1999

# Giving birth to and parenting children with developmental disabilities: an application of persoanl construct psychology

Patricia Weekes
*University of Wollongong*

## Recommended Citation

Weekes, Patricia, Giving birth to and parenting children with developmental disabilities: an application of persoanl construct psychology, Doctor of Philosophy thesis, Department of Psychology, University of Wollongong, 1999. http://ro.uow.edu.au/theses/1661

# GIVING BIRTH TO AND PARENTING CHILDREN WITH DEVELOPMENTAL DISABILITIES: AN APPLICATION OF PERSONAL CONSTRUCT PSYCHOLOGY

**A thesis submitted in fulfilment of the requirements for the award of the degree**

**DOCTOR OF PHILOSOPHY**
**(CLINICAL PSYCHOLOGY)**

**from**

**THE UNIVERSITY OF WOLLONGONG**

**by**

**Patricia Weekes, B.A. (Hons.)**

**Department of Psychology**

**1999**

# DECLARATION

The research reported here is original work. It has not been submitted, either in whole or in part, for a higher degree to any other University.

Patricia Weekes.

Date.

# ABSTRACT

This research explored the responses of people to giving birth to and parenting children with developmental disabilities. Two issues in particular were investigated: the construct pole preferences of parents and their emotional states. The content of the most influential self-referring constructs was obtained, along with the content of the structural triggers of the emotional states.

Based on a literature review from various theoretical frameworks, along with personal construct psychology, I developed a preliminary personal construct model of the adaptation process to giving birth to and parenting children with developmental disabilities. This model was tested and elaborated from qualitative and quantitative analysis of interview data collected from 81 participants. It was a longitudinal study with the first data collection being within 6 to 24 months of the diagnosis and the second data collection being 18 months later. A matched control group of 81 parents of children without disabilities was interviewed on both occasions.

The results indicated that parents of children with developmental disabilities did experience significantly higher levels of cognitive anxiety, death, mutilation, separation, guilt, and shame when compared with parents of children without developmental disabilities. The participants who could incorporate the event into their preferred way of viewing life, experienced less anxiety compared with parents who perceived themselves as being on their non-preferred construct poles.

The adaptive process was most effective when parents experienced themselves as having been de-railed by the events from their preferred construct pole and reconstrued life. In so doing they moved again to their preferred construct pole. This group of parents indicated no significant difference in the levels of their negative emotions compared to parents who gave birth to children without developmental disabilities.

# ACKNOWLEDGMENTS

From the list of those to whom I am indebted for their participation in this research, I wish most of all to thank the families involved.

In our interviews many of you spoke of your motivation for contributing as to be a means of helping in whatever way possible other families who had children with developmental disabilities. I found your generosity inspiring and feel most privileged to have been given the opportunity to hear your story. Know that your contribution has at least greatly affected my own work both as a therapist and a health worker in this field of developmental disabilities. In addition, your participation has allowed for the further development of a theoretical model which will be made available for others to study.

I am also indebted to my professional mentors--Linda Viney, my supervisor throughout this research for her intellectual clarity and her ability both to guide and challenge while acknowledging my own level of expertise; to Rachael Henry, Linda Viney and, in particular, Peter Blake for the clinical supervision which allowed me to hear more fully and understand more completely the stories presented by the families in this research; to Peter Caputi for the statistical expertise and advise offered so generously.

To Marian McGrath, RSM, I offer thanks for her support and companionship as we travelled the miles to each research participant; for her work as co-rater in the coding and scoring of data; for listening critically to my interpretations of that data.

In conclusion, I would like to thank my Congregation, the Sisters of Mercy, my community and my friends for their love, their faithfulness and their belief in me throughout this four year period. My affection for you all is great.

# TABLE OF CONTENTS

2. GIVING BIRTH TO AND PARENTING CHILDREN WITH DEVELOPMENTAL DISABILITIES: A PERSONAL CONSTRUCT PERSPECTIVE

3. AN OVERVIEW OF THE MODELS OF GRIEF

4. THE PERSONAL CONSTRUCT PSYCHOLOGY MODEL OF GRIEF

7. THE EFFECTS OF TYPE OF CHILD AND CONSTRUCT POLE PREFERENCES ON THE EMOTIONAL STATES AND EXPERIENCES OF PARENTS:
RESULTS 1

8. THE THEMES LINKED TO THE EMOTIONAL STATES AND EXPERIENCES OF THE PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITEIS:
RESULTS 2

## 9. THE FINDINGS, IMPLICATIONS AND LIMITATIONS OF A STUDY OF THE GRIEF AND ADAPTATION PROCESSES RELATED TO GIVING BIRTH TO AND PARENTING CHILDREN WITH DEVELOPMENTAL DISABILITIES

APPENDIX

## LIST OF TABLES

# CHAPTER 1

# GIVING BIRTH TO AND PARENTING CHILDREN WITH DEVELOPMENTAL DISABILITIES:

## AN OVERVIEW

In this research I am concerned with the effects on parents of giving birth to and rearing children with developmental disabilities. Approximately 4,300 (1.6%) Australians are born each year with significant defects which are diagnosed at birth or soon afterwards (Australian Institute of Health & Welfare, 1997). The number of such births showed an increase for the period of 1981-92 to 1993 (155.9 to 169.9 per 10,000) and then decreased in 1994 (164.4 per 10,000) (AIH &W, 1995, 1997). The national rates for the developmental disabilities of Downs syndrome (12.8 per 10,000) and Edwards syndrome (2.2 per 10,000) have remained relatively constant from 1985 to 1994 (AIH&W, 1997). Such statistics indicate that a significant number of families are confronted each year with the situation of having given birth to and parenting children with developmental disabilities. They do this within the social context of our Australian western culture which, I suggest, is strongly oriented towards ability, and away from disability. This research explores how this event affects the way the parents view their lives and what influence it has on their emotions.

The research uses personal construct psychology to explore the process undertaken by parents as they adapt to this new situation in their lives. While personal construct psychology has previously been applied to the field of disability from a theoretical perspective, along with that of clinical case studies, limited research using large sample sizes was able to be found. Research from other theoretical frameworks about various aspects of disability is available, but less regarding the adaptation process necessary for parents.

This first chapter will critically review the available research. It provides a means of presenting an overview of recent understanding of the effects that children with developmental disabilities have on families. Information which is available regarding the process of adaptation will also be offered. Chapter 2 will give the current thinking on the effects of disability on family relationships as seen through the eyes of personal construct theory.

The questions to be answered by this chapter are: what has the research so far told us of the experience of families who give birth to and parent children with developmental disabilities? What effect does this situation have on family, spousal, and societal relationships? How does it affect the experience and perception parents have of themselves?

## Critique of the Research Prior to the 1990's

Much of the research up to and throughout the 1980's which looked at the effects on parents of giving birth to and parenting children with disabilities was based on the assumption that the situation would result in a high degree of pathology in family functioning (Crnic, Friedrich, & Greenberg, 1983; Krauss, 1993; Margalit & Ankonina, 1991; Margalit, Raviv & Ankonina, 1992; Summers, 1988), and used a stress-related model to explain the pathology (Crnic et al.; Margalit & Ankonina; Margalit et al.; Summers). Summers proposed that the bases of the assumptions used by researchers up until this time were that families of children with disabilities were disabled families, the effect of disability was pervasive and 'bad', and 'good' families reordered their lives around the needs of the children with the disabilities. Crnic et al. proposed that it was this assumption of a pathological adaptation that led to the stress-related model to explain family functioning.

The traditional stress-related models were criticised for being unable to deal with the apparent diversity of family reactions in terms of some families managing well while others were not able to cope under similar or seemingly less challenging circumstances (Crnic et al., 1983; Summers, 1988), and the models did not adequately account for the complexities of the cyclic impact of disability on all members of the family (Crnic et al.). The difficulties of formulating models which addressed these dynamics seemed too great; researchers tended to deal with them by giving the research a narrow unidimensional focus, such as addressing specific family members (most frequently mothers) and/or a specific variable (Crnic et al.).

Throughout the 1980's theoreticians such as Crnic et al. (1983) and Summers (1988) also described much of the research relating to the impact of disability on families as lacking uniformity in definitions, having methodological inadequacies, and yielding inconsistent and conflicting findings.

Many of the methodologies used prior to the 1990's were criticised for being non-analytical (Murphy, 1982); lacking or having inappropriate control groups (Crnic et al., 1983; Murphy, 1982); having small and poorly defined samples (Crnic et al.), employing measures with poor reliability and validity (Crnic et al.); lacking a longitudinal perspective (Crnic et al.); limiting research strategies using only one type of measure such as a questionnaire or an interview or a rating scale and rarely behavioural observation (Crnic et al.). Scorgie et al. (1998) also suggest that this research has been fragmented by the diversity of methods and perspectives brought to bear on the subject.

# Critique of the Research During the late 1980's and 1990's

A sample of the research available from the late 1980's and 1990's will be presented and critiqued in the following section. This research will be presented under these themes: family, siblings, spousal relationships and perceptions of the self.

## Family Relationships

### Parental Interaction with Children with Developmental Disabilities

Margalit and Ankonina, writing in 1991, supported the notion that the traditional stress research model envisioned that stressors resulted in pathology, but also saw a trend in stress resistance researchers to emphasize people's capacity to remain healthy when stressors occur. This demonstrated the value of effective coping strategies. It was Crnic et al. (1983) who proposed this stress-adaptational model.

It was by using this stress resistant or stress adaptational model that Margalit and Ankonina (1991) and Margalit et al. (1992) conducted their research. Margalit et al. hypothesised that parents of children with disabilities would demonstrate their stress through more negative affect, and have a higher focus on avoidance coping, compared with a control group. In addition, they proposed that adaptive personal and familial factors may mediate the increased stress expected to characterize these families. Their sample was 71 parental couples with children with disabilities and 77 couples with children without disabilities, matched for parental ages, educational levels and number of children in the family. The criterion for selecting the children with disabilities was that they presented evidence of disabilities of a chronic nature interfering with normal functioning and requiring continuous special educational services. The handicapping conditions were learning disabilities, mental retardation, and emotional/behavioural disorders. The children included 45 males and 26 females with an average age of 9.96 years. The instrument used was the Affect Scale (reflecting the parents' view of their own Positive Affect, that is, alert, friendly or energetic; and Negative Affect, that is, feeling guilty, worthless or worried); and the Coping Scale (reflecting the parents' view of their own coping strategies, including Avoidance Coping with items such as 'Took it out on people when I felt angry or depressed' and Active Coping with items such as 'Made a plan of action and followed it'). In addition they used the Family Environment Scale (reflecting the parents' perceptions of their family climate yielding three domains: Relationship, Personal Growth, and System Maintenance [not defined] ) and the Child Behaviour Check List (reflecting the parents' perceptions of their disabled children's level of maladjustment indicated by statements such as 'Acts younger than his age' or 'Sees things that don't exist').

The results indicated that fathers and mothers of children with disabilities reported significantly less emphasis on family interrelational aspects and experienced less supportive family relationships, fewer opportunities for personal growth in the family, greater use of avoidance as a coping strategy, and much higher distressed affect than did parents of children without disabilities. In relation to exploring the stress resistant factors it was found that positive affect for parents of children with disabilities was significantly predicted by parental active coping, family relations, and opportunities for personal growth. For families of children without disabilities, only the personal growth variable significantly predicted positive affect. Limitations of the study include the fact that it was conducted in Tel-Aviv and so the question arises of whether the results can be generalised due to varying cultural influences related to stress; and it did not have a longitudinal component.

Margalit et al. (1992) describes further research hypothesizing that an increased use of avoidance coping (defined as efforts to deny, minimize, or escape stressful situations because they were viewed as uncontrollable and not amenable to change), would discriminate between families of children with and without disabilities. The research had a sample size of 78 parental couples (mothers and fathers) with children with disabilities, and a control group of 83 families with no significant differences on the demographic factors of age, educational level, and number of children. The criterion for selecting the children with disabilities and their handicapping conditions was the same as Margalit and Ankonina (1991). The four instruments used for data collection were the Coping Scale, Family Environment Scale, the Child Behaviour Checklist (each as described in Margalit & Ankonina, 1991 research), and the Sense of Coherence Scale (reflecting the parents' orientation of confidence and optimism). As in the Margalit and Ankonina (1991) study, the results again indicated that parents of children with disabilities reported significantly higher levels of avoidance coping and lower levels of family inter-relations, than did parents of children without disabilities. The limitations of the study include the fact that it was again undertaken in Israel, which raises the question of how much it is able to be generalised across cultures.

A theoretical limitation of the stress-related model is that associated research aims to name the environmental or relationship factors which influence the varying levels of stress. They do not attempt to explain the psychological processes involved in coping with the stress-related situtions.

Levy-Shiff (1986) examined the effects that children with developmental disabilities had on family functioning by studying the multiple interactions of mothers, fathers, and children at home. There were 20 children with mental retardation involved in the study with a control group matched for socio-economic status, gender, birth order, and developmental age. The measurement tool was a 90 minute observation of parents' behaviours (categorised into general involvement such as teaching, responding, and playing; affection; limit setting; and care taking) and children's behaviours (laughing and smiling, vocalising, offering and showing, moving towards, seeking comfort, asking for help, crying). The observation took place in the family home with two observers (one for the parents' behaviours and one for the children's), using a precoded checklist of behaviours administered every 15 second period.

The results indicated that parents of children with disabilities engaged in verbal sequences, paid attention, had physical contact, and expressed affection less than did parents of children without disabilities. The difference was much greater between the mothers and their control group for these factors than was the difference for the fathers and their controls. Also fathers of children with and without disabilities engaged in teaching and stimulating their children to a similar degree, whereas mothers of children with disabilities engaged in these activities less than did mothers of children without disabilities. On the other hand, mothers exceeded fathers in caregiving (undefined) in both groups, and fathers of children with disabilities were barely involved in this activity. Scoring of husband-wife behaviour indicated that the parents of children with disabilities had more interchanges relating to their children than did parents of children without disabilities. The study took place in Israel which for reasons stated above it may be limited in its ability to be generalised. It also used only one method of data collection. A particular strength of this study was the matching for developmental rather than chronological age of the subject children, supplying an emphasis on stress on parents related to developmental characteristics of children.

The following research, which addresses the aspect of gender and roles taken in families with children with disabilities, could well be placed under the heading of the parents' experiences and perceptions of themselves, particularly since the researcher, Traustadottir (1991), suggests that roles do become closely connected with personal identity. However, I present it under this section of parental interactions because it is a further description of this topic and is supportive of aspects of the previously presented research.

The Traustadottir (1991) research question was: How does gender influence the caring for children with disabilities in the family setting? This was a qualitative study with data being collected over a 2-year period by the researcher doing monthly participant observation in a support group for parents of children with disabilities, and through in-depth interviews of 14 families of children with disabilities. These families were purposefully chosen to reflect diversity in a variety of dimensions including class, race, educational background, single and two-parent families, income, the severity and type of disability, and age of the children with disabilities. The children with the disabilities ranged in age from 2 to 16 years and all were in the mild to severe range of intellectual disability. Many had been given multiple labels: the primary being mental retardation or emotional disturbances; the secondary label being conditions such as cerebral palsy, visual impairment, autism, and seizure disorder. The 14 families were interviewed once through an open-ended general interview schedule which was taped. The researcher's interpretation of the data is as follows: all of the mothers in the study had the main responsibility for caring for the children with disabilities. Caring was defined as caring work ('caring for' or 'taking care of'), caring about (loving the child), and an extended caring role (caring about broader community and societal concerns). Some mothers experienced this caring role as empowering (having a mission in life and a vision to fight for), others as disturbing of their desired lifestyle, and still others having a matter of fact approach, seeing it as just part of life. The fathers' primary role in these families was seen as supporter - financially and of the mothers' dedication and devotion to their children. Traustadottir concluded by suggesting that families of children with disabilities tend to follow the most traditional pattern of family life with a breadwinning husband and a full-time wife and mother. The greatest limitation of this study was that it provided only qualitative data which allows for less objective interpretations.

In summary, this sample of research indicates that families of children with developmental disabilities tend to have less supportive family relationships, are less affectionate, and pay attention to each other less than families of children without disabilities. The parents of children with developmental disabilities also have an increased use of avoidance of stressful situations because these situations are seen as uncontrollable and not amenable to change. In addition families of children with disabilities tend to uphold more traditional family roles.

To look at the other side of the story Stainton and Besser (1998) used a qualitative design directed exclusively towards researching the positive impacts of children with developmental disabilities on families. It was based on two semi-structured group interviews (n=7 and n=8) and two single family interviews. Participants were randomly selected from the membership list of the local parents' association. Participants' ages ranged from under 25 years to over 70. The children of the parents all had an intellectual disability related diagnosis and ranged in age from 0-5 to 26-35 years. The interviews were video or audio taped, transcribed verbatim and analysed using the constant comparative method. The results indicated that the following nine themes could be identified: source of joy and happiness, source of increased sense of purpose and priorities, expanded personal and social networks, and community involvement, source of increased spirituality, source of family unity and closeness, source of increased tolerance and understanding, source of personal growth and strength, positive impacts on others/community, and interaction with professionals and the service system. The limitations of this research include its small sample size, lack of quantitative analysis, and a lack of definition of the themes other than those that could be deducted from small descriptions and quotations.

## Parental Interaction With the Siblings of the Children with Developmental Disabilities

Research indicating the types of parental interaction with the siblings of the children with developmental disabilities presents complex results. One such piece of research is that of McHale & Pawletko (1992). This research examined the differential treatment of siblings in families with and without children with developmental disabilities. In addition, the research assessed the connections between differential treatment and both groups of children's adjustment and sibling relationships. The subjects were 62 children, 8-14 years old, half with younger siblings with mental retardation (no degree given) and half with siblings without identified disabilities and the mothers of all the children. The two groups were matched on children's age, gender, family size, socio-economic backgrounds, and geographic area. In at-home interviews children rated their adjustment and sibling relationships, and mothers reported on discipline strategies used with each child. Structured questionnaires were used with both the children (Childhood Depression Inventory, Revised Children's Manifest Anxiety Scale, Sibling Relationship Inventory) and the mothers (structured interview regarding discipline strategies from which scores were obtained on positive love [involving mediation, reasoning, reflection of feelings, explanations], negative love [involving ignoring, criticizing, isolation], and power assertive techniques [physical direction or punishments, threatening, withdrawal of privileges] ) for data collection. In addition, during 7 nightly phone interviews, mothers were asked about their own activities with each of their children as well as about each child's household tasks during the day of the call.

McHale & Pawletko (1992) present the following complex set of results. I am reporting only those results which are related to differences in groups due to family context (that is, families with verses families without children with disabilities).

a) In relation to activities of play and help mothers spent the most time with the children with disabilities. The children with siblings with disabilities spent more time in play with their mothers than did their control group, that is, were relatively more involved in younger siblings' activities. These children reported the highest levels of depression and anxiety; and children with siblings without disabilities who were least involved in such activities reported the least of such symptoms. (In contrast, when sibling relationship measures were the focus as opposed to activities, highly involved older children with siblings without disabilities were the most vulnerable to depression and anxiety).

b) Children with siblings with disabilities spent the most time involved in household tasks, and their siblings (the children with disabilities) spent the least amount of time on chores.

c) Mothers used more negative love, less positive love, and a higher proportion of power assertive techniques with the children with disabilities than with any other group. Children with siblings without disabilities experienced the lowest rate of power assertive techniques. The experience of more power assertive discipline was associated with more anxiety symptoms, but more positive behaviours towards siblings in children with siblings with disabilities. (Children without disabilities who experienced relatively less power assertive discipline reported the fewest anxiety symptoms, and those who experienced more of such discipline reported the least positive behaviours towards their siblings). Interestingly, relatively higher levels of positive love were associated with more anxiety symptoms in children with siblings with disabilities, but fewer such symptoms in children with siblings without disabilities. The was understood by the researchers in terms of the idea that the children with siblings with disabilities may feel guilty when they receive more favourable treatment than their siblings whose pleasures already may be limited by their disabilities.

d) Children with siblings with disabilities spent more time in conversation with their mothers than did children with siblings without disabilities. More conversation was associated with more positive relationship ratings by children with siblings with disabilities, but more negative ratings by children with siblings without disabilities. Results focusing on conversation also showed that children with siblings with disabilities reported higher levels of anxiety symptoms than did children with siblings without disabilities.

e) Children with siblings with disabilities performed relatively more chores than the children in the family who had disabilities (more than 6 hours difference on average) and reported significantly more anxiety symptoms than children with siblings without disabilities (their control group). The limitations of this study include its reliance on a relatively small sample size, and on self report measures; the parents' questionnaire was not standardised; and it did not have a longitudinal component.

McHale & Pawletko (1992) claim this study provides the first evidence for the notion that children with siblings with disabilities experience greater differential treatment than those with siblings without disabilities. Equally so, they strongly suggest that the differential treatment is a complex and multifaceted phenomenon with the correlates varying depending on the domain being examined.

Stoneman, Brody, Davis and Crapps (1987) examined the topic of sibling relationships where one of the children is mentally retarded. The subjects were 64 children (32 siblings pairs). Sixteen sibling pairs contained a child with mental retardation (7 had Downs Syndrome, 4 organic brain damage, 5 mental retardation due to other causes) and an older same sex sibling (8 males and 8 females). Nonhandicapped comparison siblings were matched on age, sex, race, and parental marital status. Younger siblings' ages ranged from four to eight years and older sibling ages ranged from 6 to 12 years. Data was collected through two home visits per family, with researchers using naturalistic observation and coding each sibling's interactions with all other family members. Observations were quantified using a coded system that has previously been used in studies. The coded roles and behaviours were as: manager (to command or request another to perform), teacher ( to explain, model, demonstrate), playmate (to play using objects/toys), interactor (to interact with another without being engaged in joint play). Other aspects recorded were: positive affective tone (hugs, kisses, smiles, etc), negative affective tone (hits, attacks, pushes, quarrels with, etc), performance in solitude (by oneself), and compliance (to respond to a managing attempt).

The results regarding the aspect of parental interactions with the siblings of children with developmental disabilities were as follows: a) mothers' interactions with older sisters were similar in frequency regardless of whether or not the younger girls in the families had developmental disabilities, but mothers interacted with older brothers who had younger brothers with developmental disabilities more than their comparison group; b) for fathers the pattern was reversed. Fathers interacted less with older sisters of children with developmental disabilities than with comparison older sisters. No difference in frequency of interaction with fathers emerged for older brothers of children with developmental disabilities compared to their control group; c) both parents spent more time with boys with disabilities than with any other group of younger siblings. The limitations of this study included relatively small sample size, only one form of data collection, and no evidence of validity or reliability was provided for the coding system used.

The research suggests that parents' interaction with siblings is affected by having children with developmental disabilities in the family. Points of vulnerability for the siblings of children with developmental disabilities as compared to siblings of children without developmental disabilities are as follows: a) spending more time in less than age-appropriate play; b) doing more household chores; c) experiencing less positive love from mothers; d) experiencing more power assertive discipline techniques, and e) particularly for older male siblings spending more time in conversation and interactions with their mothers, which also correlated with higher levels of anxiety and depression.

### Sibling Interaction

In looking at sibling interaction as an aspect of family relationships, some of the results obtained by Stoneman et al. (1987) (research is described in detail in previous section) are particularly relevant. The results indicated that the proportions of observation intervals spent in solitary play did not differ for sibling pairs, with or without children with disabilities, and that sibling pairs interacted with each other for similar proportions of observation intervals regardless of whether or not one sibling was mentally retarded. This result was not supportive of the predicted decrease in sibling interaction in families with children with developmental disabilities, but the high rates rather confirmed the importance of the sibling interaction in families with children with mental retardation. Some specific descriptions of the sibling interactions compared with their controls or comparison groups are: girls and their younger sisters with disabilities were more likely than comparison sisters to engage in non-competitive physical activities when playing together, whereas female comparison siblings were more likely to watch TV or play with toys or board games; boys and their younger brothers with mental retardation were more likely than comparison brothers to be engaged in toy play when they interacted together, whereas comparison male siblings were more likely to be watching TV or playing games. Older siblings of children with disabilities assumed manager roles more than did comparison siblings; and older sisters of siblings with disabilities engaged in teacher/helper roles more than any other group of older siblings.

Given that descriptions of sibling relationships in families with children with developmental disabilities based on statistical research are scarce, it may be of value to look at the issue of social behaviour of such children within a pre-school setting. Kopp, Baker and Brown (1992) used a sample of 15 children (3-5 years of age) who were within the mild to moderate level of intellectual disability (diagnoses included unknown aetiology, and known chromosomal disorders for example Downs Syndrome, without autism or major sensory or motor disorders). The children were screened through the use of Gesell Development Schedules & the Peabody Picture Vocabulary Test - Revised, and matched controls on gender and chronological age. The procedure involved two 12 minute observed & videotaped play periods: the first play period involved age appropriate toys that *could* elicit pretend play; the second included toys that were *likely* to elicit pretend play. Measurements were taken of each two minute play interval under the categories of: social (solitary, parallel, or social), play (nonplay, functional, constructive, and pretend), maintenance behaviours (descriptions and elaboration) and disruptive behaviours (ignore, rejection, and disruptive entry), affect (positive and negative), and regressive behaviours (I can’t or don’t want to play).

The results of this research indicated that children with developmental delays had significantly more intervals of 'no play' than did the children without disabilities; children with delays were less involved in parallel or social activities than their controls (67% as opposed to 88% respectively); and the major difference occurred in solitary activities where the children with delays were alone almost a third of the episodes. However, when the children with delays and their peers did interact there were many similarities: both groups engaged in communication that helped maintain on-going interactions, and their expressions of negative affect were not appreciably different. Children with delays did evidence more disruptive entry and regressive behaviours that may be especially alienating for peers. A significant limitation of this study is its small sample size and, as acknowledged by the authors, matching the controls on chronological age as opposed to developmental age would exacerbate the difference between the groups.

These results are not supportive of those of Stoneman et al. (1987) even with regard to the fundamental findings of the amount of time children with disabilities spent in no play or solitary activities. The different settings and relationships of family and school clearly need to be acknowledged and could be strong influencing factors, as could the ages of the children (Stoneman et al. - 4-8 years; Kopp et al., 1992 - 3-5 years).

## Spousal Relationships

Floyd and Zmich (1991), using a chronic stress model which incorporated the adaptational component, investigated marital functioning in 38 families with children in the mild to moderate range of mental retardation and evidenced impairment in adaptive functioning. The study also used a control group of 34 families matched for chronological ages and gender of the children with the disabilities, along with family income, number of children at home, families with step-parents, marital status (married or living together), age and education of parents. The measures were the Dyadic Adjustment Scale self report questionnaire which measured dyadic satisfaction, consensus, cohesiveness, and affection; and two subscales from the Family Experiences Questionnaire assessing mutual respect and support, satisfaction with shared responsibilities, and agreement about child care and discipline, along with evaluating parents' experiencing their partners as critical of them in relation to their abilities or actions in the parenting role. A further measurement was through observation of marital problem-solving interaction, which was videotaped and coded using the Communication Skills Test which assesses ability to resolve disagreements in a supportive, effective manner (using techniques such as opinion probes, summarising other's points of view, proposing solutions as opposed to put-downs, blaming, denying responsibility). Other measurements were the Achenbach Child Behaviour Checklist (assessing problem behaviours such as aggressiveness, destructiveness, and other anti-social behaviours); the Parenting Confidence Scale of the Family Experiences Questionnaire (questions include for example 'I have the knowledge I need to be a good parent'); and observation of the parent-child interaction which was videotaped and coded according to the Family Process Coding System (which scores for interactions such as commands and requests vs. coercive threats, complaints, cooperative behaviours vs. aversive actions of the children, praise, affection, physical aggression, verbal attacks, and talk).

The results indicated that, compared to the control group, significantly more negative functioning for the parents of children with mental retardation was observed during marital interactions (and parent-child interactions), however this was not reflected in the self reports of marriage (and parenting). This difference was understood in terms of expectations about marital (and parenting) strains, modulating negative sentiments for these parents. A particular strength of this research was its use of more than one type of measurement - questionnaire and coded observations, along with having a control group.

A further study in relation to marital intimacy in parents of children with developmental disabilities was undertaken by Fisman, Wolf, and Noh (1989). The purpose of the study was to examine the role of perceived parenting stress and parental depression on marital intimacy between parents of children with and without developmental disabilities. The sample consisted of parents of 124 children - 31 with autism with controls of 31 with Downs Syndrome and 62 developmentally average children; half of this latter group were matched for chronological and half for the mental age of the children with autism, and all the controls were matched for gender. The tools used for measurement were the Parenting Stress Index Form, the Beck Depression Inventory, and the Waring Intimacy Questionnaire - all self report instruments.

In relation to intimacy, mothers of children with autism scored the lowest, then mothers of children with Downs Syndrome, leaving the mothers of children without disabilities as experiencing the highest levels of intimacy. Fathers of children with autism experienced significantly lower marital intimacy than the other groups. Low scores on subscales of identity and compatibility for mothers, implying low self esteem, contributed significantly to the lower perception of marital intimacy. The limitations of the study include the lack of a longitudinal component and the use of self report instruments only.

Again, the literature seems to indicate that marital intimacy is negatively affected by the family having children with developmental disabilities. However, it is interesting that parents might begin to see intimacy differently.

## Societal Relationships

Flynt, Wood, and Scott (1992) investigated social support networks for mothers of children with developmental disabilities. Their sample group was 80 mothers (21 to 60 years with a mean age of 35.8 years) whose children had been diagnosed with moderate levels of mental retardation. The children ranged in age from 6 months to 20 years. The instruments used were the Questionnaire on Resources and Stress Short Form and the Questionnaire on Social Support. Results indicated that the degree to which mothers with children with disabilities utilised social supports remained consistent across age groups. There was a significant difference between types of social support used by the different age groups. Mothers of preschoolers relied more on intimate support (spouse) than either friendship or community support networks, compared to mothers of older children. Caution in relation to several aspects of interpretation of its findings needs to be observed in regard to this study: a slightly greater proportion of mothers in the preschool age group were married and so allowed greater opportunity for the spouse to be the primary support agent; and research using different subjects at different life cycle stages, rather than having a longitudinal component, can potentially confound results; as well, the absence of any control group prevents comparison of social support needs with parents of children without developmental disabilities.

The social component of families of children with developmental disabilities was also investigated by Bailey, Blasco, and Simeonsson (1992) through the use of the Family Needs Survey. The sample included 422 parents obtained by combining four sets of data from prior research. The sample was diverse in terms of caregiver status, geographical location, race, child age, and disability. The average age of the children with disabilities was 26.8 months, with a range from 3 to 168 months. The disabilities included motor impairment, visual impairment, mental retardation, speech or hearing impairment, and developmental delay. The measuring instrument used was The Family Needs Survey consisting of 35 items grouped into six subscales designed to document family needs (for example "I need more information about my child's condition or disability"). The major findings of the study indicated that need categories as expressed by mothers were: information, financial help, opportunities to meet other parents of children with disabilities (above needs stated in order of priority weighting), family and social support, explaining to others, child care, and professional support. Mothers expressed significantly more needs than did fathers, and primarily in family and social support, explaining to others, and child care. The factor structure for fathers was significantly different from that obtained for mothers. While the study has a large sample size it is limited by having only one instrument for measurement, this instrument having only 35 items, and in that the needs expressed could only be in response to predetermined statements, and therefore may not reflect the range of family needs.

Birenbaum and Cohen (1993), responsible for an American study, collected data in 1985-86 in relation to 308 subjects under age 25 with autism, and from 326 children and young adults with severe or profound mental retardation. They measured and reported on nonmedical expenditures and opportunity costs pertaining to maintaining children or young adults with serious developmental disabilities in their homes or in residential care. Information such as the following indicates the level of support these families obtain from society. Parents of children 10-24 years old reported that only one third of those with autism could take care of themselves, even for a few minutes. Less than one fifth of the offspring with severe to profound mental retardation could take care of themselves. Only one fourth of these 10 to 24 year old people received regular care from someone outside the household, about half from a relative. This study revealed that parents continually carried excessive expenses such as medical costs or for ramps and disabled bathrooms for their children with disabilities, without sufficient financial assistance from society.

Societal support for these families is clearly limited and the amount available does not correspond to need. In addition to the information provided in the above research on this topic parents also speak of the disapproval society displays toward them for not aborting their children (Raphael-Leff, 1993 [research described below] ), along with friends of the family and family of origin finding it difficult to accept and spend time with the children with disabilities (Darling, 1979 [research described below in the section on models of adaptation]). The continuous struggle parents have to obtain access to mainstream schools for children with disabilities is a further expression of the lack of acceptance by society of this group of people.

## The Experience and Perception Parents Have of Themselves

Giving birth to and parenting children with developmental disabilities has profound effects on parents' experience and perceptions of themselves. This aspect can be explored from the perspective of external factors such as opportunities for personal growth and explored from the vantage point of parents' perception of themselves and their situation.

The research done by Margalit et al. (1992) (described above under Family Relationships - Parental Interactions With the Children with Developmental Disabilities) indicated that parents of children with disabilities perceived themselves as having fewer opportunities for personal growth (not defined in the research) and lower levels of coherence (defined as confidence and optimism) compared to parents of children without disabilities.

Krauss (1993) used the stress model to research the child-related and parenting stress experienced by parents of children with disabilities and whether there were significant differences between the mothers and fathers' perceived experience. Child-related stress referred to behavioural and temperamental qualities of the children (for example distractibility, mood, demandingness), and parenting stress referred to dimensions of the parents' functioning (for example depression, sense of competence, relations with spouse). The data for this study was drawn from that obtained for the Early Intervention Collaborative Study 1992. This was a longitudinal, non-experimental investigation of developmental changes in children and families from their time of enrolment in early intervention programmes through the pre-school years. This longitudinal component was not maintained in the Krauss study. The subjects for the Krauss study were selected on the basis of available data and on being married. There were mothers and fathers of 121 children - 39 with Downs syndrome, 44 with motor impairment, and 38 with developmental delay. The mean age of the mothers was 30.4 years and of fathers was 32.4 years. There were significant differences across diagnostic groups with respect to children's age and prematurity status. The measures used all required self reporting. They included the Parenting Stress Index consisting of two domains: the Parent domain measuring attachment to the child, parental depression, parent health, social isolation, restrictions in role, and relations with spouse; and the Child domain measuring demandingness, distractibility, mood, degree of reinforcement to the parent, acceptability, and adaptability. The measures used also included Child Improvement Locus of Control Scale (measuring parental beliefs concerning who influences improvement in the children, parents or professionals); the Parent Support Scale (measuring parental social supports and their degree of helpfulness to the parent); and the Family Adaptability and Cohesion Evaluation Scales 11 (measuring parental perception of the degree of adaptability within the family). The results indicated that mothers and fathers reported similar levels of parenting-related stress overall and were well below those considered to be clinically significant (as opposed to being compared with a control group). There were, however, revealing differences between mothers and fathers with respect to specific dimensions of parenting stress. Mothers reported higher stress with the personal impacts of parenting such as personal health, restrictions in role, and relations with spouse, whereas fathers reported more stress related to their children's temperament (for example children's moods and adaptability) and their relationship to the children (for example feelings of attachment and of being reinforced by the children). Fathers, when compared with mothers, also perceived their families as less emotionally cohesive and adaptable. The limitations of this study include the fact that only one type of measurement was used, that being self reporting indexes. The differences in types of disability of the children, that is approximately two thirds of the subject children had developmental delays, and one third had motor impairment, could also have contaminated the results.

The effects of giving birth to and parenting children with developmental disabilities have also been addressed from a psychoanalytic perspective. Raphael-Leff (1993) presents data from clinical sources of 200 woman who were pregnant during the time of psychotherapy. Some of the women were seen in analysis or psychotherapy from one to five times per week for two to seven years each. Data were also obtained from baby observations, clinical discussions, discussion groups, therapy groups, and workshops. Some material had been collected through verbatim notes and other material transcribed from audio or video tapes. In addition, data were collected through the use of questionnaires with a sample of 81 mothers over an 8 year period at intervals of 1.5 years. In her presentation of the data related to mothers of malformed foetuses, premature babies and those born with disabilities, Raphael-Leff speaks of mothers' initial feelings of shock, rage and disillusionment in relation to their children having disabilities. At the same time they often need to face the disapproval of family and/or society for not having aborted the children. Preterm births seem to confirm mothers' worst fears of being insufficiently good for the babies, who, it is felt, are choosing to escape from inside their mothers. At first sight, these under-weight, almost transparent, premature or ill babies are totally unlike the robust dream babies imagined during pregnancy. With their newborn babies often whisked away before the mothers have a chance to become acquainted with them, the mothers are left feeling alienated. These mothers are inevitably caught up in an emotional turmoil of interrupted pregnancy, guilt at having abandoned their babies to professionals and machinery, and an irrational sense of rejection and failure at having been unable to sustain their children who have chosen, or been forced, to leave their insufficiently nurturing wombs. Mothers of ill babies worry that they have contributed to their babies' conditions, along with feeling guilty, too, about their ambivalence, shame and disappointment. The trauma continues as they find themselves separated from their children, the fruits of their pregnancies, and separated in feelings, unconsciously avoiding attachment in case the babies do not survive. Anxious, exhausted, sore, and frumpish following their ordeal, mothers may feel intimidated and unnecessary in the strange and often frightening atmosphere of the special care baby unit, where medical staff seem to abound in competence. These mothers often feel desperate isolation, and paranoia develops among thoughts that death will arbitrarily take its share of children. After such an ordeal some parents never re-establish the rhythms disrupted by such births.

