obtained and proved illuminating). Secondly, following Frey *et al.* (1989) Factors I, II and III of the Short-Form Questionnaire on Resources and Stress (Friedrich, Greenberg & Crnic, 1983) were used to gauge parents' subjective perception of stress. (Factor IV, an objective measure of physical incapacitation which is unaffected by psychosocial variables, was viewed as a stressor and used to supplement the demographic information.) Thirdly, the Judson Self-Rating Scale (Judson & Burden, 1980) was used to measure parental acceptance of the child.

Coping styles were investigated by means of the Coping Orientation to Problems Experienced scale (Carver, Scheier & Weintraub, 1989), an indication of perceived social support was obtained from the Family Support Scale (Dunst, Trivette & Jenkins, 1986) and the personality trait 'locus of control' was determined from the Pearlin Mastery Scale (Pearlin & Schooler, 1978).

Each scale was preceded by comprehensive instructions for completion in accordance with the requirements of the respective authors.

6.3.2.1 The Family Adaptability and Cohesion Evaluation Scale III

The Family Adaptability and Cohesion Evaluation Scale III (FACES III, Olson, Portner & Lavee, 1985) is a 20-item Likert scale providing measures of family functioning across two major dimensions of Olson's Circumplex Model, namely cohesion and adaptability. Each of these two constructs is measured by a 10-item sub-scale for which responses ranging from 'almost never' (1) to 'almost always' (5) are required. Respondents' cohesion and adaptability scores are used to plot their position on the two dimensional representation of the Circumplex Model, and thereby to determine within which of the sixteen family types they perceive themselves to be operating. Scores can be compared with those of other family members as well as normative data supplied by the authors.

A second measure, the 'distance from centre' (DFC) score may also be calculated from this scale. As the name suggests, the DFC indicates how far an individual's score is from the *centre* of the Circumplex Model (i.e. the desired position, representing 'balanced' functioning). This is calculated for each respondent by obtaining the difference between his or her raw score and a given sample mean (a norm for individuals) on each of the two dimensions cohesion and adaptability, squaring each of these difference scores, summing them and then extracting the square root. The higher the DFC score, the more extreme (i.e. less functional, according to the model) the family system to which the individual belongs.

Recognising that their Circumplex Model probably did not account for cultural and ethnic diversity, and seeking to increase its relevance, Olson *et al.* (1985) hypothesised that 'extreme' behaviour need not be considered dysfunctional as long as all group members were satisfied with the prevailing conditions. Under such circumstances, the need for group norms would be obviated, as the family would constitute its own control. This necessitated a means of determining what Olson *et al.* referred to as 'family satisfaction' for each individual and it is this latter measure which forms the focus of interest for this study.

In order to obtain a measure of 'satisfaction with family life', the FACES III is administered twice, first as a measure of the individual's perception of his or her current family system on the dimensions of cohesion and adaptability, and second as an indicator of the arrangement that he or she considers 'ideal' in this regard. The discrepancy between the 'perceived' and 'ideal' score on each dimension is summed and this total provides a measure of *dissatisfaction* with the existing family system, the inverse of which denotes 'satisfaction with family life'.

The advantage of these measures for the purpose of this study is that, while the Circumplex Model is grounded on the curvilinear relationship hypothesised to exist between the dimensions of cohesion and adaptability so central to theories of family behaviour, both the DFC and the perceived-ideal discrepancy scores provide *linear* measures, suitable for correlation and regression analyses.

The elegant simplicity of this instrument belies its potent discriminatory powers. It provides a wealth of information useful in both clinical and research applications. Despite attracting considerable controversy (Anderson & Gavazzi, 1990; Beavers & Voeller, 1983; Green, Harris, Forte & Robinson, 1991; Kuehl, Schumm, Russell & Jurich, 1988; Lee, 1988), its efficacy in distinguishing problem from balanced functioning has been amply demonstrated, particularly in families where an ill or incapacitated member is present (e.g. Boyce *et al.*, 1991; Krauss, 1993; le Grange, 1989).

The characteristics of FACES III are summarised in Table 6.1, overleaf.

Table 6. 1 Characteristics of FACES III
from Olson, Portner & Lavee (1985)

<u>Theoretical Domain and Model</u>	Family System Circumplex Model
<u>Focus of Assessment</u>	Perceived; Ideal; Satisfaction
<u>Number of Scales and Items</u>	2 Scales; 20 perceived 20 ideal items
<u>Norms</u>	
Normative Sample	$n = 2453$ adults across life cycle $n = 412$ adolescents
Clinical	Several types of problem families
<u>Reliability</u>	
Internal Consistency	Cohesion ($r = .77$) Adaptability ($r = .62$) Total ($r = .68$)
Test - Retest	FACES II (4-5 weeks) .83 for cohesion .80 for adaptability
<u>Validity</u>	
Face Validity	Very Good
Content Validity	Very Good
Correlation between Scales	Cohesion & Adaptability ($r = .03$)
Correlation with Social Desirability	SD & Adaptability ($r = .00$) SD & Cohesion ($r = .39$)
Concurrent Validity	Lack of Evidence
Correlation between Family Members	X = H/W/A ($n = 370$) Cohesion ($r = .41$) Adaptability ($r = .25$)
Discrimination between Groups	Very Good
<u>Clinical Utility</u>	
Usefulness of Self-Report Scale	Very Good
Ease of Scoring	Very Easy
Clinical Rating Scale	Yes

6.3.2.2 Questionnaire on Resources and Stress

The short-form of the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg & Crnic, 1983) is a 52-item true-false instrument devised specifically to assess the impact on parents and other family members of a child with a developmental delay, chronic illness or disability. Abridged from the original 252-item QRS, the short form comprises sub-scales measuring four independent factors representing the categories of Parent and Family Problems (Factor I), Pessimism (Factor II), Child Characteristics (Factor III) and Physical Incapacitation (Factor IV).

Factor I - Parent and Family Problems - consists of 20 items derived from the QRS scales of Poor Health/Mood, Excess Time Demands, Limits on Family Opportunity and Lack of Family Integration. Items such as “I get upset with the way my life is going”, “I have given up things that I really wanted to do because of _____”, “The family does as many things now as we ever did” and “Our family agrees on important matters” are employed to measure these constructs.

Factor II - Pessimism - comprises 11 items derived from the QRS scales of Negative Attitudes toward Index Case, Overprotection/Dependency, Pessimism, Overcommitment or Martyrdom and Lack of Activities. This factor assesses current and long-term pessimism regarding the child’s prospects of achieving independence. Items such as “_____ will always be a problem to us”, “I worry about what will happen to _____ when I can no longer take care of him/her”, “_____ has too much time on his/her hands” are included.

Factor III - Child Characteristics - consists of 15 items based largely on the QRS category of Difficult Personality Characteristics (11 items). The remaining items were selected from the Negative Attitudes toward Index Case and Occupational Limitations scales. This factor assesses the *parent’s subjective view* of behavioural and attitudinal problems arising from the child. Items such as “Sometimes I feel very embarrassed because of _____”, “One of the things I appreciate about _____ is his/her confidence” and “_____ is able to express his/her feelings to others” constitute this sub-scale.

Factor IV – Physical Incapacitation – which measures the child’s level of functional independence, was reduced to six items from the original 14 contained in the QRS. Examples are “____ can feed him/herself”, “____ is able to go to the bathroom alone” and “____ can walk without assistance”. This measure served to supplement the demographic information in respect of child characteristics.

Concurrent validity has been demonstrated via the significant correlation of both Factors I and II with the Beck Depression Inventory while Factors III and IV correlated with a problem checklist (of unknown origin). Factor I also correlates with the Marlowe-Crowne Social Desirability Scale. Many of the sub-scales in the original version have been completely omitted from the shorter, more convenient form and it is for this reason that Friedrich *et al.* recommend the use of a separate social support scale.

The QRS-F has been widely used both internationally (e.g. Bruce & Schultz, 1994; Cahill & Glidden, 1996; Dunst *et al.*, 1986; Frey *et al.*, 1989; Hallum & Krumboltz, 1993; Rousey, Best & Blacher, 1992; Sandler, Warren & Raver, 1995; Walker *et al.*, 1992) and locally (e.g. Lea, 1986) (Lombard, 1992 and van Rooyen, 1989 each used the original 285-item QRS together with translations thereof) and despite some criticism (Clayton, Glidden & Kiphart, 1994; Wallander & Noojin, 1995) has established itself as an efficient and reliable research tool.

6.3.2.3 Judson Self-Rating Scale

The Judson Self-Rating Scale (Judson & Burden, 1980) was designed specifically as a measure of maternal acceptance and adjustment towards a child with a disability. It is a graphic instrument consisting of 22 bipolar items separated by a seven point, visual scale. The respondent is asked to place an ‘X’ at a point along the scale which indicates his/her relative position on that particular dimension. Items were derived from the constructs of ‘positive adjustment’ identified by three professionals working with mothers of children with a disability in a community-based early intervention project. This format was chosen as it was believed to maximise simplicity and ease of administration, while still producing data suitable for statistical manipulation.

Evidence of concurrent validity was found in a correlation of $r = .88$ between low maternal self-ratings (on relevant items) and the Malaise Inventory. Furthermore, consistency was found between this and another instrument measuring similar constructs developed by Burden (1978 in Judson & Burden, 1980). Evidence of face validity and construct validity was reported.

Test-retest reliability examined in two separate studies, each conducted over a three week period, was measured at $r = .89$ and $r = .91$ respectively although significance in this regard may actually conflict with the purpose of the scale, which is to detect fluctuations in maternal perceptions with extreme sensitivity. Internal consistency is of greater relevance here and reasonable evidence of this (by virtue of correlations between key items) is claimed by the authors. Burden's hypothesis of a four-factor structure underlying the scale has not, however, been supported and hence data is based on total scores.

This scale was selected for inclusion in the study by default - it being the only measure of 'adaptation to the child' to which the researcher could gain access. Originally designed during the late 1970's for use with mothers, it contains no gender-specific items and may be readily applied to fathers. The instrument has not enjoyed the same degree of favour as some of the other scales in this study, although it has been used by such leading practitioners as Patricia Sloper and Stephen Turner of the Hester Adrian Research Centre, University of Manchester and Lyn Quine and Jan Pahl of the Health Services Research Unit, University of Kent (Sloper & Turner, 1993b).

6.3.2.4 Coping Orientations to Problems Experienced

The Coping Orientations to Problems Experienced scale (COPE; Carver, Scheier & Weintraub, 1989) is a multidimensional coping inventory measuring a comprehensive range of coping styles and strategies employed in response to stress. Five sub-scales assess conceptually distinct aspects of problem-focussed coping, five sub-scales measure discrete aspects of emotion-focussed coping and three sub-scales appraise types of coping generally regarded as less effective. One item tests substance use. See Table 6.2.

Table 6. 2 COPE Subscales and Descriptions
(Carver, Scheier & Weintraub, 1989)

Subscale	Description
<i>Problem-Focused Coping</i>	
1. Active Coping	Taking active steps to remove or ameliorate the effects of a stressor
2. Planning	Thinking about how to cope with a stressor
3. Suppression	Putting other projects aside, trying to avoid becoming distracted by other events, even letting other things slide if necessary in order to deal with the stressor
4. Restraint Coping	Waiting until an appropriate chance to act presents itself, holding oneself back and not acting prematurely
5. Seeking Instrumental Social Support	Seeking advice, assistance or information
<i>Emotion-Focused Coping</i>	
6. Seeking Emotional Social Support	Getting moral support, sympathy or understanding
7. Positive Reinterpretation	Managing distressing emotions rather than dealing with the stressor <i>per se</i>
8. Acceptance	Acceptance of the reality of the stressor
9. Denial	Refusal to believe that the stressor exists or trying to act as if the stressor is not real
10. Turning to Religion	Tendency to turn to religion in times of stress
<i>Less Effective Coping Mechanisms</i>	
11. Focus on and Venting of emotions	Tendency to focus on whatever distress one is experiencing and to ventilate those feelings
12. Behavioural Disengagement	Reducing one's efforts to deal with the stressor and even giving up the attempt to achieve goals with which the stressor is interfering
13. Mental Disengagement	Activities that serve to distract one from thinking about the behaviour or goal with which the stressor is interfering, for example, escapism through sleep or television or daydreaming
14. Alcohol and Drug Disengagement	The use of alcohol or drugs in an effort to avoid a stressor

The COPE comprises 53 items on a Likert-type scale with response options of 'not at all' (1), 'not often' (2), 'often' (3) and 'most of the time' (4). Each of the thirteen subscales consists of four items producing total scores ranging between 4 and 16. Norms for these and the item on alcohol/drug use, derived from a sample of college students ($n = 1030$), together with two measures of reliability are provided in Table 6.3 below.

Table 6. 3 Normative data for the COPE scale
Carver, Scheier and Weintraub (1989)

Subscales	<i>M</i>	<i>SD</i>	Cronbach's Alpha ^a	Test-Retest Reliability ^b
Active coping	11.89	2.26	.62	.56
Planning	12.58	2.66	.80	.63
Suppression of competing activities	9.92	2.42	.68	.46
Restraint coping	10.28	2.53	.72	.51
Social support – instrumental	11.50	2.88	.75	.64
Social support – emotional	11.01	3.46	.85	.77
Positive reinterpretation	12.40	2.42	.68	.48
Acceptance	11.84	2.56	.65	.63
Turning to religion	8.82	4.10	.92	.86
Focus on or venting of emotions	10.17	3.08	.77	.69
Denial	6.07	2.37	.71	.54
Behavioural disengagement	6.11	2.07	.63	.66
Mental disengagement	9.66	2.46	.45	.58
Alcohol / drug disengagement	1.38	0.75	-	.57

Note: ^a Cronbach's alpha coefficients; $n = 978$

^b Interval = 8 weeks; $n = 89$.

As can be seen from the reliability coefficients reported in the above table, the COPE scale boasts reasonable internal consistency and stability over time. Furthermore, Carver *et al.* (1989) report that, with the exception of active coping and planning ($r = .67$) and the two types of social support ($r = .69$), little intercorrelation exists between the various sub-scales.

Evidence of both convergent and discriminant validity are claimed by Carver *et al.* (1989). Convergent validity is demonstrated by the fact that coping strategies considered to be functional, such as planning and active coping, have been found to correlate with conceptually related personality qualities believed to be beneficial. Similarly, less helpful coping methods such as denial and behavioural disengagement have shown an inverse correlation with valued personality traits. Discriminant validity was manifest from three sources: i) hypothesised correlations between personality variables and coping strategies, although present, were weak, suggesting that while the two are related, they are not identical, ii) anticipated correlations with a social desirability scale did not materialise, and iii) the absence of any relationship between COPE scales and two other measures (monitoring and blunting) included in the study suggests that they are conceptually distinct.

The COPE scale may be used in either of two forms, one each to assess situational coping and dispositional coping. The latter version was employed in this study as, rather than being a singular event evoking a situation-specific coping response, the demands placed on parents of a child with a disability are ongoing, and thus the parents' *usual* coping styles represent the topic of interest. It is for this reason that the instrument was selected in preference to the popular Ways of Coping (Revised) Questionnaire of Folkman and Lazarus (1985) which, despite potential utility with exceptional parents (Hatton, Knussen, Sloper & Turner, 1995; Knussen, Sloper, Cunningham & Turner, 1992), is typically administered in respect of an isolated event occurring over a limited time-period.

6.3.2.5 Family Support Scale

The Family Support Scale (FSS; Dunst, Trivette & Jenkins, 1988) was designed to measure the perceived helpfulness of sources of support available to persons rearing a young child. Adopting the familiar Likert format, it comprises 18 items (plus two respondent-initiated items) rated on a five-point scale ranging from 'not at all helpful' (1) to 'extremely helpful' (5). In each case the title or description of a person likely to belong to the respondent's social network is provided for which a ranking of helpfulness is required. The response 'not applicable' (0) is offered as a sixth option to preclude the allocation of scale points in respect of someone to whom the respondent has no access (e.g. a deceased parent).

Six underlying factors have been identified by means of principal components analysis. Factor I included informal kinship items such as friends, other parents and church. Factor II included social organisations such as social groups, parent groups and co-workers. Factor III included formal kinship items such as own parents, relatives and partner's parents. Factor IV consisted of immediate family members such as spouse and his or her parents. Factor V comprised specialised professional service items such as schools, day-care centres and early intervention programmes. Factor VI included general medical service agencies.

Reliability and validity of the scale were established on a sample of 139 parents of preschool children who were either mentally retarded, physically disabled or believed to be at risk for developmental delay. Internal consistency was calculated at $\alpha = .77$ while split-half reliability was determined to be $r = .75$ using the Spearman-Brown formula. Test-retest reliability at one month was $r = .75$ for the average correlation amongst the eighteen items and $r = .91$ for total scores. Over eighteen months, test-retest scores were $r = .41$ and $r = .47$ respectively.

Criterion validity has been established for the total score, subscale scores and a range of parent, family and parent-child outcomes (Dunst *et al.*, 1986; 1988). This succinct scale has proved useful in studies examining the relationship between social support and parental health and wellbeing, parental perceptions of child functioning, family integrity

and styles of parent-child interaction (e.g. Boyce *et al.*, 1991; Dunst *et al.*, 1986; Frøy *et al.*, 1989; Krauss, 1993) and has both research and clinical relevance.

6.3.2.6 Pearlin Mastery Scale

The Pearlin Mastery Scale (Pearlin & Schooler, 1978) measures the personality trait 'locus of control' on a 7-item scale with a five-point Likert format. With response options extending from 'strongly agree' (1) to 'strongly disagree' (5) and two scale items being reverse-scored, total scores range between 7 and 35. High scores represent an internal locus of control - a strong sense of personal mastery, while low scores indicate an external locus of control - a fatalistic outlook.

Pearlin & Schooler (1978) postulated that appraisal of a stressor and the choice and efficacy of the coping response would be mediated by personality variables, notably a sense of agency, that is, confidence in oneself and one's ability to exercise control over the environment. Subsequently, Folkman and Lazarus (1984) as well as Carver *et al.* (1989) have continued the debate about the relationship between personality traits and coping mechanisms but this has not been categorically defined.

This concise instrument was developed for expedient use where limitations on time and space preclude the utilisation of a more comprehensive measure. Pearlin and Schooler have claimed an alpha coefficient of 0.72 in the original study, while Folkman *et al.* (1986), using a four-point Likert scale, had similar findings ($\alpha = 0.75$). Thus internal consistency is suitably high, given the brevity of the scale.

6.3.3 Open ended questions

Four open-ended questions were included in order to afford parents the opportunity to respond without the restrictions of the forced choice format. Questions probed the extremes experienced in raising a child with cerebral palsy and offered parents a chance to share their hard-earned wisdom.

Qualitative data reflect the life-world of the respondent in an immediate and dramatic fashion (e.g. Mulderij, 1996; Mullins, 1987). Furthermore, subtle cues revealed in this manner promote penetrating insight, foster a deeper understanding of the subject and serve to locate the study in the true context of the respondent's everyday experience. It is for this reason that the decision to include open-ended questions was taken.

6.4 Procedure

6.4.1 Pilot Study

Once the design of the questionnaire had been completed, a pilot study was conducted on a small group of parents ($n = 6$) in order to verify the clarity and 'user-friendliness' of the test items and instructions. Participants, one male and five females ranging in age from 33 to 57 years, included 1 computer technician, 1 estate agent, 2 housewives, 1 business woman and 1 occupational therapist.

The research instrument, as originally designed, included the Measure of Marital Satisfaction devised by Kelso, Stewart, Bullers and Eginton (1984) for detecting marital problems amongst parents of children attending a psychiatric clinic. The decision to include this questionnaire was prompted by the considerable evidence in the literature of an association between marital happiness and parental adaptation. This particular scale had been selected ahead of other well-known instruments which either reflected outdated social values (Locke & Wallace, 1959) or were too long and linguistically sophisticated (Spanier, 1976) for the target group.

In response to the pilot study the Measure of Marital Satisfaction was removed from the final version of the research instrument, the reasons being that:

- i) despite its seemingly simple format, questions 8 to 11 were overlooked - apparently due to the page layout;
- ii) the questionnaire took too long to complete;
- iii) it was hypothesised that the variables 'marital satisfaction' and 'satisfaction with family life' were too conceptually similar to serve as IV and DV respectively;
- iv) it was anticipated that a significant proportion of parents would not be married.

6.4.2 Data gathering

In order to access a suitably large number of potential respondents and ensure that the necessary criteria for inclusion in the study were met, several welfare associations and parent groups were approached. While each expressed an interest in the study and a willingness to contribute, certainty regarding the diagnosis of members' children could not be guaranteed. Ultimately it was decided that uniformity in this regard could best be achieved by contacting parents through an organisation for which membership was based solely on the child's diagnosis.

The Western Cape Education Department was approached for permission to solicit parent participation via a school specifically serving children with cerebral-palsy. Once the purpose of the study had been explained, the questionnaire submitted for scrutiny and minimal disruption to school activities guaranteed, consent was duly granted.

Co-operation was sought from the headmaster of the school concerned, who readily offered his staff's assistance with questionnaire dissemination and retrieval. The issue of language was raised but the headmaster gave the assurance that, while it was true that the majority of the parents were Afrikaans speaking, their fluency in English was such that he did not foresee any difficulty with the language of the research instrument. Consequently, a total of 236 envelopes, each containing two identical questionnaires (one for each parent) and a covering letter (see appendix A) were delivered to the school for distribution amongst the day scholars.

