SUBJECTIVE PERCEPTIONS OF STRESS AND COPING

BY MOTHERS OF CHILDREN WITH

AN INTELLECTUAL DISABILITY:

A NEEDS ASSESSMENT

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Declaration

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

ABSTRACT

My study aims to explore the feelings of and coping strategies used by a group of mothers of young children with an intellectual disability. I used two validated questionnaires and, at a later date, a semi-structured interview with each research participant. My analyses of the questionnaires' data provided me with tentative themes for inclusion during the semi-structured interviews. The combination of quantitative and qualitative research methodologies resulted in the confirmation and expansion of some of the data, but contradictions between other data. I used lay theory as one explanation for the contradictory findings. My study found that the mothers of young children with an intellectual disability experience a range of feelings and use a combination of different coping strategies, a pragmatic coping style being common to all the participants. I conclude by acknowledging the inherent capabilities of my research participants and encouraging service providers to empower parents of young children with an intellectual disability.

SAMEVATTING

Die doel van die studie is die ondersoek van gevoelens en hanteringstrategiee van 'n groep moeders van jong kinders met 'n kognitiewe gestremdheid. Ek het aanvanklik gebruik gemaak van twee geldige vraelyste en na afloop daarvan is 'n semi-gestruktureede onderhoud gevoer met elke deelnemer. Tentatiewe temas verkry uit geanaliseerde vraelys data is ook gebruik/ingesluit gedurende die semi-gestruktureede onderhoud. Die kombinasise van kwantitatiewe en kwalitatiewe navorsingsmetttodologiee het gelei tot die bevestiging en uitbreiding van sekere data, maar was ook weer teenstrydig met van die ander data. Ek het leke teorie gebruik as verklaring vir die teenstrydighede. My studie het bevind dat hierdie moeders 'n wye verskeidenheid gevoelens ervaar en dat hulle ook van verskeie hanteringstrategiee gebruik maak. Die pragmatiese hanteringstyl was die mees algemene onder die deelnemers. Samevattend het ek erkenning verleen aan die inherente vermoens van die deelnemers en ook diensverskaffers aangemoedig om ouers van jong kinders met 'n kognitiewe gestremdheid te bemagtig.

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CHAPTER 1. INTRODUCTION

1.1 The Study in Context

A civil society partnership was established between Down Syndrome South Africa (DSSA) and the University of Stellenbosch (US) aimed at mutual benefit through collaborative efforts to improve the quality of life for persons with an intellectual disability by enhancing their full inclusion into mainstream society. This aim is to be realised through the following broad goals:

1) development of support programmes for persons with an intellectual disability,
2) university research informed by communications from DSSA about the current grassroots needs of persons with an intellectual disability, and
3) expansion of research efforts by establishing collaborative research relationships with other universities and relevant organisations.

The first phase of the project (01/02/2001 to 31/11/2001) was a pilot study incorporating research into the needs of persons with an intellectual disability at different developmental stages in the Western Cape Province. My study forms part of the above mentioned needs assessment focusing on different aspects relating to people with an intellectual disability. My professional experience and interest in early childhood education informed my choice of focusing on the younger child with an intellectual disability.

1.2. The Problem

This study looks at the feelings and coping strategies used by some of the mothers of young children (under the age of 7) with an intellectual disability. The importance of early influences on a child's development, in all its facets from emotional, social, physical, intellectual and spiritual, are well documented, although often assumed rather than explicitly stated in books on child development, such as Santrock (1997). Bee

(1980:15) is more explicit about the importance of quality input for young children. More recently, Engelbrecht and Green (2001:59-77) have written about the topic, highlighting Vygotsky's emphasis on the impact of socio-cultural experiences available to a child. Feuerstein's notion of mediated learning experiences (M.L.E.), where a more experienced person actively facilitates a child's development, is particularly relevant in the early years (Wood, 1988, cited in Hill, 1999:10). Furthermore, Nadler, Lewenstein & Rahav, (1991:21) argue that the mother is invariably the primary caregiver, and as such I would argue that she has the most important influence on her child's development. Therefore, the feelings a mother has about her child with an intellectual disability and the ways in which she copes with her child might be important to assess in understanding and best providing complementary assistance, if needed. The ultimate goal is to contribute towards enriched quality of life for children with an intellectual disability.

1.3. The Paradigm

I present this study from an ecosystemic perspective, acknowledging that *both the individual and the environment can exert powerful influences, but they are always interactive* (O'Connor & Lubin, 1989:3). I view psychodynamic conceptualisations (eg. by Carson & Butcher, 1992:9) as part of, rather than contradictory to the ecosystemic approach. Similarly, I incorporate constructivist (eg. point 3.6. p. 49) and post-positivist (point 1.6.2. p.6) notions. Constructivist and post-positivist thinking emphasise the subjective nature of a constantly evolving reality influenced by the social context in which the individual is embedded. The ecosystemic literature also refers to individual subjectivity and the mutual influence between *the observer and the observed* in shaping each one's ever-changing perceptions of reality (O'Connor & Lubin, 1989:30).

I position my study within the broader research efforts (see 1.1. p.1), implying that this association also influences my thinking. The research participants' context is implied by numerous references in chapter 2 to the impact of society and culture, as well as to other family member dynamics.

1.4. The Significance of this Study

Similar studies done more recently in South Africa have tended to focus on social groups from traditionally more disadvantaged backgrounds (see for example, Chinkanda, 1987, cited in Parker, 1992:18 & Stavrou, 1992, cited in Parker, 1992:18). My study focuses on middle-class mothers, since few if any research studies in the more recent past have targeted this group. Furthermore, this study differs from many other national studies on similar topics in the use of the combined methodological approach, which triangulates quantitative and qualitative data (cf. Creswell, 1994:175).

1.5. Research Approach

As part of a needs analysis, this study precedes the possible implementation of interventions. My research may thus be described as evaluation research. Evaluation research is a broad term that emphasises assessing an already implemented social intervention or, as in the case of this study, a possible intervention to be planned in the future (Babbie, 1983:305). As mentioned, the study combines quantitative and qualitative methodologies. Quantitative data were produced through the use of two validated questionnaires. Qualitative data were obtained through qualitative comments on the aforementioned questionnaires and semi-structured interviews conducted with each of the research participants. The research design was emergent (Gergen & Gergen, 2000, cited in Eloff, Engelbrecht, Swart & Oswald, 2002:1) in that the semi-structured interviews were not planned at the outset, but subsequent to my analysis of each participant's completed questionnaire data. The questionnaires comprised the QRS (Short Form of the Questionnaire on Resources and Stress) and the WC-R (Ways of Coping- Revised), altered minimally after consultation with a group of participants (different from the research participants), who refined the questionnaires for use in South Africa. The altered QRS comprised 51 true/false questions to investigate the participants' feelings about having a child with an intellectual disability. The altered WC-R comprised 46 4-point

Likert Scale questions to assess the participants' preferred ways of coping with having a child with an intellectual disability.

The close ties between Down Syndrome South Africa and the school from which I obtained the research participants, who participated in the questionnaire completion and in the semi-structured interviews, made the school a convenient choice from which to obtain the research sample. Constraints of time and finances also made the choice of this particular school appropriate. Participants in the instrument refinement study also consisted of a convenience sample. The principal at the school from which the research participants were obtained, was key to introducing the study and the questionnaires. After administering the questionnaires, I conducted the semi-structured interviews. I analyzed the data by scoring the questionnaires, writing transcriptions of the tape-recorded interviews and by writing a description of each interview, including my field notes taken during the interviews. Multiple comparisons within and between participants' data were also done. Themes were extracted, a coding system devised and then the emergent themes were clustered under two main themes: feelings and coping strategies.

1.6. Assumptions

I assume the use of the first person "I" throughout the study. Jones (1992:18) says that 'realities' reflected in any research can only be the subjective constructions of the particular researcher's reality. Similarly, Le Guin (1998:68) argues against the use of the passive voice in academic writing, saying that the use of the active voice suggests to readers that the writer is willing to accept responsibility for the thoughts and ideas expressed.

1.7. A Review of the Key Constructs

1.7.1. Needs Assessment

Soriano (1995:xiv) defines a **needs assessment** as research done to obtain accurate information to assist in *better target(ing) our services and efforts.* The reference to "our" may be seen as referring to any professional service provider related to the care of children with an intellectual disability. Soriano (1995:xv) says that needs assessments may be undertaken for various reasons: to ensure appropriate resource allocation; as part of a programme's evaluation to justify funding; or to assess the needs of under-served populations. The imperative for undertaking needs assessments with regards to individuals with an intellectual disability derives from my understanding of the more recent educational dispensation, which argues for the democratic right to equitable education for all learners. South Africa's White Paper No.6 (Department of Education, 2001:7) states that learners with disabilities in South Africa are most likely to experience learning barriers and exclusion. The relevance of undertaking a needs assessment around the topic of intellectual disability can also be gauged from the associated literature, which refers to negative social perceptions towards those with an intellectual disability and their families, with associated difficulty in accessing equitable educational and health services (Parker, 1999:xi ; Waldman, 1993, cited in Parker, 1999:xi). In public discussion documents such as the National Commission on Special Needs in Education and Training (NCSNET) and the National Committee on Education Support Services (NCESS), (August 1997:32) reference is made to the move from a "welfare" model of disability to a developmental model based on basic human rights. Similarly, Engelbrecht, Green, Naicker & Engelbrecht (1999:13) refer to this as "charity discourse."

In addition, there has been a lack of information around the nature and prevalence of disability in the South African context. This has impacted negatively on the planning and development of services for individuals with an intellectual disability (Office of the Deputy President, 1997:35). The White Paper on an Integrated National Disability Strategy (Office of the Deputy President, 1997:v.) stated that data collection and research

were to be considered amongst key policy areas for attention. Recent statistics (Department o f E ducation, 2 001:9) suggest that a minority of learners with disabilities have been accommodated in the education system. This White Paper (Department of Education, 2001:13-14) has provided a clearer indication of numbers of special schools and p upils a ttending those schools, showing a mismatch between needs and provision. Pertinent to my study is the reference made to the foundation phase of education (Department of Education, 2001:49) as being the most useful time for identifying learners with special needs.

My study focuses more specifically on the perceptions of coping and stress of mothers of children with an intellectual disability from a more advantaged community, in that the research participants have their children attending a special school. I aim to share the findings of my research with parents and teachers, so that the parents might reflect and expand on their repertoire of coping strategies and the teachers may better understand the array of coping strategies that different parents find useful. My research findings could also be useful for the parents of future pupils at the school.

1.7.2. Subjective Perceptions

My study title includes the notion of "**subjective perceptions**". In using the latter term, I wish to emphasize that the research participants (hereafter referred to as the 'participants') are homogenous only in terms of having a young child with an intellectual disability. Linville, Fischer and Salovey (1989, cited in Baron & Byrne, 1991:200) hypothesize that there is a tendency to view groups of people we perceive as different from ourselves as being more homogenous than in fact they actually are. The post-modern assumption that multiple realities exist in as many forms as there are people is implied in the use of the term 'subjective perceptions'. Isen and Baron (1990, cited in Baron & Byrne, 1991:109) make an important point that aspects of cognition are affected by even small alterations in how an individual is feeling at a particular moment in time. In my own study I need to view the 'subjective realities' researched as continuously

evolving p rocesses, rather than as static e ntities. L e G range's (2001:17) p ost-positivist discussion further adds to my understanding of individual realities as being constructed from the broader social context within which a particular individual lives.

1.7.3. Stress and Coping

1.7.3.1. Stressor, Stress and Coping Strategies

The term 'stress' is often used loosely to refer both to the adjustive demands placed on a person and to the person's physical and psychological responses to demands. To ensure clarity, I use the term 'stressor' to refer to the adjustive demands themselves, the term 'stress' for the effects of the stressor on a person, and the term 'coping strategies' for a person's efforts to handle the stress (Carson & Butcher, 1992:140). As Carson and Butcher write (1992:97): *The consequences of stress depend on the coping resources available to an individual undergoing an adjustive challenge.* Situations requiring adjustment, whether negative or p ositive, a re s tressful. A l ack o f r esources in m eeting stressor demands is indicative of an individual's vulnerability. In subsequent paragraphs, I will expand on the concepts 'stressor', 'stress', 'coping strategies' and 'vulnerability.'

1.7.3.2. Categories of Stressors

Stress and coping may be understood as a dynamic and evolving process, that is, a complex p rocess, r ather t han as a static or unitary phenomenon (Folkman and Lazarus 1985:150; McConachie, 1986, cited in Parker, 1999:6). Stress and coping are interrelated and dependent on one another, since situations requiring adjustment are stressful. Typically, stress presents as a continually changing pattern of different categories of stressors co-occurring. Frustrations, conflicts and pressures are different categories of stressors. Frustrations refer to goals blocked as a result of internal or external forces; conflicts derive from two or more incompatible needs; and pressures refer to internal or

external forces which demand increased or redirected behaviour from an individual (Carson & Butcher, 1992:141-143).

1.7.3.3. Factors Predisposing to Stress

Carson and Butcher (1992:143) discuss various external factors that may predispose an individual to stress. The nature of a given stressor impacts on a person depending on the relative significance the stressor holds for that individual. The duration of a stressor has a differential impact on an individual. A chronic situation is likely to be more stressful than the same stressor experienced for an acute period only. The number of stressors co-occurring and the degree of physical or/and emotional proximity of stressful events also determine responses to stressors. The cumulative effect of stressors is a further consideration when assessing the likely effect of stress on an individual.

Carson and Butcher (1992:144) also talk about internal factors, such as an individual's perception and tolerance of stress, that interact with the above-mentioned external factors to ameliorate or aggravate individual stress responses. Subjective perceptions are influenced by an individual's personal frame of reference. Someone with a positive self-esteem may approach a challenging situation more optimistically than someone whose self-esteem is less positive. Early childhood experiences are particularly salient to an individual's vulnerability regarding later coping with stress. A sense of control moderates the effects of a stressor. If a stressor is unanticipated, an individual may not have any familiar coping strategies on which to rely, resulting in an experience of severe stress. Each individual's ability to cope with stressors can be perceived as unique, with considerable variation in vulnerability to different stressors.

Carson and Butcher (1992:143-145) also add that the nature of a stressor and an individual's subjective response to it is further impacted on by the availability and quality of external resources and social supports. Positive family and social supports may reduce the negative impact of a stressor. The tension engendered by a stressor is shared among

family members, resulting in no-one being burdened by the stressor unsupported. Sometimes, however, wellmeaning friends and family inadvertently behave in ways that increase an individual's stress. Different cultures may offer specific rituals or courses of action to support individuals in coping with specific stressors. Hughes (1999:271) states that religion is one such culturally related coping resource, which I will discuss in greater detail later.

1.7.3.4. Coping Strategies and Vulnerability

Closely related to the notion of 'stress' is the notion of '**coping.**' *The Oxford Encyclopedic English Dictionary* (Hawkins & Allen, 1991:320) describes 'cope' as meaning the ability to deal effectively/successfully with a person/task/situation/problem. Carson and Butcher (1992:147) say that a stress reaction reflects the interaction between inner strategies and environmental conditions. Internal factors may involve a person's frame of reference, her competencies, level of stress tolerance and/or motives. The environmental factors include social expectations of behaviour. More specifically, an individual's internal biological and psychological levels of functioning interact with the socio-cultural level, that is, the individual's external resources and supports. A deficit in any of the above levels leaves a person vulnerable when faced with stressors, in terms of coping with the stressor itself and also in terms of protecting the self from possible psychological disorganization.

Carson and Butcher (1992:147) discuss coping from a psychodynamic perspective, stating that an individual's approach to coping is largely influenced by her perception of her own competence. An individual who feels competent in a given situation approaches the stressor in a task-oriented way, by focusing primarily on the demands of the situation, the alternative responses possible, deciding on the best alternative and implementing the chosen solution while evaluating its effectiveness and adjusting behaviour accordingly. Alternatively, the individual who feels inadequate responds to the perceived environmental threat by engaging in defence-orientated behaviour aimed at self-

protection rather than at dealing with the stressor. Avoiding the stressor's demands manifests in several ways, most particularly by the use of ego defence mechanisms. When such defence mechanisms are used in combination with task-orientated behaviours an individual's coping attempts may be adaptive, but the exclusive use of ego defences is maladaptive. Such a maladaptive response to a common stressor is labelled as an adjustment disorder and is characterized by the individual being unable to function as usual or by displaying an excessive reaction to the stressor.

More specifically, Carson and Butcher (1992:146-151) say that vulnerability to excessive stress results in lowered functioning of both biological and psychological facets within an individual, indicative of the interconnectedness of the body-mind relationship. An example is when a response to stress is that of continual 'angst', the body reflects this by developing blood pressure problems.

Engelbrecht, Swart and Eloff (2001:258) distinguish between three broad themes of coping strategies: problem-focused strategies, which include pro-active and goal-directed behaviours; collaborative strategies, which emphasize involving the help of other people; and emotion-focused strategies, which involve values, beliefs and attitudes. In my study I focus on the coping abilities of mothers of young children with an intellectual disability.

1.7.4. Mothers

The Oxford Encyclopedic English Dictionary (Hawkins & Allen, 1991:946) defines the notion of "mother" as follows: "*1a. A woman in relation to a child, or children to whom she has given birth. b. (in full adoptive mother) a woman who has continuous care of a child, especially by adoption.*"

In my study, 'mother' refers to the biological or adoptive mother of a child with an intellectual disability, and does not include other primary caregivers even though the bulk of the child's care may be undertaken by paid caregivers. Regardless of who cares for the

child with an intellectual disability, my study assumes that the parents, and especially the mother still bear primary responsibility for the child.

1.7.5. Children

Notions about what '**children**' are and corresponding attitudes and expectations have changed over time. Recently published books on human development (Mussen, Conger, Kagan & Huston, 1984:465; Santrock, 1997:20) typically describe childhood as being between the stages of infancy and adolescence, i.e. between the ages of two years through to about eleven years of age. In my study 'children' refers to a small number of children in the preschool stage of development and considered to have an intellectual disability. The children are not directly involved in my research; rather, their mothers are involved as key informants in providing the necessary information.

1.7.6. Intellectual Disability

The core term '**intellectual disability',** has undergone many alterations over time (Ryan & Thomas, 1981, cited in Parker, 1999:1), reflecting changing social perceptions and attitudes. As yet, the label of 'disabled' continues to discriminate against the full social participation and rights of affected individuals. Current political and educational foci on equality aim to redress the status quo. My study forms part of the work being done to address some of the potential concerns around the youngest members of those labelled as 'intellectually disabled', i.e. how to maximize the coping strategies used by their mothers.

The term 'mental retardation' is used in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) which describes it as:

> ...a disorder characterized by significantly sub average intellectual functioning (an IQ of approximately 70 or below, though the 5% error margin from testing increases those categorized as mentally retarded from an IQ of 75 and below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning (American Psychiatric Association, 1994:37).

The emphasis in the DSM-IV definition is on intelligence quotient (IQ, a controversial construct of intelligence) and on 'adaptive functioning' (a subjective description). The DSM-IV definition is almost identical to the American Association for Mental Retardation (AAMR) 1973 definition of mental retardation, which emphasized adaptive behaviour and increased the notion of the developmental period from 16 years to 18 years old:

> Mental Retardation refers to the significantly sub-average general intellectual functioning (two standard deviations below the normal) existing concurrently with deficits in adaptive behaviour and manifested during the developmental period (Kaplan & Sadock, 1994:1025).

However, the DSM-IV description of mental retardation is further categorized according to IQ ranges including mild, moderate, severe and profound. The IQ range for mental retardation in the DSM-IV (American Psychiatric Association, 1994:45) overlaps with that of 'borderline intellectual functioning.' The AAMR definitions have continued to change over time in an attempt to be sensitive to the needs of individuals with an intellectual disability (Smith, 1997:167). Currently the term 'intellectual disability' is used to label those people whose intellectual functioning and adaptive behaviour do not conform to the norms of mainstream society (personal communication-Muller, 2001).

The term 'developmental delay' is currently used by the AAMR to describe a very young child (younger than 6 years) who performs below the expected level of development. Vig and Jedrysek (1996:244) perceive this term as euphemistic: implying that the child's development will speed up later to reach that of her peers. They prefer the term 'mental retardation' to describe a particular child's subnormal development. Vig and Jedrysek (1996:244) believe that labelling a young child as mentally retarded is useful both for explaining lack of developmental progress to parents and as a first step towards intervention. Parker (1999:87) contends that a formal diagnosis is useful for providing some certainty for parents. Grover (in Lea & Foster, 1990:167) cautions against rejecting disability labels, seeing them as useful descriptions to ensure correct specialized help is obtained.

In response to Vig and Jedrysek (1996), Luckasson, Schaleck, Snell and Spitelnik (1996:8) of the AAMR Committee on Terminology and Classification argue that several

reasons for using 'developmental delay' can be given. Firstly, they state that an 'at-risk' term is preferable to a disability label since doctors are often unable to give specific diagnoses when confronted by young children with developmental delays, and the fear is that applying the 'mental retardation' label may risk an unjustified self-fulfilling prophecy. The above is particularly true in cases where developmental delays may reflect modifiable environmental conditions. Secondly, reliable measures of IQ are not available for young children, whereas reliable measures of development are well documented (for example, in Engelbrecht and Green, 2001:Part II).

Apart from the debate about the most appropriate label for the very young child, the use of IQ scores for assigning a disability label is questionable. IQ scores reflect academic performance at one point in time and are influenced by a multitude of variables, such as the cultural norms of the test and the test occasion (Carson & Butcher, 1992:533; notes from Dr R. Hall, University of Stellenbosch, 2001). The DSM-IV (American Psychiatric Association, 1994:44) notes the caveat that intellectual testing procedures should take into account the ethnic and cultural background of those being tested. IQ, as a construct of intelligence, begs the question as to what intelligence constitutes. Many theories have attempted to analyze the global and/or specific elements of intelligence. No consensus has been reached as to what intelligence means, but facets of intelligence such as attention, memory, abstract thinking, problem solving and generalizing have been identified. These facets of intelligence are described as being impaired in those with an intellectual disability (Kozma & Stock in Smith, 1993:5-12).

Carson and Butcher (1992:332) cite that 25% of 'retarded' individuals have gross structural brain defects, while the remaining 75% have difficulties attributable to cultural-familial deficits. Lea & Foster (1990:14) report similar percentages regarding causation of Intellectual Disability. These percentages are similar to the level of impairment, with moderate to severe or profound retardation represented by the 25% category and mild retardation represented by the 75% category. The DSM-IV (American Psychiatric Association, 1994:41) indicates as much as 85% in the mild retardation category. It is interesting to note that definitions of intellectual disability tend to exclude mention of

causation. However, the DSM-IV (American Psychiatric Association, 1994:43) notes the following predisposing factors: heredity (5%), early alterations of embryonic development (30%), pregnancy and perinatal problems (10%), general medical conditions acquired in infancy or childhood (5%), and environmental influences and other mental disorders (15-20%). Donald, Lazarus and Lolwana (1997:144 & 232) say that in the South African context the majority of children find themselves in less than favourable environmental conditions. These authors contend that the problem with the label of 'disabled' is that it tends to obscure all the other aspects of the child which are similar to those of other (not labelled) children and who are therefore perceived as 'normal' by mainstream society. Pueschel (1995:xiii) says of children with Down syndrome that they are *more similar to the average child in the community in the ways they grow and develop, than they are different*. The impact of the 'abnormality' label negatively impinges not only on the labelled individual but also on her family. More specifically, society views mentally handicapped individuals as having reduced value, as being dependent, incompetent and unproductive and as needing to be controlled, which in turn leads to the curtailment of civil rights (Lea & Foster, 1990:8).

The above debate about the most appropriate label emphasize the perspective of intellectual disability as an intrinsic construct, a perspective known as the 'medical model' (Parker, 1999:2). The 'medicalisation' of mental disability is particularly ironic when considering the social aetiology to which it is most often attributed, as previously mentioned in this section (Lea & Foster, 1990:14). The focus on the medicalisation of intellectual disability has disempowered individuals so categorized, and led to discrimination at all levels of social functioning, with resultant negative impact on quality of life (Office of the Deputy President, 1997:11). The more recent conceptualization of intellectual disability is moving towards a social model of disability, as reflected in the AAMR's concern about labelling young children whose performance on developmental assessments may reflect environmental factors rather than intrinsic capacity. Sarason (1985, cited in Smith, 1997:167) notes that intellectual disability is not a characteristic of an individual, but a social construction based on social norms that result in diagnosis and management seeming appropriate. Lea and Foster (1990:8) draw attention to the view

that *the very concept of mental handicap is inextricably linked to the dominant social, political and professional agendas of society.*

Molteno (cited in Foster, Freeman & Pillay, 1997:114) comments that the current use of "intellectual disabilty" has already been criticized for emphasizing the cognitive rather than social functioning aspects of persons so labelled. Models for understanding intellectual disability are multiple and change at a rapid rate (Donald *et al.*, 1997:232). The latter authors contend that it is not the label *per se* that is the problem, but how the labelled individual is treated. In allowing the disability label to segregate certain people from mainstream society, society effectively ostracizes them. Regardless of changing labels, social attitudes are slower to alter and often the stigma remains (Parekh & Jackson, 1997, cited by Parker, 1999:27). The use of words with negative connotations, such as 'idiot', in common parlance indicate continued negative perceptions towards intellectual disability; simultaneously, the trend towards inclusion indicates an increased awareness and acceptance of disability (Canning, 1995:3).

In the post-apartheid society of South Africa the notion of Human Rights, with equal opportunities for all, is key to an understanding of the focus on quality of life for those with an intellectual disability. More recently, education has become more involved in ensuring better opportunities for persons labelled as intellectually disabled, particularly those in the milder intellectual disability category (Molteno cited in Foster, Freeman & Pillay, 1997:111). The notion of inclusive education derives from an attempt to redress the educational imbalance, including those individuals with an intellectual disability. Inclusive education may be seen as part of a broader social move to the inclusion of individuals with disabilities (Engelbrecht, Green, Naicker & Engelbrecht, 1999:6), from deinstitutionalisation through inclusive education to integration into mainstream employment. The move to inclusion of individuals with a disability into mainstream society underpins the notion of the principle of 'normalization', that is that every person has the right to be included into mainstream society as normally as possible.

1.8. An Outline of the Chapters

Chapter one places the study in context. I briefly present the study problem and indicate why I feel that it is significant. I describe the research approach that I used in my study. I state the assumptions implicit throughout the writing up of the study. I review the key constructs referred to before concluding with an outline of the chapters.

In chapter two I present an overview of the more recent literature about intellectual disability. I indicate prevalence rates of intellectual disability and mention the emotional impact on parents of having a child with an intellectual disability. I explore social attitudes to intellectual disability, describe possible stressors associated with mothering a child with an intellectual disability, and provide possible support options for parents with such a child.

In the third chapter I look at the research design used for my study. I clarify the use of research terminology used by different authors, and provide a motivation for combining quantitative and qualitative research approaches. I discuss the elements comprising the research: the participants involved in the instrument refinement study and in the research study, data production methods, how the research was implemented, and how the data were analysed and verified. The chapter concludes by discussing ethical considerations pertinent to my study.

The fourth chapter, 'The Study,' charts the research process, presenting the data findings obtained from the completed questionnaires and from the semi-structured interviews. The questionnaires are analysed by comparing data both between and across participant responses, including demographic data and qualitative comments. I present data tables for the first and second questionnaires. The questionnaire data are compared to the interview data and a table comparing participant interview data is given.

A discussion of my research findings forms the content of chapter 5. In a comparative analysis between the interviews I describe the feelings and coping strategies used by the research participants, with reference to associated literature. I also make comparisons

between the biographical/demographic data, first and second questionnaires and the interview data. Finally, I examine the comparison between the participants' questionnaires and interviews, with reference to theory.

Chapter 6, entitled 'final remarks,' provides an overview of the preceding chapters indicating key features, recommendations for interventions, constraints and criticisms, and recommendations for future research as well as stating the final conclusion.

CHAPTER 2. LITERATURE REVIEW

2.1. Introduction

A brief overview of the literature pertaining to the topic of mothers' stress and coping with a child having an intellectual disability is provided. To appreciate potential stressors experienced by mothers of children with an intellectual disability I present background information. I mention the prevalence of intellectual disability and then discuss the emotional impact of a child's intellectual disability on parents. I also reflect on social attitudes to intellectual disability within and between different cultures. I describe how mothers of children with an intellectual disability cope, and discuss various support options potentially available to and utilized by such mothers.

2.2. Prevalence of Intellectual Disability

One in twenty seven babies in a First World country such as the United States of America is born with a birth defect (Hughes, 1999:271). Intellectual disability affects 2-3% of the population in countries in the developed world (Kozma & Stock in Smith, 1993:2 & 29). The DSM-IV (American Psychiatric Association, 1994:44) states that

> the prevalence rate of Mental Retardation has been estimated at approximately 1 %. However, different studies have reported different rates depending on definitions used, methods of ascertainment, and population studied.

