Chapter One

PARENTS' EXPERIENCE OF DEVELOPMENTAL DISABILITY

- INTRODUCTION and OVERVIEW -

I understood the reality of my child's situation but, for me, there was another reality.

(Amanda)
INTRODUCTION

We live in a world which values beauty, intelligence, perfection and achievement. Most of us live in this world in a taken for granted manner. As a corollary, it is taken for granted that being the parent of a child with significant developmental disability is a tragedy, it is something we "know". It might be postulated that this "knowing" results from a consciousness of what it might be like to be part of a world which places little value on people with disabilities because they fall short in the areas of beauty, intelligence and perfection and are not likely to achieve in ways which we understand and value.

I used to "know" that being the parent of such a child would be a tragedy but now, as the result of parents of children with disabilities allowing me to glimpse their lives, I have developed a different understanding, one which encompasses a world in which the tragedy is only a part. It is as if, in Heideggerian terms, their unselshconscous Being-in-the-World was shattered by the knowledge of their children's diagnoses and they found themselves in a world they could no longer take for granted. Now they have found other ways of Being-in-the-World.

This thesis documents the journey undertaken by me in my quest for some understanding of an experience which was not directly available to me. I worked as a Community Nurse with families who have children with developmental disabilities. My sense told me that they confronted tragedy on a daily basis. The theoretical bases which drove my practice confirmed this belief. The parents I worked with largely belied it.

The story of this journey goes back to when I was a student of nursing and it is included because it was vital to the shaping of my thinking, the rationale for the undertaking of this project and the choice of methodology.

In recounting my story, I shall at times refer to the literature and to some perspectives of theory. However, none of the issues raised will be
discussed at this point, but will be dealt with in later chapters. I do this so as not to interfere with the flow and to inform of my personal context, which is integral to this work.

A Personal Context

My story concerns a journey, embarked upon ten years ago which, in some ways, parallels the upheaval experienced by parents of children with disabilities. There are differences - I had choices in the path I undertook, my learning was, and continues to be slow, and I look into their world as an outsider. I did, however, undergo enormous crises and adjustments due to my personal contact with people with disabilities as my view of the world began to change.

As a mother of three daughters, I undertook nursing studies as a member of the first cohort of college educated nurses in NSW in 1985. It was a time of turmoil and high excitement. Despite my purely practical reasons for undertaking the course, within weeks I was really enjoying it and realised it probably should have been my career choice twenty years before when I had chosen medicine instead (and not stayed with it).

My father had recently died following a long illness and, due to the impressive work performed by the nurses who assisted our family, I had my heart set on being a palliative care community nurse.

I was surprised to learn of the comprehensive nature of the nursing course. Broadly, we were to learn about medical/surgical (general), mental health and developmental disability nursing. I had some hold of what "general" and "mental health" nursing entailed, but what was this "developmental disability"? We were told that this represented a component of nursing previously covered by the Mental Retardation Nursing Certificate. I was furious. It was stupid, a waste of time and totally irrelevant as far as I was concerned. After all, I wanted to be a palliative care community nurse and was interested in "real" nursing. I could see the use of a knowledge of mental health nursing, but this other stuff ....!
Soon our clinical placements for the year were posted on the notice board. I refused to go and look at them as I had a gut feeling about where I would be. A friend gave me the bad news - "You're going to (a large institution for people with developmental disabilities) first, and again at the end of the year". TWICE! It wasn't fair. Being somewhat pragmatic, I felt I may as well get it over and done with first, but to have to go back was unreasonable. Other people were getting two shots at major hospitals.

The dreaded day arrived. I was nervous and frightened, but put on a brave show, joking and laughing and full of bravado. By the end of the day, I was utterly silent.

Like many people, I had no experience of people with developmental disabilities, and my introduction to about two hundred of them in one day was to be a major life event. I did not know that people with such severe disabilities existed, let alone in such numbers. I had never imagined anything like it - people in their twenties the size of small children, so twisted and misshapen they defied description; awful noises - shrieking, grunting and moaning; dreadful smells which impregnated my clothing. Some of my colleagues were smiling, talking and shaking hands with residents. I just wished the wall against which I had plastered myself would swallow me up.

That night I took up smoking again and the journey began. I was angry, and railed against the world. Why did these people exist? Why did we keep them alive? Why did they live in such awful circumstances? They'd be better off dead. Their lives were painful and miserable and not worth living.

I was utterly confused by what I had seen, and the images continued to haunt me. But a small thought, faint at first, began to nag me. If these people's lives were as awful as I presumed them to be, why were they still alive? Embedded in my belief system is the notion that if people do not wish to live, if they have nothing to live for, they will die. I thought that these people must have had many opportunities to die (they looked so fragile) and
yet, they were alive. This led me to ask why - why have they lived for so long when it would seem that everything is stacked against them? In line with my beliefs, which I do not claim to be rational, I had to consider that there must be something in their lives worth living for - otherwise they would be dead. This argument with myself was slow and painful and, along the way, I was helped by friends and teachers. They may not necessarily have agreed with me, but they allowed me to verbalise my confusions, and so assisted me on a journey which challenged and shook up many of my values and beliefs.

Upon my return to the institution the following week, I was to work with Johnnie, a slight, frail young man who had sustained severe and extensive neurological damage following encephalitis as a small baby. He was painfully thin, was very stiff, could barely walk with assistance, had countless seizures and had no speech. I had no idea what to do, so I sat in front of him to ponder. Johnnie had the clearest, purest blue eyes I have ever seen. We came to know each other over a period of time, and I began to understand his communication. I learned of his likes and dislikes, his pain and comfort, his misery and happiness. In short, I came to know him as a person. His history indicated that he had had more scrapes with death than you could count. Yet he had always pulled through. Why? I could not answer this, but felt something in his life must have made it worth living. And then, another thought struck me. If these people had defied the survival odds, if the technology of our society had contributed to their survival, then it was up to that same society to support their lives in the best way it could. Thus, I became a fledgling advocate for people with disabilities.

I was appalled by institutional life - by its sameness, its monotony, its practices, its dehumanising effects (for residents and for staff). It was not the case that many people did not try hard to provide a reasonable life for those in their care - a lot did - but their efforts were engulfed by a system which denied individuality. It appeared that staff eventually became desensitised to the conditions or left. I knew I could never work there (despite my by then
rampant idealism) and was in a state of conflict.

As the three years of the course progressed, I had a variety of clinical placements in developmental disability. At one of these, a small private institution, I had another insight. Whilst I had come to recognise people with disabilities as people, I felt that I had to like them although I had no clear reason for this. A young man at this institution irritated me enormously and I felt very uncomfortable about it. When I realised he was an individual, like all other people, and that I did not necessarily have to like all people I met, the situation improved. Simple as it sounds, this was a major leg of the journey.

Whilst still a student, I was employed as an assistant nurse in a large hospital in the palliative oncology ward. This was in preparation for my future role in palliative care. I loved it, and my original ambition still held. That is, until I did a student placement with a community nurse on a developmental disability team. A whole new world opened up, as I was exposed to a different view of people with severe disabilities. I was also exposed to a very different view of nursing. People with disabilities of all ages, were living at home with their families, and were being supported by nurses who were members of multidisciplinary teams. These nurses acted as case managers, co-ordinators, counsellors and consultants. They practised with a great deal of autonomy, but within a supportive and constructive team environment. The interests of their clients appeared to be their primary driving force. My commitment to palliative care began to be replaced by the possibility of another type of nursing, one which I would never have considered only two years before.

Upon graduation I gained employment as a Community Nurse with the developmental disability team. I had a huge case load (over two hundred families) which spanned a large geographic area. Whilst very conscious of my lack of experience, I tackled the job with enthusiasm and confidence in myself, well prepared by my education. As an individual and as a mother, I had a sense of the tragedy of having a child with a disability.
As stated earlier, I believe that most people relate to that sense; we all "know" that to have a child with a disability is a sad and shocking experience and an overwhelming tragic life event.

My education had provided me with a theoretical framework for my practice. I had learnt about the grief response and learned that parents need to mourn the loss of their perfect child before they are able to accept their "defective" child. I also learned of the concept of chronic sorrow, which described a lifelong condition of parents of children who are mentally retarded. As a nurse practitioner working with numerous families, I found my theoretical background useful, in particular the concept of chronic sorrow to which many parents related.

However, despite the usefulness of these frameworks, as I gained more experience, I realised that neither was enough to explain my observations of families. There seemed to be other things going on, things that I had no knowledge of from my education or from the literature. Parents would say things to me like:

*People think it's awful to have a disabled child, and it is sometimes, but it's not all awful,*

and,

*If I could turn the clock back, I'm not so sure that I would, because I've learned and gained so much from this experience.*

This one just floored me. That parents whose lives had, in the perception of others, been shattered, could express such a view, was extraordinary to me.

At the same time, I was developing a consciousness of what I call "interpretation of parental responses by professionals". I was hearing, from many professionals, the frequent use of descriptions such as:-

*She's denying.*
*She's over-protective.*
*He's overcompensating.*
They're not facing reality.
They expect too much.
They don't expect enough.

It seemed to me that anything parents said or did, could be interpreted as demonstrating the effects of having a disabled child. If the child was beautifully dressed, clean, neat and tidy, it was because mum felt guilty and was overcompensating. If the child was grubby, it was because she was rejecting it, and so neglecting it. I began to think "Well, they're damned if they do, and damned if they don't, and no matter what they do, they just can't win". These types of observations have been reported by a number of writers (Featherstone, 1980; Turnbull and Turnbull, 1985; Voysey, 1975). Hewett (1976) cites the example of a child with cerebral palsy needing a great deal of attention by the very nature of the condition, and decries the fact that the deleterious effects of parental "over-protectiveness" warrant professional intervention. As a result of my daily working experiences, I was becoming uncomfortable with what we, as professionals, were frequently doing to the parents of children with disabilities. I was embarrassed by hearing the same stories over and over. The parents verbalised common themes:

The doctor said "Put the child in an institution - it will be better for you and your other children".

We were told "He'll be nothing more than a vegetable, and will never do anything".

The Community Nurse said "It would be better if she just fades away".

The doctor wouldn't believe anything was wrong - I kept going back for a year.

They told me I was over-reacting.

I came to understand that, as individuals, and as professionals, we are informed by our background expectations which, in turn, inform our interpretations of the events in other peoples' lives. Margaret Voysey (1975, p. 2) tells us that: "...in a certain sense, parents' responses tell us nothing
about what it is like to have a disabled child in the family, but a lot about other people's ideas of what it ought to be like".

I developed a sense of inadequacy in my understanding of the experiences of families who had a child with a disability. Farber (1986, p. 13) spoke about a "vocabulary of crises and maladjustment" which has permeated the literature and many professionals practise from such a conceptual base. This vocabulary offers a partial explanation for the interpretations of parents' responses by professionals. As a Community Nurse, I practised within a framework of chronic sorrow which, whilst a useful and valid perspective, was not fully descriptive of parents' experience. In my observations, their experience was dynamic, conflicting and contradictory. Whilst recognising the numerous difficulties faced by these families, and cognisant of the chronicity of their situations, I was constantly impressed by the positive, happy and constructive ways in which most of them led their lives.

It was with such contradictions and confusions in my mind that I attended an Association for the Scientific Study of Intellectual Disability (ASSID) conference in late 1990. The keynote speakers were Ann and Rud Turnbull who are associated with the Beach Center on Families and Disability at the University of Kansas. I was familiar with some of their work (they are prolific authors) and looked forward to hearing them. They have worked professionally in the area of disability for a long time, and they are the parents of a son who has autism. They spoke of research being carried out at the Beach Center which they referred to as the positive contributions work. I was very excited and encouraged by the fact that research was being done which offered an alternative to the pervasively negative impact of disability. I now had an area which I was keen to explore further, and a study related to the positive aspects of disability was taking shape in my head.

However, as I began talking with parents about my thoughts and plans, I began to have doubts about the terminology. When I spoke of
"positives", parents sometimes looked a little blank, with one mother saying
Positive! What's positive about it? And yet, further discussion revealed
that they certainly perceived their children and their lives and experiences in
ways which were far from negative. It was possible that the USA work was
culturally defined and maybe a bit "up front" for Australians.

By now I had changed jobs, having taken up an academic position,
and was having lunch with a mother, Amanda, one day. Amanda, along
with her daughter Annie, had been referred to me when I was a Community
Nurse, and we had became friends. Annie, her only child, had been born
with a great many problems, which Amanda and her husband of the time
were very conscious of. Whilst alarmed, sad and upset about her new baby,
she was also excited, and said to me:

I knew her condition was serious and her prognosis poor
but, to me, she was my firstborn, beautiful child. Every
time I expressed my joy to the staff at the hospital, they
said "She's denying reality". I understood the reality of
my child’s situation but, for me, there was another
reality.

"That's IT..." I thought. For me, she summed up the contradictions and
ambiguities which are the parents' experience of disability. That afternoon, I
made a note to myself:

8.9.91
Parents -
• are not denying reality
• there is simply more than one reality
It is this "other reality" I wish to explore.

Amanda’s statement had given me the direction for the
continuation of my journey. Up until this point I had undergone
experiences which challenged my values and beliefs in much the same way,
as will be seen, as the parents' beliefs are challenged. I was in a state of
confusion due to what I saw as a lack of fit between my observations and
what the textbooks said regarding families who have a child with a disability. My state of confusion is mirrored by the parents. Their personal experience is not one of total tragedy, despite what others think and despite what they thought prior to their own experience. This incongruity frequently leaves them confused. I sensed the area was fraught with contradiction and ambiguity and this will be borne out in the parents' words. But I had come to a standstill in my journey and had no pathway through my confusion, doubts and ambiguities. The parallels between my journey and the experiences of the parents will be apparent as their stories are documented.

Amanda's other reality provided a springboard for my thinking as well as a way into its exploration. This thesis documents the journey from this point onwards, a journey which explores the other reality with the people whose lived experience this reality is - the parents of children with developmental disabilities.

OVERVIEW

This research had the working title "Parents' experience of developmental disability", and emerged from a convergence of personal life events, professional experience and theoretical shifts.

Whilst the literature predominantly depicts the impact of disability as overwhelmingly negative, my nursing practice caused me to question this negative impact in terms of its totality. Assumptions of tragedy, crisis and maladjustment not only dominate the literature, but also shape professional practice and modes of enquiry. These assumptions have resulted in a research literature which addresses issues such as stress measures and the burden of care. Some recent research has examined issues related to disability from a positive viewpoint, but an assumption of positive contributions has shaped the enquiry. Whilst my observations led me to believe that the parents' experience was not overwhelmingly negative, I did not wish to impose any assumptions regarding a positive experience upon them. I wished to explore their other reality, but did not wish to assume that
this other reality existed. For this reason an interpretive approach which allowed for exploration and the freedom to reveal meanings was essential.

Interpretive phenomenology provided the key which allowed an exploration of parents' experiences as well as an interpretation of them. Whilst aspects of the experiences of such parents have been extensively documented, it was my contention that an understanding of their total experiences and their meanings remained unclear. Of greater concern than a lack of clarity was what I considered to be the frequent misinterpretation of parents' experiences due in part to research methods which did not allow for the parental perspective. It seemed to me that, in their commitment to scientific rigour and objectivity, researchers lost the voices of the parents. Heideggerian phenomenology rejects the notion of people merely responding to an objective world of events, seeks to overcome the dichotomy between subjective and objective, and focuses on people in context who share understandings and meanings (Benner, 1985). Heidegger considered that "... because persons are fundamentally self-interpreting beings for whom things have significance, understanding human action always involves an interpretation, by the researcher, of the interpretations being made by those persons being studied" (Leonard, 1994, p. 55). This is hermeneutics, and is a method for studying human beings which flows from the Heideggerian view of the person.

This research approach enabled the parents to present their interpretations of their experiences which were, in turn, interpreted by me as researcher. This process allowed for a conceptualisation of the parents' experience which takes into account its dynamic nature, its complexity and its ambiguity. It provides a key to a broader and deeper understanding than commonly found in the literature and opens up a world of possibilities. The parents' state of being has been interpreted as one of "between joy and sorrow", with the essential word being "between". This conceptualisation, as will be explained in this work, allows for multiple meanings and opens up an understanding of Amanda's other reality.
The thesis has been organised so that a background understanding of developmental disability and its implications are provided prior to focusing on the particular research endeavour. The structure of the thesis is as follows:

Chapter Two - Developmental Disability: Denotation and Connotation, provides a background understanding of developmental disability which is essential to any comprehension of the parents' experiences. It provides a context for the "tragedy" of developmental disability and explores its meanings. There is a focus on the clarification of terminology as it is fraught with misunderstanding and confusion which frequently has a major impact on interpretation.

Chapter Three - Response to Developmental Disability: Some Theoretical Perspectives, explores the literature which seeks to explain the reactions of parents who have children with developmental disabilities. The dominant literature, which focuses on tragedy, grief and sorrow, anticipates pathology in parents, whilst a smaller and less recognised literature, which allows for a broader interpretation of parents' responses, has received scant attention. The implications of the various conceptual frameworks for research and practice are discussed, and provide the rationale for the emergence of the research question.

Chapter Four - Research Methodology: Philosophy and Approach, gives an account of the research approach used in this work. In considering interpretive phenomenology as methodology, the reasons for its use are provided, phenomenology is presented as informing the theoretical framework and hermeneutics presented as the method employed to answer the research question.

Chapter Five - Research Method: Procedures, describes the processes of the research. It is included in order that the ethics, trustworthiness and rigour of the study may be evaluated, and it documents how data were collected, handled and interpreted. The chapter provides an auditing of the conversion of the participants' interview accounts into themes.
Chapter Six - Research Participants: The People, tells the stories of the parents and their children who are the focus of this study. These parents, Amanda, Catherine, Jill, John, Sally and Stephen, were amongst the people who were responsible for the evolution of this work. The presentation of their stories became our stories, as the development of our relationships contributed to my consciousness of the other side of living with a child with a developmental disability and challenged many of the theoretical perspectives which are presented in Chapter Three.

Chapter Seven - Interpretation: Between Joy and Sorrow, provides an overview of the interpretation of the parents' experience as one of between joy and sorrow. The major themes by which the parents' experiences gain expression are presented and a model, which provides a simplified visual representation of the parents' reality, is depicted.

Chapter Eight - Between Joy and Sorrow: Sorrow, presents the parents' world of sorrows, along with its major themes of "no hope" and "despair" and the constituent themes which are part of this state of being. It demonstrates how much of the parents' sorrow derives from their dealings with others.

Chapter Nine - Between Joy and Sorrow: Joy, presents the "other" side of the parents' reality. It examines their world of joy and demonstrates the strengthening aspects of their experience. The major themes of "hope" and "defiance" provide an interpretation which enables parents to function with purpose and pride.

Chapter Ten - Between Joy and Sorrow: The Tensions, examines the themes which are the mediators of the parents' joy and sorrow. It demonstrates the "confusion, doubt and ambiguity" which are inherent in the parents' experience, and presents the conflicts and paradoxes which have resulted in the overall interpretation of their experience as "between" joy and sorrow.

Chapter Eleven - Understanding Developmental Disability: Discussion of Parents' Experience, returns to the literature, both professional
and anecdotal, with the interpretive lens of "between joy and sorrow". It demonstrates that there have been glimpses of other realities and provides reasons for the neglect of alternative perspectives. Contributions and limitations of the study are presented and implications for nursing practice, education and research are discussed.
"...their problem lies in the fact that their stigma - of all possible stigmata - is closest to what we may call the soul. Of all the attributes of man, mind is the quintessence; to be found wanting in mental capacity - in general intellectual competence - is the most devastating of all possible stigmata."

(Goldschmidt, 1967, p. vii)
In writing of the language and imagery of disability, Caseling (1993) has pointed to its confusion and ambiguity. The terminology of developmental disability is fraught with misunderstanding and, due to its association with intellectual disability, frequently conjures up a world of "unthinkable" meanings (Ballard, 1978).

To have insight into the world of parents who have children with developmental disabilities, it is necessary for us to be clear regarding who and what we are talking about, and to develop an understanding of the roots of the unthinkable meanings. In other words, what is developmental disability and why is it such an issue?

In the discipline of general semantics, it is taught that every word "denotes" something, and that every word may also "connote" something entirely different. The "denotation" is the dictionary meaning of the word, but the "connotation" is the widespread unofficial meaning or emotional charge that may be associated with the word (Kellett, 1995). In this chapter, the evolution of the concept of developmental disability is presented, along with its links with mental retardation or intellectual disability. It is argued that confusions in terminology contribute to confusion on the part of professionals and non-professionals, and that the private meanings of the language are more than its public definitions. Thus, the chapter, by defining the terminology (denotation) and examining the confusions, provides a context for the "tragedy" of developmental disability (connotation).

DEVELOPMENTAL DISABILITY

- DENOTATION -

Annie's mother had viral meningitis whilst pregnant. When Annie was born she was non-responsive, floppy and unable to feed. Her prognosis was poor and she was not expected to survive. Annie is now a delightful, outgoing seven year old who loves talking with people and going to school. She is very small for her age, and does not do the things one expects of a seven year old. In fact, she functions as most three year olds do. She is
described by many who know her as a *winner*. Annie’s diagnosis is moderate mental retardation as a result of damage to her central nervous system due to intra-uterine viral infection.

Charles lives with his mother and is a most engaging person. He is three years of age, and is just starting to walk which makes him very happy. He has had numerous admissions to hospital for severe respiratory tract infections due to a compromised immune system. Charles does not do a lot of things one would expect of a three year old. Charles’ diagnosis is Down Syndrome.

Joel is four years of age and has looks and personality that take your breath away. He has silken blonde hair, enormous brown eyes, cupid lips and a smile that wins all. He is very floppy (described as a *bowl of spaghetti*), and is working very hard at learning to crawl. His vision is impaired and he is struggling with language; currently, he has mastered three words. Joel fell into a swimming pool when he was two, and no one knows how long he was under the water. Resuscitation took twenty minutes and, for weeks, he was expected to die. Joel’s diagnosis is anoxic brain damage.

Samuel is very blonde and blue-eyed and is sturdy for his four years. His favourite activity is running, which can be hazardous for him as he is blind. It is hard for him to concentrate, so he learns very slowly. He does not speak and vocalisation is a big effort for him. He has seizures, which have proved difficult to control. He is much loved by his parents and six brothers and sisters. Samuel contracted meningitis at the age of seven months, was in coma and went into septic shock. He was not expected to live. Samuel’s diagnosis is brain damage.

Susan is fourteen years of age and is loathe to look in the mirror as she has acne. She is a computer whiz, but is unable to move herself, to feed, wash or toilet herself. In fact she is totally dependent on others. Her speech is understood only by those who know her well. She does well at her local high school, and is described as “bright”. Susan’s diagnosis is mixed quadriplegic cerebral palsy.
Adam is very beautiful in appearance - tall, slender and elegant. He is ten years of age, and reads and writes like many six year olds. Conversation is difficult as he repeats what you say. Going out in public can be trying for his mother, as Adam looks like most ten year olds (although more handsome) but behaves oddly and ignores his mother's admonitions and instructions. Adam's diagnosis is autism.

Jack is five years of age and is very clingy; in fact, it is difficult to prise him away from his mother. He is not toilet trained and does not seem to know how to play with toys. He is healthy and well nourished in appearance, but not well co-ordinated. Jack's parents dote on him and he is their only child. His mother suffered from severe post-natal depression after his birth and, at the age of five months, Jack was placed into foster care as he was not adequately fed and was receiving minimal stimulation. His mother received treatment and Jack returned home after a few months. Jack has been at a special school for nearly a year and it is hoped he will attend his local school before too long. Jack's diagnosis is uncertain, but his developmental problems are assumed to be the outcome of past severe lack of care and stimulation.

I knew all of these children when I was a community nurse, and many others with different stories. These pictures of them (using pseudonyms) have been drawn as they were at the beginning of this research. In fact, I still know Annie, Charles, Joel and Samuel - they and their parents are the participants in this study. They present a variety of pictures and each has a different diagnosis. What they have in common is that the term developmental disability may be applied.

The term developmental disability describes a severe, chronic disability which -

(a) is attributable to an intellectual or physical impairment, or combination of intellectual and physical impairments;
(b) is manifested before the person turns 18;
(c) is likely to continue indefinitely;
(d) results in substantial functional limitation in three or more of the following areas of major life activity:
   self-care
   receptive and expressive language
   learning
   mobility
   self-direction
   capacity for independent living
   economic self-sufficiency; and
(e) reflects the person’s need for a combination and sequence of special interdisciplinary or generic care, or other services, which are of lifelong or extended duration, and are individually planned and co-ordinated.

For practical purposes, this includes persons with intellectual handicap, severe epilepsy, cerebral palsy, brain damage acquired in childhood, and those with other neurological disorders, needing similar provision. (Department of Health, NSW, 1985a, p. 1)

In short, developmental disability is an encompassing term which recognises that there are common characteristics in different types of disabilities. The crucial issues contained within this broad concept are:

- severe, chronic disability
- manifested in the developmental years
- resulting in substantial functional limitations
- engendering the need for extended or lifelong services.
Developmental Disability - Evolution of a Concept

Thompson and O'Quinn (1979) have provided a description of the events that occurred in the United States of America (USA), between 1961 and 1978, which resulted in the above definition of developmental disability.

A summary of these events is presented as background in order that a clear understanding of the concept of developmental disability is made possible. This clarification is necessary so that the links between developmental disability and mental retardation, terms that are frequently confused, are made explicit.

On October 17, 1961, John F. Kennedy, President of the USA, appointed a panel of twenty-eight eminent physicians, lawyers, educators, psychologists and social scientists as the President's Panel on Mental Retardation. Its mandate was to prepare a national plan to combat mental retardation. The appointment of this panel was the starting point for the evolution of the concept of developmental disability.

One year later, the panel presented its report to the President, in which its recommendations were grouped in eight categories: research, prevention, clinical and social services, education and training, residential care, law, organisation of services, and public awareness. It anticipated the eventual evolution of the concept of developmental disability by calling for additional federal funding of the crippled children's programme so that children who were physically handicapped, and also mentally retarded, could be served more fully.

The President's proposal to combat mental retardation resulted in federal legislative changes in 1963, which were continued and broadened during 1969-1970, and provided the catalyst for the development of the concept of developmental disability. The legislation reflected the views of professionals from various disciplines associated with the field of mental retardation, as well as representatives from advocacy groups for people with disabilities. Several key points were made:-
• individuals classified under different diagnostic labels had common needs;
• people with mental retardation had other handicaps which required attention;
• people with multiple handicaps required attention to all their problems, physical and mental;
• many people did not have a diagnostic label of mental retardation, but had closely related needs, and required similar services.

The key amendment made in the 1970 legislation was the inclusion of developmental disabilities other than mental retardation in the Public Law of the USA. Further changes were made as the result of ongoing debate related to a definition of developmental disability, until the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendment of 1978 was enacted. This law provided the operating definition for developmental disability which is in current use.

This concept of developmental disability substantially broadened the baseline of service to include people who would not be categorised as mentally retarded, but who would have similar needs. The term is descriptive of outcomes for individuals who have a variety of disorders, one of these disorders being mental retardation. (Thompson & O'Quinn, 1979).

**Developmental Disability in New South Wales**

The term, developmental disability, has gained wide usage in Australia (Cocks, 1989). In 1981, the Health Commission of New South Wales (NSW) adopted the name "Division of Developmental Disabilities", in lieu of "Division of Mental Retardation Services". The Commission "... resolved to define the clients for whom the Division has responsibility in terms (appropriately modified) of the definition produced in 1975 by a National Task Force in the United States of America". (See Health Commission of NSW Circular No: 81/8 in Appendix I).
This resolve, however, was not supported by legislation and the adaption of the term was undertaken with no real change in the client base. The Department of Health (formerly Health Commission of NSW) continued to see its responsibility as providing services for people with "severe or profound intellectual disability, those people with multiple disabilities, and those people with a lesser degree of intellectual disability but who are additionally disabled by such conditions as uncontrolled epilepsy, severe behaviour disorder or mental illness." (Department of Health, N.S.W., 1985b)

It would seem that the term was adopted primarily to remove the stigmatising effects of labelling (see Health Commission of NSW Circular No: 81/8, Appendix I), but with little thought given to a clear understanding of its meanings and implications. During the early 1980s "intellectual disability" became the preferred term for "mental retardation" in NSW. This has led to a situation where, by and large, service providers have simply replaced the term mental retardation with intellectual disability and developmental disability, rather than expand the criteria for services to those based on need, as opposed to diagnosis. In NSW, at least, there was simply a change of name because in practice, significant mental retardation (or intellectual disability) was still the qualifier for service.

In 1989, responsibility for the Division of Developmental Disability services was transferred from the Department of Health to the Department of Family and Community Services, which became the Department of Community Services in 1990. Developmental Disability Services ceased to exist in 1991, and services for people with intellectual disabilities are now provided by Disability and Aged Services within the Department of Community Services, along with numerous non-government organisations. Despite the restructuring and numerous name changes, the primary criterion for service is still significant intellectual disability. This is changing as a result of the NSW Disability Services Act, 1993, and it is anticipated that all people with disabilities will be eligible for service, whatever their
diagnoses. However, services are not expanding significantly and we still have a situation where developmental disability means intellectual disability or mental retardation to many workers in the field.

Confusions with Terminology

That the terms developmental disability, mental retardation and intellectual disability are frequently used interchangeably (Fernald, 1995) is hardly surprising in view of the history just outlined. However, mental retardation is but one of the many possible aetiologies of developmental disability which is a broader term.

The concept of developmental disability was intended to serve as a qualifier for funding and services and not as a clinical determination. Scheerenberger (1987, p.16) discussed the confusion that has arisen about the exact nature of the population being referred to and quoted Herbert Grossman (1983):

Sometimes new terminology, invented to clarify and address problems, will tend to obscure or confuse the issues they are intended to address ... More recently the term "developmental disabilities" has been used and misused frequently. Mental retardation and developmental disability are not synonymous. Mental retardation is a clinical term used to describe certain clinical manifestations which can be assessed clinically. Developmental disabilities, on the other hand, is not a clinical term. It includes individuals who have a variety of physical and clinical disorders, each with different implications for clinical care, education and program planning.

In Australia, the preferred term for mental retardation is intellectual disability. Despite this preference, the term mental retardation will be sometimes used in this thesis (in particular, when referring to relevant literature) as it is a specific term, has broad international usage and wide acceptance of meaning, particularly by the general community, including
currently the NSW Department of Health (1996). I do this with an acute consciousness of its negative and labelling effects, which will be explored in this chapter.

**Further Confusions**

When used correctly the denotations of developmental disability are clear. An examination of the terminology results in the following understandings:

- developmental delay does not always result in permanent disability, but people who have developmental disabilities all exhibit, or have exhibited, developmental delay;
- to be mentally retarded is to be developmentally disabled but, to be developmentally disabled does not necessarily mean a person is mentally retarded.

For the initiated, the terminology is logical and systematic. For most people, it is jargon and leads to confusion and misunderstanding. For example, some parents are told their child is "developmentally delayed". Five years later they are wondering why she has not "caught up". Someone may then slip in the word "retardation", and a whole new world of meaning, implication and consequence opens up. Professionals have a tendency to hide behind the jargon (Hollins, 1985; Lynch & Staloch, 1988; Turnbull & Turnbull, 1985) so that, in many instances parents believe their child who is labelled developmentally delayed/disabled will "get better". This frequently leads to situations where parents are accused of denial; Hollins (1985, p. 145) believes it reflects "professional remoteness". Parents frequently do not understand the implications and ramifications of intellectual disability. One parent I know of thought it meant her child was super-intelligent, and admitted to confusion regarding her child's diagnosis and apparent function. It is for reasons such as these that I am so explicit.

Children exhibit **developmental delay** for many reasons: particular familial lateness (e.g., late walking or talking may run in families),
individual difference, interrupted development due to crisis (e.g., illness, hospitalisation, emotional trauma), lack of opportunity, reduced stimulation, prematurity, or particular impairments. The range of developmental rate is broad. A delay in development does not necessarily indicate pathology as many children do "catch up" (Illingworth, 1987). However, some delays are significant and do indicate a severe, chronic condition which will result in developmental disability. In childhood, it is usually difficult to predict the severity of long term disability, which is amongst the reasons professionals are sometimes loathe to use labels which have negative connotations. For instance, two three year old children who exhibit significant developmental delay may have very different aetiologies, opportunities, motivation and potential: one may grow into adulthood and have cognitive deficits, the other may have no significant disability. Frequently, children are so disabled by their physical conditions (e.g., cerebral palsy), that it is difficult to assess cognitive function. To label such a child "retarded" can have only negative implications. It is for such reasons that the "developmental delay/disability" terminology is functional and logical when used appropriately. Appropriate usage may still however, give rise to confusion and false expectations when the terminology and its implications are not explained to those whom it affects.

The children I refer to all have significant developmental problems. Some of them have cognitive deficits (i.e., are mentally retarded), a few do not, and we are unsure of others. They all do, however, have significant, chronic disabling conditions which will result in functional limitations in adulthood. Just how disabled they will be is not possible to accurately predict. Despite this, severe developmental disability usually implies cognitive deficits. A diagnosis, or even a suspicion of, developmental problems gives rise to fear and pain and uncertainty. Moreover, if mental retardation is diagnosed, or even suggested or implied, parents are devastated. Rod Ballard (1978), writing as a parent and as a social worker,
summed up succinctly the flavour of the related literature in his title "Help for Coping with the Unthinkable".

Why is mental retardation "unthinkable"? To develop any sense of its meaning, we need to look at what it is and why people are so fearful of it.

DEVELOPMENTAL DISABILITY
- CONNOTATION -

The first part of this chapter has outlined the links between developmental disability and mental retardation. It will now be argued that it is these links which conjure up a world of awful meanings.

Mental Retardation - Public Definitions

The most widely accepted definition of mental retardation is published by the American Association on Mental Retardation (AAMR) in a series of manuals since 1921. The ninth and latest revision occurred in 1992. It states:

Mental retardation refers to substantial limitations in present functioning. It is characterised by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (AAMR, 1992)

Sub average intellectual functioning refers to an IQ of less than 70 (Cocks, 1989). It must co-exist with impaired adaptive behaviour, and manifest during the developmental period. There are further classifications of intellectual functioning and adaptive behaviour within this definition and there are a large number of general intelligence tests and adaptive behaviour assessment tools in use. Following complex assessment, a person's impairment may be described as mild, moderate, severe or
profound. Although the system appears to provide a concise and objective classification, it has many critics. For instance, IQ tests lack reliability with some groups, do not account for language or cultural differences, are considered unfair to various minority groups (Cocks, 1989), and impose a statistical definition of "normal" upon people (Mercer, 1992).

Mental retardation may be considered as both a symptom of an underlying developmental disorder, and an assessment of potential ability to learn (Menolascino, 1977). Whilst attempts to define it are ongoing, the task is difficult as it is a complex human phenomenon. Detterman (1987), in summarising research into the theoretical notions of intelligence and mental retardation, said that whilst numerous miniature theories of intelligence have been useful as tools in guiding research in mental retardation, they have not proved capable of providing basic explanations of the phenomenon. He does, however, say that research indicates there seems to be almost no mental process unaffected by mental retardation, and refers to this pervasive finding as the "everything" deficit. However, these deficits may vary from person to person with respect to abilities and the severity of the effect.

These views of mental retardation relate to breakdown or pathology within an individual. People who are diagnosed as mentally retarded within this system are labelled as such due to a set of rather arbitrarily created and applied criteria (Bogdan & Taylor, 1976). Such labels suggest generalisations about people which create a social identity and a set of expectations (Goffman, 1963). Given that brain pathology is only consistently demonstrated in people whose IQ's are below 50 (Einfeld, 1992), there is a large number of people who are classified as mentally retarded, but in whom pathology is not identified and is, in fact, questioned by many. This lack of precision and the ongoing debate in the attempts at definition are captured by Susan Lea's (1988) question "Mental Retardation: Social Construction or Clinical Reality?" She joins a long and distinguished line of anthropologists, sociologists and educators who have questioned the phenomenon of mental
retardation as a clinical entity (e.g., Bogdan & Taylor, 1982; Edgerton, 1967; Fulcher, 1989; Jacobs, 1980, 1982; Wolfensberger, 1988).

Despite the difficulties involved in defining mental retardation and in understanding its nature, it is generally agreed that it is first and foremost an inadequacy in social conduct. People are not usually diagnosed as being mentally retarded because some specific organic cause has been located; rather, diagnoses are typically made after some degree of social incompetence has been demonstrated. The AAMR (1992) definition takes into account, with its dual concepts of intellectual functioning and adaptive behaviour, that mental retardation is a relative concept, the limits of which have meaning only in terms of social conditions (Edgerton, 1967). The behaviour of people with mental retardation represents a point on a continuum. Psychometric tests and common sense usually agree upon a diagnosis of the more severe cases of mental retardation; however, neither tests nor common sense can provide a consensus of diagnosis for those who have a mild form of mental retardation. In these cases, the relative competence of people is judged by social and cultural criteria. Edgerton (1967) said that "...mild mental retardation is a social phenomenon through and through" (p. 6), and his opinion was borne out when "an expert commission in 1967 cured millions by changing the definition of mental retardation and lowering the IQ required to be considered normal" (Spudich, 1992, p. 11). The function of the affected people had not changed, only the definition which categorised them.

It is my opinion that much of the reason for the debate regarding mental retardation as social construct or clinical reality lies in the fact that, usually, the debators are talking about two different groups of people. Those who see it purely as a social construct are referring largely to people with mild mental retardation, while those who see it as a clinical entity relate to the more severe forms of mental retardation, (i.e., the more severe the disability, the more likely it is that the condition can be identified and a cause determined). I do not see the concepts as mutually exclusive, but rather
view the phenomenon of mental retardation as a continuum which is affected by biological and socio-cultural determinants, to a greater or lesser extent. Whilst the terminology suggests homogeneity, the group represented by the label is, in fact, heterogeneous and comprised of individuals with widely different attributes and abilities.

**Mental Retardation - Private Meanings**

Whilst here the phenomenon of mental retardation may be discussed in an atmosphere of rationality, logic and academic enquiry, with an admission of the enormous difficulties imposed by attempting to define its nature, such discussion ignores the range of meanings and emotions conjured up by the term in the minds of most people.