Parents were provided with detailed instructions for completion of the questionnaire. Instructions in respect of individual scales were reproduced in accordance with the original authors' intentions. The researcher's telephone number was supplied so that additional information could be furnished where necessary. No requests of this nature were received.

Completed questionnaires were collected from the school some two months later.

6.4.3 Data Analysis

Quantitative data

As indicated, the intention of the study was to identify factors contributing to good adaptation in mothers and fathers respectively. It had been expected that a sizeable amount of the data would come from parental couples thus allowing for direct comparisons of dependent groups. Ultimately, however, responses from both parents of a given child were received in very few cases making analysis of independent groups more appropriate.

Initially, associations between independent and dependent variables were explored by means of Pearson's product moment correlation and point biserial correlation as indicated. Univariate relationships between demographic independent variables and each of the dependent measures were investigated by means of one-way analysis of variance, in the case of categorical variables, and regression (where indicated on the basis of the correlation) in the case of continuous variables. In each case maternal and paternal scores were compared by means of *t*-tests. Potentially significant bivariate relationships were then examined. Two-way analyses of variance were conducted in respect of parent by demographic variable on each of the dependent variables.

Similarly, each of the independent variables coping, social support and locus of control was examined for its relationship with the outcome measures. Direction of association and significance were noted with a view to inclusion in the final model. Input variables were included if significant at the 5% level. The question of multicollinearity of independent variables (Howell, 1992) was considered, as a degree of correlation was expected between variables such as 'seeking emotional social support' and the global social support measure, or 'positive reinterpretation of events' and 'locus of control'. Intercorrelations were not significantly high ($r < .59$). Amongst those variables ultimately selected for the separate regression analysis, no significant correlations were found.

Finally, a series of regression equations was run in respect of the selected input measures and each of the measures of adaptation in order to determine the relative contribution of input to outcome variables.

Qualitative data

Data received in response to the four open-ended questions was analysed by means of content analysis (Kerlinger, 1986). The unit of analysis for this purpose was the theme. Suitable themes were identified from the literature and through investigation of the responses themselves.

Data is reported in terms of frequencies of chosen themes in respect of each question. As before, maternal and paternal responses are examined separately.

Verbatim responses to the open-ended questions can be found in Appendix D.

Chapter Seven

Results

7.1 Quantitative Analysis

A thorough exploration of all quantitative data generated by the questionnaire was undertaken prior to a more parsimonious description of variables significantly related to adaptation. Results were based on a final sample of 79 parents, some of whom omitted one or more items on their questionnaires. The STATISTICA programme, on which the data analysis was conducted, deletes cases for which there is missing data. Consequently, some of the analyses were performed on slightly smaller samples.

7.1.1 Adaptation

As a preliminary step, correlations between all subscales of the three outcome measures of adaptation were examined. These are presented in Table 7.1.

Table 7. 1 Intercorrelations of Outcome Variables

VARIABLE	FACES Satisfaction - family life	QRS F I Parent Problems	QRS F II Pessimism	QRS F III Child Factors (Behavioural)	JUDSON Adjustment to the Child
FACES DFC	.20	.01	.05	.03	-.28*
FACES SFL		.13	.23	.27*	-.26*
QRS F I			.53*	.58*	-.32*
QRS F II				.54*	-.39*
QRS F III					-.48*

Note: Marked correlations are significant at $p < .05$

The degree of correlation between the outcome variables is in keeping with the hypothesis that each measures a related, yet discriminate aspect of the same construct, namely parental adaptation.

As can be seen from Table 7.1, the Judson scale of positive adaptation to the child has a significant, inverse correlation with all other outcome measures. This is due to the fact that, whereas a high score on the Judson scale represents good adaptation i.e. a desirable outcome, high scores on the other measures reflect greater difficulty i.e. poor outcome. Note particularly that data in respect of the variable 'satisfaction with family life' (FACES SFL) is recorded in the form of *discrepancy* scores (obtained directly from the scale) in which a high discrepancy reflects low satisfaction with family life. Thus a negative association with the Judson scale would logically result. Hence it can be seen that outcome measures other than the Judson scale can be expected to covary, each representing some aspect of adaptation from a negative perspective.

One notable exception, however, is the lack of correlation between the FACES III measure 'distance from centre' and all other scales, including the FACES III measure 'satisfaction with family life'. As indicated previously, the distance from centre (DFC) score is based on culturally determined norms. So, while it may serve as a measure of the extent to which individuals experience their family settings as *extreme* - for example 'rigidly enmeshed' or 'chaotically disengaged' as identified by Olson *et al.* (1985) - it gives no indication of their pleasure or displeasure with this reality. Consequently, it is not included here as a measure of adaptation to the child, but rather as an indication of the respondent's perception of his/her family type, to be interpreted in conjunction with the satisfaction with family life (SFL) score. Similarly, the absence of any meaningful correlation between DFC and all QRS subscales is consistent with their intended measurement of logically distinct concepts.

7.1.1.1 FACES III

Discrepancies between perceived and ideal scores on the FACES III (Olson *et al.*, 1985), representing an inverse measure of 'satisfaction with family life', were garnered from the full sample ($N = 79$) and ranged from zero to 34 with a mean of $M = 11.873$ and standard deviation of $SD = 8.115$. Given that the scale allows for a maximum discrepancy of 80, this represents a considerably positively skewed distribution

($b_1 = 0.966$ $p < .05$), indicating that the sample under consideration enjoyed a high degree of satisfaction with their family lives.

While it is technically true that a discrepancy of 80 could be recorded, such a score would indicate total disagreement with other family members in respect of the chosen lifestyle and would probably lead to swift dissolution of existing living arrangements. The score of 40 could be seen as the point beyond which dissatisfaction with family life exceeds satisfaction and is once again less likely to be tolerated. Thus a spread of 34 amongst co-habiting persons could be seen as a reasonable dispersion. In order to make this more amenable for statistical investigation however, a logarithmic transformation was performed on the data, thereby producing a reasonably symmetrical distribution (cf. Howell, 1992).

7.1.1.2 FACES III SFL and Demographic Factors

The influence of sex of parent on SFL was investigated by means of descriptive statistics, point biserial correlation and a t -test. While the mean SFL score for mothers ($M = 12.127$) was marginally higher than that of fathers ($M = 11.129$), suggesting greater dissatisfaction amongst mothers, the correlation between the categorical variable parent and the outcome measure SFL ($r_{pb} = 0.05$ $p > .05$) reflected very little association between these two variables. A t -test for difference between means of the two parent groups confirmed that the difference was not statistically significant ($t = -0.4186$ $p > .05$).

Mean scores for the four language groups in rank order showed Afrikaans speakers to have the lowest, followed by bilingual parents, English speakers, and finally Xhosa speakers reporting the highest mean SFL scores and hence the greatest dissatisfaction with family life. However, an investigation of the univariate relationship between home language of the parent and SFL, using one-way analysis of variance (ANOVA), found no significant difference between the various language speakers with respect to SFL scores ($F = 1.581$ $p > .05$).

Significant Spearman's R correlations between FACES III SFL and each of the ordinal variables education ($R = .305$ $p < .01$), employment status ($R = .275$ $p < .05$) and income ($R = .319$ $p < .01$) were computed. A comparison of SFL scores across the differing levels of education by means of one-way ANOVA revealed no significance, however, ($F = 1.0738$ $p > .05$) despite the above relationship.

Similar investigation of employment groups did produce a significant result ($F = 5.801$ $p < .005$) after which post hoc comparisons of means revealed that parents employed part-time were significantly happier with their family life than those in full-time employment. Further exploration revealed that, while this pattern held for mothers ($F = 5.615$ $p < .01$), it did not reflect the experience of fathers ($F = .952$ $p > .20$).

As income had been categorised on the questionnaire, it too was examined by means of ANOVA for which a significant result was once again obtained ($F = 6.261$ $p < .001$). Post hoc tests showed that parents earning between R2500 and R5000 per month were significantly less satisfied than each of the groups with lower monthly incomes (i.e. <R2500 and Nil), a finding that withstood two-way ANOVA for which parent groups were separated. See Figure 7.1 below. (The category R7500 –R10000 is not reflected due to absence of data for this cell.)

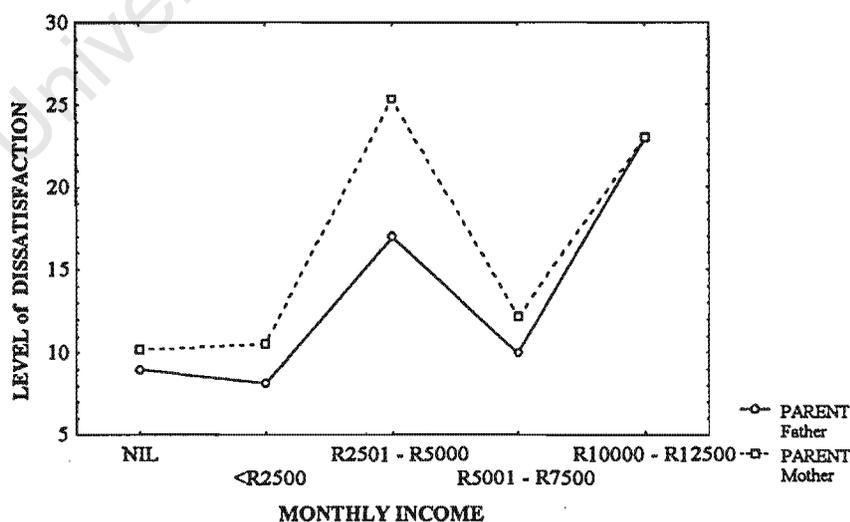


Figure 7. 1 Cell Mean Plot: Income by Parent on FACES III SFL

Computation of Pearson's product moment correlation coefficient revealed no significance in respect of the relationship between parents' age and SFL.

SFL scores for the variable 'marital status' revealed a mean score for widowed persons ($M = 5.75$) which was less than half that of the other groups. Married and single parents reported very similar mean SFL scores ($M = 11.61$ and $M = 11.53$ respectively) followed by separated persons ($M = 13.33$), with divorced persons recording the least satisfaction with their family life ($M = 16.625$). Upon investigation by means of one-way ANOVA, no significant differences were found ($F = 1.319$ $p > .05$).

Demographic information in respect of the children was also examined in relation to SFL. Factors taken into consideration were child's age, sex, position in the family and degree of disability, data in respect of the latter being obtained from subscale Factor IV of the QRS-F (see Chapter 6 Method: 6.3.2). Children were equally represented within the study in terms of sex and were also reasonably evenly distributed between parents. See Table 7.2.

Table 7. 2 Percentage Parent - Child Distribution

	BOYS	GIRLS	TOTAL
FATHERS	13.92%	16.46%	30.38%
MOTHERS	37.97%	31.65%	69.62%
TOTAL	51.90 %	48.10%	100 %

Point biserial correlation between child sex and SFL revealed an extremely weak negative correlation ($r_{pb} = -.05$ $p > .05$) indicating virtually no difference in family life satisfaction between parents of girls as opposed to boys. A t -test for independent groups found no significant difference ($t = .446$ $p > .20$) between mean SFL scores for parents of boys versus girls. As expected, further exploration of the data by means of two-way ANOVA (sex of parent by sex of child) served only to confirm this result.

The relationship between the child's age and parents' SFL, as measured by Pearson's product moment correlation coefficient, assumed a negative direction, indicating a decrease in dissatisfaction with family life concomitant with increasing age of child. The relationship proved to be insignificant, however ($r = -.15$ $p > .05$). The child's position in the family was similarly related to SFL, while the degree of disability, as measured by QRS-F Factor IV, showed a very weak positive correlation with this factor, suggesting that severe physical incapacitation was associated with greater dissatisfaction with family life. Significance was not achieved for this relationship, however.

7.1.1.3 FACES Distance from Centre

Distance From Centre (DFC) scores ranged from a minimum of .229 to a maximum of 26.299, reflecting a wide dispersion. In terms of their Circumplex model, Olson *et al* (1985) regarded a score of zero, representing the centre of the model to be the ideal. As the scores of individuals, couples or families increased from zero, so an imbalance in their functioning was deemed to exist until an extreme (presumably dysfunctional) level was reached. Scores below 6 represent balanced functioning, those between 6 and 11 are designated 'mid-range', while scores above 11 indicate extreme functioning.

Table 7. 3 FACES III DFC scores: Current sample vs. Olson *et al.* (1985).

Categories	Current Sample		Norms (Olson <i>et al.</i> , 1985)
	Mothers <i>n</i> = 55	Fathers <i>n</i> = 24	
Balanced < 6	17 (30.9%)	9 (37.5 %)	47%
Mid-range $\geq 6 < 11$	25 (45.5%)	10 (41.7%)	42%
Extreme > 11	13 (23.6%)	5 (20.8%)	11%

From Table 7.3 it is evident that fewer individuals from this sample experienced their family lives as 'balanced' and more reported 'extreme' functioning than would be expected in a normal population, according to Olson *et al.* (1985).

Amongst those who reported 'extreme' patterns of family interaction, the majority were 'rigidly enmeshed', indicating a very high degree of cohesion and an extremely low level of adaptability. No particular bias in respect of demographic variables was evident amongst this group, the only exception being that of income for which the majority reported a low level.

7.1.1.4 QRS-F

Intercorrelations between subscale Factors I, II and III of the QRS-F were examined and compared with those reported by Friedrich *et al.* (1983). See Table 7.4

Table 7. 4 Correlation matrix: Friedrich *et al.*(1983) and current study.

QRS-F FACTORS		Factor I	Factor II	Factor III
I.	Parent and Family Problems		.35*	.20
II.	Pessimism	.53*		.22
III.	Child Characteristics	.58*	.54*	

Italicised figures refer to the study by Friedrich et al. (1983) * $p < .05$

As can be seen from Table 7.4, the significant positive correlations existing between subscales on the current study contrast somewhat with the findings of Friedrich *et al.* (1983). This suggests that either the underlying factors are not as distinct as was believed by Friedrich *et al.*, or that these characteristics covary quite consistently in the present sample. An examination of each distribution (transformed to a proportion for ease of comparison) revealed that, while Factor II was normally distributed ($M = .459$ $SD = .229$ $b_1 = -.269$ $p > .05$), Factors I and III were significantly positively skewed ($M = .235$ $SD = .203$ $b_1 = 1.198$ $p < .05$ and $M = .201$ $SD = .177$ $b_1 = 1.805$ $p < .05$ respectively). The concentration of scores at one end of the scale reduces their utility with regard to discriminant analysis (Steffens, 1988).

7.1.1.5 QRS-F and Demographic Factors

Relationships between QRS-F factors and demographic variables were examined separately for each subscale, employing measures of association, correlation, *t*-tests and ANOVA as appropriate. Findings were as follows:

7.1.1.5a QRS-F Factor I

QRS-F Factor I (Parent and Family Problems) was mildly negatively correlated with age ($r = -.07$) and income ($r = -.08$) for mothers and moderately negatively correlated with age ($r = -.26$) and income ($r = -.22$) for fathers, suggesting that older parents with higher incomes experienced fewer problems than their younger, lower income counterparts. Significance was not reached in respect of these relationships, however.

Spearman's *R* correlations indicated similarly negative relationships between QRS-F Factor I and the variables education and employment. Inverse relationships of moderate strength ($R = -.41$) with education and mild strength ($R = -.16$) with employment were reported in respect of fathers, while a near zero correlation with education ($R = -.05$) and a modest inverse correlation with employment ($R = -.22$) emerged for mothers. As none of these relationships was found to be significant, further investigation by means of two-way ANOVA analysis, for example, was not indicated.

An examination of QRS-F Factor I scores for the variable marital status revealed that child and family problems experienced by mothers remained fairly constant across categories, declining only slightly in the presence of a partner, whereas the nature of the father's relationship with the mother appeared to impact on his experience of parent and family problems. This apparent interaction effect for marital status in which divorced fathers reported fewer parent and family problems as compared to mothers whereas single fathers experienced considerably more of these difficulties in relation to mothers, failed to achieve significance when subjected to two-way ANOVA testing, possibly due to the unequal distribution of the sample across these categories.

Evidence of a relationship between language and QRS-F Factor I appeared from a significant one-way ANOVA test ($F = 3.374$ $p < .05$) whereafter post-hoc comparisons revealed that Xhosa-speakers experienced parent and family problems to a greater degree than any of the other groups. Two-way ANOVA confirmed the significant main effect for language but did not produce a significant interaction effect. See Figure 7.2

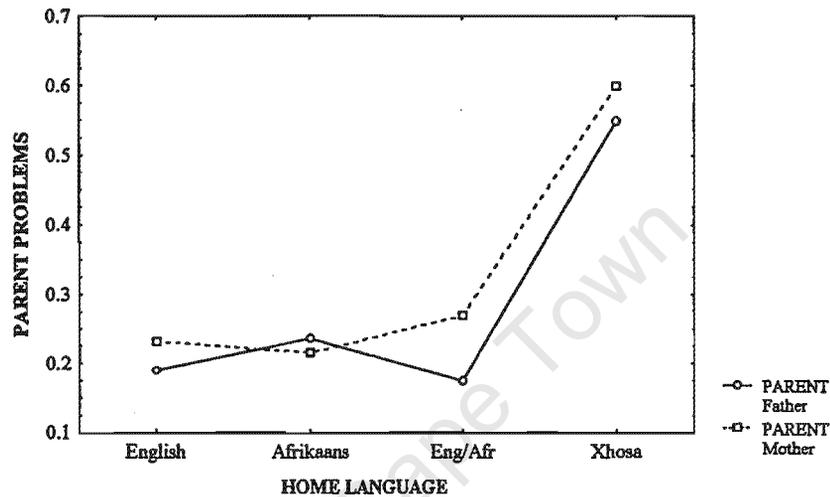


Figure 7. 2 Interaction Plot: Language by Parent on QRS-F FI

Child variables of age and position in the family showed a weak negative correlation with Factor I, which, in turn showed a near zero association with sex of child. Assessment by parent on this variable virtually eliminated any linear relationship between child age and Factor I for mothers, and position in the family and Factor I for fathers. Accordingly, negative correlations increased between child age and Factor I for fathers ($r = -.37$ $p < .10$) and position in the family and Factor I for mothers ($r = -.21$ $p < .10$) when the two subgroups were separated.

Sex of child was positively associated with Factor I for fathers, suggesting that fathers of daughters experienced more parent and family problems than fathers of sons. The direction of association was reversed for mothers, for whom the discrepancy in level of parent and family problems reported in respect of children of either sex was notably less pronounced. Here again the apparent interaction did not translate into statistical significance ($F_{1,75} = 1.452$ $p = .232$).

A significant correlation between physical incapacitation of the child and parent and family problems ($r = .51 p < .05$) was found. Upon separation of the parent groups, a strong correlation for fathers was recorded ($r = .66 p < .05$) while a reasonably strong association was found in respect of mothers ($r = .47 p < .05$). This variable seemed to be suitable for inclusion in regression analysis given that the level of parent and family problems covaried somewhat with the degree of physical handicap.

7.1.1.5b QRS-F Factor II

QRS-F Factor II (Pessimism) was found to have virtually no association with the demographic variables age ($r = .09$ for mothers and $r = -.00$ for fathers), employment level ($R = .01$ for mothers and $R = -.01$ for fathers), income ($R = -.02$ for mothers and $R = .19$ for fathers), and education ($R = -.03$ for mothers and $R = -.10$ for fathers).

Two-way ANOVA of parents across the language groups on QRS-F Factor II indicated that, while Xhosa speaking and bilingual parents held more diverse views than the other groups, mothers generally exhibited a greater degree of pessimism than fathers irrespective of the language group to which they belonged. See Figure 7.3.

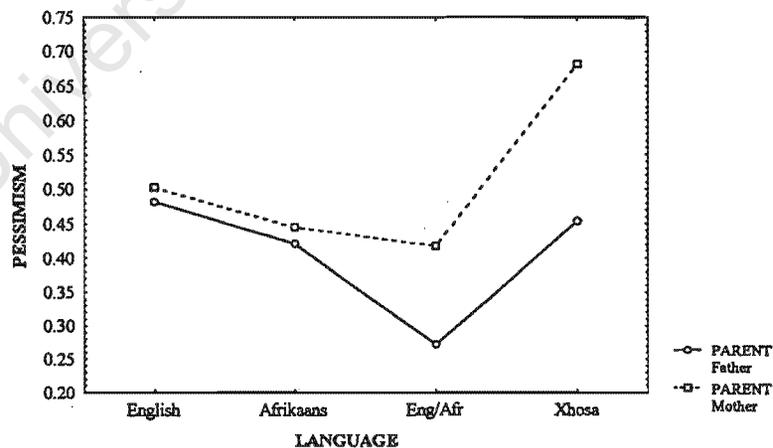


Figure 7. 3 Cell Mean Plot: Parent by Language on QRS-F F II

In keeping with the findings for QRS-F Factor I, a preliminary investigation of the data suggested an interaction effect between sex of parent and marital status for QRS-F Factor II. Similar levels of pessimism were found for both parents in intact families, whereas an inverse relationship was reported between unattached mothers and fathers on this factor. Unfortunately, this trend was not supported by two-way ANOVA which failed to reach significance for the interaction effect ($F_{2:66} = .77$ $p < .465$).