Lea and Foster (1990:3) report that figures given in the South African context are similar to world rates, with prevalence rates of 3-4 per 1000 for severe mental handicap and 20-30 per 1000 for mild mental handicap. Donald (1994, cited in Parker, 1999:15) says that the above prevalence rates given for South Africa are hard to determine. Lea and Foster (1990:4) state that the available figures are questionable given the lack of academic research and diagnostic facilities available, especially as regards the black population groups. Grover (in Lea and Foster, 1990:164) reiterates the above reference to the lack of research done within the black population groups. The lack of information available in

South Africa regarding the nature and prevalence of intellectual disability is also mentioned in the White Paper on an Integrated National Disability Strategy (Office of the Deputy President, 1997:1). The prevalence rates for developing countries are estimated to be considerably greater than for developed countries. In the South African context, the majority of the population was affected by poverty as a consequence of apartheid. Richter and Griesel (1994, cited by Parker, 1999:15) say that poverty and intellectual disability are closely correlated. This correlation means that one would anticipate a greater prevalence of intellectual disability among previously disadvantaged communities than in affluent white neighbourhoods. Parekh & Jackson (1997, cited by Parker, 1999:15) mention the latter assumption but state that there are no reliable comparative data for the different population groups.

The lack of current information about the prevalence of intellectual disability in South Africa is merely part of the greater lack of reliable information extant on all aspects of intellectual disability in this country. My study aims to add to the body of research on intellectual disability that currently is being promoted by Down Syndrome South Africa and the University of Stellenbosch.

2.3. Emotional Impact of Diagnosis of Intellectual Disability on Parents

The initial diagnosis of intellectual disability is usually made in infancy if the child is severely or profoundly affected, or at the start of school if the child's intellectual disability is mild (American Psychiatric Association, 1994:44). In severe cases the cause of intellectual disability may be attributed to organic origins, but in milder cases the causative factor is often harder to establish (Carson & Butcher, 1992:504, 507-508). More recently, the availability of reproductive technology has meant that genetic defects associated with intellectual disability are detectable before birth, with the prospective parents faced with the option of abortion (Katz Rothman, 1994:31). Molteno (cited in Foster et al., 1997:118) says that in South Africa it is usually only in the private sector that pregnant women have access to antenatal screening.

The initial reaction of parents to the news that their child has an intellectual disability is usually an experience of crisis, with a fluctuating range and intensity of emotions (Cunningham, 1984:39). The initial shock which parents experience may lead to feelings of protectiveness towards their child or it may lead to feelings of rejection, inhibiting the child-parent bonding process. Shock may act as a defence mechanism, blocking out the news of the disability until sufficient time has elapsed to come to terms with the diagnosis. Shock may be expressed overtly by crying or in a less expressed style by withdrawing from others.

The above expressions of shock are symptomatic of grief. Katz Rothman (1994:190) talks about how parents are likely to mourn their dream of a 'normal' child. Parents of a child with an intellectual disability continue to grieve over time. The conceptualization of grief as passing through various stages which terminate in 'resolution' has been described by Katz Rothman (1994:214) as trivializing the experience of grief. The parents' sense of loss may not be resolved, but is incorporated into the parents' personality. The sense of grief is not overcome by the birth of a 'normal' child in the family (Katz Rothman, 1994:215-216). Kohner and Henley (1995:78-79) say that grief is re-evoked by reminders in the environment; for example, seeing other children of a similar age may serve to remind the parent of how their child might have been. The personal nature of grief may make it an isolating experience (Kohner & Henley, 1995:72 & 76). Katz Rothman (1995:31) believes that the availability of technology for the prenatal detection of intellectual disability means that mothers in particular have the enormous responsibility of choosing between ending their pregnancy or knowingly bringing a disadvantaged child into a society which is likely to discriminate against the child. Katz Rothman (1994:180 & 189) argues that society imposes a "tragic choice" on mothers who know that their unborn child is intellectually disabled, with little support in either case.

Kozma and Stock (in Smith, 1993:103) talk about parents of the child with an intellectual disability who may also experience feelings of resentment towards parents whose child does not have the disability label. This resentment usually subsides as parents come to terms with their child's diagnosis and are able to share their feelings with family

members and friends emotionally close to them. The lack of a sense of control by parents to alter or 'fix' the situation may lead to feelings of anger and helplessness. Murphy (1995:12) says that parents of children that have been diagnosed as having an intellectual disability may fear others' perceptions of their competence. Kozma and Stock (in Smith, 1993:110) say that if parents feel that professionals have been tardy in informing them of their child's disability, they may feel betrayed. Parents may feel ashamed of having produced a child with an intellectual disability because of the associated social stigma that still persists around disability. Cunningham (1984:39) says that some confusion around the diagnosis of intellectual disability may exist for parents, that may be ameliorated by actively seeking advice and information from others, such as the relevant professionals or a support group. Kozma and Stock (in Smith, 1993:107) outline how some parents experience feelings of relief when given their child's diagnosis since it may confirm their own uneasy feelings and channel these emotions more effectively into behaviour to assist their child's optimal development.

Over time most parents of a child with an intellectual disability adapt well (Moran, Pederson, Pettit & Krupka, 1992 in Atkinson, Scott, Chisholm, Blackwell, Dickens, Tam & Goldberg, 1995:668; Roach, Orsmond & Barratt, 1999:431). Parental attitudes tend to echo the prevailing dominant social response. Parents may react in a negative and rejecting way towards their child with an intellectual disability, or may perceive the diagnosis of disability as being a test from God. Alternatively, parents may take a human rights view on the issue of disability (Dale, 1996 & Ryan & Thomas, 1981 cited in Parker, 1999:6), i.e. they would perceive all individuals as equally valuable. Help-seeking and coping behaviours by mothers vary in different cultures, reflecting prevalent cultural beliefs and attitudes around intellectual disability (Hughes, 1999:277). My study aims to assess the help-seeking and coping behaviours used by mothers of children with an intellectual disability, assuming that the behaviours reflect not only individual differences but also reflect the impact of prevailing social attitudes and understanding of intellectual disability.

2.4. Social Attitudes to Intellectual Disability

From my brief overview of the literature on intellectual disability, the predominant attitude toward intellectual disability appears to be negative. The negative connotations associated with intellectual disability range from overt comments to more subtle remarks. Carson and Butcher (1992:504) refer to individuals with an intellectual disability as posing "an economic and social burden on society... and a hardship to parents." Hughes (1999:271) refers to children with a disability as posing "significant challenges to schools, community agencies, medical facilities, and most of all, to their parents." This negative attitude is generalized as being socially disruptive for families all over the world (Hughes, 1999:277). More positively, Canning (1995:3) refers to the general public's "increased awareness and compassion." Molteno (cited in Foster *et al.*, 1997:118) refers to a Sowetan study which indicates that African mothers typically accept that termination of pregnancy for Down syndrome is appropriate, confirming that many people tend to perceive intellectual disability as a disease. Molteno further notes that in South Africa social change (eg. deinstitutionalisation) has sometimes been indicative of fiscal constraints rather than of a change in social consciousness.

Social attitudes towards intellectual disability vary according to culture. In a study of Latina mothers residing in the United States of America it was found that a positive attitude towards a child with an intellectual disability prevailed (Blacher, Shapiro, Lopez, Diaz & Fusco, 1997:483-496). In contrast, research in China noted the considerable stigma attached to having a child with an intellectual disability. The research found that many Chinese are influenced by Confucian teachings, which view the child with an intellectual disability as being a punishment for parents' disregard of correct social mores, and many believe that sympathy and support are undeserved. The degree of shame that the Confucian belief may engender in parents with a child having an intellectual disability has been found to restrict Chinese mothers from seeking help outside of their families (Yuk-ki Chen & So-kum Tang, 1997:473-480). The above international research findings might have relevance within particular communities in South Africa, given the multi-cultural nature of our society.

In the South African context research has often focused on how the child with an intellectual disability impacts on family functioning, rather than on the impact of the broader community on the functioning of the family having a child with an intellectual disability. In both of the above cases I would argue that an element of blame might be assigned in the former case to the 'demands' of the child with an intellectual disability, and in the latter case to the 'lack of support and understanding' forthcoming from broader society. I argue that a more ecosystemic understanding of the situation needs to be borne in mind when the individual, family or society is being discussed separately. One South African study that looked at support systems of mothers of 'mentally retarded' children done in two Pretoria townships by Chinkanda (1987). The aforementioned study made references to formal community support availability, but the findings indicated that most support was obtained from within the family. In the Chinkanda study (1987:13) the mother of the child with an intellectual disability assumed primary childcare responsibility and the main problem mentioned was lack of money.

2.5. Mothers and Stressors

Several researchers (Baxter, Cummins & Polak, 1995:125; Dyson, 1997:267; Roach *et al.,* 1999:431) indicate that children with an intellectual disability pose greater care-giving demands and child-related stress for their parents than do children without disability, noticeably in the early years. Molteno (cited in Foster *et al.*, 1997:120) comments that in South Africa *many families with handicapped children...have little or no support.* Beckman (1991:85) says that the nature and extent of parental stress is not a homogeneous experience but varies considerably from family to family and, according to Baxter *et al.* (1995:133), at certain life stages. The most stressful time for parents with a child having an intellectual disability appears to be at the initial diagnosis. Other high stress points are when the child with the intellectual disability starts school and again when the disabled child leaves school to commence employment. Ongoing sources of stress for families with a child having an intellectual disability include lack of consultation by professionals involved with their intellectually disabled child, the lack of

relevant information, and uncertainty as to what the future holds for their intellectually disabled child.

Researchers have argued that too much emphasis has been focused on studying maternal stress in families having a child with an intellectual disability. A corresponding lack of attention has been given to the analysis of how other family members are affected by and cope with the potential stress of daily life with a child with an intellectual disability (Beckman, 1991:585-586). There is debate as to whether mothers or fathers of children with an intellectual disability experience more stress. For example, Cummins (1976, cited by Dyson, 1997:274) argues that fathers experience greater stress than mothers in families with an intellectually disabled child. However, Kazak and Marvin (1984, cited by Dyson, 1997:274) contend that mothers are affected more by the stress engendered by having a child with an intellectual disability.

O'Connor and Lubin (1989:44) say that researchers need to study all parts of the ecosystem (in this case of the child with an intellectual disability), including not only interactions within the micro-system of the family unit, but also the elements of the broader community macro-system. The important notion of interrelatedness between individuals within and between different systemic levels and the effect that this dynamic interaction has on individual behaviour needs to be kept in mind when attempting to focus research on any one system or component thereof. Dunst, Leet and Trivette (1988:114-115) encourage professionals working with families having a child with an intellectual disability to make an ecosystemic appraisal of individual families. A more holistic approach to understanding different families may ensure that professionals provide differential and more comprehensive understanding and support. Taylor (in press, cited in Llewellyn, 1995:361) advises that families be assisted in ways in which the families themselves indicate are useful.

Notwithstanding the above, the focus of my study has been narrowed, because of the assignment feasibility constraints, to look at the mothers' 'stories' about maternal stressors, coping and support in relation to having a young child with an intellectual

disability. I would argue that focusing on maternal stressors, coping and support is pivotal to understanding the interplay of adaptation to intellectual disability by other system components. The importance of different systemic influences on maternal stress will be seen in my analysis of different coping styles and strategies used by mothers in their attempts to adapt to rearing a child with an intellectual disability.

2.5.1. Traditional Maternal Role as Primary Child Caretaker

Parker (1999:2) notes that the move from the medical model of understanding intellectual disability to a social construction of it has altered the way that care-giving is provided for individuals labelled as persons with intellectual disabilities. By 'medical model' I refer to a way of conceptualizing intellectual disability as a medical disease caused by brain pathology though indicated largely by behavioural symptoms (Carson & Butcher, 1992:56), and treated medically, traditionally in institutionalized care (Lea & Foster, 1990:15). A social construction of intellectual disability emphasizes the impact of social experiences (or the lack of them) in explaining the development of intellectual disability (Donald *et al.*, 1997:14-15). Lea (in Lea & Foster, 1990:203) compares the medical model and the social perspectives on intellectual disability, noting that the medical model assumes innate causative factors while the social view emphasizes externally acquired causative factors. Previously, the best option for caring for individuals with an intellectual disability was to place them in specialized institutions, where professional attention was available for 'the condition' of intellectual disability. Later, society's thinking shifted to the social construction of intellectual disability and to an awareness of the role that the environment plays in how individuals function. The more holistic appreciation of the nature of intellectual disability made the role of the institutions catering for the intellectually disabled defunct.

Carson and Butcher (1992:Glossary 5) define 'deinstitutionalization' as a *movement to provide chronic patients with continued psychiatric care in the local community rather than committing them to institutions*. The more recent move to deinstitutionalization and

the concomitant social expectation that the family would manage the individual with an intellectual disability, has clear implications for impacting on the family, particularly the parents and even more specifically the mother. Nadler, Lewenstein & Rahav (1991:21) talk about the increased potential for maternal stress because of the traditional child caretaker role that many mothers assume. Dunst *et al.* (1998:113) indicate that the traditional maternal role as primary child caretaker is particularly likely to be assumed in families with a child having an intellectual disability. Mothers are particularly likely to be the ones implementing home-based programmes for the additional developmental stimulation of their children with an intellectual disability during the preschool years. Booth and Kelly (1999:117) indicate that the reasons for the mother assuming the role of primary caregiver include the special needs that the child with an intellectual disability requires from her caregiver, and the general lack of competent, affordable facilities in the community. Lack of suitable facilities is cited as being the reason why many mothers of children with an intellectual disability become full-time mothers. Booth and Kelly (1999:117) say that the problem of child care includes: 1) inadequate facilities in terms of specialized teacher training, high staff turnover, appropriate activities and a child-caretaker ratio that is too high for effectively catering to the needs of the child with an intellectual disability; and 2) caretakers being unwilling to accept children with an intellectual disability. Booth and Kelly (1999:117) note that parents find the question of child care for children with an intellectual disability the most pressing problem. The problem of finding appropriate care in the community becomes more and more difficult in proportion to the severity of the child's disability and/or behaviour problems. Therefore, when the mother of a child with an intellectual disability is unavailable to care for her child, she invariably prefers to leave the child in the care of relatives rather than in centre-based care.

Various researchers (Booth & Kelly, 1999:117, 126-129; Warfield & Hauser-Cram, 1996:294-300) indicate that children with Down syndrome tend to be found in daycare from an earlier age than do children with another disability. The researchers attribute this finding to the fact that catering for children with Down syndrome requires schools to make fewer adjustments than when attempting to cater for other disabilities, particularly

children with lower adaptive functioning. The availability of some facilities for children with Down syndrome may obscure the low quality of the care that is often provided, particularly in terms of caregiver to child ratio.

Barnett and Boyce (1995) conducted a study comparing parents with a 'normal' child to parents with a child with an intellectual disability. The major problem for the parents with the child with the intellectual disability was the time the child required of the parents. The time demands of the children with an intellectual disability reported in this study correspond to the major problem of childcare demands found in the Booth and Kelly study (1999:117, see previous paragraph). Barnett and Boyce (1995:122) report that mothers of children with an intellectual disability averaged an increase in amount of time for childcare by 9 hours a week, with an associated reduction in time available for social activities. Beckman (1991:585) confirms the increased care-giving reported by parents of children with an intellectual disability.

Cuskelly, Pulman and Hayes (1998:330) also confirm the difficulties of finding appropriate childcare facilities for children with an intellectual disability found in other studies. These researchers additionally comment on the lack of help that mothers typically receive from the child's father. The lack of paternal childcare input is particularly apparent when the mother stays home full time and so reinforces the traditional maternal childcare role. Roach *et al.* (1999:432) found that fathers themselves agreed that their involvement with their children's care was considerably less than that of the children's mothers. The fathers' child care involvement was similar to that of fathers with children not having an intellectual disability, despite the fact that children with an intellectual disability require considerably more from their caretakers.

Nadler *et al.* (1991:21) say that the impact of the greater care-taking role assumed by the typical mother of a child with an intellectual disability manifests in the mothers' perceptions of self-worth. The stigma of intellectual disability that persists means that the mother of the child having an intellectual disability may feel a threatening sense of shame to her self-concept, which is more ego-central than it is for the child's father. In contrast

to the above findings, Roach *et al.,* (1999:431-432) comment that both parents of a child with an intellectual disability experience more difficulties with their perceived competence in parenting. They found that fathers' and mothers' sense of inadequacy originate in different ways. Fathers perceive a reduced sense of competence in parenting resulting from their child's diagnosis of an intellectual disability, whereas mothers experience a reduced sense of parental adequacy because of the additional care-giving demands imposed on them.

This research indicating lack of appropriate childcare facilities for children with an intellectual disability has been conducted in First World countries (eg. the Booth & Kelly (1999) study was conducted in the United States of America). Van der Westhuizen (in Lea & Foster, 1990:131-133) explains that the problem of childcare facilities for children with an intellectual disability is even greater in the South African context. In South Africa there is a need for more economical daycare centres, since many parents lack financial resources. Molteno (cited in Foster *et al.,* 1997:117) explains that developing community facilities is expensive. Fiscal constraints in the South African context mean that relatively few community facilities are currently available for children with an intellectual disability. Until quite recently, the lack of caregiver training was apparent when looking at the qualification options available. Van der Westhuizen (in Lea & Foster, 1990:133) notes that the University of South Africa offers a Diploma in Special Education, while the Technical College of South Africa offers the National Certificate in Care of Children, the Aged and the Handicapped. The courses were not found to meet the existing needs of those with an intellectual disability. Subsequently, other diploma courses have become available, for example at the University of Stellenbosch and at Vista University (personal communication-R. Newmark, 2002).

Herman and Marcenko (1997:465) and Roach *et al.* (1999:423) say that regardless of employment or marital status, mothers tend to assume primary responsibility for childcare, particularly if their child has an intellectual disability.

2.5.2. Maternal Employment

Closely linked to the traditional care-giving role that mothers of children with an intellectual disability tend to assume, is the question of maternal employment. Cuskelly *et al.* (1998:319-332) say that mothers of children with a disability indicate their children's medical needs as the main reason for not being employed. Both Cuskelly *et al.* (1998:319-332) and Barnett and Boyce (1995:115) comment that generally mothers of young children with a disability are less likely to be working full-time. The latter mentioned that mothers require more flexible work, either part-time employment or working from home. Ideal work opportunities for mothers requiring flexible work are hard to come by.

Looking more specifically at mothers of children with an intellectual disability, mothers' employment patterns tend to change as their children mature. Barnett and Boyce (1995:123) comment that when children with an intellectual disability enter school, their mothers' childcare demands are reduced, freeing time for paid employment. The typical employment trend found in the Barnett and Boyce study (1995:123) for mothers of a child with an intellectual disability highlights the importance of focusing particular attention on the stress of the mothers with very young intellectually disabled children.

Cuskelly *et al.* (1998:330) report that the lack of employment opportunities available to these mothers is associated with other stressors. They note that in some cases, lack of maternal employment results in financial stress for the family. Herman and Marcenko (1997:465) comment that the financial stress engendered by a mother's not working is aggravated by the additional expenses incurred by a child with a disability. They also say that money is especially problematic for single mothers of children with an intellectual disability. Roach *et al.* (1999:432) say that mothers of children with an intellectual disability may find that being employed adds further stress to their already demanding life situation. A lack of maternal employment, on the other hand, may also reduce opportunities to develop an extended social network.

2.6. Mothers and Coping

2.6.1. Coping Styles

Atkinson *et al*. (1995:669) contend that there is a lack of research as to whether or not mothers with a child having an intellectual disability use one coping style across time. Research analyzing the different coping styles of mothers and fathers of adult children with an intellectual disability may provide a clue to answering the question on coping style (Essex, Seltzer & Krauss, 1999:545-563). Essex *et al*. (1999:545-563) discuss how different parental coping styles aligned themselves according to gender, which may reflect the differential care-giving experiences of the genders (with more experience attributed to the mothers). The findings may reflect the learning of coping strategies with experience. Their study found that mothers tended to use a more problem-focused approach to coping with the demands of care giving for their child with an intellectual disability, rather than a more emotional-focused coping response. The preferred coping strategy (problem-focused) seemed to buffer the effects of stress on these mothers' sense of mental health. More specifically, the Essex *et al*. study (1999:545-563) found that a problem-focused response to controllable stressors reduced depression levels, whereas the use of emotion-focused coping strategies were more effective in situations perceived as not being under the control of the individual. By 'depression' I refer to mood disorder, ranging from milder symptoms such as self-depreciation, excessive dependency and an extrinsic locus of control, to more severe symptoms affecting biological functioning (Carson & Butcher, 1992:425).

Atkinson, Scoot, Chisholm, Blackwell, Dickens, Tam & Goldberg (1995:668, 673-674) say that how parents respond to stress may reflect not only gender differences in coping with the stress of parenting a child with an intellectual disability, but may also reflect individual differences in coping style. Different mothers may tend to monitor stressors in different ways. Research (Atkinson *et al.,* 1995:668) indicates that mothers who are particularly sensitive to and closely monitor stressors experience greater emotional distress than other mothers. High maternal distress levels may impact negatively on their

children's behaviour. In contrast to the group of high distress mothers, mothers who avoid stressors and thereby the associated distress appear to respond to their children with reduced sensitivity. Clearly, a balanced position is necessary for effective coping with stress. The use of approach (i.e. closely monitoring stressors) or avoidance (i.e. less attention to stressors) coping styles seems to be stable over time. Dyson (1997:275) comments that the subjective experience of stress is associated with parents' perception of their family's functioning. Each parent's coping approach impacts on the other parent. For example, the impact of the stress of childcare by predominantly one parent may affect the sense of stress experienced by the other parent.

2.6.2. Depression

Scott, Atkinson, Minton & Bowman, 1997:167) point out that previously functioning in families with a child having an intellectual disability was believed to be poor, with concomitantly higher levels of depression. While the researchers found significantly higher levels of depression in parents with an intellectually disabled child than in families with a 'normal' child, they did not find depression levels of the extent that would have been anticipated. Previous findings of high levels of parental depression are attributed to the methodological problem of using too small a sample from which to be able to generalize the findings. The more recent research by Scott *et al*. (1997:167) indicates that 80% of parents with a child having an intellectual disability do not suffer from depression or there are minimal signs of depression. The relatively low levels of depression in their research sample may have limited generalization application, given that the sample was provided with counselling support, which may have skewed the findings. Other studies (Blacher *et al*., 1997:491) also indicate that having a child with an intellectual disability does not, on its own, account for an increase in the rate of depression among parents with a child with an intellectual disability. Scott *et al*. (1997:167) found a difference between mothers' and fathers' distress levels, regardless of whether their children had an intellectual disability or not. Essex *et al*. (1999:545-563) discovered that mothers of children with an intellectual disability may deflect depression by using problem-focused

coping responses (i.e. task-oriented to immediate requirements) to situations where the mothers have some element of control. The mothers used a more emotion-focused approach (i.e. a more personal response) only when the situation offered no opportunity for control. Depression in mothers of children with an intellectual disability has also been found to relate to cultural factors.

2.6.3. Cultural Factors

In a study done in the United States of America by Blatcher, Shapiro, Lopez, Diaz and Fusco (1997:483) of Latina mothers of children with an intellectual disability, the researchers found higher levels of depression than in other mothers from the dominant cultural group. Several factors determined increased depression levels in the Latina mothers, such as the presence of family and health problems, but especially fewer interactions with contacts from the dominant culture in daily life, intimation beingthat the latter leads to social isolation and loneliness. Volenski (1995:124) and Smith (1993:116) state that parents need to have contact with other parents experiencing similar difficulties rearing a child with an intellectual disability. Nadler *et al.* (1991:17 & 21) note that parents may prefer to help themselves or to seek professional assistance because of the threat to their self-esteem if they appear unable to cope when other parents in the same situation appear to be managing. The help-seeking preference is particularly true for mothers with a child having an intellectual disability. An interesting finding in the Latina study (Blacher *et al.*, 1997:483-496) is that the mothers tended to view having to rear an intellectually disabled child less negatively than other (North American) ethnic groups. Thus the fact of the intellectual disability alone did not significantly impact on depression levels for the Latina research respondents. The Latina mothers were more inclined to increasing levels of depression when there were family disruptions, since family is very important to this ethnic group. Depression in this research group of Latina mothers tended to manifest in somatic symptoms, although the researchers found it difficult to disentangle the causative path between symptom and level of depression, as to which factor came first. The Blacher *et al.* study (1997:483-496) indicates that several factors

were found to be unrelated to maternal depression, including demographic variables such as language use, employment, education level, income and age.

2.6.4. Positive Parenting Experiences

Intellectual disability is often connoted in negative terms. Families with a child having an intellectual disability may be adversely influenced by negative social views on disability. Orr, Cameron and Day (1991:448) and Stainton and Besser (1998:57) indicate that alternatively, the parents may reframe the situation into a more positive one. Many caveats in the literature (e.g. Orr *et al.,* 1991:448) warn professionals dealing with families with intellectually disabled children not to presume that their clients perceive disability as a negative or a stressful event. Cahill and Masters-Glidden (1996:158) warn that unrealistic expectations by parents with a child having an intellectual disability are to be avoided if parents are to experience their parenting as competent. These warnings aside, most families rearing a child with an intellectual disability cope well and function effectively as a family, say Baxter *et al.* (1995:134) and Cahill and Masters-Glidden (1996:157).

In a qualitative study Stainton and Besser (1998:57 & 68) found that several positive factors resulting from having a child with an intellectual disability could be identified. Parents reported that they experienced their disabled child as a source of joy and happiness. They reported that they had developed an increased sense of purpose in life and had reassessed their life priorities. They had also expanded their social network and community involvement, and their spirituality had increased. Parents in this study indicated that the birth of their intellectually disabled child had been a source of greater family intimacy, and that as people they had become more tolerant and understanding of others. They felt that they had undergone significant personal growth and become stronger as a result, with an associated positive impact on others in their communities. The positive influences of having a child with an intellectual disability were not merely the result of using denial as a coping mechanism.

Similarly, Parker (1999:98-99) notes that most parents report positive aspects to caring for their intellectually disabled child. The parents in this research study also re-evaluated their values and developed increased patience and tolerance for different kinds of people in society.

Beresford (1994, cited by Parker, 1999:7) reports on a longitudinal qualitative study where parents are described as being positive and proactive in their approach to caring for their child with an intellectual disability, rather than as victims of negative stress.

2.6.5. Religion

Religion is often mentioned by parents of children with an intellectual disability as being an important coping resource in family adjustment. Hughes (1999:278) noted that 91% of parents said that religious belief had become a relevant part of their lives subsequent to the birth of their child with an intellectual disability. Of the sample 68% reported a positive increase in their relationship with God subsequent to the birth of their disabled child. The positive effect of r eligion may be attributed both to the effects of personal commitment and to the effects of the support of the religious community. A high degree of commitment to religion correlates positively with greater self-reliance when coping with problems and a tendency to reframe problems positively, resulting in reduced levels of depression. Parker (1999:91) indicates that religious belief may cause tension for an individual. The tension referred to stems from questioning God, for example: "Why did God give me a child with an intellectual disability?"

2.7. Support for Mothers

2.7.1. Religion

Religion may be conceived of as a coping strategy actively used by mothers of children with an intellectual disability, as seen in the previous section. Religion may also be

conceived of from the perspective of the socio-cultural impact that various religions have upon their members, as in this section. Most of the studies mentioned in this section of my study have been conducted in countries with a predominantly Judeo-Christian population. Muller (personal communication, 2001) says that the Christian tradition regards the birth of a child with an intellectual disability as a reflection on the sinful nature of the parents, i.e., the child's disability is perceived as 'divine punishment.' The belief that intellectual disability reflects parental sin is similar (though perhaps not as extreme) as the Confucian belief referred to in section 2.3. (Yuk-ki Chen & So-kum Tang, 1997:473-480). In contrast to the judgemental attitudes of both the Confucian and Christian beliefs, both Muller (personal communication, 2001) and Rogers-Dulan (1998:99) agree that the Muslim community is more accepting of the child with an intellectual disability and his family. Rogers-Dulan (1998:99) outlines how the social support aspect of religion can be conceived of as consisting of factors such as religious media, religious socialization, participation in organized religious groups and support from the religious leader (Rogers-Dulan, 1998:91-100).

2.7.2. Quantity and Quality of Resources

Dunst *et al*. (1988:108) say that an adequacy of resources for coping with the challenges of parenting a child with an intellectual disability is correlated with well-being and commitment to following professionally prescribed interventions, regardless of demographic variables such as maternal age, socio-economic status and income, child age and developmental quotient. Molteno (cited in Foster *et al*., 1997:120), writing about the South African scenario, comments on the inadequacy, of support if any available to many families caring for a child with a disability. Dyson (1997:276) says that the quantity of support available to mothers of children with an intellectual disability is insufficient, on its own, to mediate the effects of stress. Different mothers perceive different types of support as useful, depending on the type of stress they have experienced. Yuk-ki Chen and So-kum Tang (1997:473) say that Chinese mothers of children with an intellectual disability reported that all forms of support are useful,

irrespective of the stressor duration, in situations where the stress seemed to be uncontrollable. In contrast, for controllable stress the Chinese mothers found that more concrete help was of greater benefit than informational support.