Terms such as idiot, imbecile, moron, mental defective, retard, low-grade, custodial, trainable and educable have been in common use, and are still encountered. "These terms not only set the mentally retarded apart from other members of society but also convey to most people the visions of subhuman status..." (Menolascino, 1977, p. 12). This view is reinforced when we remember that such people were, until only fifty years ago, exhibited for amusement and profit (Bogdan, 1986). Most were locked away in institutions, many of which emphasised their subhuman status. These institutions have been referred to as "Hell", "Purgatory" and "Pandemonium" (Blatt, 1970; Blatt & Kaplan, 1966). Old perceptions die hard, and today we are left with a legacy of superstition and belief, "old wives' tales" and folklore, which have led to an array of negative images of people with mental retardation. Whilst there is a recognition that many of these perceptions are no longer considered to be publicly acceptable, the images have had an enormous impact on our thinking, and contribute to our private meanings (Kurtz, 1981).

In citing Fernald (1912), Kurtz, (1981, p. 16) described the following perceptions as "bizarre" and implied we no longer think like this.

The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs.
The great majority ultimately become public charges in some form. They cause unutterable sorrow at home and are a menace and danger to the community. Feeble-minded women are almost invariably immoral, and if at large become carriers of venereal disease or give birth to children who are as defective as themselves. We have only begun to understand the importance of feeble-mindedness as factors in the causation of pauperism, crime and other social problems ...

Every feeble-minded person, especially the high-grade imbecile, is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies. The unrecognised imbecile is a most dangerous element in the community.

These words are "bizarre" but may not be far off the mark in the minds of many today. People with mental retardation are still held to "cause unutterable sorrow at home" and we have only to watch current affairs programmes on television to see the expression of similar views when a neighbourhood is threatened by the intrusion of a group home for people with intellectual disabilities. In one such recent programme, a potential neighbour was expressing his concerns regarding the probability that the new residents would defaecate on his lawn. I have heard my own friends and acquaintances (supposedly well-educated, professional and middle class) articulate views which are the by-product of such perceptions. Some of the words I recall are:

*They should all be taken out, put against a wall, and shot.*

*They’re dirty.*

*I won’t have them living nearby. The children will be scared, so we’re selling our house.*

*They could do anything to the children – molest them, or anything. They don’t know what they’re doing.*
And these are remarks made by people who are careful in my presence, as they are conscious of my sensibilities.

Wolfensberger (1969), an acknowledged world leader in the field of mental retardation, provided a useful summary and discussion of some of the common historical perceptions of people with mental retardation. These perceptions have not only shaped current meanings but are held by people today. His work, with some discussion, is summarised below in order to demonstrate the roots of our private meanings which are sometimes reflected in the words of the parents in this study.

The Retarded Person as a Subhuman Organism. In the views of some, people with mental retardation lack the emotional and physical needs which are assumed for humanity. On this basis, they have been denied human rights and privileges which are a part of citizenship. Social and educational programmes reflect principles which are based on notions of sub-humanness (e.g., aversive behaviour modification techniques). This question of humanness has led to ethical, moral and legal debate as a result of inhumane practices (e.g., mass sterilisation, withholding of basic and potentially life-saving treatment, overdoses of psychoactive drugs) (Hollander, 1989). I have had students unwilling to perform a comprehensive assessment of people with intellectual disabilities because, "They have no feelings, and are not spiritual". I have heard of pain relief being withheld from a person with an intellectual disability with a severed finger on the basis of "We didn't know what it would do to him". This was from staff in a large, modern accident and emergency unit. They seemed surprised when it was suggested that it would probably relieve his pain.

The Retarded Person as a Menace. Large institutions for people with mental retardation were constructed in isolated settings in the late nineteenth and early twentieth centuries in order to isolate the deviants from society. People with mental retardation were viewed as a menace to society, being violent and destructive, and as a menace to future generations, possessing a remarkable potential to procreate, producing more people like
themselves. This image led to one of the strongest historical attempts to place restraints on people with mental retardation. Apart from being segregated, they were involuntarily sterilised as a result of eugenic programmes in the first part of this century (Scheerenberger, 1987).

The Retarded as Objects of Pity. People who are mentally retarded are thought of as "suffering", and must be pitied, sheltered and protected. They are not accountable for their behaviour and it is up to other people to bestow happiness upon them.

The Retarded Individual as an Eternal Child. This view holds that, as an eternal child, adult demands cannot be made on a person who is mentally retarded, and that decisions must be made by other people. This view is currently reinforced by the prevailing misuse of the results of IQ tools. Sometimes a person's mental age (M.A.) was given, as say, ten years. This was meant to indicate that a person's cognitive operations were at about the level of a ten year old child. This score indicates nothing about a person's social interests or emotional life, but has been frequently misused to label the whole person.

The Mentally Retarded as Burdens of Charity. People who cannot take care of themselves are seen as entitled to charitable intervention on their behalf, so that they are not denied human existence. It would seem that the recent government in NSW, with its philosophy of economic rationalism, was driven by this perception. Whilst proclaiming "rights" for people with disabilities on the one hand, it attempted to move services for such people, to the private sector, because the large, voluntary (i.e., charitable) organisations "do it better" (Conway, 1992).

The Retarded as Objects of Ridicule. Throughout history, people with mental retardation have been ridiculed. They have been stereotyped as figures of fun and it is not uncommon to see this today in a wide variety of settings. I have witnessed high school children teasing a young man from the local workshop whilst he innocuously waited at the bus stop. Recently I
heard of school children purchasing eggs to throw at a middle-aged woman with an intellectual disability, whilst she waited in a public place.

The Retarded as Objects of Shame. It has not been uncommon that people with mental retardation have been hidden by their families from the outside world. A common belief has been that such people are "sent" to families as punishment for sins (Kurtz, 1981). A few years ago, it came to light that some members of the British royal family had been hidden due to their mental retardation. I know of a child in an institution who was denied permission by his father to go on a holiday to the snow. The reason given was that ordinary people should not have to look at him.

The Retarded Person as a Holy Innocent. It is this view which holds that people with mental retardation are the special children of God, and are incapable of committing evil. In this perception, their salvation is assured, and they are thus treated as being "special". I have heard echoes of and direct statement of this view on many occasions and this perception is given voice by a number of the parents in this study.

In light of such views, it is understandable that infanticide has been used as a method of reducing the numbers of infants with disabilities in the past (Scheerenberger, 1986), and today, is still subject to debate (Kuhse & Singer, 1985). Scientific racism existed in many forms in the late nineteenth and early twentieth centuries, and this debated that persons considered to be unfit might be put to death. It was felt that only sentiment prevented such formal action then, but there would probably come a time when science would conquer sentiment (Hollander, 1989). The selective killing of people with mental retardation (along with others who were "unfit") was adopted as a state programme by the Nazi government in 1939, with such success that when Wolfensberger (1981) visited Germany in 1963, there were relatively few adults with mental retardation. Today, we have the ambiguous and paradoxical situation of condoned abortion for foetuses with handicapping conditions, whilst the rights and value of people with disabilities are actively reinforced (Saxton, 1988).
People with epilepsy and mental "deviations" were seen to be the result of evil spirits and influences. They were to be feared and were often outcast (Scheerenberger, 1986). The existence of a child with a disability was a public denouncement of parent's wrongdoings; parents blamed themselves and continue to do so. When discussing disability as stigma, Eisenberg (1982) discussed the biblical contributions to the apparent justification for stigmatising people with disabilities. He said that "Not only is the concept of individual punishment for sins and immoral behaviour found in the Bible, but the concept of the sins of the father being visited upon his children is also firmly rooted in biblical literature" (p. 5).

Thomas (1978) said that such beliefs are built into a culture and, citing Haffter (1968), said that earlier beliefs influence present day attitudes through a societal "collective unconscious". By this Haffter means that there is an enculturation of values and beliefs which are ingrained and become part of our attitudinal socialisation. It is hardly surprising then that mental retardation holds a multiplicity of meanings for people, most of which are overwhelmingly negative. Given that, by and large, people with mental retardation have been segregated, isolated and hidden, most people are never exposed to their actual needs, life experiences and humanness. As a result of such segregating practices, people with mental retardation have indeed become social outcasts, ill prepared to cope with community life, exhibiting a range of asocial and antisocial behaviours and extreme dependencies (Saxton, 1988). Private meanings, therefore, are seldom challenged and the term, mental retardation, still conjures up a world of fear and shame, a world in which most people want no involvement. Thomas (1978), in summarising attitudinal research, said that it is the use of the label "retarded", which "... allows the respondent to construct his own meaning for the term" (p. 65).
Mental Retardation - The Unthinkable

In a world which values perfection, performance and achievement, in a society which pronounces everything young, healthy, beautiful and vigorous as being "good", and everything at variance with this norm as "bad", disability triggers much fear. People with disabilities in our society are the targets of attitudes and behaviours which range from gawking, to avoidance, to outright hostility; they are the objects of pity and resentment; nothing much is expected of them and, if they do make their mark, they are treated with reverence and awe (Saxton, 1988) and become the "super crip". They face innumerable barriers, are discriminated against, and oppressed. They are marginalised and not allowed to take part in the full life of the community.

In the "status hierarchy of disabilities", mental retardation and cerebral palsy hold the lowest status. Vash (1981) stated that it is the nature of these impairments (i.e., early brain damage affecting communication) which gives them a high stigma value. Shears and Jensema (1969) undertook research which postulated that disabilities with a high level of acceptance (e.g., being an amputee, blind or in a wheelchair) are visible and associated with stereotypes, whilst those with low acceptance (e.g., cerebral palsy, mental illness, mental retardation) are associated with stigma. Resnick (1984), in summarising research related to the rank ordering of disabling impairments, said that the hierarchy of preferences towards various disability groups is consistent across ages and across cultures. Amputation, arthritis and wheelchair conditions are seen as the most acceptable; blindness, deafness, speech defects and epilepsy are ranked in the middle, and mental retardation and cerebral palsy are seen as the least acceptable.

Bogdan, Biklen, Shapiro and Spelkoman (1990) criticised such research on the basis that it "...invariably reports the unremarkable fact that people with disabilities are negatively valued in society" (p. 138), whilst failing to examine the reasons behind the stereotypes. They postulated that
there is a connection between our conception of "monsters", which are dangerous creatures, and the depiction of people with disabilities in literature, art, film, television, comics and newspapers. The imagery is of ugliness, violence, evil and fear, hand in hand with disability and physical deformity, an imagery which creates as well as perpetuates, society's prejudices. In the light then of such deeply entrenched societal fears and prejudices, there is little room for wonder at why mental retardation may be "unthinkable" for parents (Ballard, 1978).

This examination of developmental disability, its definitions and meanings, enables us to develop a sense of why it is such an issue and why people are so fearful of it. The exploration of the "unthinkable" provides a context for the tragedy of developmental disability and provides some insight into the thoughts and emotions which it engenders. Parents who are confronted with this tragedy, whilst possibly unable to articulate their fears, carry a sense of "... their [child's] stigma - of all possible stigmata - [being], closest to what we may call the soul" (Goldschmidt, 1967, p. vii).
Chapter Three

RESPONSE TO DEVELOPMENTAL DISABILITY

- SOME THEORETICAL PERSPECTIVES -

"Families who have a member with a disability have long been objects of pity. Society as a whole tends to view the presence of a child with a disability as an unutterable tragedy from which the family may never recover. Researchers and service providers in the field of developmental disabilities have mirrored this societal perception, and tend to view the family as a whole as embroiled in a series of acute crises interspersed with chronic sorrow".

(Summers, Behr & Turnbull, 1989, p. 27)
This chapter will provide the rationale for the emergence of the research question. It is my contention that practitioners and researchers have interpreted parents' responses to their children with disabilities from an overwhelmingly negative perspective which has not taken into account the diversity and complexity of parents' experiences.

If we bring a group of nurses, either experienced or neophyte, together (as I often do in classes) and ask "How do you think parents manage the knowledge that their child is significantly disabled?", a fair distillation of their responses is, "They have to mourn for the loss of their perfect, dreamed-for child before they can accept the one they have". Further questioning as to how they think the parents might achieve this, results in answers like, "They have to go through the grief response", or "They have to go through the stages of mourning". This is something that is considered essential prior to "acceptance" (and should not take longer than about twelve months). Sometimes, a brave soul questions this notion of "acceptance", which leads to discussion of "non-acceptance" being undesirable, unhealthy and not in the best interests of the child with a disability.

A more sophisticated group of professionals (i.e., specialists in the field of developmental disability) is much more familiar with the notion of "non-acceptance", but generally sees such a state as one which requires intervention. A few may be comfortable with a concept of adaptation (in the face of "non-acceptance"), and have come to expect ongoing sadness and sorrow on the part of parents, but intervention for these families would still be seen as the norm. Such a group of professionals may well have difficulty with parents who speak optimistically and hopefully of their children with disabilities, and are likely to interpret these parents' views as "denial".

This chapter examines literature which represents the concepts and theories upon which professionals base their interpretations of parents' behaviour, as well as their expectations and judgements of it. The concepts of linear, time-bound grief, mourning the loss of the perfect child, and
chronic sorrow are presented and discussed as the core theoretical perspectives in which professionals’ notions are grounded.

A smaller and less recognised literature, which allows for alternative interpretations of parents’ responses, is then presented for examination in light of its apparent sceptical reception by the professional community. This is known as the positive contributions and cognitive coping work.

DOMINANT THEORETICAL PERSPECTIVES

Given Wolfensberger’s (1969) summary of perceptions of people with mental retardation (outlined in Chapter Two), it is not surprising that the families of such people have long been objects of pity. We live in a world which promotes a success-oriented culture, and which places high value on intelligence, beauty and youth. People with disabilities have long been viewed as non-contributing members of society and as burdens (Turnbull & Turnbull, 1990). People who are poor, ugly, crippled, unsuccessful are viewed as failures and are, in Goffman's (1963) view, seen as somewhat less than humans; they have a "spoiled identity" and are "stigmatised". Society then, tends to view the presence of a child with a disability as a great tragedy from which the family may never recover, and this view is mirrored by researchers and service providers, whose task of family support becomes one of "... ameliorating the deadly pall of tragedy that hangs over the family" (Summers, Behr & Turnbull, 1989, p. 27).

The large body of literature is replete with the negative impact of disability on the lives of families (Blumel, 1988; Chetwynd, Calvert & Boss, 1986; Collins-Moore, 1984; Eden-Piercy, Blacher & Eyman, 1986; Ehlers, 1966; Erickson & Upshur, 1989; Featherstone, 1980; Flynt & Wood, 1989; Frey, Greenberg & Fewell, 1989; Gowen, Johnson-Martin, Goldman & Applebaum, 1989; Harris & McHale, 1989; Mercer, 1990; Sherman & Coccossa, 1984). The assumption that this impact is inevitably negative has led researchers to focus on stress measures and the documentation of the effects of the burden of care (Summers, 1988). In her review of the literature
related to the family with a handicapped child, Murphy (1982, p. 73) cites Howell's (1973) summary of opinions noted in earlier works: "Those who work in the field of habilitation with children are well aware of the neuroses and psychotic breaks of parents, dissolution of marriages, and adjustment problems of siblings, as well as significant behavioural problems of the handicapped child himself". The literature describes parental reactions of fear, denial, anger, frustration, guilt, grief and mourning following the initial impact of diagnosis of severe impairment in a child. This is seen as just the beginning of a chronic and relentless stress which is accompanied by a continued sadness. Implicit in this view is an assumption of distress and dysfunction in families (Beckman, 1991).

A number of approaches to explain the responses of parents to the negative impact of their child's disability can be identified in the literature. The dominant view is a time-bound model of grief, which contends that grieving occurs over a period of time, and that successful resolution of this process implies an acceptance of the child's disability (Teel, 1991). Another approach, which until recently has not commanded the same degree of professional recognition, is the concept of chronic sorrow, which contends that parents adapt, in a functional sense, to their child's condition, but do not ultimately accept it (Clubb, 1991). The influential work of Solnit & Stark (1961) examines the concept of mourning in relationship to the birth of a "defective child", and is included by many authors in discussion of time-bound models of grief (Clubb, 1991; Fraley, 1990; Lindgren, Burke, Hainsworth & Eakes, 1992; Teel, 1991).

Some of this work has evolved from the literature on death and dying and has been extrapolated and applied generally to issues of loss, including disability (Davis, 1987). Grief has come to be regarded as "... the characteristic response to the loss of a valued object, be it a loved person, a cherished possession, a job, status, home, country, an ideal, a part of the body, etc." (Engel, 1961, p. 19). Whilst the words grief, grieving and
mourning are frequently used interchangeably, there are differences. Gilbert (1994) summarised these concepts as:
grief which is defined as emotional, physiological and behavioural reactions resulting from the loss of a significant other;
grieving which relates to active efforts made to cope with and come to terms with the loss; and
mourning which is the public expression of grief.

The conceptual bases for practice with families with children with disabilities are now presented. As will be seen, the major frameworks hold the negative impact of disability as their assertion. An alternative view, which emphasises the positive impact, will be presented following discussion of the dominant literature.

**Time-Bound Grief Models**

The origin of much theory related to grief following the loss of a significant other is traced to Sigmund Freud, who considered that, whilst mourning is a significant departure from normal life, it is not a pathological response, does not require medical intervention, and resolves over time (Teel, 1991).

Lindemann’s (1944) work expanded Freud’s theory and agreed that acute grief is a normal response to a distressing situation. He suggested that grief is linear and time-bound, and that its successful completion is equated with resolution of the grief in which one is liberated from bonds with the deceased. Engel (1961) provided further support for temporal progression of grief through stages of shock and disbelief, a developing awareness of one’s loss, and recovery, which is prolonged and leads to the re-establishment of well-being. These early authors provided impetus for much of the later work related to grief. Amongst the most influential of the theorists has been Elisabeth Kubler-Ross (1969), who described five stages of grief namely: denial of the loss,
anger at the loss,
bargaining for recovery,
depression over the reality of the loss, and
acceptance of the loss.

These stages were intended to depict the process through which a dying person needed to move in order to have a "good" death. However, she indicated that a bereaved person, by moving through those same stages, could resolve loss (Gilbert, 1994). John Bowlby (1980), whose work was built extensively on attachment theory, was another major force in the development of grief models. His model has people passing through four discernible phases, namely,
numbing of the emotions,
yearning and searching for the lost loved one,
disorganisation and despair over the loss, and
reorganisation and recovery (Gilbert, 1994).

Whilst there are some differences in the phases of grief presented in various stage models, they are similar in that they propose a temporal sequence of shock, protest, despair and reorganisation, leading ultimately to acceptance. The crucial elements of such conceptualisations are:
• mourning is a normal response,
• acceptance is required for healthy resolution,
• if acceptance does not occur, adaptation cannot be reached, and a neurotic state exists.

Mourning and the Loss of the Perfect Child

Solnit and Stark's (1961) seminal paper related to the chronicity of mourning following the birth of a child with a disability. They pointed to a psychoanalytic origin and stated that Freud's work on narcissism as it related to object-loss, in this case the longed-for healthy child, was their theoretical underpinning. They described the disappointment, helplessness, humiliation, trauma, defeat and sense of failure on the part of the mother,
and believed that adaptation to the child with a disability is an overwhelming demand as there is "...no time for working through the loss of the desired child before there is the demand to invest the new and handicapped child as a love object" (p. 184). They believed that pathological reactions of guilt may lead to one of two extreme neurotic reactions: a mother's unremitting and exclusive dedication of herself to the child, or of parental intolerance leading to a denial of relationship to the child. They mentioned that fathers will have similar or related responses. In this conceptualisation, mourning is disrupted due to the child with a disability being a constant reminder of object-loss thus inhibiting resolution of grief (Teel, 1991). Solnit and Stark (1961) compared such mourning with the process that follows the death of a child, and concluded that pathological reactions to the birth of a "defective" child are to be expected. The crucial elements of their premises are:

- grief occurs as a response to the loss of the anticipated normal child;
- there is no time to resolve the grief because the unexpected child requires immediate attention;
- the parents therefore are likely to have neurotic responses;
- defence mechanisms, particularly denial, are likely to be manifested.

Solnit & Stark's (1961) work has been integrated into the time-bound models of the grief associated with the presence of a child with a disability. There is however a subtle difference in their underlying premises. In time-bound models of grief, acceptance of the situation is expected leading to a healthy resolution of grief. If acceptance does not occur then a neurotic state is implied. Solnit & Stark, however, contended that, due to the difficulty and complexity of the mourning process in such a situation, resolution of grief may not occur, and so neurotic responses are expected. The difference is one of expectation and it is this potential inability on the part of parents to resolve their grief that has been ignored in the integration of Solnit & Stark's work with that of other theorists. As we shall see, Olshansky's (1962) paper on chronic sorrow disputes the notion of acceptance, but theorists who
integrate Solnit & Stark's analysis with time-bound grief models, overlook the potential for lack of resolution in the work of Solnit & Stark. The integration of concepts of time-bound grief and mourning the loss of the perfect child will now be presented.

**Time-Bound Grief and Mourning in Relationship to the Loss of the Perfect Child**

Irvin, Kennell and Klaus (1982), who were pioneers in the field of parent-infant bonding and disruptions to this attachment, considered that Solnit and Stark's (1961) work became the foundation of most therapeutic approaches to parents of children born with congenital malformations. They presented a hypothetical model of parental adaptation to the birth of an infant with a congenital malformation (Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975) which postulated a stage model:

**shock**

**denial**

**sadness, anger and anxiety**

**adaptation**

**reorganisation.**

The commonalities between this work and that of predecessors is apparent. Interestingly, no reference is made to the work of Kubler-Ross, Bowlby or other grief researchers.

In referring to Solnit & Stark’s (1961) paper, Irvin et al. (1982, p. 233) state:

Their brilliant analysis consists of the following elements:

1. The infant is a complete distortion of the dreamed-of or planned-for infant.
2. The parents must mourn the loss of this infant - a process that may take several months - before they can become fully attached to the living defective infant ...

It appears that here is an assumption of acceptance, without reference to Solnit & Stark's (1961) contention that neurotic responses are to be expected.
Irvin et al. (1982) went on to discuss the difficulties of this particular mourning process, but in their work ultimate acceptance is implied for healthy adjustment.

Various models have been developed to explain parents' reactions to their children with disabilities which arise from congenital, cognitive and physical impairments (Clubb, 1991) and all of these suggest parental progression through sequential stages of reaction to their child's disability. Blacher (1984) reviewed the extant literature and identified the recurring themes and patterns of response, which were described as fairly discrete, sequential stages of adjustment. She collapsed the various taxonomies into three major groupings:

**Initial Crisis Responses** - most typical initial reactions are shock, denial and disbelief. Detachment, bereavement and bewilderment are sometimes reported.

**Continuing Feelings and Responses** - the broad term of "emotional disorganisation" is used to describe the stage where parents experience guilt, disappointment, anger, low self-esteem and other such feelings. Mentioned less frequently are loss, hopelessness, futility, sorrow, disappointment, loss of warmth or detachment in relationships, and physical symptoms.

**Adjustment or Acceptance** - most writers have identified emotional organisation, adjustment, acceptance or reorganisation.

Whilst there are some differences in the various models described by the numerous authors in the field, it is possible to depict a representative model of the sequential stages through which parents progress in the time-bound approach. Such a representative model is offered by Clubb (1991), who wrote of adaptation patterns of parents who have children who are chronically ill, in which the stages are labelled as follows:

**Impact**, which occurs at the time of medical diagnosis, is represented by anxiety and disorganisation, and is short-lived;
Denial, which appears to be a defence mechanism, and provides parents with time to face the reality of their situation gradually; Grief, which is manifested through feelings of anger, guilt and sadness, and terminates when adequate coping measures are demonstrated; Focussing Outward, in which appropriate coping measures are demonstrated and when parents can accept help from others and begin to adapt to their situation realistically; Closure, in which the crisis threat has been resolved and parents accept disruption to family life.

This examination of the literature illustrates that the dominant themes in all of the "stages" models are that:

- grief occurs as a response to the loss of the longed-for perfect child,
- grief is time-bound, and
- the child's disability is accepted.

The impact of these conceptualisations on professional practice has been powerful: "It is the belief of many health care professionals that parents pass through the stages of grief in an orderly manner, finally resolving their grief, and accepting their child's disability" (Fraley, 1990, p. 268). This view is reinforced in daily practice, as was illustrated early in this chapter.

However, other professionals practise from a conceptual base which questions the notion of acceptance and which holds such non-acceptance to be natural. Many such professionals draw on the concept of chronic sorrow.

**Chronic Sorrow**

Olshansky (1962) first used the term chronic sorrow to describe a pervasive psychological phenomenon observed in parents of mentally retarded children. His work was based on his clinical experience as a counsellor. He contended that chronic sorrow is a natural and understandable response to a tragic event, and is manifested throughout the lifespan of the parent-child relationship. This is in contrast to Solnit & Stark
(1961), for whom the non-resolution of mourning was an unhealthy response. Olshansky (1962) disputed the closure stage of other theorists as it symbolises acceptance, which he sees as a simplistic and static concept. He proposed that parents never fully recover from the impact of "...the terrible reality that confronts them each day" (p. 191). In 1966, he wrote that mental retardation must be viewed within its cultural context, and that for parents it is a "...many faceted symbol..." (p. 21) which is naturally viewed as an overwhelming family tragedy. Within this context, sorrow is a normal response. Olshansky (1962) believed that release from chronic sorrow may be obtainable only through the death of the parent or child, until which time, "...the woes, the trials, the moments of despair will continue" (p. 191). He said that feelings of guilt are never eliminated, and although parents direct efforts to supporting the child, and may derive satisfaction and joy from the child's modest achievements, that these efforts do not represent acceptance. Olshansky then contended that, whilst functional adaptation usually occurs, grief is never resolved and recurs throughout the lifetime of the child. This is not a neurotic response, but a normal psychological response which has a basis in reality.

Searl (1978), who wrote from the perspectives of parent and psychologist, supported Olshansky's view when he questioned the idea of stages. He said that he and his wife never did "get over" their shock, guilt and bitterness, and that, despite adjustment, experienced recurrent pain and sadness. Patterson (1956), a mother writing earlier on behalf of parents of children with disabilities, spoke of their "...great sorrow - a living sorrow" (p. 16).

In 1981, Wikler, Wasow and Hatfield, who were concerned about the two incompatible notions of time-bound grief and chronic sorrow, published the results of a survey which was designed to describe the course of parents' grief. Parents and experienced social workers essentially agreed that parents of mentally retarded children experience periodic crises during the child's development, rather than time-bound adjustment. These findings ran
"...counter to the prevalent professional view" (p. 63). Wikler et al. (1981) concluded that chronic sorrow is not an abnormal response, but rather, is a "normal" reaction to an "abnormal situation".

In a study by Damrosch and Perry (1989), who conducted a survey of parents of children with Down syndrome, fathers depicted their adjustment in terms of steady, gradual recovery, whilst the majority of mothers reported higher frequencies of chronic sorrow. This finding, regarding the mothers, paralleled the pattern of peaks and valleys and periodic crises depicted by the mothers in Wikler's (1981) work. Damrosch and Perry (1989) did not explore the reason for maternal - paternal differences but commented that some evidence was provided that mothers' "... experiences with their child's handicap are different from those of fathers" (p. 29).

In more recent years, the concept of chronic sorrow has been analysed by nurses (Clubb, 1991; Fraley, 1990; Teel, 1991; Lindgren et al., 1992), who have applied it to different groups: parents of chronically ill children or premature babies; adults with multiple sclerosis; and elderly caregivers of spouses with dementia. In fact, the recent literature generalises the concept of chronic sorrow as a framework for understanding the responses to losses experienced by the chronically ill and their caregivers. Teel (1991, p. 1311) said, "when a relationship of attachment is disrupted following an event that renders a loved one forever changed from the hoped-for child or from the known person, recurrent sadness, or chronic sorrow, is a frequently encountered response".

Lindgren et al. (1992, p. 31) identified the critical attributes or underlying assumptions of chronic sorrow as follows:

- There is a perception of sorrow or sadness over time in a situation that has no predictable end.
- The sadness or sorrow is cyclic or recurrent.
- The sorrow or sadness is triggered either internally or externally and brings to mind the person's losses, disappointments or fears.
• The sadness or sorrow is progressive and can intensify even years after the initial sense of disappointment, loss or fear.

In a response to Lindgren et al.’s (1992) work, Martinson (1992) supported the definition of chronic sorrow as a reaction to many types of chronicity, and agreed with its being periodic, pervasive and permanent. She did, however, dispute the progression and intensification of sadness over time, and contends that it is a "...relatively constant state of sadness with peaks and valleys" (p. 42).

Overall, the literature which relates to the concept of chronic sorrow is in agreement with Olshansky’s (1962) original premise, namely, that chronic sorrow is a part of a normal grief response to a tragic event. The only dissenting voice comes from Drotar et al. (1975) who refer to "... the pathological aspects of family reactions including the chronic sorrow which envelops the family with a defective child" (p. 710). Whilst this may be their interpretation of chronic sorrow, it is a misrepresentation of Olshansky’s (1962) work. The concept of chronic sorrow, in recent years, has been expanded to encompass events which have lifelong implications for the caregiver (Teel, 1991) and, with the formation of a research consortium in the USA (Eakes, Hainsworth, Lindgren & Burke, 1991) work on the application of this concept across various caregiving populations continues (Burke, Hainsworth & Eakes, 1994).

Comparison of the Concepts of Time-Bound Grief and Chronic Sorrow

As a result of her examination of the relevant literature, Teel (1991) provided a useful summary of the distinguishing components of time-bound grief (which she refers to as bereavement grief/mourning) and chronic sorrow. This summary is presented in Table 1.
Table 1 - Comparison of Time-Bound Grief and Chronic Sorrow

<table>
<thead>
<tr>
<th>TIME-BOUND GRIEF</th>
<th>CHRONIC SORROW</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>A pervasive psychic pain and sadness, stimulated by certain trigger events, which follows loss of a relationship of attachment, due to permanent inaccessibility</td>
</tr>
<tr>
<td><strong>Onset</strong></td>
<td>Precipitated by the permanent loss (exclusive of death) of a significant relationship</td>
</tr>
<tr>
<td><strong>Affective State</strong></td>
<td>Variable feelings which range from happiness and satisfaction with abilities of disabled person to intense pain and sadness following triggered recognition of disparity and loss of hoped-for relationship.</td>
</tr>
<tr>
<td><strong>Resolution</strong></td>
<td>Ongoing presence of sorrow-inspiring person prohibits resolution of episodic sadness which continues until the death of either person in the relationship.</td>
</tr>
</tbody>
</table>

(Adapted from Teel, 1991)
According to Teel (1991), the principal theme is that a loss of a relationship of attachment triggers grief. When the loss is due to death, recovery of the mourning person occurs along a temporal sequence. Whilst the progression is not necessarily constant, and vacillation among phases occurs, the grieving person will eventually move from shock to acceptance. When the loss is due to a permanent condition that renders the individual permanently changed from the hoped-for child or from a known person, periodic recurrence of psychic pain and sadness is a normal response. Whilst this differentiation of Teel's (1991) is useful, it does ignore the work of Drotar et al. (1975) which identified a "stages" model as a result of research undertaken with parents of infants with congenital malformations. It also ignores reporting of time-bound resolution in studies such as that reported by the fathers in Damrosch and Perry's (1989) study. Despite this, her comparison has appeal. It diminishes the confusion which results from the generalisation of studies based on experiences of death to situations where death has not occurred. It validates non-resolution of grief for people whose losses are ambiguous and it has implications for practice. Teel (1991, p. 1317) stated:

If the predominant model of bereavement following the death of a loved one is also applied to understanding of those who suffer an ongoing loss, the normalcy of chronic sorrow will be lost. Professionals continue to define adequate resolution of loss as adaptation to the situation. This orientation should be broadened to include support of people in their recurrent experiences of sorrow rather than to hold acceptance and resolution as the ultimate goal for all victims of loss.

**Implications of Dominant Theoretical Perspectives**

The literature has been dominated by a notion that parents' responses to their children with disabilities are negative and pathological,
and lead to such actions as denial, neglect, over-protectiveness, and the encouragement of dependency. In their review of the literature related to adaptation of families with mentally retarded children, Crnic, Friedrich and Greenberg (1983, p. 126) stated that "...investigators have seemed to rally around the concept of anticipated pathology in these families". This has led to a research bias of expected deleterious or pathological outcome. A number of authors have questioned this view and have raised issues related to its implications for research and practice. Farber (1986) wrote about the vocabulary of crisis and maladjustment forming a conceptual base for professional practice. Blackard and Barsh (1982) believed that the negative impact of disability on the lives of families is magnified by professionals, whilst Lipsky (1985) went as far as to say that negative professional myths and biases are actually imposed upon families. Writing as a mother and as a professional, Lipsky was concerned about the high profile of negative views and the fact that they are transmitted to the parents of newborns with disabilities. As early as 1956, Patterson, a mother of a child with mental retardation suggested "Some Pointers for Professionals". Her plaintive words have a familiar ring: "Why do we always face such words as 'anxieties, hostilities, frustrations, guilt-feelings', and other emotionally charged words to describe our reactions? Such pseudo scientific certainties merely serve to make parents feel even more inadequate, it seems to me" (p. 16).

A number of authors have expressed concern about the effect on children and families of such professional views. Howlin (1988) believed there is a danger of exaggerating a disabled child's role in causing problems, whilst Wright, Matlock and Matlock (1985), following a study in which parents self-rated their life satisfaction and self-adequacy, concluded that a professional assumption of distress may become a self-fulfilling prophecy. Roos (1985) believed there to be an attitude of professional hopelessness, on the part of those operating within a medical model, towards mental
retardation, which results in self-limiting and self-fulfilling prophecies which impede development.

With a recognition of the diversity and complexity of the area, Foster (1987) considered the dominant professional view to be an oversimplification, and Blacher (1984) cautioned that the emphasis on negative reactions may result in positive reactions being overlooked. This disregard for the positives has been echoed by others and, in fact, has been admitted by the researchers, Wikler, Wasow and Hatfield (1983, p. 313) in reference to their own work published in 1981. They stated:

As expected, most parents acknowledged that they felt chronic sorrow, but, remarkably, most of them also indicated they had become stronger people because of their experience.

At the time of the study, the authors discounted these findings ... They decided that methodological reasons accounted for many subjects' apparent conviction that being the parent of a retarded child had been a strengthening rather than a debilitating experience.

As indicated earlier, the time-bound stage models of grief pose difficulties as a conceptual framework for understanding parental response to children with disabilities. These models have been useful in simplifying and depicting the turbulent emotions surrounding significant loss, but it is this simplification which may pose difficulties - they oversimplify a diverse and complex process. They imply acceptance of the situation, but this has been disputed by parents (Featherstone, 1980; Patterson, 1956; Searl, 1978; Turnbull & Turnbull, 1985) and by some professionals (Clubb, 1991; Copley & Bodensteiner, 1987; Olshansky, 1962, 1966; Wikler et al., 1981). The difficulty with such models lies in the notion that if parents do not "accept", then they have not resolved their grief, which is deemed to be necessary for healthy adjustment. Professionals who work within such a framework view "non-acceptance" as pathological, and see parental acceptance as the primary goal. This was cogently argued by Teel (1991) and referred to earlier.
Olshansky (1966) believed that "the problem and process of parental acceptance have been distorted by some professionals" (p. 22). Davis (1987) questioned the notion of acceptance being applied to the parents of disabled children, as resolution entails emotional detachment and a denial of the continuity of the child's life. She believed such resolution to be inappropriate for the parents of a living child and describes parents' descriptions of their sorrow as recurrent and cyclical.

It would seem that Solnit and Stark's (1961) work, as it relates to the loss of the longed-for healthy child, has gained wide acceptance, and has been incorporated into most theoretical perspectives relating to the birth of a child with a disability. Olshansky (1966) disputed the universal application of this hypothesis, but agreed that it may be true for some parents. He based his argument on the following possibilities:

- the death of a hoped for child is not equivalent to the death of a real child, and
- for many parents, identification of mental retardation does not take place at birth, but frequently, some years later.

Whilst most conceptualisations appear to have missed Solnit & Stark's (1961) point regarding the overwhelmingly difficult task of resolution of mourning, and contend that "acceptance" is required, Olshansky (1966) tackles their premises. He held that Solnit & Stark (1961) imply that if resolution of mourning is achieved, then parents should be free of sorrow. This was not his experience. He argued that Solnit & Stark (1961) attempted to define the parents as neurotic, thus "... maintaining the tradition which has prevailed so long in the field and which has often interfered with appropriate help to these parents" (p. 22). His explanation for the attractiveness of arguments, such as Solnit and Stark's, to professionals is that "... we can do more about neurotic behaviour than we can do about mental deficiency" (p. 23), and so a justification for professional existence is promoted in a field which has frequently engendered feelings of professional helplessness.
Although developed in 1962, the concept of chronic sorrow has remained relatively dormant until recently. The advantage of using this framework to understand parental response to disability is that ongoing sorrow and non-resolution of grief are seen as normal, and thus professionals are enabled to work with parents in a supportive manner. Davis (1987) argued that, whilst chronic sorrow may be a normal response, the culture of Western society operates against its legitimisation. She said that following the crisis period, there is a requirement not to mourn and cited a study by Kennedy (1970), which found that, whilst mothers of disabled infants grieved, they felt grief was unacceptable and hid it accordingly.

Whilst chronic sorrow may be a useful guiding framework for professionals working with parents of children with disabilities, there is a possibility of its being counterproductive in that it might be all that professionals see. This is illustrated in the Wikler et al. (1983) example cited earlier when the researchers overlooked the strengthening aspects of the parents' experience as the focus was on chronic sorrow. Chronic sorrow would seem to describe well the emotional state of many parents, and is thus a useful conceptual base. However, it does not describe parents' full experience and, in fact, may mask other facets. Recent years have seen the beginnings of this concern reflected in the literature.

AN ALTERNATIVE THEORETICAL PERSPECTIVE

Anecdotal evidence, in the form of books, articles, newspaper reports, film and video, which challenges the belief that the impact of disability is pervasively negative, has been with us for years (Alexander, 1992; Evans, 1993; Featherstone, 1980; Koop, 1985; Mills, 1969; Patterson, 1956; Rioux, 1992/93; Robertson, 1992/93; Roith, 1963; Saxton, 1988; Turnbull & Turnbull, 1985). Much of this evidence has come from people with disabilities and their families, although some has come from professionals.