QRS-F Factor II showed very little association with any of the child-specific demographic variables. Near-zero correlations were found for mothers in respect of the child's age, sex and position in the family. Factor II scores for fathers showed a mild, inverse relationship with age of child and position in the family and a slightly stronger positive association with child sex, suggesting that fathers of girls experienced more pessimism than fathers of boys. This trend was not substantiated statistically, however.

By contrast with Factor I, QRS-F Factor II was found to be significantly positively correlated with degree of disability ($r = .50$ $p < .05$) for fathers, but not for mothers ($r = .22$ $p > .05$). Thus the level of the child's physical incapacitation appeared to covary significantly with subjective feelings of pessimism experienced by fathers.

7.1.1.5c QRS-F Factor III

QRS-F Factor III (Child Personality Characteristics) was poorly related to virtually all the demographic variables. For example, age was found to have a negligible, inverse correlation with this factor for mothers ($r = -.11$) and a near zero correlation for fathers ($r = .02$), while income was mildly positively correlated with QRS-F Factor III for both parent groups ($r = .18$ for mothers and $r = .17$ for fathers).

Employment status and level of education demonstrated similarly weak relationships with child personality characteristics. Calculations of Spearman's R correlations produced relationships of $R = .17$ for mothers and $R = -.16$ for fathers in respect of employment and $R = .14$ for mothers and $R = -.038$ for fathers in respect of education level. Clearly none of these relationships was significant.

Differences between mean QRS-F Factor III scores in respect of the variables 'language' and 'parent' examined by means of two-way ANOVA failed to reach significance across all eight groups ($F_{3:71} = .427$ $p > .25$). A similar result was found for the relationship between the parent groups, marital status and Factor III ($F_{2:66} = .762$ $p > .25$).

A very modest inverse correlation was found between QRS-F Factor III and age of child for both mothers and fathers, suggesting that parents of younger children perceived slightly more personality and behavioural problems within their children than parents of older children. Similar results for mothers in respect of 'position in the family' suggested that later-born children presented less of a problem than first-borns, but that birth order made little difference to fathers for whom a near-zero correlation was recorded on this variable. As before, significance was not reached for these relationships.

Consistent with results from the other outcome measures, evidence of an interaction was suggested between sex of child and sex of parent with respect to QRS-F Factor III, in which mothers reported more problems with sons, whereas fathers claimed greater difficulty with daughters. Significance was not reached, however, given the narrow dispersion of scores on this measure.

A strong positive correlation - for which significance was reached - was found between QRS-F Factor III and degree of disability for both fathers ($r = .78$ $p < .05$) and mothers ($r = .42$ $p < .05$). Thus it was evident that parents' perceptions of personality and behavioural problems originating within their child corresponded closely with the (objective) measures of physical incapacitation.

Thus no associations of significance were found between QRS-F factors and the demographic variables pertaining to the parents of sex, age, marital status, education, employment and income or the child-related variables of sex, age or position in the family. A significant association was found for home language and Factor I, but the only characteristic that had a consistently significant relationship with the stress aspect of adaptation was that of 'degree of physical incapacitation'.

7.1.1.6 The Judson Scale

Results in respect of the Judson Scale, for which eight participants provided incomplete responses, were derived from a sample of $n = 71$. Raw scores ranged from a minimum of 90 to a maximum of 154, with mean $M = 134.5$ and standard deviation $SD = 16.098$. Given that available extremes ranged between a minimum of 22 (poor adaptation) and a maximum of 154 (ideal adaptation), it was evident that the scores for this sample were negatively skewed ($B_1 = -1.0353$ $p > .05$) and (potentially) reflected a high degree of positive adjustment to the child.

As is to be expected from a distribution of this shape, an independent sample t -test comparing mean scores for mothers and fathers on the Judson scale failed to reach significance ($t = .361$ $p > .25$). Furthermore, the clustering of scores at the upper end of the scale presented a poor prognosis for the application of inferential statistics (transformation notwithstanding).

7.1.1.7 The Judson Scale and Demographic Factors

Nevertheless, the relationship between demographic factors and the Judson scale was characterised by a notable pattern of disparity across parent groups – differences in either strength or direction occurring in the majority of cases. For example, parents' age was weakly positively correlated with the Judson score for mothers ($r = .16$), yet showed an insubstantial, negative correlation with the scale for fathers ($r = -.02$).

Mothers' income showed a meagre inverse correlation with adaptation ($r = -.07$) whereas a reasonable trend in this direction was found for fathers ($r = -.38$) from which it was evident that fathers with higher earnings were less comfortable in relating to their exceptional children than low-income fathers.

With respect to employment categories, although fathers' level of adjustment improved with increasing employment, whereas mothers in full-time employment enjoyed the least adjustment to their children and those working part-time enjoyed the most, two-way ANOVA analysis failed to reach significance for these variables ($F_{2:63} = .39$ $p < .677$).

An exception to the above trend was found in respect of 'level of education', for which both parent groups showed a moderate decline in adjustment to the child with increasing status on this variable. See Figure 7.4.

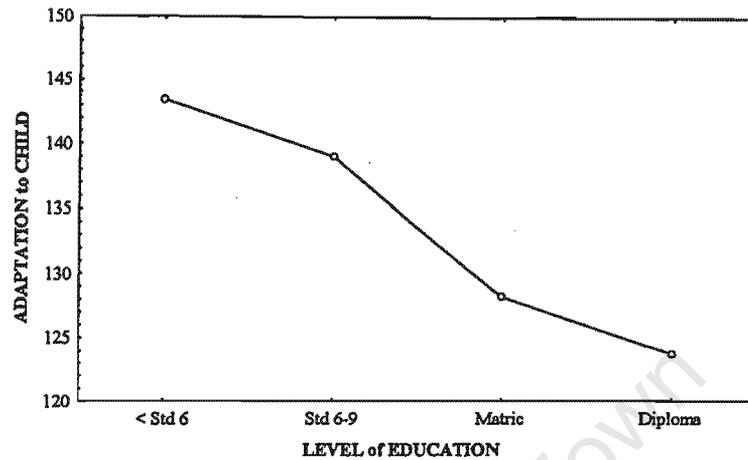


Figure 7. 4 Cell Mean Plot: Education on Judson Scale

Parents did not differ in terms of adjustment to the child when classified according to marital status, however significance was found for a one-way ANOVA test across the various home language groups ($F = 6.608$ $p < .001$). Post-hoc tests employing Tukey's HSD for unequal sample sizes provided evidence of a distinction between English and Afrikaans speakers ($t = .0139$ $p < .025$) in which the latter showed greater adjustment to their children than the former (within a spectrum of very high adjustment).

See Figure 7.5.

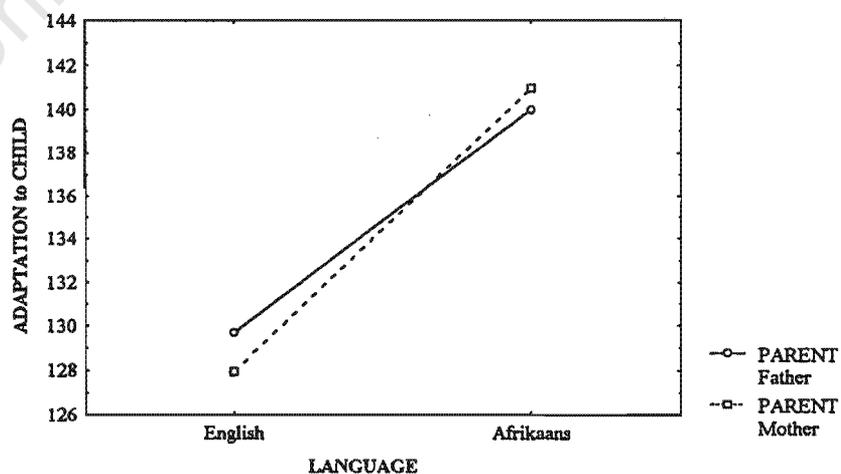


Figure 7. 5 Interaction Plot: Language on Judson Scale

Continuing the idiosyncratic trend for this scale, the child's position in the family showed little difference for fathers ($r = .08$) while being associated with better adjustment amongst mothers ($r = .24$). Conversely, whereas a negligible inverse correlation was found with relation to the child's age for mothers' scores ($r = -.04$), a moderate relationship in the same direction was demonstrated with respect to fathers' ($r = -.24$), indicating that a greater level of adjustment was reported by fathers of older children.

Weak correlations in opposing directions revealed that, in keeping with the outcome measures described thus far, fathers related slightly better to their sons ($r_{pb} = -.12$), while mothers favoured their daughters to a small degree ($r_{pb} = .11$).

Degree of disability was mildly inversely related to the Judson scale (fathers, $r = -.18$; mothers, $r = -.09$), from which it appeared that fathers did report 'poorer' adjustment to children with more severe physical incapacitation than either fathers of less handicapped children or mothers. However, distinct from the majority of outcome variables, no significant relationship was established between the Judson scale and this variable.

Thus, parents have reported an extremely high level of adjustment to their child. This has been largely unaffected by demographic variables relating to the parents or to the child. The home language of the parent was the only factor which distinguished parental responses, with English-speaking parents reporting poorer adjustment than their Afrikaans-speaking counterparts.

7.1.2 Coping

The COPE scale was satisfactorily completed by 78 of the 79 respondents. Descriptive statistics and estimates of internal consistency (Cronbach's coefficient alpha) obtained for each of the subscales in the current study are presented in Table 7.5 for comparison with the normative data (Carver *et al.*, 1989) which appeared in Table 6.3.

Table 7. 5 COPE: Descriptive Statistics and Alpha Coefficients ($n = 78$)

Subscales	M	SD	Cronbach's
			Alpha
Active coping	12.29	2.39	.62
Planning	13.17	2.12	.49
Suppression of competing activities	10.71	2.53	.44
Restraint coping	10.85	2.81	.59
Social support - instrumental	11.26	3.32	.78
Social support - emotional	11.04	3.13	.67
Positive reinterpretation	13.21	2.12	.57
Acceptance	11.85	2.73	.58
Turning to religion	13.73	2.61	.81
Focus on or venting of emotions	10.09	3.24	.71
Denial	7.95	3.23	.76
Behavioural disengagement	7.79	3.17	.74
Mental disengagement	8.87	2.76	.53
Alcohol / Drug disengagement	1.12	.48	-

In comparison with the norms established by Carver *et al.* (1989), average scores for this data set were higher on all but four subscales. Means for 'acceptance', 'focusing on and venting of emotions' and both 'emotional' and 'instrumental' social support proved remarkably similar to those of the scale's originators. Mean scores in respect of 'denial' and 'behavioural disengagement' were found to exceed those of the normative data at the five percent significance level, while the difference between means for 'turning to religion' withstood more stringent testing ($t = 10.14$ $p < .005$).

Cronbach's coefficient alpha values, ranging from $\alpha = .44$ for 'suppression of competing activities' to $\alpha = .81$ for 'turning to religion', compared reasonably well with the normative data of Carver *et al.* (1989). An acceptably high degree of internal consistency was demonstrated, particularly in view of the brevity of the subscales (4 items each) and the relatively small sample size (Cronbach, 1990).

It is evident from Table 7.5 that participants ($n = 78$) reported extensive use of a wide variety of coping styles. Overall, parents tended to favour emotion-focused coping mechanisms such as 'turning to religion', 'positive reinterpretation of events' and 'acceptance' followed by problem-focused methods such as 'planning' and 'active coping'. A series of dependent *t*-tests confirmed at the $\alpha = .05$ level that significantly more use was indeed made of these methods than of any others. A similar level of significance distinguished the least commonly employed methods, the purportedly inferior coping styles such as 'mental disengagement', 'behavioural disengagement' and 'drug or alcohol use', from those in moderate to frequent use.

Comparisons across the parent groups exposed a number of differences between mothers and fathers in respect of coping styles. Mothers reported an exceedingly high use of 'turning to religion' ($M = 14.05$ $SD = 2.58$) with 22 mothers scoring maximum points for this subscale. Although this method also ranked highly amongst fathers ($M = 12.95$ $SD = 2.55$), the coping strategy to which they most readily turned was 'positive reinterpretation of events' ($M = 13.04$ $SD = 2.42$). 'Behavioural disengagement' found least favour with both fathers and mothers.

Independent *t*-tests revealed that mothers made greater use of the emotion-focused techniques of 'acceptance' ($t = 3.006$ $p < .005$) and 'seeking emotional social support' ($t = 2.012$ $p < .05$) together with the supposedly less effective methods of 'focusing on and venting of emotions' ($t = 2.543$ $p < .025$) and 'mental disengagement' ($t = 2.828$ $p < .01$) than did fathers. Aside from 'alcohol and drug disengagement', mothers reported more extensive use than fathers of every mechanism identified within the COPE scale.

7.1.2.1 Coping and Adaptation

In order to investigate the relationship between coping and adaptation, correlations were computed for each of the COPE subscales and the five outcome measures for the full sample. See Table 7.6.

Table 7. 6 COPE: Correlations with outcome variables ($n = 78^a$)

COPE Subscales	FACES III	QRS-F	QRS-F	QRS-F	Judson
	SFL ¹	FI	FII	FIII	Scale
Active coping	-.04	-.08	-.03	-.04	.03
Planning	-.04	-.05	-.08	.14	.09
Suppression	.01	.24*	.20	.21	-.19
Restraint coping	.10	.25*	.23	.18	-.12
Social support - instrumental	.06	-.06	.13	.09	.07
Social support - emotional	-.11	-.03	.12	-.04	.27*
Positive reinterpretation	.04	-.17	-.14	-.14	.10
Acceptance	.14	.12	.19	.16	-.06
Turning to religion	-.12	.03	.10	-.19	.08
Focus on / venting of emotions	.03	.25*	.33*	.18	.00
Denial	-.04	.28*	.20	.09	-.03
Behavioural disengagement	.08	.45*	.35*	.31*	-.14
Mental disengagement	.09	.25*	.33*	.36*	-.19
Alcohol / Drug disengagement	-.10	-.01	.12	-.10	-.16

Note: Marked correlations are significant at $p < .05$

^a Judson Scale $n = 70$.

¹SFL: High score = dissatisfaction; Low score = satisfaction

Scrutiny of the above table revealed a cluster of moderately strong, significant correlations between the less effective coping methods and the QRS-F factors of 'parent and family problems', 'pessimism' and 'perceived child characteristics'. Although it was seldom the method of choice, the decision to employ 'behavioural disengagement' varied most consistently with each of these measures. Correlations of approximately the same strength and direction emerged in respect of 'mental disengagement', indicating that the practice of disinvesting energy or dissociating thoughts from the source of

distress was accompanied by higher levels of pessimism and a larger number of family and child-related problems.

Other less effective coping methods also reached significance in correlation with QRS-F Factors I and II. The tendency to 'focus on and vent emotions' was prevalent to an enhanced degree amongst parents who reported higher levels of pessimism ($r = .33$ $p < .05$) and parent-related problems ($r = .25$ $p < .05$). Similarly, the use of 'denial' as a means of coping increased concomitantly with reported family difficulties ($r = .28$ $p < .05$) and achieved a fair measure of association with pessimism ($r = .20$ $p > .05$).

The weak negative relationships formed between proactive methods such as 'planning' or 'active coping' and outcome measures, indicate that utilisation of these problem focused coping strategies was accompanied by fewer child and family difficulties for some parents. Yet, paradoxically, significant positive correlations were found for the categories of 'restraint coping' ($r = .25$ $p < .05$) and 'suppression of competing activities' ($r = .24$ $p < .05$) with Factor I, as well as similar (although non-significant) relationships with Factors II and III, indicating that parents who experienced more child- and family- related difficulties and expressed more pessimism, made greater use of these equally adaptive strategies.

Parents who engaged in the practice of 'seeking emotional social support' reported a significant level of positive adaptation to their child ($r = .27$ $p < .05$) as well as less dissatisfaction with their family lives ($r = -.11$ $p > .05$). The use of 'religion' as a coping mechanism was also associated with fewer child-related problems ($r = -.19$ $p > .05$) and more satisfaction with family life ($r = -.12$ $p > .05$) for parents as a group.

Inspection of the correlations between the various coping styles and measures of adaptation for mothers and fathers separately produced a somewhat different picture. In a textbook illustration of the phenomenon of "heterogeneous subsamples" (Howell, 1992 p257), the individual characteristics of these relationships had been masked through exploration of data for the sample as a whole.

Particularly striking was the dramatic shift from near-zero correlations to polar relationships of moderate strength that occurred in some instances. For example, correlation of 'active coping' and the Judson scale computed at $r = .03$ for the total sample, leaped to $r = .23$ and $r = -.33$ for mothers and fathers respectively. Likewise, 'planning' and the Judson scale went from a correlation of $r = .09$ for the combined group to $r = -.43$ in respect of fathers and a significant $r = .30$ ($p < .05$) in respect of mothers.

A negligible $r = .09$ between 'mental disengagement' and SFL was similarly transformed into $r = -.32$ for fathers and $r = .28$ ($p < .05$) for mothers once the two groups had been separated, illustrating the diverse conditions under which this mechanism is employed. In like manner, 'behavioural disengagement' and the Judson scale, originally correlated at $r = -.14$, assumed the disparate associations of $r = .30$ and $r = -.29$ when parents were examined independently.

Another notable example was that of 'positive reinterpretation of events' which altered from an indifferent $r = .10$ in association with the Judson scale to $r = -.30$ and $r = .29$ ($p < .05$) for fathers and mothers respectively. 'Emotional social support', initially correlated at $r = -.11$ with SFL, remained at approximately the same level for mothers, but underwent an increase in intensity to $r = -.45$ ($p < .05$) in respect of fathers.

The relationship between the Judson scale and 'alcohol or drug disengagement' recorded at $r = -.16$ for all respondents, changed direction with respect to mothers ($r = .13$) and climbed to a significant $r = -.51$ ($p < .05$) when examined in respect of fathers. Tables 7.7 and 7.8 below provide evidence of several other equally pronounced shifts when viewed in comparison with Table 7.6 above.

Table 7. 7 COPE: Correlations with outcome measures – Mothers ($n = 55^a$)

COPE Subscales	FACES III	QRS-F	QRS-F	QRS-F	Judson
	SFL ¹	FI	FII	FIII	Scale
Active coping	-.13	-.10	-.08	-.17	.23
Planning	-.04	-.05	-.09	.03	.30*
Suppression	.05	.25	.28*	.26	-.14
Restraint coping	-.04	.19	.14	.12	-.01
Social support - instrumental	.13	-.11	.16	.04	.08
Social support - emotional	-.08	-.07	.17	-.13	.20
Positive reinterpretation	-.03	-.21	-.18	-.27*	.29*
Acceptance	.19	.07	.12	.13	-.06
Turning to religion	-.16	-.04	.14	-.24	.01
Focus on / venting of emotions	.05	.21	.35*	.13	.11
Denial	-.01	.22	.22	.02	-.03
Behavioural disengagement	.14	.44*	.41*	.27*	-.29*
Mental disengagement	.28*	.19	.33*	.36*	-.21
Alcohol / Drug disengagement	-.17	-.14	.08	-.09	.13

Note: Marked correlations are significant at $p < .05$

^a Judson Scale $n = 50$.

¹SFL: High score = dissatisfaction; Low score = satisfaction

Overall, the majority of significant relationships appeared between the less effective coping strategies and the various measures of adaptation. This was particularly notable in respect of QRS-F Factor II, from which it seemed evident that a higher level of pessimism was accompanied by an increased use of these strategies by mothers. In fact, both 'mental disengagement' and 'behavioural disengagement' were significantly correlated with most of the outcome measures. 'Positive reinterpretation' was employed in conjunction with greater adjustment to the child, fewer perceived child-related and family problems and less pessimism amongst mothers. By contrast, 'suppression of competing activities' occurred in the presence of greater difficulty in all of these respects – notably pessimism. Yet, other problem-focused approaches such as 'planning' and 'active coping' related appropriately to measures of adaptation, as did the emotion-focused methods of 'seeking emotional social support' and 'turning to religion', the only exception being 'pessimism' which increased in tandem with these approaches.

Table 7. 8 COPE: Correlations with outcome variables – Fathers ($n = 24^a$)

COPE Subscales	FACES III	QRS-F	QRS-F	QRS-F	Judson
	SFL ¹	FI	FII	FIII	Scale
Active coping	.15	-.05	.05	.27	-.33
Planning	.02	-.06	-.07	.27	-.43
Suppression	-.09	.21	-.00	.05	-.28
Restraint coping	.07	.15	.07	.09	-.36
Social support - instrumental	-.39	.26	-.06	.01	.06
Social support - emotional	-.45*	.30	-.04	.07	.55*
Positive reinterpretation	.22	-.05	-.07	.02	-.30
Acceptance	-.17	-.09	.08	.02	-.04
Turning to religion	-.04	.18	-.09	-.19	.27
Focus on / venting of emotions	-.12	.32	.21	.18	-.22
Denial	-.37	.44*	.07	.05	.02
Behavioural disengagement	-.28	.44*	.18	.27	.30
Mental disengagement	-.32	.36	.27	.28	-.12
Alcohol / Drug disengagement	.03	.20	.24	-.08	-.51*

Note: Marked correlations are significant at $p < .05$

^a Judson Scale $n = 20$.