In a longitudinal study of seven years, Baxter *et al.* (1995:133) report that the support found most useful to parents focused on their current source of anxiety regarding their intellectually disabled child. Family and friends were found to be the most useful support providers after the initial diagnosis of intellectual disability had been given, while professional help was better appreciated later on in time. The support of the teacher was noted as being valued at the start of the child's school career, and legal assistance was mentioned as being useful when the child was about to leave school and plans for future guardianship needed to be considered.

2.7.3. Respite

The Oxford Encyclopedic English Dictionary (Hawkins & Allen, 1991:1231) includes under the definitions of respite the following: *n.1. an interval of rest or relief. V.tr.3. give temporary relief from care.* Parker (1999:90) notes that long-term care for a child with an intellectual disability can be very stressful. Botuck and Winsberg (1991:43) say that a supportive social network for mothers with a child with an intellectual disability has been found to be an important consideration in reducing the impact of the physical and emotional demands of chronic child care. According to Parker (1999:92-93 & 97), respite provided by the informal social network offers mothers some of the time they need to address their own needs. Herman and Marcenko (1997:458) say that sometimes mothers need to be encouraged to take advantage of respite opportunities offered. Herman and Marcenko (1997:495) further contend that respite and its quality depend on the mother's perceptions of the level of helpfulness of her support network. Sharpley, Bitsika and Efremidis (1997:26) found that social support per se was not necessarily perceived as useful by the parents of children with autistic spectrum disorder, but that the informal assistance of family members with a good understanding of the child's problems was

most efficacious in providing respite. Beckman (1991:585) says that it seems logical that family functioning improves when the mother has the necessary opportunities for respite. Improved family functioning would result from the improved psychological well-being that the respite provides for the mother. Although this seems logical, researchers Botuck and Winsberg (1991:46) also acknowledge that the positive expectancy of respite may be what actually improves the psychological functioning of mothers studied in this regard. Herman and Marcenko (1997:465) say that community respite programmes have found a positive (although small) increase in parental well-being after participation.

2.7.4. Grandparents

Support provided by the extended family in cases where there is a child with an intellectual disability has not been studied in much detail. One attempt to focus research on the extended family (Seligman, Goodwin, Paschal, Applegate & Lehman, 1997:239-301) looked at the role that the grandparents play in providing parental support. The research suggests that grandparents provide more emotional than instrumental support, particularly if they live within close proximity to their grandchildren. Geographical closeness is cited as being a negative factor in cases where grandparents are unsupportive and rejecting of the intellectually disabled child. The maternal grandparents were found to be the more supportive, particularly the maternal grandmother. The maternal grandparents seemed to be more knowledgeable about the causes and remediation of their grandchild's disability, which is important for having more realistic appraisals of the child's potential and for providing more effective support. The study on grandparent support made use of responses by the mothers of the children with an intellectual disability, and may therefore reflect what mothers rather than all family members found to be most useful in terms of support.

2.7.5. Literature

Support may also be gained from reading the literature around intellectual disability, and the information gained may help to contribute to the parents' sense of control and well-being. One example of potentially useful literature for parents with a child having an intellectual disability is the parents' guide edited by Smith (1993:113-131). This offers suggestions for coping as well as strategies for dealing with family, friends and the siblings of the child with intellectual disability.

2.7.6. Culture

In their study appraising stress and social support of Chinese mothers of adult children with an intellectual disability, Yuk-ki Chen and So-kum Tang (1997:473-480) highlight similarities and differences in attitudes towards intellectual disability between the Chinese and Western cultures. They discuss how Chinese mothers of children with an intellectual disability, like their Western counterparts, experienced difficulties with time management, daily care-taking and management of behaviour problems. The difference between the cultures may lie in the difference of cultural philosophies. As mentioned in the 'social attitudes' section, there is considerable stigma attached to having a child with an intellectual disability in China. Many Chinese are influenced by the Confucian teachings (Yuk-ki Chen & So-kum Tang, 1997:473-480), which view the child with an intellectual disability as a punishment for parents' disregard for correct social mores (i.e. norms for moral behaviour), and may believe that sympathy and support are undeserved. The degree of shame that the Confucian belief may engender in parents with a mentally retarded child has been found to restrict Chinese mothers from seeking help outside of their families.

2.8. Summary and Conclusions

The prevalence of intellectual disability in South Africa appears to be similar to the 2-3% world rate (Kozma & Stock in Smith, 1993:2 & 29), but the local data are deemed unreliable (Lea & Foster, 1990:4) given the lack of research done in major sections of the population. Statistics do not reflect the effect of intellectual disability on the broader community. Looking first at the parents of children with an intellectual disability, the emotional impact of their child's disability needs to be understood against the current socio-cultural background. Parents of children with an intellectual disability usually experience the news of their child's disability as a crisis (Cunningham, 1984:39) and proceed through stages of grief. Most parents seem to adapt well, although the grief process may never be resolved. The attitude of the broader cultural community towards intellectual disability impacts on parents' coping. Social attitudes are often negative (Hughes, 1999:277), although increased public awareness on the topic of intellectual disability seems to be leading to greater compassion (Canning, 1995:3). Molteno (cited in Foster *et al.*, 1997:117) contends that social change may sometimes reflect fiscal constraints rather than social attitudes.

Mothers of children with an intellectual disability are usually the primary caretakers for their children, regardless of marital or employment status. Children with an intellectual disability require more caretaker attention. Facilities are often lacking or inadequate, and families may require the mother's income, placing the mother in a bind between the need to work and the need to care for her child.

The stress posed by the additional care-taking needs of children with an intellectual disability may mean that caretakers devise unique coping strategies. Research (Essex, Seltzer & Krauss, 1995:669) among mothers of children with an intellectual disability found that the mothers typically cope using a problem-focused rather than an emotion-focused response. Different mothers monitor stressors by consistently responding in either an approach or an avoidance style. Mothers of children with an intellectual disability are generally more stressed, although not necessarily more depressed than other

mothers. If depression occurs it is usually associated with the demands of additional childcare or the impact of negative cultural factors. Mothers residing outside of their familiar culture may struggle to gain the support that they need from outside the immediate family. While there are difficulties in rearing a child with an intellectual disability, professionals should be careful to avoid negative assumptions. Religion is sometimes experienced as a positive coping tool by parents, although some may experience a dilemma around their religious beliefs.

Some religions seem to have a more positive attitude towards the parents of a child with an intellectual disability. Support needs to be adequate, not only in terms of quantity but in quality. Some types of support are better appreciated than other types at different times. Informal social support is important for providing respite. The assistance of grandparents may be particularly useful. Some parents find that reading literature on intellectual disability gives them a sense of empowerment. Parents from different cultures experience many similarities in their rearing of a child with an intellectual disability; differences lie in the impact that the respective cultures have on them.

In conclusion, it seems that mothering a child with an intellectual disability is stressful. The availability of quality resources may mediate the maternal stress, but these resources may be lacking in a society that views intellectual disability negatively, fiscal considerations notwithstanding. The next chapter looks at my research design, which I will use to guide the research process and against which my assumptions from the above literature review will be compared. The research design includes the use of two validated questionnaires selected on the basis of my understanding gained from the literature review of issues related to stress and coping pertinent to mothers of children with an intellectual disability. The first questionnaire focuses on the child's abilities, the mother's attitudes, the family's functioning, and the impact of society on family behaviour. The focus of the second questionnaire is the coping styles used by different mothers of children with intellectual disability. The biographical data requested at the beginning of the questionnaires are also those that the literature suggests are most relevant.

CHAPTER 3. RESEARCH DESIGN

3.1. Introduction

In this chapter I present the plan for the research study. The concepts of research design, methodology, and method are clarified in terms of how they relate to and are used by different authors on research and in my study. I indicate how my study may be described as evaluation research, and discuss theoretical notions about quantitative and qualitative research, as both approaches are combined in my study. I discuss how I negotiated access to the participants for the questionnaires' refinement study as well as the research study. I discuss methods of data production that I used for the research study: they include the use of two questionnaires and a semi-structured interview which I conducted with each participant. Next, I discuss how the study was implemented, including the questionnaires' refinement study and the research study procedures and processes. I describe the findings of the questionnaires' refinement study and the ways in which I analyzed the data from the research study. I discuss the process of data verification in three steps: 1) the reliability and validity of the questionnaires; 2) credibility in qualitative research; and 3) triangulation of the quantitative and qualitative data. I explore ethical considerations in terms of how they apply to my particular study.

3.2. Clarification of Terminology

The literature indicates that different authors describe or use terms differently. For example, Gough (2000:3-4) unpacks the concept of 'methodology', noting that it could include the reasoning behind doing research in a particular way and the assumptions guiding the research. Methodology looks at *why* particular techniques are used in a particular research project. Gough (2000:5-6) quotes Van Maanen's (1995:4) conceptualization of how methodology fits into the research process, describing the interacting research elements: fieldwork, headwork (including thinking about how research should proceed, i.e. methodology) and textwork. Gough's (2000:3-4) notion of

methodology seems closer to Mouton's (2001:56) notion of research design than it does to the latter's description of methodology: Mouton's (2001:56) notion of research design "focuses on the logic of the research". Mouton (2001:56) explains that research design refers to the overall aims and the evidence needed to address the research question, that is, *the research plan*. The research plan guides the methodological processes and procedures that are used in the implementation of the research. In contrast, Gough's methodology looks at why particular techniques are used. Mouton's (2001:56) description of methodology more closely parallels Gough's use of the term 'method' Gough (2000:3-4) uses the term 'method' to refer to ways of doing research, that is, the '*what*' of research (in contrast to the 'why' of methodology). Mouton's (2001:56) notion of methodology refers to the processes and procedures used in the implementation phase of the research. Huysamen (1998:139) implicitly distinguishes between *research design*, the first phase of research, and *methods*, which he describes as *ways in which (such) measuring instruments may be administered to participants or respondents*. The use of the above-mentioned terminology is summarised below:

Table 3.1. A Comparison of the Use of Terminology by Different Authors

Gough (2000)	Mouton (2001)	Huysamen (1998)
Methodology	Research Design	Research Design
Method	Methodology	Method

The above discussion and table indicate both similarities and differences in the use of terminology across authors. In my study I have chosen to use Mouton's (2001:56) terminology of 1) research design and 2) methodology to distinguish between the planning and implementation stages of the research.

3.3. Evaluation Research

Rossi and Freeman (1993:5, cited in Babbie & Mouton, 2001:335) define evaluation research as *the systematic application of social research procedures for assessing the conceptualization, design, implementation, and utility of social intervention programmes.* The mind map on the following page (Figure 3.1) aims to provide a clear overview of how my study may be perceived within evaluation research. The words printed in bold highlight what is relevant for my study.

3.3.1. Methodological Principles of Evaluation Research

Babbi and Mouton (2001:365) encourage researchers' evaluation to begin at the same time as programme development, rather than their trying to rely on retrospective data. My study is a needs assessment aimed at guiding future decisions around how best to support mothers of young children with an intellectual disability.

Another useful 'methodological principle' of evaluation research is that of standardization. Babbi and Mouton (2001:367) indicate the importance of standardization for meaningful data comparisons. Three forms of standardization are:

1) The standardization of research instruments. In my study I made use of two standardized questionnaires relevant to the research population of parents of children with an intellectual disability.

2) The standardization of data collection instructions. I used the same instructions on the questionnaires in every case.

3) The standardization of data capturing and data editing. In my study I used the same approach to scoring the questionnaires in each case.

Figure 3.1. The Study Perceived Within Evaluation Research

4 Aspects of Programmes of Evaluation Research: **conceptualization**

     (Rossi & Freeman, 1993:5, in   design

      Babbie & Mouton, 2001:335)   implementation

                                                      utility of programme

3 Purposes of Evaluation Research: **to generate knowledge: (to**

     (Patton, 1997 in Babbie & Mouton,   **help shape policy** says

     2001:337)   Weiss, 1990:176, in

                                                       Babbie & Mouton, 2001:339)

                                                       to judge programmes

                                                      to improve programmes

4 Types of Evaluation Research: **the evaluation of need***

     (Posavac & Carey, 1992 in   the evaluation of process

      Babbie & Mouton, 2001:341)   the evaluation of outcome

                                                        the evaluation of efficiency

Formative evaluation provides those who are trying to improve some aspect of social functioning with the needed data (Scriven 1980:6-7 in Babbie & Mouton, 2001:345).

3 Main Paradigms/Approaches in Evaluation Research:

     (Babbie & Mouton, 2001:357-359) **Experimental**   experimental

                                                        Quasi-experimental**

                  Traditions   **Qualitative/Naturalistic**

                                       Participatory/Empowerment (cf. 3.5)

*Note: I wish to emphasize that my study is an evaluation of needs.

**Quasi-experimental means that no random selection/assignment of participants was possible.

Babbie and Mouton (2001:368) discuss the possibilities of integrating quantitative and qualitative research: *it is very often the case in evaluation studies, that a combination of such methods is required.* The next paragraph expands on the relevance of why chose to combine quantitative and qualitative research approaches in my study.

3.4. Quantitative and Qualitative Research

The research design that I have chosen in this study includes both quantitative and qualitative methodologies. Quantitative methodology emphasizes numerical data comparing categories of information; while quantitative methodologies emphasize individual descriptive data (see the subsequent paragraph for more detail). I used two questionnaires (Appendix C) to obtain quantitative information in terms of nominal (true/false) data and ordinal data (more or less of an attribute) respectively. At the end of each questionnaire I provided considerable space in case respondents wished to make additional comments to the structured format of the questionnaires, thus allowing for the possibility of obtaining qualitative data. I also used follow-up interviews with the aim of generating more qualitative data. My use of interviews reflects a case study approach, about which Huysamen says (1998:168): [they] *are directed at the understanding of the uniqueness and the idiosyncracy of a particular case….*

I assumed that my use of a qualitative approach (semi-structured interviews) would complement the quantitative data obtained from the questionnaires. The interviews aimed to refine understanding of possible issues from the completed questionnaires through the use of considered questions and careful assessment of responses. In being guided for the semi-structured interview questions by the data obtained from the completed questionnaires, I was using an emergent approach to research design. An emergent research design allows for multiple realities (albeit screened through my analyses) to be represented (Eloff, Engelbrecht, Swart & Oswald, 2002). I considered the written response format of the questionnaires as complementary to the spoken format of the semi-structured interviews. Through the combination of written and verbalized responses,

I aimed at catering for the different personality preferences of different participants. In a process of triangulation (Creswell, 1994:174), I aimed to elicit possible trends in the ways in which mothers feel about, and cope with their young children with an intellectual disability through data comparisons across participants and between questionnaire and interview data for each participant.

Creswell (1994:162) compares the opposing assumptions of quantitative and qualitative research:

1)   In quantitative research the researcher starts from a theoretical base and sets out to obtain data that accord with the theory; qualitative research develops theory as the research proceeds, being open to new avenues of enquiry according to what emerges from the data. Qualitative research compares findings to existing theory after the active research process. In the more quantitative part of my study. I made use of already validated questionnaires. The questionnaires' questions reflected the theory, which suggested that parents of young children with an intellectual disability tend to experience greater feelings of stress than do parents whose children do not have an intellectual disability (cf. 2.5). In the more qualitative part of my study I made use of some data obtained from the questionnaires, but also listened for 'difference' in the emerging data.

2)   Quantitative research involves gathering quantifiable data, whereas qualitative research relies on descriptive data reports: it focuses on research subjects' unique perceptions and experiences. In my study I analyzed the questionnaires in terms of the number of positive relative to negative responses for the first questionnaire and in terms of the number of responses for each of the five coping styles represented by the different subsections of the second questionnaire.

3)   Quantitative research makes generalizations about the nature of the topic being researched; qualitative research aims to gather more specific data. The intention of my research was explorative, rather than aiming to generalize the findings beyond the group of participants with whom I worked. Instead, I used the

responses from the questionnaires as generalizations from which to devise a tentative interview schedule. I gleaned more specific data from my analysis of the individual interviews (Creswell, 1994:162).

4)   In quantitative research the researcher has a clear notion of the procedures that she intends to follow in order to gain her data; in qualitative research the researcher has a general idea of the research design, but the design is more flexible and emerges as the research proceeds. In my study I provided clear written instructions to the participants for the completion of the questionnaires. I started all the interviews with the same initial general question about the family's functioning, but thereafter I guided the direction of the interview by the emerging verbal content relevant to the particular participant.

5)   Quantitative research requires the reliability and validity of the measuring instruments to have been established before the research is undertaken; in qualitative research the researcher attempts to verify the data through various means such as the use of thick description. The questionnaires that I used in my study derived from already established research instruments in terms of both reliability and validity (see '3.8. Data Verification' for a detailed description). I obtained the 'thick description' through tape recording and transcribing the interviews and analyzing the data for anticipated and emerging themes (see '3.8. Data Verification' for a more detailed discussion).

I planned to use semi-structured interviews to obtain qualitative data to complement my quantitative use of data obtained from two questionnaires. The questionnaires have been validated, based on relevant theory. The questionnaires provide a predetermined set of questions to be answered by the participants for the purpose of gathering quantifiable data (i.e. the questionnaires require nominal or ordinal responses), to provide a general impression about how the participants feel about and cope with their young children with an intellectual disability. In contrast to the questionnaires, my subsequent use of semi-structured interviews was partially guided by the participants' free associations of ideas,

which I describe fully (thick descriptions), based on the tape-recordings and transcribed notes from each interview. The latter will provide unique representations of each participant's subjective experiences.

3.5. The Participants

One of the evaluation research approaches mentioned (see Figure 1.3) was the participatory/empowerment evaluation tradition. Fetterman (1996:5, cited in Babbie & Mouton, 2001:359) describes participatory evaluation as including those individuals, whom the programme is intended to benefit in decision-making about the evaluation. My study originated within a context of mutual collaboration between the University of Stellenbosch and DSSA and continued in a participatory manner by involving stakeholders (parents of young children with an intellectual disability) in refining the questionnaires intended for use with the research participants. The research participants were also asked for their comments about the research instruments, both the questionnaires and the semi-structured interviews. Empowerment evaluation stresses the advocacy role that research may play for those who are disempowered (Fetterman, 1996:5, cited in Babbie & Mouton, 2001:359).

3.5.1. Participants of the Questionnaires' Refinement Study

In my questionnaires' refinement study I requested four mothers from the southern suburbs of Cape Town support group for mothers of a child with an intellectual disability to assist in the initial phase of the research. I based the selection of the southern suburbs support group on convenience sampling: I was acquainted with one of the mothers from the group. I used the above-mentioned convenience group since they were able to provide me with prompt assistance. Huysamen (1998:37) notes that purposive sampling is most useful for a researcher in terms of convenience and economy. The initial group of

participants was, as in the main part of the research, self-selected from a middle-class group of parents.

3.5.2. Negotiation of Access to the Research Participants

Initially I spoke telephonically to the principal at the school from which I wanted to obtain research participants (hereafter referred to as 'the designated research school'), about wanting to undertake research involving the parents of the children currently attending the school. My introduction to the school was facilitated by my being a student associated with the University of Stellenbosch and by the collaborative research association between the University of Stellenbosch and DSSA. An interview with the principal served to present the aims of my study and the questionnaires intended for use in the study. My interview with the principal also indicated how many parents might be available to participate in my study. The principal supported the notion of my research project. I then obtained permission to undertake my research from the Western Cape Education Department. I used the principal to introduce, explain and motivate participation in the research to the intended participants. By using the assistance of the principal I aimed at eliciting a greater participant response than would be anticipated had I (as researcher) undertaken this part of the research task, since I am a Master's degree student unfamiliar to the prospective research participants. I relied on the motivation and encouragement of the principal at the designated research school to obtain the co-operation of the participants.

The resultant sample comprised a convenient group of the mothers of preschool children with an intellectual disability attending the designated research school. The sample was self-selected in that the principal explained to the mothers that they should feel free to either complete the questionnaire or not.

3.6. Methods of Data Production

I use the term 'data production' rather than 'data collection' to reflect the idea that an ultimate reality does not exist, but that reality is constructed according to one's own unique perceptions of experience (Gough, 1999: 264, cited in Le Grange, 2001:80). I see my subjective reality as being framed against the backdrop of the particular personal life experiences that I have had within a given historical time and socio-cultural background.

The main phase of my study comprised two sections:

1) the first part consisted of my obtaining data from two questionnaires (including a biographical section) completed individually by each of the participants at home;

2) the second part of the research consisted of semi-structured interviews between me, as the 'research instrument,' (Eloff et al., 2002) and the participants, either at the participants' homes or at their place of work.

3.6.1. The Questionnaires

The QRS (Short Form of the Questionnaire on Resources and Stress) and the WC-R (Ways of Coping-Revised Questionnaire) were edited by a group of 'experts' The 'expert' group consisted of mothers having young children with an intellectual disability and so qualified to comment from first-hand experience. The editing was done before I presented the questionnaires to the research participants.

I requested demographic/biographical data and a follow up interview at the beginning of the questionnaires. Biographical variables reflected the research participants':

- Name
- Date of birth
- Telephone number
- Willingness to be interviewed
- Ages of other children in the home

- Marital status
- Religious denomination (if applicable)
- Current employment status
- Home language

I chose these biographical variables, since they reflect issues in the literature around the topic of having and coping with a child with an intellectual disability (see 2.5.2, 2.6.1 and 2.6.3 for discussion particularly of the latter four above-mentioned variables). Maternal age was requested because of the association of increased risk of bearing a child with an intellectual disability (e.g. Down syndrome) with increasing maternal age, and my wish to establish whether the participants were aware of their children's disability before birth. I wished to ascertain how their feelings towards their children were impacted on, as discussed in the literature. The request for information about other siblings was made because a potentially important reference to sibling feelings was made in Smith (1993:127). Siblings may experience similar feelings to the parents and need to feel that their parents are not emotionally dependent on them.

I based the first questionnaire on the QRS (Short Form of the Questionnaire on Resources and Stress: Appendix A). The original form of the questionnaire, comprising 285 questions, was used by Holroyd (1974); the currently used, shorter form has been used by Friedrich, Greenberg & Crnic (1983). The shorter QRS consists of 52 items each requiring a true or false response. The first questionnaire (refined to 51 questions in my study) focused on the feelings mothers experience regarding their children with an intellectual disability. At the end of the questionnaire I provided space for participants' comments additional to their questionnaire responses, or for participants to comment on the questionnaire itself.

I based the second questionnaire on the WC-R (Ways of Coping-Revised Questionnaire: Appendix A), as used by Folkman and Lazarus (1985). The WC-R consists of 48 items originally in 5 different categories but presented here as one continuous sequence of questions, albeit in the same sequence as in the original questionnaire. The 5 original

categories included 1) practical coping 2) wishful thinking 3) stoicism 4) seeking emotional social support and 5) passive acceptance. Practical coping questions describe proactive behaviour by the mother. Wishful thinking questions include descriptions of behaviours that are not proactively task-oriented. The questions on stoicism include behaviours that either aim at ignoring the problem, or behaviours that exclude interaction with others on the topic of the child's intellectual disability. The questions on seeking emotional social support describe behaviours indicating a proclivity for approaching others to provide support. The passive acceptance questions are described in terms of avoidance behaviours. The second questionnaire required participants to choose between the following response possibilities for each question: 1 = not used; 2 = used occasionally; 3 = used often; 4 = used a great deal. The second questionnaire focused on preferred ways of coping used by mothers with a child having an intellectual disability. As for the first questionnaire, I provided space at the end for any comments that the participants might wish to add to their questionnaire responses. I estimated that the completion of the above questionnaires and the requested biographical data would require half an hour of the participants' uninterrupted time.

3.6.2. The Semi-Structured Interviews

I used semi-structured interviews to get spoken responses of the participants to complement their written questionnaire responses. Cantrell (1993:96, cited in Le Grange, 2001:82) refers to the importance of interviews for data production in interpretative studies and especially mentions the importance of describing participants' own words.

The follow-up interviews for my research were semi-structured. I used the analyzed data from the completed questionnaires as a guide to further information gathering during the interview process. I devised individual interview schedules to guide the interview process, focusing on the most salient points taken from each participant's completed questionnaires. I recorded the interviews using a tape-recorder if agreed to by the participant interviewed. Bogdan and Biklen (1982:74, cited in Le Grange, 2001:81)

define field notes as *a written account of the researcher's sensory and cognitive experiences.* Field notes that I took during the interviews included some observations of non-verbal behaviours too, for example discrepancies between verbal assertions and non-verbal body language. Each interview was of approximately half an hour's duration.

The interviews (Creswell, 1994:82) involved meetings between each of the participants and myself for the purpose of elucidating and elaborating upon the themes that emerged from the completed questionnaires, and for noting any contradictory data that might have emerged in the course of the conversation. I planned the interviews to be semi-structured, using the themes that emerged from the questionnaires as a tentative guide. The themes most relevant for a particular participant were highest on the agenda for that particular interview. I planned the interviews to start with a more general question before asking more specific questions. I aimed to elicit data pertaining to the themes through the general question and to use the specific questions only if the desired topics were not mentioned initially. In limiting the use of pre-decided questions I aimed to allow for flexibility, necessary for the qualitative research process. All the questions were open-ended to encourage more detailed responses. I devised an interview schedule for each interview to guide the interview process (Appendix D).

3.7. The Study Implementation

3.7.1. Refining the Instruments

The group of mothers that refined the questionnaires used in my study were acquaintances of the mother that I knew. I requested the group of mothers to peruse the original wording and format of the questionnaires intended for use with the actual research participants and to comment according to various factors stipulated by me (Appendix B). More specifically, I asked the questionnaires' refinement study participants to provide me with written comment on:

- The sensitivity of the questions

- The use of language, e.g. the need to change Americanisms/ambiguities
- The relevance of the questions, given the age group of the children I wished to refer to in my study
- The format/structure of the questionnaires
- Any other comments that might have been relevant to the final presentation of the questionnaires to the research participants.

I did not require the questionnaires' refinement participants to comment on the follow-up interviews since these were based on the questionnaire responses from the actual research study.

3.7.2. The Research Study

I requested the mothers from the research participant group to complete the two questionnaires in their own time (within a 2-week period) at home and then to return the completed questionnaires to me by leaving them in a sealed envelope at the designated research school's office. Additional to the questions posed in the questionnaires, I requested participants to complete a biographical section. In the biographical section I requested permission to arrange an individual follow-up interview with them. I conducted the interviews in the homes (or workplaces) of the participants for their convenience.

3.8. Data Analysis

Bogdan and Biklen (1982:154, cited in Le Grange, 2001:89) describe the process of data analysis:

> analysis involves working with data, organising it, breaking it down, synthesising it, searching for patterns, discovering what is important and what is to be learned, and deciding what you will tell others.

In this approach the researcher identifies categories of data and then, through a process of clustering, extracts a few broad themes (Engelbrecht, Swart & Eloff, 2001:258).

3.8.1. Findings from the Instruments' Refinement Study

The results from the instruments' refinement study indicated willingness on the part of the questionnaires' refinement group mothers to spend considerable time and effort assisting on the editorial task assigned to them. The questionnaires' refinement group participants deleted Americanisms and removed developmentally inappropriate questions. In making alterations to the original questionnaires I regarded response consensus among the refinement group participants as a prerequisite.

In sum, the changes I made to the original questionnaires were minimal, with few alterations and omissions (see Appendices A & C for a comparison between the original and altered questionnaire formats).

3.8.2. Analysis of the Research Study

First I compared the biographical data of the different participants and reflected this data (see 4.2) quantitatively for possible future research use. I analyzed the first questionnaire in terms of how responses had either a positive or negative effect on family functioning. I calculated the ratio of positive to negative responses for each participant. I made a comparison between the different participants, looking at the nature of common responses and omissions of particular questions. I provide a table (see Table 4.2) to reflect the data analysis: the table displays participants' positive and negative responses, as well as omissions. I also report on the research subjects whose response to a particular question opposed ('outlyer') the responses of all the other subjects and note the content of these questions (see Appendix D on each participant's individual interview schedule under 'other'). I noted the omissions and described common concerns emerging from the second questionnaire (see 4.4). I analyzed the second questionnaire according to the number of responses made by each participant under a particular subsection representing the different styles of coping (see Appendix A: the 2nd questionnaire, WC-R). I assessed the main style(s) of coping used by each participant and then compared these to one

another. A profile of each participant's coping approach was tabulated (see Table 4.3) for easy comparison across the participants. I calculated the number of qualitative comments made on both the first and second questionnaires. I provide examples of the verbatim comments of several of the participants (see 4.5). I compared the first questionnaire of each participant to her second questionnaire before I made comparisons between the different participants' questionnaires (see 4.6).