A close examination of the professional literature reveals fragments of evidence that some impacts of disability may be viewed as positive or, at
the very least, not distressing (Beckman, 1991; Blackard & Barsh, 1982; Lipsky, 1985; Senapati & Hayes, 1988; Stoneman, Brody, Davis & Crapps, 1987; Weber & Parker, 1981). Perhaps the greatest indictment of professional bias was provided by Wikler et al. (1983):

When asked directly, 75 percent of the parents studied (N = 27) reported feeling that being a parent of a developmentally disabled child had made them stronger. Forty-six percent felt that the experience had made them much stronger. Although most parents indicated that they experienced chronic sorrow, they also stated that they tried to keep their feelings under control. They were divided on whether it was better to express their sadness or to control it, but they knew clearly what they wanted professionals to do for them - they wanted to be encouraged to be strong. (p. 313)

This is the finding which was ignored in their 1981 study, as methodological artefact. In summarising their "mistake", the authors believe that "families may have more successes than failures in dealing with their children" (p. 313) and called for a new programme of research fuelled by these "new perceptions".

Positive Contributions

The challenge for a new programme of research has been taken up by a group of researchers at the Beach Center on Families and Disability, based at the University of Kansas, USA. The work is based on findings from a content analysis of letters sent to a Senate Subcommittee in support of regulations for the treatment of newborns with disabilities (Turnbull, Guess & Turnbull, 1988). A consistent theme was that people with disabilities enrich and enhance the quality of life for family members and friends. This content analysis revealed six categories of positive contributions made by people with disabilities to the lives of others:
• source of joy,
• source of learning life's lessons,
• source of love,
• source of blessing or fulfilment,
• source of pride, and
• source of strength.

Turnbull, Behr and Tollefson (1986, cited in Summers, Behr & Turnbull, 1989, p. 29) conducted follow-up work which expanded on the number and nature of these positive contributions and concluded that parents of children with disabilities, like parents of children without disabilities, perceive their children as making positive contributions to their lives.

The positive contributions work has provided impetus for further research in the area designed to explore "... research frameworks [which] can produce intervention strategies to help families maintain family members with disabilities at home and in their communities ..." (Behr, 1990, p. 2). The contention is that studying positive effects (as opposed to the predominant negative) will allow for the facilitation of family coping and adaptation.

Summers, Behr and Murphy (1991) undertook The Family Perceptions Research Project which explored the role of positive perceptions and successful coping among parents who have a child with a disability, extrapolating this relationship from work done in psychology which explored the relationship between perceptions and life-threatening illness.

**Cognitive Coping**

The positive contributions research has come to be known as cognitive coping and is described by Turnbull & Turnbull (1993, p. 1):

Cognitive coping is defined as thinking about a particular situation in ways that enhance a sense of well-being. Although theory development and research on cognitive coping have been ongoing in the field of social psychology for
a number of years, cognitive coping as a research focus is relatively new to the developmental disability field.

The theoretical aspects of this work were inspired by Taylor's (1983, cited in Turnbull & Turnbull, 1993, p. 3) article, "Adjustment to Threatening Events: A Theory of Cognitive Adaptation" in which she described the adjustment process used by individuals who experience personally threatening events as:

- searching for the meaning of the event,
- increasing self-esteem, and
- establishing mastery over the event in particular and over one's life more broadly (Turnbull & Turnbull, 1993).

The research team at the Beach Center stated that "... cognitive coping has the potential for enhancing the well-being of families" (Turnbull & Turnbull, 1993, p. 2). The work is ongoing and has raised more questions than have been answered (see Turnbull, Patterson, Behr, Murphy, Marquis & Blue-Banning, 1993), but a research agenda has been set, one which is anticipated to be "... a far more productive type of inquiry than the pathogenic emphasis ... found in the literature" (Turnbull & Turnbull, 1993, p. 3).

**Implications of Alternative Perspective**

The work of the Beach Center researchers is providing an alternative to the pervasive view of people with disabilities and their families as victims of perpetual tragedy. It may provide an empirical base for professionals who, in future, may be more cautious about attributing Pollyanna labels to families who express positive views. There is some evidence that the traditional deficit models of service delivery focussed on the individual child are shifting to new paradigms of support which "... incorporate practices directed at strengthening families ..." (Gavidia - Payne, 1995, p. 11). It is hoped that a more optimistic view will be given credit.
Although now there is a body of available literature, I first heard of this work at a presentation by Ann and Rud Turnbull, of the Beach Center, at a conference in 1990. Whilst I was encouraged and very excited by their presentation and workshop (Turnbull & Turnbull, 1990), many colleagues were not as impressed and, in fact, were somewhat sceptical. Upon reflection, this may have had something to do with Australian/American cultural differences. The Turnbulls were highly enthusiastic presenters and had a somewhat "gung-ho" approach in the eyes of some. Upon reviewing their words, some of this may be understandable. They spoke with a passionate enthusiasm of "positive contributions", of "visions for the future", of families having "great expectations", of "being realistic as 'out', but being optimistic as 'in'", of "dealing with struggle and winning", and of becoming "heroes as a result of tragedy". Their thoughts had meaning for me and I was impressed by their passion, but I am sensitive to the need for caution. Perhaps their words were off-putting to others for two reasons. The first is their optimistic American flavour which more circumspect Australians find naturally suspicious. Second, the emphasis was very much on the positive with a de-emphasis of the problems faced by families. Not only colleagues, but some parents with whom I talked about potential research, objected to the word "positive". Some did not relate at all to such a conceptualisation. Interestingly, discussion with the parents revealed there to be many aspects of their experience which were other than negative.

In critiquing the Turnbull et al. (1993) book, "Cognitive Coping, Families and Disability" which presents a culmination of the "cognitive coping" body of work, Blacher (1995) is sceptical about the "silver lining" agenda and refers to the "... strong empirical evidence of negative impacts (otherwise why is there a need for coping?)" (p. 688). She does however, concede: 'It is a 'work in progress'. It will, I hope, stimulate further study of how families cope effectively as well as applications of 'cognitive coping' in service delivery" (p. 689).
Voysey (1975) cautioned professionals regarding the imposition of their own grid of conceptualisations and against the selective definition of relevant areas for investigation. Whilst her comments refer to the negative impact of disability, we need to be as cautious about the imposition of a positive grid of conceptualisation. As with most phenomena, a balanced approach in which both positive and negative contributions are recognised, is sensible. The aim of my research was to allow such a balance to emerge.

**THE RESEARCH QUESTION**

This examination of theoretical perspectives, which shape professionals' interpretations of parents' responses to developmental disability, has demonstrated the overwhelming impact of a negative focus. My nursing practice with families caused me to question the assumptions which underpin such interpretations. We have seen that a more recent literature, with its focus on positive contributions, has been received with some scepticism. The issue for me became one of reconciling my own practice experience with a contradictory literature and, for a long time, I was baffled as to how I might go about this. The thoughts spun around for a long time, thoughts such as: there is a huge extant literature; often this literature appears to be biased; often the studies are very narrow and focussed on stress and burden; the literature does not reflect my practice observations; the parents' voices are missing. There - I had it. The parents' voices - ask the parents.

Then, it was **what** to ask the parents? In light of a reluctance to impose Voysey's (1975) grid of conceptualisations and a recognised scepticism regarding the "positive" terminology, I was anxious to leave the question as open as possible. It was then that Amanda gave me her wonderful other reality words (as explained in Chapter One) and I realised that it was the other reality I wished to explore. But, how would I go about this?
As it was the lived-experience of parents of children with disabilities that I wished to explore, a phenomenological approach became obvious. Interpretive phenomenology provided a bridge to the lived world of the parents (Kestenbaum, 1982) and a way of understanding and interpreting their experience. The research question thus became:

"Parents' Experience of Developmental Disability".

The remaining chapters will describe how this question was answered.
Chapter Four

RESEARCH METHODOLOGY

- PHILOSOPHY and APPROACH -

"We explain nature, but human life we must understand..."

(Dilthey, 1976, cited in van Manen, 1990, p. 4)
BACKGROUND

This chapter begins with an account of my methodological journey. It is presented in this manner in recognition of the emergent methodology and as a reflection of the ongoing debate and theoretical developments within nursing (e.g., see Baker, Wuest & Stern, 1992; Crotty, 1996; Munhall, 1994; Ray, 1994). It will be shown that, whilst the approach adopted was an interpretive one, there were a number of theoretical approaches which influenced the methods used. Darbyshire (1994, p. 189) said:

In claiming that researchers need no longer argue for the legitimacy of qualitative and interpretive methods I stress that this does not release the researcher from the obligation to explain the methods used to obtain and interpret the research data.

In documenting the ups and downs of coming to understand the theoretical assumptions which underpinned this work, the integrity of design analysis and final interpretation may be assessed.

Following this background, the chapter then concentrates on aspects of phenomenology which influenced the research approach. Phenomenology is thus presented as informing the theoretical framework and hermeneutics as the method employed to answer the research question.

The methodology used for this study was an emergent one. Whilst, from the beginning of the project, I stated that I was using a phenomenological approach, I was also stating that I would use the methods as outlined by the grounded theorists (Glaser & Strauss, 1967; Strauss & Corbin, 1990). This choice was influenced by Chenitz & Swanson’s (1987) major work, in which they stated:

Symbolic interaction is a theory about human behaviour.... Symbolic interaction focuses on the meaning of events to people in natural or everyday settings and is therefore akin to the school of philosophy known as phenomenology (p. 4)
From the beginning, I was also reading fairly eclectically about phenomenological research (Allen, Benner & Diekelmann, 1986; Anderson, 1991; Bartjes, 1991; Benner, 1985; Bergum, 1991; Carpenter, 1978; Cohen, 1987; Davis, 1978; Dovey & Graffam, 1987; Jacobs, 1980; Luckmann, 1978; Lynch-Sauer, 1985; Oiler, 1982; Omery, 1983; Rose, 1990; Solomon, 1972; Swanson-Kauffman & Schonwald, 1988) but at very much a beginning level. It seemed to me that the phenomenologists were advocating an approach which was legitimate and meaningful for my work, but were not providing me with instructions for how to do it. Hence the appeal of the grounded theorists in terms of their detailed instructions for how to conduct analysis. My intended dual approach was further legitimised by Swanson-Kauffman's (1986) advocacy for a combined qualitative methodology (grounded theory, ethnography and phenomenology) "... as a nursing-appropriate methodology that fits our unique phenomena of discernment, namely, persons, environments, health and nursing" (p. 59). It was not until I read Baker et al.'s (1992) paper on "method slurring", in which they explicate the "roots of phenomenology" and the "roots of grounded theory", that I began to understand the differences and their importance, and also realised that my work was firmly rooted in phenomenology.

Further study enabled me to realise the term phenomenology has been so widely used that its meaning has become confused. It is viewed as a philosophy, a paradigm, a perspective and as method, and sometimes is used synonymously with qualitative methods. The literature which relates to phenomenology abounds with a bewildering array of technical terms which are daunting for the novice. People from many disciplines such as nursing, education, psychology, sociology, medicine and occupational therapy claim to use the tenets of phenomenology as applied research method and as a way of examining human endeavour. In an earlier version of this chapter, I had written that my own sense of the applied literature is that it is confused and confusing.
Discussion, exploration and further reading on my part brought about some parting of the mists (Benner, 1994; Bleicher, 1980; Cohen & Omery, 1994; Crotty, 1996; Dreyfus, 1991; Hammond, Howarth & Keat, 1991; Heidegger, 1962; Husserl, 1970; Koch, 1993; Moustakas, 1994; Munhall, 1994; Ray, 1994; Stewart & Mickunas, 1990; Taylor, 1991; Thompson, 1990; van Manen, 1990; Walters, 1994) and it was with some satisfaction that I read Ray's (1994, p. 123) words:

A serious concern in phenomenologic inquiry in the nursing literature relates to the lack of philosophical understanding of phenomenology on the part of many researchers. Phenomenology often is misused or is used to refer to the qualitative paradigm ...

This lack of philosophical understanding has also resulted in a perception of a single phenomenology, as there frequently has been no attempt to discriminate between the two dominant traditions within the nursing phenomenological movement, namely, Husserlian and Heideggerian phenomenology (Walters, 1994, 1995). Koch (1993, 1995) supports this view and says that nursing "... phenomenological techniques and procedures are often brought together by the incorrect assumption that they are grounded in the same philosophy" (Koch, 1995, p. 827). She recognised also that "phenomenology" and "hermeneutics" are used interchangeably in the nursing literature and contends that nursing, as an emerging discipline, has concerned itself with methods to the detriment of an exploration of the philosophical underpinnings of these methods. Both Walters and Koch are clear about the distinction between Husserlian transcendental phenomenology and Heideggerian hermeneutic phenomenology, and agree on the implications of these approaches for nursing research.

As a result of this exploration and increasing understanding, all notions of grounded theory methods were abandoned as I came to realise that I was not utilising grounded theory. This realisation developed as a result of my increasing knowledge regarding the different intellectual
assumptions upon which grounded theory and phenomenology are based (Baker et al., 1992). This is not to say that at the beginning of my data analysis I was not influenced by my reading of grounded theory literature. As will be shown in the following chapter, my initial analysis of the text was a detailed, line-by-line, substantive analysis of the participants' words. However, this was the only major influence and it did provide me with a useful technique as a beginner in a methodology which has "no method" (van Manen, 1990, p. 30).

The methodology I used was largely informed by Heideggerian phenomenology whilst hermeneutics (interpretation) provided the framework used to develop understanding of the parents' experience in a disciplined fashion (van Manen, 1990). However, the work was also influenced, particularly in its early stages, by Husserlian phenomenology. In recognition of this dual influence on me, as well as on much of the literature I relied upon, an introduction to both philosophies will be outlined. In this way, the influence of my earlier reading will be acknowledged. Following this, I shall examine the implications of both for this research, thus providing the reasons for its use. Whilst the approach is described generally as an interpretative approach, the larger influence of hermeneutic phenomenology will be apparent. The application of this methodology will be discussed in Chapter Five as "research procedures".

PHENOMENOLOGY

Phenomenology grew out of a critique of positivism applied to human concerns (Cohen, 1987). It is not a rigid school or uniform philosophic discipline and Spiegelberg (1976), when writing of its history, used the term phenomenological movement to indicate its constant change and continuing evolution. He defined phenomenology as:

The name for a philosophical movement whose primary objective is the direct investigation and description of
phenomena as consciously experienced, without theories about their causal explanation and as free as possible from unexamined preconceptions and presuppositions.


It is often referred to as a "world view" which is concerned with our relationship to the world through consciousness.

Taylor (1991) described the nature of phenomenology as "multifaceted" and presented Spiegelberg's (1970, cited in Taylor, 1991, p. 70) compilation of six types of phenomenology which are not mutually exclusive, but unified in a common purpose. They are:

- "descriptive phenomenology" - a direct description of phenomena aimed at maximum intuitive content;
- "essential (eidetic) phenomenology" - seeks to explain essences and their relationships;
- "phenomenology of appearances" - attends to the ways in which phenomena appear;
- "constitutive phenomenology" - studies processes whereby phenomena become established in our consciousness;
- "reductive phenomenology" - relies on suspending belief in the reality or validity of phenomena; and
- "hermeneutic phenomenology" - a phenomenological interpretation which seeks to unveil hidden meanings in phenomena.

Despite the dynamic and diverse ways in which the phenomenological approach to philosophy has been applied, Stewart and Mickunas (1990) said that phenomenological philosophy can be characterised as centring on the following basic themes:

- a return to the traditional tasks of philosophy - to articulate the questions arising out of the depths of the human spirit itself, and to develop knowledge and understanding of men and women and their relationship to the world;
• the search for a philosophy without presuppositions - phenomenology aims to suspend assumptions about the nature of reality while turning to the content of consciousness itself, the phenomena;
• the intentionality of consciousness - which holds that consciousness is always directed toward an object, and is often expressed as "consciousness is consciousness of ...", and is tied to the world of experience;
• the refusal of the subject-object dichotomy - by shifting attention from the question of the reality of the world to its meaning as phenomena, the distance between consciousness and its content is overcome.

Consciousness is unified.

Stewart and Mickunas (1990) did provide caveats to such a summary in recognition of phenomenology's diversity, but consider that the above themes are characteristic.

Taylor (1991) said that, despite complex philosophical debate on major concepts, "The binding concern they (phenomenologies) share is for the direct exploration of phenomena, as a means of explicating Being" (p. 70).

The Phenomenology of Edmund Husserl

Edmund Husserl (1859 - 1938) is the acknowledged founder of modern phenomenology and the principal figure in the development of the phenomenological method (Stewart & Mickunas, 1990). Husserl's phenomenology was the culmination of Cartesian tradition "that thinks of man's relationship to the world in terms of subjects knowing objects" (Dreyfus, 1987, cited in Walters, 1995, p. 792) and "came to mean the study of phenomena as they appear through the consciousness" (Koch, 1995, p. 828). To do this, "a return to the things themselves was mandatory in order that 'uncensored phenomena' be discovered, explored and described" (Taylor, 1991).

Husserl held the view that, in striving to build up an objective view of reality, scientific practice has progressively cut off subjective experience
from the life-world to such an extent that Western man is in a permanent state of crisis, that is, he feels that science is the only source of facts, and loses consequently his lived relation to the historical and social reality of life (Husserl, 1970). Husserl therefore introduced the concept of the "Life-world" or "Lived experience" which constitutes what is taken for granted or those things which are common sense (Koch, 1995).

Husserl's phenomenology, in describing phenomena, has to cope with the essences of our subjective experience. In order to reach this essence, one has to go through a multiplicity of possible profiles which convey meaning, the essence (eidos) being the sum of all possible profiles (Thines, 1987a, 1987b). For Husserl, all experience could be transformed into its essence through a process of eidetic intuition which is the activity of seeing into the essence of a thing (Taylor, 1991).

One of the more contentious aspects of Husserl's work is the notion of bracketing or epoche which holds that the point of view of natural science is to be left out of consideration or set aside. This is his act of phenomenological reduction, during which attention is narrowed, the superfluous and accidental are ignored, whilst previous prejudice about the world is set aside. The three terms - phenomenological reduction, epoche, bracketing - are synonymous and Husserl used them interchangeably. They are metaphors which describe a change of attitude (Stewart & Mickunas, 1990; Thines, 1987a, 1987b). It is through this process of bracketing that Husserlian phenomenology claims an "objectivity of interpretation against the self-interest of the researcher" (Koch, 1995, p. 828).

In summary, Husserlian phenomenology asks about the meaning of human experience. Its reality is the life world which conceptualises people as subjects in a world of objects (Walters, 1995), and its task is a matter of describing. Its three dominant notions are:

- **intentionality** - the mind/consciousness/subject is always directed towards objects;
• essences - the distillation of experience;
• phenomenological reduction - bracketing (Koch, 1995).

The Phenomenology of Martin Heidegger

Martin Heidegger (1889 - 1976), who was Husserl's student, reinterpreted phenomenology and its methods. His phenomenology is existential, a perspective which insists that the observer cannot be separated from the world, and that an understanding of the person cannot occur in isolation from the person's world (van Manen, 1990; Walters, 1995). Heidegger's emphasis is on being-in-the-world (dasein) and how phenomena present themselves in lived experience, in human existence (van Manen, 1990). He argued that Husserl's attempt to describe everything as correlates of consciousness overlooked basic dimensions of human existence such as dread, anxiety, forlornness and death. Heidegger also argued with bracketing as the method of investigating these aspects of existence and instead, wanted to find "the basic modalities of being-in-the-world" (Stewart & Mickunas, 1990, p. 69). So, for Heidegger, phenomenology was ontology, a study of the modes of being-in-the-world of human being. Heidegger's aim was to let the things of the world speak for themselves and asked, "What is the nature of this being?" (van Manen, 1990, p. 184). So, Heidegger's phenomenology is an explication of the meaning of being.

The method that Heidegger used for this explication of being was hermeneutics (from the Greek word for "interpretation") which he considered as one of the processes which people use in making sense of their everyday lives (Walters, 1994). He argued that hermeneutics presupposes prior understanding on the part of the interpreter and that it is only possible to interpret something according to one's own lived experience (Walters, 1995).

In order to understand Heidegger's hermeneutics, we must grasp the importance of the historicality of understanding and the hermeneutic circle. Stewart and Mickunas (1990, p. 162) paint the following picture:
... imagine a circle that represents a written ... text. The circle is contained within a larger circle which represents all the artefacts of a culture. Finally both are included within a larger circle which is human existence itself, an interpretation of which opens up an understanding of one's possibilities of being.

In contrast to Husserlian phenomenology, which brackets out presuppositions, hermeneutics attempts to discover and explicate prejudgments as such prejudgments constitute our own historical horizons and comprise a pre-understanding (Stewart & Mickunas, 1990). Koch (1995) refers to the ideas of background, pre-understanding, co-constitution and interpretation as essential to understanding the historicality of understanding and the hermeneutic circle. A summary of her descriptions follows:

- **Background** - a person's history or background is handed down and presents a way of understanding the world. This is what culture gives a person from birth.

- **Pre-understanding** - the meaning and organisation of a culture which are already in the world before we understand and which become part of our own story. We bring our stories to any situation and thus pre-understanding is a structure of our "being-in-the-world".

- **Co-constitution** - refers to the assumption of indissoluble unity ("person-world"), which means being constructed by the world in which we live and at the same time constructing this world from our own experience and background.

- **Interpretation** - people encounter the world with reference to their own background understanding, and all encounters entail interpretation based on this background. For Heidegger, we are "self-interpreting beings".

In summary, Heideggerian phenomenology asks "What does it mean to be a person?" and holds that the answer to this is found in *Dasein* or being
already in the world. As such, it deals with questions of human existence by seeking the meaning of being.

**Comparison Between Husserlian Phenomenology and Heideggerian Phenomenology**

Koch (1995, p. 832) has provided a useful comparison of these two phenomenologies. Her work is reproduced below as Table 2 and illustrates the following points. Broadly speaking, Husserlian phenomenology, with its emphasis on consciousness, is transcendental. It is epistemological, in that it deals with questions of knowing and experience, and its methods are descriptive. Heideggerian phenomenology is existential, as it deals with questions of existence, is ontological in its search for an understanding of being, and its methods are interpretive.

**Table 2 - Comparing and Contrasting Two Theories of Interpretation**

<table>
<thead>
<tr>
<th>Husserlian Phenomenology</th>
<th>Heideggerian Phenomenology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transcendental phenomenology</td>
<td>Philosophical hermeneutics</td>
</tr>
<tr>
<td>Epistemological</td>
<td>Existential-ontological</td>
</tr>
<tr>
<td>Epistemological questions of knowing</td>
<td>Questions of experiencing and understanding</td>
</tr>
<tr>
<td>How do we know what we know?</td>
<td>What does it mean to be a person?</td>
</tr>
<tr>
<td>Cartesian duality: mind-body split</td>
<td>Dasein</td>
</tr>
<tr>
<td>A mechanistic view of the person</td>
<td>Person as self-interpreting being</td>
</tr>
<tr>
<td>Mind-body person lives in a world of objects</td>
<td>Person exists as a “being” in and of the world</td>
</tr>
<tr>
<td>Ahistorical</td>
<td>Historicality</td>
</tr>
<tr>
<td>Unit of analysis is the meaning giving subject</td>
<td>Unit of analysis is the transaction between the situation and the person</td>
</tr>
<tr>
<td>What is shared is the essence of the conscious mind</td>
<td>What is shared is culture, history, practice, language</td>
</tr>
<tr>
<td>Starts with a reflection of mental states</td>
<td>We are already in the world in our pre-reflective selves</td>
</tr>
<tr>
<td>Meaning is unsullied by the interpreter’s own normative goals or view of the world</td>
<td>Interpreters participate in making data</td>
</tr>
<tr>
<td>Participants’ meanings can be reconstituted in interpretive work by insisting that the data speak for themselves</td>
<td>Within the fore-structure of understanding interpretation can only make explicit what is already understood</td>
</tr>
<tr>
<td>Claim that adequate techniques and procedures guarantee validity of interpretation</td>
<td>Establish own criteria for trustworthiness of research</td>
</tr>
<tr>
<td>Bracketing defends the validity or objectivity of the interpretation against self-interest</td>
<td>The hermeneutic circle (background, co-constitution, pre-understanding)</td>
</tr>
</tbody>
</table>

(Reproduced from Koch, 1995)
The concepts in this table reflect also the work of Walters (1994, 1995). Both Koch and Walters refer to Husserl's work as a culmination of Cartesian dualism, (i.e., the mind-body split). However, this may be an oversimplification as this assumption contradicts the work of others (e.g., Cohen, 1987; Fjelland & Gjengedal, 1994; Stewart & Mickunas, 1990; Thines, 1987a, 1987b) who take the position that Husserl's goal was to break down Cartesian dualism. It is beyond the scope of this work to explore the issue further.

The table is however useful, in so far as it distils the salient differences between the phenomenologies which had a major impact on my own work and because it enabled me to see at a glance many of the shifts in my own thinking over the period of this research.

AN INTERPRETIVE APPROACH

This research was inspired by my nursing work with the parents of children with significant developmental disabilities - the parents challenged my assumptions about what life was like for them. Amanda gave the research a voice when she spoke of her other reality, and so the endeavour became one of exploring this other reality. Phenomenology looks "to the things themselves" and aims to uncover essential structures of reality (Crotty, 1996) and thus provided the methodological key for the research. Van Manen (1990, p. 62) wrote:

In phenomenological research the emphasis is always on the meaning of lived experience. The point of phenomenological research is to "borrow" other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience in the context of the whole human experience.

In keeping with interpretive phenomenology, the participants in this study are parents of children with significant developmental disabilities whose
lives are lived by experiencing the world and not by "knowing" it in Husserlian terms (Thompson, 1990). The research endeavour became one of exploring their being-in-the-world as a parent of a child with a significant disability.

As I was concerned about the predominantly negative focus of the extant literature in this area, I was determined to approach the research in as open a manner as possible; I did not wish to impose Voysey's (1975) grid of conceptualisations upon my work (see Chapter Three). For this reason, the Husserlian notion of bracketing had initial appeal. The parents had already challenged my assumptions when I was a practitioner so it became vital for me to suspend or to bracket all of my professional understandings and everyday perceptions regarding their experiences. Whilst this seemed a daunting task, I accepted such suspension of understanding as possible as I likened it to the suspension of judgement that, as a nurse, I was very familiar with. (After all, didn't I suspend my judgement on a daily basis when working with people whose values and practices were incongruent with my own?) As the work progressed however, I came to observe that this process was not happening. It seemed to me that I might be able to bracket out interpretations such as staged grief, but the parents did not. Sometimes they referred to such interpretations themselves when talking of their experiences. Over a period of time, this stance was reviewed and the Heideggerian notions of persons existing as being in and of the world, with the accompanying notions of shared culture, history, practices and language made more sense. The stance taken here is the Heideggerian one of us all being born into a world of meaning in which we are essentially cultural creatures, one in which we are taught meanings and in which a comprehensive system of significant symbols is bestowed upon us (Crotty, 1996). In fact, I later came to realise that it was the very point being made in Chapter Two when exploring the private meanings of mental retardation and its associations with fear, shame, tragedy and horror - associations which we all share culturally.
Heidegger's view of being in the world also affected my own stance as researcher, as Heideggerian phenomenology holds that there is "... no privileged position for 'objective' knowing and that all knowledge emanates from persons who are already in the world, seeking to understand persons who are also already in the world" (Leonard, 1994, p. 55). Thus, the participants and I share common everyday practical understandings and practices by virtue of our shared culture and language.

The Heideggerian view of people as self-interpreting beings involves an interpretation on the part of the researcher in order to understand human experience (Leonard, 1994). This interpretive activity is central to the research approach employed with both participants and researcher, along with their stories, culture and being-in-the-world, being within the hermeneutical circle which opens up an understanding of the possibilities of being.

At the core of phenomenology is the concept of intentionality which, according to Crotty (1996) embraces both the subjective and the objective. For Husserl, intentionality was a consciousness of; in existentialist terms "intentionality is the radical interdependence of subject and world" (Crotty, 1996, p. 40), which are always united as being-in-the-world. For this research, the notion of intentionality is captured if we think of the phenomenon of being a parent of a child with a disability as the object of these parents' experience, and the structures of that phenomenon being made accessible to me via the parents' experiences. Van Manen (1990, p. 63) calls these human experiences the "data" of human science research.

But what is this "experience" that is made so much of in phenomenology? Oiler Boyd (1993) tells us it is the "perceived world" and that "the focus on phenomenology is, then, a focus on human involvement in a world" (p. 103), whilst Munhhall (1994, p. 15) refers to "perception, which takes place through the body, [as] an individual's access to experience in the world" so that, when phenomenologists say that their aim is to describe lived experience, this becomes a description of the perceptions of that lived
experience. This concept, for me, became crucial. It was the perception of their experiences as parents of children with developmental disabilities which was the focus of the research. Whether they were telling the "truth" or recalling "reality" was not at issue. What was important was the interpretation of the experience from the individual's unique perception of event(s)" (Munhall, 1994, p. 16). Therefore, the question became one of not what was happening, but what was perceived as happening. The intention behind such a question was not, as is sometimes assumed, to get at the parents' subjective experiences for the sake of reporting how things are from their perspective, but rather, to pursue the deeper goal of exploration of the nature of their experience (van Manen, 1984).

In order to create the data from the parents' experiences we had, what I called at the proposal stage of this work, "unstructured, open-ended interviews". Very quickly though, these "interviews" became, in van Manen's (1990, p. 63) words, "hermeneutic interviews" which used a "conversational interview method". By this is meant that the process, whilst inseparable and ongoing, may be distinguished by the gathering of material and the analysis of material. The conversational interview method may be used to gather people's experiences (which in my case became the listening to and commenting on of narrative), or may serve as occasions for conversational reflection (which happened when exploring aspects of their experiences in more depth or when talking of my interpretations) and thus, "the hermeneutic interview tends to turn the interviewees into participants or collaborators of the research project" (van Manen, 1990, p. 63). Interestingly, whilst all I said to the parents was, "Tell me about your experience ...", all of them returned to the beginning, that is the beginning of the knowledge of their child's disability, and told their stories from this beginning. Along with many others, I "... (re) discovered the narrative nature of human beings ..." and viewed these participants as "... partners engaged in the distinctively historic and hermeneutic activity of storytelling" (Sandelowski, 1991, p. 161).
The approach adopted was driven largely by the work of Max van Manen (1990) who uses an eclectic approach which he calls *hermeneutic phenomenology*. He outlined the essentials of phenomenological research as:

- The study of lived experience.
- The explication of phenomena as they present themselves to consciousness, rather than as conceptualised, categorised or theorised.
- The study of essences of experience which asks, not "how", but rather, what is the "nature" of the experience.
- The description of experiential meanings we live as we live them, examples of which are designed to enable us to see the structure or the deeper significance of the experience being described.
- The human scientific study of phenomena in that it is systematic, explicit, intersubjective, self-critical and examines structures of the lived, human world (rather than the natural world).
- The attentive practice of thoughtfulness whose language awakens a person to the meaning of the experience.
- A search for what it means to be human, which may be achieved by more deeply understanding human experience.
- A poetising activity insofar as its language reverberates the world rather than speaking "of" it, and so the poem itself is the result rather than a conclusion or summary of the phenomenological study.

Van Manen spoke of there being no "method" as such if this is understood as a set of procedures, but rather of "ways" or "paths" leading to "clearings". These paths cannot be determined by fixed signposts - they need to be discovered or invented as a response to the question in hand. He spoke, however, of a "tradition" - a set of guides and recommendations which form the basis of a principled form of enquiry. This tradition is presented as "methodological structure" in which hermeneutic phenomenological research is seen as a dynamic interplay among six research activities. These are as follows:
1. turning to a phenomenon which seriously interests us and converts us to the world;
2. investigating experience as we live it rather than as we conceptualise it;
3. reflecting on the essential themes which characterise the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented pedagogical relation to the phenomenon;
6. balancing the research context by considering parts and whole.


These research activities, coupled with van Manen's orientation, formed the basis for my own procedural activities which are presented below in Table 3. This table draws upon van Manen's (1984, 1990) work, as well as that of Lauterbach (1992) as presented in Oiler Boyd (1993, p. 125). It provides an overview of the whole research process and, as such, provides a summary of the procedural activities involved in the development of this thesis.

(Table 3 will appear on the next page)
Table 3 - Concurrent Procedural Activities

|TURNING TO THE NATURE OF LIVED EXPERIENCE| • Orienting to the phenomenon of "being the parent of a child with a developmental disability"
• Formulating the question, "Tell me about your experience ..."
• Explicating assumptions and pre-understandings - outlined in Chapters Two and Three

|THE EXISTENTIAL INVESTIGATION| • Turning to participants - permissions, etc.
• Exploration of the phenomenon: generating "data"
  - personal experience
  - experiential descriptions from participants, material "gathering"
  - experiential descriptions from literature, film
• Ongoing reading of phenomenological literature

|PHENOMENOLOGICAL REFLECTION AND INTERPRETATION| • Conducting analysis: textual transformation
  - examination of individual's experiences
  - uncovering thematic aspects
  - development of structures of whole phenomenon
  - conversational reflection with participants to refine themes
  - thematic description from artistic sources
• Determining essential themes: "Between Joy and Sorrow"

|PHENOMENOLOGICAL WRITING| • Writing
• Presentation of work to professional and non-professional audiences
• Rewriting
• Refinement

(Adapted from Lauterbach, 1992, in Oiler Boyd, 1993)

In summary, the approach used for this research was an eclectic interpretive phenomenological one which has its roots in the philosophies of Edmund Husserl and Martin Heidegger. It was influenced by much
reading in the nursing phenomenological literature and was driven by the writings of Max van Manen, as well as by interpretations of his work.

Crotty (1996) might argue that the work should be referred to as "new" phenomenology, a term he used to describe nursing phenomenology with its roots in humanism. By explicating the influences on my work and the understandings I have of those influences in terms of their interpretation into an approach, I am not overly concerned about the issue of labelling. However, when Crotty describes the work of Moutsakas (1961, cited in Crotty, 1996, p. 35 - 36) as "his study [becoming] phenomenological as he moved from an understanding of their individual experience of loneliness to an insight into what makes loneliness loneliness", I believe that my work would be described as a beginning phenomenological study. As will be seen, the work done with the six parents in this study does move from some understanding of their individual experiences to some beginning insight into their being-in-the-world as parents of children with developmental disabilities, a being which is "between joy and sorrow".

The following chapter will present how the interpretive phenomenological research approach, as described in this chapter, was put into action to become the research method.
Chapter Five

RESEARCH METHOD

- PROCEDURES-

"Refinement of the phenomenological reflection is attained ... (by) moving the descriptions away from the particular to a more universal sphere"

(Morse, 1994, p. 36)
This chapter describes the processes of the research. It presents the necessary procedural activities and documents how data were generated, handled and interpreted in order that the ethics, trustworthiness and rigour of the study may be evaluated. It provides an auditing of the conversion of the participants' accounts into themes.

TURNING TO THE PARTICIPANTS

Selection of Participants

Six parents of children with developmental disabilities took part in this study. Their pseudonyms, which are alphabetically grouped within families, are:

Amanda - Annie's mother,
Catherine - Charles' mother,
Jill and John - Joel's parents, and
Sally and Stephen - Samuel's parents,

and their stories are presented in the next chapter (Chapter Six). They were all known to me from my practice as a Community Nurse. I asked them to speak with me because my nursing work with them had indicated that they had much to say. In fact, they formed a core of parents who had played a part in my questioning of the theoretical assumptions upon which much of my nursing practice was based.

Following ethics approval from the University of Western Sydney, Nepean (see Appendix II), I wrote a letter (Appendix III) to twelve parents I had worked with in the past, who had expressed interest in ongoing contact for the purposes of research, in which I explained the project and requested their participation. An information sheet (Appendix IV) and consent forms (Appendix V) were sent with these letters. Ten of these parents replied, agreeing to participate and expressing enthusiasm for the project. However, due to time constraints and density of data, only six parents were interviewed.

83
There was no particular reason for the order in which I spoke with the parents, apart from convenience. Amanda was about to leave Australia so I spoke with her first.

**Ethical Considerations**

Ethics approval was granted by the University of Western Sydney, Nepean. In recognition of the potential for painful emotions to be surfaced, the University requested that I make available referral to a counsellor should the need arise. In compliance with this request, a second information sheet (Appendix VI) was handed to the parents at completion of our initial discussions. Such referral was not requested by any parents.

That is not to say that painful emotions were not surfaced, they were, but they were part of the parents' experience and as such, were not viewed as abnormal nor as requiring intervention. A number of the parents expressed that the interviewing process in itself was cathartic and therapeutic and had provided them with an opportunity to focus and reflect on their experiences with permission. Some expressed their reticence in talking about their experiences with others due to a perception of other people not wanting to hear and not being able to relate. They were also fearful of being a burden to others.

In discussion with the parents prior to their signing of the "Consent to Participate in Research", I talked with them about issues of confidentiality and data storage in order to make clear that their privacy would be protected. All of the parents indicated that this was not an issue for them, with some saying they had no objections regarding the use of their names. In retrospect, I was pleased this discussion had taken place as, despite all the usual precautions to safeguard privacy being in place, it became apparent that when using a small sample and qualitative methodology, dilemmas can arise in relation to confidentiality and anonymity. Upon presentation of this work, it has been apparent that occasionally members of the audience may recognise a participant family. This has been due to the presentation on my
part of contextual detail which is an essential element of the qualitative approach. A professional audience may well have had access to some of this contextual detail, and so may make educated guesses regarding participant identity. Sometimes, a professional audience includes people who are also parents of children with disabilities, and such parents know other parents of children with disabilities, possibly the research participants. The world of disability becomes a rather small one when we are talking of parents, specialised professionals and qualitative research which is rich in contextual detail. This experience has developed in me a sharp consciousness of the issues related to "confidentiality" and "anonymity" and of the dilemmas we face if guaranteeing both. It seems that qualitative researchers may be able to guarantee adherence to procedures designed to protect their participants' confidentiality but would need to be cautious about a guarantee of anonymity. Ramos (1989) addressed this issue when she wrote of the conflict between the goals of research and the goal of the preservation of the privacy of individuals due to the small number of participants involved and the detail of thick description which may make identities difficult to disguise. In the case of this particular research, the dilemma was pre-empted due to the willingness of these parents to forego their privacy. Whilst satisfied with my ethical stance in this situation, I believe I "got lucky". It was not an issue I had anticipated and, in future, would document the potential for threats to anonymity.