¹SFL: High score = dissatisfaction; Low score = satisfaction

Factor I, assumed fairly strong correlations with the less effective coping styles for fathers meaning that coping tactics of questionable merit were employed where child and family problems were prevalent. Similarly, pessimism was associated with expressed emotion, avoidance and substance abuse for fathers. Notably, seeking of 'emotional social support' was significantly correlated with both SFL and the Judson scale for fathers, indicating that good adaptation in respect of both the child and the family was seen to occur in the presence of adequate emotional support. Similarly, practical assistance accompanied a sense of greater satisfaction with family life for fathers. Relatively large negative correlations between problem-focused coping styles and the Judson scale implied that poorer adjustment to the child covaried with utilisation of these (supposedly) more adaptive methods. Of particular note was the relationship between denial and Factor I, which reflected an escalation of parent and family problems in the presence of this coping mechanism for both parents.

7.1.3 Social Support

As a global measure of appropriate parent-centered assistance, the FSS provides a single score with which to perform analyses. Data from $n = 78$ respondents were available for this purpose. A normal, widely dispersed distribution was evident ($b_1 = .569$ $b_2 = -.235$ $p < .05$), from which it was apparent that considerable diversity was present amongst parents' experience of support. Descriptive statistics, provided in Table 7.9, reveal that similar distributions were reported in respect of each parent group.

Table 7. 9 FSS: Descriptive statistics

Groups	Standard		
	Mean	deviation	Minimum Maximum
Mothers ($n = 54$)	42.15	19.57	9 83
Fathers ($n = 24$)	45.33	19.26	18 87
Total sample ($n = 78$)	43.13	19.40	9 87

7.1.3.1 Social Support and Adaptation

The FSS scores did not correlate significantly with the various outcome measures. Fathers reported enhanced satisfaction with family life in the presence of greater support, yet simultaneously reported more parent and family problems under these conditions. Pessimism increased mildly with improved social support for mothers. See Table 7.10.

Table 7. 10 FSS: Correlation with outcome variables

Outcome variables	Mothers ($n = 54^a$)	Fathers ($n = 24^b$)	Total Sample ($n = 78^c$)
FACES III SFL	.08	-.23	-.05
QRS-F Factor I	.15	.38	.22
QRS-F Factor II	.17	.14	.16
QRS-F Factor III	.12	.16	.13
Judson Scale	.12	.13	.12

Judson Scale: ^a $n = 49$ ^b $n = 21$ ^c $n = 70$

7.1.4 Control

An examination of the responses to the Pearlin Mastery Scale revealed a distribution that was slightly negatively skewed ($b_1 = -.2054$ $p > .05$), from which it was evident that the majority of parents perceived themselves as having a fairly strong sense of personal mastery i.e. an internal locus of control. No significant difference was found between the mean scores for mothers and fathers ($t = 1.387$ $p > .10$) on this scale. Cronbach's alpha coefficient was calculated at $\alpha = .81$ for the total sample, which compared favourably with the $\alpha = .75$ of Pearlin and Schooler (1978).

Table 7. 11 PMS: Descriptive statistics

Groups	Standard			
	Mean	deviation	Minimum	Maximum
Mothers ($n = 54$)	25.15	4.38	16	34
Fathers ($n = 24$)	26.67	4.65	18	35
Total sample ($n = 78$)	25.62	4.49	16	35

Note: PMS range 7 - 35

7.1.4.1 Control and Adaptation

In order to examine the relationships between locus of control and adaptation, correlations between these variables were computed. See Table 7.12.

Table 7. 12 PMS: Correlations with outcome variables

Outcome variables	Mothers ($n = 54^a$)	Fathers ($n = 24^b$)	Total Sample ($n = 78^c$)
FACES III SFL	-.04	.29	.04
QRS-F Factor I	-.46*	-.52*	-.48*
QRS-F Factor II	-.32*	-.38	-.34*
QRS-F Factor III	-.34*	-.31	-.32*
Judson Scale	.25	.08	.20

Judson Scale: ^a $n = 49$ ^b $n = 21$ ^c $n = 70$

The PMS displayed reasonably strong inverse correlations with the QRS-F Factors, indicating that the perception of a sense of control corresponded with a subjective experience of fewer child- and family-related difficulties or pessimism. However, relationships with the two other outcome variables exposed sex-related differences in respect of this personality trait. Fathers experienced an increase in *dissatisfaction* with their family lives in conjunction with an enhanced sense of personal control, a trend which did not manifest for mothers. By contrast, mothers' level of adjustment towards their child corresponded with their sense of personal mastery.

7. 1. 5 Intercorrelations amongst Independent Variables.

In anticipation of multiple regression, the prospect of multicollinearity was considered and an investigation of the relationship between the input variables 'coping', 'social support' and 'locus of control' was undertaken. Few relationships of note were evident.

Social support formed a significant inverse correlation with only one coping strategy, that of 'positive reinterpretation of events' ($r = -.37 p < .05$), while locus of control was similarly related to 'denial' ($r = -.30 p < .05$) and 'behavioural disengagement' ($r = -.35 p < .05$) for mothers.

Social support was significantly positively correlated with 'seeking instrumental social support' ($r = .59 p < .05$), while locus of control formed a significant negative correlation with 'denial' ($r = -.63 p < .05$), 'mental disengagement' ($r = -.58 p < .05$) and 'behavioural disengagement' ($r = -.51 p < .05$) and for fathers.

Correlation between social support and locus of control was not significant.

7. 1. 5 Regression Model of Adaptation

In order to determine the contribution of all significant input variables towards adaptation, a series of stepwise regression analyses was run. In order to eliminate the problems associated with multivariate analyses involving a large number of independent variables (Howell, 1992), only those that had been identified as significant at the 5% level were entered in forward stepwise analysis - until the maximum amount of variance explained by these factors was reached. Separate analyses were conducted on each of the outcome variables - FACES III SFL, QRS-F Factors I, II, III and the Judson Scale- in respect of mothers and fathers.

7.1.5.1 FACES III SFL

In the preliminary stage of the analysis the variables that had been identified as significant were 'employment', 'income', 'mental disengagement' and 'QRS-F Factor IV' with respect to mothers and 'income', 'sex of child', 'QRS-F Factor IV' and 'seeking emotional social support' with respect to fathers. The results of the stepwise regression analyses in respect of FACES III SFL are presented in Table 7.13.

Table 7. 13 Stepwise Multiple Regression for FACES III SFL

Independent Variable	Step	Multiple R	Multiple R ²	Change in R ²	<i>t</i>	<i>p</i>
<i>Mothers</i>						
Income	1	.2923	.0854	.0854	2.2766	.0275
Mental Disengagement	2	.4124	.1701	.0846	2.2127	.0317
$F_{2;48} = 4.918, S_{Y.P} = 8.31$						
$R^2 \text{ Adj.} = .145 \quad p = .011$						
<i>Fathers</i>						
Emotional Social Support	1	.4535	.2057	.2057	-1.539	.1395
Income	2	.5305	.2814	.0758	1.452	.1620
$F_{2;20} = 3.917, S_{Y.P} = 6.1$						
$R^2 \text{ Adj.} = .215 \quad p = .0367$						

Hence, the regression equations were calculated as follows:

$$\text{FACES III SFL (Mothers)} = -.736 + .299 (\text{Income}) + .291 (\text{Mental Disengagement})$$

$$\text{FACES III SFL (Fathers)} = 15.274 - .323 (\text{Emotional Social Support}) + .302 (\text{Income})$$

Bearing in mind that SFL is measured in terms of discrepancy between perceived and ideal life situations such that high scores represent high *dissatisfaction* (and low scores represent high satisfaction), the above regression equations can be interpreted as follows:

- Dissatisfaction with family life was associated with higher income and greater use of mental disengagement as a coping mechanism amongst mothers. Thus mothers who were satisfied with their families tended to earn less and make less use of mental disengagement (i.e. they confronted reality).
- Satisfaction with family life was greater for fathers who received more emotional social support but earned less. Here again, fathers who earned higher salaries were more dissatisfied than lower income earners as were those who had insufficient sources of emotional support.

Note that both regression coefficients were significant in the equation for mothers but neither was significant in the equation for fathers despite the fact that more of the variance in SFL was explained by the predictor variables for fathers ($R^2_{adj.} = .215$) than for mothers ($R^2_{adj.} = .145$).

The remaining variables were excluded from the equation due to their failure to meet the “*F* to enter” level for inclusion i.e. they were removed before a subsequent variable was added (Howell, 1992).

7. 1. 5. 2 QRS-F Factors

QRS-F Factor I: Parent and Family Problems

Significant independent variables identified during the exploratory analysis were 'employment', 'language', 'behavioural disengagement' and locus of control for mothers and 'degree of disability', 'focusing on and venting of emotions', 'behavioural disengagement' and locus of control for fathers. Results of the regression analyses are tabulated below.

Table 7. 14 Stepwise Multiple Regression on QRS-F Factor I

Independent Variable	Step	Multiple R	Multiple R ²	Change in R ²	<i>t</i>	<i>p</i>
<i>Mothers</i>						
Degree of disability	1	.4908	.2408	.2408	3.857	.0003
Behavioural disengagement	2	.6296	.3964	.1556	2.463	.0174
Locus of control	3	.6869	.4719	.0755	2.725	.0089
Position in the family	4	.6979	.4871	.0152	1.194	.2383
<i>F</i> _{4,48} = 11.937, <i>S</i> _{<i>r</i>,<i>p</i>} = .15089 <i>R</i> ² <i>Adj.</i> = .444 <i>p</i> = .000						
<i>Fathers</i>						
Degree of disability	1	.6588	.4340	.4340	3.694	.0013
Locus of control	2	.7489	.5608	.1268	-2.463	.0225
<i>F</i> _{2,21} = 13.408, <i>S</i> _{<i>r</i>,<i>p</i>} = .14641 <i>R</i> ² <i>Adj.</i> = .519 <i>p</i> = .000						

Regression equations in respect of the above were calculated to be as follows:

$$\text{QRS-F FI (Mothers)} = .396 + .406 (\text{Degree of Disability}) + .275 (\text{Behave Dis}) - .3 (\text{Locus of Control}) - .13 (\text{Position in the family})$$

- Perception of parent and family problems is exacerbated by the extent of the child's physical incapacitation and the coping strategy of behavioural disengagement, but tempered to some extent by an internal locus of control and the child's position in the family for mothers. Together these factors account for 44% of the variance in mothers' perception of parent and family problems.

$$\text{QRS-F F1 (Fathers)} = .571 + .556 (\text{Degree of Disability}) - .371 (\text{Locus of Control})$$

- Perception of parent and family problems is accounted for largely by the degree of the child's physical limitations for fathers, a factor that is moderated to the extent that they have an internal locus of control. Altogether 52% of the variance in fathers' perception of stressful child and family problems is accounted for by these two variables.

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QRS-F Factor II: Pessimism

Factors that correlated significantly with stress Factor II, i.e. pessimism, for mothers were 'degree of disability', 'venting emotions', 'behavioural disengagement', 'mental disengagement', 'suppression of competing activities' and 'locus of control'. The only factors to correlate significantly with Factor II for fathers were 'locus of control' and 'degree of disability'. A summary of the stepwise regression analysis appears in Table 7.15 below.

Table 7. 15 Stepwise Multiple Regression on QRS-F Factor II

Independent Variable	Step	Multiple R	Multiple R ²	Change in R ²	<i>t</i>	<i>p</i>
<i>Mothers</i>						
Behavioural disengagement	1	.4057	.1646	.1646	2.320	.0244
Venting of emotions	2	.4609	.2125	.0479	2.079	.0427
Degree of disability	3	.5138	.2640	.0515	1.889	.0646
$F_{3;31} = 6.097, S_{Y.P} = .2082$						
$R^2 Adj. = .221 \quad p = .001$						
<i>Fathers</i>						
Degree of disability	1	.5014	.2514	.2514	2.283	.0329
Locus of control	2	.5594	.3130	.0615	-1.371	.1848
$F_{2;21} = 4.783, S_{Y.P} = .2504$						
$R^2 Adj. = .248 \quad p = .019$						

The resultant stepwise multiple regression equations were as follows:

$$\text{QRS-F Factor II (Mothers)} = .0141 + .299 (\text{Behavioural dis}) + .269 (\text{Vent. Emotion}) \\ + .230 (\text{Degree of disability})$$

- Thus it was evident that stress manifest in the form of pessimism increased as a function of use of the coping mechanism 'behavioural disengagement' and to a lesser extent from 'venting of emotions', and the degree of the child's physical incapacitation for mothers. Together these three variables accounted for 22% of the change in their subjective experience of pessimism. The remaining variables did not contribute to the overall variance and were eliminated from the equation.

QRS-F Factor II (Fathers) = .676 + .429 (Degree of disability) - .258 (Locus of control)

- In respect of fathers, stress manifest as pessimism was accounted for to the greatest degree by the child's functional limitations but mediated to a small extent by a subjective sense of control. These two variables accounted for 25% of fathers' experience of pessimism.

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QRS-F Factor III: Child Behavioural and Emotional Problems

Factors identified during the initial stage of data analysis as being significantly related to the parents' perception of behavioural and emotional problems residing in the child were 'degree of disability' and 'locus of control' for fathers and 'locus of control', 'degree of disability', 'mental disengagement', 'behavioural disengagement' and 'positive reinterpretation of events' for mothers. A summary of the regression analysis is provided in Table 7.16.

Table 7. 16 Stepwise Regression on QRS-F Factor III

Independent Variable	Step	Multiple R	Multiple R ²	Change in R ²	<i>t</i>	<i>p</i>
<i>Mothers</i>						
Degree of disability	1	.4295	.1844	.1844	2.769	.0079
Locus of control	2	.5114	.2615	.0771	-1.638	.1078
Mental disengagement	3	.5630	.3170	.0554	2.659	.0106
Positive reinterpretation	4	.6157	.3790	.0621	-2.213	.0316
<i>F</i> _{4,49} = 7.4775, <i>S</i> _{<i>y</i>·<i>y</i>} = .12129 <i>R</i> ² <i>Adj.</i> = .328 <i>p</i> = .000						
<i>Fathers</i>						
Degree of disability	1	.7799	.6082	.6082	5.844	.0000
<i>F</i> _{1,22} = 34.157, <i>S</i> _{<i>y</i>·<i>y</i>} = .15009 <i>R</i> ² <i>Adj.</i> = .590 <i>p</i> = .000						

The regression equations derived from the above analysis were as follows:

$$\text{QRS-F-Factor III (Mothers)} = .4118 + .321 (\text{Degree of disability}) - .19 (\text{Loc of control}) + .322 (\text{Mental Dis}) - .27 (\text{Positive reinterpretation})$$

- Higher scores for mothers on the stress Factor III, perceived child behavioural and emotional problems, were associated with increased physical incapacitation of the child and use of the coping strategy 'mental disengagement', together with an external locus of control and little attempt to interpret the situation in a positive light. Altogether 33% of the variance in QRS-F FIII was accounted for by these four variables.

$$\text{QRS-F-Factor III (Fathers)} = .03211 + .7799(\text{Degree of disability})$$

- Locus of control was eliminated from the stepwise regression analysis although this variable did make a small (non-significant) contribution when entered in a standard regression analysis. Ultimately, however, the degree of the child's physical disability was the only variable to be associated in large measure with fathers' perception of emotional and behavioural problems in their children. Altogether 59% of the variance in QRS-F Factor III was accounted for by this variable alone in this sample of fathers.

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7.1.5.3 The Judson Scale

Input variables identified as being significantly associated with the Judson scale of adjustment to the child during the initial stage of the data analysis consisted of the coping methods of 'planning', 'positive reinterpretation of events' and 'behavioural disengagement' as well as the demographic variable of education for mothers and 'seeking of emotional social support' and 'drug or alcohol disengagement' as well as the demographic variable of income for fathers. A summary of the regression analyses is provided in Table 7.17 below.

Table 7. 17 Stepwise Regression on the Judson Scale

Independent Variable	Step	Multiple R	Multiple R ²	Change in R ²	<i>t</i>	<i>p</i>
<i>Mothers</i>						
Planning	1	.3047	.0928	.0928	2.300	.0259
Behavioural disengagement	2	.4175	.1743	.0815	-2.154	.0364
$F_{2,47} = 4.9615, S_{Y.P} = 14.936$ $R^2 Adj. = .1392 \quad p = .011$						
<i>Fathers</i>						
Emotional social support	1	.5488	.3011	.3011	2.359	.0305
Drug / alcohol use	2	.6673	.4453	.1441	-2.102	.0508
$F_{2,17} = 6.823, S_{Y.P} = 12.802$ $R^2 Adj. = .3800 \quad p = .00668$						

The resultant stepwise multiple regression equations were as follows:

$$\text{Judson (Mothers)} = 117.92 + .305 (\text{Planning}) - .29 (\text{Behavioural disengagement})$$

- Good adjustment to the child was associated with use of the active coping strategy of planning as well as a tendency not to resort to the less effective measure of behavioural disengagement for mothers. These two variables accounted for 14% of the variance in adjustment scores.

$$\text{Judson (Fathers)} = 121.91 + .443 (\text{Emotional social support}) - .39 (\text{Drug / Alcohol use})$$

- Poor adjustment amongst fathers was associated with the avoidant coping mechanism of alcohol / drug use and lack of emotional social support (38%).

7.2 Qualitative Analysis

A content analysis was conducted on data obtained in response to the four open-ended questions that formed the concluding part of the research instrument. Themes formed the unit of analysis (Kerlinger, 1986) and included those prominent within the literature review as well as others peculiar to this specific sample. Answers were generally brief and centred around practical, emotional and behavioural difficulties.

Verbatim responses are provided in appendix D.

Response Rate

Of the 79 participants, a total of 64 (81%) provided responses to one or more questions in this section. Response rates varied across the four questions, ranging from a minimum of 51(65%) for question four to a maximum of 62 (78) for question three. See Table 7.18

**Table 7. 18 Response Frequencies and Percentages for Open-ended Questions
(*n* = 64)**

Question	Mothers <i>n</i> = 44	Fathers <i>n</i> = 20	Total <i>n</i> = 64
1	38 (86%)	15 (75%)	53 (83%)
2	40 (91%)	14 (70%)	54 (84%)
3	44 (100%)	18 (90%)	62 (97%)
4	38 (86%)	13 (65%)	51 (80%)

7.2.1 Question 1

Parents were asked to name and/or describe those aspects of parenting a differently-abled child with which they had experienced greatest difficulty. A brief description of the themes that emerged from the analysis together with their frequency is presented in Table 7.19.

Table 7. 19 Frequency and Type of Difficulties (n = 53)

Theme	Mothers (n = 38)	Fathers (n = 15)	Total (n = 53)
Emotional & Behavioural Problems <i>(includes stubbornness, hyperactivity, mood swings, temper tantrums, mental illness, lack of self-confidence, frustration, emotional withdrawal)</i>	8 (21%)	6 (40%)	14 (26.5%)
Physical Incapacitation <i>(includes inability to walk, lack of independence)</i>	7 (18.5%)	-	7 (13%)
Parenting Difficulties <i>(includes maintaining balance in respect of discipline vs. concessions for disability, overprotection, other children)</i>	5 (13%)	-	5 (9.5%)
Acceptance <i>(includes coming to terms with reality)</i>	3 (8%)	2 (13%)	5 (9.5%)
Helplessness <i>(includes inability to improve own or child's circumstances)</i>	3 (8%)	1 (6.7%)	4 (7.5%)
Embarrassment <i>(includes answering questions, accepting ridicule)</i>	3 (8%)	1 (6.7%)	4 (7.5%)
Family Problems <i>(includes enlisting help, single parenting)</i>	3 (8%)	1 (6.7%)	4 (7.5%)
Transport <i>(includes use of public transport, need to carry child)</i>	3 (8%)	-	3 (5.7%)
Communication Problems <i>(includes speech impediments, inability of parent or others to comprehend speech)</i>	3 (8%)	-	3 (5.7%)
Lack of Information <i>(includes lack of formal sources, lack of professional or public awareness)</i>	3 (8%)	-	3 (5.7%)

7.2.2 Question 2

Parents were asked to name and/or describe those aspects of parenting a differently-abled child that they had found most rewarding. A brief description of the themes that emerged from the analysis together with their frequency is presented in Table 7.20.