I tape-recorded the semi-structured interviews (if agreed to by the participant concerned) in order to transcribe the interview afterwards. I summarized each interview to clarify concerns that emerged for a particular participant and to reflect the sequence in which concerns arose during the interview process in each interview summary (see 4.7). I used the transcriptions and relevant field notes for assessing anticipated themes (in terms of themes emerging from the questionnaires) and emerging concerns. I established codes (for example '1ry' was used for references to a primary care giving role) and used the codes to facilitate the analysis process (see overleaf). Miles and Huberman (1994:55) note that coding is analysis. The key on the following page provides the codes used in my initial analysis of the interviews. I compared the interviews to one another, clustering common themes together (see Table 4.4). I compared intra-individual questionnaire-interview data (4.8). Finally, I compared similarities and differences between the interviews, clarifying the common themes (Table 4.4).

3.9. Data Verification

3.9.1. Reliability and Validity of the Questionnaires

Huysamen (1983:24) explains that reliability refers to how consistently a measuring instrument measures whatever it claims to measure, irrespective of unsystematic/error sources of variation. The sources of error variation could include factors such as the particular occasion when the measuring instrument was used, or subjectivity of a particular person scoring the measurement instrument. Huysamen (1983:35) says that

Key for Coding Used in the Transcription of the Interviews

A A	Abortion
A	Acceptance of the child
Bet	Between respondent similarities
Bl	Self-blame for 'cause' of the disability
D	Denial
Dev	The child's developmental progress
Dd	Depressed or sad mood
E	Other emotions expressed
F	Family finances
Fut	The future, especially for the child
H	Hinders coping
M	Mainstream or not
Pos	Positive comments about the child
Pr	Pressurizes the child's performance
1ry	Primary responsibility for childcare
S	Support or positive impact on coping
Sh	Shock
+	Ill health, especially in infancy
R	Rejecting comment(s) about the child
Rel	Religious
Rep	Repetition of comment within an interview
Val	Values

Note: Definitions of what I mean by *denial* and by *depressed* are provided in 4.7.

reliability is a necessary, although not sufficient condition of validity. Validity of scores from a particular measuring instrument refers to the degree *to which they satisfy their intended purpose.* Validity is understood according to three different kinds: criterion-related validity (predicts some criterion), content validity (assessing achievement in a particular course) and construct validity (measurement of a theoretical variable/construct). Construct validity is most relevant to my research. Construct validity of a measuring instrument, such as my questionnaires, *may be defined as the extent to which it indeed measures the theoretical construct it purports to measure* (Huysamen 1983:43).

The degree of reliability and validity of the original and altered questionnaires formats vary. Friedrich, Greenberg and Crnic (1983:41) note that the QRS (short form) has been used extensively in South Africa and that both the reliability and validity of the questionnaire are satisfactory. The KR-20 reliability coefficient for the short form was determined to be .951. Folkman and Lazarus (1985:775) note that the WC-R has been used across a variety of situations and that the reliability and validity of the questionnaire is acceptable (see Appendix A for the subscales with associated factor loadings). The latter finding applies in the United Kingdom, rather than in the South African context. Knussen, Sloper, Cunningham and Turner (1992:775) note that the WC-R questions were not designed specifically around disability or child-related issues. The WC-R questionnaire is considered to provide a comprehensive assessment of coping within a strong theoretical framework, and has been usefully employed with different populations and a variety of stressful situations. Knussen *et al.* (1992:779) provide the following coefficients of reliability (alpha): practical coping (.90), wishful thinking (.89), stoicism (.65), seeking emotional social support (.77), and passive acceptance (.53).

Soriano (1995:4) states that reliability and validity are influenced by:
- 1) The wording of questions

Theoretically, the alteration of the questionnaires in my research study jeopardises the reliability and validity of both of the questionnaires. However, my triangulation of the

data obtained through the questionnaires with the data obtained through the semi-structured interviews compensated for the lack of traditional reliability and validity.

- 2) The type and number of research participants

Huysamen (1998:44-46) says that the use of a purposive sample restricts valid generalisations of the research findings to the experimentally accessible population. My study included a purposive sample of twelve participants.

- 3) The type of statistical analysis used

I tallied the frequency of positive to negative responses for the first questionnaire. I tallied the frequency of responses under each sub-section of the second questionnaire according to the ordinal number indicated for each question.

- 4) Subjective interpretations of results

In my analysis of the questionnaires I included the objective scores obtained from tallying the participants' responses, and the more subjective interpretations of the qualitative comments made by the participants on the questionnaires and during the semi-structured interviews.

3.9.2. Credibility in Qualitative Research

Firestone (1987:19, cited by Merriam, 1998:151) says that credible qualitative research derives from the researcher's presence, the nature of the interaction between the researcher and participants, the triangulation of the data, the interpretation of perceptions, and a rich thick description. Creswell (1994:157-159) expands on Firestone (1987, in Merriam, 1998:151) in a comparison between reliability and validity in quantitative and qualitative research. Creswell (1994:157-159) explains that qualitative research relies on verification steps rather than the traditional focus on reliability and validity. The verification steps he suggests include:

1) describing the internal validity of the study: how the data match reality (for example, ask the participants for confirmation of identified themes);

2) discussing the external validity: the limitations of generalizing findings; and

3) discussing the reliability in terms of the limitations of replicating the study.

In my study I planned to seek confirmation from the themes elicited from the questionnaires by using questions incorporating the themes, especially if the themes were raised spontaneously by the participants during the interviews. I discuss the limitations of generalizing the findings and the limitations of replicating my study in 'Constraints and Criticisms' (6.3).

Rubin and Rubin (1995:85-92) refer to the 'credibility' of a qualitative study. Credibility comprises the notions of a) transparency, b) consistency and c) coherence of themes, and d) communicability:

a) Rubin and Rubin (1995:85) say that transparency means that a reader of a qualitative research report is able to see the basic processes of data collection. In my study I provided transparency of the research process by indicating each step of the process and by providing the data obtained at each stage of the research.

b) Consistency refers to the repetition of themes across participants and to the practice of checking why any inconsistencies within and between participants exist. In presenting my data I highlighted themes emerging from the questionnaires and later from the interviews, and I use tables for easy comparison of repetition of themes across participants.

c) Coherence of themes means that contradictory themes that emerge can be accounted for and explained. In my study I analyzed contradictory data in the context of all the data emerging from the participant(s) concerned.

d) Communicability refers to the use of 'thick descriptions' (i.e. clear and detailed explanations) of the research process, so that others would be able to replicate the steps of the study if desired. In my study I provide a summary of a transcribed interview and summaries of each of the interviews, highlighting emerging themes.

3.9.3. Triangulation

My study combines the use of quantitative and qualitative research approaches. Denzin's term (1978, cited by Creswell, 1994:174) *triangulation* refers to the combination of

methodologies in researching the same phenomenon. Creswell (1994:174) refers to Jick (1979), who says that the use of triangulation is assumed to neutralise any bias in different aspects of the research, including the data sources, investigator and methods. Greene, Caracelli and Graham (1989, in Creswell, 1994:174) add that other reasons for combining quantitative and qualitative research include:

- Different facets of a phenomenon may emerge (complementary data)
- The first method is used to inform the second method. In my study, my analysis of the questionnaires revealed themes that I further investigated in the semi-structured interviews.
- Contradictions and new perspectives may emerge from the different data sources.
- The different methods provide breadth to the study.

Morse (1991, in Creswell, 1994:182) distinguishes between simultaneous and sequential triangulation. In my study I used sequential triangulation, that is: I conducted two phases of the study with, as Morse (1991, in Creswell, 1994:182) says: *the results of the first phase essential for planning the next phase. The questions of phase one are completed before the questions of phase two are raised.* In the first phase of my research the participants completed two questionnaires. In the second phase of the research I conducted semi-structured interviews with the participants.

3.10. Ethical Considerations

Huysamen (1998:180) and Babbie and Mouton (2001:521) discuss the need for participation to be voluntary: participants should feel free not to participate in the research at any point during the research process. In my research I made the participants aware of the voluntary nature of their participation in the first line of the first questionnaire. I asked the participants to indicate on the questionnaires their willingness to participate in the second stage of the research, namely in the semi-structured interviews. Huysamen (1998:180) indicates that it is preferable to gain the informed consent of the participants. Included in the notion of 'informed consent' is that participants are made aware of the purpose of the study and the qualifications of the

researcher. The questionnaires that I used in my research indicated the purpose of the study and my student status. Babbie and Mouton (2001:522) indicate that 'informed consent' may help to protect the participants from harm, particularly from subtle psychological harm. They warn that despite every effort on the researcher's part to avoid harm to the participants, it is impossible to ensure against every eventuality. Huysamen (1998:181-182) cautions that if unanticipated harm to the participants arises during the course of the research, interviews to discuss the effects of any discomfort should be arranged for the participants. In my research some psychological discomfort might have been experienced when I asked about the participants' children with an intellectual disability. In the follow-up interviews I aimed to provide the participants with the opportunity to discuss any discomfort experienced during their participation in the research. The need for respecting the privacy of participants is also important (Huysamen, 1998:183). Babbie and Mouton (2001:523-524) emphasise the difference between anonymity, where participants are not identifiable even to the researcher, and confidentiality, a concept similar to Huysamen's (1998:183) 'privacy' In my study I assured the participants of confidentiality from the outset.

3.11. Summary

Researchers appear to use research terminology in slightly different ways. I have chosen to use Mouton's (2001:56) notions of 1) 'research design' to refer to the planning phase; and 2) 'methodology' to refer to the implementation phase of my research project. My study may best be described as evaluation research, since I am evaluating the possible need for support experienced by mothers of young children with an intellectual disability. In my study I planned to make use of questionnaires and semi-structured interviews, thereby combining quantitative and qualitative methodologies. The notion of triangulation highlighted that combining qualitative and quantitative approaches provides a stronger verification of the data than would be the case using either approach alone.

The participants included a convenience sample of four mothers from the southern suburbs of Cape Town for the questionnaires' refinement study, and twelve mothers whose children attended the designated research school. The questionnaires' refinement study involved me asking the participants to edit the questionnaires proposed for the research study. I made few alterations and omissions to the original questionnaire based on the editing recommendations. The questionnaires that I used for the research comprised the QRS and the WC-R (Appendix C). I also requested biographical particulars and qualitative comments from the research study participants on the questionnaires. The principal of the designated research school presented the research study participants with the questionnaire. I based the subsequent semi-structured interviews on the data emerging from the questionnaires. I contacted the participants telephonically regarding the setting up of the interviews.

I analysed the data from the questionnaires and interviews by comparing the data both intra-individually and between participants, in order to trace common themes. My use of triangulation assured the reliability and validity of my questionnaire format. My use of transparency and 'thick description' assured the verification of the interview data. The most relevant ethical consideration in my study was avoiding psychological distress to the participants. In the interviews I aimed to provide the opportunity for participants to discuss with me any discomfort that they may have felt completing the questionnaires or during the interview itself. The ethical considerations had to be considered before the research was undertaken, although some ethical issues arose during the course of the research process. Once the above research design was implemented, interesting findings began to emerge. I present these findings in the next chapter. The findings reflect: 1) data from the questionnaires, including biographical data and qualitative comments; 2) the interview data; and 3) intra-individual comparisons between the questionnaires and interview data.

CHAPTER 4: THE STUDY

4.1. Introduction

In this chapter I present my research findings and the analysis of the data. My study comprises two phases: 1) the completion of the questionnaires by the participants; and 2) the participation of the participants in semi-structured interviews. First I present the biographical data obtained from the questionnaires. Next I present the findings from the first and then the second questionnaires. Tables for each questionnaire provide a clear overview of the findings. I indicate the number of participants who provided qualitative comments at the end of the first and second questionnaires and provide quotations from the qualitative comments on the questionnaires. I compare the data from the first questionnaire with the data from the second questionnaire. In a brief summary of each interview, I indicate the main concerns of each participant, highlighting themes that emerged spontaneously or in response to my questions. I have included researcher comments where these clarify or interpret the interview content or process. I provide an example of part of a transcribed interview, together with the coding system (also see p.57) that I used to analyze the interviews in terms of anticipated and emerging themes. I compare intra-individual questionnaire-interview data. Table 4.4 highlights the similarities and differences between the interviews.

4.2. Biographical Data

The biographical data obtained from the completed questionnaires indicated the following factors: date of birth, other children living at home, marital status, religion, work status and home language(s). The participants' dates of birth ranged from 1956 to 1976, with the mean being approximately 1965 or currently aged 36-37 years old. Ten of the twelve participants indicated that there are other children living at home, one participant said that her child with an intellectual disability is the only child living at home' and another participant did not indicate whether there are other children in the

family too. The interview provided an opportunity for me to clarify the latter two participants' particulars in regard to the number of other children in the family: the former-mentioned participant indicated that she has two adult children; the other indicated that she only has the one child. Eleven of the twelve participants were married, the remaining one was a single parent household. Ten of the participants belonged to one of the Christian denominations and the other two were Muslim. The work status of the participants included six mothers who worked full-time, two who worked part-time, three not currently working and one mother who is self-employed (she helps with her husband's business). Home languages were English, Afrikaans or both: four of the participants were English-speaking, five were Afrikaans-speaking and three participants indicated both English and Afrikaans as their home language.

4.3. The First Questionnaire (Appendix C)

The first questionnaire (QRS) comprised 51 questions requiring a true or false response. All twelve of the participants completed the first questionnaire. I scored the first questionnaire responses of each participant in terms of whether the responses indicated either a positive or a negative impact on the family. Eleven of the twelve participants obtained higher positive to negative scores. Nine of the twelve participants made qualitative comments. Table 4.2 indicates the number of positive and negative scores for each participant's responses to the first questionnaire, as well as the questions that the participants omitted. I refer to any responses that differed from the consensus of responses to a particular question to as 'outlyers.' I indicate the 'outlyers' on the associated individual interview schedule, so that the 'difference' could be checked during the interview.

Ten of the participants omitted at least one of the questions. The respondents struggled with the true/false response options of the first questionnaire, since the options did not always adequately express how the respondents felt about the related question content. The participants omissions and related questions are presented in Table 4.1.

Table 4.1. First Questionnaire-Question Omissions

Question Number and Content	Number of Omissions
Question 12: *In the future, our family's social life will suffer because of increased responsibilities and financial stress*	4
Question 13: *It bothers me that---will always be this way.*	3
Question 31: *It is easy for me to relax.*	3
Question 37: *----cannot remember what he/she says from one moment to the next.*	4

The above omissions on the questionnaire indicated possible themes to include during the interview stage of the research process. More specifically, I formulated the following type of questions for inclusion in the interviews:

1) a question about the mothers' perceptions about the future functioning of both the family and the child with an intellectual disability;

2) a question about accepting the child with an intellectual disability; and

3) a question about who takes primary responsibility for the child with an intellectual disability.

4.4 The Second Questionnaire (Appendix C)

Eleven of the twelve participants completed the second questionnaire. The one participant who omitted to complete the second questionnaire did so erroneously and was happy to complete it at the time of the semi-structured interview. There were few omissions on the second questionnaire. The omissions for the second questionnaire appeared to have been made by chance, for example, a whole page was omitted from one of the participant's responses. There were no overlaps of omissions to questions between participants. Common concerns for many of the participants included:

1) worrying about the future care of their child with an intellectual disability;

2) other people finding it difficult to understand their child's speech;

3) the child with an intellectual disability's limited abilities;

4) not seeing the child with an intellectual disability as a 'problem' in the family; and

5) feelings of worry rather than feelings of depression.

I considered the above concerns when planning the interviews. Table 4.2 indicates the degree to which the different participants make use of a range of coping strategies (practical coping, wishful thinking, stoicism, seeking emotional social support, and passive acceptance).

4.5. Comments from the Questionnaires

Nine of the twelve participants made qualitative comments at the end of the first questionnaire. Participants tended to make reference to particular questions rather than making general comments. The reference to particular questions was particularly evident in cases where a participant found the 'true/false' response options too restricting to reflect their feelings. I confirmed the restricting format of the first questionnaire during the interviews, where I asked the participants to comment on their experience of completing the questionnaires. Seven of the twelve participants made qualitative comments at the end of the second questionnaire, although the comments tended most often to be of a general nature rather than referring to any particular question. The qualitative comments reflected feelings of sadness together with feelings of guilt about feeling sad, given that circumstances could have been worse. Several participants commented on 'acting' positively. Reference by the participants to accepting their child with an intellectual disability, and to the participants' experience of completing the questionnaires were also reflected in the qualitative comments. The following quotations reflect some of the feelings expressed by the participants:

Participant No. 1:

*....things could have been so much worse. We as parents tend to feel guilt if we allow ourselves any **sad** feeling for ourselves.*

Participant No.3:

*I cannot change him, and yet while that may make me **sad** it has never made me bitter.*

Participant No. 6:

*[I] was always reminded of those who have less and are worse off. ... by **being positive** most of the time, I get to see the funny side of everything.*

Participant No. 5:

*[I] **act positively** towards it or rather I try to. Although there are times when things get too much....*

Participant No. 8:

*Het dit in 'n groot mate **aanvaar**.*

Participant No. 3:

*I **accept**___ as he is.*

Participant No. 1:

Answering these questions as a mother can be quite tricky.

The last quotation above echoes a comment of a similar nature that one of the teaching staff at the designated research school made about how the research subjects had felt about completing the questionnaires. The above qualitative comments provided me with direction for some of the questions for the semi-structured interviews.

Table 4.2. Questionnaire 1 Responses

Participant	Positive Responses	Negative Responses	Omissions
Number 1	24	21	Nos. 7, 8, 12, 21, 29, 32, 34, 37, 38, 43, 44, 45, 47.
Number 2	40	11	Nos. 26, 37, 38.
Number 3	28	23	None.
Number 4	36	7	Nos. 1, 6, 12, 13, 22, 29, 31, 37.
Number 5	36	14	Nos. 4, 17, 26, 30, 31, 32, 33, 37, 42, 44, 49.
Number 6	32	17	Nos. 27 & 28.
Number 7	37	14	Nos. 13 & 47.
Number 8	36	14	Nos. 36, 39 & 46.
Number 9	23	27	No. 13
Number 10	31	20	None
Number 11	33	18	Nos. 12 & 19 positive/negative responses for these questions inferred from qualitative comments.
Number 12	31	18	Nos. 11, 12, 21, 23, 26, 30, 31, 41, 50 some positive/negative responses for these questions inferred from qualitative comments.

Key for Table 4.3.

Coping Styles	Question Numbers Associated With Coping Styles
A = Practical Coping	Numbers 1-17
B = Wishful Thinking	Numbers 18-35
C = Stoicism	Numbers 36-40
D = Seeking Emotional Social Support	Numbers 41-43
E = Passive Acceptance	Numbers 44-46

Table 4.3. Questionnaire 2 Responses

Participants	Coping Style	1 = not used	2 = used occasionally	3 = used often	4 = used always
Number 1	A	_	4	8	4
	B	3	8	5	2
	C	_	3	1	1
	D	_	1	2	_
	E	_	1	1	1
Number 2	A	_	1	9	7
	B	17	1	_	_
	C	2	1	_	_
	D	_	2	_	_
	E	2	_	_	_
Number 3	A	_	2	7	8
	B	7	5	5	1
	C	2	2	_	1
	D	_	_	3	_
	E	1	_	1	1
Number 4	A	_	2	7	8
	B	3	10	5	_
	C	2	1	1	_
	D	1	_	2	_
	E	_	3	_	_
Number 5	A	_	4	12	1
	B	3	13	2	1
	C	_	1	4	_
	D	_	2	1	_
	E	_	2	1	_
Number 6	A	_	4	9	3
	B	2	9	6	1
	C	_	1	2	2
	D	_	2	1	_
	E	_	_	3	_

Number 7	A	–	8	8	1
	B	2	12	4	–
	C	3	2	–	–
	D	–	1	2	–
	E	–	2	1	–
Number 8	A	1	4	10	2
	B	3	6	7	2
	C	–	2	3	–
	D	–	–	3	–
	E	–	1	2	–
Number 9	A	2	4	5	6
	B	8	4	2	3
	C	1	–	–	4
	D	–	2	–	1
	E	2	–	–	1
Number 10	A	3	3	6	5
	B	11	4	3	–
	C	–	2	1	1
	D	–	3	–	–
	E	1	–	1	1
Number 11	A	1	7	8	1
	B	11	6	1	–
	C	1	1	3	–
	D			2	1
	E			2	1
Number 12	A	1	4	5	7
	B	8	2	3	5
	C	2	1	–	2
	D			1	2
	E		2	–	1

4.6. First and Second Questionnaire Comparisons

Many omissions were apparent on the first questionnaire for many of the participants in contrast to the second questionnaire, where there were hardly any omission by the participants. The qualitative comments made at the end of the first questionnaire tended to be question-specific, rather than general comments. As noted (4.3), the participants omitted questions on the first questionnaire because they found the true/false format problematic. Only one participant felt that her personal development was being

compromised by the care-giving demands of her child (as indicated on the first questionnaire). The above participant was the participant who reflected a combined style of coping (as indicated on the second questionnaire)-high on stoicism and low on the use of seeking emotional social support. This participant was also the only one to have a higher negative than positive scoring on the first questionnaire.

My analysis of the questionnaire data, including comparisons between the two questionnaires for each participant, allowed me to form a 'picture' of each participant. My comparative analysis of the responses across the different participants suggested themes from which I could derive interview questions.

4.7. Semi-Structured Interviews

Note: I present the interview schedules in Appendix D. The interviews took place at the homes of the participants, unless otherwise stated. The interviews were devised from each participant's completed QRS and WC-R questionnaires. The participants are numbered according to the sequence in which I undertook the interviews. The interview numbers here correspond to the questionnaire data presented in Tables 4.2 and 4.3. The participants are referred to as 'the mother in each interview description. I referred to the participants in the above manner in order to ensure the participants' anonymity. First I present a description of each interview, highlighting tentative themes that emerged during the interviews. After the interview descriptions I present an example of one of the transcribed interviews (see p. 57 for interview transcription codes).

Participant No. 1 (English/Afrikaans)   27 February 2002   9h35-10h45

The mother initially commented that her child with the intellectual disability is a very sensitive child, who had been tearful that morning and that consequently the parents were also *feeling "emotional." The mother mentioned that she read about intellectual

disability and would like to be able to help other parents with children with an intellectual disability. Next, the mother talked about the **possible causes** of her daughter's intellectual disability: "I cannot tell what it is"; "I cannot blame the (nursing) sisters" (who turned her on her side during labour). The participant also said that: the baby was in intensive care at three months of age with a virus; "the doctor said it came from the birth side already, when she was still in my tummy", "something she picked up from this little child lying next to her." The mother described her daughter's **developmental progress**: "she's getting better and better." The mother is not clear about what label applies to her child: "verstandelik agter of verstandelik gestrem" The mother described herself and her husband as taking **primary responsibility** for their daughter, as the extended family live at a distance. The mother said: "I know it's wrong, but I feel that I can care for her [the daughter] better than anyone else," and "he's a father in a million." She described her 9-year-old son as being: "such a help, it's almost as if he gets things more right than what I do." The mother reverted to discussing her child's development and therapies: occupational therapy is to help with the "whole caboodle," and about her daughter's sensitive nature. The mother noted that: "Our whole life is for her [the daughter] and our son." The mother said about the **future** for her daughter: "I'll always be here for her…we're trying to make a little [financial] nest for both of them", "I pray hard enough…I believe that she [the daughter] will be able to handle herself." The mother again reverted to discussing her daughter's development: "she's always probably going to be that bit behind." The mother described her **religious beliefs and values** as being practically implemented by trying to help others. The mother reverted to discussing her daughter's development again saying: "I'm always grateful, because when I look at other parents…their children are much worse…How do they cope?" and "I'm very blessed," and "I've changed…. it [the experience of having a child with an intellectual disability] opened my eyes." The mother commented that she **accepts** the child's diagnosis although other family members say: "daar's niks fout met haar." The mother said: "the only thing that gives her [the daughter] away is her speech, and school work and motories [motor skills]." The mother again noted her daughter's good progress.

*Note: By *feelings* I refer to affective experiences and states of the participants.

Participant No. 2 (English)   **2 March 2002**   **11h15-11h45**

The mother described her child's **diagnosis** as traumatic. She referred to: "lots of sacrifices" due to the demands of a baby with an intellectual disability. The mother referred to her child repeatedly as just being "more special", but also made many other references such as " not normal", "knew there was something wrong", "there's a problem". The mother noted that she [mom] tends to be anxious and more so since the birth of this child. The mother said: "I try to take one day at a time." "I try not to worry" [about the **future**]. The mother made comments such as: "hope forward" and "fear what next" [life trauma, as she had lost a pregnancy and her mother in the year preceding the birth of her child with an intellectual disability]. The mother **compared (then denied) the birth to a death, including shock, *denial and *depression**: "it got to me...too much". The mother was **not in favour of mainstream**: "teachers won't cope". The mother *referred throughout the interview* to the **child's development**, including a reflection on the positive feedback from the child's school. The mother said, when asked about coping with a child with an intellectual disability: "work doesn't help a lot." She said that she **would like to provide more input for her child**: "could put in more to help her". The mother mentioned **other people** who had helped her to cope with having a child with an intellectual disability: her husband, aromatherapy oils, three sisters, day-mother at the creche, and the surgeon at the birth of the child. A family member had said that the child was: "still your baby," which she felt had helped her to **accept** the child. Aversive to coping was the doctor's attitude about the mother not having tested for genetic problems during the pregnancy, the "odd aunt with a 'shame' attitude", seeing mothers with healthy babies in the hospital: ("all the mothers with healthy babies and here was I...") were perceived **as hindering coping**. The mother said that she is not

Note: I use *denial* as in the ego-defence mechanisms of the psychodynamic approach. Carson and Butcher (1992: 68) define denial as *protecting the self from an unpleasant reality by the refusal to perceive or face it*. Depression may be symptomatic of an adjustment disorder (Carson & Butcher, 1992: 383), but the description of grieving (Carson & Butcher, 1992:153-154) better captures my understanding of the participants' *depression*. Their description includes shock, disbelief, intensely sad affect and after 1+ month(s) less intense feelings although still sad, yearning, with occasional acute grief.

bothered by the general public's stares. The mother referred to her daughters speech ["um" repetitions like the mother] and inability to express her [the child's] feelings.

Participant No. 3 (English)   4 March 2002   9h30-10h45

A very long interview, difficult to terminate. Initially, the mother told me both her and her husband's qualifications (the emphasis on their professional qualifications seemed to me to contrast with a later reference to their having altered their **values** of emphasizing "success"). The mother noted that her son had been "unexpected and unplanned", but had been "easy" and "undemanding" as a baby, which made it easier to **accept** him ("could take him to the most expensive restaurant"). The mother referred to the **negative impact** of her child with an intellectual disability on others, rather than on herself at several points during the interview: "it's important that she [the younger sister] doesn't feel that her life is a disaster because of him." The above references contrasted with comments made immediately prior or afterwards that were of opposite attitude, for example: "enriched our lives" [**values reassessed**]. When confronted directly, the mother said that **the diagnosis** had been "heartbreaking", "something very wrong", "I pictured a monster", **"too late to consider an abortion",** the baby was given "no assistance" at birth, but "had to make it on his own". She said that as a baby her son was "sweet, tiny, just lovely, but still hard to bond with him, because he might not make it" and that she was "terrified of it" [the baby]. The mother commented that much of her anxiety related more to being a first-time mother than to her child's disability. Later on in the interview the mother referred to how her son had looked as a baby, but added "he looked very normal" and referred to how other people find it hard to accept the older child with an intellectual disability, "because they are less cute." The mother twice alluded to her **hope of a change** "miraculously". In summary, she seemed **ambivalent about accepting** her son. She noted a strong marriage, the need for patience, and the benefit of **financial** ease (the latter to which she attributes the high number of single parent homes where there is a child with an intellectual disability). The mother mentioned **other people's support.** The mother talked about friends who prayed for the family. The mother commented on the

positive attitude of her boss at the time the baby was born and also on the attitude of work colleagues. The mother noted the support of her parents and the support from other parents at the designated research school. The designated research school staff's input, the kindness of the nurses at the hospital where the child was born, and people who had asked her about her child and who had provided the space for her to talk about her son's disability were also praised. Her husband was described as never talking about the situation. On the **negative** side, she mentioned the doctors' lack of people skills and who were too circuitous and had poor referral knowledge, some friends who lacked respect for the child and formal religious structures, the older generation's attitude that the child should be institutionalized/her grandmother ignores the child's existence. Also commented on was her lack of prior experience with people with an intellectual disability and concomitant discomfort with them. The mother referred to **the diagnosis** as being **"a shock"**, but **"I never felt punished"**. The mother does not look forward to the child leaving the current school because of the support it provides her and because her **son "doesn't fit anywhere"** [Alta du Toit School too far for her to have to drive to every day]. The mother tended to precede difficult parts of the interview with a laugh. She seemed quite 'hyped up' by the end of the interview and gave me a novel about a mother's experience of her child with an intellectual disability.