All of the parents in this study participated with enthusiasm. Their motives were apparently altruistic with expressions of their hopes of helping other parents being uppermost. I explained that the work was to be used for my Master of Nursing (Honours) but that I hoped it would prove useful in the education of health professionals. These parents all recognised that their participation would not provide them with direct benefits but hoped that parents like them would get a "better deal" in the future.
GENERATING DATA

The generation of data and their transformation into themes were actually concurrent and ongoing processes. However, these procedures will be described separately.

Experiential Descriptions from the Parents

The interviews with the parents took place over a period of about eighteen months and were mostly face-to-face conversations. Some discussion post-interview, took place over the telephone, usually as a result of my need to clarify a point or to talk through some new insight. All of the face-to-face discussions were audiotaped, whilst notes were made of telephone conversations.

I negotiated with each of the parents a suitable time and place for our discussions, allowing about two hours. Amanda, Catherine, Jill and John were interviewed separately in their homes at night, whilst Sally and Stephen, who have seven children, came to my place, on separate occasions, during the day. Each of these initial interviews was individual. This decision for the individual interviews was made during the proposal stage of this research and was based on advice from parents (not the research participants) who believed they would speak more freely about feelings in the absence of their partners. Their belief was borne out by some participants who stated they were able to say things to me that they would not have told their partners.

I had follow-up discussions with Jill and John, and with Sally and Stephen as couples in their homes, but due to Catherine’s then complicated second pregnancy and subsequent delivery of a stillborn child, as well as Amanda’s move to England, their follow-up was limited to telephone conversations. The purpose of these discussions was to allow for an expansion of some elements of our initial discussion using conversational reflection. Some themes were followed-up, explored further and validated, whilst others were discarded. In this way, the meanings of the experience
held by individuals were able to become part of a whole and these discussions became activities which generated and refined common meanings.

Immediately following each of the interviews I made notes in which I remarked upon contextual events, thoughts and emotions associated with the discussions. These notes became part of the data and are commented on in Chapter Six which tells the stories of the participating parents and their children.

Each of the interviews was transcribed (by another person), following which I read through each transcript whilst listening to the tapes. During this process I replaced names with pseudonyms, corrected any transcription errors and added contextual comments. This process allowed me to re-live the experience and to gain a sense of the whole.

At the beginning of each of the individual interviews, I said to the parents "Can you tell me about your experiences of living with your child who has a disability". Whilst I was hoping to uncover the "other side" of their experience, Amanda's other reality, I was cautious regarding any influence I may have had on their recollections. It was important that the parents had the freedom to speak from their own perspective and tell me their stories as they remembered them.

All of the parents went back to the "beginning"; that is, they told their stories as temporal narratives from either the birth of the child when the disabling condition was apparent (Amanda and Catherine), or from the time of the child's illness or accident which resulted in permanent disability (Jill, John, Sally and Stephen). Generally, about half the discussion time was spent on these narratives, during which the parents referred to many negative aspects of their experience. This seemed to act as a catharsis and was followed by more of a focus on what was occurring in the present.

By and large, I had little to say during their narratives but, once their stories moved on, the interviews became more conversational. Sometimes, I asked them to elaborate on a point and sometimes I asked a question as a
result of their comments. As time went on, my request for elaboration was sometimes as a result of thinking directed by previous interviews. An example of this occurred with Jill who had spoken of knowing that things were bad following Joel's drowning and that, very early on, the thought of brain damage had occurred to her. At this point in the study, I was interested in this theme of "knowing" and had also begun to develop a sense of people's past experience and knowledge of disability as having some meaning in the overall scheme of things (although at this stage the thoughts were not formed). So I asked her, "How did you know? What made you think that, and had you had any past experience of brain damage?"

When it seemed relevant, I sometimes introduced a point which had been discussed with other participants; Amanda had spoken of not having a map until Annie was about three. By this she meant that developmental milestones were based on the "normal" and she had no developmental map for Annie. For Amanda, this was a big issue, so I introduced the topic with the other participants, or brought it up when they spoke of hopes or expectations. In some instances, it seemed useful to discuss the parents' reactions to a particular theoretical viewpoint, and some useful discussion regarding chronic sorrow took place as a result of my introducing the concept, generally in the context of discussion related to grief, sadness or sorrow.

Experiential Descriptions from Other Sources

As previously stated, data generation, transformation, and interpretation were concurrent processes and, during this time, I continued to read widely. Parents' experiences, from a variety of sources such as books, magazine and newspaper articles, and film, as well as fragments from professional literature (see Chapter Three), were incorporated as data. Some of these sources fed into the development of structures of the whole phenomenon and where such interpretive incorporation has occurred will be indicated in Chapter Eleven. My own sensitisation to the project resulted
in data from sometimes unexpected sources. This was particularly evident when I saw the film "Lorenzo's Oil". Whilst I had gone to see the film as recreation, my researcher's attitude was soon engaged and the impact this film had on a major interpretive theme will be discussed later.

**CONDUCTING ANALYSIS: TEXTUAL TRANSFORMATION**

Transformation of the data from text to essential themes was supported by use of the computer software programme, NUD.IST (Non-numerical Data Indexing, Searching and Theorising) (Richards & Richards, 1990). As the presentation of the procedures used to transform the data from text to themes is a complex task, I shall describe how NUD.IST supported the processes and shall then provide a description of the thinking behind textual transformation which will be illustrated by using just three lines of text. In this way the processes are made transparent and the interpretive procedures may be audited.

**NUD.IST**

NUD.IST is a system for managing, organising and supporting the analysis of text data in qualitative research projects. The programme includes operations which enable the researcher to clerically manage data and the development of categories. It allows text data to be indexed at categories and allows for the retrieval of relevant data, as well as supporting the questioning of text by its ability to store ideas and explore propositions (Minichiello, Aroni, Timewell & Alexander, 1995). Given the large amount of text data generated by this project, NUD.IST enabled me to have some control over it. The transcripts, as produced by NUD.IST, were numbered by lines which allowed ready access to the text units.

**Categories**

NUD.IST supports interpretive analysis by enabling any text to be indexed, hierarchically in a tree structure of categories and sub-categories.
All text may be indexed at multiple points thus allowing relationships between the text to be later explored. The tree structure of categories allows umbrella categories to be developed which incorporate any number of specific sub-categories. A simple example of an indexing category is presented in Figure 1.

![Figure 1 - Indexing Category of "Feelings"](image)

Figure 1 represents an abbreviated depiction of the category of "feelings". In reality, there were seven sub-categories of positive feelings and twenty-three sub-categories of negative feelings.

As an example of how this category was used, whenever the parents spoke of "feelings" or wherever I interpreted their words to be reflective of "feelings", the particular line/lines of text would be indexed against the relevant sub-category. If their words did not fit within a sub-category already developed, then a new one was easily created.

At the outset, I had categories and sub-categories which related to
- demographic information - mother, father, child, gender, age, etc. ("base data")
- information about the data - initial interview, follow-up interview, etc. ("data types")
- information about the "people" being referred to by the parents - family, friends, various categories of professionals, etc. ("people")
- information about the "child", and umbrella categories of
  - "feelings"
  - "values and beliefs"
• "attitudes" and
• "behaviours".

These were my starting points, whilst the other categories and sub-categories emerged from the data. This system grew to be very large and a copy of it may be found in Appendix VII.

**Textual Transformation**

Prior to entering any data into the computer, I worked with a printed copy of each interview and wrote notes directly onto the transcript - I called this **coding**. With each transcript, following the manual coding, the information was entered into the computer - this is called **indexing** against **categories** and **sub-categories**.

Once the data are indexed, NUD.IST has a capacity which enables exploration, questioning, checking of relationships and theorising. It also allows a temporal tracking of conceptual development in that it records, in the form of "comments", notes about time and dates of the development of the indexing system, and also records all procedures undertaken in terms of linking and exploration of the categories and sub-categories. The user may also add comments to any category or sub-category which enables recording of thoughts, questions and insights.

At a later stage of the analysis, the categories and sub-categories were subsumed under denser categories which then became **themes**. In this way, the categories became structures of the themes which are the structures of the whole phenomenon.

**Coding**

Each transcript was coded line-by-line. I did this by working with the documents and writing what I believed to be the substance of what was being said in a right-hand column. I did this fairly rapidly and largely as my immediate response to the data. A typical page read:
Special things
Rejection
Child-as "reject" by others
Failure
Ambiguities
Bonds
Trust
Finding a new self
Special things
Knowing
Special things
Respect (for others)
Professionals - being a jump ahead of
Tactics
Respect
Professionals - being treated differently

Indexing Against Categories

Upon completion of the "response coding" described above, I then indexed the data into NUD.IST. This was a very slow, laborious and time-consuming process, and it involved a great deal of pondering. Sometimes, a single line of text might be indexed against four or five categories, and sometimes a few lines might be put into just one category. The categories were created as the need arose and as the data directed. This complexity is well illustrated by the following three lines of text from Amanda:

"...yes, yes you have given birth and this is actually a reject this child, "Try for another they say almost immediately" You say, "What do you mean try for another one? I flunked up this one,

and I don't want to go to hospital again" (laughing) ..."
Initial indexing of this text was at the following categories:
people/child
people/professionals/doctors
child/perceptions of/reject
feelings/negative/failure
feelings/negative/rejection
values & beliefs/re disability/negative
attitudes/towards mother/negative/rejection
attitudes/towards mother/negative/failure
attitudes/towards child/negative/rejection
confusion, doubts and ambiguities.
The entire document had been previously entered against relevant demographic and data type categories, so the cross-indexing for these three lines of text gave me a great deal of information.

As a result of this indexing, I know that a mother (with all of her relevant demographic information) is speaking about her feelings of failure and rejection. She is also speaking about her child (whose demographic details are also indexed), and about professionals (I know from previous words that she is referring to doctors). I believe that her words are reflective of values and beliefs regarding disability, and also reflect a state of what I termed "confusion, doubts and ambiguities". The indexing also tells me that this document is an initial interview.

Whilst at this early stage of indexing I was attempting to remain within the data and avoid making early conceptual leaps, I had recorded the following comment against the category of "confusion, doubts and ambiguities":

93
What do conflicting beliefs lead to?

viz. Amanda

Beliefs (mother) ......Confusion ......Beliefs (Professionals)

Doubts

Ambiguities

This comment just sat for a long time, and it was not until four transcripts had been indexed that I began to check out this early hunch. I shall explain how this was done when I am discussing exploration of the data.

This very fine reduction of the data into meaningful conceptual units resulted in an enormous indexing system which was stuck to the wall and I lived and breathed it day and night. I used to sit in front of it and say, "But what does it all mean?" One night, as I was going to bed (the indexing system was then on the bedroom wall), I had my first "ah-ha!" experience. This proved to be the first major insight which led to the beginning transformation of the data.

Category Development

This first glimmer of insight related to "positives" and "negatives". Quite unintentionally I had indexed the data in such a fashion that I had positive and negative aspects of the parents' experience staring at me from the wall. A quick highlighting with the fluoro pens made this apparent.

Under the heading of "qualities of child" were listed words such as "fighter", survivor", "happy nature", "affectionate" and "selfish". Under the heading "perceptions of child" were listed "failure" and "vegetable". I had large numbers of sub-categories under "positive" feelings and "negative" feelings, and also many sorts of attitudes towards parents and child which were grouped under either "positive" or "negative". There were also bits of "positive" or "negative" all through the indexing system, but the sub-categories under "child", "feelings" and "attitudes" were very apparent.

Whilst looking at all of this, the big question started to form: "I wonder if the positive stuff relates to what parents are saying, and if the
negative stuff relates to what professionals and other people are saying?" NUD.IST allowed me to ask these questions and gave me the answers, along with the supporting data. The answer was a resounding "yes!" By and large, when the parents referred to their children, the language was optimistic and they spoke of the positive feelings engendered by their children. However, when they referred to interactions with many professionals and sometimes, other people (friends, family, acquaintances, the general public) the language was frequently full of pain. This provided me with a starting point which enabled me to develop other insights and ask further questions.

Constant working with the data and the indexing system, ceaseless reflection and occasional spontaneous insights led to a reconceptualisation of the data into fewer, but more dense categories. Often, the data needed to be re-worked in light of some fresh idea. The categories which were now becoming themes, were developed as a conceptualisation of the relationship between each other. NUD.IST supported all of this thinking and, by illustrating with the same three lines from Amanda's interview, I shall explain how this occurred. Further along in the analysis, Amanda's three lines were also indexed at:

- child/perceptions of/negative/professionals/yes
- feelings/negative/imposed by professionals
- values and beliefs/re disability/negative/dissonant with attitudes re child
- attitudes/toward child/negative/professionals
- confusion, doubts and ambiguities/professionals' contributions

By this stage, I was asking what impact professionals had on the parents' states of being, and also if there was any conflict between the parents' values and beliefs regarding disability and their expressed attitudes and behaviours towards their children. I had developed a sense of the parents sometimes saying something which seemed reflective of deeply held negative values regarding disability and yet, speaking of their own children in a very positive light. These apparent conflicts did not occur in the same breath but rather, in different parts of the interview. I was able to question
the data, and so come up with what was to become a central theme of values and beliefs regarding disability being dissonant with parents' attitudes towards their children. This dissonance, in turn, became part of their confusion, doubt and ambiguity.

There were further insights, some productive and some leading up blind alleys, and these I mulled over and checked with the parents. My biggest blind alley related to a description of "grieving love". There was obviously pain in the experience of these parents, but they also expressed a great deal of love for their children. I read the term "grieving love" in a book review of the Sydney Morning Herald (which I was never able to find again, despite a major search) and thought "Wow! This is it." Some of the parents had spoken of "grief", but had expressed a difficulty in grieving for someone who was still there. The term chronic sorrow had meaning for some, but I thought its focus was too negative. This "grieving love" embodied, for me, the parents' experience. It was love, but the love was tinged with what might have been. The parents did not agree with me. They could not relate to it and were confused; they asked me what I meant, by which stage I was confused.

In the end, I described the parents' experience as one which is "between joy and sorrow", and much of what they say comes under this essential theme (this will be discussed in detail later). Major themes which have emerged from the data relate to "strength", "hope", "defiance" and "confusion, doubts and ambiguities". There are many minor themes about which I had to make a decision not to pursue at this stage. The processes involved in arriving at this point were long and arduous and, on many occasions, I wanted to throw it all away. I indexed myself to "confusion, doubts and ambiguities"!

Amanda's three lines of text are now indexed at:

- between joy and sorrow
- sorrows/child/perceptions of
• sorrows/child/constant negativity
• sorrows/feeling bad
• sorrows/constant negativity
• hope-despair
• despair (hopelessness)/outcomes/being a failure

For me these lines are amongst the hundreds which illustrate the pain which society imposes on parents of children with disabilities.

Whilst nearly tearing my hair out at times with the frustration engendered by the enormous amount of time the very fine indexing took (it ceased to be fun by the third transcript), in retrospect, I am glad I did not succumb to temptation to make the indexing broader. I believe the reasoning for this is well supported by Amanda's three line example. This fine indexing gave me the ability to ask many questions of the data and come up with answers which were supported by the data themselves. I also consider that this method of fine, substantive indexing prevented me from jumping to early conclusions. In some cases, the signposts were there early on (e.g., the "confusion, doubts and ambiguities" comment), but the NUD.IST programme supported the detail and so supported my desire to keep the indexing open. However, when I did begin to ask questions and draw conclusions, the detail was there for me to go back to, and the conclusions were able to be well supported. Overall, these processes provided the tools to develop a rich substantive analysis which resulted in an interpretation which reflects these parents' experience of living with a child with a developmental disability. Each of the parents has a unique expression of the experience, but this expression gains some universality through the common themes. They agreed on my summary of their reality.

Validation

Towards the end of this analysis I spoke with the parents in order to check their responses to my conceptualisations. I explained to them that, whilst I understood their experience was difficult to summarise in just a few
words, that I was attempting to capture the essence. This essence I called "between joy and sorrow". I also explained that there were other elements of their experience which I believed to be meaningful, and spoke with them about my impressions of a tension and paradox between the joy and sorrow which is contributed to by our deeply held cultural values and beliefs regarding disability which are challenged by personal experience. The other major theme I spoke with them about was my interpretation of many of their behaviours as one of "defying the implications" of their children's diagnoses. I explained that I believed they had a very realistic understanding of their children's conditions and what this meant in terms of potential function, but that they were dealing with their situations in a hopeful and optimistic manner, and it was as if a decision had been made to "defy the odds".

Their initial silence was a little unsettling and I thought "Oh, no, another blind alley". Then I got the "Yes, yes, that's it" and "Yes, very much so", "That's good", "Yes, I like that", and "You've put it very well". The phone call to Amanda in England was truly rewarding and made the research effort worthwhile. From thousands of miles away, I heard:

*The joy is defined by the sorrow that has come before.*

Whilst capturing the essence of the parents' experience of living with a child with a disability, I felt she had also somehow managed to sum up how I felt at that moment. My feeling of elation was defined by the struggles encountered with interpretation.

In summary, this chapter has described how the interpretive phenomenological research approach was put into action to become the research method. It documents those procedural activities which were presented in Chapter Four, Table 3, as belonging to "the existential investigation" and "phenomenological reflection and interpretation". It has detailed how data were generated and how they were transformed into themes which moved the parents' "... descriptions away from the particular to a more universal sphere" (Morse, 1994, p. 36).
The following chapters will move from the procedural to the essence of this project - the stories of the parents and the interpretation of their experiences as parents of children with developmental disabilities.
Chapter Six

RESEARCH PARTICIPANTS

- THE PEOPLE -

"... narrators often become an important part of the stories they tell"

(Ferguson, Ferguson & Taylor, 1992, p. 1)
This chapter tells the stories of the parents and their children who are the focus of this study. However, their stories became "our" stories, as the development of our relationships contributed to my consciousness of the "other" side of living with a child with a developmental disability and challenged many of my assumptions. It was these relationships which brought about a dawning new understanding for me and thus drove this research.

Some information regarding my nursing roles with families is provided so that the reader may have access to the context in which my relationships with these parents and their children developed.

The participants in this project were all known to me prior to its inception and are, in many ways, responsible for its evolution. I first met them in my role as a community nurse with NSW Developmental Disability Services as their caseworker.

THE NURSE

The casework role was undertaken by the nurses and social workers on the disability team and involved a broad range of interactions and activities. Assignment of a caseworker to a particular family was generally made on the basis of information available at referral, and considered the perceived need of the family matched to the interest and expertise of the case worker. Sometimes assignments were made on the basis of urgency, size of case load or referral to a specific caseworker by a friend, relative or other professional. Occasionally, when all else failed, the person who put up least resistance at the weekly team meeting took on the extra client. As a nurse, I took on most of the children with medical needs, along with many other people.

Our caseloads were enormous, and the team provided services over a large geographic area. I had over two hundred families nominally under my wing. Some I met only once or twice, many I had ongoing contact with, and a few I never met, or only spoke with over the phone. We provided services
to all families who had a member with a developmental disability, or, if in the 0-5 age range, where there were concerns regarding development. My clients with disabilities ranged in age from newborn to sixty-seven. Some of these clients lived in residential services such as hostels, group homes, nursing homes and large institutions and I never met their families, but most lived with their families, which varied in size from two people to nine. These families covered a broad spectrum of culture, belief, education, occupation, skill, interest and ability.

My job was to contact the family following referral, and arrange a home visit. This was for the purposes of introduction and assessment, and for the provision of information. As a result of this usually lengthy visit, decisions were made regarding how best the needs of this particular family might be met. Any number of actions might ensue:

- collection of information regarding diagnosis, hospitalisation, past developmental assessments, contact with services in order to obtain an overview, and often to provide information and education for the family;
- organising formal developmental assessment with medical officer, psychologist, speech pathologist, physiotherapist, occupational therapist, as appropriate;
- referral to playgroup, day care, pre-school, school, workshop, day activity programme;
- referral to specialists - paediatrician, neurologist, ophthalmologist, orthoptist, orthopaedic surgeon, genetic counsellor, psychiatrist, dentist, audiologist;
- referral to other services - generalist community nursing, Homecare, community transport, community health, respite care services;
- referral to other team members - physiotherapist, occupational therapist, speech pathologist, psychologist, social worker, medical officer, recreation officer;
• referral for services provided by team - respite care, camps, recreation activities, day programme for adults with severe disabilities, weekly programme for elderly people with disabilities;
• assistance with skills building and management of undesirable behaviour;
• anything else as required.

My job was to oversee and co-ordinate as well as to maintain ongoing contact with the family if desirable. I provided information, education, counselling and support. I saw my role primarily as the family's advocate and enabling person. When the nurses on the team were asked what they did, there was always a resounding chorus of "ANYTHING", followed by "anything which will enable a family to function to its potential". Some families required little assistance, just some information and maybe some telephone numbers - they really just needed to be pointed in the right direction - whilst others required a high level of support. They were all different and had unique problems, so frequently we operated on our wits. Appropriate interventions and services were often not to be found so we had to be resourceful, cunning and committed. It was "banging your head against a brick wall" territory. Workers frequently identified potential problems, the effects of which could be ameliorated with adequate services geared to the needs of families. However, as the services did not exist, or if they did our clients were unable to gain access, crisis situations frequently occurred, and the "band-aids" had to be applied. Often though, the wounds continued to fester underneath, and when the band-aid was removed we had a further exacerbation of the problem. Despite the difficulties I loved the job and, in the midst of the limitations, I believe that, as a team, we had achievements. We successfully lobbied for an expansion of sorely needed services which, whilst never enough, have filled some gaps.

Working with the families was usually a joy as they had so much to teach me. I made some mistakes but, by and large, I was forgiven. Sometimes, I accompanied them on their journeys through shock and
sadness, and was there when the outlook seemed a little brighter. Sometimes, I was there when the outlook was positively shining.

The people who have participated in this study all had their shining moments. I asked them to participate because, in my view, they had all made positive adaptations to a circumstance which is viewed as tragic by the world. They appeared to have a positive outlook, and did not seem to be swamped by life's misfortune. They are all articulate, and I knew they would have many things to tell me. I shall relate our stories, the stories of the development of their relationship with me, and shall then provide an outline of their demographic details as they were at the time of interview. Their names have been changed, but they are happy for their stories to be told.

THE PARENTS and THEIR CHILDREN

Amanda and Annie

Amanda, her husband of the time Alan, and their three year old daughter Annie, were referred to the team by a Community Health Centre physiotherapist for assessment and services. The physiotherapist considered Annie to be significantly delayed. The family had recently moved to the area and the mother understood the child to have problems, which she said were due to a viral meningitis infection whilst pregnant.

I visited the family in their comfortable home, and we established an instant rapport. Amanda was very vivacious and talked "ten to the dozen". She was dark and attractive, and had emigrated from Ireland some years before. Her husband, Alan, was much quieter, but appeared interested, concerned and supportive. They were in their thirties, but Alan appeared physically somewhat older. Amanda had worked as a computer operator prior to Annie's birth, and Alan had a managerial position with a computer company. He was currently on leave due to stress-related illness.

Amanda's family lived in England, and Alan's only close relative, his father, lived downstairs, and had alcohol related organic brain disease.
Alan’s mother had died recently following a long battle with multiple sclerosis. I gathered she was sorely missed, as she was referred to often. Annie had been named after her.

Annie was a delight - a tiny, dark pixie of a child. She was friendly and loving, and was obviously treasured and loved. She was on the move the whole time, pulling out books and toys, “playing” the piano, and twinkling around the floor. Physically, she was very small for her age, though well-proportioned, had dark hair, and unusual amber eyes. Her skin was dusky with a number of café-au-lait spots - an "alert" sign for particular neurological impairments. She was a little unco-ordinated and clumsy, had few discernible words (although she babbled in a "sensible" fashion with expression) and looked somewhat "odd" (another "alert" sign). Overall, she appeared to be functioning at about a fifteen month level.

Her parents regaled me with three years of horror stories. When Annie was born, following an uncomplicated labour and delivery, problems were immediately apparent. She was very floppy (hypotonic), flat and unresponsive. She was unable to suck and her breathing was compromised. No reason for her condition was evident, and she really did not improve. Her parents were aware of her poor prognosis, but they had fallen in love with her. They described her as a beautiful baby. Three weeks of uncertainty were followed by some information. A spinal tap had revealed a probable viral meningeal infection whilst in utero. A careful history then revealed that Amanda had probably contracted a sub-clinical infection of viral meningitis when about three months pregnant. She remembered headaches, a stiff neck and malaise, but put them down to being pregnant, she had had no prior experience of pregnancy, and had no close women confidantes or family on hand. She did not think to report the symptoms to her obstetrician.

Annie was transferred to a specialist children’s hospital, where she was investigated and tested. A number of anomalies were revealed which confirmed the diagnosis. Annie had organ damage as the result of an intra
uterine viral onslaught - this included brain damage, and accounted for her
general lack of responsiveness.

Annie was discharged to her parents for tender, loving care. They
were informed there was nothing to be done apart from loving her, that she
would probably die, and that if she did not, then she would be a vegetable.
(At our initial meeting, she was introduced to me as our walking, talking
vegetable). Amanda and Alan found themselves unable to accept this
wisdom, as she had a spark and a light in her eyes. They said they just force-
fed her. Getting formula down her throat was a difficult and lengthy
undertaking, but they persisted. A visit to the baby health sister for practical
assistance resulted in the words - maybe it would be better if she just faded
away. They left, to continue the battle on their own. A conversation with an
acquaintance who had a "difficult feeder" resulted in the tiny babe being put
onto solid food (cereal). Amanda said they just kept spooning it in. She was
like a ravenous little bird. After this, things looked up. Annie thrived, grew
and developed - she began to smile and interact. The family went to England
to show her off, and Amanda's mother, a special education teacher, also
noted the special light in the eyes.

Annie had a lot of difficulties and was late to do everything. The
family maintained contact with specialists at the hospital, and received
orthopaedic and physiotherapeutic assistance. They understood she was
developmentally delayed but, it seemed to me, they thought she would grow
out of it and catch up. This was a reasonable expectation - after all, she had
defied the odds.

With the family's approval, I arranged for a formal multidisciplinary
assessment. Amanda was coaching Annie on her block-stacking, so that she
would put in a good performance. Amanda and Alan, however, were
devastated by our news. Annie had significant developmental disability;
that is, intellectual disability; that is, it was not going to "get better"; that is,
it was permanent; that is, Annie was mentally retarded. This, they
understood. There were tears and confusion.
After things had settled down, Amanda told me that underneath, she knew this to be the case. It was just that everybody kept saying that Annie was "developmentally delayed", which, she believed, implied a temporary situation. She had been working very hard to make up for the delays and to help her catch up. I realised the impact it had on her when she said to me, *It's okay now, she's little and cute, but I don't think it will be too cute when she's sixteen.*

Amanda and Alan separated about twelve months later. Alan had huge, long-standing problems with alcohol - hence his sick leave and his physical ageing. He became aggressive, and finally, violent. Amanda has a very black Irish sense of humour. She used to say to me, *Well, I'm becoming an expert in brain damage - I've got the old man with the Korsakoff's downstairs, the husband with the early Korsakoff's, and the retarded child.* Alan was unable to return to employment and, following a long and difficult saga, he disappeared. His father was admitted to a nursing home, and Amanda and Annie were on their own.

When I interviewed Amanda for this research in 1991, Annie was six years of age and in a special class at the local primary school where, according to her mother, she was *picking up a lot of undesirable social habits as the class was full of boys.* She was still tiny, and totally captivating, dancing and talking non-stop. Her mother was supplementing her pension by working part-time in the local pharmacy. We had become friends, and she often spoke to me about her need for further education. Should she do science, arts, psychology, teaching, speech therapy, or maybe nursing?

The interview took place in Amanda's flat whilst Annie was at school and we were both relaxed. I had been keen to speak with Amanda as I was sure she would have plenty to say and, by this time, I knew she was returning home.

At the end of 1991, Amanda and Annie went to England so they could be near the family. Amanda is not sure if they will return. She has bought a little house, and is fulfilling her dream of an education. Annie is
going to a special school where *all the children are moderately developmentally disabled* Amanda tells me, and, of course, Annie is having a ball and is *king of the kids*.

I miss them.

**Catherine and Charles**

Catherine was referred directly to me by a friend of hers who was an acquaintance of mine. Lyn (the friend) rang me at work to ask if I could visit Catherine in hospital where she had delivered Charles two days before - the baby had Down syndrome. Lyn explained that she had worked with Catherine (in welfare services) and that Catherine was a psychologist who had a good hold on what Down syndrome was, and its implications. She said that both Catherine and her husband, Chris, were upset, but felt they were managing well and had very supportive families. Lyn saw my role as one of providing information and practical assistance regarding the options available to families with a child with Down syndrome.

I arranged to meet Lyn at the hospital the next morning, where she would introduce me to Catherine. We sat in the grounds of the hospital on a beautiful, crisp, sunny June morning, whilst Catherine, amidst tears, talked to me about her new baby, Charles. I recall few of the details but do remember talking about options for therapy, whilst commenting that my belief was that parents get to know their baby first, before getting caught up in the "early intervention roundabout", which carries with it a risk of all activity becoming focussed on therapy. I felt that Catherine was sensible and would seek assistance as required. She was still waiting to find out whether Charles had any cardiac or other problems, and was anxious regarding these outcomes (all was okay). We went inside to meet Charles, who was just beautiful, a bit yellow from jaundice, but beautiful.

We came to know each other a little over a period of time. I met Chris when he came to the centre for an assessment with Catherine and
Charles. He is a musician, and I remember he asked a number of questions regarding the future: would Charles be able to drive a car, marry, that sort of thing. Catherine was working as a consultant on child protection issues, and she took Charles with her to training sessions whenever possible. The therapists saw them regularly, and they attended an early intervention playgroup. My contact was minimal and irregular.

Charles developed a number of serious respiratory tract infections which required hospitalisation. Whilst this is not uncommon in children with Down syndrome who have compromised immunity, as he does, it is a source of constant and ongoing anxiety for his parents.

Catherine and Chris separated when Charles was about two and a half. Catherine says that she believes this would have happened despite Charles having Down syndrome, although she does believe that issues of responsibility became magnified, and that she felt this responsibility more acutely due to Charles' condition. She says that Chris was always somewhat ambivalent about having children, and that whilst this pregnancy was planned, it did happen very quickly.

Catherine was thirty-two at the time of the interview and Charles was by now, nearly three. She is a warm, friendly and thoughtful person who is very easy to like - she is the sort of person people "take to" at once. She describes her own family as a privileged, North Shore, large Catholic-type family. She went to a Catholic school and then to university where she completed her Bachelor of Science (Psychology). She says that she would not describe herself as Catholic these days, but that it has certainly had an impact on her as a person - *I jump into guilt more quickly than others*. She gave, as an example, her conflict between work and full-time mothering and believes that Charles' condition has probably exaggerated this conflict.

Catherine and Chris have an amicable relationship, and Chris is a frequent visitor to Catherine's very pretty home. The interview took place there and it was lengthy and relaxed. Charles was up for the first hour or so and was content to roam around. He was learning to walk at the time, but
needed to hold onto things. He is a relaxed and amiable child and is fond of warm cuddles. Chris arrived late in the evening, and attended to Charles whilst we continued our conversation. Following the discussion, Catherine said that she had enjoyed the experience, and that it was good to have the opportunity to speak of it all. She said that if she had more to say, she would ring me.

Catherine and I see each other on a regular basis, as we are committee members for a special needs children's centre. I did not re-interview her as she had recently lost her second child at twenty-five weeks gestation, following many weeks of difficulties. However, I did speak with her on the telephone when I wanted to clarify or validate interpretations.

Charles is now walking and continues to be a soft and happy child. He attends a day care centre, where he has the support of a special needs teacher. Catherine has reduced her work load to provide more consistency for Charles, and as partial compensation for her mother/work conflict. She believes it has paid off.

Catherine says that her experience of being in the client position, and being the receiver of help, has provided her with insight into how professionals should work with clients. I believe she has a great deal to teach us.

Jill and John, parents of Joel

The social worker at the local hospital rang wanting to make an urgent referral to the team social worker. Our social worker was out for the day, and when the referral was explained, I said that I was happy to take it on. This did not really meet with the approval of the hospital social worker who explained that "the child might die". I did not see this as a problem for a nurse, but the perception was not an unusual one as many do not understand the broad roles of nursing. The next day, the team social worker and I discussed the situation and decided between us that the referral was probably more appropriate for me given the child's complex physical status.
She pacified the hospital social worker by saying that I would call on her if I needed to. The hospital social worker was still not happy, but went along with us.

This is how I came to meet Joel and his parents. Joel was two years of age and a few weeks before had been found floating in his babysitter's swimming pool. His mother had returned to work only the week before, leaving Joel and his baby sister, Jenny (six months) in the care of their next door neighbour. It is thought that the babysitter's young daughter may have left the pool gate ajar. Another neighbour, a policeman, applied cardio-pulmonary resuscitation until the ambulance arrived, after which it took a further twenty minutes to obtain a response from Joel.

He was taken to the local hospital, and then transferred to a city children's hospital by helicopter. His parents, Jill and John, had seen him before transfer, and he was cold and multicoloured. They followed by car, and were confused and terrified. At the children's hospital, Joel was on life support systems, but he was expected to die. After two days, the decision was made to remove life support, a decision both parents were fully informed of and involved in. John instigated the actual "turning off" once relatives and friends had said goodbye. His description of his feelings at this time still causes me to shiver.

Joel did not die. Instead he underwent a series of major seizures for the next six hours. His parents say it was as if heaven and hell were battling for his soul. Jill was unable to stay with him all the time, as her anguish was unbearable. John stayed with him and held him through it. He says he wanted to put a pillow over his face so that Joel's torment would stop, and expresses gratitude to the nurse who refused to leave them alone during this time.

Despite his unexpected survival, it was considered to be short term. Joel remained in a coma and developed an infection. A decision was made to transfer him back to his local hospital for palliative care, so that he would
be closer to home, and things would be easier for his family. Jill did not want him to die at home, as the thought frightened her.

After a week or so, Joel began to show some signs of rallying. This is when a referral to the developmental disability team was made, in case he lived. His parents were right behind him, and felt that if he was showing signs of life, they wanted to encourage him. The hospital staff did not appear to be able to do a similar turnaround in thinking. They were convinced that Joel was dying, would die, that it was only a matter of time, and that his parents were unrealistic.

I arrived at the hospital and was confronted by one of the most beautiful looking children I have ever seen. He had blonde hair, dark brown eyes and looked like a cherub. He was conscious, but his movements were uncontrolled and unco-ordinated, he appeared to have little to no visual response and he was irritable. He was, however, managing his own saliva, that is, he was swallowing. When I checked this with Jill, she said he had not needed suctioning in twenty-four hours. I knew that it was vital that appropriate therapy be instigated as soon as possible in order to capitalise on any return of function. Now, the staff thought the community nurse was also "unrealistic" and I was accused of carrying out "dangerous practices" when we organised for the speech pathologist to perform an assessment of Joel's eating capabilities. At this time, he was naturally on naso-gastric feeds, but the staff seemed to be ignoring the signs of returning function (evidenced by his saliva swallowing). The assessment was performed in a safe fashion and Joel ate half a jar of custard which indicated the introduction of partial oral intake in order to promote oral function. Now the community nurse was accused of fostering hope where none existed and of potentially starving the child!

Jill and John decided to take Joel home, as they felt that, by and large, the hospital environment was antagonistic and counter-productive. A lengthy saga of difficulties obtaining information and services suitable for them then ensued. I bear part of the blame for this, as I did not provide
them with a full range of options (an oversight on my part). I did, however, introduce them to another family in a similar plight (Sally and Stephen in the next story), and they began to sort their way through the maze.

Joel did survive and he continues to develop. His family has instigated a variety of therapies, both traditional and alternative, and they are totally committed to his continued improvement. They have strong support from an extensive extended family and many friends. His cortical blindness has all but resolved, he is highly responsive and interactive, follows instructions, and although somewhat like a bowl of spaghetti, due to his mixed muscle tone and difficulties with control, is able to roll around the floor and pull himself onto furniture. He is currently endeavouring to get himself onto all fours. At the time of the first interview with his parents, when he was four years old, he had a few words. Five months later, at the second interview, he was estimated to be using about forty words appropriately.

John and Jill have had enormous financial difficulties. They both gave up their jobs to be with Joel, but John has since returned to employment. At the time of the accident, John was driving an earthmover but he returned to work with Homecare providing personal care for people with disabilities. He says he was able to do it because of his own experience and, had it not been for this, would never have considered such work. He has recently returned to driving a truck for reasons of economy. They nearly lost their home, and there were times when it seemed their financial difficulties would crush them. They have, however, survived as stronger people.

I was very anxious to interview Jill and John because of something they had said which had a profound impact on my thinking. One night, following a parent support meeting, we were having an informal discussion (Jill and John thought many of the parents to be stuck on negativity), in which they said to me that recently a friend had suggested to them that they must yearn to turn back the clock to before Joel's near-drowning. Their
reflections at the time stunned me. They said that they had told the friend that they could not honestly reply with a "yes" to this question. They said that, whilst obviously not wanting such an event to have occurred and, whilst deeply sad about Joel's accident and its outcomes for him, that they believed they had undergone experiences denied most people, and had grown and become stronger as a result. They believed they were better people.

I interviewed Jill one evening at their home, and repeated the process with John a couple of weeks later. Jill said that she enjoyed talking, and that going back over events gave her the first opportunity of thinking of some of it. She was relaxed and talkative. John was a little tense to begin with, but soon relaxed, and appeared to be making a great effort to be honest. His words were frequently well thought out. I made myself a note following these interviews: "I found them inspiring, and feel privileged to be part of their recollections".

Sally and Stephen, parents of Samuel

Samuel is the youngest of seven children, and his parents say he was the most advanced of all their kids. At seven months, he was pulling himself up to stand, and they believe that his overall development was precocious.

One morning, when he was seven and a half months old, Samuel did not wake up. His parents, at first, were not alarmed - this was not completely out of the ordinary and, when there are six other young children to deal with, a sleeping baby is a blessing. Stephen went in to check him, and pandemonium broke out. Samuel was blue, cold, clammy and struggling for breath, and his parents' immediate thought was a near cot death.