Methodological limitations of this study include the fact that the samples are flawed by a middle-class self-select bias, but this also has an advantage in representing people who are economically freer to act from internal choice or compulsion rather than external necessity. In addition, further information regarding the methodology uses was not provided.

Raphael-Leff (1991) presents research based on clinical experience of tape-recorded, in-depth discussions over a period of 15 years with pregnant and parturient childbirth education groups and workshop participants. This was supplemented with observation of 23 mother-baby couples on a thrice weekly basis. In this work Raphael-Leff speaks of the fears of giving birth to abnormality which are experienced by nearly every pregnant woman. These fears are forcefully reactivated during any time delay between birth and mothers being told of the condition of their newborn babies. During the initial contact, as with all babies, parents have to reconcile their anticipation of an imaginary baby to perception of the real baby. However, when the babies are visibly malformed, the initial reactions are ones of shock and disappointment. Raphael-Leff suggests that a number of investigators have noted greater anxiety the closer impairments are to the face and head rather than other parts of the body. What may at first appear as rejection of the babies by parents, may be better understood as an inability to accept. Acceptance of real malformed infants requires a greater adjustment to the loss of the perfect fantasy held by most mothers in relation to their unborn children. "The wrench is almost like a process of mourning in which the ideal image has to be given up in favour of the damaged one" (Raphael-Leff, p.462). The greater the visibility of the defect, the greater the disruption of the initial bonding. Raphael-Leff (1991) speaks of the humiliation which washes over the mothers as they encounter outside themselves the imperfect babies who have been part of themselves and who have just come from themselves, seeming to reflect the intolerable badness within themselves. Mothers see themselves as having been unable to produce healthy whole children. In addition to working with these fantasies, where the abnormality can be traced to a known viral infection, X-ray irradiation or drug taking, the mothers live with the knowledge of their share of 'responsibility' in producing defect. Her guilt and remorse while reliving each phase of the pregnancy may be excruciatingly painful, accompanied by sleeping difficulties, nightmares, depression and even suicidal ideas.

Further research based only on clinical cases from the psycho-analytic perspective (Brazelton and Cramer, 1990; Raphael-Leff, 1993; Genevie & Margolies, 1987) suggests several of the most significant issues are as follows - change in the identity of parents as they move from single units to parent-child relationships; the issue of expansion and integration of femininity; the challenge to become nurturer rather than the nurtured; of experiencing themselves as potent creators and producers. Associated with fertility is an increased sense of power, self-reliance and self fulfilment. Pregnancy and child birth produce a sense of immortality in terms of the wished for 'perfect' child continuing the family line. In this sense parents also image future children as succeeding wherever they themselves have failed. Children are seen as opportunities for the fulfilment of lost ideals and opportunities.

When children are born with developmental disabilities it is as though all of the above meanings have been betrayed or cut across. Rather than seeing the children as expressions of power and potency, Tracey (1993; Tracey et al., 1995) in further research based only on clinical case work, and Raphael-Leff (1991, 1993) suggest it is as if the impaired babies mirror those parts of the mothers' own self-images which are perceived as deficient, damaged and bad. Tracey (1993) proposed that fathers see themselves as failures and as having not protected their own new born children from harm. These failures are seen as public, even as the successes in producing normal children would have been.

Tracey (1993) and Tracey et al. (1995) present a similar description of the feelings of parents of children with disabilities as previously noted authors from the psychoanalytic perspective. Tracey suggests parents have feelings of shock and emotional devastation, of over-exposure and of being punished; self-blame; guilt; depression; hopelessness; anger; rage and disillusionment. The birth of the children with the disabilities often seems senseless, unreasonable and incomprehensible to parents (Tracey, 1993). Tracey and Tracey et al. suggest that mothers experience shock to the point of being without affect. The mind shuts down, as it were, so that thinking, symbolising, and a storing of the experience cannot take place (Tracey et al., 1995) The events do not change personalities but rather expose primitive areas of functioning as mothers awake from the trauma (Tracey et al.)

## The Adaptation Process

Less recent but prominent writers in the area of the adaptation process undertaken by parents of children with disabilities are Darling, and Irvin, Kennell & Klaus. Because of the significance of their contribution I will present their work before the research of the 1990s.

Darling (1979) presented a process of adaptation based on her research of 1976-77. She further elaborated the theory of this model in 1983. The 1979 research attempted to establish patterned sequences of movement from one position to another as perceived by parents in their adaptation process related to having given birth to children with developmental disabilities. She describes the process in terms of career paths starting from anomie and going to activism, but allowing for reversals and side-tracking in the process. The children involved in this research all had birth defects that were visible to lay people and interfered permanently with the children's functioning. They were aged: newborn to 19 years. The sample included 25 parents (mothers and fathers) who were randomly selected with several sample substitutions used to obtain a sufficient number. The research instruments used were a modified version of the Kuhn-McPartland Twenty

Statements Test which included four sections ( [name of the child] is........; If I could have any kind of child in the world, I would want a child who was.....; When [name] grows up he [she] will probably be.......; If I could have any kind of child in the world, I would want my child to grow up to be....... Each of these sentences was followed by 20 numbered blank spaces), and a tape-recorded interview which lasted from 30 minutes for some parents to 5 hours for others. (The interview was directed at tracing change over four time periods - prenatal, birth and early postpartum, later postpartum and infancy, and childhood and adolescence). The research results indicated that most of the parents had very little factual information about the various birth defects prior to the birth of their children, and even less direct experience with handicaps. In addition, most of them had relatively typical experiences and expectations prior to the births of their children with developmental delays.

Darling's (1979) was not a longitudinal study, but included parents of children at various ages which meant that some parents were discussing a time period they were presently experiencing, while others were discussing the same time period retrospectively. This aspect could also contaminate the data and be seen as a limitation of the study. Darling (1979) however proposes it as a strength saying that the consistency of experience among parents of children of all ages in their definitions of various stages and events is supportive evidence of the process undertaken by these parents. The sample size being only 25 parents is a further methodological limitation of the study.

The time of diagnosis is one of shock, surprise and concern (Darling, 1979). Darling suggested that the emotions of self-pity and guilt were present but short lived, a finding which is different from the proposals made by other writers which are more clinically based. During this phase parents assess and try to make sense of situations in terms of what is familiar to them, that is, expectations associated with children without developmental delays (Darling, 1979). However, for the parents the expectations did not fit the reality (Darling, 1979). The question which typifies this phase is, "What does this mean?".

The next part of the process is that of seeking out information, assistance, and resources (Darling, 1979). Parents spoke of empty feelings of not knowing what to do. Because of this feeling, the drive for knowledge became quite overpowering for many parents. The other aspect affecting this phase of seeking was related to the lack of availability of resources for this group of people. One mother was cited who spoke of society as not being geared for people with developmental delays: "Once we (society) used to send them all away and now we don't know what to do with them" (Darling, 1979, p.179).

From a time of seeking, parents move to seeing their lives as having problems without solutions. This position was represented in an insoluble question spoken by all the parents in Darling's sample: "What would happen to their children in the future?" (Darling, 1979, p.183). The problems were experienced as so insurmountable that when parents were asked whether or not they would have their children all over again just the way they were, if they could make that choice, the majority answered in the negative (Darling, 1979). One-fifth of the parents in Darling's (1979) sample answered positively to this question.

In summary, the process of adaptation for parents of children with developmental disabilities, as Darling (1979, 1983) proposes it, includes a time of postpartum anomie which is marked by a strong need for information (meaning) and direction (power or control over one's own situation). This is followed by a time of actively seeking appropriate direction which leads into a phase of testing some solutions and establishing a normalised routine, one aspect of which is the realisation that life has problems which are not always able to be solved. In Darling's (1979) research, this latter stage included positive attitude for some parents while for others it did not.

Irvin, Kennell & Klaus (1982) presented research from a broadly psychoanalytic perspective. They presented a sequence of stages which reflects the natural course of parents' reactions. This sequence is at follows:

a) Shock - feeling 'as if the world had come to an end' - entailing an abrupt disruption of usual states of feeling, irrational behaviour, feelings of helplessness, and urges to flee;

b) Disbelief - 'it's not real' - including avoidance, wishing for freedom from the situation or denying its impact;

c) Sadness, anger and anxiety - 'wanting to kick someone' - thinking of the children as nonhuman, fearful of becoming attached to them;

d) Equilibrium - increased comfort with their situation and confidence in their abilities to care for their babies;

e) Reorganisation - parents deal with the responsibilities associated with their children's disabilities. This time included parents reassuring themselves that their babies' disabilities had not been caused by something the parents might have done, and parents mutually supporting each other. The study has methodological limitations with a sample size of 20 parents only who have a wide variation in backgrounds, along with there being differences in terms of the children's malformations. The means of data collection was also only that of discussion from which the researchers looked for emerging themes. The research is also conceptually limited by the notion of it proposing there are stages through which each person must go. This limits the notion of individual responses, creativity, and the existance of varied coping mechanicisms.

More recently, Seideman & Kleine (1995) proposed a somewhat similar model of transformation undertaken by parents of children with developmental disabilities. Their study used a grounded theory methodological approach with 29 mothers and 13 fathers of 31 children with developmental disabilities, including mental retardation. Ages of the children ranged from 10 months to 69 years and the levels of mental retardation were mild to profound. A tape recorded semi-structured interview lasting 1 to 1.5 hours was used to collect the data. The data was then processed by applying the constant-comparative method until no new incidents emerged from the data. The following phases and categories of the adaptation process emerged from the data. The Entrance Phase began with receiving the diagnosis. This evoked feelings of numbness, shock, regret, being stunned, and traumatised. The process involved internalising information by struggling to find some meaningful way to interpret the problems, becoming engaged in the need to respond, telling the extended family, and planning for the differences in terms of learning where to go for help. The Performance Process involved reality construing, that is, the ongoing process of interpreting the new situations as they evolve. This phase was described as encompassing the following aspects: 'holding off reality', processing reality in terms of parents thinking about and trying to assign meaning and truth to information they receive, accepting reality whereby parents embrace information about their children as reality, dealing with crises eg hospitalisations, and interacting with nonfamily eg professionals and friends. Further aspects of the Performance Process included accepting help especially in a crisis, experiencing positive interactions with the children, comparing downward - parents describing children whom they perceived to have worse problems, or describing how their children's problems might have been worse. Additional aspects included: redefining the situation through the use of philosophical perspectives based on belief systems that influence interpretation of situations; creating management strategies used to develop a framework for performing day-to-day parenting tasks; suffering milestone distress when children fail to perform developmental tasks at an age when other children would achieve them, settling for less which encompassed giving up hopes and dreams parents had for their children, finding no end - experiencing chronic sorrow; becoming a super parent - a category given to highlight the special behaviours and skills that parents learned; striving for normality reflected in the struggle to participate in the same activities as families with normal, healthy children; adjusting celebrations included descriptions of celebrating the little things that parents of normal children take for granted; implementing child care strategies which referred to the many ways in which families adapted to incorporate the limitations of children with developmental disabilities. This research is limited by the aspects of: having a small sample size; a large age range for the children; a large variation of degrees of disability of the children; and the concept of phases which suggests a common set of events experienced by every person who had children with developmental disabilities and little room for individual differences.

In 1996 Rodriguez and Jones presented the adaptation process undertaken by foster parents of children with developmental disabilities. They used an exploratory design with grounded theory methodology. The sample included eight foster parents who had at least one child with developmental disabilities in their home. They had been involved in foster care of children with developmental disabilities from 1 to 25 years, with an average of 7 years. The ages of the children with developmental disabilities ranged from 1 to 11 years with the mean age of 4.4 years. The disabilities experienced by the children included general developmental delay, cerebral palsy, mental retardation, autism and seizure disorder. Data was collected using audiotaped semi-structured interviews. The data was coded according to common themes or categories. The presented model of adaptation is as follows:

Role Functioning Mode : All the foster parents identified an increase in their work and responsibilities as parents. This included work related to the children's specific medical, emotional, behavioural and developmental needs. The threat of death of the children was a continuous pressure.

Interdependence Mode: The children with developmental disabilities created both positive and negative effects on the parents' independence mode. The experience of cooperative parenting enriched some relationships, while others experienced diverging interests attributed to having less time together as a couple. Similarly, while some parents were able to maintain relationships with friends, others found it difficult to find the time, along with finding that their friends experienced personal difficulties in accepting the disabilities of the foster children. All foster parents' relationships were affected by the hardships in obtaining appropriate respite care (baby sitting) and the children 'fitting into' social settings.

Physiological Mode: The foster parents did not believe that their general state of health had been affected. Paradoxically however, most identified some specific negative physical stresses such as back problems, weight gain, decreased physical fitness, and less time for attending to personal medical needs.

Self-Concept Mode: Self concept was one of the most dramatically affected modes. The large majority of parents reported experiencing positive changes - general improvement, increased confidence, a sense of meaning, personal growth, and a feeling of doing something worthwhile.

The main limitation of Rodriguez and Jones's work in relation to this research topic is that the population sample is that of foster parents as opposed to natural parents of children with developmental disabilities. This could well account for the high percentage of positive changes in self concept for this group. It gives these parents a sense of "doing something worthwhile" as opposed to natural parents being confronted with the question of whether giving birth to children with developmental disabilities is 'worthwhile' and having done so are they, the parents, 'worthwhile as people'. The other serious limitation of this study is the very small sample size of eight people, with one form only of data collection and measurement.

Most of the above models of adaptative processes seem to share the following elements:

a) diagnosis - shock, surprise
b) trying to make some meaning of the situation and reality construing
c) seeking information and resources
d) seeing the situation as one of addressing problems without solutions
e) actively seeking appropriate direction and normalising routine

All of the above models name the phases and categories of issues with which parents of children with developmental disabilities are faced and which they need to process. However, these models lack sufficient explanation of the process by which some parents do redefine their situations and adapt. In doing so these models leave unanswered the question presented by Darling (1979) as to how some parents come to a position of hypothetically re-choosing their children just the way they are, that is, with developmental disabilities, while other parents do not. The research I present explores this issue.

## Conclusion

In this first chapter I have given a critical review of a sample of the recent research findings concerning the effects on parents and families of having members who have developmental disabilities, along with models of adaptation of parents in these circumstances. As a summary statement, the research results reflect that this event creates a serious disruption of the life and relationships of families, to which some adapt and perhaps others do not. However, there are problems with some of the methods used in the presented research, that I plan to remedy here. Some of the methodological differences are: the use of a large sample size; the study is longitudinal; controls are provided; the first data collection was carried on within two years of disclosure of the diagnosis; and a model was developed based on psychological processes to understand a grief response as opposed to a phase or stage model.

In chapter 2, I will present the current understanding of the effects on parents of having children with developmental disabilities as seen from the perspective of personal construct psychology.

# CHAPTER 2

# GIVING BIRTH TO AND PARENTING CHILDREN WITH DEVELOPMENTAL DISABILITIES:

## A PERSONAL CONSTRUCT PSYCHOLOGY PERSPECTIVE

In chapter 1, I presented an overview from various theoretical perspectives of the effects of giving birth to and parenting children with developmental disabilities. This overview included aspects such as relationships with family, spouse, society and self. The chapter concluded with presenting the current thinking on the adaptation process undertaken by parents of children with developmental disabilities.

The research material presented in Chapter 1 clearly reflects that a major effect on parents of giving birth to children with developmental disabilities is that it disturbs their previously held views of life and relationships. The acknowledgment of this disturbance is seen in the initial phases of the various models of adaptation which are provided. The latter phases of these models grapple with the second effect of parents finding new meanings and directions in their lives. It is these two predominant effects, disturbance in relationships and finding new meanings, that I explore through the use of personal construct theory in this chapter. I primarily use the work of Neimeyer and Neimeyer (1985) to look at the aspect of disturbed relationships and the work of McCoy (1980) on cultural shock as a metaphor to describe the process by which parents find meaning in their new situations. Those aspects of personal construct theory which are particularly relevant to these two processes are presented in this chapter, while others related to grief will be discussed in Chapter 4.

## Construction Systems Are Disturbed

### Constructs

In order to address the effect of disturbed life views, we need to understand these terms from a Kellian perspective. Kelly says: "man looks at his world through transparent patterns or templets which he creates and then attempts to fit over the realities of which the world is composed...........without such patterns the world appears to be such an undifferentiated homogeneity that man is unable to make any sense out of it" (Kelly, 1955, p.7). Kelly gives the name "constructs" to these patterns "which are tentatively tried on for size" (Kelly, p.7).

### Constructive alternativism

To emphasise that these constructs are changeable Kelly later says: "We assume that all of our present interpretations of the universe are subject to revision or replacement........we call this philosophical position constructive alternativism" (Kelly, 1955, p.11). Kelly argues that there always are some alternative constructions available to choose from in dealing with the world. We never need to be completely hemmed in, whether it be by circumstances or personal history. And so the question arises: under what circumstances do people change their constructs or for what purpose are constructs changed? Kelly addresses this aspect in terms of presenting his metaphor of a person as a scientist having theories about life, testing hypotheses, and weighing up experimental evidence for the purpose of: "ever seeking to predict and control the course of events with which he is involved" (Kelly, p.4). A secondary source on this topic is that of Viney (1990a, p. 209) who presents the Kellian notion of construct as: "a way of viewing the world" and says that "people are always trying to interpret what has happened and to anticipate what is going to happen to them".

## Construct system

Kelly (1955) also speaks of an individual's construct system, different types of constructs, and their relationship to one another. Again within the context of seeking to improve constructs and obtain better fits, "man increases his repertory ...................... by subsuming them with superordinate constructs or systems" (Kelly, 1955, p.7). A superordinate construct is defined as: "one which includes another as one of the elements in its context" (Kelly, p. 391). In this sense superordinate constructs could be seen as being the most influential in the construct system. For ease of understanding the theory and proposed model of this research, from now on in this presentation, when referring to superordinate constructs, I will write *most influential (superordinate).* Another type of construct defined by Kelly (1955) which is particularly relevant to this research is termed "core constructs - those which govern a person's maintenance processes - that is, those by which he maintains his identity and existence" (Kelly, p.356). These could be described as self related constructs. Again for ease of understanding when referring to core constructs I will write *self relating (core).*

## Sociality Corollary

Another relevant aspect in relation to disturbed life views of these parents is that the event of giving birth to children with developmental disabilities takes place within a social context of family and society. So, does personal construct theory have a social component? Does the social aspect related to children with developmental disabilities affect the construing of the parents?

Kelly (1955, p. 66-7) says: “the person who is to play a constructive role in a social process with another person need not so much to construe things as the other person does as he must effectively construe the other person’s outlook”. “While one person may play a role in a social process....through subsuming a version of that other person’s way of seeing things, the understanding need not be reciprocated” (Kelly, p.69). Kelly has described this social interaction in the Sociality Corollary. It would seem from what Kelly is saying that for a father to play a role in a social process with his son with developmental disabilities he must try to come to understand his son’s way of seeing things. For the same man to maintain his role in a social process with his friend, with this openness to him, he may need to come to understand that his friend does not or can not accept disability. Aspects of the social process such as these must challenge and perhaps change the constructs of parents.

Neimeyer and Neimeyer (1985) suggest the importance of interpersonal relationships in Kelly’s (1955) theory is implicit in the Sociality Corollary, described above. They speak of people depending on social processes to support and extend constructions of reality, and using them to create and maintain a sense of self for individuals.

Within the context of this social component of personal construct psychology, Rowe (1984) likens to death experiences those events that discontinue or cut across constructions people have given to life and relationships. I suggest that the effects of giving birth to and parenting children with developmental disabilities cut across constructions people have given to life and so create a partial disintegration of the various construct systems held by parents. The anticipated children do not exist and the children with developmental disabilities do exist. It could be assumed that parents depended upon the existence of the anticipated children for the support and extension of their presently held constructions of life and their relationships and the further creation and maintenance of their sense of self. The non-existence of the anticipated children and the existence of the children who were not anticipated create a partial disintegration of the self and the need to re-interpret life events in an effort to give meaning to their present situation.

## Relationships Are Disturbed

The research presented in Chapter 1 clearly indicated that parents' currently held constructions of life and relationships were challenged and disrupted when they gave birth to children with developmental disabilities. The research results of Chapter 1 seemed to fit best with the personal construct theoretical framework presented by Neimeyer & Neimeyer (1985) on disturbed relationships. It is this theoretical framework which I will now present.

Neimeyer and Neimeyer (1985) present four classifications in their schema of disordered relationships: disrupted, negative, absence of role relationships, and disorganised. I present and critically evaluate each in turn as it relates to parents of children with developmental disabilities.

a) *Disrupted relationships*: Neimeyer and Neimeyer (1985) speak of relationships as continually unfolding, developing and dynamic in nature. For relationships to be healthy, people need to be willing to revise their constructions of the other person. Because of the differences between the anticipated and the actual children, parents need to revise and modify their constructions of themselves, the children, and the relationships. Not to do so can create disruptions to relationships.

For parents of children with development disabilities, change is usually required at the level of self related (core) constructs and those which are most influential (superordinate) in the ways in which parents view their lives (individual's construct system). Failure to change at this level, can bring about what Neimeyer and Neimeyer (1985) and Neimeyer & Hall (1988), refer to as a *disruption* in the relational process. This disruption causes parents to experience an on-going lack of validation of their core construing of themselves as parents. It also limits the extensions of the construing processes of parents in relation to the unfolding, developing children.

Neimeyer and Neimeyer (1985) suggested that the emotions associated with disrupted relationships are anxiety, startlement, shock and threat. Kelly (1955) defined threat, fear, anxiety, guilt, aggressiveness and hostility, and presents them as related to transitions in construing. McCoy (1977 & 1981) expanded the set of emotions defined within the personal construct psychology. She stated that "emotion behaviours are seen as indicators of the state of one's construct system following awareness of a need to construe" (McCoy, 1981, p.97). So when do people become aware of the need to construe? Kelly spoke about this in terms of every "construct (having) a range of convenience....(which) would cover all those things to which the user found its application useful" (Kelly, p.95), or convenient for the job of predicting events. When a new experience can no longer be understood or predicted within people's present construct systems they may become aware of the need to reconstrue in order to more accurately predict and control events.

At this point, I believe it is worth elaborating a little further where emotions and cognitions fit within Kellian personal construct theory. Kelly did not segment the person into divisions of emotion and thinking, but rather saw experiencing (including 'feeling') and construing as part of the same process (Fransella, 1995). Fransella reminds us that construing does not have to be in words. The person who is in deep reflection or meditation is experiencing and still actively construing. "But he is using another subsystem. This is the subsystem with which he makes contact with this other world of experience" (Fransella, p.115).

The anxiety experienced in the disturbed relationships of parents is explained in terms of parents' "awareness that the events with which (they are) confronted lie outside the range of convenience of (their) construct system(s)" (Kelly, 1955, p.391). The emotion of startlement is created by: "the more sudden awareness of a need to construe events" (McCoy, 1981, p.97). Woodfield and Viney (1984, p.4) define shock as: "an overwhelming and sudden need to reconstrue events". The parents suddenly realise that the events cannot be adequately understood and predicted from within their current construct system. Threat is: "the awareness of an imminent comprehensive change in one's core structure" (Kelly, p.391). It signals the awareness of imminent comprehensive change in self-related construing.

b) Neimeyer and Neimeyer (1985) speak of *negative relationships*. Within this concept parents can become engaged in sustained and often intimate relationships with their children with developmental disabilities, but these relationships are marked by a preponderance of negative emotions. The *lack of perceived similarity* between parents and children at any significant level robs parents and children of the opportunity for consensual validation. At the extreme, parents' main source of self-definition may come from seeing themselves as everything which is different from their children with developmental disabilities, whom they intimately know but actively disdain. The negative relationship is sustained by powerful *validation by contrast*.

Personal construct psychology proposes that: “each construct involves two poles, one at each end of its dichotomy. The elements associated at each pole are like each other with respect to the construct and are unlike the elements at the other pole” (Kelly, 1955, p.96). Hinkle (1965) suggests that the different poles can be understood as preferred and non-preferred sides of the constructs. In contrasting themselves with their developmentally delayed children, parents see themselves as embodying the preferred sides of their personal constructs, and their children as embodying the non-preferred sides. Hence, the children may be seen as disabled, unintelligent and weak while they themselves are able, intelligent and strong.

Neimeyer and Neimeyer (1985) see contempt and threat as the dominant affect associated with negative relationships. Contempt is: “an awareness that the core role of another is comprehensively different from one’s own and/or does not meet the norms of social expectations” (McCoy, 1981, p.97). It would seem that these emotions are generated by an awareness that the children's way of acting, which is expressive of their identity and existence (core role structure), is comprehensively different from that of their parents. Using Neimeyer and Neimeyer's (1985) approach parents may experience the contempt as positive insofar as it reaffirms themselves as being on the preferred pole of their constructs - even though it is at the expense of the children.

A further salient emotion is guilt (Neimeyer & Neimeyer, 1985). Guilt is associated with: “the awareness of dislodgment of the self from one’s core role structure” (Kelly, 1955, p.391). Fransella (1995, p.71) describes guilt in terms of people: “doing something that violates some core way in which we see ourselves”. Guilt plays a part in negative relationships by militating against the dissolution of the bond because, in this case, parents define their core way of acting in terms of maintaining the parent-child relationship (Neimeyer & Hall, 1988; Neimeyer & Neimeyer). For example, parents might think: "If I obtained alternative care for my child, she would never survive, and I'm not that kind of person".

c) The *absence of role relationships* is a further form of disrupted relationships. This comes about through an enduring difficulty in effectively construing other people *as people* (Neimeyer & Neimeyer, 1985). Bannister (1981) speaks of this concept in terms of people with disabilities being seen as *nothing but disabled* - the construct of disability being given a pre-emptive, 'nothing but' quality. A pre-emptive construct is one "which pre-empts its elements for membership in its own realm exclusively" (Kelly, 1955, p.107) and so excludes them from the realms of other constructs. Kelly gives the example of anything which is a ball can be nothing but a ball so that balls cannot be seen as spheres, pellets, shots or anything but balls.

In addition, the construct of disability may be placed in parents' all-over view of the world in such a way that allows it to carry far too many implications, that is given a superordinate position in the hierarchical construct systems - (Bannnister, 1981). When the disability is given this superordinate position it is seen as implying a very wide range of limitations for the person with the disability, eg limitations on the ability to experience joy, love, sexuality, and toughness, travel, independence, and so on. Furthermore, in terms of the contrasting poles which every construct has, if disability is contrasted with ability, it again tends to separate the people with the disability into something other than the rest of us who are able (Bannister). I reflect on this with some cynicism, because there is a reality that none of us, in any complete sense, is able.

Neimeyer & Neimeyer (1985) proposed that the emotions associated with the absence of role relationships are a chronic sense of emptiness which follows from a lack of meaningful involvement with others, and anxiety. Depression may also be evident within this type of disturbed relationship (Neimeyer & Neimeyer). Parents may constrict their lives which can lead to isolation and depression (Neimeyer & Neimeyer). They might narrow the extent of their social involvement in order to prevent uncertainty and confusion which are aspects of depression. Kelly defines constriction as occurring: "when a person narrows his perceptual field in order to minimize apparent incompatibilities" (Kelly, 1955, p. 391).

d) Neimeyer and Neimeyer (1985) presented a fourth type of disturbed relationships which they term as *disordered.* These are usually pervasive and stem from a general deficit in social construing rather than having a focal difficulty in construing one or a few other people. These types of relationships can range from obsessive behaviours to thought-disordered schizophrenia. This category of disturbed relationships is not as relevant to parents of children with developmental disabilities as those previously described. However, if this is a pre-existing way of relating, the birth of children with developmental disabilities can compound the situation.

The disintegration of construct systems which occurs when parents are attempting to make sense of the new events in their lives can trigger the use of "tight" construing which leads to rigid or "unvarying predictions" (Kelly, 1955, p.391). This construing can be seen in obsessive behaviours, whereas schizophrenic-like thought patterns arise out of overly loose construing. Loose constructs are defined as ones: "which lead to varying predictions but retain (their) identity" (Kelly, p.391). Kelly speaks of dreams as an example of loose construing and describes them as rough sketches, without precision and somewhat ambiguous. The predominant emotions relating to disordered relationships are anxiety and threat.

I have not presented this model of disturbed relationship proposed by Neimeyer and Neimeyer (1985), nor will I present the following model relating to culture shock as presented by McCoy (1980), as descriptions in themselves of the transition process undertaken by parents of children with developmental disabilities. Rather I saw each model as being able to speak creatively to the experience of these parents in their different ways. The relationships of the parents are clearly disturbed and evoke many of the constructs, displayed in emotions, actions, and construct movement as described by Neimeyer and Neimeyer, and to this extent the model is relevant to the transition process undertaken by parents of children with disabilities. Many of the stages presented by McCoy parallel those presented in the literary research in Chapter 1. Either model addresses the specific issues or construct movement undertaken by parents of children with developmental disabilities.

## The Process of Adaptation

### Culture Shock as a Metaphor

The purpose of this chapter is to present the effects of giving birth to, and parenting, children with developmental disabilities as seen through the perspective of personal construct psychology. In this context I comment on a metaphor frequently employed by parents themselves in telling their stories for this research. The metaphor is that of migrating to a foreign land and the experience of culture shock, a concept which seemed to encapsulate for the research participants the trauma of the experience of finding themselves parents of children with developmental disabilities.

During the time of data collection for this research several parents gave me a copy of a story, authored by Diane Crutcher, which used this metaphor of culture shock. The story, published in the *Down Syndrome Association Newsletter,* Spring, 1990, speaks of familiarity with one culture and then experiencing the shock and disbelief of suddenly being in a foreign land. A time comes when there is a temptation to see only the negatives of the new culture - to see it only as "a filthy, plague infested slum full of pestilence and famine". The story goes on, however, to say that in experiencing the pain of the loss of the old culture, the "windmills", "tulips", and "Rembrandts" of the new culture are also discovered.

It was this metaphor of culture shock which led me to read with interest Mildred McCoy's (1980) understanding of the experience of people who marry and move to new cultures. She uses the term "culture-shocked marriages" and proposes that there is a five stage story to be told.

The first stage is more relevant to the tourist in this new land or short term visitor. It reminds me of the inexperienced students who come to do practicums at our agency which offers services to families who have children with developmental disabilities. The students are well integrated and secure only in their own culture. Initially they tend to view the second culture, that associated with disability, more from the perspective of similarity with their own rather than view the differences. There is often an initial buoyancy and enthusiasm, which McCoy (1977) suggests comes from a reaffirmation of identity in successfully construing the familiar. Required adjustments are seen as minimal and manageable but often prove not to be based on realistic estimations of what is actually involved in adapting and living within the new culture. At this stage there is *no sense of the pervasive differences* in values and organisation of life-style between the two cultures.

Most parents of children with developmental disabilities seem to begin in, or rapidly move to, stage two of the story which McCoy (1980) terms as *disintegration.* McCoy suggests this occurs as a function of the invalidating experiences of the new culture. She says that there is awareness of the inadequacies of the present construct systems in the face of the new and unconstrued events, as well as an awareness that the present construct systems do not provide accurate predictions. Anxiety, threat and fear predominate (McCoy). McCoy speaks of people overly loosening and tightening their construct systems in their attempts to make them more useful. The loosening may be manifest as a loss of purpose, or experienced as generalised confusion and difficulty in carrying out tasks; the tightening leads to withdrawal and/or compulsive behaviour (McCoy, 1980). At this stage parents feel very much outside of everything, yet surrounded and overwhelmed by an alien world.

The third phase of McCoy's (1980) story is when people see the old and new culture in their distinct differences. McCoy termed this phase as *reintegration.* People respond to the existence of the two cultures by holding two quite separate and parallel views of the world. Each view is relatively impermeable in terms of allowing in new or different perspectives. This allows for each view to be tested without invalidating the other. Thinking at this stage is stereotyped and judgemental, with the second culture, in this case that associated with the children with developmental disabilities, tending to be rejected. As in the original story, there is a tendency to see the second culture only as: "a filthy, plague infested slum full of pestilence and famine" (*Downs Syndrome Association Newsletter, Spring, 1990*). There is a new and essential sensitivity to cultural differences and their pervasiveness. To remain in the second culture clearly requires immanent comprehensive change to people's core ways of viewing life - the experience is one of great threat (McCoy).

The fourth stage is termed *autonomy* and is based on an understanding of the new culture, of its integrity and adequacy, and an acquisition of its values (McCoy, 1980). I suggest that these words integrity, adequacy, and acquisition of its values, are equally relevant to the culture of disability as they are to other cultures. For parents who have reached this stage of the culture shock journey there is a sensitivity to the point of view of disability, and a comfortableness with communicating about it. There is a freedom from defensiveness, and the perceived differences between cultures of ability and disability are no longer threatening. Parents are confident about their ability to cope and this leads to interactions that are relaxed and flexible. From a personal construct perspective, the two construct systems which have been evolving and are now integrated at the level of the self-related and most influential constructs, are no longer incompatible. Identity has been extended to include both sets of dimensions, and self is not construed pre-emptively, or as functionally identical with either culture. Parents in this stage often become conscious of their expertise in the second culture of disability and interpret it to other parents when the opportunity arises.

The final stage of the story is termed *independence* in which people are able to view themselves and others as human beings shaped by culture and who can value cultural differences (McCoy, 1980). These parents have an experiential knowledge which recognises the pervasive influence of culture in shaping attitudes and behaviours as well as the prospect of one culture being an alternative for another. Perhaps people who read this might initially hesitate at the prospect of choosing a culture associated with disability over one associated with ability. However, some parents in this research have made just that statement. Many workers in this field see it not as a job, but as a perspective of life through which they choose to look, as one might choose the lens of disability on a camera. This stage signifies the development of a system in which the most influential constructs of people are permeable and deal with culture and human nature. This system allows people to continue to develop their construct systems by incorporating new explorations of human diversity. There is a freedom from the constrictions imposed when people defend themselves against the changes required by interaction with another culture.

McCoy (1980) presents this transitional model in terms of stages and writes as though they are sequential. Such a view is again in line with the literature presented in Chapter 1, and that described in the following section on the work of Cunningham and Davis (1985).

## A Specific Description of the Process of Adaptation For Parents of Children with Developmental Disabilities

Processes of adaptation similar to those described by McCoy (1980) have been documented specifically in relation to the event of giving birth to and parenting children with developmental disabilities.

The first stage around the time of diagnosis might be defined as *shock* (Cunningham & Davis, 1985) or *emotional confusion* (Davis & Cunningham). It results from the interruption of continuity and predicability of events (McConachie). The construct system of parents is challenged and found inadequate to respond to the present events (Cunningham & Davis). The frequent comment made by parents is: 'I didn't know what was happening' or 'I couldn't understand' (Davis & Cunningham). Each phase after this is understood from the perspective of personal construct psychology as an attempt to formulate construct systems which are more accurate in their ability to anticipate and predict.

The second step is termed a *reactive phase* (Cunningham & Davis, 1985). Parents begin a process of reconstruing and understanding what has occurred (Cunningham & Davis, 1985). Denial, which is reverting to the construct system used prior to the diagnosis, may operate (Davis & Cunningham, 1985); tightening or loosening of construing may be a further process (McConachie, 1985); or temporary hypotheses such as killing the children or rejecting them may be tested (Davis & Cunningham).

The *adaptation* phase is signalled when parents begin to ask such questions as: 'What can be done?' This question implies a new set of recognised needs (Cunningham & Davis, 1985). At this stage parents have adopted at least a nucleus of constructs which allow them to begin to make sense of the situations (Cunningham & Davis; Davis & Cunningham, 1985).

A question of: 'How can we help?' suggests the beginning of an *orientation phase* (Cunningham & Davis, 1985; Davis & Cunningham, 1985). Here parents begin to organise, seek help, establish new routines, plan resources and learn new skills. Parents have reconstrued sufficiently to know what to do and begin to act on the problems confronting them. McConachie (1985) proposes that there is a stage when the event of having given birth and parenting children with developmental disabilities, is fully congruent with the core role structure of parents.

## Conclusion

In this chapter I have presented the idea that giving birth to and parenting children with developmental disabilities is disruptive of the perceptions most parents have of life.