Table 7. 20 Frequency and Type of Rewards (*n* = 54)

Theme	Mothers (<i>n</i> = 40)	Fathers (<i>n</i> = 14)	Total (<i>n</i> = 54)
Child's Physical Progress <i>(includes learning to walk, play, speak)</i>	9 (22.5%)	4 (29%)	13 (24%)
Child's Responsiveness <i>(includes kindness, understanding, happiness, emotional expression, co-operation shown to parent)</i>	9 (22.5%)	3 (21%)	12 (22%)
Child's Emotional Development <i>(includes social and spiritual development, increased independence, ability to deal with disability)</i>	5 (12.5%)	5 (36%)	10 (18.5%)
Child's Scholastic Achievement <i>(includes learning to read, formal acknowledgement of school performance)</i>	7 (17.5%)	3 (21%)	10 (18.5%)
Successful Negotiation of Difficulties <i>(includes finding ways to cope with the demands placed on selves as a result of the child's limitations)</i>	6 (15%)	1 (7%)	7 (13%)
Child's Self-confidence <i>(includes gains in ability to communicate with others)</i>	5 (12.5%)	2 (14%)	7 (13%)
Increased Mobility <i>(includes regaining use of legs or arms, overcoming odds, exceeding expectations in respect of mobility)</i>	5 (12.5%)	--	5 (9%)
Values <i>(includes not taking things for granted)</i>	2 (5%)	-	2 (4%)
Relationship with Child <i>(includes appreciation of parenting rôle)</i>	2 (5%)	-	2 (4%)
Sense of Accomplishment <i>(includes awareness of having 'done your best')</i>	1 (2.5%)	1 (7%)	2 (4%)

7.2.3 Question 3

Participants were invited to offer advice to other parents of children with special needs, in light of the experience that they had gained. Themes emerging from the responses, together with frequencies are reported in Table 7.21.

Table 7. 21 Frequency and Type of Parental Advice (n = 62)

Theme	Mothers (n = 44)	Fathers (n = 18)	Total (n = 62)
Support for Child <i>(includes demonstrations of affection, reassurance, encouragement, loyalty)</i>	15 (34%)	6 (33%)	21 (34%)
Acceptance <i>(includes anticipation of problems, patience, pride, understanding of child's difficulty)</i>	14 (32%)	4 (22%)	18 (29%)
Ability vs. Disability <i>(includes shift of emphasis from limitations to areas of competence, parity between exceptional and other children)</i>	7 (16%)	4 (22%)	11 (18%)
Faith <i>(includes maintenance of belief in God's purpose for the child, deference to higher power)</i>	8 (18%)	1 (6%)	9 (15%)
Assistance / Support Groups <i>(includes acknowledgement of need for outside input, inability to cope alone, benefits of support groups, incompetence of state bodies)</i>	5 (11%)	2 (11%)	7 (11%)
Optimism <i>(includes maintenance of hope)</i>	3 (7%)	2 (11%)	5 (8%)
Participation with Child <i>(includes involvement in school work, encouragement, stimulation, attention)</i>	5 (11%)	-	5 (8%)
Honesty <i>(includes apprising child of his/her limitations)</i>	1 (2%)	-	1 (1.6%)
Guidance <i>(includes provision of direction for child)</i>	-	1 (6%)	1 (1.6%)

7.2.4 Question 4

Participants were invited to offer advice to health professionals, in light of the experience that they had gained. Themes emerging from the responses, together with frequencies are reported in Table 7.21.

Table 7. 21 Frequency and Type of Advice to Professionals (n = 51)

Theme	Mothers (n = 38)	Fathers (n = 13)	Total (n = 51)
Encouragement <i>(includes exhortations for continued efforts)</i>	7 (18%)	4 (31%)	11 (22%)
Co-operation and Sharing <i>(includes requests for improved communication between parents and professionals, sharing of expertise, empowerment through information)</i>	9 (24 %)	1 (8%)	10 (20%)
Appreciation <i>(includes expressions of gratitude for assistance received)</i>	5 (13%)	3 (23%)	8 (16%)
Attitude <i>(includes requests for more optimism, fewer predictions of poor outcome, less emphasis on weaknesses, pity)</i>	4 (11%)	1 (8%)	5 (10%)
Honesty <i>(includes pleas for accurate diagnoses, prompt responses, willingness to answer questions)</i>	4 (11%)	1 (8%)	5 (10%)
Finance <i>(includes references to equipment costs)</i>	3 (8%)	-	3 (6%)
Equality <i>(includes parity amongst children)</i>	3 (8%)	-	3 (6%)
Patience <i>(includes parents and children)</i>	2 (5%)	-	2 (4%)
Faith	2 (5%)	-	2 (4%)
Skills <i>(includes experimentation, updating information)</i>	2 (5%)	-	2 (4%)
Deference <i>(includes acknowledgement of training)</i>	2 (5%)	-	2 (4%)

Other areas of concern were prolonged uncertainty in respect of the diagnosis, excessive time demands in respect of child-care, and having to account for the child's difficulties or appearance to others, each mentioned by two mothers.

The repeated need for hospitalisation was a concern of one father and one mother. Concern in respect of financial hardship as was raised by one mother, while the lack of facilities for children with disabilities was reported by another.

One father expressed concern about his child's diet by urging professionals to encourage children to eat healthily.

A number of parents entered remarks such as "none" or "no comment" which could be open to interpretation.

Overall the response rate for this section of the questionnaire was adequate, with many diverse themes emerging, although few achieved widespread endorsement.

Chapter Eight

Discussion

8.1 Adaptation

Overall, a high degree of adaptation, as operationalised within this study, was reported by the parent sample. Originally it had been anticipated that considerable diversity would be reflected in respect of adaptation levels, affording a comparison of factors associated with the two extremes - possibly by means of discriminant analysis. However, in view of the skewness of the distributions of outcome variables and the relatively small sample size, this was not appropriate (Steffens, 1988). Specifically, however the intention had been to describe characteristics of parents reporting good adaptation and this was certainly possible.

8.1.1 FACES SFL

Satisfaction with family life could be considered an overarching, global, yet somewhat oblique measure of adaptation in that it does not explicitly focus on child-related aspects of the parents' experience, yet is sensitive to disruptions precipitated by the child's needs. In other words, where accommodation necessitated by the child has compromised patterns of daily living beyond tolerable limits, this could be expected to be reflected in SFL scores. Conversely, where changes involved in catering for the child's idiosyncratic demands have not been detrimental to other family members, SFL scores should not be unduly affected. Regrettably, no norms or baseline figures are available for comparison since, firstly, SFL scores serve as their own norms (Olson *et al.*, 1985) and secondly, no similar study employing this measure was located.

In light of the unequal distribution of practical child-care reflected in the literature (Bristol *et al.*, 1988; Hallum & Krumboltz, 1993; Romans-Clarkson *et al.*, 1986), wherein a substantially larger proportion of time is devoted to this task by mothers than fathers, it would be reasonable to expect that any disparity in satisfaction with family life would reflect this gender bias. Discrepancy scores were indeed higher for mothers than

for fathers i.e. a greater difference between the perception of current living conditions and the desired state was recorded for the former than the latter, but not significantly so. In fact, discrepancy scores for both groups were extremely low, reflecting a uniformly high level of satisfaction with the present situation for both mothers and fathers.

The positive associations recorded between each of the demographic variables education, employment and income and SFL (discrepancy) scores indicate that a higher level of education, full-time employment and a concomitant increase in income were all accompanied by heightened *dissatisfaction* with the status quo. These findings reached significance for fathers only in respect of income, whereas for mothers, statistically significant differences in satisfaction level were found as a function of both employment status and income, with mothers in full-time employment, earning higher salaries, reporting the greatest dissatisfaction with family life.

Given that the sample consisted of predominantly low SES parents who demonstrated a propensity for a rigidly enmeshed family structure, a number of possible reasons for the negative association with employment emerge. Firstly, mothers may have returned to work as a matter of economic necessity (Cock, Emdon & Klugman, 1984 in Richter, 1994) and may have resented the consequent reduction in family togetherness i.e. the decrease in cohesion. Secondly, the inevitable disruption to family life brought by maternal employment would have necessitated greater flexibility with regard to practical arrangements i.e. an undesirable increase in adaptation. Together, these factors could have accounted for the decrease in mothers' satisfaction with family life that accompanied their increase in employment.

Although, logically, unattached mothers would be more likely to engage in full-time employment, mothers' discontent could not be attributed to this variable as, in keeping with the findings of Sloper and Turner (1993b), SFL scores did not differ significantly as a function of marital status. It is important to be mindful of the fact that as this is a correlational study, no inferences in respect of cause and effect can be made. For instance it is possible that mothers who were dissatisfied sought outside employment in order to escape the disliked home environment.

With respect to education, it is possible to speculate that the less educated, low income - and hence disempowered - mothers, assuming a passive, dependant position within a patriarchal family structure that valued obedience to authority, would have been unlikely to express dissatisfaction. Conversely, those with higher education would have felt entitled to question the family organisation and hence reported greater dissatisfaction.

Income was the only demographic variable significantly associated with satisfaction with family life for both parents. Clearly, financial concerns are paramount amongst low SES parents (Richter, 1994) and, in accordance with Maslow's theory of a hierarchy of needs, override any other considerations. Hence parents who reported zero income also reported very little dissatisfaction. Greatest dissatisfaction was reported for mothers earning between R2500 and R5000 monthly. In such cases, disputes may well arise over the allocation of resources. Certainly, the presence of the exceptional child exacerbates any pre-existing financial problem, for as one mother commented "...we don't have an endless supply of funds for operations, chairs, splints etc."

The lack of significance of child's age, sex, position in the family or degree of disability in fathers' satisfaction with family life parallels the findings of Sloper *et al.* (1991) and Sloper & Turner (1993b) in which none of the child-related variables contributed to the variance in life-satisfaction scores for fathers. In contradistinction to the present study, however, these earlier researchers did find significance in the relationship between the severity of the disability and mothers' life-satisfaction.

At face value, therefore, these scores suggest that parents were happy with the level of cohesion and adaptation existing within their families. Aside from this most desirable explanation however, another is possible. Despite the fact that meticulous attention to detail was paid in order to ensure that directions for completion of the scales were replicated in accordance with the authors' instructions, a number of questionnaires had to be excluded from the sample as the FACES scale had not been correctly completed. Some parents did not seem to appreciate the distinction between the first and second administration of the test i.e. the *perceived* and *ideal* versions of the scale and hence

completed only the first version. Others began to answer the second version and, possibly upon noticing its similarity to the first, abandoned this section of the questionnaire. Thus, it would seem that the distinction between these two parts of the scale, and hence its purpose, eluded many respondents.

8.1.2 QRS-F

Scores on this measure were extremely low, from which it could be deduced that minimal stress (reflecting good adaptation) was experienced by the parent sample. Given the concentration of scores at the lower end of the subscales, the considerable level of intercorrelation found between these variables was not surprising, statistically speaking. It was, however, disconcerting from the point of view of the study as it potentially brought the validity of the instrument into question. Comparable figures reported by Friedrich *et al.* (1983) were considerably lower and, in fact, non-significant in two of the three cases, confirming that discriminate aspects of stress were indeed being measured. Nonetheless, a level of intercorrelation very similar to the present study was reported by Rousey *et al.* (1992), despite a much broader dispersion of scores for each of the subscales.

8.1.2.1 Factor I: Parent and Family Problems

As reported in the results, Factor I scores were positively skewed, indicating a low level of parent and family problems amongst this parent sample. Evaluation of the relationship with each of the parent-related demographic variables sex, age, education, level of employment and income failed to produce evidence of any significant trends. Home language of the parent was, once again, the only variable that distinguished between the parent groups with respect to an aspect of adaptation. Xhosa-speaking parents reported greater difficulty in this respect than other parents, possibly due to the lack of acceptance traditionally shown to children with disabilities – and hence to their families - amongst this cultural group. Alternately, this may be an artefact of this particular sample for which the majority of the Xhosa-speaking parent reported little or no income.

The only characteristic of the child for which a significant correlation with Factor I was found was that of 'degree of disability'. Despite the non-significant relationship between these two variables reported by Friedrich *et al.* (1983) and Rousey *et al.* (1992), a relationship of this nature seems, intuitively, to be likely. Given the lack of tolerance displayed towards people with disabilities – so clearly articulated by Oliver (1996 in Kitchin, 1998) – it seems most reasonable to expect that parents of children with a more seriously disabling condition would be subject to negative social experiences. Thus responses to statements such as “members of our family get to do the same kinds of things other families do”, “there are many places where we can enjoy ourselves when [the child] comes along” or “the family does as many things now as we ever did” might well be negative – a product of social prejudice.

Furthermore, as has clearly emerged from the literature, special care-taking arrangements necessitated by the severity of the child's condition serve to curtail freedom of movement for mothers (Harris & McHale, 1989; Schilling *et al.*, 1985; Wallander *et al.*, 1990; Wallander & Venters, 1995) and to a lesser extent fathers (Bruce & Schultz, 1994; May, 1992a; 1992b), placing a heavy burden upon them. Thus items such as “I get almost too tired to enjoy myself”, “I get upset with the way my life is going” or “The constant demands to care for [the child] limit my growth and development” are more likely to be endorsed by parents of children with a higher level of physical incapacitation.

Alternately, the extremely low incidence of parent and family problems reported for this factor could be interpreted in the light of Friedrich *et al.*'s (1983) finding of a correlation between Factor I and a measure of social desirability. This, it is held, could be regarded as evidence of the use of denial as a coping mechanism, which, according to Lazarus (1981 in Friedrich *et al.*, 1983) represents an important component of the exceptional parenting process. Usually regarded as counterproductive, the use of denial in this setting may contribute positively to the experience of parent and child alike, allowing as it does for the maintenance of hope and optimism, and promoting perseverance in the procurement of services for the child (Lazarus, 1981 in Friedrich *et al.*, 1983) irrespective of the limitations with which they are confronted.

8.1.2.2 QRS-F Factor II: Pessimism

Contrasting with Factors I and III, the distribution of scores for this subscale was not significantly skewed, yet produced a mean score ($M = .459$) somewhat lower than that of Rousey *et al.* (1992) ($M = .630$). Given the volume of evidence indicating psychiatric morbidity amongst exceptional mothers (e.g. Bristol *et al.*, 1988; Bruce & Schultz, 1994; Hallum & Krumboltz, 1993; Holroyd, 1970 in Kazak, 1986; Romans-Clarkson *et al.*, 1986; Ryde-Brandt, 1991), a fair degree of pessimism was anticipated for this group. This did, in fact, materialise, but could not be connected with any of the parent- or child-related demographic variables. Clearly a degree of pessimism was being experienced by mothers, but it was not associated with their age, home language, level of education, employment or income.

Unlike Factor I (and Factor III below), the degree of disability was not significantly related to pessimism for mothers. As the pessimism subscale focuses on the concerns of the parent with respect to the child's future, employing statements such as "I worry about what will happen to [the child] when I can no longer take care of him/her.", and "[The child] will always be a problem to us", it would seem reasonable that greater functional limitations would be accompanied by increased concern regarding the future, particularly the time beyond the mother's life (Hallum & Krumboltz, 1993). The literature examining this relationship has been equivocal, with some authors reporting a distinct association between these two variables (Bradley, *et al.*, 1991; Havermans & Eiser, 1991; Lie, Börjeson, Lagerkvist *et al.*, 1994; Sloper *et al.*, 1991; Tew & Lawrence, 1975 in Kazak, 1986) and others disputing any such claim (Kolin *et al.*, 1971 in Kazak, 1986; Trute & Hauch, 1988; Wallander *et al.*, 1989; 1990; 1995). It would seem that for this sample of mothers, support for the latter group of researchers has been found. Possibly this could be attributed to the fact that many of the mothers in the sample were full-time home-makers for whom the prospect of the child's permanent dependence heralded little or no alteration to their long-term plans.

Given the extent to which fathers are typically distanced from practical arrangements in respect of the child's current and future well-being (Hallum & Krumboltz, 1993; May, 1992a; 1992b), and hence, to a certain extent, shielded from these concerns, it may have been reasonable to expect that less pessimism would be demonstrated for this group than for mothers. Findings did not reflect this disparity amongst the present sample, however.

Thus, in light of the absence of any association between parent- and child-related demographic variables and pessimism reported by mothers, similar findings in respect of fathers could have been anticipated. The significance of the correlation between the child's degree of physical disability and fathers' level of pessimism, contradicted this expectation, however. Thus, while the level of pessimism expressed by parents did not differ, the association of this variable with restrictions on the child's functional independence did. This could be ascribed to the fact that fathers are more concerned with the child's physical appearance (Bradbury & Hewison, 1994), ability (Frey *et al.*, 1989) and capacity to fulfil the rôle to which he or she was born (Leyser & Dekel, 1991) than mothers. Hence the less the child is able to meet the father's expectations, the greater would be his despondency. On a more practical level, the child's increased dependence, resulting from reduced physical capacity and employment prospects, may signify unwelcome financial drain, especially post-retirement, thereby inducing increased pessimism amongst fathers.

8.1.2.3 QRS-F Factor III: Child Behaviour Problems

As previously indicated, scores on this factor were positively skewed, indicating a very low level of child behaviour problems as perceived and reported by parents. In keeping with the other stress factors, despite tantalising tendencies to the contrary, no significant associations between parents' sex, age, home language, level of education, employment or income could be determined.

Child-related variables of age, sex and position in the family also failed to produce any results of significance. In keeping with Factor I, however, the objective measure of the child's level of disability was strongly correlated with the parents' subjective perception

of emotional and behaviour problems emanating from the child. This association may be well founded. The child whose movement is restricted by wheelchair use is likely to experience greater frustration, social isolation and depression than his or her more mobile counterpart (Mulderij, 1996). Emotional and behaviour problems may result, with negative impact on the parent-child relationship and hence on parents' perception thereof (Gilbride, 1993).

Thus, it would seem that the level of parental stress measured across the three QRS-F factors was extremely low. This constitutes a striking contrast with much of the literature in which above average stress levels were reported by exceptional parents (e.g. Atkinson *et al.*, 1995; Bradley *et al.*, 1991; Baxter *et al.*, 1995; Chen & Tang, 1997; Frey *et al.*, 1989; Friedrich & Friedrich, 1981; Kazak & Marvin, 1984; Lea, 1986; Leyser & Dekel, 1991; Reddon *et al.*, 1992; Walker *et al.*, 1992; Wallander & Noojin, 1995). However, compared with participants in past studies, except perhaps those of Leyser and Dekel (1991), most respondents in the present study belonged to a lower SES group. Thus it seems plausible that the stress introduced into their lives with the arrival of the handicapped infant, may have seemed negligible next to the more urgent and basic needs for food, shelter and employment.

The absence of any link between marital status and stress could well be accounted for by the fact that, amongst low SES groups, such arbitrary signifiers do not carry the same relevance as they do amongst the middle classes (Parker, Piotrowski & Peay, 1987 in Richter, 1994). The rate of teenage pregnancy and single parenting is high and is not stigmatised. Thus financial difficulties resulting, for example, from unemployment, may constitute a far greater source of stress (Quine & Pahl, 1985; Sloper *et al.*, 1991), but one that was not measured by this study. Hence, the exceptional parents in this sample may have a number of sources of stress with which to contend, in light of which emotional and behaviour problems present a less immediate threat.

8.1.3 The Judson Scale

In keeping with the other measures of adaptation, adjustment towards the child was reportedly very well achieved by the parent sample. This result accords with the work of Turnbull and Turnbull (1986 in Leyser & Dekel, 1991) and Lea (1986) who reported high levels of adjustment amongst parents from low SES communities. The increased incidence of (often preventable) disabilities and preoccupation with survival in the maelstrom that constituted daily living was believed to reduce the level of stigmatisation and foster acceptance amongst this group.

Once again, however, the skewness of the distribution warrants further consideration. In designing the Judson scale, Judson and Burden (1980) deliberately attempted to construct a simple measuring instrument for ease of administration to parents participating in a community health intervention project. Despite their apparent success, a number of participants in the present study, having responded appropriately throughout the questionnaire, were unable to complete this scale. For others, extreme responses dominated. Indeed the tendency to provide socially desirable answers seemed strong amongst this group, with $n = 8$ respondents scoring the maximum 154 points. This is not a new phenomenon, but one which was well documented with respect to parent samples more than twenty years ago (Voysey, 1975) and was acknowledged as a possible risk factor by the authors (Judson & Burden, 1980). Aside from anything else, the temptation to provide socially desirable responses may have arisen amongst this sample due to the (erroneous) belief that raw survey data would be made available to the institution through which the parents had been recruited.

Hence, while it is hoped that parents are indeed responding and relating to their children optimally - as these results would indicate - evidence of past investigations into parent-child relationships amongst low SES parents suggests otherwise (Halpern, 1990 in Bradley *et al.*, 1991; Richter, 1994). The multiplicity of risk factors inherent in circumstances of poverty tend to translate into poor parenting practices (Segal, 1985 in Richter, 1984), which are exacerbated in the presence of disability (Bradley *et al.*, 1991). Underreporting of poor adjustment may also stem from culture-specific variation in

terms of which this concept is understood and evaluated (cf. Slone, Durrheim, Lachman & Kaminer, 1998).

A disturbing trend that emerged upon closer inspection of the data, was the apparent contradiction evident in responses from some parents. For example, maximum endorsement was frequently provided in response to the last item on the Judson scale i.e. parents declared themselves to be 'optimistic about [their] child's future'. Yet, these same parents returned a moderately high score in respect of Factor II – reflecting pessimism in this regard. A further, perhaps more controversial, example arose where parents acknowledged via QRS-F item 52 that their child could not walk, yet, in refuting item 6 of the same scale, indicated that they anticipated no limitation in respect of his or her future employment prospects. The source of this apparent contradiction could be found in the parents' own educational and occupational history. Caught in the cycle of poverty, they may have enjoyed little in the way of formal schooling, and consequently undertaken work of a largely unskilled nature. By contrast, the level of tuition and remediation being bestowed on their child would seem to promise opportunities unknown to them. Furthermore, it is likely that an ethos of optimism is fostered within the school community, which parents may have internalised.