Participant No. 4 (English)   4 March 2002   18h30-19h00
+ 15 minutes to complete the 2nd questionnaire

The mother was curious about the long time between the questionnaire completion and the request for an interview. The father sat in on the interview and kept the children in order, despite me indicating that I only needed to talk to the mother. The mother **contradicted** her otherwise positive remarks (at one point in the interview when the husband left the room briefly). She said: "in the beginning everything was not like roses" and she referred to her hurt at her-in-laws' sad faces on first seeing their grandchild and "the cruel comments" other children sometimes make about her daughter.

She noted that **other people** never make her feel bad about her child. She said: "anyway, I don't care," but later commented that the nurses' whisperings at her door after the birth of her child had: "bothered me." The mother described her uncertainty about the **diagnosis** before her child's birth: "scared", scared of the world's reaction, "didn't know what to expect", only knowing that "something was wrong." She also mentioned that she'd been told that she was special: "chosen [by **God**] for this baby." The mother indicated that she was **anti abortion** and had refrained from undergoing tests during her second pregnancy [she said that one must not question God/"given by God"]. The mother seemed to be **very accepting of and positive** about her daughter: she made references to her appreciating and enjoying her daughter from birth: "we love her for what she is." **Financially,** both parents work and a nanny cares for the children in the afternoons. The family will soon be moving from their flat to a house. The mother noted that, apart from initially, the daughter had suffered few **health** problems other than having low immunity, though she mentioned one incidence of surgery. The mother referred to her "**hope** for the best" for her daughter's **future.** The discussion focused on the child's future schooling [**anti mainstream,** because other children might be cruel to her daughter and affect her self-esteem negatively] and a wish for her daughter to do as she chooses/be independent as an adult: "do something she wants to do." Unlike the father, she **hopes** the daughter will have a boyfriend and get married. The mother said that she expects her son to take care of the daughter in **the future**: "must be there for his sister". References were made to the daughter's **development, especially difficulty with expressive language.** The mother also commented on how much more she appreciated her child's development as, unlike a "normal" child's development, it cannot be taken for granted. The mother mentioned the need to have patience with a child with an intellectual disability. In terms of **support**, the mother mentioned several **other people.** The family has a nanny to look after the children in the afternoons. The mother socializes with friends in the area with parents who also have a child with an intellectual disability, especially a woman with a slightly older child than her daughter ("she'll understand"). The personal interest of the doctors at Tygerberg Hospital ("make me feel special"), her parents, the present-day attitude towards and options for those with an intellectual disability compared to previous eras, familiar shop assistants greeting her daughter by name and others who provide

positive input. In terms of **hindering coping**: the unclear communications from medical staff regarding the nature of the problem with the baby, the gossiping nurses, the sad expression on the faces of her in-laws at the first meeting with their grandchild, cruel comments by other children. The mother was vague ("everyone's different") when asked about support from the other mothers at her child's school and changed the subject. The mother made several references about herself as being an honest and open person. The mother sometimes laughed in response to a question ("time for self?"), or when talking about the future for her daughter; for example, she said that she expects her son to care for his sister: "may be not fair" (laugh).

Participant No. 5 (English)   6 March 2002   10h00-11h00

The hour-long interview covered several aspects: the child's poor **health** and hospitalisations as a baby, the mother's **shock, denial, depression** ("I was crying every single minute"), **anger** ("so unfair"), **rejection and neglect of the baby** ("she could cry herself to death"), **initial rejection of others' attempts to be supportive**. The mother said that when the baby was two months old "things started to turn around". Her attitude towards her child with an intellectual disability swung from anger and rejection to more accepting comments towards the latter part of the interview, where she noted that her child's recent **developmental progress** was "encouraging" her. She noted that a television programme about Down syndrome had motivated her to look up the designated research school in the telephone directory and to contact them for **support.** Other supports include the fact that she has never had a negative reaction or been blamed for her child by anyone: "I can't point a finger…no-one put me down." She is assisted occasionally by another woman, who will take the child for a weekend. The two grown up siblings sometimes help with the child, although they are not living at home. Her husband helps in emergencies, but generally the child is her **primary responsibility and she does not have enough time for herself** (she has the mornings when the child is at school and has now put her in a weekly hostel)**.** Despite the school's encouragement and education, she still finds it hard not to **self-blame** (implied) as having done something to

"cause" the child's disability: "they said it's not something you did, but I still find it very hard to **accept**." She mentioned the **importance of parental input into the child's development**: she repeatedly indicated that she does not want the child to embarrass her, so "pushes" her development. She feels "confused" about the appropriateness of **mainstreaming** her child and concerned that *the **other children's lower functioning** might hold back her daughter's development. **Finances** were only mentioned when saying that after-care was available, but cost money. For the **future** the mother would like her child [described as "a high functioning" Down syndrome child] to be at least socially independent.

Participant No. 6 (English)　　　8 March 2002　　　18h15-18h50

The mother described their family life as having been chaotic. She said about **support** received, the designated research school "turned their life around", especially the advice that she obtains from a particular teacher at the school. The mother's own mother provides a lot of support in terms of childcare, as does a women with her own "problem" children. Previously, her one sister was also able to help. She mentioned the initial referral by the child's creche, the advice of the paediatrician and the smaller class size at the private school that her son with an intellectual disability now attends ("working a dream for him"), as positives. She seems to be proactive: "I knew I had to get help". The mother also finds going to work beneficial, because then she is not the one with **primary responsibility**, as she is at home: "I enjoy work so much, because it's so different; at home I must be responsible." **Negative responses/lack of support** came from her father (disliked the son's aggressiveness), her younger sister, who is afraid of the child, strangers who commented negatively on her discipline/child's behaviour. The mother's husband, a paranoid schizophrenic, is also "not supporting" in any way. The current teacher's attitude about her son's limited academic potential is also a negative.

*Note: the above provides an example of what I refer to later (5.2.1) as comparative thinking, i.e. comparing one's child to other children in terms of overall functioning, although especially intellectual functioning tended to be implied.

The mother implied that it was easier to **accept** her child with an intellectual disability as he is adopted. She implied that the professionals had not been 100% honest about the fact that the baby had a problem ("they tell you there's nothing amiss"), and she also noted that the problem might be genetic, as the family of origin do not have a high education level. She found the abusive behaviour of her child with an intellectual disability "frightening", but said: "we've come a very long way". When the child was a baby she was anxious: "didn't know what was wrong", "didn't know what to do". The mother is in favour of **mainstream, but at a private school** where the teacher-pupil ratio is better than at government schools. The mother is not keen on a special school, as she thinks that her child is **"not so bad"** and might pick up the other children's strange mannerisms if he were to be around them. The mother mentioned her son's **developmental milestones and more recent progress**. Her son's diagnosis is 'global developmental delay', between 6 months and 2 years behind the norm. **Financially,** the family budget seems to be strained: she referred to her husband as being "already a financial burden" (i.e. before the cost involved in having a child with an intellectual disability is taken into consideration). The mother said that she has "no idea" about the **future** for her son with an intellectual disability, then said that he enjoyed cooking and may become a chef. She anticipates that he will be independent.

Participant No. 7 (Afrikaans)   13 March 2002   18h10-18h30

The mother described their **family life as normal** and as treating her daughter with an intellectual disability as normal. The **late diagnosis** was first made at four years of age (global developmental delay): mom experienced the diagnosis as **a relief**. She referred to how well her daughter's **development** is progressing, now that she is receiving **professional** input at the designated research school, though the child **cannot talk** yet. **Helpful to coping** includes the designated research school and professionals: "die skool doen beter as wat ons kan doen…die onderwsers is opgelei om hierdie kinders te hanteer," the family's unaltered attitude to the child once the diagnosis was made and help with childcare when visiting on holiday, her husband's input "my man en ek is 'n

span…ons werk saam," and the child's own trusting and affectionate nature. The other moms with children at the designated research school also "help baie…deel van 'n familie want al die kinders daar het probleme". **No negative factors hindering coping** were mentioned. **Acceptance** of the child seemed to be good: "sy's deel van die familie", "daar's seker 'n doel vir alles in die lewe". The mother's **values** where implied by the latter comment. **The future** is something that the mother "wil nie daaroor dink nie... benoudige voel in mag". About **completing the questionnaire**, the mother said it was "insiggewend…sit en laat dink", although also led to a "benoudige gevoel". The mother compared her daughter's **development** to the questionnaires' question content and was grateful that her daughter's disability was not so severe: "soveel dankbaar te wees" and "sy vorder nou so goed." **Primary responsibility** falls jointly on the mother and her husband. They are not very social, so spend much time with the children. The mother is excited about the possibility of her daughter getting in to a particular special school next year (**rather than mainstream**).

Participant No. 8 (Afrikaans)   **14 March 2002**   **14h00-14h30**

Initially, there was confusion about the time of the interview, so that it was rescheduled for a second date and at the mother's place of work rather than at her home. The mother spoke very rapidly throughout the interview. In response to the initial question about her **family's current functioning**, she first mentioned her divorce, when the child with the intellectual disability was three years old. The mother contrasted her own **acceptance** of the child to her ex-husband's rejection of the child (examples of the latter proliferated throughout the interview) which was provided as the reason for the divorce (he'd warned he would divorce her if they ever had a "problem" child). The mother's concern for the **future** of her daughter with an intellectual disability revolves around the absence of appropriate care available should she die: "bekommer baie." Longer term, she believes her son will take care of his sister, whom she sees as "sy sal altyd afhanklik wees". The mother tended to describe her painful **emotions** indirectly as "difficult" times: "difficult weekend", "difficult birth" including when asked directly: "hoe het u daaroor gevoel?,

she responded: "ek het besluit…". Later on in the interview, the mother reflected feelings of worry. The mother noted being very emotional on different occasions when her attention had been directed to her child's intellectual disability/difference, including **completing the questionnaire** for this study;" vestig aandag op die feit dat…voel al weer hartseer", and about her child's **development**: "tjank jou dood." **The initial diagnosis** was made only a month prior to the birth, owing to her insistence on tests being done because of her gut instinct that "daar was 'n probleem". She found the medical professionals at the time of the child's birth "baie oulik", especially the nursing sister. Her mother is the only person who is willing to **help** with childcare. The staff at the designated research school "het baie moeite gedoen", she also described the school as "'n gesin", noting that the other parents provided emotional support. Her other two children are protective of their sibling with an intellectual disability in social situations. **Aversive to coping** included: her ex-husband, her father's emotionality about the diagnosis, the fact that her siblings live too far away to provide assistance, colleagues suddenly ignoring her pregnancy once the diagnosis was known, children avoiding or teasing her child, a relative refusing the child's touch, some doctors who still refer to the daughter as "'n mongoloid" The mother seems fatalistic about the little **time she has for herself**: "dis deel van my lot". The mother said that **mainstream** is not an option, "want sy (die kind) kan nie praat nie." After asking me about my research, the mother spoke about her **values and feelings**: increased empathy towards disability, uncertainty about **abortion** choice, heart-sore, bittersweet experiences with her child with an intellectual disability; her comment that she was "nooit skaam vir haar" was repeated in the interview.

Participant No. 9 (Afrikaans)   **19 March 2002**   **12h30- 12h50**

A brief interview done in my car during the mother's lunch break at work. She lives on a farm. In terms of **support**, the mother mentioned the crucial role of her parents. Her husband and siblings also assist with childcare. The designated research school appears to be relied on for professional advice and education ("baie vordering"); the after-care is

useful for childcare within the context of 'normal' children. Reference was made to the positive comments of a doctor who said that the daughter's facial features were "baie mooi." She seldom sees the other parents of the children who attend the designated research school because she is at work all day: "sien weinig die ander ouers." She has few friends, although the ones she has are supportive "hulle verstaan"; other people in the community are sparse, as she lives on a farm, and she says of the farm workers' attitudes towards her child: "ek worry nie oor hulle". **Primary responsibility** for the child seems to be shared between the co-habituating members of the extended family: "[die kind se] pa help baie", "die kind wou liewers by ouma en oupa bly", although she noted that the child needed "baie aandag", "baie bedrywig", "baie stuur". Reference to the **poor health** of the child was made, especially as an infant. Reference to the child's **development** was made and she commented on the child's poor **speech** ability. She also noted that her child's abilities seemed better than those of the other children with intellectual disabilities: **"sy's nie so erg"**. The **initial diagnosis** of Down syndrome was made when the child was one month of age. The mother said that she reacted with **shock** (references to her ignorance about Down syndrome were made), **possibly depression** ("bietjie afgevoel"), but had "gou aanvaar" **(accepted)** the situation. She referred to children with an intellectual disability as "spesiale kinders". In contrast, the mother noted with reference to the **future** that the diagnosis "pla vir almal as jou kind 'siek' is." She says that she ought to have considered the future, but that she has not done so. She commented that: **"ek maak haar groot soos 'n normale kind. Ek sien nie die 'disability'."** The mother said that she had been willing to share her feelings on the **questionnaire**, that she had not found it hurtful, although time consuming because of the interruptions from the child: "baie stuur".

Participant No. 10 (Afrikaans)   **20 March 2002**   **11h00-11h40**

The mother first clarified that her son was **not** a Down syndrome child. Later in the interview, she referred to her son with an intellectual disability as: "leer gestremde". She seemed to be ambivalent about **accepting** the reality of her child's disability, both at a

conscious and at a more unconscious level: "jy moet leer om daarmee saam te leef", "gaan nie normaal raak nie", "aanvaar… maar hoop nog steeds". The mother said that it took 2-3 years to accept that their child would never be normal (after much testing and visiting doctors). The mother's ambivalence was also reflected when discussing the possibility of **mainstream schooling** for her child, where she shook her head and murmured in the negative, but then said: "seker eendag…hopelik". The mother said that she thinks her child would be happier at a special school (in contrast to earlier references to having sent the child to 'normal' play schools, including comments about the child being unhappy and not coping). The mother noted that the **initial diagnosis ("op ses maande")** had made her feel: "magteloos' hulpeloos". Other initial feelings included **denial, depression, *guilt** [had not wanted another child], and a feeling of "hoekom jy?" The mother seems to take **primary responsibility for the child's care:** the mother commented that caring for the child was "moeilik" and "vat baie uit 'n mens uit", although she noted that her husband spent much time playing with the child. Other **support** is forthcoming from her friends, the designated research school ("'n wonderlike skool"), her parents' (although she added: "sy ouma kry swaar: wil nie glo…".). The mother cited **humour** as an important aspect of family functioning: "..spot in 'n goeie lym". **Negative** factors hindering coping included: the teachers at a 'normal' school's initial unwillingness to accept her child ("maar hulle's dierbare mense"). The mother also noted the lack of communication from her husband about his feelings on the subject of their child with an intellectual disability, and the attitude of some people in the community towards her child with a disability. After the interview, negative insinuations about psychologists were also made and she advised me to "go with the flow" in terms of bringing up my own child. She noted that she was interested in and might study psychology too. The mother acknowledged that she had found completing the **questionnaire** "moeilik", confrontational [usually gets on with daily life without thinking about things] and painful. The mother said that the experience of having a child with an

*Note: This is an example of what I refer to as *guilty feelings* in 5.2.1. I mean that the participant believed that, although not logically explainable, she was somehow responsible for having 'caused' her child's intellectual disability.

intellectual disability had resulted in a **re-evaluation of values**: "ek het baie verander", "hy hou jou voete op die grond". She believed that **spiritually** the child had been God-given: "glo vir my gegee". With regards to the **future**, the mother was not sure what her child would be able to do in terms of employment; she believes that he will always be dependent upon her, although ambivalence about the latter was noted: "miskien moet ek na hom kyk".

Participant No. 11

Participant number 11 may not have appreciated her husband's arranging an appointment date for me to interview her, as he later indicated that she was ill. When I contacted the family again, I was put off with a vague reference that the mother would contact me some time in the future, which she never did.

Participant No. 12

Participant number 12 could not be found at the telephone number she had provided on her completed questionnaire.

Sample of a Transcribed Interview with Coding:

6 March 2002

Participant Number 5

Tape Position	Participant's Comments	Coding
010	I had to dedicate most of my time to her	1ry
027	In and out of hospitals most of her young life	+
030,068	(How did you feel at the time of her birth?) Very angry	E & Rep
050-051	Everything caved in on me, everything could end there	Dd
073	I didn't want to see it, I didn't want to hear it	D
079-080	(I) dumped her back ...she could cry herself to death	R & Rep
124	They (the designated research school) encouraged me and they gave me information	S
132	And then working with her I started gradually accepting	A
156	The Lord was so good	Rel
167	I never in my slightest mind thought it would happen to me…used to say the same things (about the disabled)	Sh & Val
224	There's one girl who will take the burden off me	1ry & S & R
243	but if I want her (aftercare) to look after-- (the child) then I've got to pay her	F & H
265-272	He (the eye specialist) said why don't you give her a chance and put her in mainstream…so now I'm confused	M & E
329	Then ------(child's name) isn't that bad	Dev & B
332	I'm always pressurizing her for her best	Pr
389	Dad has no part to play	H
488	She's so sweet. I amuse myself with the things she says	Pos & A
551	In the future I'm not expecting much out of her	Fut

4.8. Intra-Individual Questionnaire-Interview Comparisons

In the following intra-individual questionnaire-interview comparisons, the interview of each research participant is clarified and expanded upon by the relevant questionnaires or contradicted by the data from the questionnaires (see 5.4 for a possible explanation of the contradictory data). Again, the participant numbering here corresponds to numbering used previously, in 4.7.

Participant Number 1

On the first questionnaire (questions 2 & 9) the mother indicated that no-one in the family does without things because of the child with an intellectual disability; the interview revealed that in fact the family had been severely financially compromised by the health-related costs of the child.

The first questionnaire (question 28) indicated the mother's disappointment that her daughter does not lead a normal life; the interview revealed the mother's frustration at not being able to 'fix' things, and her denial of the extent of her child's disability: "you can hardly tell there is a problem". The mother's disappointment also seemed to be associated with guilt feelings: during the interview, the mother acknowledged feeling guilty about the possibility that she might somehow have been responsible for her daughter's intellectual disability, and also that she [the mother] felt guilty about having questioned her faith.

The first questionnaire (question 4) indicated the mother's anxiety about the future care of her child with an intellectual disability. The interview indicated that the parents have made financial plans for their children's future and that the mother believes that her child with an intellectual disability will be able to manage an independent lifestyle. The pragmatic plans for the children's future indicated in the interview correlate with the

mother's second questionnaire profile, which indicated that this mother copes mainly using a practical coping style.

As noted in the previous paragraph, the second questionnaire reflected mainly practical coping. The interview created the impression of a mother who wants to be self-reliant: the mother said that she felt that she was the best person for assisting progress of her child with an intellectual disability, and indicated that she has rejected offers of financial assistance from extended family members.

Participant Number 2

The first questionnaire (question 31) indicated that the mother found it easy to relax; during the interview the mother said: "I worry a lot." The first interview (question 32) indicated that the mother does not "worry about what will be done with the child when she gets older," although the mother worries about "what will happen to the child when she [the mother] is no longer able to care for her" (question 42). The interview clarified the contradictory questionnaire data: the mother indicated during the interview that she is anxious about the care of her daughter in the future, but tries to avoid thinking about it. She said: "I try to take one day at a time."

The second questionnaire profile indicated a predominantly practical coping style. The interview confirmed the use of some practical ways to assist with coping, such as the use of aromatherapy oils to relax. The interview also indicated the strong use of social-emotional support: the mother mentioned how her extended family had been supportive and accepting at the time of her child's birth. She also said about her husband: "I couldn't cope without him." The mother relies on professional advice: implied at the end of the second questionnaire by: "I believe that a lot can be done to help [the child]" and]confirmed during the interview by comments such as: "I'll see what __ [the designated research school staff] say."

The qualitative comments at the end of the first questionnaire indicated that communication is problematic with the child. The interview confirmed that the child's speech difficulties are currently the focus of the mother's concern.

Participant Number 3

The first questionnaire (question 2) indicated that "other members of the family do not have to do without things because of the child with an intellectual disability." The interview confirmed and contradicted the above: financial implications associated with having a child with an intellectual disability were described as: "not an issue", but: "give up things in a way, such as camping." The qualitative comment, at the end of the first questionnaire, indicated that the situation was eased because the family: "have no financial problems."

Some concern about the child's future was indicated on the first questionnaire (questions 4 & 32). The interview indicated that the mother was more concerned about the immediate future, regarding appropriate and convenient schooling for her child, rather than the distant future, when she believes the au pair would care for the child.

The first questionnaire indicated mixed emotions in relation to accepting the child with an intellectual disability: "bothered" (question 13), "disappointed" (question 28) and "sad" (question 41). The qualitative comment at the end of the first questionnaire similarly appears to indicate mixed feelings: "I [the mother] have more than adequate assistance in caring for my son, which of course makes it easier to *unconditionally* [my emphasis] accept him." The interview clarified that the mother had found it very hard to bond with her child and repeated the words: "hard to bond" three times. At the end of the second questionnaire the mother wrote: "he (the child with the intellectual disability) is a very much wanted and special part of his family's life." During the interview the mother noted that they planned to exclude her child with the intellectual disability from certain family outings, holidays and events, but then added that the child "fits in" the family.

The second questionnaire indicated a very practical coping style. The interview confirmed a pragmatic approach to coping, the mother describing herself and her husband as: "we're fixers." The qualitative comments at the end of the second questionnaire made reference to the mother's spirituality. The interview confirmed: "a strong faith, but disappointed in formal church."

Participant Number 4

The first questionnaire responses were negative only in reference to the child or to other people, but never with regard to the mother's own feelings. The interview indicated a very positive maternal attitude; except when the husband left the room the mother said: "everything was not like roses" and mentioned her hurt feelings about other people's attitude towards her child with an intellectual disability.

The first questionnaire (question 27) indicated that the mother felt that her child had "too much time on her hands", which was different from the responses of the other study participants' responses to the question. The interview clarified that the mother felt that the child was a bit bored before she had her sibling for company.

The second questionnaire indicated a practical coping style, although the pattern of responding also indicated that the mother acknowledges wishful thinking and passive acceptance. The interview indicated that the mother's view of her daughter's future is optimistic: the mother described her daughter as being able to choose a job she likes and of getting married. The mother added that the child's father does not agree with her perspective on the child's future. The mother noted that completing the questionnaires had been a "comfortable" process for her in contrast to "others are scared to face the world." At the end of the interview the mother noted that the gossiping of the nurses at the time of the child's birth had bothered her: "it made me scared about how the rest of the world would be."

Participant Number 5

The first questionnaire contained many omissions: the mother preferred to make qualitative comments at the end of the questionnaire in response, particularly to questions where she would have had to indicate a negative without further discussion. In many of the questions where the mother indicated a positive response, the interview clearly contradicted the questionnaire data. In the first questionnaire (questions 13 & 28) the mother answered 'false' for the following questions: "It bothers me that (the child) will always be this way" and "I am disappointed that [the child] does not lead a normal life." In contrast, the mother stated during the interview: "(the child) is going to catch up. I'll lift her up to my level." In the first questionnaire (questions 14 & 21) the mother indicated that she does not feel tense or embarrassed when with her child in public. The interview expanded on the mother's feelings: the mother indicated that she feared her child might embarrass her in public: "nobody never sees her, so that's fine" to: "no-one put me down, not even in the street or in the shops." The first questionnaire (question 35) indicated that there is not a lot of anger and resentment in the family. The interview expanded on the questionnaire. The mother said three times about her feelings at the time of the child's birth: " I was very angry/mad," but later on in the interview she said: "I still find it very hard to accept, but I've come to accept the way it is." In the first questionnaire (question 39) the mother indicated that the constant demands for care for the child do not impinge on her. During the interview, the mother said: "they [the family] see the pressure on me" and: "there's one girl who will take the burden off me."

The second questionnaire profile indicated much use of a practical coping style together with a stoical coping style. The qualitative comment at the end of the second questionnaire: "act positively toward it or rather I try to" confirms the impression of a stoical coping approach. The interview clarified the impression created by the questionnaire data. The mother said of the early days with her child: "I locked myself in at home…I didn't want to see anybody" and she repeatedly said about the positive comments made about her child by others: "I couldn't handle that."

Participant Number 6

The first questionnaire (question 2) indicated that "other members of the family have to do without things because of [the child with the intellectual disability]. The interview expanded on the above response; the mother indicated that she is the sole breadwinner for the family and described her husband as being: "already a financial burden." The mother also said at the interview: "we had to change our life to fit in with him [the child with the intellectual disability]." The latter remark concurs with the first questionnaire (questions 5 & 9) which indicated the personal sacrifices that the mother has made for the child.

The first questionnaire (questions 4, 32 & 42) indicate that the mother is worried about the future care of her child with an intellectual disability. The interview indicated that the mother believes her child with an intellectual disability will be able to function independently as an adult. The mother changed the topic of the conversation to the financial burden that her husband (a paranoid schizophrenic) poses for her. The mother seemed to be more focused on current concerns.

The qualitative comment at the end of the first interview indicated that the mother relied on the designated research school for support and guidance. The interview confirmed the mother's reliance on the school staff for continued advice despite the fact that her son no longer attends the school.

The second questionnaire indicated a mixed coping style; pragmatic, wishful thinking, stoicism and passive acceptance. Not much use of social supports was indicated. The interview indicated that the mother is very self-reliant, although she makes use of the advice of the staff from the designated research school and childcare assistance from her mother and a babysitter from time to time. The qualitative comment at the end of the second questionnaire seems relevant to understanding how this mother copes: "I am very lucky that I was brought up to be an optimist and was always reminded of those who have less and are worse off. This has helped me to see the light at the end of the tunnel and by being positive most of the time, I get to see the funny side of everything."

Participant Number 7

The first questionnaire (questions 4, 32 & 42) indicated that future considerations regarding the child concern the mother. The interview indicated that the mother prefers not to think about the more distant future, as it leads to: "'n benoudige gevoel in my maag." The first questionnaire indicated the mother's unwillingness to accept the permanence of the child's intellectual disability. The mother did not answer question 13: "Dit hinder my dat (die kind) altyd so sal wees", but instead wrote: "daar is nie sekerheid of sy vir <u>ALTYD</u> so gaan wees nie." During the interview, the mother indicated that she was not sure if her child would make it up to standard ("volle standard") in the future.

The first questionnaire (question 20) indicated that the mother gets upset with the way her life is going. The interview gave the impression of the mother being more accepting of the situation. The mother said: "daar's seker 'n doel vir alles in die lewe."

The second questionnaire profile indicated some practical coping, and use of social-emotional supports. The interview indicated that the family are not very social: "ons is nie baie sosiale mense", but that the parents: "werk as 'n span" and that the extended family help when visiting. The mother also relies on professional help: "die skole doen beter as wat ons kan doen: die onderwysers is opgelei…".

Participant Number 8

The first questionnaire (questions 4, 32 & 42) indicated that the mother was concerned about the future care of her child. The interview expanded on the above concern. The mother said: "ek bekommer baie." She explained that if something were to happen to her, the child's father would institutionalize the child and never visit the child.

The first questionnaire (question 35) indicated that there is not a lot of anger in the family. The interview suggested that the mother felt much resentment towards her ex-husband.

The first questionnaire (questions 33 & 39) indicated that the mother finds the demands of childcare exhausting and limiting in terms of her own development. The interview indicated that the mother has only her mother to rely on in emergencies and the rest of the time she takes primary responsibility for her children.

The second questionnaire indicates a mixed coping style profile: the mother uses a practical coping style, but is also open to seeking social supports and is passively accepting of the situation. The interview indicated that the mother has few social supports, although she makes good use of her mother's assistance and the support from the school.

The mother's passive acceptance was suggested by the comment: "dis deel van my lot", in response to being asked how she felt about the unavailability of others to help her with her children.

Participant Number 9

The first questionnaire (questions 2, 9 & 39) indicates that the mother has made sacrifices for the child. The interview indicated that the mother receives much assistance in child care from her extended family and husband: "my ouers help baie," "pa help baie."

The first questionnaire (questions 4, 32 & 42) indicated the mother's concern about the future care of her child. The interview indicated that the mother had not yet really considered the future of her child: "nog nie rerig."

The first questionnaire (question 13) indicated that the mother is bothered that the child will always be "this way." The interview clarified the above impression; the mother said: "dit pla vir almal as jou kind siek is," "ek maak haar groot soos 'n normale kind. Ek sien nie daai disability."

The second questionnaire indicated a stoical coping style. The interview indicated that the mother found the demands of her child: "baie bedrywig," "baie stuur," and "neem baie aandag." The mother said that she had very few friends and that she: "sien weinig die ander ouers" [at the designated research school], but that her extended family and the child's father assisted with child care.