Samuel had been fractious during the night and a little unwell, but nothing out of the ordinary for experienced parents. He had settled with boiled water. Sally says it took her a long time to be able to come to terms with the fact that she had done nothing wrong, and that there was nothing
she could have done which would have made any difference. Samuel had contracted Haemophlias influenza (Hib) - he developed meningitis, went into septic shock and was left with permanent brain injury. He was expected to die but, when death did not eventuate, his parents were told he would do nothing and would remain as he was. Sally had great difficulty with this as she said he was then doing less than he had when he was born. Stephen thinks they tell you the worst, so that then things can only get better.

Once Samuel’s acute condition had resolved, Sally and Stephen could see no point in his remaining in hospital as he was in a room on his own with minimal stimulation, and they believed he would be better off at home. He was blind and highly irritable. His hearing was questionable (although later testing demonstrated it was intact), and he continued to have seizures. His parents took him home, but with nothing from the hospital except a bottle of Phenobarb.

Sally made many enquires regarding therapy and assistance, and eventually found her way to the developmental disability team. I took on the referral and met the family at their home. Samuel was a robust, healthy looking, very blonde child with beautiful pale blue eyes. He was highly irritable and had a persistent high-pitched scream. He seemed so miserable, and his parents were naturally confused and anxious. However, they were educated and intelligent and appeared to have a good grasp on the situation and its implications. They presented as very rational and keen to implement therapy which would assist their son. My overall assessment of the situation was that they were managing very well, and I referred them to our speech pathologist and physiotherapist for therapy. I was to learn much later from Sally that I had fouled up. She told me that, at that stage, she was screaming out for emotional support and would have appreciated a weekly visit from me. When I asked her if she would have agreed to this level of support if I had offered it at the time, she said ruefully, No, probably not!

Over a period of time, Sally and I came to know each other a little better (Stephen was usually at work in his job as a high school deputy
principal), and I developed a huge respect and admiration for her sheer guts and determination. She explored many avenues for assistance with Samuel and has implemented therapies which are not considered mainstream. She has thrown herself into fundraising and consciousness-raising activities for people with disabilities and has become a well-known local identity. Stephen plays the violin expertly, and his group of musicians has been instrumental in fund-raising activities.

Samuel, the child who would do nothing, walked when he was just over twelve months of age. His frustration levels diminished enormously then. He is still blind, but seems to have days when he has a little visual perception. At four years of age, he is now feeding himself, and he is beginning to know about people. His parents say that, until recently, people were just large things who got in Samuel's way and simply presented obstacles to his mobility. They say he is now beginning to interact with and enjoy people. They are pleased with his progress, but have an understanding of his limitations which are likely to persist. Sally, in particular, remains angry with the negative prognoses of doctors, and fears that such lack of hope may prevent parents of such children from achieving what they have achieved.

I interviewed Sally and Stephen separately and a few weeks apart, at my home, as I lived down the street from them, and there was less likelihood of interruption. My impression is that the process was, for Sally, cathartic and therapeutic. She was with me for four hours, and tears were shed. This was comfortable and she said that, whilst she was apprehensive about it at first, she did relax. I was the apprehensive one for Stephen's interview. I had not come to know him as well as the others and found the process more difficult than usual. He appeared to be quite relaxed and seemed to speak honestly.

Stephen retired from work last year due to increasing ill health, and in order to spend more time with his family. He still does some casual teaching and is still playing music professionally. At fifty-six, he is older
than all of the other participants, and he did not speak of the enormous personal changes to himself that the others emphasised. Sally continues to be a busy mother of seven children, and an unstoppable advocate for people with disabilities in general, and her son, Samuel, in particular.

Following is a summary, in table form, of particulars of the participants and their children at the time of the initial interview. It is presented so that the reader may have ready access, in the form of a reminder, to the parents' stories.

(This summary will appear on the following page)
<table>
<thead>
<tr>
<th>MOTHER</th>
<th>FATHER</th>
<th>CHILD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AMANDA</strong></td>
<td><strong>ALAN</strong></td>
<td><strong>ANNIE</strong></td>
</tr>
<tr>
<td>Interview 1.</td>
<td>Not interviewed.</td>
<td>Six years</td>
</tr>
<tr>
<td>34 years.</td>
<td>Whereabouts unknown.</td>
<td>Brain damage due to intra uterine</td>
</tr>
<tr>
<td>Divorced.</td>
<td></td>
<td>maternal infection.</td>
</tr>
<tr>
<td>Completed high school.</td>
<td></td>
<td>Siblings: None</td>
</tr>
<tr>
<td>pharmacy assistant.</td>
<td></td>
<td>Assessed as having a moderate</td>
</tr>
<tr>
<td>Previously computer</td>
<td></td>
<td>intellectual disability. Functions at</td>
</tr>
<tr>
<td>operator.</td>
<td></td>
<td>approximately three years level.</td>
</tr>
<tr>
<td>Protestant - is involved with</td>
<td></td>
<td>Highly interactive. Attends special</td>
</tr>
<tr>
<td>local church group.</td>
<td></td>
<td>class at local school.</td>
</tr>
<tr>
<td>Financial: &quot;Struggling a lot&quot;.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Security Pension.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CATHERINE</strong></td>
<td><strong>CHRIS</strong></td>
<td><strong>CHARLES</strong></td>
</tr>
<tr>
<td>Interview 2.</td>
<td>Not interviewed.</td>
<td>Two years, 10 months.</td>
</tr>
<tr>
<td>32 years.</td>
<td></td>
<td>Down syndrome</td>
</tr>
<tr>
<td>Separated.</td>
<td></td>
<td>Siblings: None</td>
</tr>
<tr>
<td>psychologist - child care and</td>
<td></td>
<td>Probable significant intellectual</td>
</tr>
<tr>
<td>protection.</td>
<td></td>
<td>disability. Motor difficulties.</td>
</tr>
<tr>
<td>Tertiary education (B.Sc).</td>
<td></td>
<td>Standing with assistance. Placid, but</td>
</tr>
<tr>
<td>Brought up as Catholic, now</td>
<td></td>
<td>loving and interactive. Attends day</td>
</tr>
<tr>
<td>agnostic.</td>
<td></td>
<td>care.</td>
</tr>
<tr>
<td>Financial: &quot;Making ends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>meet&quot;.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>JILL</strong></td>
<td><strong>JOHN</strong></td>
<td><strong>JOEL</strong></td>
</tr>
<tr>
<td>Interviews 3 and 7.</td>
<td>Interviews 4 and 7</td>
<td>Four years.</td>
</tr>
<tr>
<td>31 years.</td>
<td>29 years.</td>
<td>Brain damage, due to near drowning at</td>
</tr>
<tr>
<td>Married.</td>
<td>Married.</td>
<td>age two years, one month.</td>
</tr>
<tr>
<td>Home duties. Casual table</td>
<td>Works as a personal care</td>
<td>Siblings: Jermy (two and a half years).</td>
</tr>
<tr>
<td>hand. Previously, a</td>
<td>assistant. Previously drove</td>
<td>Functional Status: Major motor</td>
</tr>
<tr>
<td>telephonist.</td>
<td>earthmoving equipment and</td>
<td>problems (mixed, but predominantly</td>
</tr>
<tr>
<td>Completed Year 10.</td>
<td>trucks.</td>
<td>low tone). Difficulties with co-</td>
</tr>
<tr>
<td>Brought up as Catholic.</td>
<td>Completed Year 10 (states</td>
<td>ordination and intention. Rolls around</td>
</tr>
<tr>
<td>No longer practises as she does</td>
<td>&quot;very poorly&quot;).</td>
<td>floor, pulls self up, learning to crawl.</td>
</tr>
<tr>
<td>not believe in formal religion.</td>
<td>Nominates Church of England.</td>
<td>Has a few words. Is interactive and</td>
</tr>
<tr>
<td>States she has a spiritual</td>
<td>States he is &quot;not a big fan of</td>
<td>happy. Cognitive status unknown, but</td>
</tr>
<tr>
<td>sense and a belief in God -</td>
<td>religion, but is very spiritual,</td>
<td>parents believe cognition to be intact.</td>
</tr>
<tr>
<td>this is a source of strength</td>
<td>and turns to God&quot;.</td>
<td></td>
</tr>
<tr>
<td>and helped her get through.</td>
<td>Financial: &quot;Struggling a lot&quot;.</td>
<td></td>
</tr>
<tr>
<td>Financial: &quot;Struggling a lot&quot;.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SALLY</strong></td>
<td><strong>STEPHEN</strong></td>
<td><strong>SAMUEL</strong></td>
</tr>
<tr>
<td>Interviews 5 and 8.</td>
<td>Interviews 6 and 8.</td>
<td>Four years.</td>
</tr>
<tr>
<td>36 years.</td>
<td>36 years.</td>
<td>Brain damage, due to Hib meningitis at</td>
</tr>
<tr>
<td>Married.</td>
<td>Married.</td>
<td>seven and a half months.</td>
</tr>
<tr>
<td>Home duties.</td>
<td>Retired deputy high school</td>
<td>Siblings: Six (16, 14, 12, 11, 8, 7 years).</td>
</tr>
<tr>
<td>Completed high school.</td>
<td>principal. Casual music</td>
<td>Functional Status: Severe global delay,</td>
</tr>
<tr>
<td>Brought up in Church of</td>
<td>teacher. Plays violin</td>
<td>with exception of gross motor skills.</td>
</tr>
<tr>
<td>religious affiliation, but</td>
<td>Tertiary education (Teacher's</td>
<td>No speech - difficulties with</td>
</tr>
<tr>
<td>describes herself as a</td>
<td>College).</td>
<td>vocalisation. Is very active, and is</td>
</tr>
<tr>
<td>Christian person.</td>
<td>No particular religious</td>
<td>beginning to interact with others.</td>
</tr>
<tr>
<td>Financial: &quot;Struggling&quot;</td>
<td>affiliation. States a &quot;belief in a</td>
<td></td>
</tr>
<tr>
<td></td>
<td>supreme being&quot;.</td>
<td>Financial: &quot;Struggling&quot;.</td>
</tr>
</tbody>
</table>
The preceding stories have illustrated how Amanda, Catherine, Jill, John, Sally, Stephen and I came to know each other. As well as this, their stories indicate that their experiences could well be interpreted as tragic. Probably no one would be surprised if any or all of these parents were overwhelmed with the pain of events in their lives. And yet, each of these parents had caused me to question my own assumptions and theoretical constructs. Their words and actions caused me to pause and eventually, to undertake this research.

As narrators of the stories, these parents, along with the story of my relationship with them, are integral to the work. The following chapters will now focus on my interpretation of the stories they told me of their experiences of living with a child with a significant developmental disability.
Chapter Seven

BETWEEN JOY and SORROW

- AN OVERVIEW -

"... a dynamic and complex phenomenon that transcends the sum of its parts."

(Rose, 1990, p. 61)

120
This and the following chapters deal with the activities of "phenomenological reflection and interpretation" and "phenomenological writing" (as depicted in Chapter Four, Table 3) and, as such, present the essence of this work - the interpretation of the parents' experiences. This chapter provides an overview of the interpretation and is included here to enable the reader to grasp a sense of the whole before considering the themes through which the parents' experiences gain expression. Chapters Eight, Nine and Ten will deal with these themes in detail, whilst Chapter Eleven will discuss the interpretation and its implications.

The overview of the major themes is presented as a model which facilitates a visual recognition of the gestalt of the phenomenon, along with its component parts. Swanson-Kauffman and Schonwald (1988, p. 104) stated:

While a well-done model should be universal enough to apply to each informant, it should also be simple and straightforward. A phenomenological model is like a universal skeleton that can be filled in with the rich story of each informant. The model will not account for the complete story of each informant; yet it should be applicable to each informant.

The "between joy and sorrow" model presented in this chapter derived from the phenomenological enquiry into the parents' experiences. It provides us with a "universal skeleton" which can be filled in with each of their stories.

BETWEEN JOY and SORROW

The parents in this study - Amanda, Catherine, Jill, John, Sally and Stephen - have painted a picture of living with a child with a developmental disability which is at odds with many of the commonly held notions. Whilst conscious of their pain and the many difficulties engendered by their situations, they speak of strength, joy, love, hope and optimism.
I have called their experience of being a parent of a child with a developmental disability as one which is "between joy and sorrow", a state which was revealed by the parents to have many interconnected and interwoven elements. As such, "it is a dynamic and complex phenomenon that transcends the sum of its parts ... [in which] each theme can be separated only momentarily before it merges with other themes" (Rose, 1990, p. 61).

In telling their stories, these parents presented an initial overwhelming picture of "no hope". It was clear that they were being inundated with messages of hopelessness from the people they were in contact with, and that the professionals with whom they worked were often responsible for their feelings of isolation, rejection, despair and hopelessness.

In light of negative attitudes from friends, family and acquaintances, and hopeless prognoses from professionals, it would seem reasonable to anticipate that these parents would be immobilised by a sense of despair and hopelessness. Yet, despite their acknowledged periodic pain and sorrow, they maintain hope which has enabled them to view their children with optimism. They have struggled and fought to ensure their children's survival and development, and have experienced the joys of countless successes. They have done this despite the odds, despite the negative attitudes of others and despite prognoses which indicated their children would "do nothing".

These parents speak of their children in glowing and hopeful ways. They describe them as beautiful, happy, affectionate, gutsy and cheerful, and they bring feelings of great pride, love, happiness and reward to their families. Their parents often speak of being inspired by them.

Their views are frequently at odds with the perceptions of professionals. The parents report the sometimes subtle, and sometimes not so subtle expectations of professionals to "be realistic". They recognise that the professionals have a commitment to provide honest information and advice, but believe that the professional endeavour to be truthful and
realistic, frequently leaves no room for hope. This makes them angry. As a group, they identify hopes as akin to dreams, as a belief in possibilities, and state that they cannot function without hope. Whilst being conscious of the limitations of their children, these parents maintain hope and strive to keep it alive. I have interpreted their optimistic outlook, not as one of "denying reality," but rather one of a very realistic grasp of their situations, which goes hand in hand with a recognition of a need to maintain hope and optimism in order to remain functional. I have called their stance "defiance", which for this work means a defiance of the implications of their children's devastating diagnoses. So, whilst they understand and accept their children's diagnoses, they will not accept their implications and will work towards defying the prognoses.

An interpretation of the parents' experience took shape in light of "between joy and sorrow", "hope and no hope" and "defiance and despair". This interpretation, however, seemed somehow too flat, too pat and somewhat static, and did not take account of the "confusion, doubts and ambiguities" which are intrinsic in the parents' experience.

These difficulties led to an attempt to visualise and clarify, and to tease out elements of a phenomenon which is dynamic and complex. This process enabled me to develop a model which is a simplified representation of the parents' reality, and signifies a way of making some sense of the complexity. It also illustrates the strong and powerful undercurrents of "confusion, doubt and ambiguity", and represents the dynamic interplay of "joy and sorrow". This conceptual lens I have called "the tensions". The model is presented in Figure 2 on the following page.
This model represents the major themes which emerged from the parents' stories of their experience. It depicts the state of joy as deriving from the parents' relationships with their children, whilst sorrow is a frequent response to the parents' dealings with other people. The themes should not be viewed in isolation, but rather grasped and understood within the context of the whole phenomenon of "between joy and sorrow". They should be viewed as parts of a dynamic whole, as pieces which shift and merge, and
which are interwoven to the degree of becoming dependent on each other for their very existence. Amanda said the joy is defined by the sorrow which has come before. If we turn her statement around and say "the sorrow is defined by the joy which comes after", I believe we have the essence of the experience. Both statements represent the "truth" of their situations. Their experience is one of paradox and ambiguity, and one which is fraught with conflict, confusion and doubt. This gives rise to a concept of "tension" which provides us with a powerful lens through which to interpret the parents' experience, a lens which helps us to confront the challenge of understanding the multiplicity of individual experiences, and which enables the development of insight into those experiences which, whilst individual, can find expression in common themes.

The model allows for movement, and the reader is asked to imagine the circles as becoming bigger and smaller, of shifting so as to become eclipsed by their counterparts, or of having just slivers exposed (see Figures 3, 4 and 5). By and large, the parents relate their stories as being full of pain and sorrow at the outset. Their children were given no hope and the parents sometimes despaired. As time went on, the children became sources of joy and their parents developed hope and optimism and made decisions to support their children, to "defy" the advice they were frequently given. This is not to say that currently their experiences are only joyous. They carry the memories of past pain and frequently encounter more - it is part of their daily reality. Nor is it to say that the early experiences were full of sorrow for all parents; there were moments of joy, and for Catherine, her joy overwhelmed her pain.

The major themes will be presented in the following three chapters, along with their contributing elements and the words of the parents will support the interpretations. Chapter Eight will deal with the theme of "sorrow" and its component parts. As illustrated in Figure 3, the parents' lack of hope and resultant despair, along with the sub-themes which
contribute to their sorrows, particularly when dealing with other people, will be presented.

SORROW

OTHER PEOPLE SORROWS
- Dying
- Finding Out
- A Death in the Family
- On Their Own
- Fears and Worries
- Grief
NO HOPE and DESPAIR

Figure 3 - Between Joy and Sorrow: SORROW

Chapter Nine will deal with the theme of "joy" and its component parts as illustrated in Figure 4. The parents' hope and their defiance of the implications of their children's diagnoses, along with the sub-themes which contribute to their joys as parents of children with disabilities, will be presented.

JOY

THE CHILD JOYS
- Not Dying
- Little Things
- New Perspectives
- Becoming Stronger
HOPE and DEFIANCE

Figure 4 - Between Joy and Sorrow: JOY

Chapter Ten will deal with the theme of "the tensions" and its component parts as illustrated in Figure 5. The parents' confusion, doubts and
ambiguities, along with the sub-themes contributing to this state, will be presented. The concept of the often paradoxical nature of their experiences will be introduced as the theme, "both sides of the rhythm".

THE TENSIONS

CONFUSION, DOUBTS and AMBIGUITIES
• Dissonance of Values and Beliefs
• Conflict of Values and Beliefs
• No Maps
• Guilt
• Grief
• Professionals
BOTH SIDES OF THE RHYTHM

Figure 5 - Between Joy and Sorrow: THE TENSIONS

This overview has been presented in order that the reader may grasp the phenomenon of "between joy and sorrow" as a whole prior to the presentation of evidence which, of necessity, reduces the parents' experience to its constituent elements. A model was presented to indicate the ways in which the various themes relate to and complement each other, and as a way of providing a simplified representation of a complex and dynamic whole.
Chapter Eight

BETWEEN JOY and SORROW

- SORROW -

Somebody has entered our private sad little
world that normally we keep locked away

(Amanda)
This chapter presents the parents' world of sorrows and contends that much of the parents' sorrow derives from their dealings with other people. The constituent themes of

- Dying,
- Finding Out,
- A Death in the Family,
- On Their Own,
- Being Vulnerable
- Fears and Worries, and
- Grief

are presented, along with the major themes of

- No Hope and Despair

**SORROW**

When used to describe an emotion or a state of being, the word "sorrow" conjures up thoughts of suffering, sadness, disappointment, unhappiness, loss, grief, heartache, pain, anguish and despair. The word may also be used as something which causes these emotions, so that "a sorrow" becomes an agent of emotional anguish. And when we "feel sorrow" for someone, it has connotations of pity, regret and sympathy. The parents in this study have a lived experience of "sorrow" with all of its shades of meaning.

Whilst my intention was to surface the "other" side of the parents' experience, in so doing, their sorrowful state of being could not be ignored; to do so would have denied their total experience. Many themes emerged in relationship to sorrow, and it became evident that the parents' dealings with "other people" and, in particular professionals, gave rise to much heartache.

**Other People**

In this study "other people" means any people to whom the parents referred apart from their partners and their children. During analysis,
whenever a parent spoke of any other person, including partners and children, the data were cross-indexed accordingly. There were many subcategories within "people", which included mother, father, parents, child, siblings, family (hers), family (his), friends, acquaintances, general public, bureaucrats, professionals (broken down into further relevant subcategories), and others. (See Appendix VII, under [3] "people"). This very specific coding of "people" gave me a powerful analytical tool which enabled me to examine the parents' experience in relationship to other people.

Early on in the analysis, much of the data were clustered in a way which indicated there were positive and negative perceptions of the child, that the parents had positive and negative feelings, and that positive and negative attitudes, values and beliefs were often reflected in people's statements, interactions and behaviours.

On the surface, it appeared that the positives were associated with the parents' own experience of their children, whilst the negatives seemed to be there as a result of dealings with "other people", frequently professionals. A careful analysis confirmed these associations. When the children were referred to as failures and vegetables, it was in the context of dealings with professionals. When the parents spoke of feeling stupid, failures, rejected, powerless, angry, resentful, frustrated, uncomfortable and hurt, it was often in direct response to other people, particularly professionals. They sometimes reported the attitudes of professionals as patronising, non-committal and not-interested towards themselves, whilst attitudes of labelling, rejecting and rigid towards their children were mentioned. It was clear that the parents had, at times, been overwhelmed with negative messages from people they were in contact with, and that the professionals with whom they worked had often been responsible for their feelings of isolation, rejection, despair and hopelessness. The voices of the parents speak for themselves.

... so much writing off, so much rejection. Yes, yes, you have given birth and this is actually a reject this child. 'Try
for another one', they say almost immediately. You say, "What do you mean, try for another one? I flunked up this one ..." (Amanda)

I was a bit surprised about some people like, I've got a friend ... and her almost spontaneous reaction was 'Are you going to keep him?' (Catherine)

... this is the child they left for dead. This is the child they said would die and he hasn't died. And yet nobody's interested ... (Jill)

How can you know? A vegetable! Ha! It's a joke. No, I think doctors have got their place ... (John)

Samuel can't do, Samuel can't do! I mean, I'm well aware of what he can't do. I don't need people to tell me what he can't do. And, but, just from a parent's perspective, it's a, it really is a knock to you, and to all the work that you've put in, and that your child's put in, to get a report from somebody that just highlights all the things he can't do, with no mention of other things and how much he's improved. (Sally)

... after he had come out of the coma and so on, we were hit with the fact that he was going to be a vegetable. (Stephen)

I do not wish to imply that associations with professionals and other people are, of necessity, negative. Nor is it intended to suggest that all of the negatives discussed by parents were associated with other people and professionals. Frequently, the negatives were there as an intrinsic part of
their experience. Their very situations give rise to much sadness, and their stories are full of grief and devastation.

**Sorrows**

A great many things have contributed to, and continue to be a part of the parents' sorrow. Although their biographies and their situations are individual, there is a shared consciousness as evidenced by the themes.

**Dying**

Two of the children, Joel and Samuel, had been assailed by events where the anticipated outcome was death. They were dying and their parents stayed with them. It goes without saying that the death of a child is one of the most tragic events experienced by human beings. Waiting for one's child to die is almost unendurable. Jill says:

> I sort of try to explain to people, 'You think of a broken heart and how much it hurts. You think of something like this and it is a trillion times more painful'. There's just nothing to compare with it. I don't think losing anyone, but I think your kids - if you've lost your kids, that's the most devastating thing ever ....

Stephen speaks of Samuel's imminent death as a change of our whole being and Sally still sheds tears when speaking of it.

Jill's account of Joel's life and death struggle is spine tingling, and both she and John liken his six hours of seizures, following removal of life support to a battle with the devil:

> ... it was sort of like the devil had got into his body and was playing with him ... I felt like the devil was actually present there, and a lot of people would think, 'Oh, that's a load of crap'. But that's the way I felt, like he was there. And he was, you can imagine he was jumping around laughing,
thinking 'Ha, ha, ha! Look at the pain you're in now. I'm going to make it even worse'.

Both Jill and John were involved in the decision to remove Joel from life support, and John speaks of having to go in and tell the staff it was time. He speaks of his utter helplessness and powerlessness, and of feeling like a little boy in the face of such an event, and of how he cried on the phone, telling his Dad,

*He's my boy. We've only had him for a while, and he's gonna die ...*

The memories of these events are sharply etched in the minds of the parents and have become the part of their state of being which is full of sorrow.

**Finding Out**

"Finding out" or "coming to know" of their child's changed potential was a recurrent theme for the parents. For Jill, John, Sally and Stephen, the changes were real - their children had been healthy and had been doing all the things one might expect for children of their age. For Amanda and Catherine, the changes were those of dreams - very soon after birth, it was apparent that Annie and Charles would not be like other children.

However the particular circumstances varied, and whether the "knowing" was rapid or extended, the sadness and anguish are shared by all. For Catherine, the diagnosis of Down syndrome had an immediate impact. She knew what it meant - for her the "coming to know" was immediate. Whilst she was not disappointed, she

*... suddenly felt panicky for his future ... and it was like euphoria and a sledge hammer simultaneously ...*

Amanda's "finding out" about Annie really took about three years. Whilst it was apparent at birth the child had problems, for a very long time Amanda and her husband, Alan, took these to mean physical problems which she would outgrow. Despite the doctors' predictions of *vegetable*, the
brightness in Annie's eyes belied such a prognosis. Amanda admits to knowing in her heart that things were not normal but, due to the professionals' emphasis on developmental "delay", logically believed that she would one day catch up. She speaks of the challenge to her illusions when she actually faced Annie in a whole group of children, and of this being

such an overwhelming shock because I'd become really high on the fact that she was going to pre-school.

Reality began to take shape when, at three years, Annie was referred to the Developmental Disability Team. For the first time, her parents began to develop a picture of the permanence of her condition which involved a confrontation with the mental thing which she says she had always avoided.

The words massive brain damage frequently occur during the stories of Jill, John, Sally and Stephen. The prognoses for their sons were similar. Joel's parents were told,

... that his head was disconnected from his body, and that's the way he'll be. So, he won't feel any love, he won't feel any hate, he won't feel anything ... (Jill)

and Samuel's parents were told much the same:

... I was told that night that he had massive brain damage and would never do anything, be no different to what he was there. At that stage he couldn't even hold his head up.

(Sally)

This represents the initial "coming to know" for Joel's and Samuel's parents, and has since given rise to a great deal of anger, as they believe these words represent sentences for their children. Both these children have defied the odds and are functioning at levels which were never predicted by the professionals. These parents are still "finding out", but function within a day-to-day framework from which expectations regarding their children's futures have been removed. Their "coming to know" is an ongoing and dynamic process which now, in fact, holds much hope. This does not
remove however, the devastating impact which finding out about their children has had on them. They all remember the sadness and carry the scars which are just some of their many sorrows.

A Death in the Family

This theme took shape as Catherine was speaking of some of the unexpected responses she had after Charles was born and, as it developed, became an umbrella for two other themes, "no celebration" and "being treated differently".

Amanda speaks of Annie's disability being a taboo subject with some friends and family:

You had to avoid that issue because it's like death you know. People sort of don't know how to deal with it ...

She also speaks of the difficulties of having a new baby with problems because people seem unsure how to respond. The birth is not celebrated by others, and yet nor is it an occasion for open mourning - the baby's still alive.

I asked Catherine about this lack of celebration following Charles' birth. The members of her family were fine, but she remarked upon what were, to her, some peculiar responses from others.

... and I had people that were sort of friends of my parents, that I hadn't had anything to do with in fifteen years, who sent things, and they didn't send them to any of my siblings' children when they were born ... and it reminded me of the same stuff that had happened when my Dad died ...

... It was the same kind of stuff, you know, neighbours that you've just said 'Hello' to at Christmas time all appear ...

She was somewhat startled when the hospital social worker, with whom she had had some fairly peripheral contact was ...

... offering me all sorts of things like her home telephone number, and if I wanted a break, she'd be quite happy to come round and take Charles from me and I was thinking,
'No, I've only just got him! I don't want to get rid of him, I've only just got him'.

Jill and John speak of losing some of their friends (not their true friends) because, they think, some people just cannot deal with their situation and, in the same vein, Sally remarks upon how people find it very hard to cope with. She says that initially, many people came around to visit but, after that, they

... didn't see anybody for months. Months and months.
And I felt like, it was like they were just curious to see whether he had grown an extra head ... and once they'd seen that he looked exactly the same, he just looked normal, there was nothing sticking out of the side of his head or anything, they just couldn't handle the whole situation ...

It would seem that confrontation with severe disability, in any actual or potential form, frequently leads to the same confusion which death engenders - people may be unusually helpful, sympathetic, or totally avoidant. Whatever it is, the parents recognise the "difference" in people's responses and are very conscious of "being different", much as when there is a death in the family. Much as death brings about great sorrow, so too does being treated as if there has been a death.

On Their Own

... and there was just me to care for her ...

... nobody can help you, or will help you in the early days, in a way that you inside need it.
...I felt like I was the only person with baby problems ...
It was just a no man's land.
...if I was to get anything for Annie, I had to go about it on my own. (Amanda)
... she’s only a mother - you wouldn’t want to believe her...

I went and read the ward notes, and the stuff that she (the doctor) had written was really amazing - like ‘resistant mother’, ‘unwilling to co-operate’, you know, all this sort of stuff... (Catherine)

I have to do his therapy. No one else is going to do it.
I believe it’s all left up to you. (Jill)

I was very isolated for a long time.
I sort of had the role of being the strong person thrust upon me...
I really needed someone to rely on, and that sort of person just wasn’t available.
Doctors are constantly kicking you in the teeth all the time.
You have to learn to get yourself back up again very quickly. (Sally)

The words paint a picture of isolation, loneliness and lack of support.
As the parents speak, there is sometimes an overwhelming sense of their being "on their own". The parents of Annie, Joel and Samuel continue to be angry with what they perceive to be a "dumping" by the system. Medical science saved their children, but they were sent home to be "on their own".

'O.K., we can’t find what might be wrong with her, but take her away, take her home’. And we felt that we'd been left with the responsibility of trying to keep this child alive, and it was just too much. (Amanda)

I didn’t know what to do with him. 'Here, we saved his life - aren’t we good. Now take him home'. (Jill)
I came home from hospital with no information at all as to where to go, what help was available, what help I needed...
(Sally)

For the individuals, the level of family support varies, so that their feelings of being "on their own" in an overall sense moves along a continuum, with Amanda voicing the greatest sense of emotional isolation, and Catherine the least. However, all of the parents express a sense of aloneness when it comes to dealing with the system - they are all fighting the system in one way or another. The language of "fighting" was so pervasive, that "a fight" became one of the analytical themes. This "fighting" language though, was frequently associated with the sense of isolation imposed by their situations. Amanda captured the dual themes well:

You had to fight on your own.

This sense of being "on their own" has had a large impact on the parents. It has made them feel isolated, sad and lonely, and contributes to their overall state of sorrow.

Being Vulnerable

This theme arose from notions of being hurt and in pain, of being powerless and having little control in many situations which have arisen as a result of being the parent of a child with a disability. John, whilst waiting for Joel to die, gives poignant expression to this theme:

I was out of solutions, I didn't know what to do. I was just, what do I do next? I'm drained. I've had it. I feel like I'm falling asleep on my feet. I just had nothing else left.

He spoke these words very softly and with many pauses and, in doing so, exposed his continuing pain. Jill describes John at the time as being

...like a little kid who was saying, like he said he felt so powerless, like a little child, and yet he was basically saying, 'Here, take my son's life ...'
The theme finds expression with all of the parents and in varied circumstances. Catherine found that being a receiver of help put her in ... a more vulnerable position than I've ever been in before. She feels that being a parent of a child with a disability puts her in a spotlight in which

... your parenting ... is all seen, noticed and talked about in a way that is not for most other people in the community.

It's like your performance is so much more visible and assessed by somebody else who may or may not be someone whose views you respect, but they're going to make judgements about it.

She spoke of her determination to be a working mother being threatened by the subtle messages from therapists who do the emotional blackmail number on her and insinuate she should be with her child because he has a disability, and says... it's like all your foundations get a bit of battering. Being a parent of a child with a disability

... makes it much more difficult to be assertive like you can be in every other area of your life.

Sally wanted

... someone to know I was vulnerable like everybody else.

That I really wasn’t this really big strong person that everybody thought I was

and, like Jill, relates the vulnerability to being like

... a little girl, and I just wanted somebody to come and put their arms around, you know, just pick me up and tell me everything was going to be all right.

As she spoke these words, she was crying. Her situation, at the time, was painful, and its memory has been incorporated into her overall experience of sorrow.
Fears and Worries

"Being frightened" and "being worried" were states which found expression in the stories of all of the parents. They often spoke of hard things and, at times, of the worst things.

Jill sums up the feelings of John, Sally and Stephen when they were waiting for their sons to die. She speaks of the death of a child as being the biggest fear and says, ... you're basically living your worst nightmare. Jill's and John's nightmare was exacerbated by having to make a decision to remove Joel's life supporting technology:

... the hardest thing I've ever had to do was just walk in and say, 'O.K., turn it all off'. (John)

They were worried about making the right decision, and fearful for its outcome.

There were many other causes of "fears and worries". Catherine had initial fears about having more children. Amanda, Jill and John had fears about cognitive impairment in their children; Jill and John continue to do so, but consider Joel to have normal intellectual ability. They all worry about their children having, in Catherine's words, a particularly rough time and are fearful for the ways in which others may respond to them:

... he's going to be a man one day, and people are frightened of that kind of thing ... I didn't want people to be frightened of him, and I'd rather he die than have people frightened of him ... (Jill)

From time to time, the parents worry about "doing the right thing" and appreciate confirmation in order to allay their fears:

(The nurse) ... gave us confidence in ourselves in telling us that we were providing a good and stimulating home atmosphere for Annie, which we tried desperately hard to do ... (Amanda).

This theme is very important for Catherine who worries
... that the frivolity of childhood doesn't get a look in (due to) making life a therapy setting, not a carefree life and is fearful for the effects of ... not having the opportunities to be a carefree child on his emotional development.

Financial worries loomed very large for Jill and John who both ceased earning as a result of Joel's accident. They caused more hassles than anything else (Jill) and John says, The financial side of it is the demon in the whole thing. They continue to have financial worries and fear they may never again recoup their losses.

All of the parents worry about the future. This began as soon as their children's conditions were apparent, and continues to be a major concern.

... it was like I suddenly felt panicky for his future . (Catherine)

... I thought who's going to look after him when we're old, 'cause the first thing I thought of was brain damage . (Jill)

It is an unknown path for us. Just where is this little chappie going to finish up, or if he ever finishes up, what's he going to be like? We don't know. I think, you know, you tend to worry a bit too, looking into the future, or trying to look into the future. Just how dependent is he going to be on other people? (Stephen)

Amanda sums up one way of dealing with this fear of the future:

What I had to do was actually try and bury the worry. I don't think about that today ...

She is backed up by Jill who says:

I won't let myself think of the future. I could not deal with the present if I did.

Whilst they all have such ways of dealing with their fears and worries, for the parents, the fears and worries are never removed. The consciousness that the world's not a wonderful place (Amanda) gives rise to
much anguish and many concerns regarding their children with disabilities. This anguish is incorporated into the parents' "sorrows".

Grief

This theme embodies a concept of a deep sorrow which has associations of loss. In Chapter Three, the constructs of grief, mourning and chronic sorrow were examined as responses to having a child with a disability. These frameworks were presented as they have had a major impact on the thinking of professionals who work with families who have a child with a disability but which, in my view, have a number of shortcomings. For this reason, I was anxious to explore the notions with the parents.

Whilst all of the parents spoke of their experience in ways which might conjure up images of grief, Sally was the only one who initiated any actual "grief talk". For her the issue is important:

_The biggest problem is being able to go through a grieving process ... I needed to be able to because, even though I still had this child, it wasn't the child that I'd had before._

However, for her, this grieving was complex because,

_There was the guilt, because I really wanted to grieve, but how could I when I still had a child?_

I introduced the concepts of grieving and of chronic sorrow with Jill and John, Sally and Stephen, and with Catherine during follow-up interviews. I did not have this opportunity with Amanda due to her being overseas. Jill and John find it difficult to ascribe a label to their feelings and talk of there being

... _no support for people who have "lost" a normal child who is now disabled._

They suggest that maybe they _block out_ some of the thinking about _the way he was_. It is, however, evident that the memories are there:
Just before the accident, just days before the accident, he used to run out in the front yard to the truck, and hop in the truck, and I used to chase him from one side of the cab to the other trying to get him out, and it’s that sort of thing. That doesn’t happen any more. I walk in and say ‘hello’, and give him a cuddle and he, you know, talks to you and that, but it’s not the same. (John)

Sally and Stephen both relate to the concept of chronic sorrow and believe that the sorrow is always there in the background, but comes to the surface from time to time:

I think you go through those periods of time when your sorrow is almost paramount, and then you go beyond that (Stephen)

However, there is much confusion and ambiguity about the whole notion of grieving which Sally’s words reflect:

If you grieve for something that is gone, that’s fine. It’s gone and over with. You can grieve, you can go through all the processes and you can put it behind you. But when it’s a child that you’re grieving for, the loss of the child that was, you still have the child that is. So, you can’t stack it neatly up and put it away. It’s something that is there all the time and, even though you may think that you have resolved things, and yes, I’ve come to terms with this or whatever ... In a sense you do, but by the same token there will always be something that will trigger it off.

Catherine was somewhat clearer when discussing grief. She states that she did not have a loss and that the fact of Down syndrome does not represent loss:

Charles and Down syndrome are intrinsically attached - there is no Charles without it. Without Down syndrome he would not be Charles.
She recognises a sadness, but having recently had a child who was stillborn, was adamant that there was no basis for comparison. She does, however, relate to the description of chronic sorrow, but thoughtfully added,

*Chronic is not quite right. Periodic might be better. It is a stream which bursts up at intervals.*

As stated, I was unable to have any detailed discussion with Amanda, but remember speaking about chronic sorrow with her in the past. She was interested enough to read Olshansky's (1962) paper and told me that she found it useful and that it had meaning for her.

The issue of "grief" appears to be a perplexing one for the parents, and the "confusion, doubt and ambiguity" which surrounds it will be dealt with more fully in Chapter Ten.

Despite these confusions, it is clear that grief and chronic sorrow are part of a state of being which is reflective of deep and abiding sorrow.