8.2 Independent Variables

The present parent sample made extensive use of virtually all of the coping mechanisms represented by the COPE scale. Mean scores exceeded those of the scale's originators in respect of ten of the fourteen subscales, significantly so in the case of 'behavioural disengagement', 'turning to religion' and 'denial', the latter once again confirming Lazarus's (1981 in Friedrich *et al.*, 1983) contention about the usefulness of this strategy for exceptional parents.

Hence it was evident that parents employed both problem and emotion focused coping strategies, lending support to the notion of a dualistic function of coping, proposed by leading researchers in the field (Folkman *et al.*, 1986; Holahan & Moos, 1985; Lazarus, 1993; Lazarus & Folkman, 1984), namely that of dealing with the problem and

mediating or regulating the accompanying emotions. Furthermore, this pattern of coping accords with Carver *et al.*'s (1989) hypothesis that, contrary to expectations, seemingly mutually exclusive styles of coping may be employed simultaneously by a given individual.

The proclivity amongst the current sample for emotion focused tactics such as 'turning to religion', 'positive reinterpretation of events' and 'acceptance' accords with existing research by Billings and Moos (1981) in which it was reported that people with less education tend to make greater use of avoidant coping strategies and less use of practical, problem focused methods than those with more education. Use of these methods suggests a somewhat passive, fatalistic, possibly societally-induced (Fairfield, 1983; Shapiro, 1983; Tavormina *et al.*, 1981) outlook that would be accompanied by an inverse association with locus of control. The direction of this relationship proved to be as expected, but not significantly so. However, the use of these approaches exemplified Lazarus and Folkman's (1984) theory of cognitive reappraisal. Clearly the source of stress was permanent and could not be diminished, leaving the individual (parent in this case) no alternative but to reframe his or her perceptions of the situation more favourably in the hope of reducing the ultimately deleterious effects of stress.

Despite the preference amongst both parents for 'turning to religion', this coping strategy did not relate well to any of the measures of adaptation. In the case of mothers a positive correlation suggested that an increase in pessimism accompanied the use of this coping method, a similar finding for fathers emerging in respect of perceived parent and family problems. Clearly the correlational nature of this work precludes any causal inferences, however absence of any significant association with adaptation raises questions as to the efficacy of this method.

Indeed, it was the ostensibly less effective and reportedly little used coping mechanisms of 'mental disengagement', 'behavioural disengagement' and 'drug or alcohol use' that related significantly to adaptation. Fortunately, these relationships occurred in the desired direction. Despite low reporting of the mechanism overall, where drug or alcohol use was acknowledged, it was associated with a decline in adaptation for fathers,

confirming the well publicised rôle of alcohol in the destruction of family relationships. The positive association between parent and family problems and use of the avoidant tactic 'behavioural disengagement' accorded with Bailey *et al.*'s (1992) findings wherein fathers who felt excluded from the parenting process exacerbated their situation by focusing their efforts elsewhere. A similar correlation between 'mental disengagement' and parent and family problems lent support to the alternate practice of 'emotional divorce' utilised by fathers under similar circumstances (Tavormina *et al.*, 1981).

Of the fourteen coping mechanisms measured, 'behavioural disengagement' and 'mental disengagement' were most consistently related to adaptation for mothers. As in the case of fathers, these methods were less popular, but to the extent that they were used, appeared in association with increased stress and family problems in general and poorer adjustment to the child. Mothers' prospects for use of these strategies seem remote, given the pivotal nature of their care-taking rôle (Bristol *et al.*, 1988; Byrne & Cunningham, 1985; Gallagher *et al.*, 1983; Harris & McHale, 1989), yet perhaps it is precisely this feature that accounts for the disruption associated with their non-compliance.

Counterintuitively, greater use of the problem-focused coping methods 'active coping', 'planning', 'suppression of competing activities' and 'restraint coping' was associated with poorer adjustment to the child amongst fathers. It is postulated that this may occur in the presence of social pressure, wherein fathers feel obliged to demonstrate their leadership. Paternal decision-making under such circumstances may tend towards the authoritarian, particularly in a low SES setting (Richter, 1994). Alternately, the plans enacted by the father may involve extended out of home care, thereby reducing opportunities for contact – with a concomitant decline in the father-child relationship.

The lack of association between scores on the Family Support Scale and the measures of adaptation was contrary to expectations. Notwithstanding the speculation around this concept, its positive association with well-being has been clearly articulated (Cohen & Wills, 1985; Haggerty, 1980 in Byrne & Cunningham, 1985; Sarason & Sarason, 1985) – especially amongst exceptional parents (Baxter *et al.*, 1995; Chen & Tang, 1997;

Kazak & Marvin, 1984; Knoll, 1990; Lea, 1986; Lonsdale, 1978; Quittner *et al.*, 1990; Schilling *et al.*, 1984; Young & Roopnarine, 1994). Furthermore, Friedrich *et al.* (1983) acknowledged the importance of this measure in relation to stress and advocated the use of a suitable social support scale when conducting a study involving stress. The particular scale employed in this study was specifically designed for use with parents of young children and explores the avenues of support likely to be available to this group. Despite its simple format, it has proven satisfactory in a number of studies (e.g. Boyce *et al.*, 1991; Dunst *et al.*, 1986; Frey *et al.*, 1989; Krauss, 1993), with results comparable to the current work appearing in only one, namely that of Boyce *et al.* (1991).

A reasonably wide dispersion of scores on this scale promised greater interpretative properties, yet the failure of this variable to correlate with adaptation rendered its inclusion in any regression equation inappropriate (Howell, 1992). It would seem therefore that the moderating effect of social support, as conceptualised within the buffering hypothesis (Cohen & Wills, 1985; Quittner *et al.*, 1990), was not demonstrated in this study. This finding was, however, consistent with the work of Dalgard *et al.* (1995) in which the buffering hypothesis proved effective only amongst persons with an external locus of control. As participants in the current study exhibited a predominantly 'internal' orientation, their reliance on social support was presumably similarly diminished.

By contrast, the simple, but time-honoured measure of locus of control, the Pearlin Mastery Scale (Pearlin & Schooler, 1978), generated results of a most compelling nature. As indicated above, in general, parents reported a strong tendency towards an internal locus of control, with 20 % ($n = 16$) of respondents recording scores greater than or equal to thirty. This parent sample believed themselves to be both responsible for and capable of actively shaping their own (and therefore their child's) destiny.

The reasonably strong inverse correlations between locus of control and the outcome measures of stress indicated that higher levels of stress manifest in people who perceived themselves as having little prospect of altering their personal circumstances or, stated positively, those who deemed themselves capable of controlling their environment, also

experienced less stress. This lent support to the notion of a moderating effect of locus of control on subjective levels of stress (Folkman *et al.*, 1986; Lefcourt, 1983 in Henderson & Vandenberg, 1992; Pearlin & Schooler, 1978) and corroborated the findings of Frey *et al.* (1989), Henderson and Vandenberg (1992), and Krauss (1993) that adaptation to an exceptional child was positively associated with an internal locus of control.

It is perhaps ineffectual to examine coping, social support and locus of control independently, when the literature is replete with examples of their interrelatedness. For instance, it is held that persons with an internal locus of control tend to prefer problem focused coping methods (Anderson, 1977 in Folkman, 1984) whereas those with an external locus of control have difficulty in executing such behaviours (Lazarus and Folkman, 1984), preferring to avail themselves of emotion focused tactics. Findings of the present study were equivocal in this regard. Whilst 'planning' and 'active coping' were amongst the preferred coping methods, their association with locus of control was negligible, despite the reported preponderance of internals within this group. In keeping with the contention of Folkman and colleagues, however, the emotion focused strategies of 'denial', 'behavioural disengagement' and 'mental disengagement' did produce the anticipated (significant) negative correlation with locus of control. Furthermore, in accordance with the composition of this sample, such behaviours constituted the least favoured coping methods.

Similarly, the absence of an association between locus of control and social support in the current study ran counter to Lefcourt *et al.*'s (1984) contention that, by itself locus of control does not serve as a consistent moderator of stress, but that in interaction with social support its effects become reliable. Meanwhile Dunkel-Schetter *et al.* (1987) view the receipt of social support as a function of the characteristics of the individual, amongst other things. A most influential aspect in determining whether or not support will be provided is the coping behaviour of the potential recipient. In essence it is believed that persons in the support network respond to cues from the target individual, with active help-seeking strategies being appropriately rewarded (Dunkel-Schetter *et al.*, 1987). Clearly an interaction with locus of control is at work here. Those who consider themselves able to influence their surroundings – and the people therein – will

confidently solicit assistance from members of their social network (i.e. engage in proactive problem focused coping behaviours). The forthcoming assistance will negate the stressor and simultaneously reinforce the individual's perception of his or her personal efficacy.

A parallel can be drawn with the concept of perceived rôle restriction (which, it has been argued, is closely allied to locus of control - see section 4.7.1). Acknowledging the preclusion of a claim of causality consequent upon their research, Wallander and Venters (1995) have postulated that any influence that perceived rôle restriction may exert on maternal adaptation would necessarily inform mothers' general sense of life satisfaction, which, in turn, would colour their perceptions of available social support and hence their ability to cope. An inability to cope would reinforce their perception of rôle restriction, thus completing the uroboric cycle.

Clearly a survey such as this is not placed to evaluate these circular relationships, but an awareness of their potential interaction and/or mutual reinforcement, illustrates the complexity of this topic and the arbitrariness of the point of entry (i.e. the nomination of dependent and independent variables).

Overall it seems that some support was found for the model of stress and coping proposed by Lazarus and Folkman (1984) in that the mediating effect of coping behaviours on adaptation in response to stressors was demonstrated. The similarity with which factors contributed to outcome across the different adaptation measures in the case of fathers served to indicate a high degree of consistency amongst this group. The wider range of variables related to outcome for mothers reflected a greater sensitivity to the distinct aspects of adaptation for this group. Parents were united in their reporting of 'degree of disability' as the most consistent contributor to adaptation. Thereafter, in accordance with the work of a several other investigators (Frey *et al.*, 1989; Sloper *et al.*, 1991; Sloper & Turner, 1993b; Tavormina *et al.*, 1981) diverse patterns emerged for the two parent groups, with adaptation consistently predicted by locus of control for fathers, while a variety of less adaptive coping strategies formed the only significant predictors for mothers.

8.3 Qualitative Data

Parental responses to this section of the questionnaire covered a broad range of topics. Answers tended to be brief and to the point, with little elaboration. Many of the themes that had been identified in the literature appeared amongst the spontaneous responses, as well as several others not previously encountered. However, sentiments expressed in this section of the questionnaire, did not always accord with those of the preceding scales. For instance, in stark contrast with the distribution of the QRS-F Factor III, the child's emotional and behavioural difficulties constituted a most prominent problem, with 21% of mothers and 40% of fathers describing various facets of this in response to the first question. Similarly, while factors relating to the severity of the child's impairment featured amongst the most oft-cited sources of difficulty encountered by exceptional mothers, no mention of this factor was made by fathers, despite the strong predictive properties of this variable in respect of paternal adaptation.

Communication problems which were subsumed under Factor III, but separated for the qualitative analysis, were reported by 8% of mothers, in addition to the above, yet were not cited by any fathers. As communication difficulties are common, but not universal amongst children with cerebral palsy (Nelson, 1990), this may simply have reflected the constitution of the sample.

Contrasting with the hypothesis of Lea (1986) that parents from low SES communities were less affected by or subject to stigmatisation in respect of their children with disabilities, a small number (8%) of mothers expressed concern in this regard. In particular, mothers dreaded being asked to account for the atypical appearance of their child as well as his or her becoming the object of ridicule in this respect. An issue that was not directly assessed by the research instrument, but which had been identified in the literature review was that of the paucity of appropriate information and services available to parents. A small number of mothers berated the authorities for this as well as condemning the apathy and ignorance of the general public. Despite recent improvements in anti-discriminatory legislation, the onus for enlightening the public still seems to rest on small groups of concerned parents. It is evident from the above that

parents were adversely affected by and dissatisfied with the attitudes and behaviour of the public towards people with disabilities in general, and their children in particular.

Other areas of difficulty identified by parents included the maintenance of a balance between their treatment of the exceptional child and the other children in the family. The temptation to protect and indulge the former had to be tempered with the knowledge that this was in the interests of neither the child nor his/her siblings. Discipline was reported to be difficult to enforce with consistency, in view of the child's disadvantaged position.

Disempowerment was expressed in a number of ways, through the practical problems of single parenting, particularly within a situation of financial hardship, through difficulties in soliciting social support and through a sense of helplessness with regard to the child's (and their own) circumstances.

Despite the fact that the children were of school-going age, one mother cited the uncertainty caused by the delay in reaching a diagnosis and the ensuing struggle to reach acceptance as the most harrowing aspects. Many denied that any difficulties had been encountered. One mother preceded her denial with confirmation of the sacrifices she had made on her child's behalf – “ I had to put everything aside to be their (*sic*) for her” – thereby supporting Lazarus's (1981 in Friedrich *et al.*, 1983) theory regarding the value of denial as a coping mechanism amongst exceptional parents.

As indicated at the outset, the tendency of health professionals to focus on the negative aspects of exceptional parenting devalues the parenting experience. For this reason, parents were invited to describe some of the rewarding aspects of this rôle. Not surprisingly, developmental issues such as gains in physical competence and emotional responsiveness featured prominently amongst parents' most valued recollections, as did scholastic achievements and gains in the child's self-confidence.

Notably, however, aside from expressions of satisfaction with regard to specific aspects of their child's progress or their relationship with him/her, a few parents numbered redefinition of their own values including the setting of simple goals and overcoming

obstacles amongst their greatest rewards. This was clearly demonstrated in the work of Wickham-Searl (1992), Hornby (1992) and de Graaf and de Graaf-Posthumus (1998) in which a shift in values together with unexpected gains in empowerment as well as personal emotional and spiritual development were recognised and appreciated by parents in retrospect.

Consequently, all of the advice offered by parents to their counterparts was imbued with optimism. Thirty-four percent of parents exhorted others to demonstrate support and affection for their child, while a similar number of mothers stressed the need for acceptance amongst parents of their child's limitations, an issue that had been raised by several parents as the source of greatest difficulty. The emphasis on maintenance of hope, faith and the seeking of social support implied that these were tasks with which the respondents themselves had struggled.

It seems therefore that responses to this part of the questionnaire lent support to the theory of coping advanced by Lazarus and Folkman (1984), which holds that where the stressor acting upon an individual cannot be removed, the means by which it is effectively managed will most often constitute some form of emotion focused coping. As demonstrated in the quantitative results in which parents favoured tactics such as 'turning to religion' and 'positive reinterpretation of events', the majority of the recommendations offered here essentially required parents to alter their perception of the situation (e.g. shift emphasis from their child's limitations to his/her strengths) or place responsibility for the difficulty elsewhere (e.g. Allah). Clearly these approaches link with the individual's perception of locus of control.

Advice for members of the helping professions reiterated some of the concerns identified in the literature such as the desire for honest, accurate information (Burden & Thomas, 1986; Mitchell, 1997; Mullins, 1987; Quine & Pahl, 1986), the opportunity to ask questions (Sloper & Turner, 1993a) and timely disclosure (Lonsdale, 1978; McNaughton, 1991) of both the diagnosis and prognosis of the child's condition. Parents also objected to the generally pessimistic approach evident amongst health care providers.

In keeping with the findings of Byrne and Cunningham (1985), Johnson *et al.* (1998), McNaughton (1991) and O'Sullivan *et al.* (1992), comments such as "...teach the parents how to handle and raise their child to their fullest capacity (*sic*)" and "...help us parents eg workshops in understanding our children" indicate that some parents expected medical specialists and therapists to offer advice that traditionally falls outside of their particular area of professional expertise. Again this highlights the conflict between the information obtained via the quantitative and qualitative results.

Taken at face value, the quantitative results suggest that parents have adapted well and have no need for outside intervention, yet the responses to the open-ended questions belie this result.

8.4 Findings of the Study

Ultimately the findings from the study were as follows:

- Consistent with previous work in low SES communities, a uniformly high level of adaptation was reported amongst the parent sample;
- No significant difference existed between maternal and paternal levels of adaptation to a child with cerebral palsy;
- Parent-related demographic variables of age, marital status, level of education and employment were not significantly related to adaptation for either of the parent groups;
- Income was significantly related to satisfaction with family life for both parents, with those earning between R2500 and R5000 significantly less satisfied than any other group;
- Adaptation varied for the different language groups. Stress resulting from parent and family problems was significantly greater amongst Xhosa-speakers than any other group. Afrikaans-speakers demonstrated significantly better adjustment to their children than English-speakers;
- Child characteristics of age, sex and position in the family were not significantly related to adaptation;
- The child's level of physical incapacitation related significantly to the degree of stress experienced by both mothers and fathers;

- Mothers and fathers made equal use of the emotion focused coping methods of 'turning to religion', and 'positive reinterpretation of events' as well as the problem focused methods of 'planning', and 'active coping'. Mothers made significantly more use of the emotion focused coping mechanisms of 'acceptance', 'seeking emotional social support' and 'focusing on and venting of emotions' than did fathers;
- Parents did not differ significantly in their perception of available social support;
- Parents did not differ significantly in their subjective perception of locus of control. This variable was significantly inversely related to the subjective experience of stress.
- The variables 'degree of disability' and locus of control were the most useful predictors of adaptation in respect of fathers. The variables 'degree of disability', behavioural disengagement', locus of control and 'mental disengagement' contributed most consistently towards adaptation for mothers.
- Emotional and behavioural problems constituted the most frequently cited source of difficulty for parents;
- Evidence of the child's physical, emotional and scholastic progress were the most rewarding aspects of parenting;
- Maintenance of optimism by means of emotion-focused coping methods was most frequently recommended;
- Greater honesty, openness and increased optimism on the part of health professionals was desired by parents.

8.5 Limitations of the Study

A number of limitations were evident in the present study, some of which were unavoidable due to the nature of the area of investigation, while others could be ascribed to the inexperience of the researcher and hence presented themselves during the research process. Characterised by the enthusiasm of the neophyte, this work was too ambitious and would clearly have benefited from some judicious pruning in the design phase.

A cross-sectional, correlational survey of this nature has limited utility particularly in view of the uncertainty regarding direction of causation. It is the contention of this researcher and others before her (Kazak, 1986; Quine & Pahl, 1989; Sloper & Turner, 1993b) that the true impact of the exceptional child on the lives of the parents can only be measured by means of a longitudinal study, however the practical limitations of such an undertaking are generally regarded to be prohibitive.

The number and range of participants was less than ideal for sound quantitative analysis. Reasons for the poor response rate have been advanced (see 6.1.1). Representativeness of the sample was questionable given that respondents were recruited from one central source (despite concerted efforts to engage other groups) and as such represented a convenience sample (Berkowitz & Donnerstein, 1982; Steffens *et al.*, 1988). Furthermore, bias may have entered due to the fact that responses were provided on a voluntary basis and, given the low response rate, systematic non-response bias may have been operating (Rosenthal & Rosnow, 1991). With respect to some of the demographic variables such as education and income for which an uneven distribution was found, it had been anticipated that, being the only school within a very large geographical area catering for children with cerebral palsy, SES of a broader range would have been represented amongst the parent body. The poor response from fathers was particularly regrettable, and it seems that their notorious reluctance to participate in work of this nature was once again demonstrated.

The low response rate may have been further exacerbated by the research instrument itself. Despite assurances to the contrary, it seems likely that a majority of potential respondents for whom English was a second language may have been discouraged by the

unfamiliar terminology employed in the scales. This, together with the considerable length of the questionnaire, may have served as a deterrent for many parents.

Furthermore, self-report instruments are known to be subject to numerous problems. Aside from language difficulties and the problem of social desirability referred to earlier, Folkman and Lazarus (1984) have identified honesty, memory lapses or distortions, and defence mechanisms as further potential hazards to reliability. Thus the advantage of anonymity is offset by a lack of control over the authenticity of the data.

A further methodological shortcoming of this work is the absence of a control group. This has been a matter of some debate amongst researchers in this field. While the inclusion of a control group would undoubtedly have produced a theoretically superior research design, thus rendering any findings more compelling, the practical difficulties inherent in such a practice have been well documented (Cahill & Glidden, 1996). Burden and Thomas (1986), for instance, described attempts to obtain matching groups as having the potential to reach "nightmare proportions" (p140), while Lea (1990) simply referred to "the sheer difficulty of the research area" (p217). Similarly, after a comprehensive review of related work, Byrne and Cunningham (1985) noted that control groups were rarely included.

8.6 Implications for Future Research

As already indicated, from a theoretical point of view, the longitudinal study constitutes the ideal means by which to establish whether the presence in the family of a child with cerebral palsy has any impact upon the parents. Where this is not feasible, cross-sectional studies could focus on parents of children at certain key ages such as at school entry, adolescence and at school leaving.

The research instrument should be tailored to the target population. Where a low level of education exists amongst respondents, a simpler format for gathering data should be employed. For example, while the parents in this survey reported an extremely high level of adaptation by means of the scales, the qualitative data revealed numerous areas of difficulty not addressed in the present study. It would seem that perhaps the less structured, more flexible and perhaps less threatening qualitative approach could produce data that is more illuminating. Furthermore, in light of the above, it may be best to incorporate a social desirability measure.