This event tends to result in some deterioration of the self in so far as the present perceptions or constructs parents have prove to be inadequate in making sense of new situations and allowing for accurate anticipations and predictions. The construct systems of these parents are challenged and found wanting. Personal construct psychology proposes that the emotions which are evident at this time are indicators of the awareness parents have of their need to change. While the journey of reconstruing life evokes much emotion, in so doing parents again see the 'windmills', 'tulips', and 'Rembrandts', but this time in the new culture which includes disability.

This chapter has emphasized that while on one hand change threatens the consistency and continuity of core aspects of self (Neimeyer, 1995), on the other hand it is endemic to being human (Neimeyer).

In chapter 3, I will present the varying models of grief which are seen to be applicable to parents of children with developmental disabilities. This is followed in Chapter 4 by the personal construct perspective of the grief experience.

# CHAPTER 3

# AN OVERVIEW OF THE MODELS OF GRIEF

In Chapter 1 and 2, I addressed the effects on parents of giving birth to and parenting children with developmental disabilities. In Chapter 1, I presented the research results which came from a variety of theoretical perspectives; and in Chapter 2, I looked at the effects through the eyes of personal construct psychology.

This same pattern of presentation - moving from a variety of theoretical frameworks to the perspective of personal construct psychology - will be repeated in Chapter 3 and 4 in relation to the process of grieving. This Chapter will present grief from the long standing perspective of the psychoanalytic model, the pychodynamic models, and the model of chronic sorrow, before examining the personal construct model of grief in Chapter 4.

## Introduction

Parents of children with developmental disabilities experience the loss of the 'normal' children for whom they had prepared and with whom they had imagined themselves in relationship. At the same time they are confronted with the presence and demands of the children with the disabilities. It is the losses incurred in this experience which engender grief (Olshansky, 1962; Solnit & Stark, 1961; Worthington, 1994). Current thinking on this grief process has led to a variety of proposed models.

## A Psychoanalytic Model (Freud and Bowlby)

The psychoanalytic depiction of grief, essentially containing the concepts of decathexis and internalisation of the 'object', was outlined by Freud in his paper entitled *Mourning and Melancholia* in 1917. The work of mourning involves the reality testing that the loved object (including person, country, liberty, ideal) no longer exists. All libido (life energy) is withdrawn from its attachment to the object. The withdrawal of libido is a struggle because people do not wish to abandon a libido-position, not even when a substitute is already beckoning. The task is carried out over time and with much cathectic energy, while all the time the existence of the lost object is held in the mind of the mourner. "Each single one of the memories and hopes which bound the libido to the object is brought up and hyper-cathected, and the detachment of the libido from it accomplished" (Freud, 1917, p.154). Only then is the ego capable of loving in a free and uninhibited manner again.

The psychoanalytic concept of melancholia, as presented by Freud (1917), contains the aspects related to mourning with additional components. Melancholia may be triggered by conscious and/or unconscious loss. The person experiences an extraordinary loss in self esteem and is full of self-reproach. These aspects are understood in terms of: "the self-reproaches (being) reproaches against a loved object which has been shifted on to the patient's own ego" (Freud, 1917, p.158). The psychological process related to melancholia is firstly an object-choice, followed by the attachment of libido to the object, then due to some real injury or disappointment the object-relationship was undermined, the object-cathexis proved to have little power of resistance and was abandoned, but the free libido was withdrawn into the ego rather than directed to another object and established what Freud calls: "an identification of the ego with the abandoned object" (Freud, 1917, p.159). In this way the loss of the object became transferred into a loss in the ego. A necessary condition for melancholia is that the object-choice was made on a narcissistic basis. This narcissistic identification with the object can result in the love-relation never being given up.

Freud's own criticism of the model of grief presented in this paper on Mourning and Melancholia (1917) is that the material on which it is based is limited to a small number of cases and therefore its validity to be generalised must be in question. Having said that, thinking in the field of psychoanalysis to this day still refers to this model.

For the parents of children with developmental disabilities the loss, understood within this Freudian framework, occurs at several levels. As presented in Chapter 1, parents mourn for the longed-for children, for whom fears were held of being damaged, but were imaged to be perfect (Raphael-Leff, 1991, 1993; Solnit & Stark, 1961; Tracey, 1991). There is loss related to parental identity relating to aspects such as femininity, masculinity, the capacity to nuture, perceptions of personal power, self-reliance and self fulfilment, opportunities for a sense of immortality and the fulfilment of lost ideals and possibilities (Rachael-Leff, 1991, 1993; Solnit & Stark, 1961; Tracey, 1991).

Using this psychoanalytic model, Solnit (1961) describes the mourning process as related to parents of children with developmental disabilities as: "disappointed, highly charged longings for the normal child may be recalled, intensely felt, and gradually discharged in order to reduce the impact of the loss of the expected loved child. This process, which requires time and repetition, can liberate the mother's feelings and interests for a more realistic adaptation" (Solnit, 1961, p.526).

The grieving process for these parents is compounded by the fact that there is no time to work through the loss of the desired children before there are the demands to invest time and energy in developing attachments to the new and disabled children (Hagman, 1996; Solnit & Stark, 1961). The presence of the children with the disabilities creates a disruption to the normal birth processes and the resulting grief reactions. In addition, all of this is occurring at a time when parents are experiencing the physiological and psychological depletion that arises out of any pregnancy and birth. These are essential factors in the traumatizing effect of giving birth to children with developmental disabilities.

The criticism levelled against the psychoanalytic work of Solnit and Stark (1961) is that it is said to have untestable assumptions, ill-defined concepts, and is difficult to translate into direct suggestions for interventions (Davis & Cunningham, 1985).

Bowlby (1980) is another theorist who is psychoanalytically based in his thinking, but suggests that his concepts differ from the classical theories of Freud. Bowlby's theories are research-based. He proposed that the responses people have to the loss of close relationships moves through a succession of phases. Bowlby does not speak directly of the situation of parents giving birth to children with developmental disabilities, but does speak of the loss of partners and the death of children. He proposes that there are four phases of mourning.

The first is a phase of *numbing* (Bowlby, 1980) punctuated by outbursts of anger. People are often tense, apprehensive, and overwhelmed by panic. In relation to terminally ill children, the process of mourning begins for the parents at the time of diagnosis. Most people are stunned and, to varying degrees, unable to accept the news of the loss. This is indicated in comments such as, 'I just couldn't take it all in'; 'I couldn't believe it'; 'I was in a dream'; 'It seemed unreal'.

This moves into a time of beginning to register the loss. It is a time of intense pining with spasms of distress and tearful sobbing. There is also restlessness, insomnia, and preoccupation with thoughts of the lost person. Bowlby considered this to be in no way abnormal. At this time there is a strong urge to *search and recover* (Bowlby, 1980) the person who has gone. In the case of children with terminal illness this searching was displayed in the parents' challenging both of the diagnosis and the prognosis of a probable fatal outcome. Bowlby sees this disbelief as neither an advantage nor disadvantage in itself, but its influence depends on its dominance and its persistence despite contrary evidence. Activity of parents in this situation may be frantic. It is often directed towards the sick children with a tendency to neglect all else. The great majority of parents blame themselves initially, but, with reassurance, it was only the minority in the various studies who showed persistent self-blame.

Only if people can endure the pining, the searching, the endless examination of how and why the loss occurred, and the anger, are they able to gradually recognise and accept that the "loss is a truth permanent and that ...life must be shaped anew. .......In this way only does it seem possible for (people) to fully register that...*old patterns of behaviour have become redundant and have therefore to be dismantled*" (Bowlby, 1980, p.93). Bowlby speaks less of the instinctual, libidinal energy involved in the process of mourning, and more of the growing awareness of the mourner of the need to discard old patterns of thinking, feeling and acting before new ones can be fashioned.

The final phase begins when people start to *examine the new situations in which they find themselves and consider ways of meeting them* (Bowlby, 1980). This entails a redefinition of self as well as the situation. No longer is the man a husband but a widower. Similarly, "just as pregnancy itself is a normal crisis in which there is no turning back, so defect or retardation is a condition which cannot be undone" (Solnit & Stark, 1961, p.527).

Bowlby (1980) is strong in his claim that while redefinition of self and the situation is infused with emotion, it is no mere release of affect, but a cognitive act on which all else turns. It is a process of reshaping internal representational models of self and the world so as to align them with the changes that have occurred in the life situation. Although Bowlby addresses the emotions and cognitions of people as separate entities, it could be seen as a development to address these as the one identity involved in the process of reshaping. In addition, are psychological processes best represented by the strong division of internal and external worlds as is suggested by Bowlby? Further limitations of the work of Bowlby could include the following: his primary data are observations of the behaviours of young children in grief situations; from these data an attempt is made to describe certain early phases of personality functioning and, from them, to extrapolate forward (Bowlby, 1980). As such the only evidence for this phase theory is that of clinical interpretation of behaviour. The existence of the phases has not been demonstrated through rigorous research methods, nor has the proposal that people actually move from one phase to the other. In addition, conceptually a stage model limits the adaptation processes to occurring in a certain order. It does not seem to take into account the concept of individual differences and the fact that the immediate environment or culture can make a tremendous difference.

### Some Psychodynamic Models (Parkes, Kubler-Ross, Warden, and Rando)

Parkes and Bowlby were colleagues and shared many of their understandings of grief (Bowlby, 1980). Parkes developed the notion of the *assumptive world* (Parkes, 1971) which, for him, includes everything individuals know or think they know. It includes the interpretations people give to the past and their expectations of the future, their plans and prejudices. When any major change occurs in the environment with which the self interacts and in relation to which behaviour is organised, there is a need for a reconstruing of the assumptive world. That is, a need for restructuring perceptions and plans as to how to better cope with the new, altered life situations.

This change not only requires the development of fresh sets of assumptions, but also the abandonment of previously held ones. Before the new assumptions are accepted, people become aware of the inadequacies of those presently held. Grief is the painful reviewing of redundant assumptions and restructuring of the assumptive world. It is this level of change which is required with the birth of children with developmental disabilities (Parkes, 1971). Once the old assumptions and ways of thinking have been given up, people are free to take stock and to learn new solutions, and find new ways of predicting and controlling happenings within their life situations. Grief is the damage done to the assumptive world in this process (Parkes, 1972). The change, and therefore the damage, is at the level of identity which includes roles people have in life, bodily characteristics, powers and possessions (Parkes, 1972).

The tasks of grieving as seen by Parkes and Weiss (1983) are three fold. *There needs to be an intellectual recognition and explanation of the loss* (Parkes & Weiss, 1983) To reduce anxiety, people must be able to make sense of situations for themselves. This requires developing an explanation of how, in this case, the loss occurred, including identification of a cause which led to an inevitable outcome. This adequate account of happenings is not sufficient for recovery, but it is necessary. Unless the question of 'Why?' is answered, the bereaved can never relax their vigilance against the threat of new loss.

Secondly, there must be repeated confrontation with every element of the loss until the intensity of distress is diminished to the point where it becomes tolerable and the pleasure of recollection begins to outweigh the pain. This phase of *emotional acceptance* (Parkes & Weiss, 1983) looks like a repeatedly obsessive review of thoughts and memories associated with the loss. The result is that the bereaved no longer feels the need to avoid reminders of loss for fear of being flooded by grief, pain or remorse. It is not that they are impervious to new pangs of grief - in fact, even in a good recovery, the bereaved may never achieve an invulnerability to distress on being reminded again of how much was lost. What is achieved in the review is that the bereaved no longer suffers a continuous, oppressive awareness of loss and pain and no longer needs to avoid thinking of the loss in order to function without distraction.

The final phase is that of a new identity ( Parkes & Weisss, 1983; Parkes, 1972). This simply means people develop a reasonably consistent set of assumptions about themselves and the world. It is on these assumptions that choices and plans are made. They should, therefore, correspond reasonably well to our actual wishes, potentials, and situations.

The advantage of Parke's theory is that it does present the psychological processes undertaken by people in their adaptation process. However, it is again phase based and as such the limitations mentioned under Bowlby also apply to Parkes.

A more recent author, Sturniolo (1996), speaks of the same concept in terms of life scripts. Most family systems are not scripted for the occurrence of children being diagnosed with developmental disabilities. The process of adaptation involves families examining their present meaning systems around the 'perfect children' who were not born and constructing new life scripts incorporating a meaning system that responds to the diagnosis of their children having developmental disabilities.

A popular writer who is again psychodynamically based, but posits a stage theory of grief, is Kubler-Ross (1969). She presented five distinct stages which people move up and down in relation to their process of dying. The first stage is proposed as *denial and isolation* - 'No, it cannot be true'. This partial denial is considered to be used by almost all patients from time to time. It has a function of being a buffer after unexpected shocking news. It gives way to *anger*, rage, envy, and resentment which is displaced onto others such as family, medical staff, and visitors and projected into the environment at times almost at random. *Bargaining* is an attempt to enter into some sort of agreement which may change or postpone the inevitable. It includes elements of a prize for 'good behaviour', a self imposed 'deadline' such as "let me have this and not that", and an implicit promise that the person will not ask for more if this one change or postponement is granted. If the above should occur, the latter promise is never kept and a further postponement is requested. Kubler-Ross associated this bargaining with guilt. Anger and rage are replaced with loss and *depression.* One is a reactive depression rising from external losses including family disruptions and finance. Another depression Kubler-Ross associates with death is associated with the impending loss of all love objects. *Acceptance* is the fifth and final stage. This is where the grieving, and in this literature, dying people, have been able to express their envy for what they themselves do not have, and anger towards those who do not have to face what they themselves have to face. They have mourned the impending loss and now contemplate the reality with a certain degree of quiet expectation.

This stage model has received intense criticism in the loss and grief literature over the last two decades. The limitations include ones related to methodology such as Kubler-Ross presenting little information about her sample or measurements, the psychiatric interview as a technique of data collection never being evaluated, and results never being presented beyond a broard summary (Doka, 1995-6). The theoretically based criticisms include the fact that Kubler-Rosss is ambiguous about the notion of stages (Doka). On the one hand stages are generally considered to be linear in notion whereas Kubler-Ross' model allows for individuals to jump stages or move back and forth between stages (Doka). In addition it is considered that Kubler-Ross presents a preferred manner of coping with dying rather than supporting many and varied ways of coping. Doka (1995-96) names other criticisms which include that denial and acceptance are more complicated than the model allows; that denial can be a very positive coping mechanism at times; that individuals have a considerable range of reactions to dying beyond those mentioned; that dying persons may experience many reactions simultaneously rather than one after another; that the model neglects individual differences, seeing dying as a process in itself rather than as part of an individual's life processes; that comparatively little attention is given to hope; and that the personal resources and characteristics of the dying person's environment can affect the ways individuals cope with death.

Doka (1995-6) goes on to speak of a task-based theory related to loss and grief. He suggests that task models have an active perspective focusing on coping activities or work rather than viewing the person as passively responding, and allow for a more individualised approach and a self determinative perspective.

Worden (1991) spoke of the limitations of the concept of stages along with those of the phase model as presented by Parkes and Bowlby. He suggests that phases also imply a certain passivity - something that the mourner must go through. Worden presents the concept of task which implies that the mourner needs to take action and can do something. This gives the mourner some sense of leverage and hope. Also, the concept of task implies that mourning can be influenced by intervention from the outside.

Worden (1991) presents the work of Freud, Bowlby, and Parkes as the underpinning of his theory. He says that although the tasks do not necessarily follow a specific order, there is some ordering suggested in the definitions. In addition, incompleted grief tasks can impair further growth and development. Worden's model of mourning - the adaptation of loss - presents the following four tasks. The theory is presented in terms of the death of people.

Task 1: To accept the reality of the loss. There is a need to come full face with the reality that people are dead and will not return. This phase may involve searching behaviour, not believing (displayed through denying facts of the loss), meaning of the loss, denying that death is irreversible, or denying the finality of death through spiritualism.

Task 2: To work through to the pain of grief. This involves emotional and behavioural pain. This task can be negated through not feeling, as in cutting off feelings.

Task 3: To adjust to an environment in which the deceased is missing. This adjustment has three aspects: the development of new skills and the taking on of roles which were previously performed by the deceased person; an adjustment of the mourner's sense of identity; and an adjustment of the mourner's sense of the world - their fundamental life values and philosophical beliefs. The bereaved person searches for meaning in the loss and its attendant life changes in order to make sense of it and to regain some control of life.

Task 4: To relocate the deceased emotionally and move on with life. This task is not to help the bereaved give up their relationship with the deceased, but to help to find an appropriate place for the dead in their emotional lives - a place which will enable them to go on living effectively in the world. The incompletion of this task is <u>not</u> loving. The completion of this task is hindered by holding on to the past attachment rather than going on and forming new ones.

Worden (1991) deals with complicated mourning in terms of concepts related to why people fail to grieve. He proposes that the reasons are due to relational, circumstantial, historical, personality, and social factors. He describes how grief goes wrong under the heading of "chronic grief reaction" which is defined as one which is excessive in duration and without a satisfactory conclusion. Resolution is seen in terms of assessing which of the tasks of grieving have not been resolved and why; delayed grief which consists of inhibited, suppressed, or postponed reactions and requires Task 2 to be reworked; exaggerated grief in which the person experiencing the normal grief reaction feels overwhelmed and resorts to maladaptive beahaviours.

I consider Worden's (1991) model as lacking accounts of the psychological processes relating to these forms of complicated grief processes. A detailed analysis of the psychological processes undertaken by people in relation to the various forms of completed grief are not given, although various techniques to address complicated grief are provided. In addition, when Worden speaks of the limitations of the concept of stages in terms of their seriatim, the same could be said of the task concept. This follows, especially when he places it in the context of child development, saying that each task on a particular level needed to be completed if childrens' adaptations were not to be impaired when trying to complete tasks on higher levels.

The last work I will review in this section on the psychodynamic models of grief is that of Therese Rando who is a prominent psychotherapist in the USA in the area of grief. In her works, Rando (1984; 1986a; 1986b) presents the cognitive and intrapsychic processes of grief. She proposes three main categories which include:

a) Decathexis: Based on the Freudian notion, Rando describes the process of the griever - in order to avoid the overwhelming feelings that accompany recognition of separation - creating within her mind a representation or mental image of the deceased. It is from this introjected image of the deceased that the mourner must withdraw her emotional energy. All the feelings, thoughts, memories, and expectations that bound the mourner to the deceased are gradually worked through by being revived, reviewed, felt, and loosened;

b) Developing a new relationship with the deceased: As the mourner reorganises her life in the absence of the deceased person, a new relationship based on recollection, memory and past experiences is structured. To be healthy, this relationship must contain certain aspects. These include the memory that the deceased lived and died; a clear realistic image of the deceased in which the griever has reconciled all the differing aspects of the deceased's personality and all the experiences the griever had with that person; and for the griever to decide consciously which parts of the old life and relationships should be retained and which must be relinquished. This latter aspect must include finding ways of remembering without impeding decathexis and reinvestment in others;

c) Formation of a New Identity: The griever must come to the realisation that the loss has changed her personally; part of the griever has died with the deceased in that the interactional part of the self created by the unique and special relationship now exists only in memory. In addition, she can also augment herself in that she can adopt new roles, skills, behaviours, relationships, and new assumptions about the world, a world without the deceased. What has been both lost and gained must be given a perspective.

The main limitation of Rando's model is that the emphasis is on the process of grieving, as opposed to a detailed description of the behaviours which other theorists have given. Personally, I judge the former to be of more value than the latter, because it provides a description of psychological processes which can better inform the clinical situation compared to a list of behaviours. However, it does limit the usefulness of this model.

## The Model of Chronic Sorrow for Parents of Children with Developmental Disabilities

Solnit and Stark (1961) addressed the grief of parents of children with developmental disabilities through the psychoanalytic model, it was Olshansky (1962) who began the dialogue through the framework of *chronic sorrow.*

### Definition and Assumptions

Olshansky (1962) was one of the first to use the term and proposed it as a nearly universal reaction among parents whose children were severely or moderately developmentally delayed. He stated that although the intensity of this sorrow would vary with people, times, and circumstances, these parents would suffer chronic sorrow throughout their lives as a natural and understandable response to a tragic fact. In more recent literature, it is described as the long-term, periodic sadness experienced in reaction to continual losses (Hewson, 1997; Lindgren, 1996; Lindgren, Burke, Hainsworth, & Eakes, 1992).

A linear model of grief, similar to those described in the previous psychoanalytic writings, has a basic theme of adjustment as the healthy end point (Worthington, 1994). There is a certain sequence to the grief process, beginning with the normal emotional state, the loss or grief event, denial, anger/depression, and moving towards recovery. On the other hand, chronic sorrow involves more of a cyclical model, which assumes that parents of children with developmental disabilities go through a series of recurring, sometimes predictable, stresses that force them through sequences of continual adjustments. Worthington suggested that to assume that families will get used to these stresses is not appropriate. Cyclical grief for these parents entails the positions of family normalcy, to the grief provoking events (threats to health, financial stress, sibling rivalry, milestones not met), to emotional disarray (depression, denial, lethargy, anger), to emotional healing with coping skills reasserted, to family normalcy, around again to another grief-provoking event and so on.

The assumptions associated with the chronic sorrow model are as follows.

1. For linear grief the future is generally knowable (Worthington, 1994). The future is unknown for parents of children with developmental disabilities. The condition of the disabilities are often changing and what implications they have vary with the ages and social realities of both the children and the parents. This changing presentation of the loss results in an on-going grieving for these parents (Bruce & Schultz, 1992). To this degree resolution is not the goal of the process (Lindgren et al., 1992).

2. There is no predictable end point for the grief situation. With linear grief a loved person dies and the partner slowly learns to live with that loss and begins to see an end point to the intense sorrow. Whereas, generally, parents of children with developmental disabilities can see no end point to their losses and therefore their sorrow ( Lindgren et al., 1992; Olshansky, 1962; Worthington, 1989, 1994).

3. With parents of children with developmental disabilities the source of the grief remains physically present offering a constant reminder of the loss (Worthington, 1994). This includes not only the children with the disabilities themselves, but also the demands for constant care, accompanied by other family and professional demands. With the death of children, they are not forgotten, but over time many of the depressing memories are replaced by more comforting ones. The 'self selection' of memories seems part of the normal psychological healing process (Olshansky,1962; Worthington, 1989, 1994).

4. For these parents the sorrow can be progressive and can intensify even years after the initial sense of disappointment, loss or fear. This is seen as being related to the build up of the numerous losses that are a part of a disabling condition, and the impact such losses have on parents (Lindgren et al, 1992). Some parents of children with developmental disabilities may experience relatively constant states of intense sadness with peaks and valleys (Martinson, 1992).

5. Chronic sorrow is a normal reaction to multiple losses over time. Resolution is not a goal. Because the losses occur constantly there is no possibility of

sustaining the emotion, moving through the grief process, and reinvesting energy again (Lindgren et al., 1992).

The greatest limitation of the chronic sorrow model is related to its assumptions: the situation of giving birth to children with developmental disabilities can only be viewed one way, that is, as a tragedy; the situation itself determines parents' emotional states of sadness and grief; there is no recognition of the influence of people's varied perceptions of the situation on emotions; these parents are given no option but to live with long-term, periodic sadness and grief; and these parents, as an absolute statement, will not be able to respond in ways other than sadness, to even predictable stresses, associated with their children's lives. These assumptions do not allow for individuality, creativity, the forming of alternative views of life, the factor of choice, and freedom. Methodological limitations of this model will be discussed at the conclusion of the presentation of related empirical research.

## The Nature of the Loss

The model of chronic sorrow has the nature of the loss still associated with the non-existence of the expected 'perfect' child, along with the lost ideals and fantasies associated with the future of such children (Worthington, 1989). It presents a second source of grief as the on-going losses associated with the existing children (Worthington, 1989); and a third source, as the impact the whole situation has on the family over time (Stein & Jessop, 1984). This third source can include coping with various behaviours associated with disability such as socially unaccepted sexual and aggressive behaviours (Bruce & Schultz, 1992); coping with the increasing awareness of the disabilities and resulting depression which occurs in the children and later adults who have the disabilities (Minde, Hackett, Killou, & Silver, 1972); and the decreasing stamina and energy of the parents themselves in their own ageing process (Bruce & Schultz, 1992).

## Research on the Chronic Sorrow of Parents of Children with Developmental Disabilities

The first researched study on chronic sorrow was conducted by Wikler, Wasow and Hatfield (1981) and explored the pattern of the grief experienced by parents of children with developmental disabilities. This was a descriptive, survey study including a selection of linear graphs used to depict the grief pattern over time. They found that both parents and social workers perceived the responses of parents as continual ups and downs. Parents reported that the later developmental years of the children were as painful as, if not more painful than the earlier years, supporting the presence of chronic sorrow in their lives.

In a follow-up study by Vines (1986) the emotions of fear, sadness, guilt, nervousness, anger, and helplessness were reported by parents of mentally and/or physically disabled adolescents. They spoke of the resurgence of these feelings at developmental milestones which the children could not pass. The feelings were stronger among parents of the mentally disabled children as compared with the physically disabled children. Vines presented the experience as a concept of "regrief" rather than chronic sorrow.

Chronic sorrow was also documented by Fraley (1986) in relation to a sample of parents of premature infants. These parents experienced a resurgence of the sorrowful feelings initially experienced at birth whenever the child experienced a stressful event such as illness, surgery, identification of a new medical problem, delay in achievement of a developmental task, manifestation of behavioural problems or entry into day care. At these times specific emotions included sadness, depression, helplessness, frustration, fear, self- blame, and emptiness.

Damrosch and Perry (1989) studied chronic sorrow in parents of children with Downs Syndrome and compared mothers and fathers. They used an adapted version of the graphs developed by Wikler, Wasow, & Hatfield (1981). Mothers reported their patterns of sorrow as periodic occurrences with peaks and valleys. The fathers reported more gradual, steady recovery.

Using a structured questionnaire, Burke (1989) researched the occurrence of chronic sorrow in relation to mothers of school-age myelomeningocoele children. Chronic sorrow was operationalised with a description of sadness at the time of initial diagnosis and at least at one later recurrence of the same feeling. Using this definition, chronic sorrow was identified in 91% of the sample of 47 mothers. The sorrow recurred with management crises, the child's failure to reach developmental norms, unending caregiving, and other painful experiences.

Bruce, Schultz, Smyrnios, and Schultz (1994) used published scales with 58 mother-father dyads of children aged 1-4 years, 5-10 years, and 11-21 years. They reported no significant age-related differences in regard to parental intrusive thinking; levels of avoidance behaviour; intensity in wishing for what might have been; and current upset when recalling the time of diagnosis. Grieving, defined in relation to these aspects, appeared to be a feature of the parenting experience irrespective of the age of child. The researchers did find that mothers' scores were significantly higher than fathers' on all measures except on the Wishing Scale. In relation to this aspect they were comparable.

There are few empirical studies principally concerned with the construct of parental grief from the viewpoint of chronic sorrow. Many of those that do exist are criticised for their methodological weaknesses (Bruce & Schultz, 1992). Damrosch and Perry (1989), Vines (1986), and Wikler, Wasow and Hatfield, (1981) each relied upon a single point of time data collection on which to draw conclusions (Bruce & Schultz, 1992). Martinson (1992) was critical of Burke's (1989) operational definition whereby two points of measurement of sadness was defined as chronic sorrow. One would expect parents of healthy children to have at least two points of sadness regarding their children. Furthermore, parents have been provided with a description of chronic sorrow and asked to consider whether it is applicable to their current emotions in the research by Damrosch and Perry, and Wikler et al. (Bruce & Schultz).

Due to a lack of validating measuring instruments research has also relied upon the detection of emotions thought to comprise the stages of grief (Bruce & Schultz, 1992). Again this is seen in the work of Vines (1986) and Fraley (1986). Frequently, parents are asked to recall emotions retrospectively, another problem in this research.

### The Challenge of the Model of Chronic Sorrow for Parents of Children with Developmental Disabilities

This model challenges families and professionals to abandon the "static" (Olshansky, 1962) or linear (Worthington, 1994) concepts of grief which suggest acceptance as being the healthy end result and to move towards a model of chronic sorrow as being natural rather than a neurotic response. Such a model expects the need for professional assistance for a longer period of time, and at various times in the lifestyle of both the parents and the children. Most importantly, the concept helps service providers and families identify, explore and predict future stresses and therefore how best to respond to them. It is on these anticipated needs that psychological and social programmes for such parents should be built (Worthington, 1994).

Worthington (1989) suggested that professional hesitancy to adopt a model of cyclical grief is related to the desire to heal, and to a lack of comfort with on-going pain. Medical advances such as immunizations and prenatal care have helped prevent many infant deaths, and on one hand professional personnel and certainly society have come to expect healthy, pain free living. Ironically, the other side of the story is that the number of children with chronic illness is growing. The ongoing aspect of illness, disability and pain is contrary to the healing concept of health professionals.

Davis (1987) philosophically explored chronic sorrow as it related to the expectations of society. She contended that society expects people with visible disabilities and those who care for them to mourn because such a disability is viewed by the rest of society as a tragedy that is analogous to death. Visible grief reassures observers that their own values are appropriate and their own non-disabled condition is normal. The people themselves who have disabilities are expected to be permanently enmeshed in the tragedy, since not to mourn would call into question the high value society places on health and fitness.

On the other hand, Davis (1987) suggests that society expects the families of children with disabilities to mourn through a process which is time limited. After the crisis -

diagnosis period, society requires these parents not to mourn, and suppression or at least control of the grief is expected. Society does not tolerate the visibility of grief that is not resolvable because it again threatens the desire society has to distance itself from pain, suffering and disability. Davis (1987) argues for the recognition of recurrent grief, along with interventions to help people deal with the conflict between the need to mourn and expectations society places on them to hide grief.

## Conclusion

In this chapter I have presented the dialogue between grief models which resolve (the psycho-analytic, psychodynamic, and stage models) and ones which have chronic sorrow without resolution (the chronic sorrow model). I have also presented the various problems related to each of these models. Then I refer to the previous chapter and to McCoy's (1980) account of culture shock and I am drawn to a personal construct model of these processes which can provide an understanding and appreciation of the integrity, adequacy and values of both cultures: the expected 'perfect' non-existent children, along with the unexpected children with disabilities, who are present. A personal construct model provides an optimistic view of growth, proposes a range of psychological processes allowing for individual differences, and sees the effects experienced by people depending on constructs validated (not pleasant and unpleasant events). Winter and Watson (1999) describe personal construct theory as viewing people actively creating their own realities, the major concern being their viability (not validity), the approach allows for a distinction between individual's core processes and peripheral expressions of these, and there being a concern with the individual's protection and perpetuation of the integrity of their system, since the maintenance of perceived identity becomes as important as life itself.

# CHAPTER 4

# PERSONAL CONSTRUCT PSYCHOLOGY MODEL OF GRIEF

In Chapter 3, I have presented an overview of the prominent models of grief and have related some of these directly to the experience of parents of children with developmental disabilities. These models encompassed psychoanalytic and psychodynamic thinking including the notions of phases and stages, and task models, along with the concept of chronic sorrow, but they do not do justice to the experiences of these parents. I choose personal construct theory because it provides an optimistic view allowing for choice, freedom, change and adaptation. It provides a range of psychological processes which allows for individual differences; and proposes that the effects of experiences depend on constructs or life views being validated or not (rather than on pleasant and unpleasant events). This chapter will present the processes involved in grieving as seen through the perspective of personal construct psychology.

I have presented, in Chapter 2, some of the concepts of personal construct psychology which were particularly relevant to the effects on parents of having children with developmental disabilities. Further concepts which are integral to the grief process will be presented in this chapter. Emotional experiences, being part of the process of construing, are discussed further in this chapter. The chapter concludes by proposing a model, within the framework of personal construct psychology, of the grief process undertaken by these parents.

## Personal Construct Psychology

### Theory and Assumptions

To recap the essence of the theory presented in Chapter 2, I restate that individuals create constructs which interlink to form a personal construct system. These systems allow people to make sense of the world in terms of predicting and anticipating future events. A person's construct system is always able to be revised and replaced. They determine how people act.

## Constructs - Bipolar

A further aspect of the nature of constructs is that they are bi-polar. "A construct is a way in which some things are construed as being alike and yet different from others" (Kelly, 1955, p.74). Fransella (1995, p.41) elaborates the notion in this way: "aspects of a situation are similar to *and thereby* different from other aspects of that situation". This seems to suggest that when aspects of a situation are similar to each other, by the nature of this condition they are different from other aspects of that situation. Dalton and Dunnett (1992, p.13) emphasise that Kelly is speaking of "contrast.....not opposite". Button (1985, p.7) speaks of the concept in terms of "rather than viewing 'goodness' as a category in its own right, its meaning (is) defined in terms of what it has been contrasted with, for example, 'badness' ". Perhaps it would be hard to imagine what a construct such as happiness might mean if we had not experienced sadness, or the construct of disability if we had not experienced ability.

## Slot Rattling

Constructs, being bi-polar, provide people with dichotomous choice, and either one of the two ends of the construct may be chosen through which to perceive a situation or act upon it (Kelly, 1955, p.89). The contrasting ends often include the aspects of preferred and non-preferred. When people are under pressure to reconstrue they are likely to rattle around between the old slots of an existing construct rather than reconstrue (Kelly, 1955, p.90).

## Constructs as Pathways of Movement

An alternative move to slot rattling is for people to reconstrue. "One way to think of the construct is as a pathway of movement" (Kelly, 1955, p.89). When confronted with the need to move, people can construct new pathways within construct systems which allow them to access areas which were not previously accessible. Neimeyer (1995) and Guidano (1991) take up this notion of constructs as pathways and speak of them as interconnecting to form personal organised meaning systems.

## Freedom and Determinism

In Chapter 2 I introduced constructive alternativism. I now elaborate on this notion as it relates to the philosophical stance of freedom and determinism. Kelly speaks of the one important kind of determinism being the control of a superordinate construct over its subordinate elements (Kelly, 1955, p.15). This implies that the elements do not determine the constructs, therefore, "man, to the extent that he is able to construe his circumstances, can find for himself freedom from their domination. It implies also that man can enslave himself with his own ideas and then win this freedom again by reconstruing his life" (Kelly, p.15). "Ultimately a man sets the measure of his own freedom and his own bondage by the level at which he chooses to establish his convictions" (Kelly, 1955, p.16). And so the question arises: what role do circumstances play in relation to determinism?

Dalton (1993) says that the notion of constructive alternativism in personal construct psychology does acknowledge that circumstances do impose limitations. She, Dalton, uses the example of some people when in solitary confinement in prison who create sustaining imaginative inner lives in order to survive, while others constrict into depressions and emptiness. Circumstances do impose limits, there are always alternatives to choose from, and people do not have to be completely hemmed in by circumstances or previous personal history (Dalton, 1993; Fransella & Dalton, 1990; Kelly 1955). In summary, determinism exists to the extent that people are governed by the nature of their most influential (superordinate) constructs; freedom comes from the ability to reconstrue life (Dalton, 1993; Fransella & Dalton, 1990; Kelly, 1955).

## Choice and Degrees of Awareness

### Preverbal Constructs

The availability of choice of alternative construing is influenced by the degree of cognitive awareness people have of their constructs and construct poles (Fransella, 1985, Viney, 1996). The degree of awareness is influenced by various types of construing.

Kelly (1955, p.340) defines a preverbal construct as: "one which continues to be used even though it has no consistent word symbol". They tend to find expression through being acted out in behaviours such as crying, dribbling, and yelling. The origin of preverbal constructs is related to those elements of which an infant could be aware. These elements include sustenance and dependency relations which are not dispersed but reliant on particular people. The notion of preverbal constructs, at least in part, deals with what is otherwise named as the 'unconscious' (Kelly, 1955, p.344). Kelly goes on to say that preverbal constructs "represent a kind of core of the ... construction system ... and (as such, people use) a preverbal type of construction to maintain (their) integrity and unique identity in the face of difficulties" (Kelly, 1955, p. 341-2).

### Submergence

People's degree of awareness is also influenced by submergence. This is where a pole of a construct is submerged and as such less available for application to events (Kelly, 1955, p.390). For example, 'able' may be available and 'disable' not available. Kelly (1955, p.348) says that people often construe themselves as a potential element for inclusion in the context of the submerged pole of the construct. The purpose of submergence is related to fear of needing to reconstrue, with far reaching and devastating results (Kelly, 1955, p.348). Button (1985) believes that Kelly clearly implies that the unconscious purpose of keeping the pole submerged is to avoid construing oneself in that light (Button, 1985). The submerged end carries unacceptable or incomprehensible implications, which the parents are unwilling to put to the test at that time.

### Suspension

Kelly speaks of the phenomena which are popularly identified as 'forgetting', 'dissociation', and 'repression' within the theoretical framework of suspension. A suspended element is: "one which is omitted from the context of a construct as the result of revision of the person's construct system" (Kelly, 1955, p.390). Certain aspects of previous experience may not be able to be handled as part of the present construct system and so become rejected or forgotten. In this way the aspect of choice is again affected.