**No Hope and Despair**

Despair is a state of being which is characterised by a complete loss or lack of hope. It will be clear by now that, in telling these stories, the parents have presented an overwhelming picture of "no hope". They have been inundated with messages of hopelessness from "other people" which have been responsible for feelings of isolation, rejection and despair. It would seem reasonable to expect that the parents would be immobilised by a sense of despair and hopelessness. By and large, this has not been the case, and this discussion will take place in Chapter Nine. Whilst there are many messages of "no hope", "despair" finds only occasional expression.

The parents' words to date are full of negativity from others and reflective of much personal sorrow. Many of these words carry implicit meanings of "no hope" but, on occasions, they are very specific.

... *you weren't given any hope, that was the thing that was always kept from you, the hope, any glimmer of it ...*  
(Amanda)
By and large, the parents hold many of the professionals with whom they have worked to be responsible for the "no hope" messages:

I always went in there very hopeful. I always went in there, I suppose, rather naive expecting them to say 'Wow! Hasn't she come on'. But, you never got that. (Amanda)

... and nobody ever had anything positive to say ...

... he won't do this, he won't do that, no we can't do anything for him ...

they wouldn't commit themselves to saying, 'Yes, that's a positive aspect' and ... I found that frustrating because ... all

I was after was these little bits of hope ... (Sally)

All of the parents were adamant that professionals should leave some room for hope (recognising that the task may be difficult) and are angry about its removal:

I don't think anybody has the right to take away everything,

which is what happens just too many times. (Sally)

Stephen believes he has the explanation:

I feel that they do it because, if they give you hope and it doesn't happen, then you're devastated from then on, but if they give you no hope and something changes, then you feel as though you're in front for life.

At times, the parents speculated on possible outcomes for the "no hope" messages. Sally and Stephen believe that hopeless prognoses from professionals may immobilise parents to the point of taking no action so that the prognoses become "self-fulfilling prophecies". They believe such messages may be cause enough for parents to place their children in institutions where, they believe, the "no hope" is reinforced. Jill and John did, in fact, consider institutional placement for Joel when they were convinced he would die. Jill now says,
I think it's sad that obviously there are a lot of people out there that didn't listen to their dreams, otherwise there wouldn't be so many kids in institutions, would there?

There are instances of the parents being immobilised by their despair, of them feeling utterly helpless and powerless. Jill needed to be swallowed up in a hole when Joel was dying and, when he first came home she ... just sat there and cried and I just sort of said, I just don't know what to do ... It was just sort of like despair, you know, what do you do now?

Jill, John and Sally all speak of feeling like a child in the face of their helplessness. Catherine speaks of this impotence as a heavy sense of the mountain which comes upon her as a result of other people's focus on what Charles "can't do".

The despair brought on by utter helplessness in the face of total loss of hope was given its most poignant expression by parents of two of the children. With tears pouring down her face, Sally told me of her fleeting desire to put a pillow over Samuel's face, and John still thanks the nurse who stayed with him during the six hours of Joel's seizures which John wanted to finish by putting my hand over his mouth. Both Sally and John were awkward with these disclosures, but are willing to present their moments of humanity as illustrative of the depth of their despair.

All of the parents spoke of messages of "no hope" being imposed upon them. They are angry with a professional approach which leaves no room for hope, and believe such negativity to be counterproductive. They have illustrations of the helplessness which having no hope may lead to, and are able to speak of the possible effects of total despair.

In summary, this chapter has presented the major theme of "sorrow" and has demonstrated that the sub-themes of "dying", "finding out", "a death in the family", "on their own", "being vulnerable", "fears and worries" and "grief" are engendered by their situations as well as by their dealings with other people. The interconnected themes of "no hope" and
“despair” are woven into the fabric of the state of being of sorrow and are expressive of the parents’ darkest hours. The interpretations presented in this chapter are largely congruent with the traditional assumptions of what it is like to have a child with a disability. Chapter Nine will challenge those assumptions.
Chapter Nine

BETWEEN JOY and SORROW

- JOY -

It's a joy completely of its own making.

(Amanda)
This chapter presents the "other" side of the parents' reality. It examines their world of joy and illustrates the contribution to this world made by their children. It presents the theme of "joys", along with its constituent themes of

- Not Dying,
- Little Things,
- New Perspectives, and
- Becoming Stronger.

The major themes of "hope" and "defiance" are introduced and it is argued that these provide an interpretation which enables parents to function with purpose and pride.

**JOY**

The term "joy" may be used to describe a state of being which has connotations of pleasure, gladness, enjoyment, hope, success, delight, optimism, wellbeing, satisfaction, fulfilment, enchantment, exaltation and exhilaration. The parents in this study have undergone all of these feelings in relationship to their experience of having a child with a developmental disability. The word joy is also used as a source of delight within itself - "a thing that causes delight". For these parents, their children are sources of delight.

**The Child**

When the parents speak of their children, they usually do so in glowing terms. They use words such as: fighter, survivor, happy-natured, generous, affectionate, unselfish, gutsy, beautiful, cheerful, and often emphasise their normal qualities.

Amanda respects and admires Annie. She frequently depicts her as a struggler, battler, fighter and survivor, as someone who has guts - And my respect just grew and grew; this tiny little thing had such guts. She has learnt to rely on her spirit and is thrilled with her achievements. She
describes her as charismatic, and says the people at Annie’s pre-school thought so too. This may seem an unusual term to describe a child, but it is one to which I can certainly relate. In Chapter Six I have described Annie as "... a delight - a tiny dark pixie of a child ... with unusual amber eyes." She has a highly engaging personality and when I spoke with Amanda recently in England she said ... everybody loves her. She also describes Annie as affectionate, unselfish, helpful, and refers to her jolliness and happy nature. She loves the way Annie consoles her and other people when she senses they are sad, and believes that Annie inspires her to cope:

She copes with it so well, that for me not to cope would be very poor on my part.

Catherine loves and admires Charles, and derives enjoyment from watching his development as an individual. She speaks of Charles’ response to the patronising people in supermarkets:

Charles has got these really intuitive little skills in there, and he gives these people the dirtiest looks ... He’s quite choosy, and I like it.

She describes him as a beautiful, responsive, warm child from whom she gets the beautiful, responsive, warm child goodies.

Jill is very proud of Joel. When she speaks of him the pace sometimes reaches a point that is hard to keep up with, and her face shines with joy as she relates his doings. She describes him as an achiever, but recognises the constant hard work he does against a lot more odds than most other people ever know. She says he has always been a happy and beautiful boy, and we think he’s wonderful. She derives pleasure from his normal qualities, such as naughtiness, and says,

I look at Joel as a boy who can’t talk, as a normal little kid who just can’t talk so that you can understand him. And he rolls around rather than walks...

Her pride in him enables her to deal with the curiosity of others with typical Australian equanimity:
... if we ever go somewhere, people look at him funny. I think I’m just so proud of him and what he’s achieved, I couldn’t give a stuff.

John is also very proud of his son and says:

I look up to him. He’s got my admiration. Something I would like to have is the guts he’s got.

He derives pleasure from the everyday little things:

He says ‘Dad,’ and a big smile ... how can you not be happy with that? and emphasises the laughter in their lives. He and Joel laugh, joke and play together, and John takes great pleasure in

... acting like a monkey. He loves it! Goes bananas - he laughs and carries on, and Jenny laughs and carries on.

Sally has gained a great deal of inspiration from Samuel. She recognises his struggles and enormous determination and sees his achievements as

... an absolute miracle. And I want people to recognise that. I want people to recognise what he’s done.

She says that anything that is put in his way simply becomes an obstacle for him to work out how to get round, through, under, over, or whatever ... and ascribes his success to his intrinsic qualities, despite overwhelming odds. She also highlights his normal qualities, and whilst recognising his changed functional potential says,

... he’s still the same happy natured, still bright, cheerful, just adorable little person that he used to be.

Stephen speaks of Samuel as a normal, naughty little boy and is happy with the small achievements:

He’s reached that stage now, he’s dragging everything down off the table, breaking bowls and dishes ... 

Whilst somewhat more reticent than the other parents, he recognises that priorities have changed, so that ... we’re thrilled by different things, and despite their losses, what we’ve got is good.
It is clear, when speaking with the parents, that their children act as a source of joy. They are animated and enthusiastic when recounting events, and their voices are full of pride and love. Positive moments of ordinariness in which their children are presented as nothing more than little children, fuel their joy. Whilst occasionally, they refer to the child as a source of joy in relationship to other people, as when Jill tells the story of Joel’s first birthday party following his injury:

You looked around and everybody came ... and it was just sort of like looking around and thinking, he had that much of an effect on so many people’s lives ... positive changes not negative changes ...

Their overwhelming message is one of finding the joys for themselves. Amanda put it this way:

You’ve got to grab positive things for yourself. No one’s going to give them to you.

It is apparent in the discussion which relates to "sorrow" that the parents maintain joy, optimism and hope, often in the face of overwhelming negativity. They frequently do so because of the inspiration they derive from their children so that, whilst aspects of their experience of being parents of children with disabilities contribute to an overall state which has its joyful moments, the children themselves are a major source of joy in their lives.

**Joys**

In an apparently contradictory manner (if one considers the sorrows), the parents emphasise their experience as being positive. Their emphasis has more than their children as its focus - they insist that the experience itself is a positive one. They believe they are better people and have been strengthened. John goes so far as to say I wouldn’t miss what I’ve been through for anything. Despite their insistence on the experience as positive, the analysis of its elements has proved to be a lot more complex and elusive
than the identification of the negative components. This has to do with the intangibles of their experience and the difficulties they encounter when they attempt to put into words their joys. They say things like it's confusing, it's hard to explain and it's difficult to describe, but are nonetheless definite about the experience being positive. My own grappling with the positives led me to pose the question to Sally at the end of our initial discussion:

I know this is difficult but, as a quick response, would you say that the total experience of the illness and then the adjustment to that and now the living with the situation has been overall negative or overall positive?

Her very quick response was, Overall positive. Yes. When I asked if she could tell me why, her answer reflected the intangibles:

- sense of self worth and self esteem
- higher opinion of myself
- better sense of myself, who I am, and where I fit into the world
- the children have benefited in a positive sense
- it's been good for the children
- if you look for the positives, they'll happen.

This last statement is, I believe, at the crux of the difficulties. The parents do derive joy from the experience, but frequently it is a self-constructed joy. They actively reconstruct the events so that they have meaning. They develop new perspectives and the experience gives new meaning to life - in their words, they are strengthened. Sally sums it up:

I choose to look at it as a positive growing experience for me.

Despite the confusion, doubts and ambiguities (which will be discussed in the next chapter), a number of themes emerged which contribute to the parents' state of pleasure, enjoyment, hope, success, delight, optimism, wellbeing, satisfaction, fulfilment, enchantment, exaltation and exhilaration. These states of being are summarised in the word, "joy."
Not Dying

For the parents of Annie, Joel and Samuel, the very existence of their children has been the source of much joy and delight. These children were not expected to live, to pull through, to make it. In Annie's case, it was even suggested by the Clinic Sister that this might be a good thing:

... she hadn't taken anything other than a little bit of water in two days, and I said 'I'm afraid she's going to fade away,' and the nurse said, 'Maybe it's better if she does'. (Amanda)

These parents wanted desperately for their children to live despite the almost certain disabling sequelae. They are left with a sense of exhilaration about the very being of their children and continue to exalt in their winning of the battle, a battle which, in Jill's and John's case is perceived as an actual fight with the devil.

Little Things

... it's like you're a million times more happy because he's done it, because he wasn't supposed to be able to do it. (Jill)

In the eyes of the parents "little things" become special and serve as a source of joy. The things which were once taken for granted take on new meanings and enable them to maintain hope and be happy. Sometimes these "little things" become very special and serve as beacons for optimism in the face of minimal expectations. Amanda takes great pleasure in recounting the story of a visit to the neurologist when Annie had "failed every test:"

... and then she picked up a toy and dropped it and said, 'Shit.' And he just looked at me and I didn't know where to put my face, and I was thrilled because he wasn't expecting it; taken him off guard, and that's what I liked. I felt much better after that.

Jill loves the "little things" which seem to prove Joel's "normality."
He's so happy and he's such a tease; I mean he can tease the hell out of Jenny and can be naughty, but I love all those things. I love the fact that he's naughty now because it's a normal thing for him to be naughty ... I love the fact that he gets dirty now ...

and she takes a special pleasure in the things that go unnoticed in other children:

*The other day he put his hand up to his face ... now I never even noticed he didn't do it until he did it for the first time and, to me, that was a big thing.*

John, in remembering Joel's getting onto his hands and knees as a big event, is now looking forward:

*When he gets up and walks and takes his first few steps, I'll cry again. I'll be happy.*

This statement encapsulates the apparent contradictions and illustrates how the parents frequently construct their joys by focusing on the "little things."

Sally expands on this theme, whilst deriving comfort from her perception of Sam's happiness:

... he has his own joys in life. I mean he really loves sitting up and having cuddles, and you know, I mean, and once again it comes down to your perception of things. I mean I think that probably a lot of people with disabilities are perfectly happy with their lot, and other people perceive that their quality of life isn't quite what it should be and that, you know, once again comes to putting yourself in the person's shoes. I mean really, if you look at it, we should envy Samuel because he's perfectly happy with his life. I mean he is very contented.

He's a very happy child.

Both Sally and Stephen recognise their joy in Sam's small achievements, and believe it is related to a general lack of expectations.
... we get far more reward from everything that Samuel does than we have from any of the other kids.

Catherine takes the theme a step further. She believes that, as a parent, she takes joy in the little things, but that, generally, this is not reinforced by others. She speaks of constantly being confronted by "can't" instead of "can," and makes a plea to professionals to focus on the "can do." She believes that if professionals gave time and energy to the "little things," then a sense of optimism, rather than impotence, would be encouraged.

Overall, the "little things" in the lives of the parents find many joyous expressions. They express hope and optimism as a result of their children's small achievements. They sometimes express a sense of fulfilment in their changed circumstances - they now take the time to notice the "little things." And they are frequently delighted and enchanted by every sign of their children's continuing existence and development.

New Perspectives

This theme was developed largely as a result of the words of three of the parents, Jill, John and Sally. Whilst Catherine referred to the experience as a personal growth challenge recognising that it's the me stuff that's changing out of it all, and Stephen referred to a rethinking of his values, it was clear that for Jill, John and Sally, the experience had wrought overwhelming changes in personal values and beliefs and, as such, carried significant meaning for them. Amanda did not explicitly discuss the development of new perspectives but, in relating her story, it was evident she had undergone some major life changes and, along the way, had developed fresh sensibilities.

The theme has proved somewhat difficult to explicate due to its inter-relatedness to a number of other categories. These include "making meanings", "you've gotta have a good attitude", "reframing", "relationships", "coping", "special", "spiritual things" and elements of many other categories. The ephemeral nature of many of the things discussed also
contributed to the complexity. The parents spoke of increased understanding, tolerance, awareness, self-esteem, knowledge and of being non-judgmental. However, much thought, debate and discussion led me to the conclusion that the link between all of these concepts was that of the experience itself lending new meaning to life and resulting in a changed outlook - thus "new perspectives." The parents see these "new perspectives" as very positive and as a source of satisfaction, optimism and fulfilment.

A remark made by Jill to me some years ago had been one of the prompts for this research. Her words then gave me pause, and did so again during our recorded conversation:

Penny. You said to me once (it was not long after the accident, it was probably only a couple of months) and you said to me one night someone had said to you, 'I'll bet if you could turn the clock back, you would'. And you said 'I really had to think hard about that because yes, sure you don't want it ever to have happened, you wish it hadn't happened, but, by the same token, we've changed so much and so many things have happened to us and we've become different people, that I'm not too sure that I could say in all honesty that I'd wish the clock turned back.'

Jill: I still feel that way, even more, because, I mean it's been longer.

Penny: Could you tell me about it?

Jill: Well, I just feel like if I could turn back the clock and have him normal and know what I know now, yes. But I don't think it is worth trading what I know now for Joel to be normal, because it's my tolerance ... the way your life changes as far as kids and things but (pause) it gives you a whole new look at human nature and how kind people can be, how nice, how many nice people there are in the world, you don't look at that. You're too busy living your life and you don't look at
that. How many disabled people there are in the world and what a raw deal they get ... It’s just everything - the way we look at each other ... I love the fact that I’m not scared of death ... I’m aware (of things) ... and to be aware makes all the difference sort of thing. And see, I couldn’t trade anything like that ... and you think the effect and the change his accident had on so many people’s lives, positive changes, not negative changes. And how can you trade that? You can’t you know (soft). Not even just for us, but for them too. It’s just (pause), it’s not worth it, it’s really not worth it just for him to be normal again. You know, just not worth it.

John introduced the thought himself:

I’d love to see him back to the way he was. I wouldn’t miss what I’ve been through for anything (soft). He (pause), I mean, who was it, someone said to us ‘If you could turn back time, would you go back?’ I would say no...

Sally expressed a similar view:

... I have found it’s been very rewarding, while at the same time, I mean, obviously if I had a magic wand that could make none of it have ever happened, I would do.

Penny: You would, would you?

Sally: I would. I mean, I have to add to that, if I could, if I could go back to the day before Samuel got sick with the knowledge that I have, with the, I think I’m a much better person for what has happened to Samuel. Me personally, I think I’ve grown a lot. I have a much greater understanding of people in general ... it changes your perspective ... I did a lot of soul searching. I completely re-thought my values. I think I’m a much calmer person ... you really can’t take life for granted. You can’t take your kids for granted. You really should make the most of it ...
Jill, John and Sally are very definite that the experience itself has given them "new perspectives" on life, which they see as positive. Jill and John speak at length about how these new perspectives brought about marked life changes.

As a result of Joel’s accident, his parents gave up work. After some time, John gained employment as a personal care assistant with Homecare - a job he says he could never have managed prior to the accident:

... there was a time where old age, people being frail or very, very sick in the way of dying um, or disabled people, and it sounds terrible, but I know that’s the way a lot of people feel, used to make my skin crawl alright, because it’s something so foreign to me right...

He now rejoices in his ability to form relationships with all sorts of people and in making ... them laugh, or feel a little bit better. Jill is happy about the changes in John and recognises them in herself. They both speak of their increased knowledge and understanding of people with disabilities and say, We’ve been privileged, believing that their knowledge ... leads to understanding.

The parents speak of developing a new perspective on relationships. Whilst they have lost some friends, ongoing relationships are sometimes strengthened. The experience has enabled Sally to stand back and become more accepting of what she sees as some of Stephen’s shortcomings:

... I’ve accepted that, and that’s fine. And, I think, because of that, we actually have a much better relationship. We have a stronger marriage ...

She puts this down to her changing values and her increased ability to accept people for the way they are. She recognises her changed values when she recalls growing up with a mother who had expectations of ... everyone and everything to be perfect, and acknowledges a sense of achievement in her own acceptance of things. In speaking of her own dealing with her experience, she has surprised herself and makes the rueful comment: I didn’t think I could handle that much imperfection.
The new perspectives on life have often come about as a result of a process of active construction on the part of the parents. They use strategies which I called "reframing" and "making meanings." Sometimes the strategies overlap and become blurred, and sometimes, in reframing an event, meaning is created. Amanda comforts herself with the thought that Annie is ... actually better than she could have been due to the care she took in pregnancy. Joel's and Samuel's parents also use this "it could be worse" tactic; Jill laughingly recalls saying to her mother:

... well, look at it this way Mum, he'll never grow up to be an axe murderer ... He won't be a heroin addict, he won't be an axe murderer ...

and in comparing her experience to that of parents of children with leukaemia says:

Their parents have to watch it for months or years or whatever ... so I said he was lucky. We weren't there when it happened. We didn't have to pull him out of the pool. We didn't have to try and revive him. We didn't have to do any of that. We were spared so much ...

This tactic was used on a number of occasions by all of the parents except for Catherine. Things could have been much worse for them, and there were many people who were worse off than they are.

In the creation of meaning some of the parents speak of spirituality. John, in particular, believes his spiritual sense to have deepened and this is a source of joy to him. Jill believes that people with disabilities are God's angels. They're so special. Amanda reports that her father said children like this are given to special people. Whilst being thankful for his lovely thought, she rejects the notion, as does Catherine, when people have expressed similar thoughts. She says I didn't like it much. Catherine relates that, in her experience, a lot of people see that having a child with a disability is God's purpose or something, but that this has no meaning for her. In fact,
Catherine appeared not to engage in "making meaning" strategies. She says:

*I don't feel like I need a reason. It just is.*

In the active construction of new perspectives, John stood out. He has a phrase which he seems to use as a mantra: *You've gotta have a good attitude.* At the follow-up interview with John and Jill, I said that this "good attitude" seemed to me to be a conscious strategy. They agreed:

John: *It's a conscious decision. Your attitude rubs off on the kid.*

Jill: *A positive attitude is the only thing that works.*

John: *Your attitude makes you tougher and stronger. If you've got a piss-poor attitude, then you're really going to go downhill, aren't you?*

He says that it is his experience which has been responsible for his positive attitude which has given him a whole new outlook on life:

*It just makes it a better way to live ... I'm a better person now than I was. I was drinking heaps. I was drinking way too much ... Probably more sensible. Better priorities ... I find it very hard now to tolerate people with bad attitudes, bad attitudes ... What you've got here with your family can't be replaced.*

This overt construction of John's caused me to examine the words of the other parents from this perspective. It is a strategy which they all use. Amanda speaks of her positive attitude in comparison to the constantly negative attitude [which] was so destructive from professionals and Catherine says that we need a paradigm of optimism. Jill speaks of looking at the positive. Stephen, cautious as usual, says that we'll keep trying, and do as much as we can with what we've got, but the theme finds more definite expression with his wife:

*Nobody would wish to have a disabled child. Nobody would wish to go through what we went through. But if you look on the positives, if you look for the positive things, then*
they'll happen ... I try to look for positive things in whatever happens, and I mean there's nothing I can do to change what happened, so I have to make the most of the situation. And I choose to look at it as a positive growing experience for me.

(Sally)

Overall, their experiences have led to the development of "new perspectives" by the parents. That these changed outlooks have significance and meaning, and are a source of much satisfaction is most apparent in the stories of Jill, John and Sally. The theme finds its greatest expression in the words of John who is exhilarated by his new-found good attitude.

**Becoming Stronger**

I'm a much stronger person. I used to be a bit of a doormat.
I'm one of those people that everybody used to walk (soft) all over, and I knew it was happening. That was the worst part about it ... Now, I stand up for myself, and that's something that wouldn't have happened. I mean that all came out of standing up for Samuel and sort of fighting for his rights, that I sort of began to think, well, you know, I can do this. I can, it's all right to tell people how you feel. (Sally)

The parents pay credence to the notion of becoming stronger in the face of adversity, and so, see their experiences as strengthening. This theme is also interwoven with those already discussed and separating it from its background presented the usual difficulties. It does, however, stand on its own and is a strong theme. The parents often use "strength" words and speak of being strengthened in many ways and in numerous contexts. It frequently appears that their "becoming stronger" is an outcome of the numerous strategies used to develop "new perspectives." This strength is certainly seen as positive and highly desirable, and sometimes a certain amount of pride is evident in its expression:
You’ve got to pull out every inner strength you’ve got for you and the baby, and that’s what makes you special. (Amanda)

Often, although the words are not used, the theme of "becoming stronger" is implicit:

You are learning things that you wouldn’t have otherwise learnt, and facing things that you haven’t otherwise had to face and gained knowledge that you wouldn’t have otherwise gained ... (Catherine)

Various elements of their experience make the parents stronger. As already suggested, they identify strength as an outcome of meeting challenges, and view this as positive. They associate being strong with having hope (this will be discussed in the next section "hope and defiance") and, for some, a sense of the spiritual is strengthening.

Humour is also seen as an aspect of becoming stronger:

... it’s hard to describe the laughing except that it’s healthy. It gives you the strength to go onto the next step. (Amanda)

During our conversations there was much laughter and frequent wry and black humour as incidents were recalled. Jill says they often laughed because it was sort of too exhausting to cry all the time and John views laughter as therapeutic. It’s brilliant.

Overall, the parents have been strengthened in one way or another and they view this as "good." The only dissenting voice comes from Stephen’s non-committal words:

... the whole experience tends to bond the family a bit ... I think it’s made us sort of more, well stronger personalities as such. That can be a good and a bad thing (laughter) but, you know, I suppose it has. I think it does strengthen you individually, to have to go through this sort of trauma, but whether it’s good or bad, who knows? I don’t know.

Despite Stephen’s doubts, the parents emphasise the strengthening aspects of their experience. They view their "becoming stronger" with a variety of
emotions, from guarded optimism to deep pleasure to outright delight. It is a very significant element of their joyous state of being.

**Hope and Defiance**

Despite negative attitudes from family, friends and acquaintances, hopeless prognoses from professionals, and bouts of hopelessness and despair (Chapter Eight) the parents are not immobilised. In fact, they are all highly functional and speak of their hopes and dreams. It occurred to me that they would probably have labels such as "denial" and "not facing reality" pinned onto them in some contexts and yet, my gut instinct told me this would not be appropriate.

The thinking began to take shape as a result of the parents themselves being very careful to distinguish between hopes and expectations. They all recognise that they are sailing in largely uncharted waters and so do not have many expectations for their children. They do, however, have hopes and dreams and believe they are essential to their healthy functioning. John expresses it thus:

... a little bit is better than nothing, and you have to have some sort of goal or a dream to work towards. I mean everything in life is, that has been done, has been done with a purpose or a dream.

Sally explains the difference:

... with Samuel, nothing’s expected and everything he does is a bonus, so you get so much joy back because you don’t expect anything. I mean you have these hopes, but you still don’t expect.

It was apparent that the parents were speaking of hopes and dreams as "a belief in possibilities" (van Manen, 1990, p.123) and not as things which they expect to happen. But I still kept asking myself "How do they manage to maintain such hope and optimism in the face of sometimes overwhelming pessimism?" And then, I had some "Eureka" experiences!
The first of these occurred when I was reading "Head First: The Biology of Hope" (Cousins, 1989). When speaking of his work with cancer patients, Cousins describes the responses of some people as unexpected, in that they did not have a panic response and did not become depressed. In fact, many physicians thought they were "denying." Cousins, 1989 (p.83) said:

... they didn't deny the diagnosis; they denied and defied the verdict that was supposed to go with it. The defiance took the form of a blazing determination and it was a window on the future.

"This is it!" I thought. I just knew that here was a key. These parents did not deny their children's diagnoses; in fact they had a deep and realistic understanding of their children's conditions. But they were denying the prognoses; they were defying the "no hope" and "vegetable" verdicts which they had been given with the diagnoses. Their "defiance" of the verdicts was enabling them to function, and their "blazing determination" was often exemplified in their "fighting" language. Their hopes and dreams provided their "window to the future," without which they would be immobilised, and in Sally's opinion, the hopeless prognoses would have become "self-fulfilling" prophecies as parents would do nothing to ensure their children's development. This "defiance" found expression in many of the parents' words:

Assessments are always devastating. They were always devastating because you weren't given any hope. That was the thing that was always kept from you, was hope, any glimmer of it. And so you had to fight on your own ...

(Amanda)

When he started to feed they still wouldn't acknowledge that he'd even changed at all ... we were told we could do absolutely nothing, and then he frowned. Oh! that wasn't
nothing - he frowned. And then he actually took some food.
It might have only been a spoonful, but he took it and that
was something. To us that was some major thing, and to
them it was nothing. (Jill)
But he’s doing a hell of a lot more than they ever said he’d
ever do, and he’s still gonna do more. (Jill)

And then you find people saying: ‘Well, we’ve gotta look at
the, we’ve gotta be realistic here’ - parents you know, people
like that. ‘You can’t do that, you shouldn’t do that’. They try
to take these things away from you. I know, what I want, to
do, with him, with me, with my wife, with my family. I’m
gonna do it, and that’s all there is to it. I don’t care what other
people think. I know what I can do, and I know that I’m
gonna do it. You’ve gotta have these dreams... (John)

I don’t tend to look too far ahead (into the future). Um, I
mean, I know what I would like (pause) (smiling) but, and I
know what I don’t want for him in the future, but as to what
it really will be, who knows? I mean it’s really (pause), I
honestly believe that Samuel can go as far as he wants to, yeah
if he wants, not if able, as he wants. Because he’s sort of
shown over the last couple of years that he can go a lot further
than he is able, and then he becomes able to do it. (Sally)

Yeah, we held out hope, I think, well I certainly did. I held
out hope right the way through. (Stephen)
Let’s face it, the actual prognosis was not very bright. But to
be totally negative in the prediction I think is wrong.
Certainly proved wrong with him. (Stephen)
I’m not denying reality - I just don’t want to feel heavy all the
time. If you take on the heaviness, you can’t run the
marathon - if you take on the optimism, you can jump the
hurdles. (Catherine)

The second Eureka experience took place after seeing the film,
"Lorenzo's Oil" (Mitchell & Miller, 1992), in which the parents of a child
who has a degenerative neurological disorder which results in certain death,
defy all odds and fight for his survival. For me, the parallels between the
behaviour of Lorenzo's parents and the parents in this study were striking.
In the film, Lorenzo's parents had a very firm grasp on the reality of their
child's condition, but with a ferocity and a "blazing determination" set about
educating themselves and tracking down a therapy which would help their
son. They did this in the face of overwhelming pessimism, and accusations
of being denying, non-accepting and unrealistic from professionals and other
parents of boys with the same condition, but said they would "not expose
themselves to doubt and despair". For me, Lorenzo's parents had what I
called "a very large dose of defiance." They were not denying the diagnosis -
in fact they expended enormous energy in educating themselves about it -
but they did deny and defy the supposedly inevitable verdict which went
with the diagnosis. At the time of writing, none of the parents in this study
has seen the film (they suspect it may be too confronting for them), but they
have acknowledged my interpretation and relate to the parallels as described
by me.

Many of the themes and elements already discussed may be seen as
expressive of this theme of "defiance" by looking at the parents' stories in
light of this interpretation. The parents took great pride in their
achievements, and in those of their children. They related how they had
"overcome the odds" and spoke of the courage of their children in doing so.
They derived a great sense of satisfaction (in retrospect) from meeting the
challenges engendered by their situations and believe they are now stronger
and more resilient. In caring for their children, they have, and continue to
"defy the implications" - there have been suggestions of "it's not worth it."
They have developed tactics and strategies to obtain therapeutic services for
their children, despite the fact that for three of the children the predictions
related to "doing nothing." They have developed a sense of "being on their
own" because "no one will do it for you." They use strategies such as
"reframing reality" to develop "new perspectives" so that they are able to
function in hopeful and optimistic ways, and frequently their "defiance"
finds expression in having a good laugh. Of course, as the parents have
indicated in many ways, they are unable to "defy the implications" if they do
not have hope. It is by being hopeful, and by having dreams that they
maintain their "blazing determination" to overcome the odds.

This "defiance" is maintained despite the pessimism of many
professionals (although I sometimes ask myself "Is it because of the
pessimism"?) and despite a general lack of support for their hopes and
dreams. Sally tells us of the boost she received from one professional:

... nobody ever had anything positive except for this one
Chinese doctor I went to, the acupuncturist and, I mean he
was just, I think he gave me enough adrenalin to keep me
going for the next four weeks because after having gone
through such a terrible down period of he won't do this, he
won't do that, no we can't do anything for him. To me this
Chinese fella who didn't speak a word of English (everything
was done through an interpreter), and at the end of the
consultation he said, 'You know, do these points every second
day and in twelve months he'll be fine.' And I went home
and said to Stephen, 'I don't care whether what he said is
right or not.' It was just such a boost to have somebody
actually say that he was going to be all right. Realistically, I
knew that when he meant all right he didn't mean that
everything was going to be back to normal, but it was just very
few and far between getting those bursts of somebody saying that things were going to be fine.

In relating this incident, she is indicating her appreciation of reality, but recognising that she needs hope in order to be able to function and keep going.

When I spoke with the parents during follow-up discussions, about these themes of "hope" and "defiance," they were all quite vocal, and sometimes expressed their dissatisfaction with what they see as the expectations of professionals. Amanda, whilst suggesting that the word "defiance" was maybe too brave, nevertheless related to the implicit notions. In speaking of her dealings with some professionals who have suggested "no hope" for Annie and have made demands on Amanda of "being realistic," she says,

It's impossible for us to live in that state ... 'Being realistic' is too much. You can't cope with it and it makes you unhealthy. If you were 'realistic', you wouldn't get out of bed in the morning.

and

The professionals couldn't cope with our situation, it terrified them. I could cope with what she was - to me, she was perfect.

Catherine expressed a sense of recognition when I said, "Defiance, not denial." She said that the focus on the "can't do's" leaves her feeling incredibly heavy, and that she would like to see a new paradigm of optimism which focuses on the "do's." She said that, as a parent, the focus on "can't do's" leads to a heavy sense of the mountain which results in parental impotence. She said she is ... not denying reality - I just don't want to feel heavy all the time.

Sally and Stephen, whilst recognising the task of professionals as difficult, make a plea for allowing some hope:

... there's got to be a way of yes, you've got to be able to tell people without building their hopes up too much but, by the
same token, I don't think anybody has the right to take away everything. Which is what happens just too many times ... I mean, they're not God, they don't have the ultimate power, they don't have a crystal ball that can see into the future, so why pretend they do? ... All you need is a slim, just leaves us with a slim chance that something ... This is a big thing, they won't commit themselves.

In much the same vein, Jill and John speak of

Experts 'being realistic' leads to a big chunk being taken out of your dreams.

They believe that the negative attitudes of others could result in an inertia that might, in fact, become comfortable as you could sit in the ditch for as long as you like, but you don't achieve anything. John, in his inimitable style, captures the theme vividly:

Fly with the ducks, and you become a duck. Fly with the eagles, and you become an eagle.

In summary, the interpretations presented in this chapter might be described as the raison d'être for this work. It was Amanda's other reality which provided its impetus, and it is the parents' "other reality" which has been given voice in the joys of their experiences. The implications of these interpretations will be discussed in Chapter Eleven. The parents speak convincingly of the joys derived from their children, along with a sense of personal development and achievement which has resulted because they are the parents of children with disabilities. They give voice to their changed modes of being-in-the-world when they speak of "little things", "new perspectives" and "becoming stronger". They are clear about the necessity for optimistic and hopeful ways of being and derive much joy from enabling their children to defy the implications of their diagnoses.

Whilst having a personal sense of achievement in surfacing these parents' "other reality", I have asked myself why it is so often neglected by
professionals. The indications from this work are that the parents’ joys are often ambiguous and their experience is one of conflict and paradox. Their experience is modulated by what I have called “the tensions” and it is these tensions which will be presented in the next chapter.
Chapter Ten

BETWEEN JOY and SORROW

- THE TENSIONS -

The joy is defined by the sorrow that has come before"

(Amanda)
This chapter presents the themes which are the mediators of the parents' joy and sorrow and which are captured as "the tensions". It demonstrates the "confusion, doubt and ambiguity" inherent in the parents' experiences which gains expression through the sub-themes of

- Dissonance of Values and Beliefs,
- Conflict of Values and Beliefs,
- No Maps,
- Guilt,
- Grief, and
- Professionals.

It presents the conflicts and paradoxes which have resulted in the overall interpretation of their experiences as "between" joy and sorrow, which, as you will see, allow us to glimpse "both sides of the rhythm".

Conceptually, "the tensions" is a more difficult area than either "joy" or "sorrow" and this is due to the very nature of the themes. The parents' words do not always fit as neatly as in the previous chapters and so are presented with more discussion in recognition of their frequently ambiguous nature.

**BETWEEN**

The state of being which I have called "between joy and sorrow" is just that - it is "between". It is neither joy nor sorrow, but rather a phenomenon which is complex and dynamic and which has many interconnected and interwoven elements. The joy and sorrow are themselves interdependent; the joys are frequently there because of the sorrows, and the sorrows would not be there without the sense of joys lost.

**The Tensions**

The notion of "tensions," with its connotations of dissension, disharmony, discord, divergence, pulling, stretching, straining, energy, vigour and of powerful forces in opposition, reflects the dynamic and
frequently contradictory and ambiguous state of being which is "between joy and sorrow." It will be seen that these "tensions" are a result of a multitude of "confusion, doubts and ambiguities" which the participants confront as parents of children with disabilities, and which reflect the sometimes paradoxical nature of their joy and sorrow, defiance and despair, and hope and no hope. "The tensions" light up the turbulent undercurrents of the parents' experience and provide us with a window through which "both sides of the rhythm surface" (Parse, 1990, p. 10).

Confusion, Doubts and Ambiguities

From early in the analysis, the presence of disorder, disharmony, disbelief, uncertainty, scepticism, equivocation, ambivalence, vagueness, double meaning and lack of clarity was apparent. From these sorts of meanings arose the theme "confusion, doubts and ambiguities," which found expression in a multitude of ways.

The parents speak of confusing emotions, confusing information, confusing advice, conflicting information and advice, ambiguous prognoses, of their own observations being in conflict with the information they were being given, of not knowing what to expect and sometimes, of simply not knowing what to do. They have entered a world in which, with the exception of Catherine, they have no experience and no knowledge, and they have no signposts and no maps. They are torn by joy in the survival of their children but, at the same time, question the cost. They thank God for saving their children and recognise they are lucky to be alive but, in the same breath, express their sorrow at what they are missing out on. They grieve for the loss of the children as they knew them and, at the same time, feel unjustified in their grief as these children continue to exist. They describe their children in glowing terms whilst recognising that, prior to their experience, they did not value people who are like their children, that they were afraid of them and had little to do with them. Their assumptions are being constantly challenged, and this makes for a powerful and conflicting
undertow - an undertow which acts as a tension between the experience of joy and sorrow.

Despite the difficulties and the confusions, a number of themes common to the state of confusion, doubt and ambiguity, were identified.

**Dissonance of Values and Beliefs**

Whilst the parents always speak of their children in glowing, positive and optimistic ways, there are occasions when their words are reflective of negative values and beliefs regarding people with disabilities. At first, I thought that this talk had to do only with "other people" (as discussed in Chapter Eight) and occurred only when they were reporting interactions with friends, family, professionals and others. This, however, was not always the case.

There are occasions when the parents speak of how they used to feel about people who are different, but this is in the context of how their attitudes have changed. John says that such people used to make my skin crawl and Jill speaks of being about six making fun of a spastic and of her mother nearly killing her. Sally is embarrassed about her previous prejudice and the fact she never thought she could handle that much imperfection. In such contexts, the parents are expressing a satisfaction with the attitudinal changes they have undergone as a result of their personal experience, and they look upon the changes as contributing to their "new perspectives" and personal growth, and as part of their joy.