Studies should include samples that are more representative of the demographics of this country. Thus parents from both low and high SES groups should be included in order to determine with certainty the rôle of this variable in adaptation.

As much of the support that parents received came from the school, it might be worthwhile to compare adaptation amongst parents of children who do not receive formal schooling with those who do. Similarly, as the move towards mainstreaming gathers momentum, adaptation amongst parents whose children are integrated with the non-disabled could be contrasted with those who opt to continue with special schooling.

In view of complaints arising in response to the qualitative section of the questionnaire, a comparison between parents' service needs and expectations of professionals could provide a useful avenue of enquiry.

The rôle of the family type in adaptation was not fully explored in this study. Future studies could examine the relationship between these two factors in greater depth.

When all is said and done, it is hoped that this work can contribute in some way to increasing awareness amongst readers of the unfounded assumptions and prejudices faced by people with disabilities. Perhaps the most useful finding in this respect has been that satisfaction with family life is not contingent upon adherence to prescribed norms.

Work of this nature inevitably succeeds only in scratching the surface of the exceptional parent's experience. No matter how thorough the investigation, the extremes of emotion, disappointments and triumphs, the lived experience, can only be known by those for whom it has been a reality. The researcher must acknowledge his or her position as simply a medium through which the parent's voice is warranted.

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University of Cape Town



Department of Psychology

University of Cape Town · Rondebosch 7700 · South Africa
Telephone: (021) 650-9111
Fax No: (021) 650-3726

Dear Parent,

In preparation for a Master's Degree in Psychology, I am currently undertaking a survey amongst parents of children with special needs. The Western Cape Education Department has agreed to collaborate with the university and has granted permission for Eros school to be involved in the study.

It is my belief that, in order for mental health services to be more effective, professionals need to improve their understanding of the demands and rewards experienced by exceptional parents such as you. By taking part in this research, you can provide valuable insight into the dynamics operating in parents' daily lives, as they try to satisfy their children's needs as well as their own. You, as a parent, are the expert in this area and hence it is *your opinion* which is of the greatest value to mental health workers. I hope you will take this opportunity to express it.

Accompanying this letter you will find two questionnaires, one for each parent. They should take approximately twenty minutes each to complete. It is important to answer honestly - otherwise we will not be able to learn anything useful from this work. All information is confidential, so do not write your name on your response sheet. Remember - there are no 'right' or 'wrong' answers - just answers that are most appropriate for *you*.

After the questionnaires have been completed, please replace them in the envelope in which you received them, seal the envelope and return it to school for collection.

Note, if your partner is unwilling or unable to complete his/her questionnaire, I would still like to have *your* input – so please send your forms back. Should you require any further information, you are welcome to contact me in the Psychology Department at 650-3417.

Thank you for making a personal contribution to academic research.

Yours sincerely,

Judy Austin
Intern Psychologist

**CONFIDENTIAL
QUESTIONNAIRE**

to be completed by:

Mother

Demographic Information

Mother

1. What is your age? years

2. What is your home language?

3. What is your marital status?

Single Married Separated Divorced Widowed

4. a) What is your highest formal educational qualification?

b) What is your occupation?

c) What is your gross monthly income?

< R2500	R2500- R5000	R5001- R7500	R7501- R10000	R10001- R12500	>R12500
---------	--------------	--------------	---------------	----------------	---------

Your child with special needs

5. What is your child's age? years

6. What is your child's sex? Male Female

7. Indicate your child's position in the family. (e.g. First of three children.)

Only child

OR

of children

**CONFIDENTIAL
QUESTIONNAIRE**

to be completed by:

Father

Demographic Information

Father

1. What is your age? years

2. What is your home language?

3. What is your marital status?

Single Married Separated Divorced Widowed

4. a) What is your highest formal educational qualification?

b) What is your occupation?

c) What is your gross monthly income?

< R2500	R2500- R5000	R5001- R7500	R7501- R10000	R10001- R12500	>R12500
---------	--------------	--------------	---------------	----------------	---------

Your child with special needs

5. What is your child's age? years

6. What is your child's sex? Male Female

7. Indicate your child's position in the family. (e.g. First of three children.)

Only child

OR

of children

FAMILY AND HOME LIFE

Please read the following statements carefully and then decide for each one how frequently this happens in your family NOW. Circle the number that corresponds with your answer.

1 = almost never 2 = once in a while 3 = sometimes 4 = frequently 5 = almost always

- | | |
|--|--|
| <p>1. Family members ask each other for help.
1 2 3 4 5</p> <p>2. In solving problems, the children's suggestions are followed.
1 2 3 4 5</p> <p>3. We approve of each other's friends.
1 2 3 4 5</p> <p>4. Children have a say in their discipline.
1 2 3 4 5</p> <p>5. We like to do things with just our immediate family.
1 2 3 4 5</p> <p>6. Different persons act as leaders in our family.
1 2 3 4 5</p> <p>7. Family members feel closer to other family members than to people outside the family.
1 2 3 4 5</p> <p>8. Our family changes its way of handling tasks.
1 2 3 4 5</p> <p>9. Family members like to spend free time with each other.
1 2 3 4 5</p> <p>10. Parent(s) and children discuss punishment together.
1 2 3 4 5</p> | <p>11. Family members feel very close to each other.
1 2 3 4 5</p> <p>12. The children make the decisions in our family.
1 2 3 4 5</p> <p>13. When our family gets together for activities, everybody is present.
1 2 3 4 5</p> <p>14. Rules change in our family.
1 2 3 4 5</p> <p>15. We can easily think of things to do together as a family.
1 2 3 4 5</p> <p>16. We shift household responsibilities from person to person.
1 2 3 4 5</p> <p>17. Family members consult other family members on their decisions.
1 2 3 4 5</p> <p>18. It is hard to identify the leaders in our family.
1 2 3 4 5</p> <p>19. Family togetherness is very important.
1 2 3 4 5</p> <p>20. It is hard to tell who does which household chores.
1 2 3 4 5</p> |
|--|--|

Please read the following statements and consider how you would LIKE your family to be, IDEALLY. Circle the number that corresponds with your answer.

1 = almost never 2 = once in a while 3 = sometimes 4 = frequently 5 = almost always

- | | |
|---|---|
| <p>21. Family members would ask each other for help.
1 2 3 4 5</p> <p>22. In solving problems, the children's suggestions would be followed.
1 2 3 4 5</p> <p>23. We would approve of each other's friends.
1 2 3 4 5</p> <p>24. The children would have a say in their discipline.
1 2 3 4 5</p> <p>25. We would like to do things with just our immediate family.
1 2 3 4 5</p> <p>26. Different persons would act as leaders in our family.
1 2 3 4 5</p> <p>27. Family members would feel closer to each other than to people outside the family.
1 2 3 4 5</p> <p>28. Our family would change its way of handling tasks.
1 2 3 4 5</p> <p>29. Family members would like to spend free time with each other.
1 2 3 4 5</p> <p>30. Parent(s) and children would discuss punishment together.
1 2 3 4 5</p> | <p>31. Family members would feel very close to each other.
1 2 3 4 5</p> <p>32. Children would make the decisions in our family.
1 2 3 4 5</p> <p>33. When our family got together, everybody would be present.
1 2 3 4 5</p> <p>34. Rules would change in our family.
1 2 3 4 5</p> <p>35. We could easily think of things to do together as a family.
1 2 3 4 5</p> <p>36. We would shift household responsibilities from person to person.
1 2 3 4 5</p> <p>37. Family members would consult each other on their decisions.
1 2 3 4 5</p> <p>38. We would know who the leader was in our family.
1 2 3 4 5</p> <p>39. Family togetherness would be very important.
1 2 3 4 5</p> <p>40. We could tell who does which household chores.
1 2 3 4 5</p> |
|---|---|

This questionnaire deals with your feelings about a child in your family. There are many blanks on the questionnaire. Imagine your child's name filled in on each blank. Give your honest feelings and opinions. Please answer all the questions, even if they do not seem to apply. If it is difficult to decide TRUE (T) or FALSE (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please begin. Remember to answer all the questions.

- | | | | |
|--|-------|---|---|
| 1. doesn't communicate with others of his/her age group | | T | F |
| 2. Other members of the family have to go without things because of | | T | F |
| 3. Our family agrees on important matters. | | T | F |
| 4. I worry about what will happen to when I can no longer take care of him/her. | | T | F |
| 5. The constant demands for care for limit growth and development for someone else in our family. | | T | F |
| 6. is limited in the kind of work he/she can do for a living. | | T | F |
| 7. I have accepted the fact that might have to live out his/her life in some special setting or home. | | T | F |
| 8. can feed himself/herself. | | T | F |
| 9. I have given up things I really wanted to do in order to care for | | T | F |
| 10. is able to fit into the family social group. | | T | F |
| 11. Sometimes I avoid taking out in public. | | T | F |
| 12. In the future, our family's social life will suffer because of increased responsibilities and financial stress. | | T | F |
| 13. It bothers me that will always be this way. | | T | F |
| 14. I feel tense whenever I take out in public. | | T | F |
| 15. I can go and visit friends whenever I want to. | | T | F |
| 16. Taking on a vacation spoils pleasure for the whole family. | | T | F |
| 17. knows his/her own address. | | T | F |
| 18. The family does as many things together now as we ever did. | | T | F |
| 19. is aware who he/she is. | | T | F |
| 20. I get upset with the way my life is going. | | T | F |
| 21. Sometimes I feel very embarrassed because of | | T | F |
| 22. doesn't do as much as he/she should be able to do. | | T | F |
| 23. It is difficult to communicate with because he/she has difficulty understanding what is being said to him/her. | | T | F |
| 24. There are many places where we can enjoy ourselves as a family when comes along. | | T | F |
| 25. is overprotected. | | T | F |
| 26. is able to take part in games or sports. | | T | F |
| 27. has too much time on his/her hands. | | T | F |
| 28. I am disappointed that does not lead a normal life. | | T | F |
| 29. Time drags for, especially free time. | | T | F |
| 30. can't pay attention for very long. | | T | F |
| 31. It is easy for me to relax. | | T | F |
| 32. I worry about what will be done with when he/she gets older. | | T | F |
| 33. I get almost too tired to enjoy myself. | | T | F |
| 34. One of the things I appreciate about is his/her confidence. | | T | F |
| 35. There is a lot of anger and resentment in our family. | | T | F |
| 36. is able to go to the bathroom alone. | | T | F |
| 37. cannot remember what he/she says from one moment to the next. | | T | F |

38. can ride a bus.	T	F
39. It is easy to communicate with	T	F
40. The constant demands to care for limit my growth and development.	T	F
41.accepts himself/herself as a person	T	F
42. I feel sad when I think of	T	F
43. I often worry about what will happen towhen I can no longer take care of him/her	T	F
44. People can't understand what tries to say.	T	F
45. Caring for puts a strain on me.	T	F
46. Members of our family get to do the same kinds of things other families do.	T	F
47.will always be a problem to us.	T	F
48.is able to express his/her feeling to others.	T	F
49.has to use a bedpan or diaper (nappy).	T	F
50. I rarely feel blue.	T	F
51. I am worried much of the time.	T	F
52.can walk without help.	T	F

Think of how YOU, as an individual, feel about your child.

Here you are asked to indicate whether *your feelings and behaviour* are closer to the statement on the right or left side of the scale, by placing a cross on one of the seven lines in-between. See the following examples:

Tall	-	X	-	-	-	-	Short
Weak	-	-	-	-	X	-	Strong
Good natured	-	-	X	-	-	-	Irritable

In control of things	-	-	-	-	-	-	Helpless
My child and I have lots of fun together	-	-	-	-	-	-	My child and I don't have any fun together
Relaxed	-	-	-	-	-	-	Anxious
Nobody is interested	-	-	-	-	-	-	Lots of people are interested
Enjoying my child	-	-	-	-	-	-	Not enjoying my child
Confident in asking questions about my child	-	-	-	-	-	-	Afraid to ask questions about my child
Wary of what 'experts' tell me	-	-	-	-	-	-	Trust what 'experts' tell me
Hard to show affection towards my child	-	-	-	-	-	-	Easy to show affection towards my child
Proud of my child	-	-	-	-	-	-	Ashamed of my child
Comfortable with my child	-	-	-	-	-	-	Ill at ease with my child
Cold	-	-	-	-	-	-	Warm
Active	-	-	-	-	-	-	Passive
My child seems unhappy	-	-	-	-	-	-	My child seems happy
Calm	-	-	-	-	-	-	Worried
Indulgent with my child	-	-	-	-	-	-	Firm with my child
Not noticing any progress in my child	-	-	-	-	-	-	Noticing great progress in my child
Confident	-	-	-	-	-	-	Unsure of myself
Know how much to expect of my child	-	-	-	-	-	-	Don't know how much to expect of my child
Comfortable with medical people	-	-	-	-	-	-	Ill at ease with medical people
Depressed about my child	-	-	-	-	-	-	Happy about my child
Alone with my worries about my child	-	-	-	-	-	-	Able to share my worries about my child
Pessimistic about my child's future	-	-	-	-	-	-	Optimistic about my child's future

DEALING WITH STRESS GENERALLY

The following section concerns the many ways in which people respond when they confront difficult or stressful events in their lives. You are asked to indicate what you **GENERALLY** do and feel, when you experience stressful events. Obviously, different events bring about somewhat different responses, but think about what you **USUALLY** do when you are under a lot of stress. When considering each item, think of a broad range of stressful events which you have experienced.

Please circle the number which corresponds with the statement that applies to you when you deal with stressful events.

1 = not at all 2 = not often 3 = often 4 = most of the time

In general, when I experience a difficult or stressful situation...

- | | |
|---|---|
| <p>1. I talk to someone about how I feel.
1 2 3 4</p> <p>2. I make a plan of action.
1 2 3 4</p> <p>3. I talk to someone who could do something concrete about the problem.
1 2 3 4</p> <p>4. I turn to work or other substitute activities to take my mind off things.
1 2 3 4</p> <p>5. I just give up trying to reach my goal.
1 2 3 4</p> <p>6. I go to movies or watch TV, to think about it less.
1 2 3 4</p> <p>7. I drink alcohol or take drugs, in order to think about it less.
1 2 3 4</p> <p>8. I keep myself from getting distracted by other thoughts or activities.
1 2 3 4</p> <p>9. I think about how I might best handle the problem.
1 2 3 4</p> <p>10. I accept the reality of the fact that it happened.
1 2 3 4</p> <p>11. I force myself to wait for the right time to do something.
1 2 3 4</p> <p>12. I admit to myself that I can't deal with it, and quit trying.
1 2 3 4</p> <p>13. I look for something good in what is happening.
1 2 3 4</p> <p>14. I pretend that it hasn't really happened.
1 2 3 4</p> <p>15. I hold off doing anything about it until the situation permits.
1 2 3 4</p> <p>16. I try hard to prevent other things from interfering with my efforts at dealing with this.
1 2 3 4</p> <p>17. I think hard about what steps to take.
1 2 3 4</p> <p>18. I refuse to believe that it has happened.
1 2 3 4</p> <p>19. I get upset and let my emotions out.
1 2 3 4</p> <p>20. I take additional action to try to get rid of the problem.
1 2 3 4</p> <p>21. I learn to live with it.
1 2 3 4</p> <p>22. I restrain myself from doing anything too quickly.
1 2 3 4</p> | <p>23. I get upset and I am really aware of it.
1 2 3 4</p> <p>24. I try to get emotional support from friends or relatives.
1 2 3 4</p> <p>25. I ask people who have had similar experiences what they did.
1 2 3 4</p> <p>26. I do what has to be done, one step at a time.
1 2 3 4</p> <p>27. I learn something from the experience.
1 2 3 4</p> <p>28. I try to come up with a strategy about what to do.
1 2 3 4</p> <p>29. I act as though it hasn't even happened.
1 2 3 4</p> <p>30. I try to find comfort in my religion.
1 2 3 4</p> <p>31. I take direct action to get around the problem.
1 2 3 4</p> <p>32. I focus on dealing with this problem, and if necessary let other things slide a little.
1 2 3 4</p> <p>33. I make sure not to make matters worse by acting too soon.
1 2 3 4</p> <p>34. I seek God's help.
1 2 3 4</p> <p>35. I get sympathy and understanding from someone.
1 2 3 4</p> <p>36. I say to myself "this isn't real".
1 2 3 4</p> <p>37. I accept that this has happened and that it can't be changed.
1 2 3 4</p> <p>38. I pray more than usual.
1 2 3 4</p> <p>39. I let my feelings out.
1 2 3 4</p> <p>40. I sleep more than usual.
1 2 3 4</p> <p>41. I try to get advice from someone about what to do.
1 2 3 4</p> <p>42. I try to see it in a different light, to make it seem more positive.
1 2 3 4</p> <p>43. I reduce the amount of effort I'm putting into solving the problem.
1 2 3 4</p> <p>44. I feel a lot of emotional distress and I find myself expressing those feelings a lot.
1 2 3 4</p> |
|---|---|

45. I daydream about things other than this.

1 2 3 4

46. I talk to someone to find out more about the situation.

1 2 3 4

47. I put my trust in God.

1 2 3 4

48. I put aside other activities in order to concentrate on this.

1 2 3 4

49. I give up the attempt to get what I want.

1 2 3 4

50. I discuss my feelings with someone.

1 2 3 4

51. I concentrate my efforts on doing something about it.

1 2 3 4

52. I try to grow as a person as a result of the experience.

1 2 3 4

53. I get used to the idea that it happened.

1 2 3 4

Listed below are people and groups who are often helpful to members of a family raising a young child.

This questionnaire asks you to indicate how helpful each source is to *your family*.

Please *circle* the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How *helpful* has each of the following been to you in terms of raising your child.

NA = not available 1 = not at all 2 = sometimes 3 = generally 4 = very 5 = extremely

1. My parents

NA 1 2 3 4 5

2. My spouse or partner's parents

NA 1 2 3 4 5

3. My relatives / kin

NA 1 2 3 4 5

4. My spouse or partner's relatives / kin

NA 1 2 3 4 5

5. Spouse or partner

NA 1 2 3 4 5

6. My friends

NA 1 2 3 4 5

7. My spouse or partner's friends

NA 1 2 3 4 5

8. My own children

NA 1 2 3 4 5

9. Other parents

NA 1 2 3 4 5

10. Co-workers

NA 1 2 3 4 5

11. Parent groups

NA 1 2 3 4 5

12. Social groups / clubs

NA 1 2 3 4 5

13. Church members / minister

NA 1 2 3 4 5

14. My family or child's physician (doctor)

NA 1 2 3 4 5

15. Early childhood intervention programme

NA 1 2 3 4 5

16. School / day-care centre

NA 1 2 3 4 5

17. Professional helpers (social workers, therapists, teachers, etc.)

NA 1 2 3 4 5

18. Professional agencies (public health, social services, mental health, etc.)

NA 1 2 3 4 5

Other sources of help - (e.g. housekeeper)
Please specify :-

19.
NA 1 2 3 4 5

20.
NA 1 2 3 4 5

QUESTIONS ASSESSING LEVEL OF PERSONAL CONTROL

Please indicate how strongly you agree or disagree with the following statements by circling the number that corresponds with your choice.

1 = strongly agree 2 = agree 3 = undecided 4 = disagree 5 = strongly disagree

1. I have little control over the things that happen to me.

1 2 3 4 5

2. There is really no way I can resolve some of the problems I have.

1 2 3 4 5

3. There is little I can do to change many of the important things in my life.

1 2 3 4 5

4. I often feel helpless in dealing with the problems of life.

1 2 3 4 5

5. Sometimes I feel that I am being pushed around in life.

1 2 3 4 5

6. What happens to me in the future mostly depends on me

1 2 3 4 5

7. I can do just about anything I really set my mind to do.

1 2 3 4 5

1. What aspects of parenting a differently-abled child have been most *difficult* for you?

2. What aspects of parenting a differently-abled child have been most *rewarding* for you?

3. In view of your experience, what advice would you give to other parents of children with special needs?

4. In view of your experience, what advice would you give to health professionals?

THANK YOU FOR COMPLETING THE QUESTIONNAIRE.

Appendix C

While a child's environment has a great effect on her/his personality and behaviour, this influence is not a one-way process. How your child behaves affects your outlook and your behaviour as well. The following questions concern two aspects of your home environment – your general mood and your marriage relationship.

Please complete the items by *circling* the number next to or under the appropriate answer. If there are any items you prefer not to answer, please leave them blank.

PLEASE DO NOT COMPARE YOUR ANSWERS WITH YOUR SPOUSE.

1. In your family who has made the decisions in each of the following areas?

	Almost always husband	Shared equally	Almost always wife	Does not apply
a) where you live	1	2	3	4
b) whether wife works	1	2	3	4
c) how to handle the children	1	2	3	4
d) when to spend time with relatives and in-laws	1	2	3	4
e) how to spend money	1	2	3	4

2. When you and your spouse disagree, does it usually end that

- 1 wife or husband gives in
- 2 disagreement is avoided or unresolved and decisions are made separately
- 3 you reach a compromise that you both like

3. In the past six months how often have you and your spouse agreed on ways of handling situations involving your children?