## How Does Change Occur?

Change is inherent in being human. Psychological health is sustained by involvement in ongoing revision and change to an individual's construct system (Fransella, 1972; 1975; 1985; 1988; Neimeyer & Neimeyer, 1993; Viney, 1996). Kelly (1955, p.14) observes: "Each day's experience calls for the consolidation of some aspects of our outlook, revision to some, and outright abandonment of others". Psychopathology is seen in terms of a construct system being impervious to change (Neimeyer & Neimeyer, 1993). So how can changes be made to construct systems?

As stated in Chapter 2, in the reviewing and forming of new constructs, Kelly (1955) suggests that people act as scientists, in that they form hypotheses and test them for their predictability. New outlooks begin in the form of hypotheses (Fransella, 1985; Neimeyer, 1995; Viney, 1996), and through testing them people continue their stories (Mair, 1989), giving further meaning to the events in their lives (Leitner, 1988; Viney, 1996 ).

Kelly describes the decision-making processes relating to change through a cyclic model. He terms it as the C-P-C Cycle which is: "a sequence of construction involving, in succession, circumspection, pre-emption, and control, and leading to a choice which precipitates the person into a particular situation". Circumspection is where people employ a series of propositional constructs in dealing with a situation at hand. A propositional construct does not disturb the membership of other elements in the realm (Kelly, 1955, p.109), nor make a commitment to other elements in the realm (Kelly, 379). For example, a roundish mass may be considered, among other things, as a ball, in doing so there is no reason therefore to believe that it could not be lopsided, valuable, or have a French accent (Kelly, p.109). A pre-emptive construct is "one which pre-empts its elements for membership in its own realm exclusively" (Kelly, p.379). This also contains elements of control which is obtained more precisely now through superordination. In pre-emption, the person is saying, this is the crux of the matter, and for now, the problem will be dealt with as if it were this and this only (Kelly, p.379). At this point the person is disregarding the relevancy of all the other issues that may be involved (Kelly, p. 380). The final aspect of choice or control is where the person chooses that alternative in a dichotomised construct, which he or she anticipates will provide the greater possibility for extension and definition of the construct system (Kelly, p.380).

In less technical, but less powerful language, the process might be described as an event occurring to which people respond by surveying all the issues concerned, (Dalton, 1993) along with a number of different interpretations of the same event (Leitner, Dunnett, Anderson, & Meshot, 1993). People then move to focusing on the main factor governing the decision making which will lead them to predict the outcome more surely (Dalton). This leads into the moment of choice in which the decision needs to be integrated into the hierarchical construct systems (Dalton; Leitner et al, 1993).

Other types of construing relating to change are termed tightening and loosening. Tight constructs are those "which lead to unvarying predictions" (Kelly, 1955, p.357); even the elements which lie at the outer edges of the range of convenience of the construct are consistently construed as belonging either to the like or the unlike grouping. In a healthy person the core constructs are tight and yet subordinate to other patterns in such a way that allows for a person's integrity to remain intact and unthreatened when he or she finds it necessary to make exceptions to customary views held of the world or actions performed. The extreme of tight predictions could lead to obsessive behaviours and rigid thinking. Loose constructs are: "those which lead to varying predictions but which ...... retain their identity" (Kelly, p.357). Loose constructs are like rough sketches allowing for flexible interpretations and ambiguities. Loosening may be accompanied by anxiety, erratic and sometimes bizarre behaviours. New constructs are formed by loosening up old ones and tightening up the tentative formulations which begin to take shape in the resulting disarray (Kelly, p.357). In the processes of circumspection and pre-emption people might construe in ways which lead to loose or tight construing (Button, 1985; Dalton, 1993; Fransella & Dalton, 1990; Viney, 1996). Loose construing opens up vague yet stimulating vistas of meaning; while tight construing leads to more precise and constrained meanings (Viney, 1992a; 1996).

Change also involves constructs being permeable, that is: "imply(ing) additional elements" (Kelly, 1955, p.109). The constructs do not change but can accept new elements within their range of convenience and to which they can therefore be applied (Dalton & Dunnett, 1992).

## What Are Emotions ?

As stated in Chapter 2, McCoy (1977; 1981), following Kelly, saw emotional behaviours as indicators of the state of the construct system following awareness of the need to reconstrue. Mascolo and Mancuso (1992) explore further the relationship between emotions and construct systems. They suggest that: "to the extent that a person-as-system detects discrepancy between event related input and existing standards and concerns, he or she becomes physiologically mobilized as part of the process of reducing the discrepancy to a subjective optimal level" (Mascolo & Mancuso, 1992, p.29). They then distinguish between emotional experiences and emotional states. Emotional states have three components: they are generated by the appraisal of the relationship between events and a person's desires, motives, goals or concerns; bodily reactions including changes in arousal functioning; and various motive-action tendencies which function in the service of one's motives and concerns. Emotional experiences consist of the conscious, constructed awareness of the three aspects of the emotional states. For Mascolo & Mancuso (p.29) this awareness is different from cognition. They define cognition as the processes by which persons construct meaning out of input, and state that it therefore follows that the vast majority of cognitive (constructive) processing proceeds nonconsciously.

It is the emotions - indicating both the conscious and non-conscious challenges to, and changes in, the construct systems - which I wish to explore in this research. I will use Mascolo & Mancuso's (1992) terminology of emotional states and emotional experiences in the following chapters.

Mascolo & Mancuso (1992) and Mascolo (1994) also extend the personal construct treatment of emotion by emphasising that while people are cognitively active in forming their own standards or construct systems, the construing occurs within social and cultural contexts. They propose that the states and experiences of guilt, shame and pride have their origins in social interaction. Therefore the guilt appraisal of, 'I am responsible for committing a wrong-doing' has its origins in moral evaluations of self-caused actions by socialization agents; and the shame appraisal of, 'I have failed to live up to social standards in the eyes of others' is formed in interactions in which others express disappointment or disgust for actions they deem as socially unworthy (Mascolo, p.90).

## A Personal Construct Account Of The Grief Process

Woodfield and Viney (1984-5) generated an explanation of the normal process of grief and mourning from the perspective of Kelly's theory of personal constructs, using widowhood as an example. They said that prior to this time there was no consistent theoretical formulation available by which the psychological states associated with bereavement could be understood and anticipated, except that presented from a psychodynamic approach. In essence they saw the psychological states associated with bereavement being accounted for in terms of the difficulties involved in changing parts of the personal construct system. They conceptualised such changes in terms of two concurrent processes occurring, those of dislocation and adaptation. The approach was presented as a nonphasic one.

The real or apparent failure of the present construct system to deal with the new events was termed dislocation (Woodfield & Viney, 1984-5, p. 4). Adaptation occurs when the construct system is altered to adapt to the new set of events (Woodfield & Viney, p.4).

The dislocative psychological states were presented as shock and numbness, stress, anger, anxiety, guilt, sadness and despair. Adaptation included the processes of assimilation, which involves incorporating the elements into the construct systems, and accommodation, which in turn requires the construct system to adapt and adjust. This process consists of the active elaboration and re-organisation of the personal construct system. The adaptive psychological states have been named as assimilation through denial, hostility, idealization, depression, and aggression.

Viney continues to use the same model of the grief process in relation to widows in 1990b, and then in relation to dying, in 1991.

Neimeyer (1999) proposes that the field of grief counselling is in revolution and outlines from a broader constructivist approach a model of mourning that argues that meaning reconstruction in response to a loss is the central process in grieving.

1) Innovating upon culturally available systems of belief, individuals construct permeable, provisional meaning structures that help them interpret experiences, coordinate their relationships with others, and organise their actions towards personally significant goals,

2) these frameworks of meaning are anchored less in some 'objective' reality, than in specific negotiations with intimate others and general systems of cultural discourse,

3) the meanings are as variegated as the local conversations in which individuals are engaged and as complex as the cross currents of shared belief systems that inform their personal attempts as meaning making,

4) people may feel varying degrees of "authorship" over the narratives in their lives, with some having a sense of deeply personal commitment to their beliefs, values, and choices, while others feel estranged from those beliefs and expectations that they experience as imposed on them by others in their social networks or by communal ideologies,

5) loss is an event that can profoundly perturb one's taken for granted constructions about life, sometimes traumatically shaking the very foundations of one's assumptive world,

6) this meaning construction view emphasises the subtle nuances of difference in each griever's reaction (thus responding to the key deficiency in traditional models of grieving that all or most bereaved persons responding similarly to loss at an emotional level),

7) the professional needs to address the bereaved individual from the position of 'now knowing' rather than the position of presumed understanding and 'expert knowledge',

8) grieving is an active process. Bereavement thrusts survivors into a period of accelerated decision making,

9) the reconstructive processes entailed in grieving cannot be understood as taking place within isolated subjectivities, divorced from a larger social world. Grief is linked with the responses of others, each constraining and enabling the other. Bereavement requires survivors to recruit social validation for their changed identities.

## Emotional States Of Parents Who Have Children With Developmental Disabilities

### Cognitive Anxiety

From a medical perspective, Selikowitz (1990), a consultant paediatrician, describes the initial reactions of parents to the diagnosis of their children having developmental disabilities in terms of shock, including experiences of numbness, and being shattered or devastated. Selikowitz, along with Levene, Tudehope and Thearle (1990) all coming from the medical perspective, describe the physical reactions of parents as including feeling cold or perspiring; being nauseated; and close to fainting; choking; experiencing dyspnoea, empty feelings, weakness, fatigue, insomnia, and loss of appetite. The parents present as unable to listen or understand, because they hear isolated phrases only. They experience denial or a sense of shutting down their minds. Selikowitz quotes a father as saying: "When the doctor mentioned the diagnosis, I felt numb all over. I saw the doctor's mouth open and close, but the only words I heard were 'Down Syndrome' and 'retardation'" (Selikowitz, 1990, p. 4). Parents also reported cognitive confusion in terms of an inability to read the signs related to their children's health and disabilities and form conclusions. Another parent said: "I kept on going to check whether she was still breathing....Eventually, I realised I was becoming over anxious..." (Selikowitz, 1990, p.5).

Selikowitz's (1990) work presents theory based on clinical observation and is not based on rigorously collected data. His theory includes parents having expectations of their unborn children which require adjustment after the births. He describes these parents as ordinary people reacting to an extraordinary situation.

As stated in Chapter 1, the research of Irvin et al. (1982) comes from a broadly psycho-analytical perspective, and reported experiences of parents similar to those of Selikowitz in terms of shock and numbess. Darling (1979, p.131), whose work is also described in Chapter 1, stated that: "parents are faced with events or observations that do not fit.....with the theme of having had a normal baby".

Davis and Cunningham (1985, p.256), from a personal construct perspective, state that at the time of the disclosure of the diagnosis, parents' constructs around the anticipated children and associated type of parenting are massively and suddenly invalidated. They are unable to anticipate or predict either immediate or long term events. This inability to predict is related to situations such as what is wrong with the children, what are the causes of the disability, should the parents consent to operations or not, will the children live, walk, talk, and so on (Davis & Cunningham, 1985). Davis & Cunningham's (1985) research results indicated that the predominant question of the initial response for parents was: 'What does it mean?' McConachie (1985), also writing from a personal construct perspective, suggests that the predominant experience of this stage is one of a strong sense of 'not knowing'. Both of these descriptions are consistent with the personal construct notion of cognitive anxiety.

Kelly defines anxiety as: "the awareness that the events with which one is confronted lie outside the range of convenience of one's construct system" (Kelly, 1955, p.391). It is the "recognition that one is inescapably confronted with events to which one's constructs do not adequately apply" (Kelly, p.366).

Viney & Westbrook (1976, p.141) explore this notion further and define cognitive anxiety as "occurring when the individual is unable to anticipate and integrate experiences meaningfully". They suggest cognitive anxiety can occur as a result of one or more of the following conditions: in the face of new stimuli, when extra constructs are needed but not available, when stimulus is incongruent and leads to conflicts within construct systems, when responses are unavailable and uncertainty is generated, and when there are high rates of stimulus presentation which interferes with cognitive processing.

It would seem clear that the descriptions presented from the medical perspective (Levene et al. 1990; Selikowitz, 1990), the psychoanalytic ( Irvin, Kennell, & Klaus, 1982), and the developmental (Darling, 1979), along with those from personal construct psychology (Davis & Cunningham, 1985; McConachie,1985), are compatible with at least one or all of the conditions proposed by Viney and Westbrook (1976) as being related to cognitive anxiety.

### Threat

In Hannan's (1975) biography he described feelings of rage, aggression, thoughts of killing his child, feelings of failure, and fear at the strength of his emotional experiences. McConachie (1985) suggested that, in personal construct theory terms, such feelings would seem to represent threat. Threat is defined by Kelly (1955, p.391) as: “an awareness of an imminent comprehensive change in one’s core constructs”. Threat occurs when the changes are in relation to the self; are seen as comprehensive and as bringing about substantial differences to the fundamental meaning of the lives of the people; represent multifaceted alternative self-relating structures; and are close to occurring.

Parents of children with developmental disabilities report experiences of threat at the level of their personal identity and existence (Breen, 1989; Raphael-Leff, 1993; Solnit & Stark 1961). They express it in terms such as: "losing their sanity" (Selikowitz, 1990, p.1) or "feeling that their world has come to an end" (Irvin et al, 1982, p. 232 and Selikowitz, 1990, p.1). The ways in which they previously perceived life no longer make sense or have meaning. In varying degrees, parents become aware of imminent, comprehensive changes that will need to occur at the level of their most self-related and influential constructs.

The sources of threat are around death and mutilation of the parents themselves or their children, and experiences of separation. Irvin et al (1982) reported that in most instances in the research in which they were involved (previously described in Chapter 1), mothers feared for the lives of their babies, despite strong reassurances. At other times this experience evoked thoughts around death experiences. Selikowitz (1990, p. 5) quoted a father as saying: "The only other time I felt like I did then was when my father died. It's like a death, it's worse than death, because the difficulties aren't over". And there is always the loss of the expected children (Selikowitz, 1990).

There is mutilation of the children through the disabilities themselves and also through corrective surgery (Irvin et al., 1982). Separation occurs between parents and children, within family relationships, spousal relationships, society and self. (See Chapter 1 for full descriptions of these research results).

### Guilt

From a personal construct perspective, Davis (1983) suggested that such parents act in ways they have never done before, or could never have envisaged themselves doing. For Kelly (1955, p.391) guilt: "is the awareness of dislodgement of the self from one's core role structure". Core role structure is defined as "one's deepest understanding of being maintained as a social being" (Kelly, 1955, p.370). Mascolo & Macuso (1992) see guilt as following an appraisal and judgement by self of having committed a wrong-doing in relation to this social role. Mascolo (1994) suggests that the standard by which wrong-doing is determined is an internalisation of social and cultural norms.

Because the social and cultural norms are made part of the core role constructs, it is by these constructs that people conceptualise themselves as social beings and anticipate their own behaviours. When people find themselves doing things they would not have foreseen themselves doing, present core role structures become invalidated, and the whole network of constructs through which people view themselves is in danger. Bannister (1966) suggests that people become unpredictable to themselves - a fate so fearful that people kill themselves rather than sustain it.

The experience of guilt being related to parents of children with developmental disabilities is reported by several authors (Davis & Cunningham, 1985, Harris & Kositsky, 1983; Kennell & Klaus, 1982; Levene et al., 1990; Selikowitz, 1990; Willett, Patterson, & Steinbock, 1986). It is expressed in phrases such as: "I felt that I must have done something terribly bad..." (Selikowitz, p.7). Mothers have told of their preoccupation, to the point of obsession, with the events that preceded the births of their babies, finding fault with themselves for what was and was not done (Harris & Kositsky; Selkowitz; Willett et al.). Parents wonder about hidden physical or moral defects in themselves (Harris & Kositsky); and fathers wonder whether arguments or the physical activity of sexual intercourse between the parents could have caused the disability (Harris & Kositsky). Parents can feel guilty about their inability to care for their new born children who need special care (Levene et al.); or guilt about the lack of affection they experience for their children (Willett et al.)

Parents can also feel guilty about their own reactions (Schild, 1976). Common feelings are of rejection, hostility and destruction towards the children with developmental disabilities. When parents are unable to tolerate these negative feelings, they can feel guilty about their own reactions. The sources of guilt are many.

Because these authors come from varied perspectives such as medical, psychoanalytic, developmental, or stress-related models, a common understanding of guilt cannot be assumed, however the descriptions and verbal comments can be seen as compatible with the personal construct perception of guilt.

## Shame

Shame is also an emotion which is formed in relation to societal and cultural norms (Mascolo, 1994). It is an appraisal and judgement that: 'I have failed to live up to social standards in the eyes of others', (Mascolo, 1994). McCoy (1980, p. 97) defined it as an: "awareness of dislodgment of the self from another's construing of one's role". Parents who give birth to children with development disabilities often see themselves as having acted outside the expectations of others if they were the sort of person others thought they were.

For these parents shame can be expressed in many forms. It is frequently an aspect of parents' reluctance to announce the birth of their children and to tell people of the disabilities (Bailey, Blasco, & Simeonsson, 1992; Darling, 1983; Klaus & Kennell, 1982). One parent described their response to the diagnosis as: " We both cried. What were we going to tell people?" (Darling, 1979); "I felt I had let everybody down....I couldn't bear to face them" (Selikowitz, 1990). Related to this is the hesitancy on part of families to venture into public places with their children (Darling, 1983).

A further aspect of shame is the intense feelings of inadequacy parents have regarding their ability to care for their children (Irvin et al, 1982). Parents can also feel inadequate about interacting with professional personnel (Schild, 1976).

## Time and the Grief Process

The question regarding a time frame, for the existence of the above emotion states within the grief process, is a difficult one, because of the variation which occurs due to individual differences. Having said that, Worden (1991) speaks of resolution after grief taking between one to two years or longer. Schleifer (1983) found that after two years the majority of mourners *begin* to re-establish themselves. On the other hand, Parkes (1972) suggests that it takes three or four years to reach stability after a time of grief. This researcher began to interview parents within 2 years of the disclosure of the diagnosis of the children's disabilities, with a second data collection taking place 18 months later. Theoretically, this time frame would allow parents to gain some stability after the initial shock and yet still be in the process of grieving at the time of the first data collection. It could also be predicted that eighteen months later some parents may have reconstrued and stabilised their lives again while others would still be in the process of doing so. This would allow the reseach to tap the grief process at different points.

## A Model Of The Grief Process Undertaken By Parents Of Children With Developmental Disabilities

I propose the following model of grief as that which depicts the process undertaken by parents of children with developmental disabilities. It uses the concepts of personal construct psychology (Kelly, 1955), and the empirical literature relevant to the topic. The model consists of 16 propositions, regarding construing, change, and emotions of these parents.

## General Propositions Regarding Construing

*1. People who have given birth to and are parenting children with developmental disabilities are oriented to make sense of life.* Each individual does this by creating his or her own construct system or view of the world which allows the person to predict and anticipate future events.

*2. The ways in which parents view the world will determine how they act.* This is in relation to self, and as parents, partners, and members of society.

3. *Because these parents are under pressure they will have a tendency to slot rattle,* that is, move to the other end or pole of their presently held constructs or views of life, rather than develop new constructs. The contrasting poles often include the elements of preferred and non-preferred e.g. able being preferred and disabled being non-preferred.

*4.* Rather than slot rattle, they might *reconstrue and in so doing find alternative pathways of movement.* Constructs or world views do not stand in isolation but form an inter-connecting hierarchical system in which some constructs are more self-related (core) than others and some more influential (superordinate) over others. Together the constructs form organised systems through which meaning or sense is given to events.

*5.* Without disregarding the limitations imposed by the circumstances brought about by children with developmental disabilities, *there are always alternative ways of seeing events.*

*6. The availability of choice is influenced by the degree of awareness parents have of the constructs or world views which they hold.* The birth of children with developmental disabilities is likely to tap self-related (core) constructs, in particular those relevant to identity and existence and ones relating to dependency as experienced by infants who have only a few people on whom they rely for sustenance. It is likely that these constructs were formed during infancy, do not have word labels, and are not readily available to awareness. They find expressions through actions such as behaviour associated with emotions. At other times, parents might be aware of one pole of their construct and not the other. The unconscious purpose of keeping the pole out of awareness is the need to avoid construing themselves in that light. The submerged pole might carry unacceptable and incomprehensible implications. In addition, people's awareness of construing might be limited by single elements of events being omitted from consciousness.

## Propositions Regarding Change

7. Change is intrinsic to being human. Before the births of their children, parents often have had limited experience associated with disabilities and so struggle to make sense of events. Their world views are under challenge, and to be psychologically healthy, *parents need to revise their construct systems, and replace them if they are found wanting* in the face of the new events.

8. In the process of forming new constructs, *parents make hypotheses and test them for their degree of accurate predictability.* All actions of parents are considered in this light. Parents may explore the implications of rejecting or killing their children. These are often initial and temporary hypotheses to be tested in order to achieve one of a number of possible adaptations.

9. In their decision making processes *parents are involved in the CPC cycle* (Circumspection, Pre-emption, and Control or Choice). They survey all the issues involved along with varied interpretations of them (Circumspection); they focus on the crux of the matter (Pre-emption); and then choose a particular course of action (Control-Choice).

*10. The processes of change involve loosening up old construing* which leads to varying predictions, *and tightening up the tentative formulations* which begin to take shape in the resulting disarray. Tight construing leads to unvarying predictions.

*11. Construct systems differ in their degree of permeability.* Some superordinate constructs, while remaining unchanged, can accept new elements within their range of convenience. These new elements can then be applied and give meaning to situations.

## Proposition Regarding Emotions

12. Many *emotions* are evoked for parents of children with developmental disabilities. They *reflect the state of their construct systems* which, consciously and unconsciously, have been affected by the events.

*13. Parents of children with developmental disabilities experience cognitive anxiety.* Their present construct systems are unable to anticipate and integrate the new experiences in a meaningful way.

*14. The experiences of parents which are particularly related to death, mutilation and separation evoke threat.* These parents become aware of the need for imminent, comprehensive change to occur at the level of their self-related and often most influential constructs, about existence, damage and loss.

*15. These parents experience guilt.* They often act in ways not envisaged by them previously. They see themselves as having acted outside their core social roles.

*16. Shame is also a predominant emotion.* Parents become aware of having acted outside of others' perception of the core social role of the parents.

This model identified the general propositions regarding construing for parents of children with developmental disabilities. It speaks of propositions related to change and to emotions. The four emotional states and experiences are proposed as the most salient for parents of children with developmental disabilities. These, along with their associated constructs, are examined in this empirical work.

From this model the aim of the research will be defined, along with the research questions and hypotheses to be tested. I present these in the following chapter.

# CHAPTER 5

# RESEARCH AIMS, QUESTIONS AND HYPOTHESES

## The Aims Of The Research

My primary aim in this research is to explore the process by which people adapt to the events of giving birth to and parenting children with developmental disabilities. The particular aspects of the adaptation process addressed are: the emotions of individual parents (mother or father) and process of movement of the construct system whether that be through reconstruing or moving between the preferred and non-preferred poles of existing constructs. The content of self-related and most influential constructs will be noted, along with the content of the external trigger of the emotions.

Quantitative data were used to test statistically the hypotheses of the research which were derived from the model. Qualitative analysis of the transcripts provided information on the content of the constructs and the external triggers of the emotions. These types of information allowed for further elaboration of the model.

## Research Questions Based On The Model

The research questions which addressed the emotional states and experiences, and the movement within the construct system, whether that be through re-construing or moving between preferred and non-preferred construct poles, are as follows:

a) What were the levels of intensity of the emotions of individual parents (mother or father) of children with developmental disabilities compared to individual parents who had children without developmental disabilities ?

b) What percentage of individual parents changed their life views in response to giving birth to children with developmental disabilities, as indicated in a change of content of core superordinate constructs between the first and second time of data collection?

c) What were the levels of intensity of the emotions of individual parents with children with developmental disabilities who perceived themselves as being on their preferred, compared to their non-preferred, construct pole?

d) What were the levels of intensity of the emotions within the pattern of change and no-change in construct pole preferences over time?

The seven hypotheses derived from the questions are listed below and the results of the analyses relating the data to them are provided in Chapter 7.

## Hypotheses Based On The Model

### Hypothesis About the Levels of Intensity of Emotions of Type of Child

1. The literature suggests that parents of children with developmental disabilities experience the emotions that any new parent might feel, but at a higher level of intensity and with additional themes particular to the situation (McConachie, 1985). It was therefore hypothesised that individual parents who had given birth to children with developmental disabilities would experience higher levels of cognitive anxiety, death, mutilation, separation, guilt and shame anxiety than individual parents who have given birth to children without developmental disabilities.

### Hypothesis About the Percentage of Individual Parents who Changed their Construct System by Reconstruing

2. Given that superordinate constructs are most resistant to change (Fransella, 1995), it is hypothesised that a small percentage only of individual parents will reconstrue at the level of their self-related, most influential constructs. The large majority will adapt to the new event by moving between preferred and non-preferred poles of their presently held constructs.

### Hypothesis About the Levels of Intensity of Emotions of Construct Path Preferences

3. The research literature on the effects on parents of giving birth to children with developmental disabilities suggests that for some the experience was devastating and that the meaning life held for them was irrecoverable. But for others it was an initial shock, but was later described as a meaningful and positive experience. On this basis it was hypothesised that individual parents who had given birth to children with developmental disabilities, who perceived themselves as being on the non-preferred pole of their most influential self-related constructs, would have higher levels of cognitive anxiety, death, mutilation, separation, guilt, and shame anxiety than individual parents in similar situations who perceived themselves as being on their preferred construct poles.

### Hypotheses About the Levels of Intensity of Emotions Of Construct Path Preferences Patterns Over Time

4. Personal construct psychology is a theory of change (Kelly, 1955). It was therefore expected that the levels of the emotional states of parents would be influenced by the factor of time. It was hypothesised that the levels of emotions would vary over time, irrespective of the construct pole preference patterns.

The use of a longitudinal design will make it possible to look at variation of change and no change in construct pole preferences over time. The longitudinal design will include Time 1 of data collection. This will occur within a time period of a minimum of six months and a maximum of two years after the disclosure of the diagnosis. Time 2 of data collection will be 18 months later. This time span of 18 months between Time 1 and Time 2 will be identical for all research participants. Analysis of the variations as they occur over time will indicate four differing patterns of construct pole preferences. Based on Hypothesis 3 about the effects of time, the following four hypotheses were formulated.

5. It was hypothesised that individual parents of children with developmental disabilities who perceived themselves as being on the preferred poles of their most influential self-related constructs at Time 1 and Time 2 would have, over time, either stable or decreased levels of cognitive, death, mutilation, separation, guilt and shame anxiety.

6. It was also hypothesised that individual parents of children with developmental disabilities who perceived themselves as being on the non-preferred poles of their most influential self-related constructs at Time 1 and Time 2 would have, over time, either stable or decreased levels of cognitive, death, mutilation, separation, guilt and shame anxiety.

7. It was further hypothesised that individual parents of children with developmental disabilities who perceived themselves as being on the non-preferred poles of their most influential self-related constructs at Time 1 and on the preferred poles of their constructs at Time 2 would have, over time, decreased levels of cognitive, death, mutilation, separation, guilt and shame anxiety.

8. It was hypothesised, too, that individual parents of children with developmental disabilities who perceived themselves as being on the preferred poles of their most influential self-related constructs at Time 1 and on the non-preferred poles of their

constructs at Time 2 would have, over time, increased levels of cognitive, death, mutilation, separation, guilt and shame anxieties.

## Accounts Of The Hypotheses Testing And Qualitative Data Analyses

The analyses of data relating to these hypotheses will be presented in Chapter 7 through the quantitative results which focus on the emotions of individual parents (mothers or fathers), type of child, and construct pole preferences. Chapter 8 presents the qualitative findings dealing with the situational themes which evoke the emotions of the individual parents. The methodology used to make the hypotheses functional will be presented in the next chapter, Chapter 6.

# CHAPTER 6

# THE METHODS USED TO ACCESS THE PROCESS OF ADAPTATION UNDERTAKEN BY PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

In Chapter 5 I presented the aim and hypotheses of the research that were generated by the model provided in the previous chapter. In Chapter 6 I give the methodology used to test these hypotheses.

In this research, I have used both quantitative and qualitative methods to access the process of adaptation undertaken by people who give birth to and parent children with developmental disabilities. The hypotheses were tested by looking at changes in content of core, superordinate constructs and comparisons of the emotional states and experiences of parents, with their perceptions of being on their preferred or non-preferred construct pole. A qualitative analysis of the interview data was used to obtain the content of the most influential constructs of parents and the content of the external situations which challenged the construct systems.

This chapter includes information regarding the sampling of the research participants, the processes of data collection, and the types of statistical analyses which were used. The first section gives the sampling and recruitment procedures, along with descriptions of the participants, and the degree to which the samples are representative of their parent population. The second section describes the theoretical issues, procedures and instruments used in relation to the collection of the data. The third presents the analyses of the data.

## The Sampling Procedure

Stratified purposeful sampling was employed in this research. This procedure allowed major variations in the population to be captured while common core themes were able to emerge (Patton, 1990). The sample size was 81 individual parents, that is, either the mother and/or the father, of children with developmental disabilities. Seventy seven percent of times both the mother and the father of the family were participant researchers, and 23% of the times only the mother or the father participated in the research. The sample was purposefully stratified on the following demographic factors: Gender, Age of Parents, Place of Residence, Education Level, Annual Parental Income and Professional Support Systems Available. Close to 40% of the sample was male and 60% female. There was an approximately even distribution of percentages in each of the age groups 18-25 years, 26-30 years, 31-35 years and 36-40 years, with a smaller percentage in the 41-45 age bracket. The ratio of country to city as place of residence was approximately 2:3. Education level was such that nearly 50% of participants had completed the four year School Certificate or less, while the remainder had attained a higher level of education. Annual Parental Income was evenly distributed in the following strata - less than A$15,000, A$31,000-40,000 and more than A$40,000. The A$15,000 - 30,000 stratum had approximately twice as many research participants as the other income brackets. The availability of Professional Support Systems was another stratum considered. Fifty two percent of respondents indicated there was sufficient professional support available, while 48% indicated that there was not sufficient support available (see Appendix A, Table A1, for specific details of demographic characteristics of the participants.)

It is also appropriate to think of this sampling procedure as theory-based, in which case: "the researcher samples...people on the basis of their potential manifestation ... of important theoretical constructs. The sample becomes, by definition, representative of the phenomenon of interest" (Patton, 1990, p. 177). Patton gives examples of constructs being defined which include person-environment interactions, instances of identity crises, of social deviance, or creativity.

For this research parents were selected on the basis of their potential manifestation of the theoretical constructs presented in the grief model in Chapter 5. They were parents who perceived themselves as having given birth to and parenting children with developmental disabilities. The assumption therefore was that they would be exhibiting the grief process detailed in the model. Parents who provided medical evidence documenting their children's disability, but did not perceive their children as having developmental disabilities, were not accepted as participants in the research. It was considered that they would not manifest the processes presented in the model.

This was purposeful rather than random sampling. As such, the degree to which it is statistical representative and its ability to be applied to a larger population needed to be treated with caution (Patton, 1990). Random selection was not used because of the relatively small number of volunteers from which a sample could be obtained. Sedlack & Stanley (1992) suggested that purposeful sampling calls upon the expertise of the social scientist. When circumstances prevent the use of more stringent probability methods, the knowledge obtained from such research can be valuable.

## Recruitment

Participants were recruited to the project through maternity hospitals, community centres, support groups and other organisations which provide services for families of children with developmental disabilities. Research Project Information Sheets were distributed through the notice boards or newsletters of centres ( see Appendix B for a copy of the Information Sheet). Upon request, information on the sheets was discussed with appropriate staff of the organisation. The volunteer research participants either rang the researcher directly, or gave their names and phone numbers to the organisation with the understanding that the researcher would use the phone numbers to contact them. Centres were in city areas - Sydney, Canberra, Albury, Wagga, Griffith and Wollongong; and in small country towns throughout southern New South Wales, Australia including Yass, Young, Boorowa and Cootamundra.

## The Participants

### The Sample of Parents of Children With Developmental Disabilities

The sample of parents of children with developmental disabilities included 81 individual parents who perceived themselves as having given birth to and parenting children with developmental disabilities. These parents had been given the diagnosis of their children's disabilities within the last two years. Seventy percent of the children were under two years of age and a further 26% were less than four years of age. The diagnoses could be classified as Down Syndrome, Cerebral Palsy and Global Developmental Delay. All children were in the moderate to profound range of developmental disability as described by the parents, who were reporting diagnoses provided by medical personnel (see Appendix A, Table A.1 for full details of the demographic characteristics of these participants).

These participant researchers included individual parents, mothers and/or fathers of children with developmental disabilities in their family settings. Each parent was treated separately since each spoke of his or her individual perception even if this at times was of the same child and within the same family situation. Demographic information relating to the parents was collected and presented in the section on sampling procedures and representativeness of the group. Further information regarding family structure was also collected. Thirty one percent of the children with the developmental disabilities were either first born, the parents having had subsequent children or they were only children. The remaining 69% of the children were not the first born children in the family. Eighty five percent of the families had one child with a disability while 15% had two children, the subject child being their second with a disability.

### The Matched Controls of Parents of Children Without Developmental Disabilities

The sample of 81 individual parents of children with developmental disabilities were matched with parents of children without developmental disabilities on the following demographic variables: Age of Child, Gender of Parent, Age of Parent within Five (5) Years, Parental Status, Residence, Level of Education, Level of Family Income, and Placement of Child in the Family (see Table 6A for details). These parents were obtained through notices being placed at play groups and pre-schools. They indicated their willingness to participate in the reseach through signing consent forms. These parents were interviewed at a place convenient to themselves. They often chose their own home or a quiet area of their play centre.

Table 6A Comparison of Demographic Profiles of the Research Participants, Parents Of Children With Developmental Disabilites, With Their Controls in Percentages.

| Variable | Category | Demographic Profiles | |
|---|---|---|---|
| | | Participants In %s | Control Group In %s |
| Age of Child | < 2 yrs | 70 | 70 |
| | 2 - 4 yrs | 26 | 26 |
| | > 4 yrs | 04 | 04 |
| Place of Child in Family | Only/First | 31 | 29 |
| | Other | 69 | 71 |
| Gender of Parent | Male | 59 | 59 |
| | Female | 41 | 41 |
| Age of Parent | 18 - 25 years | 21 | 20 |
| | 26 - 30 | 26 | 30 |
| | 31 - 35 | 27 | 22 |
| | 36 - 40 | 17 | 19 |
| | 41 - 45 | 09 | 09 |
| Parental Status | Single/Separated/Divorced | 09 | 10 |
| | Married/ de-facto | 91 | 90 |
| Residence | Country | 38 | 38 |
| | City | 62 | 62 |
| Education Level | Year 10 & < | 49 | 52 |
| | > Year 10 | 51 | 48 |
| Income | < $15,000 | 14 | 14 |
| | $15-30,000 | 44 | 42 |
| | $31-40,000 | 25 | 27 |
| | > $40,000 | 17 | 17 |

## The Sample of Parents of Children With Developmental Disabilities And the Controls

The study was longitudinal with the first time of data collection being within two years of disclosure of the diagnosis of the children having developmental disabilities. As seen in Table 6A 70% of the children were less than two years of age and 96% less than 4 years of age. This timing was in line with ethical considerations in regard to the degree of shock experienced by these parents at the time of the disclosure. The second data collection was taken 18 months later. In accordance with the theory presented in Chapter 4, under the heading of Time and the Grief Process, it could be predicted that some parents would have reconstrued within this time frame while others would not have completed the process. This would allow the research to tap different elements of the grief process.

In all there were 308 interviews. At Time 1 there were 81 parents of children with developmental disabilities and 81 matched controls. Interviews took place from early January, 1993 to late March, 1994. Eighteen months later, at Time 2, there were 74 participant research parents and 74 control parents. The reduction in numbers at Time 2 can be accounted for by the fact that two parents had moved overseas for the purpose of obtaining improved services for their children, two parents had moved and were unable to be contacted, and three fathers were unavailable because of work commitments.

## The Representativeness Of The Sample of Parents of Children With Developmental Disabilities

The question of the degree of representativeness of the research sample was addressed in two ways. One was by comparing the demographic data of the research sample with the specific population of parents of children with developmental disabilities in Australia using the 1993 Survey of Disability, Ageing and Carers. The second was by comparing it with the general population, through the use of the 1991 Census of Population and Housing. These comparisons of demographic data are presented in Table 6B.