No qualitative comments were made on the questionnaires; the interview was similarly sparse in spontaneous data volunteered.

Participant Number 10

The first questionnaire (questions 4, 32 & 42) indicated that the mother was concerned about the future of her child. The interview indicated that the mother: "wil nie daarooor dink nie," that her: "man praat nie... gesels nie daaroor nie," although other people have encouraged her to think about the subject of the child's future. The mother noted that she has not altogether accepted that her child will always be intellectually disabled: "aanvaar, maar hoop nog steeds." The mother's ambivalent acceptance of the child's disability was indicated in the first questionnaire; question 13 (responded to in the affirmative): "it bothers me that (the child) will always be this way." The response to question 13 contrasted to question 28, where the mother indicated that she is not disappointed that the child does not lead a normal life. The interview reiterated the mother's ambivalent feelings: "'n mens dink jy aanvaar, maar aanvaar jy rerig?".

The first questionnaire (question 35) indicated that there is not a lot of anger and resentment in the family. The interview indicated that the mother might have angry

feelings. The mother said that she realized that she had to fight for her child, as nobody in the community would help prepare her child for life. The mother's tone of voice was angry. She immediately followed the above assertion with: "everybody's fine."

The first questionnaire (questions 33 & 44) indicated that the demands of the child do not put a strain on the mother. During the interview the mother said that she needs to be aware of where the child is twenty four hours a day, which: "vat baie uit 'n mens uit,' and said: "hy slaap by my: dis moeilik."

The second questionnaire indicated a fairly practical coping style, though less use of other ways of coping. The interview indicated that the primary childcare resides with the mother, although her husband helps too: "Hy (die kind) geniet dit om met sy pa te wees… (pa's) 'n rustige mens." The interview indicated that the mother was involved in a home programme to assist her child's development and had been proactive about getting her child admitted to a "normal" school when he was younger.

Participant Number 11

Participant number 11 declined participation in an interview, so that no comparison between the completed questionnaire and the proposed interview was possible.

Participant Number 12

Participant number 12 was not contactable at the telephone number provided on the completed questionnaire form, so that no comparison between the completed questionnaire and the proposed interview was possible.

4.9. Between Interview Similarities and Differences

Table 4.4 comprises two parts, including the themes that emerged as common to many of the participants during the semi-structured interviews. The themes include:

1) Primary child care responsibility and child care assistance from the father.

2) Other people who help or hinder each mother's coping with her child with an intellectual disability.

3) The developmental progress of the child with an intellectual disability.

4) The mother's perception of the future for the child with an intellectual disability.

5) The mother's feelings about her child attending a mainstream or special school.

6) The financial impact of having a child with an intellectual disability in the family.

7) The mother's need to provide more time to assist her child with an intellectual disability.

8) The mother's experience of the child's initial diagnosis of having an intellectual disability.

9) The mother's level of acceptance of the child with the intellectual disability/the disability diagnosis.

10) The impact of having a child with an intellectual disability on the mother's values and the impact of the mother's values/religious beliefs on how the mother perceives her child with an intellectual disability.

I indicate each participant's perceptions about the different themes in order for comparisons of similarities and differences.

Table 4.4. Comparison of Interview Data

Participants	Primary Childcare	Other People	Child's Progress	The Future	Schooling
No. 1	Both parents: mostly mother.	Oblique criticisms of professionals & other parents.	Positive comments made by mother, except about poor speech.	Financial provision has been made. The mother anticipates that the child will have an independent lifestyle.	Ambivalent: does not want slower children to hold back her child's progress.
No. 2	Both parents: husband very accepting and supportive.	Doctor critical that no prenatal tests (& by implication abortion). General public tends to stare at the child.	Positive comments; except about the child's speech.	Avoids thinking about the future: feels both hope & fear.	Opposed to mainstream: feels the teachers will not be able to cope.
No. 3	The au pair looks after the child after school, including some weekends. The father never talks to the mother about his feelings concerning the child.	Critical of the lack of candid & immediate information about her child from professionals & critical of the lack of appropriate referrals to other relevant professionals. Positive about the teaching staff at the child's school & the other parents.	Negative comments: felt that not enough input was provided in the earlier years of the child's development.	The au pair would look after her son, in the event that her husband & herself were unable to care for the child.	Mainstream not an option for her severely disabled child.
No. 4	Both parents are involved in the child's care, after work hours. The husband was described as being "very strong" (emotionally).	Found the doctor "vague" about the problem before the birth. The medical staff at the hospital make her feel special, though she had felt hurt by the nurses gossiping at the time of the child's birth. She finds parents in her	Very positive comments: some of the comments seemed exaggerated in comparison to the observable behaviour of the child at the time of the interview.	Sees the child as being independent, having normal social/intimate relationships & making independent choices about work options.	Anti-mainstream: fears that other children's cruel comments might affect her child's self-esteem.

		community with a child with an intellectual disability supportive.			
No. 5	The child is a weekly border at school, as mother found the demands of caring for her child excessive; father's work demands make him available to help during emergencies only.	Positive about medical professionals, teaching staff, the general public; but critical of the counsellor she saw after her child's birth & of parents who don't provide much input for their disabled child.	Reference to the child having been sickly as an infant. Reference to not tolerating a lack of progress. Pleasure indicated by the child's more recent signs of some independent behaviours.	Said that she does not expect much from her child, but appropriate social skills at the least.	Confused as to the appropriate schooling options for her high functioning Down syndrome child.
No. 6	The mother takes primary responsibility for the child, after work. Her husband, a paranoid schizophrenic, provides no assistance.	Critical of the medical profession, who said that the child was normal at the time of the adoption. Positive about the designated research school staff; less happy about the current teacher's negative attitude towards her child's potential.	Reference to her child's development as being: "not so bad" & comments about recent independent behaviours.	Believes that her child will be able to function independently as an adult & possibly work as a chef, given his current interest in cooking.	In favour of mainstream, but at a private school where the teacher pupil ratio is better than at the government schools.
No. 7	Both parents assist with the child's care & see themselves as "'n span."	Very positive about the school & about the helpful attitude of the other parents of children with an intellectual disability.	Reference to the child's delayed development, but also to her good, current developmental progress.	Avoids thinking about the future, because it makes her anxious.	In favour of a special school, rather than mainstream, because she feels that her child needs individual attention.
No. 8	Single mother takes primary responsibility: ex-husband unwilling to help even in emergencies. Her mother helps out	Found the nursing staff a positive support, but some doctors used terms such as "mongoloid", when referring to her	Referred to her child's speech difficulty.	Fearful of the immediate future should something prevent her caring for the child, but longer term believes that her son will	Believes that her child will not be a candidate for mainstream schooling, because she cannot talk.

	sometimes.	child. She had high praise for the designated research school staff. She has little opportunity of seeing the other parents at the school. She experiences some negative attitudes towards her child from her brother in law & from some of her older children's friends.		take care of his older, disabled sister.	
No. 9	The extended family members, with whom they reside, help the parents with the child's care, when the child is home from aftercare.	Noted the positive comments made about her child's features by the doctor at the time of the child's birth. The mother has little opportunity of interacting with the other parents at the child's school.	Commented that: "sy's nie so erg" & referred to much recent progress in the child's development Reference to the child's speech difficulties.	Although she felt that she ought to have done so, she had not thought about her child's future.	Not thought about whether to mainstream her child or not, as the child is still very young.
No. 10	Does not work & so takes primary responsibility for the child, though the father spends time caring for the child too.	Said that she had to fight for her child, as the community would not help him otherwise. She finds that some people have an unfortunate attitude towards her child. The mother was complimentary about the designated research school. She was disparaging about a psychologist acquaintance but positive about another of her friends.	Quick to point out that her child is "leer gestremde" & not Down syndrome. She noted that his development was only half that of a "normal" child of the same age.	Said that: "'n mens wil nie daaroor dink nie" but that he might be involved in sports in the future, as he currently enjoys ball games.	Indicated that her child would be happier at a special school, but also said that she hoped that he would be able to attend a mainstream school "one day."

Table 4.4 Continued

Participants	Financial Impact	Assisting the Child	Experience of the Diagnosis	Acceptance of the Child	Values
No. 1	Lifestyle severely affected.	Sees herself as the best one to help the child.	Maternal guilt about possibly being "the cause" of the disability.	Verbal acceptance of the child; frustrated at not being able to "fix" the child.	Shame at having questioned her [the mother's] faith. Much reference to "sin".
No. 2	Hoping to be able to stop working in the near future.	Wants to be home so as to have more time for input into the children.	Compared it to the trauma of loss through death & similar feelings of shock, denial & depression. The mother compared herself negatively to other mothers with "normal" infants.	Verbal acceptance & said that the family accepted the child 100%. Emphasis on maximum parent effort to help the child's development.	Anti-abortion for personal & religious reasons.
No. 3	Financial constraints not relevant to this family, which the mother considers to be correlated with the lack of marital strain. Therapies for the child cost R1000 per month. The au pair is another expense.	Described her husband & herself as "fixers", though she noted that her child was undemanding & could entertain himself.	Described the diagnosis as "heartbreaking", & referred to all the dreams they, as parents-to-be, had had.	Verbalized acceptance; though noted that others sometimes found the child hard to accept. The mother noted that intellectually disabled children are harder to accept as they get older & are less cute.	Values were reassessed: formal religious structures were found to be disappointing. Friendships & relationships reassessed.
No. 4	Reference was made to both parents being employed & to moving from their flat to a house.	Reference was made to encouraging the child's independence. Reference was made to: "we just enjoy her."	Uncertain of what the problem was & therefore, scared as to what to expect.	Very positive about her child from the start.	Anti-abortion: believes that one should not question God. The mother feels that she has been especially chosen to be this child's mother.
No. 5	Financial constraints curb childcare assistance & material provision.	Therapy is not enough: parental input is vital.	Very angry about the diagnosis, as she felt that she had taken care of her health during the pregnancy.	Comments ranged from very rejecting to positive (the latter towards the end of the interview).	Many references to being afraid that her child's behaviour might embarrass her. Passing reference to God was

					made in positive terms.
No. 6	Reference to her husband as already being a "financial burden" on her & as being the sole breadwinner for the family.	Reference to telephoning the designated research school staff for guidance around coping with her child's behaviour.	Realized that something was "amiss" soon after the adoption.	It was easier to accept the diagnosis because the child was adopted.	Mother noted that she enjoyed being at work, because she did not have to assume primary responsibility at work as she did at home.
No. 7	No reference was made to the financial impact of having a child with an intellectual disability during the interview.	The qualified teachers are better able to assist the children's progress than the parents.	Relieved by the diagnosis, as they had realized that something was "wrong" with their child.	Verbalized acceptance of the child, saying that she is part of the family.	Said: 'daar's seker 'n doel vir alles in die lewe."
No. 8	Commented on the helpfulness of the school in obtaining therapy for her child at reduced cost, given that she does not have a medical aid.	No mention was made of wishing to assist her child more.	Reference to a "swak naweek" after the diagnosis of her soon to be born infant with an intellectual disability.	Mother's acceptance of the child; in contrast to the father's rejection of the child.	Become more empathic about people with an intellectual disability. The mother questions why she had to have a child with an intellectual disability.
No. 9	No mention of financial considerations was made during the interview.	No mention was made of wishing to assist her child more.	It was a shock & that initially she "het 'n bietjie afgevoel", but had quickly accepted the situation.	Accepts the child: she doesn't see the disability, but treats the child as she would a "normal" child.	No reference was made to values.
No. 10	Mentioned that the therapies for the child are very expensive.	Mentioned her involvement with her child in a home programme; but no mention of wanting to provide further assistance was mentioned during the interview.	Commented about feeling: "magteloos", "hulpeloos" & had wondered "hoekom jy (ek)?" The mother had felt guilty, as the pregnancy was not wanted & she was in denial for 2-3 weeks after the birth of the child.	Expressed both acceptance of the child, but simultaneously: "hoop nog steeds" for a miracle.	Felt that the experience of having a child with an intellectual disability had changed her & given her greater insight into the question of disability.

4.10. Summary

The true/false response options of the first questionnaire were problematic for many of the participants, who felt that neither option adequately explained how they felt about the question content. Participants tended to make qualitative comments in lieu of answering some of the questions on the first questionnaire. The participants found the Likert-type scale of the second questionnaire more flexible than the first questionnaire format, and so there were no deliberate question response omissions.

The results of the second questionnaire indicated that the participants all made use of a pragmatic coping style, often in conjunction with other coping styles. The qualitative comments on the questionnaires indicated that some participants feel guilty if they take any time to address their own needs or interests. The participants' sadness about having a child with an intellectual disability, the participants' acceptance of their child with an intellectual disability and the participants' attempts to remain positive were all indicated in the qualitative comments on the questionnaires. A transcript of part of one of the interviews, together with the associated coding system, reflects the participant's emotions, values and attitudes, and what helps or hinders her coping with having a child with an intellectual disability coding system.

My summarized descriptions of each interview indicate the sequence of topics that were covered and indicate the key notions that arose in each case. The intra-individual questionnaire-interview comparisons revealed that there were contradictions in what participants said at different points of the research process. I present the comparison between the different participants' interview data in table form (Table 4.4), organized according to emerging themes in the data. The emergent themes from the data that I have described in this chapter are clustered under 'feelings' and 'coping strategies' (5.2) in the next chapter, with reference to the literature from the second chapter. The next chapter also includes between participant biographical data-questionnaires-interview comparisons; a between participants' questionnaire-interview comparison and an overview of the major themes identified (Figure 5.1).

CHAPTER 5. DISCUSSION

5.1. Introduction

In this chapter I discuss the findings of the study and relate the data to the literature. I provide interpretation of the data by discussing feelings and coping strategies common (or different) across the interviews. I compare the biographical data of the participants as well as their questionnaire-interview data. I suggest lay theory as one possible explanation of the contradictory nature of the data from the questionnaires as opposed to the interviews. Lay theory (Furnham, 1988 cited by Skinner, 2000) refers to the lay person's implicit construction of reality, which often contains contradictory beliefs held simultaneously without cognitive dissonance. I indicate the major themes identified through the process of analysis in Figure 5.1.

5.2. Comparative Analyses Between the Interviews

In an analysis of the interviews, I assessed each one in terms of different feelings and different coping strategies used by each of the participants. I compared the overlap or uniqueness of how the different participants felt about their child with an intellectual disability and how they cope with having a child with an intellectual disability below.

5.2. 1. Feelings

By *feelings* I refer (as in 4.7, footnote of Participant No. 1) to participants' affective experiences and states. *The Oxford Encyclopedic English Dictionary* (Hawkins & Allen, 1991:517) defines "feeling" as *a particular emotional reaction*. The feelings that most commonly emerged included: anger, guilt, denial, fear, or hope for the future, religious acceptance, and some fears of social rejection. Some participants mentioned having felt "relieved" when receiving their child's diagnosis. Other participants indicated feelings of shock, denial and depression at the time of the initial diagnosis of their child having an

intellectual disability, and some of the participants indicated sad or depressed feelings at the time of their interview with me. Many of the participants also indicated positive feelings of pride/enjoying their child with an intellectual disability. Six of the participants ended the interview reflecting on positive feelings about their child and described an anecdote involving their child with an intellectual disability. The impression that I gained from the progression of many of the participants to describing positive feelings about their child with an intellectual disability, was that the indicated participants were feeling more relaxed as the interview progressed. The literature about the feelings of mothers with a child with an intellectual disability (discussed in chapter 2) mostly indicated similar feelings to those found in my study.

Denial was the most commonly apparent "feeling strategy" employed by the participants, and included **anger and hope**. The literature mentions the grief that parents with a child with an intellectual disability experience (Katz-Rothman, 1994:190). Denial is one of the dimensions of grieving (Santrock, 1997:606-607). I assumed expressions of denial from the following types of comments or themes referred to in the interviews:

1) Hope for the future. Examples include: "If I don't help it, how will it come right?" "she'll do something she wants to do when she's grown up…we have dreams for her," and: "she's going to catch up," and: "aanvaar [die diagnose], maar hoop nog steeds," and: "we were waiting for him [the child with an intellectual disability] to be different." Hope for the future was explicitly indicated by seven of the ten participants. The other three participants' "hope" was indicated only by references to the child's currently good developmental progress.

2) Fear for the future was indicated by seven of the ten respondents, so that there was an overlap between expressions of hope for the future for the child with an intellectual disability at the same time as a fear and avoidance of considering the future. All except one participant had not given thought to the long-term future of their child with an intellectual disability. Six of the participants indicated that they do not want to think about the future regarding their child with an intellectual disability, since it upsets them, for example: "ek kry 'n benoudige gevoel in my maag. Ek wil nie daaroor dink nie. Two participants said about their child with an intellectual

disability's future: "I don't know." One participant said: "ek bekommer baie daaroor." Two participants said that they were sure that their child with an intellectual disability would be independent as adults, although one of the participants preceded her comment with an uneasy laugh.

3) References by nine of the ten p articipants to the n ormality of the c hild: either the child's appearance or to how the participant is bringing up the child, for example: "ek maak haar groot soos 'n normale kind; ek sien nie daai disability," and: "he looks very normal." The p articipants' emphasized that (or how) their child w as d ifferent from other children with an intellectual disability, for example one participant described her child as being: "leer gestremde" and started the interview with: "een, hy's nie 'n Down sindroom kind nie!".

1) Constant references to the child's developmental progress throughout all of the interviews, with the assertion by the participants i n n ine o f t he t en i nterviews t hat their child's development was not so bad: "sy's nie so erg" and: "she's advanced for her Downs and for her age." All of the participants who sent their children with an intellectual disability to a "normal" aftercare indicated that they did so in order that their children were not in the company of intellectually disabled children (who b y implication were more disabled than their children) the whole day. All of the participants n oted d uring t he i nterview h ow well their children with an intellectual disability were progressing at the moment.

2) Two of the participants explicitly acknowledged pressurizing the progress of their children with an intellectual disability: " I'm always pressurizing her for her best," and: "I push her a little bit."

3) Half of the participants indicated that others (usually professionals) should do/should have done more for their child with an intellectual disability or are/were incompetent, for example: "they (the doctors) were not good at referring to the right places." The five p articipants w ho felt t hat o thers could have done more for their child with an intellectual disability indicated that they, the mothers, are the best for assisting their child with an intellectual disability. For example, one participant repeated throughout the interview that: "I do best…I'm the b est for the c hild," and another participant said: "ek het besef dat ek vir my kind moet veg. Niemand anders gaan vir my kind vir

die lewe voorberei." The belief that they are best contrasts with other participants, who indicated that they believe that the professionals are the best ones to assist the development and learning of their child with an intellectual disability, for example: "Die skole doen beter as wat ons (die ouers) kan. Die onderwysers is opgelei om hierdie kinders te hanteer."

Anger was also indicated by comments such as: "you won't get the truth out of them [the doctors], they all stick together." The latter comment was highlighted in the interview by its contrast to all the other positive references about the thoroughness of the doctors. One participant explicitly stated three times that: "I was so angry/mad." The participant was angry because she felt that she had been careful about her health during pregnancy and yet had produced a child with an intellectual disability; whereas others in poorer circumstances gave birth to normal infants, which seemed "unfair." One participant said: "I don't care," (about what other people say about her child with an intellectual disability). Towards the end of the interview the same participant said: "It bothered me (the nurses gossiping at her door after the birth of her child with an intellectual disability)… and made me scared about how the rest of the world would be."
Kozma and Stock (in Smith, 1993:103) noted that feelings of anger and helplessness might arise as parents of young children with an intellectual disability find themselves unable to 'fix' the disability. One participant said: "we're fixers. We're [her husband and herself] not fragile people: we would have liked to know, to have been able to do things" [for their child with an intellectual disability]. Another participant said about her feelings at the time of her child with an intellectual disability's diagnosis: "voel hulpeloos, magteloos." Often the tone of voice, rather than the verbal content alone, indicated the participants' feelings of anger.

Five of the ten participants seemed to have **guilty feelings** associated with their child with an intellectual disability. One participant noted that she feels guilty if she takes any time for herself and commented that: "it's a sin if I complain." One participant said: "they [the staff at the designated research school] said it's not something you did, but I still find it hard to accept." A participant commented that she feels guilty about taking for granted

the developmental progress of her other, not intellectually disabled child. One of the participants felt that her child with an intellectual disability: "has been my lesson. I would have been that kind of person" [that is, rejecting of people with an intellectual disability]. One participant (see 4.7, Participant No. 10) overtly expressed feeling guilty about her child with an intellectual disability, as she had not wanted another child.

Two of the participants explicitly indicated a **fear of social rejection** because of having a child with an intellectual disability. The one participant said: "I don't want others to point fingers", and although she later said: "I can't point a finger at neighbours, friends church, any of the family, no-one put me down", she still pressurizes her child's performance: "I suppose I expect too much." Murphy (1995:12) noted that parents with a child with an intellectual disability might fear others' perceptions of the parents' competence. The second of the above-mentioned participants said that: "…. [the nurses' gossiping] made me scared about how the rest of the world would be." The latter statement contrasted with an earlier statement in relation to how the participant felt about completing the questionnaire: "comfortable, honest, others [parents with a child with an intellectual disability] are scared to face the world." Two of the participants made no mention of how they feel in public. The other six participants focused on different social aspects and had different responses to their experiences. One of the participants said that some of the public stare at her child with an intellectual disability, but that she understands them and experiences their behaviour as "normal." One of the participants said that she had been "disappointed" in some of her friends' responses to her child with an intellectual disability. One of the participants said about the farm labourers on the farm where she lives: "ek worry nie oor hulle." One participant said about her child with an intellectual disability: "ek sal nooit skaam vir haar wees." Kozma and Stock (in Smith, 1993:110) said that some parents experience feelings of shame about having a child with an intellectual disability. Two of the participants said that the siblings' [of the child with an intellectual disability] friends had been rejecting/the siblings had feared their friends' negative reaction to the sibling with an intellectual disability. One of the participants said that she had received criticism from members of the public for the way in which she had handled her child with an intellectual disability's behaviour at the shops. One of the

participants also said that her doctor had implied criticism of her not having tests before her child's birth (with the implication that she should have had an abortion). From the above comments, the impression that I gained is that some of the general public lack understanding about children with an intellectual disability and tend to be insensitive around the issue. The participants' responses to the public ranged from understanding to hurt feelings and angry responses. Some of the participants indicated positive responses from the public: "everyone knows and loves her" [the child with an intellectual disability]. Canning (1995:3) noted that the public tends to react negatively to people with an intellectual disability, but that there is: "an increasing awareness and compassion."

Kozma and Stock (in Smith, 1993:103) say that **relief** often follows confusion around the child with an intellectual disability's diagnosis. Once professional clarification has been obtained, parents often feel relieved and are able to channel their emotions to helping their child with an intellectual disability's optimal development. One of the participants experienced the diagnosis of her child with an intellectual disability as: "dit was 'n verligting" and another participant said: "I didn't know what to expect. It was a relief to see her" [her child with an intellectual disability]. Three participants' relief was implied by: "I pictured a monster; he was so sweet" and: "Ek het bekommer hoe erg verstremd sy gaan wees…. [and later said] sy's nie so erg nie" and: "ek het nie geweet hoe lyk 'n Downs. Die dokter het gese haar [the child with an intellectual disability] features is baie mooi."

In contrast to the above participants' feelings of relief, the other participants reported feelings of **shock, denial and depression** at the time of the birth of their child with an intellectual disability. The participants referred overtly to feelings of shock and disbelief, while depression was gauged from descriptions of behaviours such as: "I was crying every minute." Four of the latter-mentioned (of five) participants indicated feelings of sadness or depression at the time of their interview with me. A participant said about the time of her child with an intellectual disability's birth "I was crying every single minute" and said about the present time " it's not easy, but I've learnt to treat every day as it

comes." Cunningham (1984:39) says that feelings of shock may be expressed overtly by crying or by withdrawing. The participant above indicated that she *both* cried and withdrew. Another participant said about the first time she heard of her child's developmental progress from the school (recently): "'n mens tjank jou dood." A participant said about the time of her child with an intellectual disability's birth: "it got to me…too much", and about the present [said as she dissolved into tears]: "I couldn't cope without him" [her husband]. The latter participant compared her feelings at the birth of her child with an intellectual disability to grieving the loss of a loved one: "like accepting a death." Katz-Rothman (1994:190) says that the feelings of shock are symptomatic of grief: the parent is mourning the loss of the dream of a 'normal' child. One participant said that she had felt: "magteloos, hulpeloos" at the time of her child's initial diagnosis and said repeatedly (three times) about the present: "dis moeilik", and that being confronted with the fact again [as in my research] "maak seer." Kohner and Henley (1995:78-79) say that parental grief that their child has an intellectual disability may be re-evoked by reminders in the environment. One of the participants, who had been relieved to see how normal her child with an intellectual disability looked, said: "one should plan [for the future], but then one would be depressed and miserable."

Pride and joy of the child with an intellectual disability are indicated by the following examples quoted from two different participants: "her [the child with an intellectual disability] eyes are terribly alert," and: "we just enjoy her."

5.2.2. Coping Strategies

As noted in 1.1, coping strategies refer to *efforts to deal with stress* (Carson & Butcher, 1992:140). More specifically, I use the notion of 'coping strategies' here, in contrast to the 'feelings' in the above paragraph, to refer to actions that the participants take or to the way in which they think or speak about their child with an intellectual disability. The participants used coping strategies mainly around support or assistance (advice and childcare) for the child with an intellectual disability. Coping strategies included the use

of professionals (medical and educational) for advice and for therapies (e.g. occupational therapy). The participants obtained emotional support from the designated research school staff and in some cases from the other parents whose child attended the school. Most of the participants coped by becoming pragmatically active in assisting their child with an intellectual disability or involved in the school that their child with an intellectual disability attended. Most of the participants also cited their husbands' emotional support as helpful to coping, together with the childcare support provided by the husbands. Different participants obtained childcare support from different sources, including from older siblings, grandparents, paid help and, in one case, a friend. The participants' ways of thinking and of talking were also used as coping strategies. Most of the participants avoided thinking about the future regarding their child with an intellectual disability (consciously or unconsciously). Some of the participants indicated the use of passive acceptance. Some of the participants made use of the passive voice when talking about a painful topic and one participant indicated the usefulness of humour for coping. Little time was available to or utilized by participants for relaxing.

The most commonly used coping strategy included **the use of professionals**, although perceived professional helpfulness varied according to the individual professional concerned, and often mothers felt that the professionals' input was limited to appointments in contrast to the mothers' 24-hour-a-day availability. All of the participants had high praise for the assistance that they receive(d) from the designated research school and several participants' mentioned how the staff go beyond the call of duty in trying to assist the participants and their children with an intellectual disability. One participant said: "the teachers' extra love and care is huge." The participants made very little reference to the use of psychological counselling. One participant, to whom a counsellor had been sent shortly after the birth of her child with an intellectual disability, commented negatively on the experience. Baxter *et al.* (1995:133) say that typically parents of a child with an intellectual disability find the support of friends and family most helpful initially and the support of professionals more useful at a later stage. One of the participants commented that she thought very little of the way in which her psychologist friend was bringing up his own children, possibly implying that she would

not seek psychological assistance. Three of the participants commented favourably on the support received from doctors: one commented on the thoroughness of the specialists, two others commented on the doctors' manner, either making them feel special by always recognizing them or by commenting on how pretty their child with an intellectual disability was. Three of the participants commented that it is difficult to get the truth out of doctors regarding their child's disability. One participant felt that doctors are not good about referring parents on to other specialists. One participant indicated that she had been offended by the doctor's reference to her child as "'n mongoloid." Two of the participants had felt judged by a doctor (for not having had antenatal tests done and by implication an abortion). Only one negative comment was made about a physiotherapist, who had nearly dropped a child. The participants' comments about occupational therapy were very positive, if it was not taken for granted, since the therapy happens during the school day. One participant said: "OT. (occupational therapy) helped a lot." The designated research school was described by three of the participants as being: "like a family."

Three of the participants who work seemed to leave their child with an intellectual disability's developmental progress to the teachers and other professionals: one of the above participants indicated explicitly that the teachers work best with children with an intellectual disability, as they are trained to do so. The other nine participants referred to the importance of **their own input** in assisting their child with an intellectual disability's progress. The participants' degree of input varied from continuous pressure on the child to a more relaxed attitude: "we just enjoy her" [the child]. One participant made no reference to currently assisting the development of her child with an intellectual disability herself, but mentioned being part of the school's governing body. One participant seemed to reject help from others: "I prefer to do things myself," although this participant acknowledged help from the teachers and the occupational and speech therapists. This participant indicated a wish to help other parents with children with an intellectual disability in the future.

The participants all indicated that there is very little time for them to relax or to take **time out for themselves**. Dyson (1997:267) notes that children with an intellectual disability have greater care-giving demands than do other children. Time-out activities mentioned by the participants included solitary activities such as watching a television programme or using aromatherapy oils in the bath. Barnett and Boyce (1995:122) say that the greater care-giving demands of children with an intellectual disability result in less time for mothers' social activities.