I did, however, develop an awareness of something else in their words. I had a vague sense of disturbance and unease which led me to a close examination of the parents' stories with a focus on values and beliefs, and to whom these might be attributed. By and large, the parents were attributing negative values and beliefs about their children and about people with disabilities to "other people," mainly professionals. However, there were occasions when their words appeared to be reflecting negative values and beliefs about people with disabilities, although never in relationship to
their own children. Amanda provides the most powerful examples of these apparent contradictions:

... my fears for Annie's future would be because all I could relate to was this post war stuff of the old lady who lived up the road and her mentally retarded teenage daughter, and we'd always see them going shopping together. It was just this horror of horror of that ...

and later,

I felt that at sixteen (Annie), I would be Mrs. A., and her retarded daughter

and

... there was a suggestion that I take her along to a playgroup for Down's syndrome children, but I didn't feel that was the situation. Annie didn't have Down's and that was giving her only a sort of low priority people to learn from, and she had this sort of brightness about her eyes ...

I was particularly struck here by the apparent split in perception, by the low value placed on others with disabilities against the personal value of her own daughter.

There are glimpses of this dissonance with all of the parents except Catherine and Stephen. Jill and John demonstrate some discomfort with the suggestion of intellectual disability and express relief in their belief that Joel is not intellectually handicapped. They are concerned that he be educated without having to get stuck into a room full of intellectually handicapped people.

There were also occasions when it was difficult to assign an attribution of negative values and beliefs, so that I might find myself asking questions of the data: "Is this statement reflective of how 'other people' feel, or is it reflective of how Amanda/John, etc. think other people feel based on her/his experience?", or "Is this statement reflective of how they feel now, or of the way they used to feel?" Usually, I could not answer these questions.
Due to my own confusion regarding these "confusions, doubts and ambiguities", and my sense of their significance to the parents' experience, I returned to the parents to explore these issues more fully (with the exception of Amanda who was in England). With Jill and John I discussed the notions of "public meanings" of disability which, in their case, appeared to have been challenged as a result of their personal experience. They are adamant that their views have changed enormously and that they admire people with disabilities. They believe that they have developed non-judgemental attitudes, and speak of the general ill treatment and negative attitudes towards people with disabilities being a result of lack of education, knowledge and integration. They reflect on their own past responses as being due to fear, a lack of knowing how to behave when confronted by differences in people. And yet, there is a suggestion that they still consider Joel to be different from those who are held in low esteem:

Yeah, so when I thought 'massive brain damage,' I'm thinking he's just such a beautiful little boy, and now he's going to be this yuh! yuh! (gesticulating), you know, sort of thing, and how horrible to see him like that. You know, he's had his moments, but even when he was, you didn't care because you loved him so much. (Jill)

This statement within its context reflects, I believe, the dissonance and powerful tensions. My interpretation is: I used to believe people with disabilities were "yuk" (or maybe I still do). I thought my son might be like that, but he's not. But even if he is like that, it doesn't matter because I love him.

Sally and Stephen were able to relate to this notion of "confusion, doubt and ambiguity" within themselves a little more explicitly. In the follow-up discussion with them we talked of the conversations with participants illustrating that parents speak positively, whilst "other people" speak negatively, and concluded that the "negative talk" is reflective of cultural values and beliefs (Sally had discussed this in our initial
conversation). I indicated to them that whilst the parents do have positive attitudes, I was getting glimpses of negative values and beliefs seeping through and that, whilst the personal experience certainly results in changed attitudes, it seemed to me there is a hanging on to deeply embedded cultural beliefs which results in some ambiguity. Both Sally and Stephen recognised this and expanded somewhat. We explored the idea of their experience leading to changes in their beliefs, but with the recognition that it is difficult to get rid of old values and beliefs entirely, particularly when these are being constantly reinforced by others. The three of us laughingly agreed that the area was fraught with confusion!

My analysis of Catherine's conversation indicated none of this apparent dissonance. She, unlike the others, had education relating to people with disabilities coupled with both personal and professional experience. It was as if culturally defined values and beliefs had been challenged and dealt with prior to the birth of her son. She demonstrates a much clearer understanding of the long-term implications of the disabling conditions of childhood and is clear that her concerns relate to other people using the disability as the basis for hurt. As an individual, the fact of Charles' disabling condition is of no significance: Without Down syndrome, he would not be Charles, but she knows that he will probably have a shit time because of the disability at the hands of others. So, whilst Catherine is at times subject to the "confusion, doubts and ambiguities" shared by all of the parents, it would seem that a "dissonance of values and beliefs" is not contributing to this. She is however, troubled by some conflicts in the area of values and beliefs which will be discussed shortly.

Despite the fact that there are not a great amount of data to support this dissonance, it may be a significant consideration in the development of insight into the parents' experience in which "confusion, doubt and ambiguity" are inherent.
Conflict of Values and Beliefs

I get really worried that the frivolity of childhood doesn’t get a look in. (Catherine)

Catherine speaks of the balancing acts which seem to go hand in hand with being a parent of a child with a disability. She frequently finds herself caught in conflicts which arise due to Charles’ condition.

Because of all the special needs stuff, particularly around therapeutic needs and because of, you know, needing early intervention, needing physio and needing all the other things that he needs ... And I wonder, and that’s the psychologist in child welfare in me thing what, because there have been occasions where people have suggested things to me that, with my professional hat on, verge on emotional abuse, in my perspective. And I think, oh, where is the line between promoting his development and making life revolting? Making life into a therapy setting, not a carefree life ...

She recognises that he needs a fighting chance because the world out there is not a wonderful, happy, glowing, benevolent place, but raises the question of where to draw the line, and expresses concern about his developing self-esteem because of everybody telling him that he had to do more than he was doing. The other parents are all actively involved in therapeutic programmes with their children, but none gave voice to this particular conflict.

Catherine also finds that her guilt buttons are pushed by being a working mother. She had always intended and planned to work after the birth of her child and believes that, under ordinary circumstances, this would not have been an issue. She speaks of interactions with professionals who very subtly indicate that she should be with her child because he has a disability, and so lead her into conflict with her own beliefs:

I do it very easily, and sort of saying oh, maybe I’m not supposed to, maybe I’m supposed to be. Should I be?
Shouldn't I be? You know, and I do another trip on the merry-go-round.

Logically, she believes she is able to deal with her decision to be a parent who works outside of the home, but considers she has the beliefs of others imposed upon her and becomes confused because Charles has a disability.

With regard to schooling, all of the parents are finding themselves in a position of compromise. They have all said that they believe children with disabilities should be integrated and attend mainstream local schools with the necessary support. In practice our current system does not support such integration for their children, and so all are currently finding ways of dealing with this assault to their beliefs. Amanda, now in England, considers Annie is getting more attention in her special school. Catherine is resigned to the fact that Charles will probably be labelled "moderately intellectually disabled" and will attend the special class within the local school. Jill and John will keep Joel at home and teach him, rather than have him in a special school, and currently Sally and Stephen are driving Samuel two days a week to a specialist school situated some fifty kilometres from where they live, as the bus trip is too long and tiring for him. They believe the compromise to their beliefs, that is, regarding mainstream local education, is worth it for the excellent progress he is making. All the parents consider that they have little to no choice in such matters because the system does not accommodate choices for children with disabilities. They find themselves in frequent conflict - a conflict between what they believe they should do, and what they find themselves having to do because their children have disabilities.

There are other instances of such conflict in the lives of the parents because of their children's disabilities. Jill and John do not believe in placing children in institutions and yet, when confronted with their own helplessness in the face of Joel's imminent death, considered such placement as their only alternative. Amanda does not believe in smacking children, and yet has admitted to resorting to the occasional slap because Annie didn't
understand anything else. Sally and Stephen believe that all of their children should be treated equally, but Joel's condition dictates otherwise.

The parents find their values and beliefs under constant challenge, and frequently find themselves in a position of compromise due to the pragmatic aspects of their situation. They are able to be logical and provide explanations for themselves, but these conflicts contribute to their "confusion, doubt and ambiguity."

No Maps

It was just a no man's land. (Amanda)
Amanda referred, on many occasions, to a sense of "confusion, doubt and ambiguity" which was brought about by having "no maps." She had no idea of what lay ahead of her or of what to expect and points to this as being a result of Annie's difference:

I knew she wasn't fitting in with any criteria that life's normal healthy children do, and all the books are based on nice, normal, healthy children. I had the usual new mother's library of nice healthy children's books and, from the beginning, when I used to look at them, she didn't fit into any of them. I just thought, 'Well, these books are written about other children. They're not written about Annie.' Began to throw them out, one by one - they were no use to me. There was absolutely no map at all of what I could expect from her.

She speaks of her searches, and of a constant seeking for guidance and information. The clinic sister was of no help - she only knew about "normal" children, and the doctors used confusing terminology. People referred to Annie's developmental "delay," so Amanda thought this might be a temporary situation. She wanted somebody who could provide some sort of map. This was not forthcoming for over three years when she was
referred to the specialist developmental disability service about which she says:

... this is the first helping hand we've had in what seems like a whole turbulent sea of Annie's life.

She felt there was knowledge and expertise which enabled some of the clouds of confusion to part so that

Now I've got a map and, although it's not the one I dreamed of when I was pregnant, it's still a positive one. It means she'll get the most out of life and I've got all sorts of wonderful ideas about that.

Given that this was such an issue for Amanda, I was anxious to discover whether this lack of a map had such an impact on the other parents.

Catherine, with her knowledge of potential outcomes for people with disabilities, says that things have been a bit different to what I anticipated but, for her, this has not been an issue. However, she does admit to some tension when she says if you knew what he was capable of you could relax so that she could make decisions related to reasonable expectations about therapy.

Jill says I don't have a map as yet. I don't have expectations of him but, once again, this does not trouble her. She is so thrilled by his progress that she believes anything to be possible and, to her, the sky's the limit. John reinforces this hope and believes that whatever he wants to do, he can do. There is, however, some apparent contradiction in Jill's and John's statements for, whilst they say they do not have expectations, there are times when they speak of Joel living independently and working with computers. So, whilst the "no maps" do not explicitly bother Jill and John, there is a sense of some "confusion, doubt and ambiguity."

Sally and Stephen recognise that, due to Samuel's illness, the image is shattered. They speak of all parents having some sort of map for their children but that, under normal circumstances, these maps change slowly. In their case, this change occurred suddenly, so that they no longer have any
expectations. Whilst they are comfortable with this, they are conscious of 
shadows and say they will always wonder what he would have done if...
Even though Sally and Stephen deny a large impact from the lack of a map 
for Samuel, it is evident from their words that this contributes to some 
"confusion, doubt and ambiguity."

Whilst "no maps" was a major source of confusion for Amanda, the 
other parents are less clear about its impact. However, "confusion, doubt 
and ambiguity" for all of the parents is indicated by the often ambiguous 
nature of their words. Overall, I consider the notion of "no maps" to be a 
major element of "the tensions" through which we view the parents’ 
experience.

Guilt

But there’s so much guilt that comes into it. (Sally)

Jill, John, Sally and Stephen are at times haunted by a sense of failure 
of their parental responsibility. Logically they have come to understand that 
they were in no way to blame for the events which overcame their children, 
but this does not always prevent the feelings of guilt. Their words carry a 
similar ring:

I wasn’t there and he’d always been safe, and when the time 
came he wasn’t safe and it really mattered, there was no one 
there for him and that was really hard for me to deal with. 
(Jill)

I’m his dad, his idol sort of thing, and there’s nothing I can 
do. See, that was the hardest part. I never swam after the 
accident for two years. I think it might have been I didn’t 
want to hear the sound of water ’cause I kept going through 
my mind what was he thinking when he was drowning? 
Where’s Dad? Where’s Mum? (John)
... the doctor said to me there was nothing I could have done that was anything different. It's just one of those things that came up on him during the night, but still that didn't matter. I was his mother and it was my responsibility to make sure that he was all right, and I didn't. So there was that sort of, that irrational guilt. (Sally)

You try and work out where, if you went wrong anywhere or what you could have done to avoid this, and that takes a long while to work out, but there's nothing you can do to avoid it. (Stephen)

Whilst Amanda and Catherine certainly do not carry around this particular guilt, it is a question they recognise they have had to work through. Amanda argues that she took many healthy precautions prior to and during her pregnancy and believes that it was her own health which ensured Annie's foetal survival. Catherine understands Down syndrome to be a chromosomal hiccups and not due to anything she had done. She did, however, consult a geneticist to reinforce her understanding and to allay feelings of anxiety

... about the future of having other children because both Chris and I had been in Europe when Chernobyl blew up and we automatically had a scary feeling that that's what it was.

So, it seems that for all of the parents to a greater or lesser extent there are undercurrents of "confusion, doubt and ambiguity" brought on by a sense of guilt as to their own contributions to their children's conditions.

For Sally, the notion of guilt was important. She says, ... there were just so many branches of guilt ..., and her words relating to her guilt about grieving conjure up the turbulent and confusing images which contribute to "the tensions."
There was the guilt because I really wanted to grieve, but how could I when I still had a child? ... I felt like, you know, my baby has died. This is not, so you know, trying to juggle so you've got the sort of, you know, that guilt. Then a feeling that I should grieve when I still had him, you ungrateful person! You know, I mean, he's still here. How can you grieve for him? And that was something that I felt I couldn't express to anybody, because I thought now that's the reaction I would get. You know, don't be, you know you've still got a baby there.

Sally also had ... the guilt of spending so much time with Samuel. Stephen echoed her concern and spoke of the balancing of attention in a family with so many children. Jill and John also express some ambivalence about the effect that their focus on Joel may have on his sister, Jenny. On the one hand, they feel bad in case Jenny is missing out, on the other hand, she is learning to be generous and independent!

Jill speaks of guilt in other contexts. As Joel's mother, she felt she should be sitting with him all the time when he was "dying", but found herself unable to do so. Whilst she dismisses this with an explanation of everyone copes differently, it continues to bother her.

As already mentioned, Catherine came into conflict with herself regarding her decision to be a "working mother." She identifies this conflict as pushing my Catholic guilt buttons and recognises that it is always there, just beneath the surface, so that she constantly argues with herself:

... you then sort of go home thinking, ‘Oh, should I really be, you know, like, can I sell everything I've got so I don't have to work any more?’

She refers to this as a major pull for her.

Overall, the parents speak of feeling guilty for a variety of reasons. They recognise the often irrational nature of these feelings and, in
attempting to describe their conflict, their very language often reflects their
"confusion, doubt and ambiguity."

**Grief**

Whilst grief has been presented as contributing to the parents’ sorrow
(Chapter Eight), it is necessary here to look at another aspect.

Grief is confusing. This was an issue which arose during the follow-up
interview with Sally and Stephen. None of the other parents spoke of
grief in quite this way, but it was of such importance to Sally in particular,
that I believe the confusion of the grief is significant to the overall picture.
Her words vividly express the constant tensions:

> If you grieve for something that is gone, that’s fine, that’s
gone and over with. You can grieve, you can go through all
the processes and you can put it behind you. But when it’s a
child that you’re grieving for the loss of the child that was,
you still have the child that is. So, you can’t stack it neatly up
and put it away. It’s something that is there all the time, and,
even though you may think that you’ve resolved things, and
yes, I’ve come to terms with this or whatever ... In a sense you
do, but by the same token, there will always be something that
will trigger it off.

Her words speak for her.

**Professionals**

On numerous occasions the parents indicate that many of the
professionals with whom they have had dealings have been responsible for
"confusion, doubt and ambiguity." The reasons are varied, but issues related
to the imparting of information and advice predominate. The parents speak
of lack of information, confusing and conflicting information and advice,
and a covering up with and hiding behind jargon. They also speak of their
own observations and conclusions as often being in direct conflict with what they are being told by professionals.

Amanda recognises that she lived in a state of confusion for three years and often felt as if she was on a roundabout due to a lack of directness.

Quite often I think they deliberately covered up their own doubts with medical terminology. You’d always have to ask, and you felt really stupid having to ask that. And also, they were very guarded in what they said, so you always felt they were hiding something from you.

As far as our own feelings were concerned, our fears, they avoided anything like that. They scribbled out another name for you to see - a social worker. Or try this number, or you have to ask such and such a person, and they clung to their fields of specialisation ...

On top of the avoidance, was the difference in opinion from professionals.

Midwifery nurses like to offer their opinions on what was wrong with her (when they spoke to us at all), which was terrible because each one would say that the doctors didn’t really know what they were doing and, that in their opinion, this was what was wrong with the baby because they’d seen many babies before. So, we got into this hassle of gaining more confusing information, going to the doctor and asking the doctor about it, and the doctor getting angry with the nurses. It was just a bit of a mess.

Jill and John also encountered differences in opinion from professionals,

... but at this stage we’d been told his brain’s swelling, and then she’s telling me they don’t know if his brain’s swelled, so I didn’t know what to think...

along with information that was meaningless:
... I said 'What do they mean by massive brain damage?', and he said 'Well, it could be anything from not being the full quid, to not being able to do a thing for yourself.' And I thought, well that's a hell of a range!

This hell of a range contrasted with the predictions of others:

... we were basically told that his head was disconnected from his body, and that's the way he'll be. So, he won't know you're there, he won't feel any love, he won't feel any hate, he won't feel anything. And I thought, well that's not living ...

They also became confused as sometimes explanations and advice they received contrasted with common wisdom.

We didn't talk to him a lot because he was spasming so bad, they said don't talk to him because what you're doing is you're sending messages to his brain because his brain's scrambled they're going haywire so that's what's making him spasm. Don't touch him because you're sending electrical impulses to his brain which is doing the same thing. That's what we were told. Yet you always hear, talk to them ...

Jill and John still question such advice and consider that their own observations did not provide validation.

Samuel's parents also had cause to doubt some professionals:

... he'd been put in a room on his own, he could see nothing. He was totally blind which I had been saying to them all week. He can't see anything, and this doctor put down his lack of response, not to the fact that he couldn't see anything, but that he was just so brain damaged he didn't recognise me. Anyway, when we got the results of the visual EEG a week later, it registered zero, which proved that what I'd said was right, and that it wasn't that he wasn't responding to me, he couldn't see me. He couldn't see anybody.
Sally kept questioning and said that

little things that he (Sam) did made me doubt what this
doctor had told me.

Her persistent doubts and lack of trust in what she was being told caused she
and Stephen to take Samuel home as they ... just didn't feel that they were
doing anything for him at the hospital. However, this proved to be the
beginning of more confusion. Sally says:

I came home from hospital with no information at all, as to
where to go, what help was available, what help I needed, and
it was really just a matter of working through.

Some of Catherine's experiences with Charles' frequent
hospitalisations have contributed to a state of "confusion, doubt and
ambiguity." She speaks of young doctors jumping immediately to the most
intrusive intervention due to assumptions based on the fact that he had a
disability. She believes they tend to play it safe and treat the disability rather
than the presenting illness. Her doubts have been validated by the seeking
of a second opinion, but she has been left feeling really uncomfortable:

I was kind of getting the emotional blackmail number, you
know, like if you really care about your child, you won't take
the risk stuff ...

She also speaks from her dual perspective as a professional and as a receiver
of help, which makes her very conscious of the "confusion, doubt and
ambiguity" which are present as a result of the professional/parent
relationship:

... it's to do with being accustomed to being a person who's
capable, and running my own life, and all that, and got some
status and stuff, to suddenly being not ... It's about being a
receiver of help. That's what it's about. It's like there's
something about the dynamic of being the receiver of help
that automatically puts you in a position of vulnerability to
competent and incompetent workers ... It's a very out of
control feeling ... It's like if you get the pat on the head routine, it's like the feelings overtake you at the time, and you forget how to be assertive like you can in every other area of your life, and then later you think, that revolting person, why didn't I tell them to bugger off!

Professionals then, make major contributions to "the tensions" which are part of the parents' everyday being, and yet, there is frequently a recognition on the part of the parents that the professionals' job is difficult, and so they sometimes provide excuses for them. Amanda's words embody the parents' confusion, the professionals' confusion, the constant waxing and waning implicit in their experience.

... they don't want to give you information which you will come back later and say is misleading, and the nurses were the ones that give misleading information. They didn't always. In a way, I suppose they thought they were helping. I suppose they were afraid of the questions I might ask.

The words themselves are full of "confusion, doubt and ambiguity."

Both Sides of the Rhythm

I was often struck by the seemingly paradoxical nature of the parents' experience as reflected in many of their comments. Catherine, when speaking of the diagnosis of Down syndrome within a short time of Charles' birth, says, It was like euphoria and a sledge hammer simultaneously, and describes her overall experience of being his mother as one of ecstasy mingled with misery.

As I thought and reflected further on the parents' descriptions of their experience, I was struck by Rose's (1990) analogy of the ocean, which led me to conceptualise elements of the parents' experience as waves. This conceptualisation was expanded by Parse's (1990, p. 10) description of "both sides of the rhythm surface[ing] ..." and, overall, these conceptualisations seemed to conjure up images of powerful undercurrents which are there as
essential parts of the ocean of experience, and which contribute to "the tensions."

As a group, the parents carry a consciousness of their state of being which is "between joy and sorrow." Amanda speaks of this as a type of universal consciousness, common to parents of children with disabilities, when she speaks of making contact with strangers in the street who were accompanied by children with disabilities:

*In that moment that our eyes met she, there was an absolute glow of love for the baby. You know when you catch somebody unawares, and they show their entire soul and then they close down quickly ... and this completely unprotected parent who, in that moment, shows you all the hurt and all the love ... I think it's really important that people smile, because they are presenting an awful lot of pain at that moment.*

All of the parents refer to in some way or another, the joy being there because of the pain:

*And you're a million times more happy because he's done it, because he wasn't supposed to be able to do it. (Jill)*

*Strength and love, a protectiveness that comes out in you much more, and I think you're in tune with your child a lot more because of so much writing off, so much rejection ... (Amanda)*

*When he gets up and walks and takes his first few steps I'll cry again. I'll be happy. (John)*

*We get far more reward from everything that Samuel does than we have done from any of the other kids ... (Stephen)*
They recognise that, if it had not been for the sorrow which has gone before, then the joy would not be there. Jill actually expresses it,

_My pain comes from what happened originally...

as does Sally,

...to appreciate the ups, you've got to experience the down.

And if you can come through that, and come out at the other end, I do think it makes you appreciate what you've got.

When exploring these notions with Sally and Stephen, the word _shadow_ was used. They believe that, no matter what, no matter how much Samuel defies the odds, their joy will always be shadowed by a sense of what might have been. Sally, when speaking of the sorrow, says: _It's always there, you never lose it_ and says that the grief and love are _not flowing together - they're separate entities_. Our attempts to grapple with the complexities were lengthy, but Stephen and Sally captured some of it:

Stephen: _I think you go through those periods of time when your sorrow is almost paramount, and then you, you go beyond that..._

Sally: _It's very complex though - there's so many things that come into it... because life isn't all positive or all negative, it's a balance of both._

Their words, along with those of Amanda, Catherine, Jill and John, express the "betweens" of the experience. Theirs is not an experience in which everything is put into one melting pot and results in something which is homogeneous, but rather, one in which many separate elements are apparent, sometimes glimpsed very quickly before receding, and sometimes apprehended as something which is paramount for a period of time. There is a recognition of the dependence and interdependence of many of the elements, and a knowledge of Amanda's

_The joy is defined by the sorrow that has come before._

The consciousness of this dependence and interdependence, the waxing and waning nature of various elements of their experience, the
apparent opposites and paradoxes are all part of the lens which is called "the tensions."

In summary, the parents' experience may be described as one of "between joy and sorrow," but the identification, description and interpretation of the various elements which comprise this state have proved to be complex and difficult. This is because their experience is neither one thing nor another - it is a dynamic, intricate and often ambiguous state which is full of contradiction and paradox.

We all carry deeply embedded values and beliefs regarding people with disabilities which reflect the culture in which we live. (See Chapter Two). By and large, most of us have negative assumptions relating to people with disabilities. The parents in this study have had their assumptions challenged by their personal and intimate experience, but this is frequently a confusing and perplexing experience, and one which is ongoing and subject to constant revision. They frequently find themselves in conflict - conflict brought about by the differences in their experience of their children as opposed to the public meanings of disability, meanings which used to be part of their own assumptions. Their views regarding their children are frequently at odds with those of others. A conclusion which is persistently finding voice with me is that the parents are not sad because of the disability, but rather because of what it means.

It seems that, whilst the parents have carried negative values regarding disability, those values have been challenged and so, are changing. So, the values regarding disability have changed in relation to their own children, but they are constantly exposed to the negative values of others, so their old values are being reinforced. This makes for enormous "confusion, doubt and ambiguity" as evidenced by the discussion related to dissonance of values and beliefs.
Sometimes, the parents' values are in explicit conflict as a result of the fact that their children have disabilities, so they are often forced to make pragmatic decisions. This creates extra tension in their lives.

Their "confusion, doubt and ambiguity" is exacerbated by many other factors - not having any maps, by guilt, by grief which cannot clearly be described as a loss, and by their dealings with some professionals.

Whilst being adamant about the positive aspects of their experience, the parents also carry with them a great deal of sorrow. They speak of their lives in ways which allow "both sides of the rhythm to surface" (Parse, 1990, p. 10), and which are reflective of the turbulent undercurrents which are ever present.

By identifying all of these notions as contributing to "the tensions", we have a way of viewing the experience of these parents as individual, dynamic and complex.
Chapter Eleven

UNDERSTANDING DEVELOPMENTAL DISABILITY

- DISCUSSION OF PARENTS' EXPERIENCE -

"Life has meaning only in the struggle. Triumph or defeat is in the hands of the Gods ... So let us celebrate the struggle"

Swahili Warrior Song (cited in Mitchell & Miller, 1992)
This chapter returns to the literature, both professional and anecdotal, with the interpretive lens of "between joy and sorrow". It demonstrates that there have been glimpses of "other realities" and suggests reasons for the neglect of alternative perspectives. Contributions and limitations of the study are presented, and it is argued that the phenomenological interpretation of the parents' experience of developmental disability provides insight and understanding which has implications for nursing practice, education and research.

DISCUSSION

Whilst the findings of this research endeavour are grounded in the words of the parents and are presented with this support in Chapters Seven to Ten, this chapter presents a discussion of the interpretations in light of some relevant literature. I do this because some literature and stories had an impact in terms of insights and interpretations during the progress of this work and contributed to the phenomenological reflection, interpretation and writing and so supported the textual transformation of the parents' stories. The second reason for this return to the literature is to address the assumptions prevalent in both the professional literature and areas of professional practice which, from the outset, I challenged and which provided an impetus for this work.

This study came into being as a result of a dissatisfaction with the interpretative power of dominant paradigms regarding parents' responses to their children with disabilities. These paradigms were presented in Chapter Three. As a practitioner, I listened to the words of parents which sometimes surprised me and, as a result, I reviewed and questioned the conceptual bases from which professionals, including nurses, view the impact of disability on the lives of families. I was concerned that the assumption that this impact is inevitably negative has led researchers to focus on stress measures and the effects of the burden of care, and that the implications for practice include an assumption of distress and dysfunction in families. It was argued that the
unquestioning use of such theoretical underpinnings to interpret and describe the behaviour of parents of children with disabilities has had many negative implications for these families, and that labels which imply dysfunction are frequently used - labels such as "denial", "not accepting", "not being realistic", "overcompensating", "guilt" and "unresolved grief."

Most of the families with whom I worked as a nurse demonstrated healthy functioning, and many made an enormous impact on me by virtue of their energy, strength, optimism and humour. To describe these people as "overcompensating" and "denying reality" seemed fruitless and potentially destructive, and yet, this is what I heard from colleagues and other professionals.

The Research Question

At the beginning of this journey I set out to explore Amanda's other reality and, as it draws towards its destination, I ask myself the question "Did I find it?" The simple answer is "Yes."

The parents in this study have painted a picture of living with a child with significant developmental disability which is at odds with many of the commonly held notions. They speak of their children in glowing and positive ways, and derive a great deal of pride and pleasure from them. They speak of their own growth as human beings, and consider they have been strengthened as a result of their experiences. They are optimistic and speak of love, hope and joy.

Early on in this project I was asked what I would do if I found other than the "other", that is, the documented grief, distress and tragedy. I responded that such findings would be included and presented. This has occurred. The parents spoke of isolation, hopelessness, despair, grief and a great deal of sorrow, and this has been presented and included as an integral component of their experience. To have ignored it would have denied them their total reality.
The evidence for the parents' "other reality" was overwhelming, and so I had to ask myself why this was so frequently overlooked, not recognised or ignored. I believe it has something to do with the contradictory and paradoxical nature of their experience, and the "confusion, doubt and ambiguity" implicit in their reality. For this reason, the conceptualisation of the parents' reality as one which is "between joy and sorrow," and which is viewed through a lens of "tensions" provides us with a model which is dynamic and whole and considers the complexities. These "tensions" create an opportunity for discovering the links between the elements of joy and sorrow. This model, by allowing "both sides of the rhythm to surface" provides a view, which is neither all positive nor all negative, but one which allows us to consider the shifts and changes, the glimpses, glints and reflections, and the interwoven, colourful and complex fabric of the parents' experience.

My return to the literature and media, wearing the lens of "between joy and sorrow," has proved to be an enlightening experience. Whilst, at the outset, I knew there to be glimpses of the "other," I am now struck by an expanded view - some of these glimpses have taken on new meaning in light of the research outcome. As I have progressed on the journey, other literature has also played a part in the interpretation of the parents' experience. A discussion of the parents' experience with reference to this literature, follows.

Sorrow

The presence of pain and sorrow as an integral part of the experience of living with a child with significant disability is hardly surprising - the parents have experienced an overwhelming life event of which they retain a consciousness and to which they give voice. What is somewhat surprising is the enormous contribution made by others to their sorrow.

In telling their stories, the parents presented an initial overwhelming picture of "no hope." It was clear they were being inundated
with messages of hopelessness from the people they were in contact with, and that the professionals with whom they worked were often responsible for their feelings of isolation, rejection and despair. In Chapter Two, a discussion regarding the private meanings and connotations of developmental disability was presented. In this I argued that intellectual disability holds a multiplicity of meanings for people and that these meanings have resulted in societal attitudes which dehumanise people with intellectual disabilities. The words of the parents indicated that these values, beliefs and attitudes are still prevalent and often define the behaviour of family, friends, acquaintances and professionals.

In an article in The Age newspaper Alexander (1992) said, "...people who have intellectually disabled children still must face the trauma of dealing with outdated attitudes" and quoting Anderson's research about the effect on parents of having a child with Lennox-Gastaut Syndrome, said that parents have to deal with

... such attitudes in the very people they first turn to for help - the medical profession ... Quite often the doctor will say to the parents of a child who is intellectually disabled: 'There is nothing we can do.' What they mean is there is nothing medically that can be done, but often the parent goes away thinking that there is nothing that can be done ... there were endless stories of insensitivity about doctors...

In providing a partial explanation for such behaviours, Anderson is again quoted:

Doctors are part of society ... Attitudes to people with disability have a historic background to them. If you go all the way back, peoples' attitude to disability was that God was punishing the family for something they had done ... Vestiges of these attitudes still exist in the community today.

It would seem that, for most people, the thought of having a child with a disability is "unthinkable" (see Chapter Two) and that this belief is so
deeply embedded in us that it affects the way in which we respond to and deal with disability, even at a professional level. In Chapter Eight one of the parents, Stephen, postulates that the messages of "no hope" might have to do with doctors purposely painting the worst scenario so that things can only get better. Most of the parents recognise that professionals have a duty to provide accurate, honest information, but they are still angry that hope was removed from them. They see more sensitive communication as the tool to provide honest information, whilst maintaining hope.

The parents are subject to many painful emotions which have been presented in Chapter Eight. These emotions have occurred, and sometimes endure, in association with things such as predictions of death, loss, fears and worries related to their current situations and their children's futures. Some of the parents speak of grief, (although Catherine says she didn't have a loss). Those who speak of grief find it confusing and disorderly and not something which is likely to be neatly resolved. A notion of "acceptance" is confusing. On the other hand, the parents relate to the concept of "chronic sorrow" as they see sorrow as part of their everyday being. Catherine, Sally and Stephen however, debate the notion of "chronic," with Catherine suggesting that "periodic" might be a better description. The experience therefore of these parents causes us to question the concepts of grief, mourning and chronic sorrow which were presented in Chapter Three.

Stephenson and Murphy (1986) have written of "existential grief" in relationship to the chronically ill and disabled. They said "Existentialism has much to contribute to our understanding of grief, as it focuses on humanity's efforts to make experience meaningful." (p. 135). They argued that existential grief exists as a result of attempts to find meaning in loss, whilst reactive grief is the sadness felt over the loss of someone or something loved, but that both exist in every response to loss to a varying degree. They referred to people having "mixed emotions," "ambivalent feelings" and "guilt" as part of existential grief, which are words used by parents in this study. Such an interpretation may well be more useful than
those in common use as it may enable practitioners to assist parents in a search for meaning rather than to label them as having pathological grief responses. Stephenson and Murphy conclude with "It is an irony that the victims of chronic illness or disability are forced to confront a more authentic existence than society as a whole." (p. 144). This research indicates that this holds true for parents of children with disabilities.

In summary, sorrow is integral to the state of being a parent of a child with significant disability. Whilst much of this sorrow would seem self-evident, it is apparent that a great deal of pain derives from the societal values and beliefs regarding disability which are mirrored in the words and behaviours of friends, family and professionals. In a better world, this pain could be avoided. On the other hand, the existential pain cannot be avoided - no amount of education and attitudinal change can prevent such sorrow. The parents in this study acknowledge their sorrow and confront it head on. They are using their suffering as a challenging and growing experience, and believe they are stronger as a result. In this way, their grief is placed in a larger context and they find meaning.

Joy

Try as I might, I cannot feel tragic about a baby who shakes with silent laughter as his sister wraps tinsel round his head. Most of all, Euan has made me realise just how much we underestimate our capacity for loving. (Evans, 1993)

... we have been so privileged to have been his parents, not only did we cope but we got so much joy in seeing him grow and develop. The enormity of the disability, faded as we grew to know and love him as a person. (Anonymous, ["Dot"] 1993, p.6)
I have discovered the joys of raising a child with disabilities can outweigh the challenges. In fact, raising a child with disabilities offers some of life's greatest moments and sweetest rewards. (Jennings, 1993, p. 16)

It has caused me to be more sympathetic toward people with such problems. Our love for this child seems deeper as we realise her need for greater understanding. (Wikler, Wasow & Hatfield, 1983, p. 314)

... this boy's delighted interpretations in what might be called 'dance' - of joy in rain, joy in sound, in the blowing of leaves is an eye-opener for those interested in mime and rhythm. (Clancy, quoted in Mills, 1969, p. 5)

The words are familiar, and expressive of the themes found in the stories of Amanda, Catherine, Jill, John, Sally and Stephen. The voices belong to parents of children with disabilities who were speaking over a span of twenty-four years, and yet such expressions of joy are paid little credence in the professional literature. When the positive and optimistic words of parents are noted, they are sometimes dismissed as methodological artefact, as statistically insignificant, or are explained away by interpretations which are informed by the researcher's assumptions. Voysey (1975, p. 16) said, "If parents' responses counter the assumption of pathology, they may be variously re-interpreted in accordance with the observer's categories" and she has provided us with examples gleaned from the literature:

- statistical "fiddling"
- mothers' responses reflect "putting a good face on it" or "an unwillingness to admit to difficulties"
• mothers' inability to recognise seriousness of child's condition arises from "a general attitude of guilt and rejection," "an unwillingness to acknowledge severe limitations"

• families who do not break down have a strong possibility of becoming "too cohesive" and the children with disabilities will become "over-dependent" because their mothers are "over-protective."

All of this returns me to one of my original contentions - the parents of children with disabilities "just can't win." However, whatever the reasons for little attention being paid by professionals to parents who voice joy and optimism, (or if they do pay attention it is with an interpretation of pathology), the parents in this study are very clear - their children with disabilities are a great source of joy.

The parents are also clear about the experience itself being a strengthening one. They have constructed meaning and developed new perspectives on life as a result of their experiences and the challenges presented. Their perceptions are in line with the seminal work of Victor Frankl (1963) who, in writing of "Man's Search for Meaning," contended that those who have meaning in their lives survive and are healthy. Taylor, Wood and Lichtman (1983) proposed a theory of victims' responses to their victimisation, termed "selective evaluation." They proposed that victims, whom they define as "one who is harmed or made to suffer from an act, circumstance, agency or condition" (p. 21) and which include situations such as disasters, crime, illness and stigma, react to their aversive state by "selectively evaluating themselves and their situation in ways that are self-enhancing" (p. 19). Their work with people who had undergone life-threatening attacks, illness, natural disasters and other such events resulted in accounts which indicated that these people had not only "overcome the victimising aspects of their situation, but [had] actually benefited from their experience." (p. 20). Taylor (1989) has taken this work further and written of peoples' ability to benefit from tragedy. She questions the long held assumption that accurate perceptions of reality are a critical component of
mental health and challenges the established wisdom. Her research indicates that normal human thought and perception are marked by positive self-enhancing illusions about the self, the world and the future. These, she calls, "positive illusions," and believes they are instrumental in enabling people to overcome adversity in their lives. Brown (1993) raises the question of these positive illusions being merely defence mechanisms in disguise, but draws a distinction based upon defence mechanisms being unconscious and involving distortions of reality, whereas positive illusions are a cognitive reinterpretation which are subject to control and revision and, as such do not involve major distortions of reality, but rather involve variations in how reality is interpreted or represented.

This work provides support for the parents' interpretations of their experience. This evidence was presented in Chapter Nine under the headings "New Perspectives" and "Becoming Stronger" which finds further support in the "positive contributions" work of the Beach Center researchers presented in Chapter Three. It will be recalled that the work of Turnbull, Guess and Turnbull (1988) resulted in six categories of the contributions made by people with disabilities to their families:

- source of joy
- source of learning life's lessons
- source of love
- source of blessing or fulfilment
- source of pride
- source of strength

During the early stages of this project, I questioned the use of this work in Australia, due to some sceptical responses from colleagues and parents, and concluded that maybe it was somewhat culturally specific. However, the words of the parents in this study obviously confirm the work of these researchers, and a book published since then, (see Turnbull et al., 1993) as a culmination of some of this work, holds promise for professionals working with families. Given my own early attraction to this work and the
confirming nature of Amanda's, Catherine's, Jill's, John's, Sally's and Stephen's experience, I am left somewhat puzzled by its rejection by many in 1990. I am forced to conclude it had something to do with language - maybe Australians have difficulty relating to terms such as "positive contributions," "visions for the future" and "great expectations," but are comfortable with John's You've gotta have a good attitude!