Table 6B Comparison of Demographic Profiles of the Research Participants of Parents Of Children With Developmental Disabilites With The 1993 Survey of Disability, Ageing and Carers for Australia and the 1991 Census of Population and Housing Data in Percentages.

| Variable | Category | Demographic Profiles | | |
|---|---|---|---|---|
| | | Participants | Survey Data | Census Data |
| Age of Child | < 2 yrs | 70 | 15* | -- |
| | 2 - 4 yrs | 26 | 53* | -- |
| | > 4 yrs | 04 | 32* | -- |
| Disability | Down Syndrome | 28 | 17* | -- |
| | Cerebral Palsy | 18 | 17 | -- |
| | Global Delay | 53 | 66 | -- |
| Place of Child in Family | Only/First | 31 | 33 | -- |
| | Other | 69 | 67 | -- |
| No. of Child. in Family | 1 | 26 | 10* | -- |
| | 2 | 32 | 38 | -- |
| | 3 | 25 | 35 | -- |
| | >3 | 17 | 17 | -- |
| Gender of Parent | Male | 59 | -- | 46 |
| | Female | 41 | -- | 54 |
| Age of Parent | 18 - 25 years | 21 | 13* | -- |
| | 26 - 30 | 26 | 28 | -- |
| | 31 - 35 | 27 | 40 | -- |
| | 36 - 40 | 17 | 12 | -- |
| | 41 - 45 | 09 | 08 | -- |
| | 18 - 25 | 21 | -- | 08* |
| | 26 - 35 | 53 | -- | 43 |
| | 36- 45 | 26 | -- | 49* |
| Parental Status | Single/Separated/Divorced | 09 | 12 | 13 |
| | Married/ de-facto | 91 | 88 | 87 |
| Residence | Country | 38 | 42-Other | 13* |
| | City | 62 | 58-Capital Cty | 87* |
| Education Level | Year 10 & < | 49 | 32* | 60 |
| | > Year 10 | 51 | 68 | 27 |
| Income | < $15,000 | 14 | 18 | 19 |
| | $15-30,000 | 44 | 38 | 24* |
| | $31-40,000 | 25 | 22 | 13* |
| | > $40,000 | 17 | 22 | 29* |

Note to Table 6B: The figures in Table 6B represent percentages.

* indicates that the research participants were outside 25% of the figures for the Survey or Census Data.

Percentage groups not totalling 100 indicates that some respondents did not complete that section of the questionaries.

Notes: The 1993 Australia Survey of Disability, Ageing and Carers:

The figures are for Australia and the research participants were from NSW.

Even within Australia the numbers sampled were low and therefore the estimates have a high sampling error attached to them (Widdowson, Australian Bureau of Statistics, Belconnen, August, 1996).

Notes: The 1991 Census of Population and Housing Data :

The Census figures related to Gender, Age, and Geographic Location of Parent came from the section titled Living with a Partner. These people did not necessarily have offspring. Family Type came from the section titled of that same name: Offspring 0-5 yrs section. Education Level came from the section titled: Qualifications of all persons 15 yrs and over. Percentage groups for the Education Level on the Census not totalling 100 indicated that 13% of participants did not complete this section.

Table 6B indicates a high rate of compatibility between the research sample group of parents of children with developmental disabilites and the population of the 1993 Survey of Disability, Ageing and Carers, together with a reasonable compatibility with that of the Census Data. This suggests that the sample group was representative of the general population, particularly of parents of children with disabilities in Australia.

The scores for the demographics of Type of Disability, Place of Child in Family, Number of Children in Family, Age of Parent, Parental Status, Residence, and Income for the research sample and the Survey were on the whole compatible. There was a higher percentage of parents in this research who had an education level of the School Certificate or less compared the with Survey Data, although the number of parents with the School Certificate or more was within the range of 25% of the Survey Data. There were clearly more research participants whose children with disabilities were less than two years of age than was evident in the Survey. This was predictable since the research targeted families who had been given the diagnosis within two years of being interviewed.

The research data concerning the parents of the children with developmental disabilities was compatible with the Census for the demographics of Gender of Parent, and Parental Status. More parents in the 18 - 25 age group participated in the research than in the general population, and fewer people in the 36 - 45 age group were involved. There were more people in the group of research participants who lived in the country and fewer in the city than was representative; the subject group tended to have a higher level of education; and tended to be more in the income bracket of $15 - 30,000 than the general Census population.

## The Approach To Data Collection

### Theoretical Appropriateness

The methods used for data collection needed to fulfil certain criteria. They needed to be based on the assumptions of personal construct psychology. Secondly, the theory building component of the research needed to be recognised. The participants needed to be given maximum freedom of expression so that the refined model might reflect their experiences as fully as possible. In addition, ethically, the methods of data collection needed to be sensitive to the tendency of parents to want to speak freely and without interruption.

## The Design

The design of the research was longitudinal, with control groups. Data was collected from individual parents of children with developmental disabilities, and the matched controls, at both Time 1 and Time 2.

## The Assumptions of Personal Construct Psychology Relating to Research

Viney (1988, 1992b) identified the mutual-orientation method of data collection as being the most supportive of the assumptions of personal construct psychology. The Kellian assumptions particularly pertinent to research methods include the notion of constructive alternativism (Kelly, 1955, p.3). This emphasises that people know their worlds through personal experience, from a subjective rather than objective perspective, and form internally generated interpretations and meanings that can differ and be reversed (Viney, 1992b). Coupled with this emphasis on the uniqueness of the individual, is the assumption that there are some constructs which are common to the meaning systems of different people (Kelly, 1955). When people construe events in similar ways, it is assumed that their psychological processes are similar (Commonality Corollary). And, when people try to put themselves into the shoes of another person and to see the world through that person's eyes, they may play a role in relation to that other person (Sociality Corollary). Methods used for data collection need to maintain the richness and complexity of the meanings held by individuals, along with acknowledging that interaction does occur between researcher and participants. They would also need to support the ethically appropriate sharing of power.

The Mutual-Orientation method of data collection begins with the researcher trying to understand the inner worlds of the participants (Viney, 1988). Viney suggested that focused interviews were appropriate methods to achieve this. The present research used this technique. It allowed for greater flexibility and closer relationships to develop between the researcher and the participants. Parents were able to be assisted to talk about their experiences and were relieved of related anxieties. This approach upholds the Kellian notion of credulous listening, that is, if you want to know about the experiences of the participants, then ask them about them. A significant part of data collection are the methods the researcher uses to reflect upon the data. Viney (1988) suggests that content analysis has the advantages of dealing with meaning and encouraging researchers to use care in defining their interpretations. The research used content analysis scales.

## The Building of Theory

The methods of data collection were chosen because the research was concerned with building theory rather than proving an established one. Strauss and Corbin (1990, p.23) speak of "grounded theory" being derived inductively from the study of the phenomenon, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. They stressed that data collection, analysis and theory always stand in reciprocal relationship with each other. The area for study is selected, but the methods of data collection need to be such that "what is relevant to that area is allowed to emerge" (Strauss and Corbin, 1990, p.23). Duffy (1992) comes from the same position. She suggests that when the aim of the research is the generation of theory, the phenomenon itself must guide the data gathering process. The constructivist criterion of research which highlights the need to focus on the experience and interpretations of the participants (Viney, 1987b) is also relevant to this aspect of the research.

There has been very limited investigation of the psychological impact of giving birth to and parenting children with developmental disabilities, especially from the perspective of personal construct theory. As an aim of this research was to build theory, an interview technique was used. The first section of the interview had a biographical basis and the second was of minimal structure. This technique enhanced the probability that the findings would be based on the experience of the parents of the phenomenon rather than on the expectations of the researcher of their experiences.

Data collection methods were based on the assumption that the constructs of the parents relating to the developmental disabilities of the children were located in their verbalisations about them (Agar, 1986; Viney, 1986). The data collection was also based on the Kellian principle of credulous listening, whereby the listener accepts the responses of the speakers as representing their personal constructions of life (Kelly, 1955).

## Freedom of Expression

In order to allow what is relevant to the area of study to emerge and so build upon the theory, it is important that the methods of data collection facilitate freedom of expression of participants. In this study participants needed to be directed to focus their reflections on the topic of inquiry and at the level of their most influential self-related constructs. They needed, however, to be assisted to associate as freely as possible and not be restricted by the directions of the researcher.

Individually and as a group, parents who give birth to, and parents of children with developmental disabilities have a unique story to tell. Often in the supportive environment of a clinical research interview, parents were inclined to express themselves freely both verbally and non-verbally. The non-verbal expressions included hesitations, long pauses, and often crying. The method of data collection needed to be sensitive to the quality of the interaction, and to recognise and value subjective data. It needed to be unobtrusive and provide minimal constraint on the verbalisations of the participants. This maximised the possibility that samples of speech would be true reflections of the experience.

### The Interview

The researcher conducted the majority of interviews. However a second interviewer was used when both parents were participants and were available at the same time. Given that the interviews on average took two hours, it was considered too intrusive to stay in the homes of people to conduct one interview immediately after the other. The primary interviewer had a Bachelor of Arts Honours (Psychology), the second interviewer had a Bachelor of Arts (Social Science) and was in the process of completing her fourth year. All interviews were conducted in private, the time and place being that which was convenient to the participant. Most often this was in the person's own home, in separate rooms if both parents were participating, or in a pre-arranged room(s) at a local centre.

The interview itself was composed of three sections. The initial stage was that of rapport building. This included restating the purpose of the research and stressing confidentiality of information obtained from parents. Consent forms were signed and permission to tape-record a section of the interviews was obtained (see Appendix C for a copy of the Consent Form). This was followed by the segment of data collection, which will be presented in more detail in the following sections. The concluding stages of the interview were directed at validating those constructs which were allowing the parents to best cope with their present situations. This was achieved by asking parents the question: "What would you tell someone else about how to cope with this experience?"

In response to indicators from the parents, information regarding the availability of professional assistance was also discussed together with an invitation to contact the researcher personally if the research participant wished to do so.

## Instruments Used For Data Collection

### The Core Process Interview

The Core Process Interview was used to access the most influential self-related constructs and whether the parents saw themselves as being on their preferred or non-preferred construct poles. Jones (1993) devised a Core Process Interview as a means of tapping the "core purposes" for living for participants (Jones, 1993). It is a biographical approach in which participants are asked to recall experiences at four different times in their lives which for them were fulfilling and motivating (Jones, 1992). The stories were further explored in terms of what was important about each of them for the participants. The focus was to identify the most influential themes of construing. The technique was based on Hinkle's (1965) work on implications, informally termed “laddering”. Parents were then asked to formulate the over-riding constructs on which these personal stories were based.

Having elicited individuals’ most influential self-relating constructs, the interviewer then asked participants on which pole of the constructs, the preferred or non-preferred, they perceived themselves as being, at a given time (See Appendix D for details of the complete interview process). Through this Core Process Interview (Jones, 1993), the most influential self-related constructs of parents were explored, along with their perception of themselves as being on their preferred or non-preferred construct poles.

### The Appropriateness Of Using The Core Process Interview

The Core Process Interview was seen as appropriate for use as an instrument for data collection for two main reasons. It was sensitive to the psychological needs of this particular population in that it emphasised those parts of the construct systems of parents which were fulfilling and motivating. Secondly, it held credibility for adequately accessing the most influential self-related constructs and construct poles of participants, which was the focus of the research. It was sufficiently non-directive, however, to allow what was relevant to emerge, hence supporting the theory-building component of the study.

## Sensitivity To the Needs of the Participants

Parents of children with developmental disabilities tend to perceive themselves as disempowered by circumstances and having been 'painted into a corner'. Ethically, the choice of research techniques would not wish to enhance such experiences and yet with this population of parents they could easily do so.

As already noted, the Core Process Interview (Jones, 1993) requires participants to recall those life situations, and therefore choices, which for them were motivating and fulfilling. It presents the option of choosing to recall a potent, validated self (Rowan, 1989). As such it makes explicit the Kellian notion of constructive alternativism whereby there are always alternative constructions of life and "no one needs to be completely hemmed in by circumstances" (Kelly, 1955, p.11). The use of a data collection technique, which in itself explicitly presents this notion of choice, is being sensitive to the psychological needs of this particular population.

## Credibility

Kelly (1955) describes self characterisation with a specific methodology which is not used in this research. What is common to this research is the analysis of raw verbal data, produced by a person in relation to his or her self, from which the personal construct system, along with the personal categories and dimensions which structure the person's world, can be ascertained.

The Core Process Interview is also credible in terms of it upholding the Kellian notion of 'credulous listening' (Jones, 1992). It respects people as 'personal scientists', each with a unique theory of the world, and if you want to know something about someone, you should ask them.

Leitner (1985) presents a pilot study of eliciting self-related constructs by Self Characterisation. These constructs are related to early memories, significant life events, repetitive fantasies, what should be written on tomb stones, and constructions of God compared to constructs elicited by Repertory Grids. Participants rated the Self Characterisations as describing the self more centrally than the constructs elicited by the Grids. In addition, the most central constructs were elicited through discussing God, mile-post dreams, and significant life events.

Procter and Parry (1978) reported using biographical antecedents of participants' constructs. They first elicited superordinate constructs by laddering and then asked participants to think of the times in their lives when they began to use these constructs. They were also required to indicate from what earlier constructs they evolved. Ravenette (1977, 1980), although working with children, has also used a number of construct eliciting techniques which are forms of Self Characterisation.

Such methods are described by Neimeyer & Neimeyer (1993) as adapted characterisation techniques and considered to be effective for accessing people's self-relating constructs. They suggest they are good choices when attempting to understand people who are struggling with issues of self definition, this being particularly relevant to parents who had recently experienced giving birth to children with developmental disabilities. Winter (1992) also affirms the use of adapted characterisation techniques in their varying forms, such as the use of naturalistic material of letters, diaries, memoirs, and autobiographies, and the use of questionnaires, open-ended interviews, and free response methods, as appropriate techniques for accessing people's constructs and construct systems.

Jones ( 1993) reported using the Core Process Interview in several research projects and with great success. However, there is little published information available. Jones (1992) does report the use of the Core Process Interview technique in relation to research on the varied values from which doctors and management worked in the Health Service in Britain.

### The Use Of Repertory Grids as Support Instruments for the Core Process Interview

Leitner's (1985) study, referred to previously in relation to eliciting self-related constructs by self-characterisation and repertory grids, showed a high rank order correlation between ratings on the two instruments. If participants rated the grid- elicited constructs highly on the 10 point scale, they also tended to rate the interview-elicited constructs highly.

More recently Dempsey & Neimeyer (1995) reported a study comparing Repertory Grids with Implications Grids. Although Implications Grids were not used in this study, Hinkle's (1965) implication technique was used, which makes the study of Dempsey and Neimeyer (1995) of relevance. Their findings found support for the convergence of the two measures at several levels. These include the degree of relationship between specific pairs of constructs, the average degree of connectedness of each individual construct to the system as a whole, and the overall relatedness of constructs in the system.

This research also compared data obtained from the Core Process Interview and Repertory Grids. The sum of the dichotomous constructs elicited from the first 23 Core Process Interviews was 14 in all. ( See Appendix E for a copy of the Repertory Grid). This relatively small number of constructs was obtained because of the frequency with which parents used certain constructs such as "having relationships - not having relationships" and through the researcher combining labels which were understood as having similar meaning such as "free - restricted/shut down". This collapsing of construct labels was verified by a co-rater to the level of 93% agreement. In this sense the sum of the dichotomous constructs elicited from the first 23 Core Process Interviews was used as supplied constructs in a Repertory Grid for the entire group of 81 participants of parents of children with developmental disabilities. These constructs were rated on a 7 point scale, 1 and 2 being most influential and relevant to the provided element such as 'self', and 6 and 7 being of little or no influence and relevance to the provided element. Ratings of 3 to 5 indicated that the construct was part of the person's thinking but not particularly relevant. The results indicated there was a 98% concurrence between one of the most influential self-related constructs obtained through the Core Process Interview and one of the constructs on the Repertory Grid being given a 1 or 2 rating.

## Content Analysis Scales

Cognitive anxiety was measured by the Cognitive Anxiety Content Analysis Scale. Death anxiety, mutilation, separation, shame and guilt were measured by Gottschalk et al. (1969) Content Analysis Sub-scales.

### Cognitive Anxiety Scale

It was hypothesised that the type of children, with or without developmental disability, and construct path preferences would influence the levels of emotions of parents. The instruments used to measure the emotional levels were content analysis scales. These gave a quantitative measure to the content of verbal samples collected from parents. The techniques involved in Content Analysis Scales are based on measures developed by Gottschalk et al. (1969).

Cognitive anxiety was measured by the Cognitive Anxiety Scale (Viney & Westbrook, 1976). It was formulated from the personal construct psychology concept of anxiety. Such anxiety was defined as occurring when people were unable to anticipate and integrate experience meaningfully (Viney & Westbrook, 1976). These authors suggested cognitive anxiety tended to arise in the following situations: where the stimuli were extremely novel; where extra constructs were needed but not available; in the face of incongruent stimuli; where responses were unavailable and so uncertainty was generated; and where there was a high rate of stimulus presentation. Examples of comments scored for Cognitive Anxiety from these research participants were: "I didn't expect it"; "I wondered what was happening"; "It was such a big thing to take in"; and "I hadn't had anything to do with disabilities". (See Appendix E for an example of a Content Analysis Scale).

### Death Anxiety Subscale; Mutilation Anxiety Subscale; Separation Anxiety Subscale

Death anxiety, mutilation, separation, guilt, and shame were measured by their respective sub-scales of the Total Anxiety Scale (Gottschalk et al., 1969). Anxieties relating to death, mutilation, and separation are understood as experiences of threat within the perspective of personal construct theory, as argued in the model presented in Chapter 5.

Within the theory of personal construct psychology threat is defined as the awareness of an imminent, comprehensive change in self-relating constructs (Kelly, 1955, p.361). The prospective change must be substantial. Kelly gives the example of death as threatening because it signifies fundamental changes to the meaning of life. The changes must appear to be comprehensive, that is, represent multifaceted alternative constructs of life (Kelly, 1955, p.361-2). Further examples given by Kelly are people feeling threatened by the likelihood of showing infantile behaviour in certain situations, or being threatened by the prospect of really changing their outlook. In addition, Kelly (1955) suggests that threat does not always appear in the shape of human beings, but can also be associated with inanimate events or objects such as birthdays or the passing of time. The threat comes from these events or objects being given interpretations which require changes in self-related construing.

The Gottschalk et al. (1969) Death Anxiety Subscale was used to score references to death, dying, threat of death, or anxiety about death experienced by, or occurring to, self, others, or inanimate objects. Examples of comments from the research scored for Death Anxiety were: "We could die tomorrow"; "My child was dying"; and "We buried our child".

The Mutilation Anxiety Subscale (Gotschalk et al., 1969) scored references to injury, tissue damage, physical damage, or anxiety about injury as well as threat of such being experienced by or occurring to self, others, or inanimate objects. In the majority of cases, Downs Syndrome is caused by an additional chromosome which results in the production of excessive proteins. As a result, some body cells fail to sub-divide as rapidly as they should. In addition, there is disruption in the migration of cells that occurs in the formation of different parts of the body, notably in the brain (Selikowitz, 1990). This research therefore scored references to Downs Syndrome on the Mutilation Scale. Similarly, phrases referring to brain damage and cerebral palsy were scored, along with references to disability. Examples which were scored included: "I had to have a Caesarean"; "My son is Down Syndrome"; "There were several holes in his heart"; and "He would have to be operated on straight away".

References to desertion, abandonment, ostracism, loss of support, loneliness, loss of love or somebody or thing which was loved, or threat of such experiences by or occurring to self, others, or objects were scored on the Separation Anxiety Sub-scale (Gotschalk et al., 1969). Examples scored in this research were: "I was doing it myself [without my husband]"; "[We had to learn to love him from a distance] because we couldn't get close"; "[I wish I knew what it would be like] to have her call me Mummy".

As detailed in the model in Chapter 5, instances of death, mutilation and separation are presented as experiences of threat to existence, the body, and relationships respectively. The constructivist concept of threat is then appropriately measured on the Content Analysis Sub-scales of Death, Mutilation and Separation.

### Guilt Anxiety Scale

Within personal construct theory, guilt is associated with individuals' deepest understandings of their roles as social beings. It is experienced by individuals when they perceive they have acted in ways which have apparently dislodged them from these social roles (Kelly, 1955, p.370). The Gottschalk et al. (1969) Guilt Anxiety Sub-scale scores refer to adverse criticism, abuse, condemnation, moral disapproval, guilt or threat of such as experienced by self or others. Comments from this research which were scored as guilt are as follows: "I feel guilty"; and "I must have done something wrong".

### Shame Anxiety Scale

McCoy (1981) defines shame from a personal construct perspective, also in relation to social roles. Individuals experienced it when they were aware of having acted in ways which dislodged them from others' construing of the individuals' social roles. An example of a statement which was scored as ridicule in this research was "They think you're a rat". A statement of inadequacy was "[I know I should be able to,] but I can't cope". The personal construct concept of shame was scored by the Gottschalk et al. (1969) Shame Anxiety Scale.

### Methodological Appropriateness

This research was longitudinal and required instruments of data collection which were appropriate to this aspect of the design. Content analysis does allow for repeated measures to be made without the contamination of practice effects (Viney, 1986). It is a useful technique for estimating change in emotions over time.

These scales have been used with a variety of populations. These populations include people who are dying (Viney et al., 1994), and people who are ill (Viney, 1983). More specifically relevant to this study, the content analysis scales have also been used to identify some of the patterns of experiences of women in times of transition in their lives (Viney, 1980), to study specific aspects of life changes relating to child bearing (Westbrook, 1978), to look at the grief experienced by spousal care givers of dementia patients (Rudd, Viney & Preston, in press), and differentiate the levels of anxiety in

Community Based Aids Care given before and after counselling (Viney, Crooks & Walker, 1995).

The Reliability of the Content Analysis Scales

In the studies reported by Viney (1986), the average inter-judge reliability co-efficient for the Cognitive Anxiety Scale was .96 with the range of co-efficients being .71-.99. The co-efficient for the Total Anxiety Scale was .90 with the range of co-efficients being .76-.94. Internal consistency for the Total Anxiety Scale has been judged to show sufficient statistical independence to be used individually to assess the relative importance of different sources of anxiety (Viney, 1986). Reported stability estimates for the Cognitive Anxiety Scale over five occasions was 0.63; and for the Total Anxiety Scale, over five occasions, was 0.64 (Viney, 1986).

Interjudge reliability for this research was established by the involvement of a co-rater who scored all 81 transcripts, before receiving any informtion regarding the participants, and independent of the other rater. The means and standard deviations of scores for each of the Content Analysis Scales for the first and second rater are provided in Table 6C (see below).

Table 6C.

Means and Standard Deviations of Scores For Each of the Content Analysis Scales for Rater 1 and Rater 2

| Anxiety Scale | Rater 1 |  | Rater 2 |  |  |
|---|---|---|---|---|---|
|  | M | SD | M | SD | F |
| Cognitive | 1.71 | 0.57 | 1.74 | 0.56 | 2.32 |
| Death | 0.68 | 0.38 | 0.69 | 0.39 | 1.47 |
| Mutilation | 1.36 | 0.51 | 1.36 | 0.53 | 0.06 |
| Separation | 1.85 | 0.72 | 1.82 | 0.72 | 6.08* |
| Guilt | 0.64 | 0.48 | 0.64 | 0.48 | 0.91 |
| Shame | 0.82 | 0.49 | 0.80 | 0.49 | 3.83 |

d.f. = 6, 75. *p < 0.5.

Correlations of the content analysis scale scores were Cognitive Anxiety 0.93, Death Anxiety 0.99, Mutilation 0.96, Separation 0.98, Guilt 0.99, and Shame 0.99. Comparisons by multi-variate analysis of variance, (MANOVA), of the means and standard deviations of the six content analysis scale scores showed no significant overall difference. (multivariate F [6,75] = 2.55, $p < .05$). As shown in Table A.3 further analysis of the scores for the six scales showed no significant differences between the mean scores of the two raters on the Cognitive Anxiety Scale, Death Anxiety, Mutilation, Guilt and Shame Scale. There was significant difference between the two raters for separation anxiety (see Table 6C). The mean scores for Rater 1 and Rater 2 on the Separation Anxiety Scale, are 1.85 (s.d. 0.72) and 1.82 (s.d. 0.72) respectively. The difference between the means was minimal (0.03). Although there is statistically significant difference between the two raters on the scoring of the Separation Anxiety Scale, this is not considered to be clinically significant. Statistically the difference can be explained by the reasonably large sample size (81) and the high level of correlation between the raters, allowing for minimal difference to be found significant (See Table 6C).

## The Validity of Content Analysis Scales

Several studies indicate that the two content analysis scales used in this study do in fact measure the states which they purport to measure. The Cognitive Anxiety Scale successfully discriminates between women's experiences of the differing stages of childbearing (Westbrook, 1978); girls transferring from primary to high school (Viney, 1980); women relocating to new communities (Viney & Bazeley, 1977); and the effects of counselling on the anxiety of relatives of seriously injured or ill patients (Bunn & Clarke, 1979). Viney and Westbrook (1976) found the cognitive anxiety scale to be independent of sex and age of participants but it did correlate with occupational status; they found it significantly correlated with measures of state anxiety, but not trait anxiety; and that it discriminated the accounts given of people of situations which were unpredictable from those which were predictable. In more recent studies the scale has discriminated physically ill and injured people from others (Viney, 1990b); the differing levels of cognitive anxiety of people who were dying in different medical settings (Viney et al, 1994); spousal care givers who cared for their partners with dementia at home compared with those who provided ongoing nursing care (Rudd, Viney & Preston, in press).

Gottschalk and Gleser (1969) found significant correlation of the Total Anxiety Scale with psychiatrists' ratings of anxiety and psychological measures of anxiety; and they found that the Scale responded to psychological and drug experimental manipulations. It is reported to have significant correlation with self reports of anxiety and with ratings of anxiety-related behaviours by observers (Gottschalk, 1979b). Westbrook and Viney (1982) found it discriminated chronically ill patients from other people. Viney and Westbrook (1982b) found the Total Anxiety Scale to be independent of sex, age, and educational level. Viney's more recent studies (Viney, 1990b; Viney et al., 1994), using the Total Anxiety Scale, found it able to discriminate for the population of ill, injured, and dying patients; and it was found to discriminate the differing levels of anxiety and guilt for spousal care givers who cared for their partners with dementia at home, compared with those who provided ongoing nursing care (Rudd, Viney & Preston, in press).

## Collecting Data to be Analysed through the Content Analysis Scales

The participants were asked to respond to the following open-ended request. Five minutes was the maximum amount of time given to this aspect of the data collection.

> I'd like you to talk to me for a few minutes about your life at the moment in relation to giving birth to and parenting a child with a disability - the good things and the bad - what it is like for you; but I'd rather not reply to any questions you may have until a five minute period is over. Do you have any questions you would like to ask now, before we start?
> (Adapted from Viney & Westbrook, 1981a)

With permission from the parents, the verbal reponses were recorded and later transcribed onto a word processor. Each tape was replayed and checked against the transcriptions for accuracy of verbal and non-verbal content. Non-verbal content included hesitations, long pauses, crying, and some response to the baby in the arms of the parents.

### Scoring of the Verbalisations using Content Analysis Scales

Scoring required the division of the transcripts into clauses. Standard instructions indicated which categories of content were scored for each scale. Weightings were added to those scales measuring emotions which were considered to vary in intensity (Viney, 1986). This applied to each of the subscales of the Gottschalk, et al. (1969) Total Anxiety Scale and the Viney, et al. (1976) Cognitive Anxiety Scale. Verbal samples of 70 words or less have been found to be unreliable indicators of the content analysis scale variables (Gottschalk et al., 1969). In the present study, the longest interview consisted of 1620 words, and no interview consisted of less than 95 words. As participants who spoke for longer periods of time had greater opportunities to express their emotions, the raw score for each scale was entered into an equation which corrected for the number of words in the verbalisation (See Appendix F for an example of an equation for the calculation of scores for a Content Analysis Scale).

# Statistical Analysis

## Quantitative Analyses

The quantitative data were analysed statistically by submitting them to procedures from the SPSS computer programme, Version 5, (1993). Hypotheses were tested using multi-variate procedures.

The emotions of parents of children with and without developmental disabilities were compared in terms of scores on the six content analysis scales at the time of the first interview with a multi-variate analyses of variance (MANOVA) (Hypothesis 1). The same statistical procedure was used to assess the effects of construct pole preferences on emotions using the scores on the six content analysis scales at the time of the first interview (Hypothesis 2).

Change and no change on construct pole preferences at the time of the first interview when compared to that of the second gave rise to the creation of four groups of construct pole patterns. The interaction of these groups of patterns with time, on emotional levels (Hypothesis 3), was analysed through comparing the scores of the six content analysis scales at the time of the first interview with the scores at the time of the second interview through the use of a MANOVA.

Hypotheses 4 through to 7 addressed the within-group effects of the interaction of construct pole preference patterns over time on emotions. Again the scores of the six content analysis scales at the time of the first and second interview were analysed through repeated applications of MANOVA. Simple main effects and interactional effects between groups were also investigated. This was done by comparing the scores on the content analysis scales for each group formed from construct pole preferences with the control group.

### Qualitative Analyses

Qualitative analyses were aimed at elaborating the model presented in Chapter 5 of the grief process of parents of children with developmental disabilities. The transcripts of the verbalisations at the time of the first interview were used to establish the situational themes related to each of the emotions. The themes were obtained manually by the researcher and verified by the co-rater. The percentages of parents who spoke of each theme were also obtained.

## Summary Of The Methods Used In This Study

In this chapter I have presented details of the methodology used for the data collection, along with the analyses used in this research. Statistical analyses of measures were used to test hypotheses arising from the model. Qualitative analyses of data were also used to elaborate further the model by establishing themes related to the grief process of parents of children with developmental disabilities.

Chapter 7 presents the results of the statistical analysis of the emotional content of the parents' interviews. This is followed in Chapter 8, with the results of the qualitative analysis of the reactions of parents who give birth to children with developmental disability.

# CHAPTER 7

# THE EFFECTS OF TYPE OF CHILD AND CONSTRUCT POLE PREFERENCES ON THE EMOTIONAL STATES AND EXPERIENCES OF PARENTS:

## RESULTS 1

In this chapter I present the quantitative findings of this research in relation to the transition process undertaken by parents who give birth to children with developmental disabilities. The chapter particularly attends to the effects on emotional states and experiences of type of child (able or disabled) and construct pole preferences (the perception parents have of themselves as being on their preferred or non-preferred construct pole). The findings will be further elaborated through the presentation of qualitative data in Chapter 8. The analyses of both the quantitative and qualitative data were directed by the model of grief presented in Chapter 4 and the hypotheses detailed in Chapter 5.

The initial quantitative analysis explored the effects of type of child on the cognitive anxiety, together with anxiety related to death, mutilation, separation, guilt and shame of parents. The percentage of parents of children with developmental disabilities who change the content of their most-influential, self related constructs over time is provided. The relationships between construct pole preferences of parents of children with developmental disabilities and their emotions were then investigated. The longitudinal component of the study introduced the factor of time. This analysis therefore involved the grouping of parents according to their construct pole preference patterns of change and no change over time. The interactional effects of construct path preferences and time were statistically explored, as were the differences within and between groups.

## Statistical Analysis of the Data

Means and standard deviations were calculated for the Content Analysis Scales and Grid Data. Multivariate Analyses of Variance (MANOVAS) and Analyses of Variance

(ANOVAS) were used to detect differences between the samples of data. Alpha levels of .05 were used for all statistical tests.

## Tests Of The Research Study Hypotheses

Eight hypotheses were examined. These hypotheses were based on those presented in Chapter 5, but are now worded in terms of the operational definitions used in this research.

### Hypothesis About Tthe Effects on Emotional Level of Type of Children

Hypothesis 1 predicted that parents who had given birth to children with developmental disabilities would have higher scores on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Content Analysis Scales compared to parents who had given birth to children without developmental disabilities. Table 7A (see below) presented the means and standard deviations of each of the content analysis scales scores for parents of children with and without developmental disabilities at Time 1.

Table 7A

Means and Standard Deviation of Scores for Each of the Content Analysis Scales at Time 1 For Parents of Children With and Without Developmental Disabilities with Univariate F Values.

| Anxiety Scales | Parents of Children With Disabilities n=81 M | SD | Parents of Children Without Disabilities n=81 M | SD | F |
|---|---|---|---|---|---|
| Cognitive | 1.71 | 0.57 | 0.93 | 0.61 | 70.37*** |
| Death | 0.68 | 0.38 | 0.52 | 0.15 | 11.79** |
| Mutilation | 1.36 | 0.51 | 0.61 | 0.29 | 133.66*** |
| Separation | 1.85 | 0.72 | 0.79 | 0.45 | 128.26*** |
| Guilt | 0.64 | 0.48 | 0.53 | 0.17 | 3.29 |
| Shame | 0.82 | 0.49 | 0.54 | 0.22 | 21.93*** |

df = 1, 160. $^{**}p < .01$. $^{***}p < .001$.

Results of the analysis of the data which related to the effects of the type of child on the emotional level of parents were obtained by comparisons by MANOVA of scores for the six Content Analysis Scales. At Time 1 results showed significant differences overall between parents of children with and without developmental disabilities, multivariate $F$ (6, 155) = 44.69, $p < .001$. Parents of children with developmental disabilities rated significantly higher scores on the Cognitive, Death, Mutilation, Separation and Shame Anxieties Scales compared with parents of children without developmental disabilities (see Table 7A). The statistical scores for parents with and without children with developmental disabilities were not significantly different on the Guilt Scale (see Table 7A). These results were predominantly supportive of Hypothesis 1.

### Comparison of Levels of Emotional States and Experiences of Parents of Children Without Developmental Disabilities With Viney's (1980) Scores for Becoming a Mother

Viney (1980) reported scores on the Content Analysis Scales of Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties for 92 women who had given birth to their first child between two and seven months prior to data collection. Using Viney's (1980) data, a 95% confidence level was generated and the participant parents of this research, who had children without developmental disabilities, lay within Viney's scores at Time 1 (See Appendix H for means and standard deviations). This outcome offered further support for Hypothesis 1.

### Comparison of Levels of Emotional States and Experiences of Parents of Children With Developmental Disabilities and Viney's (1980) Scores for Parents with Threat to Children

Data was also collected by Viney (1980) from 16 women whose children were suffering from life-threatening illness or severe injury. Using the data a 95% confidence level was created and the parents from this research who had children with developmental disabilities lay within Viney's scores at Time 1. The score for separation for this research was the exception. With regard to this, parents from this research who had children with developmental disabilities lay outside the 95% confidence level of Viney's data. (See Appendix H for means and standard deviations).

The compatibility of the scores between the two groups offered further support to Hypothesis 1. It was noteworthy that the research group rated higher on the Separation Anxiety Scale compared with parents whose children were suffering from life threatening illnesses or severe injuries.

### Hypothesis About the Percentage of Individual Parents who Changed their Construct System by Reconstruing

The content of individual parent's constructs at Time 1 and Time 2 were examined by the researcher. A co-rater also examined 30 of the 81 participant research's laddered constructs, and a compatibility of 92% was obtained. It was considered that if one of perhaps a series of constructs was present at Time 1 and Time 2, it would be found as a position of no-change. It was decided that the wording of such constructs could be different, but an obvious consistent meaning needed to be present to obtain a position of no-change. Examples of constructs having a position of no-change are :

"Knowing - Anxiously waiting to see what it's going to be like" at Time 1 and
" Knowing/being able to predict the future - Not knowing what will happen in the future" at Time 2 (Participant Researcher No. 38);
"To be able to be fundamentally myself with an identity - No movement, not being myself, being a no-body" at Time 1 and
"To have integrity, an identity - stuck, superficial, a no-body" at Time 2 (Participant Researcher No. 42).

Examples of constructs changing are:

"Making a contribution - useless" at Time 1 and

"Being normal/ relaxed - anxious, aggressive" at Time 2 (Participant Researcher No. 56; "Family - Alone" at Time 1 and "Accomplishment - No accomplishment" - Time 2 (Research Participant No. 66).

The number of individual parents who retained a position of no-change in relation to at least one of their most-influential self-related constructs was 90%. This result was supportive of Hypothesis 2. It was predictable, due to the notion of superordinate constructs being most resistant to change, along with these participant parents being a research group as opposed to a clinical group undergoing therapy.

### Hypothesis About Emotional States and Experiences of Construct Pole Preferences

It was hypothesised that parents who had given birth to children with developmental disabilities, who perceived themselves as being on the non-preferred pole of their most influential self-related constructs, would have higher scores on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Content Analysis Scales than parents in the same situation who perceived themselves as being on their preferred construct pole (Hypothesis 3). The means and standard deviations for each of the scales with Preferred and Non-Preferred Construct Poles are presented below in Table 7B.