Two participants mentioned the support they felt from their **faith**: one participant mentioned actively praying for help, although she acknowledged having questioned her faith at the time of the birth of her child with an intellectual disability. The other participant mentioned the support obtained from friends praying for her family. This participant said that she had found the formal structures of religion "disappointing." The literature (Hughes, 1999:278) indicates a more supportive role by religious communities. Muller (personal communication, 2001) said that the Christian view of intellectual disability was that it was a form of divine punishment. In contrast to Muller's opinion stated above, the latter mentioned participant said: "I never felt punished."

The perceived support provided by **other parents** whose children attended the designated research school varied. Two of the participants who work did not refer to the other parents during the interview. Four of the participants who work indicated that they seldom interact with the other parents: "sien weinig die ander ouers." One of the participants who does not work did not refer to gaining support from the other parents; the other three participants commented favourably on the support they gained from the other parents. One participant indicated that she wishes to help support others by starting a coffee morning on Saturdays for mothers with young children with an intellectual disability. One participant said that support between parents whose young child has an intellectual disability comprises notes and letters asking about the health of an ill child. One participant said that she gains support from the parent of an older (than her own child) child with an intellectual disability in her community, but not from the other parents at the school that her child with an intellectual disability attends. Only one

participant said that she *received* support from other parents with a child with an intellectual disability. Possibly, the lack of time available to working parents or the different home backgrounds of the participants might explain the lack of mutual support between mothers of children with an intellectual disability.

All except one participant commented favourably on the input from their child with an intellectual disability's **father**, in terms of emotional support, childcare and involvement in the child's life. One father had rejected his child, had left the family and never visited the child with the intellectual disability. The above finding that most fathers are emotionally and pragmatically supportive of their partners contrasts to the literature (Cuskelly *et al.,* 1998:330), which indicates that typically fathers of children with an intellectual disability assist little with childcare. However, the participants in my study who do not work did receive less childcare assistance from their husbands.

All the participants received some support from **extended family members**. Two participants received childcare assistance during the times that the grandparents visit the family on holiday, two of the participants receive emotional support or an attempt to provide such support from their parents, and three of the participants receive childcare assistance on an ongoing basis from their own mothers. Parker (1999:90) says that often the maternal grandmother is the most supportive grandparent. One participant lives with her family of origin and receives daily childcare assistance from them. One participant especially mentioned both the emotional and childcare support she receives from her sisters. One participant receives sporadic childcare assistance from her two grown up children.

Six of the participants, who work, make use of **aftercare facilities** for their children with an intellectual disability. One of the participants who currently works is planning to stop work in order to be able to spend more time with her child with an intellectual disability. One participant who does not work has a full-time au pair to assist with childcare after school hours, and indicated that the family go on holiday without the child with an intellectual disability, who is left behind in the care of the au pair. One participant has a

nanny to care for her children in the afternoons. Two participants care for their children after the children's school hours. One of the participants (who does not work) has recently made her seven-years-old child a weekly border at (junior) school and said that aftercare at the designated research school (i.e. at the school from which I obtained research participants) had been too costly to use regularly. Most of the young children with an intellectual disability referred to in this study are therefore cared for mainly by paid help away from home. The above findings seem to contrast to Booth and Kelly's (1999:117) assertion that most parents prefer their child with an intellectual disability to be cared for by a relative rather than by paid childcare. Or, perhaps the lack of availability of family members to care for the children with an intellectual disability is reflected in the pattern of paid help indicated in my study.

Only one of the participants mentioned receiving childcare support from **a friend**, although one other participant mentioned that friends had prayed for her family and that her friends were happy to include the child with an intellectual disability on social occasions. The latter two participants were more affluent than the others whom I interviewed. A different participant said that she had made friends with and received support from another mother with a child with an intellectual disability in her community. One participant said that she had some company from a younger woman in the community, who initiates social interaction. The other participants indicated that they were not very sociable/did not go out much/had very few friends. Two of the participants were explicit: "ons is nie baie sosiale mense," "ek het nie vriende…hier en daar…hulle verstaan" [about her child with an intellectual disability]. The other participants' description of their lives implied that they do not find much opportunity for friendships. As noted previously, childcare demands of children with an intellectual disability might curb social interaction (Barnett & Boyce, 1995:122).

All the participants engaged in **comparative thinking**, i.e. comparing the development of their own child with an intellectual disability with that of other children with an intellectual disability. Nine of the ten participants concluded that their own child was "not so bad" in terms of developmental progress. All of the participants referred either to how

normal their child with an intellectual disability looked, or to how the participants brought up the child as normal. Three of the participants had their child with an intellectual disability attending a normal school, for example the aftercare school. One participant had sent her child to a normal preschool before acknowledging that her child was miserable there, and having to remove him from the school.

One participant had made concrete plans regarding her **child's future** (invested money); the other participants indicated that they had not given the distant future much thought and that they preferred to **avoid thinking about it**. Baxter et al. (1995:133) say that the uncertainty regarding the future for the child with an intellectual disability is a continuous source of stress for their parents. The general impression that I gained from the discussion about the future with the participants was that they were able to acknowledge that their children have an intellectual disability in the present, but find it hard to acknowledge that the their children will *always* have an intellectual disability. Most of the participants seemed to use the coping strategy of focusing on current concerns about their child with an intellectual disability:-perhaps because the participants feel that they are able to control and do something pragmatic about assisting their child with an intellectual disability in the present, or perhaps acknowledging the permanence of their child with an intellectual disability's diagnosis is too emotionally painful. Baxter et al. (1995:133) note that parents with a child with an intellectual disability find help with current stressors the most useful.

Several of the participants used **passive acceptance** as a way of coping with the unalterable intellectual disability of their child. Some of the participants explicitly indicated their passive acceptance of their child's intellectual disability. Examples include: "I've come to accept the way it is" (the child's intellectual disability), "ek glo hy's vir my [by God] gegee," "daar's seker 'n doel vir alles in die lewe," "dis deel van my lot." One participant implied passive acceptance in statements such as: "it would be a sin if I complained." Passive acceptance should not be confused with passivity. All of the parents indicated interest in assisting their child with an intellectual disability. Two of the participants said: "we're fixers." One participant said: "I fear what (trauma) next?".

One participant indicated that the family uses **humour** as a way to cope. One participant said: "for me, coping is about **talking**." Three of the participants made **use of the passive voice** during part of their interview with me; for example: "one sends messages, letters," and "'n mens wil nie daaroor dink nie." Although not conclusive, the use of the passive voice might indicate the participants' distancing from the emotional content of what they were saying to me and as such is a coping strategy.

One of the participants referred to a book (Beck, 2001) about being the parent of a child with an intellectual disability. After reading the book myself, I noticed that the participant had mentioned things in the interview that seemed to correspond with her own experience/context. For example, she said that 80% (the percentage indicated in the North American book) of children with an intellectual disability live in single parent-homes. The participant referred to having had a particular antenatal test (alpha-fetoprotein, as in the book). The participant seemed to have found support in being able **to identify with the author of the book**.

The above coping alternatives would seem to indicate that all of the participants rely on the child with an intellectual disability's school staff, paid childcare help, and their husbands' input for day-to-day coping with their child with an intellectual disability. Also apparent from the above paragraphs is the degree to which participants are central to caring for their child with an intellectual disability. One could perceive the way in which the participants chose to think about (or avoid thinking about) their child's intellectual disability as impacting on coping with the situation.

5.3. Between Participant Biographical Data-Questionnaires-Interview Comparisons

The biographical data did not indicate the participants' residential area; I requested only contact telephone numbers on the questionnaire schedules. Setting up the interviews at the participants' homes revealed a range of socio-economic backgrounds. The range of socio-economic class was greater than anticipated, as I had assumed that most of the

participants would be from a similar, middle-class suburb to the designated research school location. The range of socio-economic backgrounds makes the similarities between participant responses all the more interesting, suggesting that, while not a homogenous group, there are common feelings and concerns to the experience of parenting a young child with an intellectual disability. Examples include the participants' initial reaction to the diagnosis of intellectual disability, and to a way of coping that focuses on current concerns about their child with an intellectual disability. Socio-economic differences are also relevant: one of the participants indicated that being financially affluent made accepting her child with an intellectual disability easier and placed less strain on marital relations. The interesting question that is raised from the above is whether affluence alone is sufficient for better maternal coping, or whether other factors, the degree of the child's intellectual disability in relation to parental expectations for example, are more closely related to maternal coping with a child with an intellectual disability. In the case above, the participant noted that being financially affluent had helped her to "unconditionally accept" her child with an intellectual disability, which is a contradiction in terms. Eleven of the twelve participants who completed the questionnaires indicated dual parent households, and the interviews suggested that the dual parent households comprised supportive marital relationships. My sample might be biased in terms of some self-selection of participants, and might not reflect the majority of households parenting a child with an intellectual disability.

Ten of the twelve participants who completed the questionnaires indicated that there are other siblings living at home. Nine of the ten participants who took part in the interviews indicated that there were other siblings (i.e. without an intellectual disability) living at home. Only one participant referred to another sibling in the qualitative comments on the questionnaire, but all ten participants referred to the other siblings during the interviews. One participant discussed how the other sibling might feel about having a sibling with an intellectual disability. The other participants discussed how the other siblings cope with (e.g. explaining to friends about the sibling with an intellectual disability) and help their sibling with an intellectual disability. The questionnaires were more directing than the interviews, so that the impact of the child with an intellectual disability on other siblings

living at home was not clearly indicated by the questionnaires in contrast to the interviews. The references in my data to the other siblings indicated a possible additional stressor for the participants. A further study might look at the impact of, as well as on, the siblings of a young child with an intellectual disability on the mother's ability to cope.

5.4. Between Participants' Questionnaire-Interview Comparison

In chapter 4 (4.8. 'Intra-Individual Questionnaire- Interview Comparisons') I noted that it had became evident that the participants tended to contradict themselves. The participants tended to indicate opposite responses on the questionnaires in comparison to the interviews. The data gained from the questionnaire responses reflected the participants in a more flattering way than did the data from the interviews. An example of the above contention: participants might indicate that caring for a child with an intellectual disability poses no strain on their coping ability, whereas the same participants indicated during the interviews that caring for a child with an intellectual disability poses a considerable strain on their coping abilities. The contradictory nature of the questionnaire relative to the interview data highlights the importance of combining quantitative and qualitative methodology components in my study. The use of either methodological approach alone would have resulted in a less accurate understanding of the research topic.

It may be useful to consider Furnham's lay theory (1988, cited by Skinner, 2000:39-43) as providing a possible explanation for the conflicting questionnaire-interview data that my study generated. Lay theory is the study of the lay person's implicit construction of reality. Furnham (1988, cited by Skinner, 2000:39-43) notes that, in contrast to scientific theories, lay theories are often inconsistent, with two mutually contradictory ideas or beliefs being held simultaneously by an individual without cognitive dissonance occurring. Lay theory says that individuals derive explanations of the world from their own experiences, personal histories and from whatever knowledge they can glean from other sources. Any explanation about a particular topic reasoned by an individual is likely to be embedded within the context of the given individual's network of beliefs about life

in general. Groeben (1990, cited by Skinner, 2000:42) believes that lay theories have a core influence on behaviour. Sherr (1989, cited by Skinner, 2000:43) argues that the lay theories which individuals construct and act on are more important than any formal knowledge to which they have access. The latter contention is important when considering how best to assist mothers coping with a child with an intellectual disability. The implication of lay theory would seem to indicate that the provision of general suggestions for coping with a child with an intellectual disability might be of limited usefulness. With regard to these implications of lay theory, the high praise from the participants of my study for the ongoing emotional support provided to mothers by the designated research school contrasts to the participants' more ambivalent attitude towards the other professionals from whom they receive assistance. The designated research school seems to provide support that is perceived as being more personal than that received by the participants from elsewhere. The more personal support provided by the designated research school is also suggested by references made by several participants to the said school as being 'like a family'. The daily interaction between the participants and the school staff might mean that support offered by the staff is able to be more specifically tailored to take into account the mother's personality and needs, and not focus solely on the child.

Figure 5.1. The Major Themes Identified

<u>**Feelings:**</u>

> Denial
>
> Anger
>
> Simultaneous feelings of hope & fear for the future
>
> Guilt
>
> Acceptance of child with an intellectual disability
>
> Fear of social rejection
>
> Relief or shock, denial & depression: diagnosis
>
> Sadness
>
> Pride & joy

<u>**Coping Strategies:**</u>

> Mothers' involvement
>
> Use of professionals (medical & educational)
>
> Time out for mothers
>
> Support of/from other parents of child with an intellectual disability
>
> Fathers' involvement
>
> Extended family members' support
>
> Aftercare facilities
>
> Friends' involvement
>
> Comparative thinking
>
> Future planning
>
> Passive acceptance
>
> Humour
>
> Talking about the situation
>
> Passive voice: possibly for emotionally distancing
>
> Identification with author of book on parenting a child with an intellectual disability

5.5. Summary

The participants in my study mentioned a range of feelings around having a child with an intellectual disability. They referred both to current feelings as well as to how they had felt at the time of their child's initial diagnosis. The overall impression that I gained of the participants' feelings about their child with an intellectual disability included that of ambivalence: the participants' indicated both hope and fear for the future well-being of their child with an intellectual disability. They also indicated current feelings of anger, guilt, denial, acceptance (religious/passive), fear of social rejection, sadness, and joy. The participants' feelings associated with the initial diagnosis of the child with an intellectual disability ranged from shock and denial, anger, depression and guilt to feelings of relief.

The participants used a range of coping strategies. It was evident that all of the participants made use of the support from the designated research school, as well as from paid aftercare options. The nuclear family also provided some support although the extended family was, in nine of the ten cases, less available to provide assistance. Noticeable in most cases was the degree of maternal involvement with the child with an intellectual disability, with a concomitant lack of time to cater to the mothers' own needs or interests. Figure 5.1 provides an overview of the major themes (feelings and coping strategies) identified in this chapter.

The contradictory data between participant questionnaire and interview data were explained in terms of lay theory. The implications of lay theory for my study are that support for mothers caring for a child with an intellectual disability cannot be conceived of as a homogeneous entity. Rather, support is most likely to be effective when it takes into account individual's constructions of the participants' subjective realities.

My final chapter summarizes the findings from the preceding chapters, makes recommendations for interventions, highlights the shortcomings of my study and makes recommendations for future research on the area of parenting a child with an intellectual disability.

CHAPTER 6. FINAL REMARKS

6.1. Introduction

In this final chapter I sketch an overview of the foregoing chapter contents, make recommendations for interventions, discuss the constraints and criticisms of my study, make recommendations for future research, and state my final conclusion.

6.2. An Overview of the Study

In chapter 1 I placed my study in the context of the broader needs assessment being undertaken by the University of Stellenbosch in a civil society collaboration with DSSA. The joint aim is to work towards the improvement of quality of life for people with an intellectual disability throughout their life span. I outlined the study problem as focusing on the feelings and coping strategies used by the mothers of young children with an intellectual disability. My objective was to assess the need for support by the mothers and how best this might be provided, with the ultimate aim of improving the quality of life for young children with an intellectual disability.

I indicated the significance of my study, with my attention on a middle-class group of parents, who potentially have access to more supports afforded by financial status than do lower socio-economic groups. Also, I indicated that my combined use of quantitative and qualitative methodologies might be unique in examining my research topic in the South African context. I explained the research design used in the study. As a needs assessment my study may be described as evaluation research (Babbie, 1983:305). To evaluate the participants' potential needs I used two validated questionnaires and then used the questionnaire findings to guide semi-structured interviews in an emergent research design (Gergen & Gergen, 2000, cited in Eloff, Engelbrecht, Swart & Oswald, 2002:1). The participants consisted of convenience samples: four mothers for refining the questionnaires before the questionnaires were presented to the research participant group

of twelve mothers. I analysed the questionnaires both quantitatively and qualitatively. I tape-recorded and transcribed the semi-structured interviews, then compared the data from the questionnaires and from the interviews both intra-individually and between participants. I devised codes for indicating initial theme clusters across participant data. I discussed my assumption of the use of the first person throughout the study (Jones, 1992:18), reviewed key constructs associated with my study and noted that definitions of terms associated with intellectual disability reflect society's changing perceptions about people with an intellectual disability. I provided an outline of the subsequent chapters.

In chapter 2 I provided an overview of the more recent literature about parenting a child with an intellectual disability. Prevalence rates of intellectual disability in South Africa are uncertain, given the lack of research done across the broad spectrum of society. Additional stress for mothers parenting a child with an intellectual disability is engendered by the multiple roles often necessitated in families parenting a child with an intellectual disability. Professionals wishing to assist mothers parenting a child with an intellectual disability need to remember to remain unbiased, rather than assuming that parenting a child with an intellectual disability will be perceived by all parents as a negative experience. Also important is the finding that different types of supports have been found to be useful at different points in time for mothers parenting a child with an intellectual disability. Particularly relevant to the South African context, with its multi-cultural population, is research that indicates the important influence of socio-cultural attitudes towards intellectual disability.

In describing my research design in chapter 3, it became evident that different researchers' use terminology to describe the planning and implementation phases of research in different ways. I needed to clarify how I used terminology in my own study and decided to use Mouton's (2001:56) "research design" to refer to the planning stage of my research and "methodology" to refer to the implementation stage of my research. I explained my research as being subsumed under the notion of evaluation research. I referred to quantitative and qualitative theory. I minimally altered the two questionnaires used (QRS and WC-R) after consultation with the questionnaires' refinement group

participants. I used the findings from the completed questionnaires as a basis from which to guide the semi-structured interviews. The school from which I obtained the research participants introduced the questionnaires to the participants. I set up and undertook the interviews at the participants' homes or, if more convenient, at the participants' place of employment. I analysed the questionnaires mainly by multiple comparisons between the participants (similarities, common omissions, unique responses for the first questionnaire, and coping style profile comparisons for the second questionnaire), before I compared the first and second questionnaires within and between participants. Apart from the quantitative scoring that I did for the questionnaires, I used triangulation of the quantitative and qualitative data for verification purposes. I also indicated that transparency in my research and the use of 'thick description', were necessary for verifying the qualitative data. The main ethical concern of my study was to avoid distress for the participants. One of the designated research school staff mentioned to me that completing the questionnaires had been emotionally taxing for some of the participants. In the follow-up interviews I aimed to provide an opportunity to compensate for any discomfort experienced by the participants. I asked each of the participants directly about how they felt about participating in my research and how they had experienced completing the questionnaires.

I presented the data findings obtained from the completed questionnaires and from the semi-structured interviews in the fourth chapter. I analysed the questionnaires by comparing data both within and between participant responses, including biographical data and qualitative comments. The participants preferred the Likert-type scale format of the second questionnaire to the true/false format of the first questionnaire. There were several response omissions on many of the participants' first questionnaires, with concomitant qualitative comments. The interviews confirmed that participants' had found the true/false response options too limiting to reflect how they felt about particular questions. The findings from the second questionnaire indicated combined use of coping strategies, although a pragmatic coping style featured for all the participants. Common across participants were qualitative comments reflecting the participants' feelings of guilt, sadness, acceptance of the child with an intellectual disability, and of trying to be

positive. I devised a coding system for a close analysis of the interviews, based on the common themes that emerged from my descriptions of each interview. Contradictions between what the participants indicated on the questionnaires and what participants said at the interviews became apparent when I compared the two sets of data. Common themes from the interviews included:

1) primary childcare,

2) experience of other people's support,

3) the child with an intellectual disability's developmental progress,

4) the perceived future for the child with an intellectual disability,

5) preferred schooling options,

6) the financial impact of having a child with an intellectual disability,

7) desire to be involved in assisting the child,

8) experience of the initial diagnosis of intellectual disability,

9) level of acceptance of the child with an intellectual disability, and

10) values (including religion).

In the discussion of my findings in chapter 5, I indicated that participants referred to a range of feelings (current or associated with the initial diagnosis of intellectual disability). Current participant feelings associated with having a child with an intellectual disability included:

1) simultaneous feelings of hope and fear for the future,

2) denial,

3) anger,

4) guilt,

5) acceptance of the child with an intellectual disability,

6) fear of social rejection,

7) sadness and,

8) pride and joy.

My analysis of the coping strategies used by the participants indicated that the participants relied heavily on the designated research school staff for support. In nine of

the ten cases, the participants had little regular assistance from extended family. Rather, daily support relied on paid childcare (school in the mornings; aftercare/nanny/au pair in the afternoons) Working participants seemed to share child care with their husbands more than did stay-at-home mothers. The two mothers not working complained that their husbands did not discuss feelings about their child with an intellectual disability with them. It was not clear whether the participants' lack of time for themselves was due to the demands of caring for a child with an intellectual disability, or whether the participants chose to focus extra time on their child with an intellectual disability. The latter option may reflect the participants' need to gain a sense of control of the situation. I compared the biographical data of the participants before comparing the questionnaires and interview data between participants. I offered an explanation for the contradictory data between the questionnaires' responses and the interview data for individual participants in terms of lay theory (Furnham, 1988, cited by Skinner, 2000:39-43).

6.3. Recommendations for Interventions

The implication of lay theory is that support for mothers parenting a child with an intellectual disability cannot be conceived of as a homogeneous entity, but that individual perceptions need to be taken into account by any professional wishing to provide assistance. The need for ongoing emotional support would be useful, given the additional stress that mothers parenting a child with an intellectual disability indicated. At present, the designated research school seems to fulfill an important role in the provision of instrumental and emotional support. One participant said that she feared not having the school's support once her child left the school, and another participant mentioned that she still seeks support from the designated research school staff despite her child no longer attending the school. Preliminary findings from my study suggest that mothers parenting a child with an intellectual disability might benefit from being encouraged to empower themselves by forming their own mothers' group to provide an informal forum for the sharing of ideas and for the development of mutually supportive relationships.

6.4. Constraints and Criticisms

The most apparent shortcoming in my research design is that mentioned in an article on the WC-R (Knussen *et al.*, 1992:776), where reference is made to **response bias**, i.e. a tendency of participants to answer according to perceived social desirability of the response alternatives. Similarly, Huysamen (1998:66-67) refers to the *reactivity of research* or Hawthorne effect, i.e. the impact on participants' knowing that they are part of a research undertaking. The **Hawthorne effect** is anticipated both because the researcher is an unknown 'semi-professional' psychologist and because of the involvement of the school in terms of the principal encouragement of mothers to participate in the present research. Some attempt to address this problem is reflected in the semi-structured follow-up interviews. However, I would argue that participants who agreed to take part in the interview phase of the research as well as in the completion of the questionnaires might well be those individuals most impacted by the Hawthorne effect. With hindsight I could have done a piloting test re-test with the questionnaires' refinement group participants to increase the reliability of the questionnaires.

The above contention about the Hawthorne effect also highlights another shortcoming of the research design: that the voluntary nature of the participant participation may at each level (questionnaires and then interview) mean that participants select themselves. The result of **self-selection** is that the resultant data findings are biased and constrain the possibility of **generalising** the findings to other populations. Data bias is also anticipated because of the participant selection being from only one school and so involving a very **small sample**, which again might restrict the possibility of **generalising** data results to other populations. However, Merriam (1998:210, cited in Engelbrecht, Swart and Eloff, 2001:257) reminds us that when working within a qualitative methodology it is assumed that *the general lies within the particular; that is, what we learn in a particular situation we can transfer or generalise to similar situations subsequently encountered*. Similarly, the analysis of data looking for trends in the ways in which mothers feel about and cope with their child with an intellectual disability may offer only tentative indicators of feelings and behaviour. The sample size constraints were unavoidable given the limited

scope of a Master's study. My aim was therefore not to attempt to generalise the findings beyond the research group used, but rather to view the findings as a starting-point from which further research might be informed. The triangulation of quantitative and qualitative data in my study may, to some extent, serve to ameliorate concerns about the Hawthorne effect and sample bias.

The **psychological discomfort** commented on by some of the participants in my study, gave me cause for concern. A warning at the start of the questionnaires about the possible negative impact of participation might be useful, together with a clearer indication about the possible *benefits* of participating in such a study (such as the opportunity to work through feelings and to discuss concerns with the researcher).

The participants found the first questionnaire's **true/false format too limiting** to adequately answer some of the questions in a way that clarified their feelings about the question content. To compensate, the participants preferred to write qualitative comments on the questionnaire. The use of qualitative comments in place of quantitative responses meant that scoring the true/false questionnaires involved some of my subjectivity in interpreting whether a particular qualitative comment reflected a true or a false response option. For future research I might not use the questionnaire format, although it was most appropriate for eliciting useful initial data.

6.5. Recommendations for Future Research

Future research could bear in mind the reference in my literature review to the fact that different cultures impact on maternal coping with a child with an intellectual disability differently. The literature around coping with a child with an intellectual disability includes much research from countries other than South Africa, making findings less valid for local use. My study raised queries about whether working mothers in South Africa gain more support from their partners than do their counterparts in other countries, or whether the husband participation indicated in my study rather reflected

methodological issues. The research done within the South African context mentioned in this study reflects small-scale research studies focusing on particular segments of the South African population at one time. Several of the aforementioned studies were done, as in the case of my research, for the purpose of an academic course requirement, and as such were limited in scope. What might be more useful would be either one large, more comprehensive study or the use of several similar studies done at the same time.

The combined use of quantitative and qualitative research methods to triangulate findings could be useful for future research. The above recommendation is based on my readings on such an approach, for example Creswell's (1994) *Research Design: Qualitative and Quantitative Approaches* (see my references), as well as information about current researcher feelings being expressed at a recent conference in Johannesburg about the usefulness of triangulation (personal communication Skinner, 2002).

I would suggest that future research look for other (than lay theory) explanations for participant response discrepancies. The use of a social desirability scale, as mentioned in the literature review, might also be useful in assessing possible reasons for contradictory data findings.

The criticisms of my own research might guide future research. The use of true/false questionnaires I found to be less useful than the Likert-type scale for assessing a subject as emotionally laden as coping with one's child with an intellectual disability. Also, the emotional discomfort reported by some of the participants suggests that future research might be more careful about addressing this possibility with potential participants beforehand.

Future research might want to expand on the focus of my research. One aspect that might be particularly interesting would be to assess how mothers of young children with an intellectual disability feel about the aftercare facilities available in South Africa. It would be interesting to ascertain whether (as indicated in the literature from abroad) South African mothers have the luxury of staying home if unsatisfactory aftercare is available

or whether cheaper labour, such as nannies, forms an alternative childcare option for some middle-class families. One related research focus for possible future research is the impact of siblings on the mothers' perceptions of coping in a family having a child with an intellectual disability. Another option would be to assess how mothers' perceptions of coping in the early years of their child with an intellectual disability correlated with their later perceptions of coping.

6.6. Conclusion

My study concludes with an emphasis on acknowledging the inherent strengths and capabilities indicated by the participants in my study. My recommendations stem from my belief in helping to empower individuals to help themselves, rather than imposing strategies from an external position. In sharing the findings from my study, I hope that those who are in a position to provide mothers of young children with an intellectual disability with support will feel encouraged by the vital role that they are playing/might play. I further hope that mothers parenting a child with an intellectual disability will recognise the potential benefit to be derived from mutually supporting one another.

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APPENDIX A: The Original Questionnaires' Formats

The First Questionnaire: QRS

The Second Questionnaire: WC-R

THE FIRST QUESTIONNAIRE: QRS

of Factors III and IV, Child Characteristics and Physical Incapacitation, should be investigated with the presumption that scores on these factors would increase given more severe involvement and disability in certain groups of children. We expected that Factors I and II, Parent and Family Problems and Pessimism, should tap more subjective discomfort in these groups of parents, perhaps related to parental depression, lack of social support, and marital dissatisfaction. A shorter and more pyschometrically sound assessment measure of resources and stress in parents of handicapped children should encourage further and much needed research related to the process of coping and adaptation in these families, as well as the identification of those variables that facilitate this process.

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APPENDIX A

A Short-Form of the Questionnaire on Resources and Stress

This questionnaire deals with your feelings about a child in your family. There are many blanks on the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of 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 of the questions.

1. _____ doesn't communicate with others of his/her age group.   T   F
2. Other members of the family have to do 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 of someone else in our family.   T   F
6. _____ is limited in the kind of work he/she can do to make a living.   T   F
7. I have accepted the fact that _____ might have to live out his/her life in some special setting (e.g., institution or group home).   T   F
8. _____ can feed himself/herself.   T   F
9. I have given up things I have 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 visit with friends whenever I want.   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 over-protected.   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 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 to _____ when I no longer can 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 feelings to others.   T   F
49. _____ has to use a bedpan or a diaper.   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

Knussen and others

Ways of Coping (Revised) questio

investigating the many possible transactions among the variables in the coping process, especially when relying on mainly self-report measures, and the use of relative scoring techniques would appear to aid such analyses (Vitaliano *et al.* 1987). It was concluded that the WC-R is potentially useful to those investigating stress and coping in parents of children with disability.