	Always	Usually	Sometimes
a) praising the good things they do	1	2	3
b) what their responsibilities should be	1	2	3
c) when or how to discipline them	1	2	3
d) sharing the responsibility of their care	1	2	3

4. Over the last six months, have you been getting on each others nerves around the house?

- 1 rarely
- 2 occasionally
- 3 often

8. Do you tell your spouse about things that are on your mind – like what is worrying you, things that make you feel unsure of yourself or problems your friends have shared with you?

- 1 rarely
- 2 usually
- 3 always

5. Have there been any problems that caused serious difficulties in your marriage?

- 1 none
- 2 one or two
- 3 three or more

9. Do you ever wish you had not married your present spouse?

- 1 rarely
- 2 occasionally
- 3 frequently

6. How satisfied are you with your ability as a couple to talk over and resolve your differences?

- 1 very satisfied
- 2 moderately satisfied
- 3 dissatisfied

10. In the past two years have you been separated because of conflict?

- 1 No
- 2 Yes

7. In the past month how much tension or quarrelling has there been between you and your spouse?

- 1 very little
- 2 a moderate amount
- 3 a great deal

11. In the past two years have any of your quarrels led to physical violence and injury to each other?

- 1 No
- 2 Yes

12. How happy are you with the way you and your spouse handle the following aspects of your family life?

	Always happy	Usually happy	Seldom happy	Does not apply
a) talking with each other	1	2	3	4
b) showing affection	1	2	3	4
c) trusting each other	1	2	3	4
d) having sex	1	2	3	4
e) going out with the kids	1	2	3	4
f) spending time with relatives and in-laws	1	2	3	4
g) spending time with the children	1	2	3	4
h) managing money	1	2	3	4
i) sharing the responsibilities of your home	1	2	3	4

13. Most couples experience different degrees of happiness at different times in their marriage. The questions below concern your general satisfaction with your marriage as it has been for you in the past year.

	Almost always happy	Happy most of the time	Hardly ever happy
a) everything considered, how happy are you in your marriage?	1	2	3
b) how happy do you think your spouse is in your marriage?	1	2	3
c) is time spent with your spouse happy for you?	1	2	3
d) how do you think your spouse feels about time spent with you?	1	2	3

Appendix D

Verbatim responses to open-ended questions posed in the research questionnaire.

1. What aspects of parenting a differently-abled child have been most *difficult* for you?

- As it concerned me the father of this child I have to be patient with the child because some he gets difficult and stubborn. But no matter that problem of my child I will always be and understand him. We are already use to this difficulties of him and its not a problem for us.
- Frustration of not having information available and general public ignorance about disabled people. No enough facilities for these children.
- Time consumption spent with the child.
- The continuous speech development. Having to talk to you child constantly to develop her speech. Answering questions in public that makes you as a parent feel uncomfortable and sometimes putting you on the spot.
- Disciplining my daughter and yet at the same time feeling sorry for her because she is not able to do some things for herself. But there needs to be a balance between discipline and love.
- Maybe a little by not seeing his first step or running. Climing on stuff is out. People asking about his big head (actually I don't worry what other people say, he's mine and that's all that matters).
- The fact that she is born like this.
- To talk to him.
- To carry my child wereever we wanted to go.
- Being in and out of hospital.
- Not enough assistance and information available in SA
- None
- Is just the fact that my child couldn't walk was the most difficult time for me.
- Hyperactive

- I must always explain to people that he has a problem and can be blamed for things he do wrong.
- There is no difficulty experienced with J-----.
- The temper our child shows when she cant have things her way.
- When ever my child cry.
- The first 3 years of his life. Then the doctors told me what was wrong with him. It was difficult to accept but once you are guided with the problem you learn to live with it.
- To see them suffer and answer questions that is not easy to answer.
- If my child cry out for help and you can't do anything.
- Due to her epilepsy one tends to be overprotective and often overlook behavioural problems especially when she was younger. One sometimes has different rules for the children which could lead to problems.
- At this moment nothing is really difficult except that he's so stubborn as a result he does not want me to shout at him. At times he does not want to communicate with others.
- Dissepline the abled child to help the disable one.
- Sudden change of moods.
- Om as moeder jou kinders alleen groot te maak is dit moeilik om dit wat hulle harte bekeer te gee.
- Mentially handicap (hyperactive)
I have a son that is mentally ill and hyperactive. At first it was very very difficult to cope with him, but not understanding his situation I servive (cope).
- None.
- The most difficult part was carry her to hospital and from hospital by taxi or bus.
- He had no confidence in himself.
- At first it was difficult to accept that my child was differently-abled. You learn to cope with the situation once you get help of the professionals.
- Children making fun of him.

- S---- would very seldom listen to me - he is very fond of doing his own thing.
- Sometimes stubborn.
- A child that is unable to do anything for him/herself.
- To cope with I-----'s stubbornness/manners.
She couldn't do anything herself. I had to help her most of the time.
Trying to handle her according to her disability.
- Mood swings.
- When the abled child felt rejected.
- The fact that my child are been spotted by other normal children. That really makes me sometime futrated. I tried to tell them the God or Alla has his own strength in doing things.
- The very first month because of not really knowing what was wrong with my child. Then the first 3 months as a crying baby. Then all the tests afterwards and really finding out what is really wrong with my baby and the fact asking yourself "why me Lord" and you have to accept it. But now he is the joy of my heart.
- Because his my first born I have experienced difficulty with my giving birth of which at the time I was 7 months along I had a Caesarean due to high blood pressure. My son had haemorrhage that has taken me a few yrs to adapt having a son with C.P. and epileptic as well, but time healed me and I fully accept it.
- The most difficult time is to work and walk. Sometime he talk allowon so I get worried. He doesn't want to play with other children.
- The things that are most difficult is that I can't afford some financial needs for my children especially my disabled child. I am unemployed and my husband's wages cannot afford my child's needs like school fees, donations school uniforms, lunch, clothes. I just feel helpless sometimes because my child.
- I find it very difficult with my child because I am alone and a working mother but I always do my best to give her and discipline her.
- There was nothing difficult this far for me.
- You have to be their always to see if she's doing the right things. I had to put everthing aside to be their for her. I didn't had much difficult aspects of parenting.
- Other people do not understand of accept that my child is not the same as a normal able-minded child.

- My daughter has a speech impediment, making communication (listening on my side) sometimes very difficult in understanding what she's saying. This can become very stressful for me as a parent and frustrating for my child.

- His frustrations.

- Realising that your child really is different from other children, and not only physically but also mentally.

- To me, nothing seems unreal to teach or learn my child only because he is disabled. I let him grow up as a normal child there is only a few things that he can't do but I don't let that get me under, so as a matter of fact I take it as he is.

- In due fact that I'm a health care worker, it was not so difficult as an inexperienced person. In fact it was a pleasure and triumph to raise my child as near as normal as a normal child at birth.

- The travelling to and from hospital with public transport.

2. What aspects of parenting a differently-abled child have been most *rewarding* for you?

- As for me the father of him the most rewarding thing of this child is just to care and love them although the problem they give and have.
- I will always love him for his kindness and understanding ways sometimes.
- The little progress he may make.
- Very rewarding. Teaches you to appreciate thing you have got and not take anything for granted.
- To see continuous progress daily.
- The knowledge that she can speak her mind (although not always acceptable). Read difficult words even spelling it. She is capable of expressing her feelings and showing her emotions. She knows her surroundings and whats evolving around her.
- To see her grow socially and spiritually. She is able to communicate with grownups. The love that she has in her life which draws people to her. The good progress in her school work. Her personality and the way she handles her disability.
- To see her develop confidence and be able to interact with others. The love that we give my daughter and receive in return is very rewarding. To realise that we have done our best and have no regrets.
- That he is almost like a normal child, although he is paralyzed from waist down. He can be just as cute; smiling, laughing, getting dirty. Really loving him like he's normal, and receiving his love back.
- The fact that she has become a student of [name of] School and that she gets a diploma last year.
- To play outside.
- The day that I saw my child give his first steps.
- Seeing progress in my child.
- The fact that he can used his legs again was the most rewarding.
- Learning to cope with it.
- The aspect that is when my child become differently abled.
- His ability to walk when it was predicted that he will never be able to.

- My son is a very loving and caring child. Now that his father passed away he is more caring towards me. At night when he prays he will pray for his father, and that him and his other brother and sisters must listen to me. He is very strong willing and able child. He do not believe in cannot do the same as the others.
- The progress she makes in life.
- The child is more loving and concern. He appreciates whatever you do.
- My rewarding aspect about my child is that during the years he became independent and it is very satisfying.
- To see them smile and be happy.
- Progressing in life.
- Small improvements e.g. in using her impaired hand/arm when we had input her therapy.
- He does everything for himself. We share the ideas.
- When the able child can communicate with the disabled child.
- She gets a diploma last year.
- When the abled child could do something for them self
- Caring and Charing.
- Wanneer 'n kind met sy skool rapport huis toe kom en jy sien waartoe hy in staat is wanneer hy sukses behaal.
- Mild/moderate mentally handicap/Down Syndrome
I also work with disabled children. I think that makes it easy to cope and understand them.
- The way she treats life and the cheer she exudes.
- The most rewarding time of my life was when she start talking.
- He has more confidence in himself. He is more open.
- He is more happy since he has been at [name of school].
- In spite of his disability he always had the guts to try everything he tackles. He normally succeeds in. He never excepts no for an answer. He believes that he can conquer everything he lays his hands on.

- He listen and understand when you talk to him.
- Just to see my child happy
- A child like my child.
- I learnt alot at support groups at school.
I got to deal with I-----'s defects.
I handled her as I would handle a normal child (not that she has a great defect). I was strict with her.
- Lovableness, honesty, tidiness.
- Always willing to help. Willing to learn and do things for herself.
- The rewarding of my child is that she could care for herself. And that she is a helpful hand in handling household things.
- The day he said "AHH" keeping his hands between his legs and forcing myself to take him to the toilet. I always told him as small as he was "I accept you as you are but I can't see myself changing nappies the rest of my life". Thank God he understood me and up to today he understands everything you tell him but can't just talk back to you in a complete sentence.
- The fact that I as a mother has learnt a lot concerning my child's disabilities, and strongly believe that my child is capable of dealing with anything that a normal child deals with.
- Does not understanding why I cannot afford the things that other children's parents can. He cries sometimes because I don't have a car so when there are school meeting I can't go because I have no transport.
- She is very obedience and that helps a lot.
- To come home from work and find him there. Just to hug me and to kiss me.
- There are so many. C----- is a very sensitive child. She's very independent, selfasure, and have lots of confidence, and that's the most rewarding aspect for me.
- The closeness between my son and myself.
- To see them grow up happily and do things to the best of their ability.
- Watching her progressing and persevering. Seeing her as a happy, stable, well balanced child, not lacking anything else in life other than this "small" setback as

“differently-abled”. Listening to her laugh, talking, walking, eating, sleeping, waking, bathing herself, using the toilet, going to school, doing her homework, more progress....the list goes on and on.

- understanding.

- When you sometimes think “this is it” and then they learn a new word or do a new movement that you as parent knew nothing about and it all comes as a big surprise. That is a great feeling!! Your child has progressed in some small way!!

- A lot of things has been rewarding to me the fact that my child is able to do things for himself and the fact that he thinks as a normal child have been most rewarding to me as a mother. We as parents must just learn to cope with our kids.

- In raising and parenting a disabled, needs guiding, advice, observing and professional need and help from experienced people. In fulfilmenting that experience, it is great to see my child blossomed.

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3. In view of your experience, what advice would you give to other parents of children with special needs?

- To other parents I would tell them in view of my experience of my child is to love and care for this children. Although things goes wrong just be there for them, because they needed it most . Just see everything in the wright light and then everything will go wright among this problem of children with special needs.

- Love your children.

- Join a support group as soon as you can and stay clear of government run aid centres. These people have no idea what they are talking about.

- If possible, depending on the handicap treat your children as “normally” as possible and do not place limitation on them. You may be surprised at what they are able to achieve.

- Spend as much time when them doing school work. There is a light at the end of the tunnel. You will see the difference in their work and in them as an individual. Take an interest in your childs school work and progress. It is hard work and we are preparing them for the future.

- Give them stacks of love and sow a lot of knowledge in there lifes.

- Give them a lot of love. They are very special and we are going to need a lot of patience. When times get tough don't bottle it all up. Never shun your child. God has placed them in our care.

- The best things to do is to stand by your child. Be proud on the gift you got. Also take one day at a time. Don't worry about next year, etc. Just have strength to stand by what your child needs.

- Learn to live with it and love your child.

- Put your trust in the Lord and never stop praying.

- Go for help and be patient.

- Believe in God.

- Get together as parents – in groups – to assist one another – do not think you can do it on your own.

- To love and care for them. To have patients and understand their needs.

- To have faith in the Lord. And to encouraged your child and stand with him or her what ever the situation might be.

- Lots of attention and love.
- To treat your child the same way you treat your other children and give him or her the love and support he or her deserve and don't give up on your child's future.
- Always give them lots of love and support them.
- Accept not only your child but his limitations too, and treat him the same as you would treat any other.
- If you have other children. Do not spoil the one who has a problem. Think positively. Do not let him do as he wants to. Give him a little extra attention, but without hurting the other children's feelings. You as a parent and the other children must help him when he needs it.
- No comment
- Firstly you have to accept what is wrong with your child. And never be ashamed of your child. Treat him with respect.
- All your child need is guidance from the parent and try and listen to what they say.
- Have faith and trust in the Lord for he has never made mistakes.
- Treat them as you would other children, but give extra attention and time to their deficits.
- It is of utmost significance that we love these children and care because they are the gifts from God, no matter what is happening we have to accept them. They are not there because they like, God has made them to be like that.
- That the parent have patience with the child's special needs.
- Patience lots of it. Love lots of love. Caring lots of caring. Understanding.
- Get involved.
- Do not lose faith.
- Omdat my kinders se pa hulle eenkant toe geskyf het wil ek aan ander moeders sê gee baie liefde aan julle kinders en bid baie want dit is waar julle hulp vandaan sal kom.
- To get involve in other organisations that are promoting awareness regarding our disabled children.
- Not to treat differently than normal children because that is what they are.

- I would give other the advice never to give up on there children, and always give them moral support.
- Jy moet hom of haar op die-selfde maat soos die ander kinders lief he. Moet nooit moed verloor oor die kind nie.
- You must accept that your child is different.
- That you should love them the way they are. Treat your child as a normal child.
- Never be ashamed of your child. He/she has the right to live - just like other children. Never treat that child differently from your other children.
- Be there for your child when they need you. Help them wherever you can. Encourage them.
- To have patientce.
- To have patience with their children. Help them at all times if they cannot cope. Try to assist you child in all respective ways. You should handle them as normal children. Show and tell them that you love them. Don't make them feel neglected.
- Lots of love and affection. Make quality time. Positive thinking.
- Give them all the love, support and incouragement. Teach them to be independent and that they are no different to anybody else.
- Try to understand your child and the fact that she are just different. That is the side of possitive thinking.
- Moet nie moed verloor vir jou kinders nie dink attyd on hom of haar soos onder kinders.
- I know it is hard to accept and it takes a lot of "patience" from everybody in the family but please don't give up. Talk normal to these "special children", show them "love and care" and they learn to understand you. They are very affectionate and knows when you are scolding them. It sometimes causes "stress" amongst the family but don't give up. Just ask God to give you the strength.
- To be understanding, caring and have lots of tolerance, and not to be treated with disability.
- My advice is to take care of him or her. Don't leave allown. They can do what he or she want most spesial dergeneis like go to separet room and make mass.

- They must not give up because disabled children are just like other children. If you talk to your child, have most of the time spending with him/her, you'll see that they can make you happy. You must not feel sorry for your, whenever he/she wants to do something, just let him/her do it and try to encourage him/her.
- Have lots of patience and always attend to their needs.
- Do not treat him differently, treat me like a normal child.
- You just had to give them lots of love, that's the most important advice I can give because they are children with special needs, and they are very sensitive and they need all the love you can give.
- Pay as much attention to your child as you can. Encourage him/her to do everything that he/she is able to.
- When you first discover they have special needs – act on them immediately. There are qualified people who can assist you. Finances should be second on the list – your child's future is first – so act on them immediately.
- Love them the same as you would if they were “normal”.
Let them know, at the right age, what is wrong with them – why they are different. Let them know that there is nothing wrongly with being differently-abled – as God only created good. Each person has a purpose in life. They too will discover theirs.
- Give them lots of love and support.
- You have to learn to live with it. Accept your child the way he/she is and try to find a suitable day school as soon as possible. They have to be stimulated as early as possible. I am totally against institutions as these children need extra loving and attention (not spoiling) that they should only be able to get a home.
- They need your love, and doing things together with parents.
- They need your love, and doing things together with parents. And encourage them to do more than what they really do.
- Just to accept the child as he/she is then it be more rewarding to you as a parent, not to make let your child do things he/she can't do just show them your appreciation in life.
- In my capacity, I wood advice parents with disabled children, to seek help and take the advice from professionals, make the fullest use of it in the interest of the child.
- Take good care of your children and give them all the love and support that they need because they are very special.

4. In view of your experience, what advice would you give to health professionals?

- In view of my experience as for my disabled child I have to say to health professions they have done a great job and to continue in the community with your well-done jobs especially the professionals who was working with my child. Thanks for saving his life and keeping him growth and health so well. To you I have to say may God bless you.

- Be more positive and optimistic about the disabled.

- Work more closely with parents who have experience. Health workers may be qualified in this field, but they have no physical contact with disabled people, therefore what they preach is always wrong.

- Keeping up to date with the latest medical advanced is imperative. They also should not focus on the negative aspects but rather have a more positive regard.

- I don't know because I haven't had the need to use the services of one except an ENT doctor.

- Take time to explain to parents what is happening to their child. Answer the question truthfully. Follow up on how things are going. Are the parents coping?

- N----- always got good doctor's help. Maybe they can stop telling you to come back, come back, all the time and to rather tell you straight-forward what the suspect is wrong with your child.

- Do not think of them as abled children but children that can do things like normal children.

- Helping the child and care for them but parents must also help.

- To do everything in the best interest of my child.

- None.

- To have faith and trust in the Lord.

- Be patient with the child as well as the parents and explain more to the parents how to handle some situations.

- Keep on doing the good work.

- Do not predict the child's limitations before there is any limitations present.

- All I can say is I am very pleased and happy for him being at [name of] school. Hes health and education is improving daily.

- No comment.
- To empower us as parents of disabled children.
- I would not know what to say to health professionals but “thanks” for what they did for my child in the past and keep up the good work.
- To thank them and hoping they will continue in all the good deeds they perform everyday.
- Ask the Lord for strength from day to day to keep on performing your duties like you normally does.
- Be considerate - you do not know what the parents are feeling - empathise but do not show pity.
- They must encourage parent to care about their children because one day can make wonders.
- To lend a helping hand to someone with a disabled child. To give good advice to the parents.
- To give people the right advice. To diagnose a proper one. To help where they can.
- Keep the good work up.
- In view of my experience as for my disabled child I have to thanked the health professionals for doing a great job and to continue working with your community especially the professionals who was working with my child. Thanks for his strongness and for the child he is today. Thanks for his good health and saving his life from he was a little boy. Many thank and may God bless you.
- Keep on doing things for others who need you.
- To help us as parents eg workshops in understanding our children = especially when they become teenagers
- I could not give the professionals any help because they are very good in there jobs.
- Keep up your good work and I only wish to hope parents could do more if it can be afforded by them.
- I would give the health professionals the advice to treat the children equally as they would treat the other patients.
- Keep on experimenting, learning more.

- To encourage the children to eat healthy.
- To have patience.
- They should be treated normally in respect to their disabilities/defects.
- To grant more money to schools of this nature.
- That they must keep with their good professional help. I would like to help in her education especially in her English and other subjects, and that she could educate to become someone who could help others.
- I appreciate it very much that what everybody has done to my little boy. He has been in a special "day care centre" from the age of 18 months. He has improved tremendously since that time with all the help of the special teams from teacher, physio and speech therapist and all other teams involved. Keep up the good work. These SPECIAL kids need you. Thank God.
- I most of the time accept what the professionals quote to me, as they have more experience in this field than I do.
- Disabled children always are different from others only because they have different needs.
- They should be patient with the children.
- There is no advice that I can give but just to love and take care of the child.
- I just want to thank all the health professionals for their care and understanding. My advice to them is keep on with your good work and never get tired of our special children because they need you.
- They need to explain clearly and simply what they want parents to know.
- Keep on being compassionate to differently-abled, as well as the parents. Keep on being honest (straight forward) in your diagnosis. Don't keep back any information from the patient or parents. Continue to advise and refer them to how and where they can continue treatment required. Allow them to trust your diagnosis. Allow them to ask questions.
- Most of them that I have met in the last 4 yrs have been most understanding. What they could try and realise is, that we don't have an endless supply of funds for operations, chairs, splints etc.
- Give them all your support and encourage them to do their therapy.

- My advice to my child's health professionals is a thanks of appreciation for what they have done to my child's experience in his/hers growth.

- In fact I would advise professionals to teach the parents, how to handle and raise their child to their fullest capacity. In my experience I have learned that a disabled would like to be treated as normal, as they have the same needs as a normal accept that they are disabled.

- Tell parents to seek professional help when they think something is wrong with their child. Always tell parents the truth about the situation of the child and what they can expect in the future.

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