Table 7B

Means and Standard Deviations of Scores for Each of the Content Analysis Scales at Time 1 For Parents' Placement of Themselves on their Non-Preferred and Preferred Construct Poles with Univariate

F Values

| | Non-Preferred Construct Pole n= 42 | | Preferred Construct Pole n=39 | | |
|---|---|---|---|---|---|
| Scales | M | SD | M | SD | F |
| Cognitive Anxiety | 1.94 | 0.63 | 1.50 | 0.41 | 14.02*** |
| Death Anxiety | 0.84 | 0.39 | 0.53 | 0.31 | 15.74*** |
| Mutilation | 1.54 | 0.61 | 1.20 | 0.33 | 9.73** |
| Separation | 2.26 | 0.68 | 1.48 | 0.53 | 34.03*** |
| Guilt | 0.81 | 0.58 | 0.48 | 0.30 | 10.67** |
| Shame | 0.99 | 0.58 | 0.65 | 0.29 | 11.44** |

df = 1, 79. **p < .01. ***p < .001.

The effects of placement of self on construct pole preferences on emotions were explored (see Table 7B). Comparisons by MANOVA of the six content analysis scale scores at Time 1 showed significant differences, overall, between parents who perceived themselves as being on their non-preferred construct poles and those who perceived themselves as being on their preferred construct pole, (univariate F (6, 74) = 15.76, p < .001). Parents on their non-preferred construct poles had significantly higher scores on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Scales than parents on their preferred construct poles. These results were supportive of Hypothesis 3.

### Hypotheses About Emotional States and Experiences of Construct Pole Preference Patterns Over Time

The longitudinal component of the research produced four groups of parents according to patterns of change and no change of construct pole preferences over time. These groups were: parents who perceived themselves as being on their preferred poles at Time 1 and Time 2; those who perceived themselves as being on their non-preferred poles at Time 1 and Time 2; those who perceived themselves as being on their non-preferred poles at Time 1 and on their preferred poles at Time 2; and those who perceived themselves as being on their preferred poles at Time 1 and non-preferred poles at Time 2. A fifth group was that of the controls, being parents of children without developmental disabilities.

The next section describes the experimental interactional effects of group, (formed by construct pole preference patterns and the control group) by time, on emotions. This will be followed by within and between group differences.

Hypothesis 4 proposed that parents in each of the groups (formed by construct pole preferences and the control group) would obtain different scores on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Content Analysis Scales from Time 1 to Time 2. The following Table, 7C, gives the means and standard deviations for each of the Scales at Time 1 and Time 2 for each of the groups of parents formed from their construct pole preference patterns. Table 7D provides the means and standard deviations for each of the Scales at Time 1 and Time 2 in relation to the control group.

Table 7C

Means and Standard Deviations of Scores for the Content Analysis Scales at Time 1 and Time 2 for Each of the Groups Formed from Construct Pole Preference Patterns

| Parents' Construct Pole Preferences at Time 1 & and Time 2 | Anxiety Scales | Time 1 |  | Time 2 |  |
|---|---|---|---|---|---|
|  |  | M | SD | M | SD |
| Time 1 & Time 2: Preferred Poles (n=20) | Cognitive | 1.57 | 0.35 | 1.00 | 0.61 |
|  | Death | 0.49 | 0.38 | 0.40 | 0.11 |
|  | Mutilation | 1.18 | 0.38 | 0.77 | 0.39 |
|  | Separation | 1.28 | 0.66 | 0.69 | 0.38 |
|  | Guilt | 0.43 | 0.28 | 0.38 | 0.11 |
|  | Shame | 0.56 | 0.30 | 0.58 | 0.35 |
| Time 1 & Time 2: Non-Preferred Poles (n=26) | Cognitive | 1.85 | 0.53 | 1.58 | 0.63 |
|  | Death | 0.84 | 0.38 | 0.56 | 0.43 |
|  | Mutilation | 1.54 | 0.60 | 1.39 | 0.71 |
|  | Separation | 2.23 | 0.66 | 2.38 | 0.72 |
|  | Guilt | 0.88 | 0.62 | 0.47 | 0.26 |
|  | Shame | 0.90 | 0.61 | 1.02 | 0.64 |
| Time 1: Non-Preferred Poles Time 2: Preferred Poles (n=13) | Cognitive | 2.04 | 0.82 | 0.64 | 0.33 |
|  | Death | 0.80 | 0.45 | 0.47 | 0.31 |
|  | Mutilation | 1.60 | 0.61 | 0.71 | 0.37 |
|  | Separation | 2.25 | 0.77 | 0.76 | 0.61 |
|  | Guilt | 0.68 | 0.48 | 0.38 | 0.11 |
|  | Shame | 1.14 | 0.54 | 0.46 | 0.19 |
| Time 1: Preferred Poles; Time 2: Non-Preferred Poles (n=15) | Cognitive | 1.51 | 0.46 | 1.63 | 0.78 |
|  | Death | 0.56 | 0.24 | 0.49 | 0.25 |
|  | Mutilation | 1.20 | 0.29 | 1.60 | 0.67 |
|  | Separation | 1.66 | 0.27 | 2.09 | 0.57 |
|  | Guilt | 0.55 | 0.33 | 0.49 | 0.33 |
|  | Shame | 0.84 | 0.31 | 0.97 | 0.55 |

Note: 7 cases (research participants) were rejected because of missing data.

Table 7D

Means and Standard Deviations of Scores for the Content Analysis Scales at Time 1 and Time 2 for the Control Group

| Group | Anxiety Scales | Time 1 M | Time 1 SD | Time 2 M | Time 2 SD |
|---|---|---|---|---|---|
| Control (n=74) | Cognitive | 0.91 | 0.61 | 0.51 | 0.24 |
| | Death | 0.52 | 0.15 | 0.47 | 0.15 |
| | Mutilation | 0.62 | 0.30 | 0.49 | 0.17 |
| | Separation | 0.78 | 0.47 | 0.52 | 0.28 |
| | Guilt | 0.53 | 0.17 | 0.45 | 0.09 |
| | Shame | 0.54 | 0.22 | 0.49 | 0.21 |

Note: 7 cases (research participants) were rejected because of missing data.

Hypothesis 4 was addressed through analysing the effects of the interaction of group and time on emotions (see Table 7.C and 7.D). This was explored through comparisons by MANOVA of scores for each of the six content analysis scales, at Time 1 and Time 2, for each of the groups, including the controls. The results showed significant differences overall in scores obtained at Time 1 and Time 2 due to the interaction of group by time, (multivariate $F$ (24, 482) = 7.17, $p < .001$). There were significant differences in the scores for the Scales of Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties, depending on the interaction of group, by time, (univariate $Fs$ (4, 143) = 9.51, 4.11, 11.13, 22.88, 4.57, 7.02, $p < .01$ respectively).

## Within Group Effects

The within group effects on emotions of the interaction of construct pole preference patterns were explored. These effects were addressed in Hypotheses 5 to 8. See Tables 7.C and 7.D for the means and standard deviations on which the following analyses for these Hypotheses were based.

Hypothesis 5 focussed on parents who did not change from their preferred construct poles from Time 1 to Time 2. It was predicted that parents of children with developmental disabilities, who perceived themselves as being on their preferred poles of their most influential self-related constructs at Time 1 and Time 2, would either have no significant change or reduced scores on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Content Analysis Scales from Time 1 to Time 2.

The effects on emotional level of this pattern of construct pole preferences were explored via a repeated multivariate analysis of variance (MANOVA). The analysis showed significant differences overall in the scoring obtained at Time 1 and Time 2 by parents of children with developmental disabilities who remained on their preferred construct poles over time, (multivariate $F$ (6, 138) = 6.71, $p < .001$). There was no significant change in the scores on the Death, Guilt and Shame Anxiety Scales between Time 1 and Time 2, (univariate $F$s (1, 143) = 1.66, 0.34, 0.02 respectively, $p > .05$). Scores on the Cognitive, Mutilation, and Separation Anxieties Scales were significantly decreased from Time 1 to Time 2, (univariate $F$s (1, 143) = 13.88, 11.39, 18.78, $p < .01$ respectively).

The effects on the emotional level of parents who did not change from their non-preferred construct poles over time were addressed by Hypothesis 6. It predicted that parents of children with developmental disabilities who perceived themselves as being on their non-preferred poles of their most influential self-related constructs at Time 1 and Time 2 would either have no change or reduced scores on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Content Analysis Scales from Time 1 to Time 2.

Comparisons by MANOVA showed significant differences overall in the content analysis scales scores at Time 1 and Time 2 for parents of children with developmental disabilities who were on their non-preferred construct poles at Time 1 and Time 2, (multivariate $F$ (6, 138) = 9.75, $p < .001$). The scores on the Mutilation, Separation and Shame Anxiety Scales showed no significant differences from Time 1 to Time 2, (univariate $F$s (1, 143) = 1.77, 1.62, 1.50 respectively, $p < .05$). The scores on the Cognitive, Death, and Guilt Anxieties Scales significantly decreased from Time 1 to Time 2, (univariate $F$s (1, 143) = 4.22, 19.89, 29.27, $p < .05$, respectively).

Hypothesis 7 looked at the effects on the emotional level of parents who changed from their non-preferred construct poles at Time 1 to their preferred construct paths at Time 2. It was proposed that parents of children with developmental disabilities who perceived themselves as being on the non-preferred poles of their most influential self-related constructs at Time 1 and on their preferred poles at Time 2 would have significantly decreased scores on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Content Analysis Scales from Time 1 to Time 2.

Statistical analysis by MANOVA showed significant differences overall in the scores at Time 1 and Time 2 for parents of children with developmental disabilities who were on their non-preferred poles of their most influential self-related constructs at Time 1 and on their preferred pole at Time 2, (multivariate $F$ (6,138) = 29.52, $p < .001$). The scores for each of the six scales of Cognitive, Death, Mutilation, Separation, Guilt and

Shame Anxieties were also significantly decreased from Time 1 to Time 2, (univariate Fs (1, 143) = 54.19, 15.17, 36.15, 79.29, 7.84, 26.28, $p < 0.01$ respectively).

Hypothesis 8 addressed the effects on the emotional level of parents who changed from their preferred construct poles at Time 1 to their non-preferred construct poles at Time 2. It was hypothesised that parents who perceived themselves as being on their preferred poles of their most influential self-related constructs at Time 1 and on their non-preferred poles at Time 2 would have significantly increased scores on the Cognitive, Death, Mutilation, Separation, Guilt, and Shame Anxieties Content Analysis Scales from Time 1 to Time 2.

Comparisons by MANOVA showed significant differences overall in the scores of the content analysis scales obtained at Time 1 and Time 2 for parents of children with developmental disabilities who were on their preferred construct poles at Time 1 and had changed to their non-preferred pole by Time 2, (multivariate F (6, 138) = 2.96, $p < .01$). The scores on the Mutilation and Separation Anxieties Scales had significantly increased from Time 1 to Time 2, (univariate Fs (1, 143) = 8.14, 7.64, $p < .01$). Scores on the Cognitive, Death, Guilt, and Shame Anxieties Scales indicated no significant change, (Fs (1, 143) =0.46, 0.69, 0.35, 1.08, 143, $p > .05$).

Comparisons by MANOVA showed significant differences overall in the scores of the Content Analysis Scales obtained at Time 1 and Time 2 for the control groups, that is, parents of children without developmental disabilities, multivatiate F (6, 138) = 7.11, $p < .01$. The scores on the Cognitive Anxiety, Mutilation, and Separation, and Anxiety Scales had significantly decreased from Time 1 to Time 2, univariate Fs (1, 143) = 24.29, 4.60, 13.36 respectively, $p <.05$ . The scores on the Death, Guilt, and Shame

Anxiety Scales indicated no significant change, $\underline{F}s$ (1, 143) = 2.24, 3.19, .87 respectively, $\underline{p} > .05$.

## Between Group Effects

After significant multivariate contrasts were established for the interaction of group by time on emotions, simple main effects and interactional effects were then explored. Contrasts were made of each group formed from construct pole preferences with the control group for each content analysis scale at Time 1 and Time 2. Table 7.E (shown below) presents the multivariate contrasts for each group (formed form Construct Pole Preferences) with that of the control for each of the Scales at Time 1 and Time 2.

Table 7E

Multivariate Contrasts of Each Group (Formed from Construct Pole Preferences) with the Control Group for Each Content Analysis Scale At Time 1 and Time 2. with t Values

| Group Compared With Control | Anxiety Scales | Time 1 t - Value | Time 2 t - Value |
|---|---|---|---|
| Time 1 & Time 2: Preferred Poles (n=20) | Cognitive | 4.56*** | 4.12*** |
| | Death | -0.48 | -1.14 |
| | Mutilation | 5.42*** | 2.68** |
| | Separation | 3.63*** | 1.51 |
| | Guilt | -1.14 | -1.62 |
| | Shame | 0.24 | 0.93 |
| Time 1 & Time 2: Non-Preferred-Poles (n=26) | Cognitive | 7.21*** | 10.04*** |
| | Death | 4.91*** | 1.71 |
| | Mutilation | 9.83*** | 9.45*** |
| | Separation | 11.55*** | 17.75*** |
| | Guilt | 4.32*** | 0.43 |
| | Shame | 4.29*** | 6.14*** |
| Time 1: Non-Preferred Poles; Time 2: Preferred Poles (n=13) | Cognitive | 6.55*** | 00.88 |
| | Death | 3.36** | -0.01 |
| | Mutilation | 8.01*** | 01.72 |
| | Separation | 8.92*** | 01.74 |
| | Guilt | 1.37 | -1.42 |
| | Shame | 5.40*** | -0.27 |
| Time 1: Preferred Poles; Time 2: Non-Preferred Poles (n=15) | Cognitive | 3.72*** | 8.52*** |
| | Death | 0.50 | 0.40 |
| | Mutilation | 5.03*** | 9.32*** |
| | Separation | 5.66 | 12.09*** |
| | Guilt | 0.18 | 0.80 |
| | Shame | 2.84** | 4.47*** |

df = 143. *p < .05. ** p < .01. *** p < .001

As shown in Table 7E the analysis indicated that parents who remained on their preferred pole of their most influential self-related constructs at Time 1 and Time 2 rated significantly higher scores on the Cognitive, Mutilation and Separation Anxieties Scales at Time 1 compared to controls. There was no significant difference between the two groups on the Death, Guilt and Shame Anxieties Scales at Time 1. Scores on the Cognitive and Mutilation Anxieties Scales remained significantly higher than controls at Time 2. The scores of the Death, Guilt and Shame Anxieties Scales were not significantly different from controls (see Table 7E).

Parents who remained on the non-preferred poles of their most influential self-related constructs at Time 1 and Time 2 scored significantly higher levels on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Scales at Time 1 compared to controls (see Table 7E). Table 7E shows that at Time 2 this pattern was repeated in the scoring on the Cognitive, Mutilation, Separation and Shame Anxieties Scales. Death Anxiety Scale scores also tended to be greater than controls. The score for Guilt Anxiety was not significantly different from controls.

As shown in Table 7E the third group of parents, those who were on the non-preferred poles of their most influential self-related constructs at Time 1 and on their preferred poles at Time 2, scored significantly higher levels on the Cognitive, Death, Mutilation, Separation and Shame Anxieties Scales at Time 1 compared to controls. The rating for Guilt Anxiety for this group of parents was not significantly different from that for the controls at Time 1. At Time 2 there were no significant differences on any of the scales between the parents of children with disabilities and the controls (see Table 7E).

Parents who were on their preferred poles of their most influential self-related constructs at Time 1 and on their non-preferred poles at Time 2, scored significantly higher on the Cognitive, Mutilation, Separation and Shame Anxieties Scales at Time 1 compared to controls (see Table 7E). The scores for Death and Guilt Anxieties were not significantly different from those for the controls. At Time 2 parents of children with developmental disabilities scored significantly higher levels on the Cognitive, Mutilation, Separation and Shame Anxieties Scales compared to the controls. Death and Guilt Anxieties Scores were not significantly different (see Table 7E).

## A Summary of Quantitative Findings Relating Type of Child and Self-Placement Construct Pole Preferences to the Emotional States and Experiences of Parents

The results of the analyses supported Hypothesis 1, indicating that parents of children with developmental disabilities obtained higher scores on the Cognitive, Death, Mutilation, Separation, and Shame Anxieties Scales compared with parents of children without developmental disabilities. There was no significant difference between the two groups of parents in relation to their scores for the Guilt Anxiety Scale.

Few parents of children with developmental disabilities adapted to their new situation through reconstruing the content of their superordinate, core constructs. Most change occurred through slot rattling, that is, changing from one pole of the construct to the other. In this, Hypothesis 2 was confirmed.

Results were also supportive of Hypothesis 3. Parents who gave birth to children with developmental disabilities who perceived themselves as being on their non-preferred poles of the most influential self-related constructs did experience higher scores on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Scales, compared with parents in the same situation who perceived themselves as being on their preferred construct poles.

Parents in each of the groups, formed by construct pole preferences and the control group, obtained different scores for each of the Scales of Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties. Hypothesis 4 was supported.

The effects of construct pole preference patterns over time on the content analysis scale scores were addressed in Hypotheses 5 to 8. They, too, were generally supportive. Parents who remained on their preferred construct poles over time showed no significant change in their scores for the Death, Guilt and Shame Anxieties Scales between Time 1 and Time 2. Cognitive, Mutilation, and Separation Anxieties Scale scores significantly decreased from Time 1 to Time 2. Parents who remained on their non-preferred construct poles over time showed no significant change in their scores for the Mutilation, Separation and Shame Anxieties Scales from Time 1 to Time 2. However, their scores for the Death, Guilt and Cognitive Anxieties Scales significantly decreased over time.

The scale scores of parents of children who had disabilities being on their non-preferred construct poles at Time 1 and on their preferred construct poles at Time 2 showed that the levels of scoring for each of the six scales were significantly decreased from Time 1 to Time 2. Parents who were on their preferred construct poles at Time 1 and on their non-preferred construct poles at Time 2 showed significant increases in scores for the Mutilation and Separation Anxieties Scales over time. Their Cognitive, Death, Guilt, and Shame Anxieties Scale scores indicated no significant change.

Between group (formed from construct pole preferences and the control group) effects on scale scores were also made. They indicated the following trends. Parents who remained on the preferred pole of their most influential self-related constructs at Time 1 and Time 2 scored significantly higher on the Cognitive, Mutilation and Separation Anxieties Scales at Time 1 compared with controls. The scores on the Cognitive and Mutilation Anxieties Scales remained significantly higher than controls at Time 2. Parents who remained on the non-preferred pole of their most influential self-related constructs at Time 1 and Time 2 scored significantly higher levels on the Cognitive, Death, Mutilation, Separation, Guilt and Shame Anxieties Scales at Time 1 compared to controls. At Time 2 this pattern was repeated for the Cognitive, Mutilation, Separation and Shame Anxiety Scales. Parents who were on their non-preferred poles of the most influential self-related constructs at Time 1 and on their preferred pole at Time 2 experienced significantly higher levels of Cognitive, Death, Mutilation, Separation and Shame Anxieties Scale scores at Time 1 compared to controls. At Time 2 there were no significant differences on any of the scale scores between the parents of children with disabilities and controls. Finally, parents who were on their preferred poles at Time 1 and on their non-preferred poles at Time 2 scored significantly higher on the Cognitive, Death, Mutilation, Separation and Shame Anxieties Scales at Time 1 compared with controls. At Time 2 they were still scoring significantly higher on the Cognitive, Mutilation, Separation and Shame Anxieties Scales compared with controls.

These quantitative findings will be further elaborated in the following Chapter which provides qualitative analysis. I will also explore the themes the parents of children with developmental disabilities associated with the emotions of cognitive anxiety, death anxiety, mutilation, separation, guilt and shame.

# CHAPTER 8

# THE THEMES LINKED TO THE EMOTIONAL STATES AND EXPERIENCES OF THE PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES:

## RESULTS 2

In the previous chapter I presented the statistical findings of this research regarding the emotional states and experiences of parents in relation to type of child and construct path preferences. In this chapter I present the content of the self-referring and most influential constructs and the themes linked to the emotional states and experiences of cognitive anxiety, threat, guilt, and shame of parents of children with developmental disabilities.

In Chapter 4 I presented the preliminary model of the relevant grief process for parents of children with developmental disabilities. It proposed that parents would experience new events which would challenge their self-referring and most influential constructs. The new events would not be able to be anticipated and integrated in meaningful ways (cognitive anxiety). By experiencing situations relating to existence, bodily safety, and separation, parents would become aware of the need for imminent and comprehensive change to occur in their construct systems (threat). They would appraise themselves as having committed wrong in accordance with their internal social standards (guilt) and evaluate themselves as having failed to live up to social standards in the eyes of other people (shame). The accounts given by parents in this study supported the proposed model.

In this chapter I have reported the superordinate constructs of the parents, and the themes linked to the emotional states and experiences of cognitive anxiety, threat, guilt, and shame. These themes will be illustrated through quotations selected from the texts of the interviews. The identification number of the relevant participants will be included at the end of each quotation. The quotations selected will exemplify the accounts given by the participants and make valuable contributions to understanding the reactions of parents to giving birth to and parenting children with developmental disabilities.

## The Self-Relating Most Influential Constructs of the Parents of Children with Developmental Disabilities

As I detailed in Chapter 6 on Methodology, the sum of the dichotomous self-relating and most influential constructs obtained from the first forty (40) Core Process Interviews were listed. Table 8A presents that list, along with the number and percentage of parents who spoke of these constructs at Time 1. These superordinate constructs were obtained through a laddering process which was part of the Core Process Interview. Refer to Chapter 6 for the reliability of describing these constructs as superordinate.

Table 8A.

Content of the Most Influential Self-Referring Constructs of Parents of Children with Developmental Disabilities and their Frequencies and Pertcentages

| Construct | | Participants-Frequency | Participants-Percentage |
|---|---|---|---|
| Having relationships- | Not having relationships/Emptiness | 40 | 49 |
| Achievement/ Contribution- | Failure | 22 | 27 |
| Predictable/ Knowing/Having Direction | Unpredictable/ Not knowing/ Aimless | 20 | 25 |
| Relaxed/Normal | Anxious/Hell | 19 | 23 |
| Free | Restricted/ Shut Down | 16 | 20 |
| Wisdom/Life having meaning | Shock/Shallow/ Without meaning | 13 | 16 |
| Hopeful | Depressed | 13 | 16 |
| Having identity | Loss of identity/ Consumed | 12 | 15 |
| Having control/ Choice | Being controlled/ No choice | 8 | 10 |
| Peace of Mind | Guilt | 7 | 9 |
| Accepted | Rejected | 6 | 7 |
| Living | Dying | 5 | 6 |
| Allowing/Helping the person with the disability to live | Allowing/Helping the person with the disability to die | 3 | 4 |
| Difference | Disability | 1 | 1 |

Table 8A shows that the most frequently presented self-relating and most influential dichotomous constructs were: Having - Not Having Relationships/Emptiness; Achievement/Contribution - Failure; Predictable/Knowing/Having Direction - Unpredictable/Not Knowing/Aimless; Relaxed/Normal - Anxious; Free - Restricted/Shut Down; Wisdom/Life having Meaning - Shock/Shallow/Without Meaning.

### The Themes which Linked with the Emotional States and Experiences of Cognitive Anxiety, Threat, Guilt, and Shame

Themes were obtained from the five minutes of verbalisations given by the parents. In response to an open ended request to speak about their lives at that time in relation to giving birth to and parenting children with developmental disabilities. The invitation was to speak about the positive and negative aspects. The themes were obtained manually by the researcher and verified by a co-rater, with a 96% agreement. Table 8B presents the emotional states and experiences, the percentage of the total group of parents who spoke of each emotion, the themes associated with each emotion, and the percentage of the 'emotion' group which spoke of each situation.

Table 8B. The Emotional States and Experiences, the Percentage of the Total Sample of Participants who spoke of each Emotion, the Themes Linked with each Emotion, and the Percentages of the Sample which Spoke of Each Situation.

| Emotional States & Experiences | Percentage of Sample who spoke of the Emotion | Theme | Percentage of Emotional Group which used each Theme |
|---|---|---|---|
| Threat | 99 | Death/Mutilation | |
| | | - Child | 99 |
| | | - Self | 35 |
| | | Relationships | |
| | | - Medical staff | 47 |
| | | - Parent-Child | 42 |
| | | - Partner | 37 |
| | | - Extended family | 41 |
| | | - Friend | 36 |
| | | - Place in society | 35 |
| | | - Nuclear family | 22 |
| | | Separation | |
| | | - Physically from disabled child | 37 |
| | | - Expected child | 14 |
| | | Identity | 22 |
| | | Control | 22 |
| Cognitive Anxiety | 98 | Uncertainty | 81 |
| | | Numbness | 60 |
| | | Shock | 49 |
| | | Not knowing | |
| | | - Future | 49 |
| | | - Present | 30 |
| Shame | 70 | Inadequacies | |
| | | - Personnel | 47 |
| | | - Disability | 39 |
| | | - Can't remember | 28 |
| | | - Parenting | 16 |
| | | - Can't tell | 12 |
| Guilt | 42 | Parenting relationships & practices | 50 |
| | | Causing disability | 32 |
| | | Ways of coping | 21 |
| | | Partner | 9 |

## Cognitive Anxiety

### Shock, Numbness, Uncertainty, Not Knowing

Table 8B indicates that 98% of parents experienced cognitive anxiety in not being able to anticipate and integrate events meaningfully (Viney & Westbrook, 1976). The associated themes were shock, numbness, denial, uncertainty, and a sense of not knowing. The following quotation exemplifies the descriptions given by parents in relation to cognitive anxiety.

Mr.T. was speaking two years after the birth of his daughter who had Down Syndrome. *One of the down sides when J was born (was) the initial shock. When we found out that* ***she*** *was born it was like a bomb shell........It was very upsetting. I don't know why I was upset. I don't know whether I was upset for myself because I didn't have a perfect child. I don't know. Or was I upset for J. I think it was probably more that. Or maybe that we had made a child with a disability. Maybe it was that. Then maybe it was (in relation to) how difficult her life would be. I can't say why (or) what upset me at the time.....and then there was always the worry about .... whether she was healthy or not healthy......... just the unanswered questions* (T1/3).

### Shock

It was clearly shocking for the father, quoted above, when J was born with Down Syndrome. For him the experience was like a "bomb shell". He was confronted with a situation which evoked for him a sudden need to reconstrue what having children might mean (Woodfield & Viney, 1984-5). The experience was overwhelming for him. Other commonly used expressions relating to shock were: *traumatised, shattered, just couldn't believe it* and *taken back pretty well* (S1/62, C1/11, R1/22, J1/2. J1/75).

## Numbness

The description given by Mr. T. also indicates numbness and denial. His actual words suggest that the "bomb shell" was the birth of his daughter. From the context it can be clearly understood that the bomb shell was Mr. T. knowing that his daughter has Down Syndrome, but this was not actually stated. His verbalisations also did not include naming the disability itself. Both of these aspects could suggest a lack of ability to construe, or a numbness towards this element (Woodfield & Viney, 1984-5).

The themes of being numb and in denial were often evident in the language used by parents. Some did not say the name of their child in association with the disabilities. For example, one parent said: *They told me **it** had Down Syndrome* (J1/37). Others, while seemingly knowing the disability, did not name it. Instead, they used language such as: *the problem* (M1/50). Parents also spoke directly of their inability to construe events. An example is: *The Doctor's words were that it was life threatening....(but) I wasn't going to let her die....I told them it was nonsense* (W1/60).

Emotional numbness was also an aspect. This was indicated by parents relaying the facts of a situation but being unable to express their associated emotions or directly denying having an emotional reaction. This is powerfully evident in both what the following mother says and how she says it. She is describing her reaction to being told that her child would die. *They told me that when he died they would take all the tubes off him and let me bath him and dress him and play with him and cuddle him and everything. And get him ready for the funeral ....and the organ donation and everything. With organ donation...they just cut them and take what they need and then sew them up and you don't even know......I just didn't worry about it. I just kept thinking what I had to* *do when I got home, just kept thinking you know, I've gotta fix H's room up and do this and do that. That's all I kept thinking* (J1/38).

### Uncertainty

Uncertainty was expressed by the majority of parents. It was predominantly in regard to their own reaction to the events. Their statements included phrases such as: *I did not know what to do next; I just couldn't understand why,* and *I guess it was hard to explain it to myself for a long time* (W1/50). This inability to make sense of the events and integrate them meaningfully into the construct system was frequently part of the story that the parents presented. To return to the quotation from Mr. T., even two years after the diagnosis this father was struggling to make sense of his reaction and give it meaning. He remained unsure as to what it was about the event, which was so upsetting and disturbing to him.

### Not Knowing

The experience of 'not knowing' was a further significant aspect of cognitive anxiety. It was common in situations of medical personnel being unsure of the diagnosis, prognosis and best treatment for the children. This left parents unsure of the present conditions of their children and therefore unable to predict and anticipate the future. Another prominent issue here was the longer term prognosis including the abilities of the children to walk, talk, hear, learn, see, work, relate, drive cars - *the list goes on and on.* As Mr. T. said, *just the unanswered questions* (T1/30).

## Threat

## Existence, Bodily Safety, Relationships

Shock, numbness, denial, uncertainty, and non-knowing are related to events not yet integrated into construct systems. However, parents became aware of the need to integrate the various elements relating to the disabilities of their children into the way in which they viewed life. Comprehensive changes needed to occur at the level of their self-related construing. They therefore experienced threat (Kelly,1955). The degree of change expressed by many parents is exemplified in the following quotation: *It just changes you and your life completely* (G1/37).

The stories told by the parents reflected the experience of threat in similar proportions to which they reflected cognitive anxiety. Ninety nine percent of the group as a whole experienced threat. Three predominant themes emerged: threat to existence, bodily safety, and relationships.

### Existence

The threat to existence occurred in two forms: one was that of the imminent or future death of the children or the parents themselves; and the other was a threat to internal, psychological existence in the form of the loss of self identity and/or a sense of impotency in terms of parents losing control over their own personal lives.

I offer two quotations which exemplify the stories told by the parents in relation to the death of their children. For some parents the strongest threat was related to their children dying soon after their birth; for others the children had terminal illnesses and the parents waited for the deaths.

The following is an example of the intense trauma experienced by parents in relation to the threatened death of their new born children. *Everything was fine again and then he just packed it in. They shoved the tube back in his mouth and screamed for us to come ...and say good bye to him....They just kept trying to keep him alive for us to say good bye to him. They put us in a room and told us we had five or ten minutes until he died. They came back in twenty and he was still pink ...They told us to hang around for 4 or 5 days .. we were expecting him to die at any moment* (C1/70).

For parents of children who have a terminal illness the experiences are different but just as threatening to their own self construing. An example is the following quotation from Mr. J. He had given up work in order to be the primary care taker of his child. During the second interview he said: *I used to get a lot of help from everyone but now I don't get any. She's (wife and mother) scared, I suppose. She doesn't want the responsibility of J dying on her. I think everyone realises the fact that he's going to die soon, probably within the next couple of months....if he dies on me, he dies on me and we can only hope that we can live with it* (J2/40).

It was within these contexts that parents spoke of their own death. For some mothers their own lives had been directly threatened due to complications related to the birth of their children. For other parents it evoked past events such as car accidents or strokes which had threatened their lives. Still others spoke of their own inevitable death in the future.

The degree to which the life threatening experiences of the children tapped into the self-related construing of the parents was often indicated in the language they used. In the following quotations the mothers were actually referring to their children , and yet used plural pronouns such as: *They put drips in us; We were having heart surgery; We* *were having trouble breathing.* The reverse also occurred when mothers would say: *We were having a caesarean* (L1/34).

Threat to psychological existence was expressed in terms of loss of personal identity and good will towards the self. The following is a typical description given by parents. This was a father speaking about himself after having given birth to a son with developmental disabilities some four years previously. *Our energy, our enthusiasm has just gone out of us. I used to be a certain kind of person. I used to be M.C (name). My friends would tell me this is what M.C. was - he was fairly casual, relaxed and had a good attitude to life and could cope. And what's happened is that he's all drained away. You just keep - losing yourself, losing your identity, your good will for yourself* (M1/25).

The issue of loss of control is equally common (see Table 8B) and threatening to psychological existence. One mother made the following comments, *I just found it an extremely daunting thought that my life had been taken away from me. My life as I knew it had been taken away from me....I miss that life a lot...* (G1/26).

This loss of control by parents of their personal lives encompassed issues such as their capacity to plan, to set themselves a direction, and to experience a sense of potency about their decision making. Specific issues were in relation to personal time, availability of medical procedures, the amount of time professional personnel spent with their children, and being 'forced' to open their private homes to so many professional personnel. Some parents spoke directly about the impotency of their choice to have a *normal* child.

### Bodily Safety

Threat to bodily safety occurred through mutilation of self and the children, or through damage to tissue in the course of medical and surgical procedures performed on mothers. Mutilation of children included genetic, chromosomal and physical malformations, along with medical operations and procedures.

The degree to which the disability tapped into the self-related construing of the parents was well evidenced in the quotation used at the beginning of this chapter from Mr. T. I again quote it here: *I don't know whether I was upset for myself because I didn't have a perfect child. I don't know. Or was I upset for J.* (the child) *I think it was probably more that. Or maybe that we had made a child with a disability* (T1/3).

The self-related constructs which were commonly challenged by the disabilities were the ability to have perfect children; the inability of parents to 'protect' their children from mutilation; and the issue of the parents having produced disability. These three issues threaten the self-related constructs which most parents held for themselves.

### Relationships

The threat to relationships occurred predominantly through the process of being separated from that which was anticipated. The types of relationships which were affected included that of the parent-child, partner, the nuclear family, extended family and friends, and societal relationships.

## Parent-Child Relationship

The loss of the parent-child relationships began with the unfulfilled expectations which were held prior to the birth of the children. Many parents spoke of: *going through the process of grieving - related to the idea of not having a child that you expect, a healthy child I guess* (J1/2). Other parents spoke of the ghosts of the children they had dreamed of and the children with the disabilities who were present as: *the child(ren) who (were) kind of dead but still live with us* (M1/26).

The loss was frequently exacerbated through physical separation of parents and children. Because of their medical conditions, children were taken to neo-natal speciality units. For country people this included the transfer of children to city hospitals. The stories of the parents included aspects such as: *At first we learnt to love him from a distance because we couldn't get close...being in another town and then the machines in intensive care...we were a bit removed* (J1/2).

There is a loss of the expected parent-child interaction both at the time of infancy and then as adult children of parents. Parents grieved for fundamental aspects of parent-infant relationships such as the basic infant recognition of mothers. A typical picture was presented in the following quotation: *I wish she'd.... I don't know what it would be like to have her call me mummy. And if she was hurt (for her) to give me a cuddle and to hear her talk...just if she'd know who I was.....it would be nice for her to know I was her mummy. (For her) to look at me and know* (S1/7). A father spoke of his disappointment - *just for father-son reasons. To have someone to do things with, to make things with. Z tries but he'll never be able to comprehend a lot of the things I enjoy* (P1/5).

A frequent comment referred to the loss of the expected relationships between parents and adult children. This included the development of more equal friendships between parents and children. In addition there was the knowledge that there would be no future in which the parents could again enjoy more solitary relationships with each other free from the demands of dependent children. The following quotation exemplified the comments of many parents: *We were pretty devastated when he was born. Now we are going to have to look after him for the rest of our lives* (D1/8).

### Partner Relationships

The relationships between the partners were also affected. Both men and women spoke of their increased difficulty in sharing their emotional life with each other after the birth of their children with developmental disabilities. This resulted in increased relational and often physical distance between each other.

Another common issue was that the majority of the care-taking role of the children with the disabilities tended to be left to the mothers. Often mothers expressed resentment when their partners weren't present at times of crisis. One woman said: *The whole time I was doing this by myself without my husband* and *That's when she went on me (*died*) and G..(*husband*) wasn't there...that's what has upset me most* (S1/12).

### The Nuclear Family

Parents spoke of the loss of expected family life. Issues included the reduced amount of time available to usual family interactions, given the increased demands of the children with the disabilities. One parent described the situation as: *It's hard on T* (the daughter without a disability) *...From the time she was born everything was Z...Z...Z...*

(the son with the disability). *People walk up and say, 'How is Z.... and ignore her and I think that's why she bursts into tears really quickly.......".* (S1/5). This quotation depicts two concerns expressed by parents in relation to their nuclear family: even when the family was together, parents were aware of the lack of time and attention available to siblings; and attention from people outside the family was mainly directed to the children with the disabilities, again leaving aside the siblings. Additional concerns included the amount of time that older siblings, particularly, spent away from the family environment while the children with the disabilities and their parents were in hospitals, and, secondly, the amount of caretaking the eldest female children had adopted, and the eldest daughters, even from a young age, were described as being worried that they themselves would produce children with disabilities. Also, the number of the children that the parents planned to have was often reduced in response to having given birth to children with developmental disabilities. One parent said: *We were worried about having more children. We would have liked to....It would be very risky and we decided not to.* (S1/5).