APPENDIX

The subscales with associated factor loadings.

Practical Coping

I try to analyse the situation in order to understand it better. (0·69)

I make a plan of action and follow it. (0·67)

I talk to someone who can do something concrete about the problem. (0·67)

I think up a couple of different solutions to problems. (0·64)

I try to come out of experiences better than I went in. (0·62)

I try to make myself feel better by exercising or getting involved in something. (0·62)

I try to get professional help. (0·61)

I draw on my past experiences. (0·61)

I try to see things from the other person's point of view. (0·57)

I try not to burn my bridges but leave things somewhat open. (0·55)

I rediscover what is important in life. (0·52)

I try not to act too hastily or follow my first hunch. (0·51)

I stand my ground and fight for what I want. (0·50)

I usually know what has to be done so I keep up my efforts to make things work. (0·49)

I try to change or grow as a person in a good way. (0·47)

I took for the silver lining, so to speak; try to look on the bright side of things. (0·47)

I am inspired to do creative things. (0·44)

Wishful Thinking

I wish that I could change how I feel. (0·78)

I wish that the situation would go away or somehow be over with. (0·69)

I daydream or imagine a better time or place than the one I am in. (0·68)

I wish that I could change what has happened. (0·64)

I have fantasies or wishes about how things might turn out. (0·63)

I try to change something about myself. (0·58)

I accept that I bring problems on myself. (0·56)

I hope a miracle will happen. (0·56)

I prepare myself for the worst. (0·55)

I tell myself things that help me to feel better. (0·53)

I take it out on other people. (0·53)

I make a promise to myself that things will improve next time. (0·49)

I criticize or lecture myself. (0·47)

I avoid being with people in general. (0·47)

I accept the next best thing to what I want. (0·46)

I do something which I don't think will work, but at least I feel I'm doing something. (0·45)

I go over in my mind what I might say or do. (0·45)

I refuse to believe that it has happened. (0·44)

Stoicism

I go on as if nothing has happened. (0·64)

I find new faith. (0·54)

I maintain my pride and keep a stiff upper lip. (0·53)

I remind myself how much worse things could be. (0·49)

I make light of the situation; I refuse to get too serious about it. (0·43)

Seeking Emotional Social Support

I talk to someone about how I am feeling. (0·65)

I ask relatives or friends I respect for advice. (0·62)

I talk to someone to find out more about the situation. (0·51)

I accept sympathy and understanding from someone. (0·46)

I let my feelings out somehow. (0·42)

Passive Acceptance

I accept it, since nothing can be done. (0·58)

I turn to work or substitute activity to take my mind off things. (0·58)

I try to keep my feelings from interfering with other things too much. (0·53)

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APPENDIX B: The Letter For The Pilot Study Participants

NOTE TO EXPERTS PARTICIPATING IN THE PILOT STUDY

Please find attached a copy of the questionnaire (3 pages) I hope to use with mothers having a young child with an intellectual disability. The attached questionnaire is compiled from two well documented questionnaires in the literature. The latter mentioned questionnaires are presented verbatim here. Some changes may be relevant to our South African context and to the age child to which I will be referring in my study (preschool level, ages 3-7). A researcher may not change an already "established" questionnaire on whim, but needs the consensus of experts on the subject. Please comment on:

1) the sensitivity of the questions.

2) The language used, for example, the use of Americanisms, or do any of the questions seem ambiguous?

3) the relevance of the questions, given the age child (3-7 years old)that I will be referring to in my study.

4) The format/structure of my questionnaire.

5) Any other comments relevant to the use of the attached questionnaire.

Thank you for your time and input.

Frances Hill

(M.Ed.Psych., University of Stellenbosch)

<u>APPENDIX C</u>: The Altered Questionnaires' Formats

The Biographical Data

The First Questionnaire: QRS

The Second Questionnaire: WC-R

QUESTIONNAIRE / VRAELYS

I would greatly appreciate it if you would be willing to complete this questionnaire.

Please return the completed questionnaire (9 pages) within the next two weeks by posting it in the box provided in the (designated research) school office. The purpose of this study is to better understand how mothers feel about and cope with their young child having an intellectual disability. There is no need to write your name on the questionnaire. Your responses will be kept confidential.

Ek sal dit baie waardeer indien u bereid is om hierdie vraelys in te vul. Plaas asseblief die voltooide vraelys (9 bladsye), binne die volgende twee weke, in die doos by die Chere Botha skoolkantoor. Die doel van hierdie vraestel is om 'n beter begrip te vorm van moeders se gevoelens teenoor hulle kinders se intellektuele beperkings en hoe u dit hanteer. Geen name hoef ingevul te word nie. U antwoorde sal vertroulik hanteer word.

Please complete the following background information:
Voltooi asseblief die volgende agtergrondsinligting:
Your date of birth: …………………………………………..
U geboortedatum: …………………………………………..

The number of children you have: ………
Hoeveel kinders u het: ………

Are you a single parent? ……….
Is jy 'n enkel ouer? ………

Religious denomination (if applicable): ………………………………..
Godsdienstige denominasie (wanneer van toepassing): ………………………

Your current employment status (please circle the relevant response):
full time / part time / not employed.
U huidige werksituasie (kring asseblief die relevante antwoord):
 voltyds / deeltyds / werkloos:

Your home language:
U huistaal:

The following set of questions deals with your feelings about your child with an intellectual disability. Please answer the following questions by circling either the **T** (true) or the **F** (false) response options. Please imagine your child's name filled in on each blank. If it is difficult to decide between **T** (true) or **F** (false) respond according to how you / your family feel / do most of the time. If you have any comments to add, please write these in the space below the relevant question.

Die hieropvolgende stel vrae handel met u gevoelens teenoor u kind wat 'n intellektuele gebrek het. Geliewe die vrae te beantwoord deur of die **W** (waar) of die **V** (vals) antwoord keuses te bring.Neem asseblief aan dat u kind se naam op elke spasie verskyn. Sou dit moeilik wees om tussen **W** (waar) of **V** (vals) te besluit, antwoord volgens hoe u u gesin meesal voel / optree. As u enige kommentaar wil byvoeg, skryf dit asseblief in die spasie onder die relevante vraag.

1------------- doesn't communicate with others of his / her age group.   **T**   **F**
1…………..kommuniker nie met ander van sy / haar ouderdomsgroep nie.   **W**   **V**

2 Other members of the family have to do without things because of -------------.   **T**   **F**
2 Ander lede van die gesin moet sonder dinge klaarkom vanwee……………….   **W**   **V**

3 Our family agrees on important matters.   **T**   **F**
3 Ons gesin stem saam oor belangrike sake.   **W**   **V**

4 I worry about what will happen to ----------- when I can no longer take care of him / her.   **T**   **F**
4 Ek bekommer my oor wat van …………gaan word wanner ek hom / haar nie langer sal kan versorg nie.   **W**   **V**

5 The constant demands for care for ---------- limit growth and development of someone in our family.   **T**   **F**
5 Die voortdurende versorgingseise van…….. strem die groei en ontwikkeling van iemand in ons gesin.   **W**   **V**

6 ------------ is limited in the kind of work he / she can do to make a living.   **T**   **F**
6 Die soort werk wat………..kan doen om 'n bestaan te maak is beperk.   **W**   **V**

7 I have accepted the fact that ----------- might have to live out his / her life in some special setting (e.g. institution or group home).   **T**   **F**
7 Ek het die feit aanvaar dat………….miskien hy /sy lewe in een of ander spesiale omgewing (byv. 'n inrigting of groepstuiste) sal moet sluit.   **W**   **V**

8 -------------- can feed himself / herself.   **T**   **F**
8……………kan homself / haarself voer.   **W**   **V**

9 I have given up things that I have really wanted to do in order to care for -----------.   **T**   **F**
9 Ek het dinge prysgegee wat ek baie graag sou wou gedoen het om na…om te sien.   **W**   **V**

10 ------------- is able to fit into the family social group.   **T**   **F**
10…………..kan by die gesin se sosiale groep inpas.   **W**   **V**

11 Sometimes I avoid taking ------------- out in public.   **T**   **F**
11 Soms vermy ek dit om…………….in die openbaar uit te neem.   **W**   **V**

12 In the future, our family's social life will suffer because of increased
      responsibilities and financial stress.   **T**   **F**
12 In die toekoms sal ons gesin se sosiale lewe ly vanwee toenemende
      verantwoordelikhede en finansiele stres.   **W**   **V**

13 It bothers me that ----------- will always be this way.   **T**   **F**
13 Dit hinder my dat…………altyd so sal wees.   **W**   **V**

14 I feel tense whenever I take ------------- out in public.   **T**   **F**
14 Ek voel gespanne elke keer dat ek………in die openbaar uitneem.   **W**   **V**

15 I can go visit with friends whenever I want.   **T**   **F**
15 Ek kan ter enige tyd by vriende besoek afle.   **W**   **V**

16 Taking ---------- on vacation spoils pleasure for the whole family.   **T**   **F**
16 Om………..met vakansie saam te neembederf die hele gesin se plesier.   **W**   **V**

17 -------------- knows his / her own address.   **T**   **F**
17……………ken sy / haar eie adres.   **W**   **V**

18 The family does as many things together as we ever did.   **T**   **F**
18 Die gesin doen nog net soveel saam as ooit.   **W**   **V**

19 ----------- is aware who he / she is.   **T**   **F**
19…………besef wie hy /sy is.   **W**   **V**

20 I get upset with the way my life is going.   **T**   **F**
20 Ek raak onsteld oor hoe my lewe verloop.   **W**   **V**

21 Sometimes I feel very embarrassed because of --------------.   **T**   **F**
21 Partykeer voel ek baie verlee weens…………………   **W**   **V**

22 ------------- doesn't do as much as he / she should be able to do.   **T**   **F**
22……………doen nie veel soos wat hy / sy eintlik in staat is nie.   **W**   **V**

23 It is difficult to communicate with ------------ because he / she has difficulty
      understanding what is being said to him / her.   **T**   **F**
23 Dis moeilik om met…………te kommunikeer want hy /sy vind dit moeilik
      om te verstaan wat aan hom / haar gese word.   **W**   **V**

24 There are many places where we can enjoy ourselves as a family when ------------.
      comes along.   **T**   **F**
24 Daar is baie plekke waar ons ons as gesin kan geniet wanner…………saamgaan.   **W**   **V**

25 ------------ is over-protected.   **T**   **F**
25………….is oorbeskerm.   **W**   **V**

26 ----------- is able to take part I games or sports.   **T**   **F**
26…………is in staat om aan speletjies of sport deel te neem.   **W**   **V**

27 ---------- has too much time on his / her hands.   **T**   **F**
27…………het te veel tyd op sy / haar hande.   **W**   **V**

28 I am disappointed that ----------- does not lead a normal life.   **T**   **F**
28 Ek is geleurgesteld dat………….nie 'n normale lewe ly nie.   **W**   **V**

29 Time drags for ------------- ,especially free time.		T	F
29 Die tyd sleep vir……….., veral vryetyd.		W	V
30 ------------ can't pay attention very long.		T	F
30………….kan nie baie lank aandag gee nie.		W	V
31 It is easy for me to relax.		T	F
31 Dis vir my maklik om te ontspan.		W	V
32 I worry about what will be done with ----------- when he / she gets older.		T	F
32 Ek bekommer my oor wat met………….gedoen sal word wanneer hy / sy ouer word.		W	V
33 I get almost too tired to enjoy myself.		T	F
33 Ek word amper te moeg om myself te geniet.		W	V
34 One of the things about ------------- is his / her confidence.		T	F
34 Een van die dinge omtrent………is sy / haar vertroue.		W	V
35 There is a lot of anger and resentment in our family.		T	F
35 Daar is baie boosheid en gebelgdheid in ons gesin.		W	V
36 ------------- is able to go to the bathroom alone.		T	F
36…………..kan alleeen badkamer toe gaan.		W	V
37 ------------- cannot remember what he / she says from one moment to the next.		T	F
37…………..kan nie onthou wat hy / sy se van die een oomblik na die volgende toe nie.		W	V
38 It is easy to communicate with -------------.		T	F
38 Dis maklik om met…………te kommunikeer.		W	V
39 The constant demands to care for ----------- limit my growth and development.		T	F
39 Die gedurige eise om………..te versorg beperk my groei en ontwikkeling.		W	V
40 -------------- accepts himself / herself as a person.		T	F
40……………aanvaar homself / haarself as persoon.		W	V
41 I feel sad when I think of --------------.		T	F
41 Ek voel treurig wanner ek aan……….dink.		W	V
42 I often worry about what will happen to ----------- when I no longer can take care of him / her.		T	F
42 Ek bekommer my dikwels wat met………….sal gebeur wanneer ek nie langer hom / haar kan versorg nie.		W	V
43 People can't understand what ---------- tries to say.		T	F
43 Mense kan nie verstaan wat…………probeer se nie.		W	V
44 Caring for ------------- puts a strain on me.		T	F
44 Die versorg van………plas my onder druk.		W	V
45 Members of our family get to do the same kind of things that other families do.		T	F
45 Ons familielede kry dit regom dieselfdedinge te doen as ander gesinne.		W	V
46 ------------- will always be a problem to us.		T	F
46…………..sal altyd vir ons 'n probleem wees.		W	V

47 ------------- is able to express his / her feelings to others.	T	F
47…………..is om staat om sy / haar gevoelens uit te druk teenoor anders.	W	V
48 ------------- has to use a bedpan or nappy.	T	F
48………….moet 'n bedpan of luier gebruik.	W	V
49 I rarely feel blue.	T	F
49 Ek voel selde terneergedruk.	W	V
50 I am worried much of the time.	T	F
50 Ek voel dikwels bekommerd.	W	V
51 ------------- can walk without help.	T	F
51………….kan sonder hulp loop.	W	V

The following set of questions looks at preferred ways of coping with your child with an intellectual disability. Please answer all the following questions by circling the most appropriate number where:

1 = not used
2= used occasionally
3= used often
4- used a great deal

If you have any comments to add, please write these in the space below the relevant question.

Die hieropvolgende stel vrae kyk na die beste maniere om met u kind wat 'n intellektuele gebrek het reg te kom. Geliewe al die hieropvolgende vrae te beantwoord deur die geskikste nommer te bring waar:

1=nie gebruik nie
2=af en toe gebruik
3=dikwels gebruik
4=baie gebruik

As u enige kommentare wil byvoeg, skryf dit asseblief in die spasie onder die relevante vraag.

1 I try to analyze the situation in order to understand it better.	1	2	3	4
1 Ek probeer die situasie ontleed om dit beter te verstaan.	1	2	3	4
2 I make a plan of action and follow it.	1	2	3	4
2 Ek maak 'n plan van aksie en volg dit.	1	2	3	4
3 I talk to someone who can do something concrete about the problem.	1	2	3	4
3 Ek praat met iemand wat tasbaars aan die probleemkan doen.	1	2	3	4
4 I think up a couple of different solutions to problems.	1	2	3	4
4 Ek dink 'n paar verskillende oplossings van probleme uit.	1	2	3	4
5 I try to come out of experiences better than when I went in.	1	2	3	4
5 Ek probeer beter by ondervindings uitkom as toe ek ingegaan het.	1	2	3	4

6 I try to make myself feel better by exercising or getting involved in something.	1	2	3	4
6 Ek probeer myself beter te laat voel deur aan oefening deel te neem of by iets betrokke te raak.	1	2	3	4
7 I try to get professional help.	1	2	3	4
7 Ek probeer professionele raad te kry.	1	2	3	4
8 I draw on my past experiences.	1	2	3	4
8 Ek put uit my vroeere ondervindings.	1	2	3	4
9 I try to see things from the other person's point of view.	1	2	3	4
9 Ek probeer dinge vanaf die ander persoon se oogpunt te sien.	1	2	3	4
10 I try to leave things somewhat open.	1	2	3	4
10 Ek probeer om dinge ietwat oop te laat.	1	2	3	4
11 I rediscover what is important in life.	1	2	3	4
11 Ek herontdek wat belangrik is in die lewe.	1	2	3	4
12 I try not to act too hastily or follow my first hunch.	1	2	3	4
12 Ek probeer om nie te hasstig op te tree nie of om my eerste voorgevoel te volg nie.	1	2	3	4
13 I stand my ground and fight for what I want.	1	2	3	4
13 Ek staan vas en baklei vir wat wat ek wil he.	1	2	3	4
14 I usually know what has to be done so I keep up my efforts to make things work.	1	2	3	4
14 Ek weet gewoonlik wat gedoen moet word, dus hou ek aan met my pogings om dinge te laat werk.	1	2	3	4
15 I try to change or grow as a person in a good way.	1	2	3	4
15 Ek probeer om te verander of te groei as mens op 'n goeie manier.	1	2	3	4
16 I look for the silver lining, so to speak; try to look on the bright side of things.	1	2	3	4
16 Ek hou die blink kant bo, kan jy se, probeer om die ligsy van dinge te sien.	1	2	3	4
17 I am inspired to do creative things.	1	2	3	4
17 Ek is geinspireer om skeppende dinge te doen.	1	2	3	4
18 I wish that I could change how I feel.	1	2	3	4
18 Ek wens ek kon verander hoe ek voel.	1	2	3	4
19 I wish that the situation would go away or somehow be over with.	1	2	3	4
19 Ek wens die situasie wil weggaan of op een of ander manier oor wees.	1	2	3	4
20 I daydream or imagine a better time or place than the one I am in.	1	2	3	4
20 Ek dagdroom of stel voor 'n beter tyd of plek as die waarin ek is.	1	2	3	4
21 I wish that I could change what has happened.	1	2	3	4
21 Ek wens ek kon verander wat gebeur het.	1	2	3	4

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22 I have fantasies or wishes about how things might turn out.   **1**   **2**   **3**   **4**
22 Ek het fantasiee of wense oor hoe sake dalk mag uitdraai.   **1**   **2**   **3**   **4**

23 I try to change something about myself.   **1**   **2**   **3**   **4**
23 Ek probeer iets aan myself verander.   **1**   **2**   **3**   **4**

24 I accept that I bring problems on myself.   **1**   **2**   **3**   **4**
24 Ek aanvaar dat ek probleme aan myself afbring.   **1**   **2**   **3**   **4**

25 I hope a miracle will happen.   **1**   **2**   **3**   **4**
25 Ek hoop 'n wonderwerk sal gebeur.   **1**   **2**   **3**   **4**

26 I prepare myself for the worst.   **1**   **2**   **3**   **4**
26 Ek berei myself voor op die ergste.   **1**   **2**   **3**   **4**

27 I tell myself things that help me to feel better.   **1**   **2**   **3**   **4**
27 Ek vertel myself dinge wat my help beter voel.   **1**   **2**   **3**   **4**

28 I take it out on other people.   **1**   **2**   **3**   **4**
28 Ek haal dit uit op ander mense.   **1**   **2**   **3**   **4**

29 I make a promise to myself that things will improve   .   **1**   **2**   **3**   **4**
29 Ek belowe myself dat dinge sal verbeter.   **1**   **2**   **3**   **4**

30 I criticize or lecture myself.   **1**   **2**   **3**   **4**
30 Ek kritiseer of berispe myself.   **1**   **2**   **3**   **4**

31 I avoid being with people in general.   **1**   **2**   **3**   **4**
31 Oor die algemeen vermy ek kontak met mense.   **1**   **2**   **3**   **4**

32 I accept the next best thing to what I want.   **1**   **2**   **3**   **4**
32 Ek aanvaar die naasbeste ding tot die wat ek wil he.   **1**   **2**   **3**   **4**

33 I do something which I don't think will work, but at least I feel
         I'm doing something.   **1**   **2**   **3**   **4**
33 Ek doen iets wat ek nie glo sal werk nie, maar ek voel   **1**   **2**   **3**   **4**
         ten minste dat ek iets doen.

34 I go over in my mind what I might say or do.   **1**   **2**   **3**   **4**
34 Ek oorweeg in my gemoed wat ek miskien moet se of doen.   **1**   **2**   **3**   **4**

35 I refuse to believe that it has happened.   **1**   **2**   **3**   **4**
35 Ek weier om te glo dat dit gebeur het.   **1**   **2**   **3**   **4**

36 I go on as if nothing has happened.   **1**   **2**   **3**   **4**
36 Ek gaan voort asof niks gebeur het nie.   **1**   **2**   **3**   **4**

37 I find new faith.   **1**   **2**   **3**   **4**
37 Ek vind nuwe geloof.   **1**   **2**   **3**   **4**

38 I maintain my pride and keep a stiff upper lip.   **1**   **2**   **3**   **4**
38 Ek behou my trots en wys nie my gevoelens nie.   **1**   **2**   **3**   **4**

39 I remind myself how much worse things could be.   **1**   **2**   **3**   **4**
39 Ek herinner myself daaraan hoeveel erger sake kon gewees het.   **1**   **2**   **3**   **4**

40 I make light of the situation; I refuse to get too serious about it.	1	2	3	4
40 Ek beskou die situasie in 'n ligte luim: ek weier om te ernstig daaroor te raak.	1	2	3	4
41 I talk to someone about how I am feeling.	1	2	3	4
41 Ek praat met iemand oor hoe ek voel.	1	2	3	4
42 I accept sympathy and understanding from someone.	1	2	3	4
42 Ek aanvaar simpatie en begrip van iemand.	1	2	3	4
43 I let my feelings out somehow.	1	2	3	4
43 Ek gee op een of ander manier uiting aan my gevoelens.	1	2	3	4
44 I accept it, since nothing can be done.	1	2	3	4
44 Ek aanvaar dit, aangesien niks gedoen kan word nie.	1	2	3	4
45 I turn to work or substitute activity to take my mind off things.	1	2	3	4
45 Ek wend my tot werk of ander aktiwiteit om my van dinge te laat vergeet.	1	2	3	4
46 I try to keep my feelings from interfering with other things too much.	1	2	3	4
46 Ek probeer keer dat my gevoelens ander dinge te veel hinder.	1	2	3	4

Please write any other comments you may wish to make about this questionnaire here:
Skryf asseblief enige kommentaar wat u graag wil maak oor hierdie vraelys hier neer.

_____

_____

_____

_____

_____

Thank you very much for your time taken to complete this questionnaire.
Baie dankie vir die tyd wat u met die invul van hierdie vraelys afgestaan het.
Frances Hill.
M.Ed. Psych. Student, University of Stellenbosch

APPENDIX D: Individual Interview Schedules

Individual Interview Schedule: **Participant No. 1**

Individual Interview Schedule: **Participant No. 2**

Individual Interview Schedule: **Participant No. 3**

Individual Interview Schedule: **Participant No. 4**

Individual Interview Schedule: **Participant No. 5**

Individual Interview Schedule: **Participant No. 6**

Individual Interview Schedule: **Participant No. 7**

Individual Interview Schedule: **Participant No. 8**

Individual Interview Schedule: **Participant No. 9**

Individual Interview Schedule: **Participant No. 10**

Individual Interview Schedule: **Participant No. 11**

Individual Interview Schedule: **Participant No. 12**

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 1.   Tel.
Date: February 2002
Child's name: X
Other: 8 year old son. Self-employed.
Found the T/F choice too limiting: lots of omissions & qualitative comments in & after text.
Practical & more use of social supports than others.
"Unstable" answering the questionnaire; "grateful: things could be worse"; guilt re. sad feelings. Not easy to relax.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping? (see "other").

How do you feel about the **future** of the family and the **child? "I'll always take care of her."**

How did you feel about completing the questionnaire? "tricky,"

Secondary questions

Who *accepts* the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness?" **Not easy to relax."**

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 2.   Tel.
Date: February 2002
Child's name: X
Other: English/Afrikaans. Works. 10year-old.
        Difficulty understanding what the child is saying. Pride, frustration, acceptance
        but proactive re. helping child, though see coping style.
        Practical vs. other coping strategies.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping?

How do you feel about **the future** of the family and X? **Outlyer: not worried re. the future.**

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness?

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULES

Name: Participant No. 3   Tel.
Date: February 2002.
Child's name: X
Other: English/Afrikaans.2 years 10 months sister. Not employed.
          Complete page 8 of the questionnaire.
          Easier to accept child 'cos no financial problems & lots of assistance.
          Qualitative notes very clear re. feelings.
          Outlyers include: spoils holiday pleasure.
          "school is a happy place."vs. "sad, though not bitter."
          "spiritual growth"+ sister is a compassionate "soul." + references to "acceptance."
          Strong emphasis on practical coping.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping? Spiritual or other ways of coping.

How do you feel about the **future** of the family and for **X?**

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness?

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 4.   Tel.
Date: February 2002
Child's name: X
Other: Works. Child of 4 years 7 months.
        Omitted the 2nd questionnaire & 9 questions from the 1st questionnaire.
        Outlyer; child has too much time on her hands.
        No qualitative comments.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping?

How do you feel about the future of the family and the child?

How did you feel about completing the questionnaire? No qualitative comments.

Secondary questions

Who *accepts* the child most/least?

Who takes ***primary responsibility*** for the child? Associated feelings: guilt/sadness?
Child has too much time on her hands; mom has too little time?

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 5.   Tel.
Date: February 2002
Child's name: X
Other: Only child at home. Not employed.
        Practical, stoical & some use of other coping approaches.
        Found T/F difficult: lots of qualitative comments, especially for negative
        responses. Things that stood out:
        "one would have to be perfect", "professionals" (in inverted commas), "*act*
        positively", "times when *things* get too much", "accepted *things*."

Questions:

Describe your family life since the birth of the child.

What (who) helps/hinders coping?

How do you feel about the future of the family and the child?

How did you feel about completing the questionnaire?

Secondary questions

Who accepts the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness?

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would
turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 6.   Tel.
Date: February 2002
Child's name: X
Other: Works. 12yearold son.
          Mainly stoical; practical, passive.
          Contradictions: negative impact of child on mom/family, yet says is an Optimist.+
          little use of social supports, but found school useful (control issues).
          Omissions re. disappointment (27), time on hands (28) and hasty decisions (12)

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping?

How do you feel about the **future of the family and X**?

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least? **Ambivalence? Negative impact on mom's / family's functioning.**
+
Who takes *primary responsibility* for the child? Associated feelings: guilt / sadness? **Depression? Taught optimism. "Light at the end of the tunnel", "positive most of the time."**

Probes:

Why stoical coping **versus social supports**? If the latter, when would use, whom would turn to and why/why not? **Found school very helpful.**

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 7.   Tel
Date: February 2002
Child's name: X
Other: Afrikaans. 2.5 yearold son. Works.
          Practical, wishful, stoical…i.e. variety of coping.
          Q1 outlyer q.20: upset with the way her life is going.
          Difficulty answering T/F re. future of child; qualitative comments instead.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping?

How do you feel about the **future** of the family and **the child?**

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness? **Upset with way her life is going.**

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 8.   Tel.
Date: February 2002
Child's name: X
Other: Afrikaans. Other children: 10 & 4.5 years old. Single. Works.
        Question marks & qualitative comments for Q1: questions 36, 39 & 46.
        Makes use of all coping strategies.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping?

How do you feel about the **future** of the family and the **child?**

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness?
Time for self?

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 9.   Tel.
Date: February 2002
Child's name: X
Other: Afrikaans. Works. Only child +
    1st questionnaire more negative impact responses.
    Very stoical; not much use of social supports.
    Outlyer: mom's development limited.
    Omission: Bothers me that child will always be this way.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping?

How do you feel about the **future** of the family and the **child? Omission re. "it bothers me that the child will always be this way."**

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness? **Mom's development limited (outlyer)+ see probe. Time for self?**

Probes:

Why stoical versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 10.   Tel.
Date: February 2002
Child's name: X
Other: Afrikaans. 9-year-old twins + 7 year old. Part time employed.
         Mostly practical; little social support.
         No omissions. No outlyers.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping?

How do you feel about the future of the family and the child?

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness?

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 11.   Tel.
Date: February 2002.
Child's name: X
Other: Other children aged 22, 18 & 15. Part time employed.
          Mostly support & passive acceptance: less practical than others.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping? Uses support & passive acceptance more than others

How do you feel about the future of the family and the child?

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least?

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness?

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?

INDIVIDUAL INTERVIEW SCHEDULE

Name: Participant No. 12   Tel.
Date: February 2002
Child's name: X
Other: Afrikaans. 2 adolescents. Does not work.
Lots of qualitative comments in text + question marks: lots of omissions, notably associated with negative feelings.
2nd questionnaire: confusing results.

Questions:

Describe your family life since the birth of the child.

What helps/hinders coping?

How do you feel about the future of the family and the child?

How did you feel about completing the questionnaire?

Secondary questions

Who *accepts* the child most/least? **Acknowledgement of negative feelings?**

Who takes *primary responsibility* for the child? Associated feelings: guilt/sadness?

Probes:

Why practical coping versus social supports? If the latter, when would use, whom would turn to and why/why not?