## Relationships with Extended Family and Friends

Relationships with extended family and friends were also threatened. Some grandparents were seen as rejecting the children with the disabilites because of concern that the disabilities were inherited. Others were seen as refusing to acknowledge the presence or severity of the disability.

Friendship groups were frequently mentioned. Some of the comments were: *We've lost friends as a result of A....*(the child with the disability) *coming into the world.* (S1/2) and: *The down side is that you get disappointed with your friends that they don't feel the same way you do.* (S1/4). As indicated in the quotations, parents reported that some of their friends simply did not know how to respond and they reduced their contact with the families; other parents experienced more direct and overt rejections. A further group spoke of differences developing between themselves and their friends regarding their thinking about disability and life in general. Each of the groups expressed feelings of hurt and disappointment regarding their loss of friendships.

New and unanticipated friendships were also mentioned. Parents spoke of their friendship networks extending to other parents of children with disabilities. This offered them a common basis for redeveloping their philosophy of life, along with the opportunity for an increased empathetic understanding of their situation. Such groups also offered practical advice on parenting and teaching children with disabilities, and information regarding services.

Still others expressed concern regarding their tendency to develop friendships so predominantly based on the common ground of being parents of children with disabilities. Parents spoke of these friendships being safe but perhaps limiting because of the restricted common ties between them as people.

### Societal Relationships

Frequently the expectations parents had of medical staff were not fulfilled. Many parents had anticipated higher levels of medical competence regarding diagnosis, prognosis and medical procedures, along with more effective doctor-patient relationships. Parents were often dissatisfied with the circumstances under which they were told of the diagnosis. These included situations in which mothers were given the information without their partners being present, or in a public ward surrounded by other patients. Mothers were sometimes left alone immediately after receiving news of the children's conditions, and there were cases in which mothers were left with the responsibility of communicating the information to their partners. Parents also had a sense of being over-burdened with the possible medical complications their children might develop, and there was often a lack of affirmation of the positive and healthy attributes of their children. In addition, parents frequently complained of not being listened to by doctors when they wanted to discuss the children's conditions.

The perception parents previously held of their position in society was often significantly challenged by the birth of their children with developmental disabilities. Where they once saw themselves as belonging, they now see themselves as only tolerated. Other parents expressed the same notion in terms of a lack of acknowledgment on the part of society of people with disabilities. Parents expressed anger at the popular thinking that segregated environments were the best 'place' for these people. Segregated environments included special units at schools, or workshop employment, or separated housing and lifestyles. One parent expressed this notion in the following way: *Once you're incapacitated...you're out of the particular service, or school, or anywhere else...you've got to go to a segregated environment....segregated employment, segregated living and just a segregated life on its own.* (S1/3).

This rejection from society was also expressed in terms of the difficulty in obtaining baby sitters. Parents spoke of this in terms of finding baby sitters who would *accept* their children; not be *frightened* of them; and not feel *ashamed* of being with them.

## Guilt

As shown in Table 8B, 42% of the parent sample described themselves as thinking and acting in ways they would have never envisaged themselves as doing, or as Mascolo (1994) suggested, having judged themselves as having committed a wrong-doing in relation to their social role. The situational themes associated with this emotional state and experience are blaming self; parenting relationships and practices; personal coping mechanisms such as the use of alcohol; and partner relationships.

A major theme, more prominent in the women than the men, was: *what did I do wrong to cause this disability*? (D1/56). Many women questioned their behaviours during pregnancy regarding such aspects as eating, stress, or relational issues. Many others spoke of a generalised guilt and described a sense of blaming themselves for everything. Men stated feeling guilty about bringing children with disabilities into the world and guilt related to their own reproductive ability.

Parents were self-critical of the way they related to their children with developmental disabilities. Demonstrations of this included refusing to allow themselves to become emotionally involved with their children, either failing to accept, or limiting contact with them; and entertaining thoughts of putting their children up for adoption. Parents described themselves as being inappropriately selfish, cruel, aggressive, angry, and out of control emotionally towards their children with developmental disabilities and their siblings. While realising that their expectations were too high, they continued to make inappropriate demands of their children with disabilities. For other parents, guilt was triggered by comments primarily from medical staff regarding the care of their children. Such comments related to over-protectiveness, on one hand, to suggestions of neglect around issues such as feeding, failure to thrive, and the use of alternative rather than traditional forms of medical care.

In addition to the 50% of parents who reported on their relational and parenting practices in ways indicating guilt, a further 12% spoke directly of their guilt in relation to their thoughts of wanting to hurt their children, of taking active steps toward killing their children, or wishing they would die. For some these thoughts were connected with post-natal depression.

Parents expressed guilt regarding their personal ways of coping with the disabilities. Such responses included the excessive consumption of alcohol and demand for sexual activity; they became overly selfish, emotional, sensitive, and tended to deny the severity of the disability.

Parents also felt guilt around their relationship with their partner. This was primarily associated with having blamed their partner for the disabilities, and not having given the partner relationship sufficient attention.

## Shame

Seventy percent of the sample (see Table 8B) were rated as having judged themselves as having failed, in the eyes of other people, to live up to social standards. This was expressed in a variety of ways - through feelings of personal inadequacy, inability to cope, to remember, to parent adequately, or even to tell people of the disabilities, because of a sense of shame.

Predominantly, parents spoke of a variety of personal inadequacies. Many told of feeling inadequate in their emotional response to the situation. Descriptions such as: *cracked up*, *snapped*, *going crazy*, *wiped out*, and l*ack of inner strength* (D1/80) were typical. Others felt inadequate in relation to their capacity to be assertive, intelligent, tolerant, and physically strong.

Parents, and in particular men, spoke of their shame in not having produced a perfect child. The impact of this was highlighted when the control group of parents spoke of their feelings of satisfaction, and of being seen as successful when they produced children without disabilities.

A particular expression of the theme of personal inadequacy was that of parents feeling unable to cope with their children having developmental disabilities. Others spoke directly of their inability to cope with having produced children with disabilities. Parents expressed thoughts of: *I just can't cope*, *can't face the idea*, *can't see the children* (L1/58).

Parents frequently told of their inability to remember or explain aspects associated with events they themselves had introduced in their non-directed verbalisations. Again and again the phrases of: *I can't remember*, *I've forgotten...*, and *I can't explain* (L1/58) were used. A fuller explanation of the process is provided in the following statement from a mother: *I can't really explain it because I don't like looking at um...I just don't like looking at that part....I can't remember ...I just don't like to remember.... because it hurts* (A1/48).

Parents expressed feelings of inadequacy regarding their parenting relationship and practices. They spoke of being much more aware of, and sometimes consumed in, thinking about the disability, and in so doing losing sight of their relationship with their children. Others struggled with what they saw as an incapacity within themselves to love their children with developmental disabilities.

There were feelings of inadequacy linked to caring for the children when they returned from hospital. Associated with this was being unable to cope with the continuous medical attention they were expected to provide for their children in the home environment. This included administering medication through injections on a daily basis, tube feeding their children, and giving them oxygen. Still others spoke of the shame of being unable to care adequately for their children or *just switching off* from their child due to post-natal depression.

A less frequently expressed theme was parents' inability to tell others of the disabilities: *because everyone thought you would have a normal child* (V1/38). A further aspect of this theme was the hesitation of parents in taking their children into public places.

## Conclusion

In this chapter I have presented the self-referring construing and the themes linked with each of the emotional states and experiences of cognitive anxiety, threat, guilt and shame of parents of children with developmental disabilities. In the following chapter I will discuss the interpretations of these findings and the implications for the personal construct model of their grief presented in Chapter 4.

# CHAPTER 9

# THE FINDINGS, IMPLICATIONS AND LIMITATIONS OF A STUDY OF THE GRIEF AND ADAPTATION PROCESSES RELATED TO GIVING BIRTH TO AND PARENTING CHILDREN WITH DEVELOPMENTAL DISABILITIES

I begin this, the final chapter of the thesis, with a review of the research process. The main findings for both the quantitative and qualitative data of the research are reiterated and discussed, as they provide elaboration and clarification of the grief processes undertaken by parents in response to giving birth to and parenting children with developmental disabilities. The revised personal construct model of grief and adaptation is presented. The clinical implications and limitations of the study are provided, followed by a summary of the conclusions of the study

## A Review of the Research

The primary aim of the research was to explore the grief and adaptation processes undertaken by parents who give birth to and parent children with developmental disabilities. Personal construct theory was used to interpret existing research and as the framework within which a preliminary model of grief was developed. Data were collected by means of uninterrupted verbalisations in response to an open ended question, a structured interview, and a grid. The methodology accessed the most influential, self-related constructs of parents, along with their perception of themselves as being on their preferred or non-preferred poles of these constructs. Comparisons were made of the levels of cognitive, death, mutilation, separation, guilt and shame anxiety of parents of children with and without developmental disabilities; and of parents of children with developmental disabilities who perceived themselves as being on their preferred construct poles, with parents who saw themselves on their non-preferred construct poles. A longitudinal aspect of the study allowed for comparisons over time. Qualitative analysis was used to elaborate on the themes linked with the emotional states. The preliminary model of grief was adjusted in accordance with the results.

The new model of grief relating to having given birth to and parenting children with developmental disabilities consists of a series of specific and elaborated propositions concerning the relationship between the meaning or sense parents make of the event and their subsequent action, the adaptation process within the construct system, and the emotional states of parents.

## The Main Quantitative Findings

### Emotional Levels of Parents Having Children with Developmental Disabilities

The existing literature indicates that parents who give birth to children with developmental disabilities experience to the extreme whatever any new parent feels, as well as having additional themes particular to their situation (McConachie, 1985). This pattern of emotional response was confirmed by the results of this research. Parents who gave birth to children with developmental disabilities had significantly higher levels of cognitive, death, mutilation, separation, and shame anxiety compared to parents whose children were without developmental disabilities. This predicted pattern was not evident in relation to guilt. Parents of children with and without developmental disabilities were not significantly different in their level of guilt.

The result of no difference between the two parent groups (that is, parents of children with and without developmental disabilities) in relation to guilt might best be understood in terms of a lack of sensitivity of the research instrument when placed within the confines of three minutes of verbalisations. The instrument used, namely the Guilt Anxiety Sub-scale of the Total Anxiety Scale, was designed to tap verbal rather than preverbal references to feelings of guilt (Gottschalk, Winget & Gleser, 1969, p. 45). However, within a personal construct framework, I propose that it is worth considering that the events of giving birth to and parenting children with developmental disabilities may tap into preverbal rather than verbal constructs which may not then be available as specific scorable phrases within the confines of three minutes of verbalisations. The events being researched may well tap into deep seated constructs which the parents acquired as babies and have to do with dependency and the sustaining of life, with security and being safe (Kelly, 1955). It is likely that these constructs would be very influential but may not be able to be expressed in words.

This research also offers further support for this notion. The majority of the parents who did verbalise phrases which were scorable on the Guilt Scale also perceived themselves as being on the preferred pole of their construct. This could suggest that for this group of parents the situation was not so threatening as to derail them from their preferred way of viewing life and as such were more able to express guilt. Whereas parents on the non-preferred pole of their constructs were less able to express guilt.

The results of this research in relation to guilt are also supportive of those obtained by Darling (1979) who suggested that the feelings of excessive guilt for parents of children with developmental disabilities tended to be short lived. Darling (1979) suggests that the process was assisted by the parents' having access to appropriate genetic and chromosomal information which allowed them to view the birth of their children in ways which were less self blaming.

### Emotional Levels of the Parents with Different Construct Pole Preferences

This research indicates that parents differ considerably in both their short and long term responses to giving birth to and parenting children with developmental disabilities. Over the eighteen month period of this research some parents were able to give meaning to the events, became emotionally closer to their children, more confident, and effective, whereas others remained, or became caught in a meaningless world which allowed them little control.

The results of this research indicated that parents who perceived themselves as being on the preferred pole of their most influential, self-relating constructs experienced lower levels of cognitive, death, mutilation, separation, guilt and shame anxiety, compared to parents who perceived themselves as being on their non-preferred construct poles. Parents who integrate the events of giving birth to and parenting children with developmental disabilities meaningfully into their preferred way of viewing life do experience reduced anxiety, compared with parents who experience themselves as derailed from their preferred side of their fundamental views of life. This result is non-supportive of the notion that parents of children with developmental disabilities are condemned to high levels of anxiety and recurrent grief (Olshansky, 1962; Worthington, 1994, 1989). It is supportive of the literature (Bowlby, 1980; Parkes, 1971, 1972; Parkes & Weiss, 1983) which suggests that the levels of anxiety and resolution of the grief process are dependent on the capacity of parents to reconstruct the way they see life (whether that be through formulating new constructs or moving from one pole of the construct to the other) and give valued meaning to these events.

For many parents, from a clinical perspective, this result offers much hope. For other parents this research result may be perceived as yet a further indication of personal failure. From my perspective as researcher and clinician, I would like to highlight the fact of the degree of difficulty that some people have in giving valued meaning to the birth of children with developmental disabilities. The degree of difficulty is connected to the constructions parents and society have of life. In addition, any attempts to reconstrue life are being made within contexts which involve life-threatening situations, on-going mutilation of self and others, and of many circumstances which engender feelings of being separated from the person or the resources that are so desperately loved or needed, along with feelings of guilt and shame. To construe life in a meaningful way in these circumstances is extremely difficult and painful.

As the researcher, I experience the stories of these parents as giving flesh to the words of Rowe (1984), "it is in grief that we experience most acutely the ...... meaninglessness of life". Rowe suggests that it is a death-like experience when events cut across or threaten the continuity of those most important and personal things for which we plan and anticipate. Although parents fear that something may "go wrong" with their infants, people do not plan to conceive children with disabilities. To do so always cuts across their expectations. It is a death-like experience, to which it is extremely difficult to make sense of, or give meaning. I would hope that when parents cannot make sense of these events in their lives, it could be viewed in terms other than yet another failure.

### Emotional Levels of Parents of Children with Developmental Disabilities with Different Construct Pole Preferences Patterns Over Time

The research results indicated that the factor of time, of itself, had significant effects on the emotional levels of these parents. The direction, that is whether the level of the emotions increased or decreased, varied with construct pole preference patterns and specific emotions.

Parents who remained on the preferred pole of their constructs experienced decreased levels of cognitive, mutilation and separation anxiety over a period of eighteen months. This indicated that over time these parents were able to integrate the experience of having children with developmental disabilities into their originally held view of life to an ever increasing degree. Their presently held construct system was not under threat of needing to change comprehensively, particularly in relation to the elements of bodily mutilation and relational separation. When parents were able to give meaning to the events, they were increasingly able to connect with their children and the associated events. This resulted in fewer feelings of separation. Feelings of being abandoned, or feelings of loss in relation to not having their anticipated 'normal' child or not having sufficient support, or loneliness, were lessened. It is note-worthy that these changes occurred in the light of these parents reporting similar levels of anxiety about death or the threat of such initially and again eighteen months later. This group of parents also remained constant in viewing themselves as dislodged from their deepest understanding of how they perceived themselves as parents and members of society. Along with, remained unchanged in seeing themselves as dislodged from the perceptions that other people had of them in their role as parents and members of society.

Those parents who remained on their non-preferred construct poles experienced significally decreased levels of cognitive, death, and guilt anxiety over time. Again these parents integrated the events more meaningfully into their particular views of their personal worlds. They also felt significantly less guilty over time. Within the framework of personal construct theory, did these parents begin to perceive themselves in a way as 'disabled' (expressed through their inability to be on their preferred construct pole) and saw a connection between ‘being disabled’ and ‘producing disability’? In other words, had their self esteem become so low over time that they had a sense of, “what more could I expect of myself but to produce 'disability'?” In this way they experienced less of a sense of being dislodged from their own core social structure. The results indicated that the experiences of mutilation and separation were just as anxiety producing for these parents initially as they were eighteen months later. Such events were still outside the range of convenience of the construction of life held by these parents. The parents were also left not knowing what to do in the face of events. They remained constant in their feelings of being dislodged from the perceptions that other people had of them in their role as parents and members of society.

Parents who moved from their non-preferred to their preferred construct poles over time experienced significantly reduced emotional levels in relation to the each of the researched emotional states. These parents moved to experiencing themselves as being on their preferred poles of their most influential constructions of life. Linked with this change was an increased integration of the situations in ways which allowed such events to be meaningful and better anticipated. The results also indicate that the disabilities/mutilation of the children could be better understood and were less anxiety provoking. They were less cutting ( in terms of the meaning of this word as used by Rowe, 1984) which allowed for more connection with the disability and hence with the child. With a greater sense of connection with the disability came fewer feelings over time of separation, abandonment, and loss. It could also be anticipated that this increasing connection between parents and children flowed on to a reduction in guilt anxiety. Parents could see themselves as producing children with whom they connected, rather than experiencing the initial reaction of having done something which they could not see themselves as doing. This group of parents also had a sense of having increased their adequacy to cope with situations. At the same time they felt less shame.

Some people moved from their preferred to their non-preferred most influential construct poles over time. They moved to seeing themselves as being on the non-preferred poles of their meaning systems. Over time they remained basically unchanged in the degree to which they integrated and gave meaning to the events. While their concerns about death remained unchanged, the disability and mutilation aspects of their experiences became more 'cutting' and produced increased anxiety, as did their separation experiences. These parents remained constant in the degree to which they considered that in producing children with disabilities they had done something outside that which they would expect of themselves. The degrees to which they felt inadequate, shameful and embarrassed also remained unchanged.

### Between the Two Samples of Parents

I will now discuss only the most pertinent results for each of the samples of parents as determined by construct pole patterns in relation to the control sample. The discussion will be confined to the differences which still existed between the parents of the children with disabilities and the matched parents of children without disabilities eighteen months after the initial data collection.

The results indicated that parents who remained on the preferred poles of their most influential and self-related constructs over time, eighteen months after the initial data collection, experienced higher level of cognitive and separation anxiety compared to controls. Although parents had not been derailed from the preferred poles of their constructions of life, they still struggled to integrate their experiences fully. They were aware that this process of integration would require comprehensive changes to those constructs which related to the self and in particular to the element of mutilation of self and child.

Parents who remained on their non-preferred construct poles over time, eighteen months after the initial data collection, experienced significantly higher levels of cognitive, mutilation, separation and shame anxieties compared to matched parents of children without disabilities. This group continued over time to find it difficult to integrate the events meaningfully, their constructions of life continued to be threatened by the events, and they continued to perceive themselves as being outside the perceptions that other people had of them in their role as parents and members of society. They continued to experience higher levels of cognitive anxiety, threat, and shame, compared with matched parents of children without disabilities.

Those parents who initially were on their non-preferred construct poles and eighteen months later had moved to their preferred construct poles, rated no significant difference in emotional levels at this point, on any of the researched states compared with matched parents of children without disabilities. Perhaps this group most of all had participated in the adaptation process. They had assimilated their new experiences and given them meaning within their preferred way of viewing life. The construct system eighteen months after the initial data collection was no longer under the threat of needing to change, particularly in relation to the elements of existence and death, disability/mutilation, and relationships. Through giving birth to children with developmental disabilities, these parents saw themselves as acting in ways in which they and other people would anticipate they might in their roles as parents and as members of society.

Parents who moved from their preferred to their non-preferred construct poles, continued over time to experience significantly higher levels of cognitive, mutilation, separation, and shame anxiety compared with parents of children without disabilities. This sample struggled to make sense of the events in a meaningful way. Their construct system remained under threat, particularly in relation to mutilation and separation elements; and they continued to perceive themselves as having been dislodged from the perceptions which other people had of them in their role as parents.

## The Main Qualitative Findings of the Research: Elaborating the Emotional States of Grief Related to Giving Birth to and Parenting Children with Developmental Disabilities

In this section I will discuss the qualitative data presented in Chapter 8 in order to elaborate the emotional states of the grief process for parents of children with developmental disabilities. I will use as its framework the preliminary model of parenting children with developmental disabilities as presented in Chapter 5.

The initial model of grief proposed that these parents would experience cognitive anxiety, threat expressed through death, mutilation, and separation anxiety, guilt and shame. The research results supported the model. This was particularly so in relation to cognitive anxiety and threat, which was expressed by 98% and 99% of the group respectively. The expression of shame by 70% of the group also supported the model; as did to a lesser degree, guilt, which was expressed by 42% of the initial model of grief. The explanation for this latter result regarding guilt has been provided early in this chapter in relation to the quantitative data.

From such results it can be understood that parents who give birth to children with developmental disabilities in our society struggle to integrate the experience and give it meaning within their preferred poles of their individual construct systems. The parents described their reactions in terms of shock, numbness and denial. The meanings communicated in their stories were the same as those presented in the personal construct concepts of these words. The parents were aware that the events confronting them did not fit with the ways they saw life. With this came an awareness of an overwhelming and sudden need to make sense of the birth of their children with disabilities. Others, on reflection, were aware that they were unable to construe the events, and still others became aware that they had denied aspects related to the developmental disabilities of their children. Feelings of uncertainty were a further factor of cognitive anxiety. The experiences of 'not knowing what to do next' and not understanding because the situations were all so new, were very common. Another significant factor which engendered cognitive anxiety was the sense of not knowing what the future would hold for themselves or their children. Medical personnel were consistently reported as not being able to provide diagnoses, prognoses and/or treatment plans. Each of these factors made it that much more difficult for parents to make sense of, and increase their predictive ability in relation to having given birth to children with developmental disabilities.

The parents became aware that imminent comprehensive change needed to occur at the level of their superordinate, core meaning systems. They became aware that change was required at the level of their identity and its maintenance. The elements which threatened their present ways of viewing the world were related to existence, bodily safety, and relationships. The element of existence incorporated such aspects as death related to self or their children, or awareness of loss of personal identity, or loss of control over their personal lives. Bodily safety incorporated disability and mutilation of self or children. Relationships included separation from the expected child, physical separation of parents and children, loss of parent-child relationships, loss of relationships between partners, loss of family life, loss of relationships with extended family and friends, loss of expected relationships with medical staff, and loss of the parents' place in society. Experiences such as these confronted parents. They became aware that they would have to adapt and adjust in order for these elements to be incorporated into the way they viewed life in relation to themselves.

Approximately half of the parents expressed guilt in ways which were able to be scored on the Guilt Scale. I suggest that many others may have experienced guilt at a preverbal rather than a verbal level. The thinking behind this statement has been elaborated earlier in this chapter. The research results are supportive of others such as Davis (1983) who reported that parents become aware of themselves acting in ways in which they had never before reacted, or could envisage themselves acting. In terms of personal construct theory, the stories of the parents reflected an awareness of themselves as having been dislodged from their deepest understanding of how they perceived themselves acting as parents and members of society. Guilt was expressed by parents in terms of blaming themselves for the disability of their children, their parenting relationships and practices, their personal coping mechanisms under the given circumstances, and their relationships with their partners.

The preliminary model of the grief processes undertaken by parents of children with developmental disabilities also proposed that these parents would experience shame. They would experience an awareness of being dislodged from the perceptions that other people had of them in their role as parents and members of society. The majority of the parents involved in this research spoke of this aspect. The parents had internalised societal standards regarding levels of personal adequacy and many found themselves wanting. There were expectations that they "could cope" with disabilities and parents spoke of the pain of not being able to meet these expectations. There were certain anticipations around being able to remember, or hold in mind, as it were, the various aspects which created so much tension, but many parents found themselves simply unable to remember many of their experiences. Parents saw themselves as stepping outside the expectations of others in regard to parenting relationships and practices and in their ability to tell and discuss the disabilities of their children with others. The majority of the parents involved in this research experienced shame.

## A Revised Personal Construct Model of the Grief and Adaptation Processes Related to Giving Birth to and Parenting Children with Developmental Disabilities

The findings of this study as they relate to the model of the grief processes of parents who give birth to, and were parenting children with developmental disabilities are presented below. The preliminary model was presented in Chapter 4. A more elaborate model based on the results of this research is now presented.

The research has enabled the revised model to elaborate on the following aspects: the reconstructing (whether that be related to construct content or construct pole) by parents takes place at the level of their most influential and self related constructs; the effects on emotions of change and no-change on construct pole preferences; and the effects of time. The results of the research present a changed emphasis in the processes parents undertake in response to giving birth to children with developmental disabilities. The results emphasise a process of adaptation encompassing grief, as opposed to a pathway depicted primarily as grief.

## General Propositions Concerning the Processes of Grief and Adaptation of Parents to Giving Birth to Children with Developmental Disabilities

1.2 The meaning parents give to, or the sense they make of, having given birth to and rearing children with developmental disabilities will determine how they act.

## Propositions Concerning The Construct or Meaning Systems of Parents

2.1 Parents struggle at the level of their most influential and self-related constructs in their attempts to make sense of having given birth to, and parenting children with developmental disabilities. Each construct is two sided and these events have the capacity to propel parents into the preferred as well as the non-preferred poles of their constructs.

2.2 Verbal constructs are accessed by those aspects of the adaptation process which evoke cognitive, death, mutilation, separation and shame anxiety. There is evidence to propose that preverbal constructs ("deep seated constructs acquired...as a baby, and are usually connected to love, warmth, feeding" [Dalton & Dunnett,1992], safety and security) are tapped by those aspects of the adaptation process which evoke guilt.

2.3 The most adaptive process (indicated when parents of children with developmental disabilities at Time 2 have no significant difference in their emotional levels from parents of children without developmental disabilities) include parents who initially see themselves as being on their non-preferred construct pole and over time as being on their preferred construct pole. This group of parents recognised that the events had the effects of initially placing them on the non-preferred pole of their most influential self-related constructs. Over time however, they had assimilated the new experience and given it meaning within their preferred way of viewing life.

## Propositions Concerning The Emotional States of Parents

3.1 The meaning systems of the majority of parents are initially ineffective in being able to make sense of the situations confronting them, and, as a result, parents experience significantly higher levels of negative emotions compared with parents who give birth to children without developmental disabilities.

3.2 Parents who can incorporate the event into their preferred pole of their construct system do experience reduced anxiety compared with parents who, in the light of having given birth to children with developmental disabilities, perceive themselves as being on their non-preferred poles of their most influential self-related constructs. This pattern remains consistent when parents change their construct pole preferences over time.

3.3 Time itself has significant effects on the emotional levels of parents. Higher or lower emotional levels are influenced by construct pole preferences patterns over time and specific emotions.

3.4 When initially confronted with the events, parents are unable to anticipate and integrate the experiences meaningfully. This results in cognitive anxiety.

3.5 The meaning systems of parents are threatened and they experience death, mutilation and separation anxiety.

3.6 By giving birth to children with developmental disabilities, parents perceive themselves as having been dislodged from their deepest understanding of the way they perceived themselves as parents and members of society. The parents experience guilt.

3.7 Giving birth to children with development disabilities also engenders shame. Parents are aware of being dislodged from the perceptions that other people have of them in their role as parents and members of society.

## The Clinical Implications Of The Research

The research results and the ensuing model have the following clinical implications:

1. The event of giving birth to, and parenting children with developmental disabilities does not automatically mean that parents will have higher levels of negative emotions on an on-going basis, compared with parents of children without developmental disabilities. Clinicians need to allow their own and the client's options in this area to remain open. The results of the research reinforce the clinical approach of constructive alternativism.

2. Often such an event makes it harder for parents to reconstrue the way they see life, so that giving birth to, and parenting children with disabilities is able to be given valued meaning. The therapeutic process requires clients to reconstrue at the level of their most influential and self relating construing. It may also include preverbal constructs.

3. Results indicate that the most therapeutic process (indicated by the only group of parents who had levels of negative emotions not significantly different from parents of

children without developmental disabilities) is for parents to become aware of having been derailed from their preferred pole of their constructs through their experience with developmental disabilities. Then clinicians can work with such parents as scientists searching out more effective constructions of life (whether that be in the form of construct content or construct pole) which take into account new events. Through such a process the emotional levels of parents can move to being within normal ranges.

4. For some parents the experience of having given birth to, and parenting children with developmental disabilities makes the task of reconstruing life to the point of being on the preferred pole of their personal constructs extremely difficult. Not reconstruing is understood as a way of coping at that time. It is important for clinicians and clients to remember that the demanding therapeutic process of reconstruing is often occurring at the same time as parents are facing on-going life-threatening situations to self and others, mutilation, and separation from people and resources.

## The Aim Achieved

The elaborated model of the grief process along with the clinical implications indicate that the research has resulted in a greater understanding of the process of adaptation undertaken by parents of children with developmental disabilities. The process of adaptation centrally involves the most influential self related constructs of parents.

Parents who can incorporate the event into their preferred pole of their construct system experience less anxiety compared with parents who, in the light of having given birth to children with developmental disabilities, perceive themselves as being on their non-preferred poles.

The adaptive process is most effective when parents, who experience themselves as de-railed by the events, reconstrue, and in doing so move again to their preferred construct poles. It is only that group of parents who undergo this process of adaptation who experience no significant difference in their levels of anxiety to giving birth to, and parenting children with developmental disabilities compared to parents who give birth to children without developmental disabilities.

By being able to state the process of adaptation for parents of children with developmental disabilities as clearly as this, the primary aim of this research, as indicated in Chapter 5, has been achieved. The content of the most influential constructs has been described in Chapter 8, along with the external triggers of the emotional states and experiences.

## The Limitations Of The Study

This research could have used random rather than stratified purposeful sampling. On the one hand this would provide an increased likelihood that the subject sample used was representative of the population (Tabachnick & Fidel, 1989). On the other hand, the sample used in this research was representative regarding the demographic data, when compared with the demographic data collected in the 1993 Survey of Disability, Ageing and Carers for Australia and the 1991 Census of Population and Housing Data. In addition, the sample size was comparatively large, being 81 for each sample. In the light of these factors, future research may be improved in terms of its methodology by canvassing more research participants and then using the process of random sampling.

While I am confident that the sample has external validity for the population which has characteristics similar to those described in the demographic data, it is restricted to English-speaking parents living in Australia at the present time. I am not confident that the results could be generalised to include people of different cultural or spiritual backgrounds. In this statement I include Aboriginal people or people of non-Westernised cultures. It would be of great benefit to reproduce this study in other cultures.

The sample of research participants could also have a bias because they were all volunteers. They were parents who agreed to participate in the study after reading Research Project Information Sheets in maternity hospitals, community centres, support groups and so on. However, an equally important consideration was that research participants need to be obtained in an ethical manner. In addition they must be willing to speak honestly about their life experience.

With further regard to internal validity, the effects of many extraneous variables were taken into account (see Appendix A, Table 1A for Demographic Data). However, on reflection, a variable not taken into account was that of the presence in the children of a disorder which was terminal. It could be predicted that the presence or absence of this factor would have a significant effect on the emotions of parents.

A compounding factor could also be that 70% of the children were under 2 years of age, 26% between 2 and 4 years of age, 4% over four years of age (see Appendix A). As such, the time the parents had spent with their children had varied and perhaps influenced their emotional states. On the other hand, the first data collection occurred in the time frame of a minimum of six months and a maximum of two years of disclosure of the diagnosis.

The present study limited itself to researching five anxiety emotional states of parents of children with developmental disabilities. Literature and logic suggest that other emotions are evoked by the effects of these events on construct systems. Further research clearly needs to encompass other emotional states.

Content Analysis Scales were used to measure the emotions of the parents. Cognitive Anxiety was able to be measured through its own scale devised by Viney & Westbrook (1976). Death, mutilation, separation, guilt and shame were all measured by means of subscales of the Total Anxiety Scale (Gottschalk et al, 1969). Separate measuring instruments for each of these anxiety emotions may have provided stronger validity.

A further concern is connected with my suggestion that giving birth to, and parenting children with developmental disabilities may tap nonverbal constructs held by parents. A limitation exists in that the anxiety scales score only what is verbalised. A counter thought is that even though parents may have a limited awareness of the meaning and level of influence of their nonverbal constructs, these constructs are in fact often expressed verbally, and therefore are able to be scored by the anxiety scales.

## Suggestions For Further Research

I think the next step is to take this model and its clinical implications into the therapy room. Research could be devised which gives even greater understanding of the process of adaptation as parents are moving from their non-preferred to their preferred construct poles. Questions that arise include: Are there similarities in the way parents see life at the end of the therapeutic process? Are there some central themes which are processed first?

It would also be of considerable value to extend the longitudinal component of this study. These same parents could be interviewed in relation to their construct path preferences and emotional states at times of significant developmental and transitional points in the lives of their children. This could be when the children with developmental disabilities are around five years of age when in our society children enter school, and then again when the children are about thirteen years of age when children begin high school. Such studies would further enhance our understanding of the grief and adaptive processes for parents of children with developmental disabilities.

An off-shoot of this research is related to the siblings of children with developmental disabilities. Is their adaptation process similar to that of their parents or does it vary? In addition, the same questions and methodology used in this research could be applied to the people themselves who have developmental disabilities. As they adapt to being challenged by having developmental disabilities do they see life in such a way that allows them to be on the preferred side of their construct systems?

# Conclusion

The findings from this research indicate that the events of giving birth to, and parenting children with developmental disabilities in our society are highly challenging to the ways of making sense of life and the meaning they give to life. This challenge produces cognitive, death, mutilation, separation, guilt, and shame anxieties. This results of this research indicated that the most effective adaptation process involved: parents growing in their awareness that they perceived such events as having placed them on the non-preferred poles of their most influential self-related constructs; and over time integrating the events, and giving them meaning within their preferred ways of viewing life. This process led to the reduction of their negative emotions to levels equal to and no greater than those of parents of children without developmental disabilities.

To summarise the adaptation processes, the results of this research indicate that:

i) we need not be caught into set emotions or experiences but rather can be liberated by how we construe events and have these constructions validated;

ii) it seems most therapeutic if we can allow for the possibility of events de-railing us from presently held constructs, which opens up possibilities of reconstruing.

REFERENCES

Agar, M. (1986). Speaking of ethnography. London: Sage Publications

Anderson, E. (1988). Siblings of mentally handicapped children and their social relations - research supplement. British Journal of Special Education, 15(1), 24-26.

Australian Bureau of Statistics. (1991). Census of Population and Housing: Basic Community File. Sydney, NSW: City Officers.

Australian Bureau of Statistics. (1993). Survey of Disability, Ageing and Carers. Belconnen, ACT: Cameron Officers.

Australian Institute of Health & Welfare - Lancaster, P. & Pedisich, E. Congenital malformations Australia: 1981 - 1992 - Birth defects series Number 1. (1995) Sydney: AIHW National Perinatal Statisticans Unit.

Australian Institute of Health & Welfare - Lancaster, P., Hurst, T., Day, P., Huang, J., & Shafir, E. Congenital malformations Australia: 1993 and 1994 - Birth defects series Number 2. (1997) Sydney: AIHW National Perinatal Statisticians Unit.

Bailey, D., Blasco, P. & Simeonsson, R. (1992). Needs expressed by mothers and fathers of young children with disabilities. American Journal on Mental Retardation, 97(1), 1-10.

Bannister, D. (1966). A new theory of personality. In B. Foss (Ed.). New horizons in psychology. London: Harmondforth.

Bannister, D. (1981). Construing a disability. In A. Brechin (Ed.), Handicap in a social world (pp. 231-236). Sevenoales: Penny Liddiard, John Swain.

Bargh, J.A., & Shul, A. (1980). On the cognitive benefits of teaching. Journal of Educational Psychology, 72, 593-604.

Bensen, G., & Lindsey, J. (1984). Supporting handicapped children's nonexceptional siblings: a new and urgent role for professionals. Techniques, 1.

Birenbaum, A., & Cohen, H. (1993). Mini-symposium: helping families. Mental Retardation, 31(2), 67-74.

Blacher, J., Nihira, K., & Meyers, C. (1987). Characteristics of home environments of families with mentally retarded children: comparison across levels of retardation. American Journal of Mental Deficiency, 91(4), 313-320.

Bowlby, J. (1980). Attachment and Loss: Volume 3. Loss - Sadness and Depression. Ringwood: Penguin Press.

Brazelton, T., & Cramer, B. (1990). The earliest relationship: Parents, infants and the drama of early attachment. Sydney: Addison-Wesley Publishing Company, Inc.

Breen, D. (1989). Talking with mothers. London: Free Association Books.

Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: adaptation and spousal support. Developmental Psychology, 24(3), 441-451.

Bronfenbrenner, U. (1979). The ecology of human development. Cambridge: Harvard University Press.

Bruce, E.J., & Schultz, C.L. (1992). Complicated loss: considerations in counselling the parents of a child with an intellectual disability. The Australian Counselling Psychologist, 8(2), 8-20.

Bruce, E.J., Schultz, C.L., Smyrnios, K., & Schultz, N.C. (1994). Grieving related to development: a preliminary comparison of three age cohorts of parents of children with intellectual disability. British Journal of Medical Psychology, 67, 37-52.

Bunn, T., & Clarke, A.M. (1979). Crisis intervention: An experimental study of the effects of a brief period of counselling on the anxiety of relatives of seriously injured or ill hospital patients. British Journal of Medical Psychology, 52.

Burke, M.L. (1989). Chronic sorrow in mothers of schoolage children with a myelomeningocele disability. Dissertation Abstracts International, 50, 233-234.

Button, E. (1985). Personal construct theory: the concepts. In E. Button (Ed.), Personal construct theory and mental health. (pp.3-30). Sydney: Croom Helm Ltd.

Corr, R. (1993). Coping with dying: Lessions that we should and should not learn from the work of Elizabeth Kubler-Ross. Death Studies, 17, 69-83.

Crnic, K.A., Friedrich, W.N., & Greenberg, M.T. (1983). Adaptation of families with mentally retarded children: a model of stress, coping and family ecology. American Journal of Mental Deficiency, 88(2), 125-138.

Crutcher, D. (1990). Untitled story. Down's Syndrome Association, Spring Edition of News.

Cunningham, C., & Davis, H. (1985) Working with parents: frameworks for collaboration. Philadelphia: Open University Press.

Dalton, P. (1993). The meaning of choice and the threat of change. In L.M. Leitner & N.G.M. Dunnett (Eds.), Critical issues in personal construct psychotherapy. Florida: Krieger Publishing Company

Dalton, P., & Dunnett, G. (1992). A psychology for living. Brisbane: John Wiley & Sons.

Damrosch, S.P., & Perry, L.A. (1989). Self-reported adjustment to chronic sorrow, and coping of parents of children with Down syndrome. Nursing Research, 38, 25-30.

Darling, R.B. (1979). Families against society: a study of reactions to children with birth defects. London: Sage Publications.

Darling, R. B. (1983). The birth defective child and the crisis of parenthood: redefining the situation. In E.J. Callahan & K.A. McKluskey (Eds.), Life-span developmental psychology. London: Academic Press Inc.

Davis, B.H. (1987). Disability and grief. Social Casework: The Journal of Contemporary Social Work, 68, 352-357.

Davis, H. (1983). Constructs of handicap: working with parents and children. Changes, 1, 37-39.

Davis, H., & Cunningham, C. (1985). Mental handicap: people in context. In E. Button (Ed.), Personal construct theory and mental health (pp. 246-261). Sydney: Croom Helm.

Dempsey, D., & Neimeyer, R. (1995). Organisation of personal knowledge: convergent validity of implications grids and repertory grids as measures of system structure. Journal of Constructivist Psychology, 8, 251-261.

Doka, K. (1995-6). Coping with life-threatening illness: a task model. Omega, 32(2), 111-122.

Duck, S.W. (1983). Sociality and cognition in personal construct theory. In J. Adams-Webber & J. Mancuso (Eds.), Applications of personal construct thory. Toronto: Academic Press.

Duffy, M.E. (1992). A theoretical and empirical review of the concept of suffering. In P.L. Starck., & J.P. McGovern (Eds.), The hidden dimension of illness: Human suffering. New York: National League for Nursing Press.

Fisman, S., Wolf, L., Ellison, D., Gillis, B. et al. (1996). Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities. Journal of the American Academy of Child and Adolescent Psychiatry, 35(11), 1532-1541.

Fisman, S. N., Wolf, L. C., & Noh, S. (1989). Marital intimacy in parents of exceptional children. Canadian Journal of Psychiatry, 34, 519-525.

Floyd, F. J., & Zmich, D. E. (1991). Marriage and the parenting partnership: perceptions and interactions of parents with mentally retarded and typically developing children. Child Development, 62, 1434-1448.

Flynt, S., & Wood, T. (1989). Stress and coping of mothers of children with moderate mental retardation. American Journal of Mental Retardation, 94(3). 278-283.

Flynt, S., Wood, T., & Scott, R. (1992). Social support of mothers of children with mental retardation. Mental Retardation, 30(4), 233-236.

Focht-New, V. (1996). Beyond abuse: Health care for people with disabilities. Issues in Mental Health Nursing, 17(5), 427-438.

Fraley, A.M. (1986). Chronic sorrow in parents of premature children. Children's Health Care, 15(2), 114-118.

Fransella, F. (1972). Personal change and reconstruction. London: Academic Press.

Fransella, F. (1975). Need to change? Essential psychology series. London: Methuen.

Fransella, F. (1985). Individual psychotherapy. In E. Button (Ed.), Personal construct theory and mental health. Sydney: Croom Helm.

Fransella, F. (1988). PCT: still radical thrity years on? In F. Fransella & L. Thomas (Eds.), Experimenting with personal construct psychology. New York: Routledge & Kegan Paul.

Fransella, F. (1995). George Kelly. London: Sage Publications.

Fransella, F., & Dalton, P. (1990). Personal construct counselling in action. London: Sage.

Freud, S. (1917). Mourning and melancholia. In E. Jones (Ed.), Sigmund Freud: Collected Papers (pp. 152-170). London: Routledge.

Friedrich, W. N. (1979). Predictors of the coping behavior of mothers of handicapped children. Journal of Counselling and Clinical Psychology, Vol. 47, 6, 1140-1141.

Friedrich, W. N., & Friedrich, W. L. (1981). Psychosocial assets of parents of handicapped and nonhandicapped children. American Journal of Mental Deficiency, 85(5), 551-553.

Gallimore, R., Cootes, J., Weisner, T., Garnier, H. et al. Family responses to children with early developmental delays: Accommodation intensity and activity in early and middle childhood. American Journal of Mental Retardation, 101(3), 215-232.

Garcia-Bodaroicco, J.E. (1996). "Mourning and melancholia" 80 years later. Revista de Psicoanalisis, 53(1), 39-52.

Genevie, L., & Margolies, E. (1987). The motherhood report: How women feel about being mothers. New York: Macmillan Publishing Company.

Gottschalk, L.A. 1979b. The content analysis of verbal behaviour: Further studies. New York: Spectrum.

Gottschalk, L.A., & Gleser, G.C. (1969). The measurement of psychological states through the content analysis of verbal behaviour. Berkeley: University of California press.

Gottschalk, L.A., Winget, C.N., & Gleser, G.C. (1969). Manual of instruction for using the gottschalk-gleser content analysis scales: anxiety, hostility and social alienation-personal disorganisation. Los Angeles: Univeristy of California Press.

Guidano, V. (1991). The self in process: toward a post-rationalist cognitive therapy. New York: Guilford Press.

Guidano, V. (1995). Constructivist psychotherapy: a theoretical framework. In R.A. Neimeyer & M.J. Mahoney (Eds.), Constructivism in psychotherapy. Washington: American Psychological Association.

Hagman, G. (1996). The role of the other in mourning. Psychoanalytic Quarterly, 65(2), 327-352.

Hannan, C. (1975). Parents and mentally handicapped children. New York: Penguin Books Ltd.

Harris, H., & Kositsky, A. (1983). The premature baby book: A parents' guide to coping and caring in the first years. New York: St. Martin's Press.

Harris, V., & McHale, S. (1989). Family life problems, daily caregiving activities, and the psychological well-being of mothers of mentally retarded children. American Journal of Mental Retardation, 94(3), 231-239.

Herman, S.E., Marcenko, M.O., & Hazel, K.L. (1996). Parents' perspectives on quality in family support programs. Journal of Mental Health Administration, 23(2), 156-169.

Hewson, D. (1997). Coping with loss of ability: "Good grief" or episodic stress responses? Social Science & Medicine, 44(8), 1129-1139.

Hinkle, D. (1965). The change of personal constructs from the viewpoint of a theory of implications. Unpublished PhD Thesis, Ohio State University.

Irvin, N., Kennell, J., & Klaus, M. (1982). Caring for the parents of an infant with a congenital malformation. In M. Kaus & J. Kennell, Parent-infant bonding. London: The C.V. Mosby Company.

Jeffcoate, L, Humphrey, A., & Lloyd, P. (1976). The family and the preterm baby. London: George Allen and Unwin Ltd.

Jellinek, M. (1994). Reflections on Worthington's model of cyclical grief. Clinical Paediatrics, May, 301-302.

Jones, H. (1992). Biography in management and organisation development. Management Education and Development, 23(3), 199-206.

Jones, H. (1993). The core interview process. EPCA Newsletter, 2(1), 19.

Jones, H., & Watson, J. (1993). Highlights of our lives: Core process interviewing -Workshop presented at The Xth International Conference on Personal Construct Psychology. Townsville, Australia.

Kelly, G. (1955). The psychology of personal constructs - Vol. 1 & 2. London: Routledge. (Republished in 1991).

Kennell, J.H., & Klaus, M.H. (1982). Caring for the parents of premature or sick infants. In M. Kaus & J. Kennell (Eds.), Parent-infant bonding. London: The C.V. Mosby Company.

Kopp, C., Baker, B., & Brown, K. (1992). Social skills and their correlates: preschoolers with developmental delays. American Journal of Mental Retardation, 96(4), 357-366.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. American Journal of Mental Retardation, 93(4), 393-404.

Kropf, N.P. (1997). Older parents of adults with developmental disabilities: Practice issues and service needs. Journal of Family Psychotherapy, 8(2), 37-54.

Kubler-Ross, E. (1969). On death and dying. New York: Collins Books.

Kuchenhoff, J. (1996). Mourning, Melancholy and the destiny of object relations. A re-reading of Freud's "Mourning and Melancholy". Jahrbuch der Psychoanalyse, 36, 90-117.

Leitner, L.M. (1985). Interview methodologies for construct elicitation: searching for the core. In F. Epting & A.W. Landfield (Eds.), Anticipating Personal Construct Psychology. London: University of Nebraska Press.

Leitner, L.M. (1988). Terror, risk, and reverence: Experiential personal construct psychotherapy. International Journal of Personal Construct Psychology, 1, 251-261.

Leitner, L.M., Dunnett, N.G.M., Anderson, T.M., & Meshot, C.M. (1993). Unique aspects of personal construct psychotherapy. In L.M. Leitner & N.G.M. Dunnett, (Ed.), Critical issues in personal construct psychotherapy. Florida: Krieger Publishing Company.

Levene, M.I., Tudehope, D. & Thearle, J. (1990). Essentials of neonatal medicine. Sydney: Brooks Waterloo.

Levy-Shiff, R. (1986). Mother-father-child interactions in families with a mentally retarded young child. American Journal of Mental Deficiency, 91(2), 141-149.

Lindgren, C.L. (1996). Response to "Chronic sorrow in persons with Parkinson's and their spouses". Scholarly Inquiry for Nursing Practice, 10(4), 367-370.

Lindgren, C.L., Burke, M.l., Hainsworth, M.A., & Eakes, G.G. (1992). Chronic sorrow: a lifespan concept. Scholarly Inquiry for Nursing Practice: An International Journal, 6(1), 29-40.

Lindsey, J., & Stewart, D. (1989). The guardian minority: siblings of children with mental retardation. Education and Training in Mental Retardation, 24(4), 291-296.

Mahoney, M.J. (1991). Human change process: the scientific foundations of psychotherapy. New York: Basic Books.

Mair, J.M. (1989). Between psychology and psychotherapy: a poetics of experience. London: Routledge.

Malone, D.M., & Kropf, N. (1996). Growing older. In P.J. McLaughlin & P. Wehman (Eds.), Mental retardation and developmental disabilities. Austin, US: Pro-Ed.

Margalit, M., & Ankonina, D. B. (1991). Positive and negative affect in parenting disabled children. Counselling Psychology Quarterly, 4, 289-299.

Margalit, M., Raviv, A., & Ankonina, D. (1992). Coping and coherence among parents with disabled children. Journal of Clinical Child Psychology, 21(3), 202-209.

Martinson, I.M. (1992). Response to "chronic sorrow: a lifespan concept". Scholarly Inquiry for Nursing Practice: An International Journal, 6(1), 41-42.

Mascolo, M.F. (1994). Towards a social constructivist psychology: The case of self-evaluative emotional development. Journal of Constructivist Psychology, 7, 87-106.

Mascolo, M.F., & Mancuso, J. (1992). Constructive processes in self-evaluative emotional development. Advances in Personal Construct Psychology, 2, 27-54.

McConachie, H. (1985). How parents of young mentally handicapped children construe their role. In D. Bannister (Ed.), Issues and approaches in personal construct theory (pp. 105-126). London: Academic Press Ltd.

McCoy, M. (1977). A reconstruction of emotion. In D. Bannister (Ed.), New perspectives in personal construct theory (pp. 93-123). London: Academic Press.

McCoy, M. (1980). Culture-shocked marriages. In. A.W. Landfield & L. Leitner (Ed.), Personal construct psychology: psychotherapy and personality (pp. 141-165). Brisbane: A Wiley-Interscience Publication.

McCoy, M. (1981). Positive and negative emotion: a personal construct theory interpretation. In H. Bonarius, L. Holland, & S. Rosenbery (Eds.), Personal construct psychology: recent advances in theory and practice (pp.95-104) London: MacMillan.

McHale, S., & Pawletko, T. (1992). Differential treatment of siblings in two family contexts. Child Development, 63, 68-81.

Minde, K.K., Hackett, J.D., Killou, D., & Silver, S. (1972). How they grow up: 41 physically handicapped children and their families. American Journal of Psychiatry, 128(12), 104-109.

Murphy, M.A. (1982). The family with a handicapped child: A review of the literature. Developmental and Behavioral Paediatrics, 3, 73-82.

Neimeyer, G. (1995). The challenge of change. In R.A. Neimeyer & M.J. Mahoney (Eds.), Constructivism in psychotherapy. Washington: American Psychological Association.

Neimeyer, G., & Hall, A. (1988). Personal identity in disturbed marital relationships. In F. Fransella & L. Thomas (Eds.), Experimenting with personal construct psychology (pp. 297-307). London: Routledge & Kegan Press.

Neimeyer, R. (1999). Narrative strategies in grief therapy. Journal of Constructive Psychology, 12(1), 65-85.

Neimeyer, R., & Neimeyer, G. (1985). Disturbed relationships: a personal construct view. In E. Button (Ed.), Personal Construct Theory and Mental Health (pp. 195-387). Sydney: Croom Helm.

Neimeyer, R., & Neimeyer, G. (1993). Constructivist assessment: what and when. In G. Neimeyer (Ed.), Constructivist assessment. New Delhi: Sage Publications.

Olshansky, S. (1962). Chronic sorrow: a response to having a mentally defective child. Social Casework, 3 (4), Parkes, C.M. (1971). Psycho-social transitions: a field of study. Social Science & Medicine, 5, 101-115.

Parkes, C.M. (1972). Bereavement - studies of grief in adult life. London: Tavistock Publications.

Parkes, C.M., & Weiss, R. (1985). Recovery from bereavement. New York: Basic Books, Inc., Publishers.

Patton, M.Q. (1990). Qualitative evaluation and research methods. (2nd ed.). Newbury Park: Sage Publications.

Procter, H., & Parry, G. (1978). Constraint and freedom: the social origins of personal constructs. In F. Fransella (Ed.). Personal construct psychology 1977. London: Academic Press.

Rando, T. (1984). Grief, dying and death: Clinical intervention for caregivers. Illinois: Research Press Company.

Rando, T. (1986a). A comprehensive analysis of anticipatory grief: perspectives, processes, promises, and problems. In T. Rando (Ed.), Loss and anticipatory grief. (pp. 3-37). Canada: Lexington Books.

Rando, T. (1986b). Understanding and facilitating anticipatory grief in the loved ones of the dying. In T. Rando (Ed.), Loss and anticipatory grief. (pp. 97-130). Canada: Lexington Books.

Raphael-Leff, J. (1991). Psychological processes of childbearing. Melbourne: Chapman & Hall.

Raphael-Leff, J. (1993). Pregnancy - the inside story. London: Sheldon Press.

Ravenette, A.T. (1977). Personal construct theory: an approach to the psychological investigation of children and young people. In D. Bannister (Ed.). New perspectives in personal construct theory. London: Academic Press.

Ravenette, A. T. (1980). The exploration of consciousness: personal construct intervention with children. In A.W. Landfield and L.M. Leitner (Eds.), Personal construct psychology: psychotherapy and personality. London: Wiley.

Richardson, S., Koller, H., & Katz, M. (1988). Job histories in open employment of a population of young adults with mental retardation:1. American Journal of Mental Retardation, 92(6), 483-491.

Rodriguez, J., & Jones, E. (1996). Foster parents' early adaptation to the placement of a child with developmental disabilities in their home. Journal of Paediatric Nursing, 11 (2), 111-117.

Roesel, R., & Lawlis, G. (1983). Divorce in families of genetically handicapped mentally retarded individuals. American Journal of Family Therapy, 11, 45-50.

Row, D., & Elam, P. (1987). Sibling and mental illness - heredity verses environment. Journal of Children in Contemporary Society, 19(3-4), 115-130.

Rowan, J. (1989). Sub personalities - the people inside us. London: Routledge.

Rowe, D. (1984). Constructing life and death. In F.R. Epting & R.A. Neimeyer (Eds.), Personal meanings of death (pp. 97-113). London: Hemisphere Publishing Corp.

Rudd, M.G., Viney, L.L., & Preston, C. The grief experienced by spousal caregivers of dementia patients: the role of place of care of patient and gender of caregiver. In Press. University of Wollongong.

Schild, S. (1976). The family of the retarded child. In R. Koch & J. Dobson (Eds.), The mentally retarded child and his family. New York: Brunner/Mazel Publishers.

Schleifer, S., et al. (1983). Suppression of lymphocyte stimulation following bereavement. Journal of the American Medical Association, 250, 374-377.

Scorgie, K., Wilgosh, L., & McDonald, L. (1996). A qualitative study of managing life when a child has a disability. Developmental Disabilities Bulletin, 24(2), 68-90.

Scorgie, K., Wilgosh, L., & McDonald, L. (1998). Stress and coping in families of children with disabilities: an examination of recent literature. Developmental Disabilities Bulletin, 26(1), 22-42.

Sedlack, R.G., & Stanley, J. (1992). Social research theory and methods. Sydney: Allyn & Bacon.

Seideman, R.Y., & Kleine, P. (1995). A theory of transformed parenting: parenting a child with developmental delay/mental retardation. Nursing Research, Feb, 38-44.

Seligman, M. (1982). Siblings of handicapped children. In M. Seligman (Ed.), A guide to understanding and treating the family with a handicapped child. New York: Grune & Stratton.

Selikowitz, M. (1990). Down syndrome: The facts. Oxford: Oxford University Press.

Shafer, M., Hill, J., Seyfarth, J., & Wehman, P. (1987). Competitive employment and workers with mental retardation: analysis of employers' perceptions and experiences. American Journal of Mental Retardation, 92(3), 304-311.

Shapiro, E.R. (1996). Grief in Freud's life: reconceptualising bereavement in psychoanalytic theory. Psychoanalytic Psychology, 13(4), 547-566.

Solnit, A.J., & Stark, M.H. (1961).Mourning and the birth of a defective child. Psychoanalytic Study of a Child, 16, 523-537.

Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. Journal of Intellectual & Developmental Disabilities, 23(1), 55-70.

Stein, R.E., & Jessop, D.J. (1984). General issues in the care of children with chronic physical conditions. Pediatric Clinics in North America, 31, 189-198.

Stoneman, Z., Brody, G., Davis, C., & Crapps, J. (1987). Mentally retarded children and their older same-sex siblings: naturalistic in-home observations. American Journal of Mental Retardation, 92(3), 290-298.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research. Grounded theory procedures and techniques. London: Sage Publications.

Stringer, P., & Bannister, D. (1979). Introduction. In P. Stringer & D. Bannister (Eds.), Constructs of Sociality and Individuality. London: Academic Press.

Sturniolo, J. (1996). I demand a rewrite: When your child does not fit your script. In J.D. Atwood, (Ed.), Family scripts (pp. 333-384). Washington: Accelerated Development.

Summers, J.A. (1988). Family adjustment: Issues in research on families with developmentally disabled children. In V.B. Van Hassett (Ed.), Handbook of Developmental and Physical Disabilities (pp. 79-89). Sydney: Pergamon Press.

Tabachnik, B.G., & Fidell, L.S. (1989). Using multivariate statistics (2nd ed.). New York: Harper Collins.

Tracey, N. (1991). The psychic space in trauma. Journal of Child Psychotherapy, 17(2), 29-45.

Tracey, N. (1993). Mothers and fathers speak,- on the drama of pregnancy, birth and the first year of life. Mosman: Apollo Books.

Tracey, N., Blake, P., Warren, B., Hardy, H., Enfield, S., & Schein, P. (1995). A mother's narrative of premature birth. Journal of Child Psychotherapy, 21 (1), 43-64.

Traustadottir, R. (1991). Mothers who care: Gender, disability, and family life. Journal of Family Issues, June, 211-228.

Vines, D.W. (1986). Regrieving in parents of disabled adolescents. Dissertation Abstracts International, 46, 387.

Viney, L.L. (1980). Transitions. Sydney: Cassell.

Viney, L.L. (1983). Images of illness. Florida: Robert E. Krieger.

Viney, L.L. (1986). The assessment of psychological states through content analysis of verbal communications. In L.A. Gottschalk, F. Lolas, & L.L. Viney. (Eds.). Content analysis of verbal behaviour: Significance in clinical medicine and psychiatry. Heidelberg: Springer.

Viney, L.L. (1987). Interpreting the interpreters. Florida: Robert E. Krieger.

Viney, L.L. (1988). Which data-collection methods are appropriate for a constructivist psychologist? International Journal of Personal Construct Psychology, 1, 191-203.

Viney, L.L. (1990a). The construing widow: dislocation and adaptation in bereavement. In E.M. Stern (Ed.), Psychotherapy and the widowed patient. (pp. 207-222). London: Haworth Press.

Viney, L.L. (1990b). A construct model of psychological reactions to physical illness and injury. Advances In Personal Construct Psychology, 1.

Viney, L.L. (1991). The personal construct theory of death and loss: Towards a more individually oriented grief therapy. Death Studies, 15: 139-155.

Viney, L.L. (1992a). Can we see ourselves changing? Towards a personal construct model of adult development. Human Development, 35, 65-75.

Viney, L.L. (1992b). Social science research in the 1990s: the contribution of constructivism. International Journal of Personal Construct Psychology, 5:295-305.

Viney, L.L. (1996). Personal construct theory: A handbook. New Jersey: Abler.

Viney, L.L., & Bazeley, P. (1977). The affective reaction of housewives to community relocation. Journal of Community Psychology, 5.

Viney, L.L., Crooks, M., & Walker, B. (1995). Anxiety in community based aids care given before and after personal counselling. Journal of Clinical Psychology, 51, 274-279.

Viney, L.L., Walker, B.M., Robertson, T., Lilley. B., & Ewan, C. (1994). Dying in palliative care units and in hospital: a comparison of the quality of life of terminal cancer patients. Journal of Consulting and Clinical Psychology, 62(1).

Viney, L.L., & Westbrook. M.T. (1976). Cognitive anxiety: A method of content analysis for verbal samples. Journal of Personality Assessment, 40, 141-150.

Viney, L.L., & Westbrook, M. (1981a). Measuring patients' experienced quality of life: The application of content analysis scales in health care. Community Health Studies, 5, 45-52.

Viney, L.L., & Westbrook, M.T. (1982a). Patients' psychological reactions to chronic illness. Journal of Applied Rehabilitation Counselling, 13, 38-44.

Viney, L.L., & Westbrook, M.T. (1982b). Patterns of anxiety in the chronically ill. British Journal of Medical Psychology, 55.

Weiss, R.S. (1975). Marital separation. New York: Basic Books.

Westbrook, M.T. (1978). Analyzing affective responses to past events: Women's reactions to a childbearing year. Journal of Clinical psychology, 34, 967-971.

Westbrook, M.T., & Viney, L.L. (1982). Psychological reactions to the onset of chronic illness. Social Science and Medicine, 16.

Widdowson, J. (1996). Appraisal of Survey of Disability, Ageing and Carers. Belconnen, ACT: Australian Bureau of Statistics, Cameron Officers.

Wikler, L.M., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: parent vs. professional depiction of the adjustment of parents of mentally retarded children. American Journal of Orthopsychiatry, 5(1), 63-70.

Willett, M.J., Patterson, M., & Steinbock, B. (1986). Manual of neonatal intensive care nursing. Toronto: Little, Brown & Co.

Williams, R., & McKenry, P. (1981). Marital adjustment among parents of mentally retarded children. Family Perspectives, 3, 175-178.

Winter, D.A. (1992). Personal construct psychology in clinical practice. London: Routledge.

Winter, D., & Watson, S. (1999). Personal construct psychotherapy and the cognitive therapies: different in theory but can they be differentiated in practice? Journal of Constructivist Psychology, 12(1), 1-22.

Woodfield, R., & Viney, L. (1984-5).A personal construct approach to the conjugally bereaved woman. Omega, 15(1).

Worden, J. (1991). Grief counseling and grief therapy: a handbook for the mental health practitioner, 2nd edition. New York: Springer Publishing Company.

Worthington, R.C. (1989), The chronically ill child and recurring family grief. Journal of Family Practice, 29(4), 397-400.

Worthington, R.C. (1994). Models of linear and cyclical grief - different approaches to different experiences. Clinical Pediatrics, May, 297-300.

# APPENDIX A

# DEMOGRAPHIC CHARCTERISTICS
# OF PARTICIPANT RESEARCHERS

## Appendix A

Table A1

Demographic Characteristics of Participants

| Variable | Category | Number | Percentage |
|---|---|---|---|
| Age of Child | < 2 yrs | 57 | 70 |
| | 2 - 4 yrs | 21 | 26 |
| | > 4 yrs | 03 | 04 |
| Disability | Down Syndrome | 23 | 28 |
| | Cerebral Palsy | 15 | 18 |
| | Global Dev Delay | 43 | 53 |
| Gender of Parent | Male | 33 | 41 |
| | Female | 48 | 59 |
| Age of Parent | 18 - 25 yrs | 17 | 21 |
| | 26 - 30 | 21 | 26 |
| | 31 - 35 | 22 | 27 |
| | 36 - 40 | 14 | 17 |
| | 41 - 45 | 07 | 09 |
| Parental Status | Single/Sep/Div | 07 | 09 |
| | Married/De Facto | 74 | 91 |
| Residence | Country | 31 | 38 |
| | City | 50 | 62 |
| Level of Education | Cert. & < | 40 | 49 |
| | School Cert & > | 41 | 51 |
| Level of Annual Family Income | < $15,000 | 11 | 14 |
| | $15 - 30,000 | 36 | 44 |
| | $31 - 40,000 | 20 | 25 |
| | > $40,000 | 14 | 17 |
| Place of Child In | Only/First | 25 | 31 |
| Family Other | | 56 | 69 |
| No. of Children In Family | 1 | 21 | 26 |
| | 2 | 26 | 32 |
| | 3 | 20 | 25 |
| | >3 | 14 | 17 |
| No of Child In Family with Disability | One | 69 | 85 |
| | Two | 12 | 15 |
| Sufficent Professional Support Available | Yes | 42 | 52 |
| | No | 39 | 48 |

# APPENDIX B

# RESEARCH PROJECT
INFORMATION SHEET

Appendix B

## INFORMATION TO PARTICIPANTS
## 1994

Dear Parents,
My name is Patricia Weekes. I am presently doing a doctoral course at Wollongong University and have chosen to do my research in the area of developmental disabilities from the perspective of the experience of the parents.

The methodology uses an interview technique which asks you to remember happy, motivating or fulfilling times in your life and from this we discuss what is most important to you. You are then asked to talk about your life at the moment in relation to giving birth to and parenting children. For some of you it will be parenting children with developmental disabilities, for others it will parenting children without development disabilities. The conversational interview will take approximately one and a half hours. It has been used in other research and has been rated by participants as interesting and often beneficial.

I would like to speak with 80 families who have children with developmental disabilities aged between 6 and 24 months OR parents who have been informed within the last two years of their children having developmental disabilities regardless of their present age. The study is longitudinal, so that you would be asked to participate in a second interview approximately 18 months after the first one. If you participated in the first interview there is no obligation to participate in the second.

The information received is completely confidential. The results of the completed research will be presented to the University as the thesis for my degree and I hope to use it as a basis for developing therapy programmes in my future work in this area.

I really appreciate it if you possibly participate in this research.

If you can help, regional contact numbers are - Albury (060) 253 869; Canberra (06) 293 1375; Cootamundra (069) 421 030. You could leave your name and address or phone number and I will contact you to arrange a time and place convenient to yourself for us to meet. Alternatively, you could ring me directly in the evenings on (042) 29 2024 or write to 15 Harbour Street, Wollongong, NSW, 2500.

Thank you for reading this request,
Patricia Weekes (Psychologist)

Supervisor: Professor Linda Viney, University of Wollongong.
If you would like to contact by supervisor, please do so on (042) 213 693.

Any concerns regarding the conduct of this project may be directed to:
The Secretary of the University of Wollongong
Human Research Ethics Committee (phone 21 4457).

# APPENDIX C

# CONSENT FORMS

# SIGNED BY PARTICIPANT RESEARCHERS

Appendix C

## CONSENT FORM TO PARTICIPATE IN A RESEARCH PROJECT

This consent form is related to a study which aims to explore the way parents of children with developmental disabilities see life, along with the emotions which this situation engenders. The emotions of parents who give birth to children without a disability also need to be considered. The following sessions will involve responding to the question: What are the good things and bad things you've experienced in relation to giving birth to and parenting your child?

Please be assured that the information you provide will be used for research purposes only and will be treated with complete confidentiality.

Any complaints regarding the conduct of the research may be directed to:
The Secretary of the University of Wollongong Human Research Ethics Committee, (Phone 21-4457).

## STATEMENT OF INFORMED CONSENT

I,..................................................have been informed of the aims of this study and understand my participation is voluntary, and that all information will be treated with the strictest confidentiality.

Signed.......................................
Date...........................................

# APPENDIX D

# CORE PROCESS

# INTERVIEW

Appendix D

## CORE PROCESS INTERVIEW

(JONES, 1993)

The specific steps involved in Core Process Interviewing are as follows.

### A. MY LIFE TILL NOW

The interviewer's comments were

> "I want you to think back over your life and divide it into four section/chunks which feel like natural divisions of time. Can you tell me what they are please?"

An example, might be from 0-13; 13-19; 19-25; 25-now.

### B. REMINISCENCES

> "Can you recall in the first period, for example 0-13, two occasions when you felt really wonderfully about life and tell me about them while I write down what you say?"

The interviewer wrote down the participants' responses verbatim.

An example was,

"As a child I remember living with my grandmother. My mother had died by then and Dad couldn't look after us by himself. It was hard but it was **somewhere to go** and that was my greatest fear, having no where to go".

### C. UNIQUE QUALITIES

> "What was the special quality about that time? What was important about it for you?"

For example:

"Well, while it wasn't great, it offered me some **stability**, some **security**- just some place I knew I was to go to after school. That's a big thing when for a while I didn't have such a place. I didn't know where I was going to sleep the next night".

### D. OTHER HAPPY TIMES

Parents were asked to describe, in a similar way, seven other occasions in their lives when they felt really good about things.

> "Can you think of another occasion when you felt as happy as then...during that time period...Now, two memories from each of the other time periods.."

To continue the example:

"When I meet Peter, he was more mature than other boys. I could rely on him completely. I knew when I married him I knew I was going to be with him for the rest of my life. He offered me **stability**".

"I was so excited when I fell pregnant - it was a planned pregnancy and it was like my body had done what I wanted it too. I could **control another part of my life**".

## E. REVIEW

After the reminiscing was done, the notes were passed back to the participants and they were asked to use a coloured highlighting pen to highlight what seemed particularly important in terms of fulfilment. The instructions were:

> Now, highlight the phrases that best completes the sentence:
> For me to be fulfilled...."

Within a short time a statement emerged from the highlighted passages.

## F. FULFILMENT

For example,

"For me to feel fulfilled, I need a **secure, stable** family life in which I had can stand up for myself with my husband. I need to have **direction,** know where I'm going and for life to be **predictable.** I need to have **control over** my life.

## G. VALIDATION

This statement was written down verbatim and handed to the participants for affirmation or further change in terms of it being a statement of core purpose.

## LADDERING

Laddering questions (Hinkle, 1965) were used as part of the interview technique to further explore or usually validate the degree to which the process had tapped into the most influential self-related constructs of parents. The alternative paths of the constructs were then elicited, along with parents' perception of themselves as being on their preferred or non-preferred paths.

# APPENDIX E

# COPY OF REPERTORY GRID

## Appendix E

NAME.......................................
ID NO.........................................

Instructions:

There are 14 life views which you are asked to rate on a 7 point scale. No. 1 indicates that the life view is most influential in your way of looking at life and is also most relevant to self. No.7 indicates that the life view is of little or no influence in your way of looking at life and is not relevant is the self. Please rate each of the life views or constructs in terms of their influence and relevance to the your self on the 1 to 7 point scale.

| **Life Views - Constructs** | | | **Self - Element** | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Relaxed/Normality | - | Anxious/Hell | | | | | | | |
| Free | - | Restricted/Shut Down | | | | | | | |
| Predictable/ Knowing Having Direction | - | Unpredictable/ Not knowing/ Aimless | | | | | | | |
| Accepted | - | Rejected | | | | | | | |
| Peace of Mind | - | Self Blame/Guilt | | | | | | | |
| Wisdom/Life Having Meaning | - | Shock/Shallowness/ Without meaning | | | | | | | |
| Achievement/ Contribution | - | Failure | | | | | | | |
| Living | - | Dying | | | | | | | |
| Hopeful | - | Depressed | | | | | | | |
| Having Relationships | - | Not having Relationships/Empty | | | | | | | |
| Having Idenity | - | Loss of Identity/ Consumed | | | | | | | |
| Having Control/ Choice | - | Being Controlled/ No choice | | | | | | | |
| Difference | - | Disability | | | | | | | |
| Allowing/helping person with disability to live | - | Allowing/helping person with disability to die | | | | | | | |

# APPENDIX F

# THE CODING CATEGORIES
# FOR A CONTENT ANALYSIS SCALE:
# AN EXAMPLE

Appendix F

## COGNITIVE ANXIETY SCALE

Cognitive anxiety, experienced by self, is scored if:

1. There is novel stimuli, eg *I'm not used to doing that.*

2. Extra constructs are needed, eg *I didn't know the first thing about it.*

3. There was incongruous stimuli, eg *The visits to the doctor sometimes left me a bit mystified.*

4. There was a high rate of stimulus presentation, eg *It's a bit bewildering, (things coming so fast).*

Cognitive anxiety, experienced by others, is scored if:

5. There is novel stimuli, eg *He was faced with a new experience.*

6. Extra constructs are needed, eg *She doesn't seem to be very sure of herself.*

7. There was incongruous stimuli, eg *It didn't fit in with his beliefs.*

8. There were unavailable responses, eg *He was not sure/ what to do about it.*

Cognitive anxiety expressed but denied, is scored if it is occurring as a result of:

9. Novel stimuli, eg *I wasn't scared (although it was all new).*

10. Extra constructed needed, eg *(Even though I was anxious)/ I felt/ I knew it all.*

11. Incongruous stimuli, eg *(Things didn't fit)/ but he didn't worry then.*

12. Unavailable responses, eg *No knowing what to do doesn't worry him.*

13. High rate of stimulus presentation, eg *(Everything was happening at once) but I just relaxed.*

# APPENDIX G

# AN EXAMPLE OF AN EQUATION FOR THE CALCULATION OF SCORES FOR A CONTENT ANALYSIS SCALE

# Appendix G

## The Equation For The Calculation of Scores for the Content Analysis Scale for Cognitive Anxiety

Cognitive Anxiety Score = (Frequency x Weight) C.F. + 1/2C.F

where Frequency = the total number of times a particular category is scored;

Weight = the figure attached to that category to indicate degree of personal involvement;

and C.F. = the correction factor of total number of words in the verbal sample divided into 100.

# APPENDIX H

# VINEY'S 1980 SCORES FOR THE EMOTIONAL STATES RELATED TO BECOMING A MOTHER AND WHEN THREAT OCCURRED TO THE CHILDREN OF PARENTS

Appendix H

## Viney's Scores for the Emotional States Related To Becoming a Mother and Threat to the Children

| Emotional State | Becoming a Mother | | Threat to the Children | |
|---|---|---|---|---|
| | Mean | SD | Mean | SD |
| Cognitive | | | | |
| Anxiety | 1.62 | .74 | 1.50 | .75 |
| Death | 0.52 | .21 | 0.66 | .46 |
| Mutilation | 1.07 | .64 | 1.88 | .68 |
| Separation | 0.90 | .52 | 0.71 | .45 |
| Guilt | 0.49 | .19 | 0.54 | .26 |
| Shame | 1.08 | .70 | 0.83 | .66 |