Also presented in Chapter Nine were the themes of "hope" and "defiance." Even though they are conscious of the limitations of their children, the parents in this study maintain hope and strive to keep it alive. Their stories abound with a sense of optimism and hope and I believe that it is their expressions of optimism which leave such parents open to accusations of "denial of reality" and "non-acceptance." Remember Amanda's words which distilled the research question for me:

... they said, 'She's denying reality.' I understood the reality of my child's situation but, for me, there was another reality.

It is my impression that all of the parents in this study have a firm grip on reality - they all demonstrated a very clear and informed understanding of their children's conditions and possible functional outcomes. However, they still maintain hope, a hope which was defined in Chapter Nine as "a belief in possibilities". As a group, they differentiate between hope and expectations, and see hope as akin to dreams, whilst expectations are more real. It is the expectations they have learned to live without - they recognise they are sailing in largely unchartered waters - but maintain they cannot function without hopes and dreams. Experience tells me that when parents speak of hopes and dreams, they leave themselves open to professional interpretations of "unrealistic expectations," and yet, these parents are clear in their own discrimination.

As mentioned in Chapter Nine an alternative interpretation to that of "denying reality" presented itself in the work of Cousins (1989) who said "They didn't deny the diagnosis; they denied and defied the verdict that was supposed to go with it" (p. 83). This statement led to the theme of
"defiance," which provides a positive and action-oriented reconceptualisation of words and behaviours which have traditionally been interpreted as pathological. This "defiance" of their children's prognoses enables the parents to function with hope and optimism and to carry out therapeutic regimes which would be pointless if they paid heed to the predictions of "will do nothing" and "vegetable." Cousins (1989) holds that such an optimistic outlook does not necessarily equate with a pathological denial of reality. He provides an interpretation which is based upon an understanding of reality, but a refusal to accept the implications which this reality suggests.

Russell (1993) although not using the terms "defiance" or "positive illusions," has drawn aspects of this work together. He argued that, despite ample research evidence of the adaptive and protective role of denial, health professionals have failed to embrace these positive aspects, maintaining the view that denial is essentially maladaptive. He held that this view "has a clear cultural and historical basis and is associated with a common religious belief that denial blocks acknowledgment, acceptance and repentance of sin" (p. 938). These views of denial as a pre-requisite to a cure in psychiatric illness, and by inflexible interpretations of stage models of loss, which hold that the ultimate goal of acceptance is unobtainable as long as denial exists have been reinforced in clinical practice. Traditionally, emphasis has been placed on the need to acknowledge reality, and denial has been seen as maladaptive. In light of work by people such as Taylor (1989), Russell (1993) cautions health professionals against asking their clients to be "unrealistically realistic," and suggests that "denial buffers the individual against what is sometimes a bleak reality" (p. 940). This statement echoes the parents' talk regarding hopes and dreams and, in particular, Amanda's If you were 'realistic', you wouldn't get out of bed in the morning and Catherine's If you take on the heaviness, you can't run the marathon - if you take on the optimism, you can jump the hurdles.
In summary, the parents in this study give voice to many things which they consider to be joys - these joys derive from their children and from their experiences as parents of these children. The same joys are heard in the words of other parents, but most of these joyous words appear in literature which would be identified as anecdotal, and therefore lacking in credibility in the minds of many professionals. I have argued that the positive aspects of being a parent of a child with a disability have received scant attention in the professional literature and that, in fact, parents' expressions of joy, hope and optimism are frequently interpreted as "a denial of reality." I have presented some alternative interpretations and language which I believe do these parents greater justice and recognition. In line with the phenomenological underpinnings of this project, the parents' expression of their being-in-the-world with their children must be accepted as their reality. I am led to pose the question, "Why do professionals persistently deny such parents their reality?" and am left thinking that it must be related to the meanings that we all attach to disability.

The Tensions

During the course of this project I wrote a memo - it is still on my wall - which says "Parents not sad because of disability, but of what it means????" Recently, on reading Vohs (1993), I had another "ah-ha" experience:

When Jessica was diagnosed at age one, I knew something bad, really terrible, had happened. I was very confused, upset, and scared. I personally did not have to make up the interpretation about the badness or wrongness of the situation. It was something everyone knew, a given: To be disabled or to have a child with a disability is a tragedy. Of course, by the time she was a year old, I was also hopelessly in love with her. And, from early in Jessica's infancy, I was committed to having a life of joy. This new information
about Jessica did nothing to diminish my love or my commitment; it meant that now I would just have to be in love and committed in spite of this situation. It was as if the "in spite of" translated into a permanent little dark cloud or shadow under which I would have to live and with which I would have to cope.

I can still remember the moment - Jessica was around two and a half - when I became aware of this little cloud and its attendant mood of sadness. Nothing extraordinary was going on, it was just a quiet afternoon. The immediate justification for the mood was, "Of course I am sad. This is a terrible situation. Jessica has cerebral palsy." Almost simultaneously came a question about what exactly was the matter. I asked myself if anyone was in pain or was suffering and instructed myself to observe what actually was happening. I looked at Jessica. I saw a beautiful toddler, playing happily, grinning, and cooing. It was a warm Spring day. I checked myself out - I felt good, I had friends, we had food, shelter. We were comfortable. Neither of us was suffering at that moment.

Yet, there was the sadness and it was connected to the fact that Jessica had cerebral palsy ... In looking a little deeper into the cause of the sadness, what I saw was that the disability meant something, and it was the meaning, not the actual disability, that caused me sadness. (pp. 52 - 53)

I suggest this is at the crux of "the tensions" which come about as the result of the "confusion, doubt and ambiguity" and of living in a state of "between" as presented in Chapter Ten. Vohs' words have been presented extensively as I believe she captures the essence of the difficulties encountered by parents of children with disabilities. We all live in a world of inherited meaning, and the parents in this study are no different in this sense from the "others" we have discussed. Where they do differ is in the realm of personal
experience so, whilst they carry within themselves the cultural meanings of
disability which relate to its fundamentally tragic nature, their assumptions
are being constantly challenged.

Another mother, Pat Evans (1993) has written that "every woman
who gives birth to a handicapped child does so in a climate of rejection and
fear". In recounting her own journey from fear to love, she calls her
transformation one which came "out of the rubble of broken dreams." Like
the parents in this study, her assumptions have also been challenged but she,
along with all of the others, still live in a world which generally devalues
people with disabilities - hence their state of being which has been described
as "the tensions."

A return to the literature with the "joy and sorrow" view, has
resulted in a number of instances in which these very words are used,
indicating to me that many parents have had a grasp of this notion of
"between joy and sorrow" in which "both sides of the rhythm" and the
interdependence of the themes are apparent. Mills (1969), a highly
experienced and respected Sydney social worker, identified this
interdependence as a result of her practice. She wrote of families "... in many
ways being on a deeper level because of the suffering and sorrow and the
intensity of pleasure when the child takes a step forward" (p. 2), and one of
the mothers she quoted spoke of "accepting both joys and sorrows from God"
(p. 4). In the Wikler, Wasow & Hatfield (1983) paper which admitted
overlooking strengths in previous research, a mother is quoted as saying,
"We hit many peaks and valleys. I would say that there is some sorrow, but
our happy moments overshadow the bad times. Our daughter has been a joy
and a sorrow" (p. 314). The authors reported "a curious combination of
sadness and strength ..." (p. 314). It is this "curious combination" which this
work indicates has been problematic and which validates a lens which
enables us to view joy and sorrow as "between" and full of "tensions."

In summary, the stories of the parents frequently reflected grey areas
which we called "confusion, doubt and ambiguity." The notion of "both
sides of the rhythm" was introduced to give a sense of the dynamic, interdependent, interactive and paradoxical nature of their experiences. In this discussion, some possible explanations for their state of being which we have called "the tensions", have been presented.

CONTRIBUTIONS AND LIMITATIONS OF THE STUDY

This study used a method which was informed by phenomenology. It presents the voices of six parents (from four family groups) regarding their experiences of living with children with developmental disabilities. An interpretation of these experiences has been presented within a model of "between joy and sorrow," important elements of which relate to "hope and defiance" and "no hope and despair." This research therefore is in no way representative of all parents of children with disabilities, but an illustration of what life with such children is like for these parents.

As such, this research is not intended to be generalised as an explanation of other parents' experience. In fact, such a notion is antithetical to the roots of the method and also to my own initial concerns regarding the labelling and interpreting of parents' responses and actions. This work set out to explore the "other" reality and its outcome provides some glimpses of this "other." It is intended to open our eyes and minds to other possibilities, to provide us with a different perspective when viewing the lives of parents of children with disabilities, and to serve as a reminder of the dangers of generalisation. So, whilst in one sense this lack of generalisability might be seen as a limitation, it was never a goal of this research.

Whilst we cannot apply it to the experiences of others, the work has validity as illumination and insight. The parents in this study have validated the interpretations and a number of conference presentations have been based on this work (Kearney, 1993a; Kearney, 1993b; Kearney, 1993c). The responses and feedback have been most encouraging. A number of parents of children with disabilities, nurses and other professionals in the field have indicated the "meaningfulness" of the work. They have indicated
that it makes sense to them based on their own experiences of parenting and/or professional practice, that it provides them with a framework for thinking about the things they have "known" about for a long time but have not seen in the professional literature, and that it provides an alternative view.

For me, the biggest limitations have been those imposed by time and complexity. I would very much have liked to continue working with these parents and others to further explore and refine the interpretations. There is much work to be done, particularly in the thematic area comprising "the tensions".

The work has implications for professional practice and the education of health care practitioners, but I have been challenged with the question, "Is it nursing research?" In the eyes of nurse academics, it is not, and this has been seen by them as a limitation of this work. Whilst I "knew" it was nursing research, the question had confounded me and I had muttered about "implications." However, Taylor (1991) clarified the issue:

... phenomena can be taken to mean the subjective experience of individuals, whatever they are and however they are interpreted by those individuals. Meleis (in Moccia, 1986, p. 12) wrote that 'nursing phenomena, are human phenomena,' including experiences and perceptions of things common to nurses and patients (p. 78)

The parents' experience is of enormous concern to nurses as we provide nursing care to them and their children in many settings and under many circumstances. Indeed, it was in my provision of such care that the research question took shape. If the assumptions which underpin nursing practice have no meaning for such parents, then surely nursing practice will be lacking. If I persistently label a parent's "hope" as a "denial of reality," then my nursing practice will not be credible and could well have damaging effects.
There were times during the course of this research that I was troubled by the fact that two of the families had children with acquired disabilities, whilst the other two had children with congenital disabling conditions. Whilst the major themes of this study were given voice by all of the parents, there were instances when I had a sense of a major qualitative difference in their experience. Four of the parents had children whom they had grown to know and love prior to catastrophic events which resulted in significant brain damage, so that these children changed and became different. The other two parents had children in whom disabling conditions were apparent from the time of their births, so their parents came to know them with disability as an intrinsic part of their being. They did not have to undergo major changes in their children. Whilst this has not been a major issue for this study, and I have chosen to ignore these differences, if I were to have my time again, I would explore the issues with one or the other, not both.

The children in this study are all still young and small in size so I am left asking myself if the parents' hope and optimism will still be so strong in twenty years time. Experience tells me that families often (but not always) find the going rougher as their children grow and develop and sometimes become more difficult to live with. I would be very interested to maintain contact with these parents as their children become adults. However, the research outcome in the form of the model of "between joy and sorrow" is flexible and dynamic and is thus able to accommodate changing emphases.

These limitations are acknowledged and are reflections of a reality which is fundamental to any research undertaking. I do not consider they detract from the insight gained as a result of the study.

**Implications for Nursing Practice**

Nurses work with people with developmental disabilities and their families in all areas in which nursing is practised. Some nurses are specialists in disability and so their practice is focussed upon such people, but
most have not chosen this path and view their expertise as lying elsewhere. However, whatever their area of practice and expertise, most nurses will have encounters with people with disabilities and their families and many nurses will work directly with the parents of children with developmental disabilities. Some of these areas include:

- maternity, which is usually where the children with identifiable, congenital conditions are born
- child and family health nursing practice, mainly in the community setting
- paediatric nursing, mainly in the hospital setting
- accident and emergency nursing
- critical care nursing
- medical nursing, for example, when children are hospitalised for pneumonia
- surgical nursing, during stays for major and minor procedures, and
- specialised developmental disability nursing practice in both institutional, small residential and community settings.

The six parents in this study have had numerous encounters with nurses in relationship to their children with disabilities in the following settings:

- large city maternity hospital
- small maternity unit in small district hospital
- neonatal intensive care unit
- neurological ward in large city children's hospital
- accident and emergency - local hospital, metropolitan teaching hospitals, city children's hospitals
- during helicopter transfer
- intensive care units - general and children's hospitals
- paediatric high dependency unit in metropolitan teaching hospital
- general ward in city children's hospital
- paediatric ward in local hospital
- outpatient clinics in city children's hospitals and metropolitan teaching hospital
• community settings - baby clinics, local chemist shop, developmental disability assessment centre
• home - visits from generalist community nurses, child and family health nurses and developmental disability nurses.

This list is not exhaustive, but gives a sense of the prominence of nursing in the lives of these families. Unfortunately, many of the encounters these parents had with nurses leave a lot to be desired. Whilst they spoke of some nurses with admiration, there were many from whom they did not receive support and who were, in fact, quite damaging. This is true also for other professionals with whom they have had contact.

Early on in this thesis, I argued that the responses of parents with children with disabilities are frequently interpreted from a basis of pathology. They are also interpreted from a history of cultural meanings which we all carry with us, and so we make assumptions about what life with a child with a disability must be like. If parents' responses, behaviours and ways of being do not conform with our expectations of what they ought to be, then we variously interpret them according to perceptions based on our own values. This work offers practitioners a fresh perspective and a broader lens through which to view families' experiences of living with a child with a developmental disability. The pain, suffering and sorrow are an integral part of their experience, but so are many joys, hope and optimism.

Some parents spoke of communications with health professionals which left no room for hope. They recognise the professionals' commitment to truth and their own right to open and honest communication, but consider that this is possible whilst still leaving room for hope, without which they despair. They believe that their healthy functioning is dependent upon a framework of optimism, and they make a plea for support from professionals. Maybe, this work will allow a professional view which considers and incorporates hope.

These six parents have painted a picture of their experience of living with a child with significant disability which is at odds with the orthodox
viewpoint. We may interpret their joy, hope and optimism as a "denial of reality," but such an interpretation has the potential for us, as professionals, to deny the parents their reality. Rather, if professionals allow alternative interpretations to provide explanatory power, we are more likely to provide parents with the constructive support they require from us. So, rather than referral to a psychologist who will enable parents to "accept" and "come to terms with the reality" that their child with cerebral palsy will never walk, why don't we assist parents in their search for the therapist who will assist them in their dream and help their child to walk? It is time for professionals and in particular, nurses, to join the parents, to support their blazing determination and to provide them with every assistance which will enable their children to defy the implications of their devastating diagnoses.

**Implications for Education**

The theoretical bases which underpin practice in the area of parents' experience of developmental disability were presented in Chapter Three. Currently, in our classrooms students learn of parental responses which are interpreted from a base of psychoanalytic theory and responses to loss. They may be introduced to the concept of "chronic sorrow" and, in rare instances, possibly the "positive contributions" work of the Beach Center researchers.

The introduction of this "between joy and sorrow" work would serve to expand the horizons of students, and would provide them with a model which is comprehensive and dynamic, and considers the parents' experiences as a whole. By having an awareness of the parents' experience as one which is mediated by "the tensions," professionals-in-training would have a visual conceptualisation of parents' experience as one which is ambiguous, and full of conflict, confusion and doubt. By using such a model for teaching purposes, students might be given a way of conceptualising an extremely complex experience, which might prevent them from jumping to conclusions, making judgements and imposing generalisations upon people. This model allows for a view of individual experience and ways of being. As
mentioned earlier, the work has already received some attention as a result of conference presentations, and there have been requests for copies of the model to be used for educational purposes. These people have remarked on its usefulness for teaching in the disciplines of nursing, education and medicine.

As educators, we are also responsible for changing the culture. Whilst many societies are endeavouring to improve life for people with disabilities and their families, with a recognition of rights which are protected in legislation, we still have a long way to go. Legislation for inclusion and integration are now in place, but our next step has to do with "belonging" (Renwick & Brown, 1996). People with disabilities still, by and large, do not belong - they are still viewed negatively and are devalued. As a consequence, their families are often marginalised (McPhail, 1996). Our next step is to separate the circumstance from the meanings associated with it. Vohs (1993) says, "A fundamental belief about the tragic nature of the situation informs one world view. Acceptance of disability as a legitimate part of life informs another" (p. 59) and holds that neither is "right" nor "wrong", but that the fruitful question is to explore interpretations as useful or empowering. "If disability is an ordinary part of life, there is no longer a need to cope with the obvious and inherent tragedy of disability" (p. 59).

As educators, we are well placed to take some first steps, with role modelling, language and a presentation of the stories people have to tell - stories which shine for their very ordinariness and shared humanity. Our everyday actions and conversations can help change the culture and we are in a position to role model if we choose our language and metaphors with care and enthusiasm. The stories of ordinary people can make a huge difference. For example, Karen, who has typed the interview transcripts, commented that listening to the stories enabled her to develop a different view from what she would have previously interpreted as only tragic. She was impressed that the parents are "just ordinary people - like me!" I asked the question at the time "Good enough reason to disseminate the
information?" To date, people with stories to tell have had a huge impact on the students I have taught, not primarily because they are coping with enormous tragedy but because they are ordinary. With such strategies, maybe we can equip our future professionals with a sense that learning to speak differently about disability is part of their job.

On a broader level, this work has implications for community education. The parents have expressed a view which is not overwhelmed with tragedy. The voices of these parents, and of others like them, need to be heard in the public media so that their experiences can be part of the creation of a new vision.

**Possibilities for Further Research**

The meanings generated in this study have come about as a result of my interpretation of the experiences of six parents of their lives with their children with disabilities. As such, these meanings are embedded in the understandings and contexts of these parents and have a uniqueness which will not be replicated. If a similar exploration were to be undertaken by someone else, it would be from a different perspective, and other explanations would evolve.

Given that the topic is so large and a creative methodology has been used, much remains unsaid. There are avenues which remain unexplored, and areas which were ignored. Personally, I will always have a sense of this work as incomplete and unfinished.

However, I do believe that a number of areas warrant further research. The notions of grief are very muddled and often conflicting. I suspect that the work of Stephenson and Murphy (1986) which relates to "existential grief" holds promise for its interpretive power, and the concept of "chronic sorrow" requires further investigation. For now, the concept of "sorrow" will suffice, as it provides a sense of a state of being, but I am left with a realisation that we have only skimmed the surface.
Rigorous study of the parents' active construction of positive meaning could be useful for its potential to support parents' adaptation. A great deal of work related to this has been undertaken by the researchers at the Beach Center, and its usefulness for parents in Australia requires investigation. Allied to this are the "whys" of "sorrowful" versus "joyous" states of being, an understanding of which could guide the practice of professionals, and possibly assist in the identification of families who would benefit from intervention and those for whom it would be superfluous.

Research on a larger scale, using the main concepts of this study to guide theoretical sampling using a grounded theory method, has the potential to further explore and validate the interpretations.

SOME CLOSING REFLECTIONS

The journey is drawing to an end and, whilst it has at times been an almost magical voyage of discovery, with times of high energy, activity and insight when "The storm blast came ... And chased us south along," but many more of being "Alone, alone, all, all alone, Alone on a wide wide sea!" (with apologies to Coleridge's Ancient Mariner), I look forward to reaching port.

Working with Amanda, Catherine, Jill, John, Sally and Stephen enabled me to develop some insight, and we hope that this insight may be of some use to others. It has also heightened awareness of my own shortcomings and caused me to reflect on my nursing practice with a degree of embarrassment as I remember some of my own opinions and judgements. The parents' motivation for being a part of this endeavour was the hope that it will help others. My obligation to them now will be fulfilled by thoughtful practice, teaching and research.

These parents allowed me into their worlds and provided us with a view of their experiences which challenges prevalent assumptions. Their voices must be taken notice of, and practitioners must develop a consciousness of the experience of living with a child with a disability as one
which is highly individual and not subject to mass generalisations. There is pain, suffering and sorrow, and also joy, hope and optimism. Their lives are a struggle, but there is a sense of joy as they live their lives with their children.

I dedicate a "Swahili Warrior Song" (cited in Mitchell & Miller, 1992) to Amanda, Catherine, Jill, John, Sally and Stephen:

Life has meaning only in the struggle.
Triumph or defeat is in the hands of the Gods ..... 

So let us celebrate the struggle.
APPENDIX 1

HEALTH COMMISSION OF
NEW SOUTH WALES
McKell Building
Rawson Place
SYDNEY. 2000

217.6666 ext. 5662 (Mr. C.

File No: 1943
Circular No: 81/8/
Issued: 30 March 1981

Brewster)

A) 79
B) 66
C) 83
D) 67
E) 21
F) 33
G) 32
H) 14
I) 16
J) 54
K) 39

(Distributed in accordance with Circular List/s A to K inclusive).

Change in name of Division of Mental Retardation
Services to Division of Developmental Disabilities

At its meeting on 19 February, 1981, the Commission resolved to adopt the name “Division of Developmental Disabilities” in lieu of the name “Division of Mental Retardation Services”.

The Commission further resolved that Regional Retardation Teams change their names to “Developmental Disability Teams” to legitimise their broader role.

The Commission also resolved to define the clients for whom the Division has responsibility in terms (appropriately modified) of the definition produced in 1975 by a National Task Force in the United States of America.

The publicity for the change of name will be handled by the Division of Health Promotion.

The definition as modified:

The term “developmental disability” means a severe, chronic disability of a person which:

a) is attributable to an intellectual or physical impairment or combination of intellectual and physical impairments;

b) is manifested before the person attains age 18;

c) is likely to continue indefinitely;

236
d) results in substantial functional limitations in three or more of the following areas of major life activity:

- self-care,
- receptive and expressive language learning
- mobility
- self-direction
- capacity for independent living
- economic self-sufficiency;

e) reflects the person’s need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and co-ordinated.

The change of name and new definition of clients was considered to be necessary for several reasons:

a) It is extremely difficult in babies and young children to predict with accuracy their intellectual potential except in the most profoundly affected. Because of this it is clear that with early education and therapy programmes for children who are diagnosed as having some degree of developmental disability, Regional Mental Retardation Teams are working with children who are not by strict definition mentally retarded.

b) Because of the stigma attaching to the term “mental retardation” some parents are reluctant to make use of clinics and teams which are so named. This often results in the loss of many valuable months of therapy and remedial education.

c) Less importantly, perhaps, there is a need to keep abreast of community attitudes, both here and overseas.

[Signed] Roderick McEwin

Roderick McEwin
Chairman
APPENDIX II

UNIVERSITY OF WESTERN SYDNEY
Nepean

MEMORANDUM

To: Penny Kearney - Faculty of Health Studies
From: Acting Administrative Assistant, Research Office
Subject: Parents experiences of developmental disability
Date: 20.8.92

The Human Ethics Review Committee has granted approval to the above project.

The Protocol Number that you have been allocated in relation to this project is:

HERC1992/03

This approval is valid for twelve months from 15 April, 1992.

[Signed on behalf of]

JULIE FLEMING

File No: 88/216
90/109
APPENDIX III

FACULTY OF HEALTH STUDIES

14 July 1992

Dear

At some time in the past, I have probably mentioned to you that I was planning to undertake research related to parents who have children with developmental disabilities. Well, - the time has finally come!

I am writing to you in the hope that you may be prepared to be a member of this project.

I am enclosing an Information Sheet and a Consent Form. If you have any queries, please do not hesitate to contact me on (047) 51 2564.

Would you please fill out the tear-off slip at the bottom and return to me in the enclosed stamped envelope.

I look forward to hearing from you.

Yours sincerely

Penny Kearney

I am/am not interested in being a participant in the research project, "Parents’ Experience of Developmental Disability”.

I understand that if I agree, I may be contacted by phone by Penny Kearney.

Signed: ......................................................

Telephone No: .............................................

239
APPENDIX IV

[PK/Research Proposal/Appendix IV]

INFORMATION SHEET 1

My name is Penny Kearney. I am a Registered Nurse, having completed my studies as a mature age student in 1987. From 1988 to 1991 I worked as a Community Nurse in Developmental Disability Services. During this time I worked with approximately two hundred families in the Penrith, Hawkesbury and Blue Mountains areas, all of whom had at least one member who had a significant developmental disability. My work encompassed a broad and varied range of activities - case work, counselling, information, support, co-ordination of services, advocacy. I worked in my clients' homes and they came from all walks of life. This experience taught me a great deal and, as a result of it I have developed a commitment to people with developmental disabilities and their families.

For the past twelve months I have been employed as a Lecturer at the University of Western Sydney, Nepean, where my primary role is the teaching of Developmental Disability Nursing Studies to undergraduate students of nursing. My community nursing experience has enabled me to develop insights which hopefully will be put to constructive use by these students in whatever field of nursing they enter. I believe it is essential for all nurses to have some understanding of developmental disability as they will encounter people with developmental disabilities and their families in whatever area of practice they choose.

I am also a mother. My three daughters are aged sixteen, fifteen and thirteen years, and so I've had some experience (and continue to have) in the trials and tribulations of parenthood.

As the major part of my Master of Nursing (Honours) at the University of Western Sydney, Nepean, I am conducting research about

240
parents' experience of developmental disability, and the factors which may have influenced this experience.

There is, in fact, a lot already known about the "impact of disability", but my experience in working with families taught me that professionals and academics certainly do not have the full picture. For this reason, I believe it critical that we explore this area from the point of view of the experts - the parents of people who have disabilities - those people who live with this "impact" on a daily basis.

The other area I plan to explore relates to factors which may influence families' experiences. In this way, I would hope that, eventually, professionals may be able to help people to deal with their situation in a constructive fashion.

In order to explore these areas, I want to talk with parents of people with disabilities. This would mean an interview of considerable length at a time and place convenient to you. I plan to audiotape the interviews to ensure accuracy. Apart from myself, the people who will have access to the tape are my two supervisors, Dr. Tim Griffin and Sangar Rao, and a typist who will type up the transcripts. You will not be identified apart from the use of your first name on the tapes. Pseudonyms will be used on the transcripts. Any identifying data will be kept separate from the transcripts, and I shall be the only person with access to this. I plan to store this data securely in order to provide data for further study, provided you consent to this. Otherwise, it will be destroyed upon completion of this work.

It may be necessary for me to talk with you again as the research progresses in order to clarify points, and I plan to conduct "confirming" interviews, possibly in groups, as the research draws to a close.

The information on the tapes will be analysed by me, in conjunction with my supervisors, and will be used in a thesis report and possibly, form the basis of articles for publication or a book.

I understand that this type of interviewing has the potential for memories to raise issues which may sometimes be distressing. I have
experience and skills in these situations, and will be available for further contact if required. It is my belief, however, that it is only by the recounting of parents' experiences, and their documentation, that we can build a picture of the "experience of disability".

It is my hope that the information collected may provide the groundwork for further research, and will go towards enabling professionals to provide constructive and appropriate supports and services for people with disabilities, and their families.

You will be able to withdraw from the study at any time.

If you have any questions, don't hesitate to contact me on (047) 36 0384 - work, or (047) 51 2564 - home.

Thank you,

Penny Kearney.
APPENDIX V

Faculty of Health Studies
Telephone: (047) 36 0384

CONSENT TO PARTICIPATE IN RESEARCH

Project Title:

PARENTS' EXPERIENCE OF DEVELOPMENTAL DISABILITY

I have been asked to participate in the above research project conducted by Penny Kearney, who may be contacted on the above telephone number.

I give my free consent by signing this form. I understand that:

1. The research project will be carried out as described in the Information Sheet, a copy of which I have retained.

2. If I do not volunteer, or decide to withdraw, my decision will be accepted.

3. My consent to participate is voluntary and I may withdraw from the research at any time. I do not have to give a reason for the withdrawal of my consent.

4. I have read and understood the Information Sheet and had all my questions answered to my satisfaction.

Signature:............................................ Date:..................................................

I consent to the secure storage of data which may form the basis of future research, and may be published. However, my right to privacy will be retained, and personal details will not be revealed.

Signature:............................................ Date:..................................................
APPENDIX V

Faculty of Health Studies
Telephone: (047) 36 0384

CONSENT TO PARTICIPATE IN RESEARCH

Project Title:

PARENTS' EXPERIENCE OF DEVELOPMENTAL DISABILITY

I have been asked to participate in the above research project conducted by Penny Kearney, who may be contacted on the above telephone number.

I give my free consent by signing this form. I understand that:

1. The research project will be carried out as described in the Information Sheet, a copy of which I have retained.

2. If I do not volunteer, or decide to withdraw, my decision will be accepted.

3. My consent to participate is voluntary and I may withdraw from the research at any time. I do not have to give a reason for the withdrawal of my consent.

4. I have read and understood the Information Sheet and had all my questions answered to my satisfaction.

Signature:.............................................. Date:..................................................

I consent to the secure storage of data which may form the basis of future research, and may be published. However, my right to privacy will be retained, and personal details will not be revealed.

Signature:.............................................. Date:..................................................

243
APPENDIX VI

INFORMATION SHEET 2

Thank you for your participation in this research project. Your time is much appreciated, and your recounting of your experiences is invaluable.

Sometimes conversations such as we have just had can raise powerful memories. Frequently, this is not a problem, but sometimes it can lead to feelings of confusion and some distress.

If this happens to you, I am willing to discuss further with you any issues we may have raised. If you would prefer, I can arrange a referral for you to an experienced counsellor.

If you have ANY questions, don't hesitate to contact me on (047) 360 384 - work, or (047) 512 564 - home.

Thank you,

Penny Kearney.
APPENDIX VII

Q.S.R. NUD.IST Power version, revision 3.0.5.
Licensee: UWS,Nepean.

PROJECT: PARENTS' EXPERIENCE

(1) /base data
   (1 1) /base data/interviewees
   (1 1 1) /base data/interviewees/gender
   (1 1 1 1) /base data/interviewees/gender/male
   (1 1 1 2) /base data/interviewees/gender/female
   (1 1 2) /base data/interviewees/age-group
   (1 1 2 1) /base data/interviewees/age-group/20's
   (1 1 2 2) /base data/interviewees/age-group/30's
   (1 1 2 3) /base data/interviewees/age-group/40's
   (1 1 2 4) /base data/interviewees/age-group/50's
   (1 1 2 5) /base data/interviewees/age-group/60's
   (1 1 2 6) /base data/interviewees/age-group/other
   (1 1 3) /base data/interviewees/religion
   (1 1 3 1) /base data/interviewees/religion/upbringing
   (1 1 3 1 1) /base data/interviewees/religion/upbringing/christian
   (1 1 3 1 1 1) /base data/interviewees/religion/upbringing/christian/catholic
   (1 1 3 1 1 2) /base data/interviewees/religion/upbringing/christian/protestant
   (1 1 3 1 1 3) /base data/interviewees/religion/upbringing/christian/agnostic
   (1 1 3 1 1 4) /base data/interviewees/religion/upbringing/christian/other
   (1 1 3 1 2) /base data/interviewees/religion/upbringing/athiest
   (1 1 3 1 3) /base data/interviewees/religion/upbringing/none
   (1 1 3 1 4) /base data/interviewees/religion/upbringing/other
   (1 1 3 2) /base data/interviewees/religion/current
   (1 1 3 2 1) /base data/interviewees/religion/current/christian
   (1 1 3 2 1 1) /base data/interviewees/religion/current/christian/catholic
   (1 1 3 2 1 2) /base data/interviewees/religion/current/christian/protestant
   (1 1 3 2 1 3) /base data/interviewees/religion/current/christian/agnostic
   (1 1 3 2 1 4) /base data/interviewees/religion/current/christian/other
   (1 1 3 2 2) /base data/interviewees/religion/current/athiest
   (1 1 3 2 3) /base data/interviewees/religion/current/none
   (1 1 3 2 4) /base data/interviewees/religion/current/other
   (1 1 4) /base data/interviewees/marital status
   (1 1 4 1) /base data/interviewees/marital status/now
(1 1411) /base data/interviewees/marital status/now/married
(1 1412) /base data/interviewees/marital status/now/single
(1 1413) /base data/interviewees/marital status/now/sep.divorced
(1 142) /base data/interviewees/marital status/then
(1 1421) /base data/interviewees/marital status/then/married
(1 1422) /base data/interviewees/marital status/then/single
(1 1423) /base data/interviewees/marital status/then/sep.divorced
(1 15) /base data/interviewees/income
(1 151) /base data/interviewees/income/very well-off
(1 152) /base data/interviewees/income/well-off
(1 153) /base data/interviewees/income/making ends meet
(1 154) /base data/interviewees/income/struggling
(1 155) /base data/interviewees/income/great struggle
(1 16) /base data/interviewees/education
(1 161) /base data/interviewees/education/School Cert.
(1 162) /base data/interviewees/education/HSC
(1 163) /base data/interviewees/education/tertiary
(1 164) /base data/interviewees/education/post-grad.
(1 165) /base data/interviewees/education/other
(1 17) /base data/interviewees/occupation
(1 171) /base data/interviewees/occupation/home duties
(1 172) /base data/interviewees/occupation/professional
(1 173) /base data/interviewees/occupation/white collar
(1 174) /base data/interviewees/occupation/blue collar
(1 175) /base data/interviewees/occupation/other
(1 2) /base data/child
(1 21) /base data/child/gender
(1 211) /base data/child/gender/male
(1 212) /base data/child/gender/female
(1 22) /base data/child/age
(1 221) /base data/child/age/0-5
(1 222) /base data/child/age/6-12
(1 223) /base data/child/age/13-18
(1 224) /base data/child/age/19-25
(1 225) /base data/child/age/26-40
(1 226) /base data/child/age/>40
(1 23) /base data/child/birth order
(1 231) /base data/child/birth order/one
(1 232) /base data/child/birth order/two
(1 233) /base data/child/birth order/three
(1 234) /base data/child/birth order/four
(1 235) /base data/child/birth order/>four
(1 24) /base data/child/aetiology of disability
(1 241) /base data/child/aetiology of disability/congenital
(1 2411) /base data/child/aetiology of disability/congenital/genetic
(1 2 4 1 2) /base data/child/aetiology of
disability/congenital/environmental
(1 2 4 1 3) /base data/child/aetiology of disability/congenital/unknown
(1 2 4 2) /base data/child/aetiology of disability/acquired
(1 2 5) /base data/child/age at diagnosis
(1 2 5 1) /base data/child/age at diagnosis/birth
(1 2 5 2) /base data/child/age at diagnosis/>1
(1 2 5 3) /base data/child/age at diagnosis/1-2
(1 2 5 4) /base data/child/age at diagnosis/3-5
(1 2 5 5) /base data/child/age at diagnosis/other
(1 2 6) /base data/child/lives
(1 2 6 1) /base data/child/lives/home
(1 2 6 2) /base data/child/lives/institution
(1 2 6 3) /base data/child/lives/other
(1 3) /base data/siblings
(1 3 1) /base data/siblings/gender
(1 3 1 1) /base data/siblings/gender/male
(1 3 1 2) /base data/siblings/gender/female
(1 3 2) /base data/siblings/numbers of
(1 3 2 1) /base data/siblings/numbers of/1
(1 3 2 2) /base data/siblings/numbers of/2
(1 3 2 3) /base data/siblings/numbers of/3
(1 3 2 4) /base data/siblings/numbers of/4
(1 3 2 5) /base data/siblings/numbers of/other
(1 3 2 6) /base data/siblings/numbers of/nil
(1 4) /base data/other people

(2) /data types
(2 1) /data types/individual interviews
(2 1 1) /data types/individual interviews/initial
(2 1 2) /data types/individual interviews/follow-up
(2 2) /data types/group interviews
(2 2 1) /data types/group interviews/both parents
(2 2 1 1) /data types/group interviews/both parents/initial
(2 2 1 2) /data types/group interviews/both parents/follow-up
(2 3) /data types/documents
(2 3 1) /data types/documents/by parents
(2 3 1 0) /data types/documents/by professionals
(2 4) /data types/other

(3) /people
(3 1) /people/mother
(3 2) /people/father
(3 3) /people/parents
(3 4) /people/child
(3 5) /people/siblings
(3 6) /people/family
(3 6 1) /people/family/his
(3 6 1 1) /people/family/his/parents
(3 6 1 2) /people/family/his/siblings
(3 6 2) /people/family/hers
(3 6 2 1) /people/family/hers/parents
(3 6 2 2) /people/family/hers/siblings
(3 7) /people/friends
(3 8) /people/aquaintances
(3 9) /people/neighbours
(3 10) /people/professionals
(3 10 1) /people/professionals/specialist
(3 10 1 1) /people/professionals/specialist/nurses
(3 10 1 2) /people/professionals/specialist/doctors
(3 10 1 3) /people/professionals/specialist/therapists
(3 10 1 4) /people/professionals/specialist/others
(3 10 1 50) /people/professionals/specialist/collected
(3 10 2) /people/professionals/non-specialist
(3 10 2 1) /people/professionals/non-specialist/nurses
(3 10 2 2) /people/professionals/non-specialist/doctors
(3 10 2 3) /people/professionals/non-specialist/therapists
(3 10 2 4) /people/professionals/non-specialist/others
(3 10 2 50) /people/professionals/non-specialist/collected
(3 10 3) /people/professionals/?specialist or not
(3 10 3 1) /people/professionals/?specialist or not/nurses
(3 10 3 2) /people/professionals/?specialist or not/doctors
(3 10 3 3) /people/professionals/?specialist or not/therapists
(3 10 3 4) /people/professionals/?specialist or not/others
(3 10 3 50) /people/professionals/?specialist or not/collected
(3 10 50) /people/professionals/collected
(3 11) /people/community
(3 12) /people/general public
(3 13) /people/strangers
(3 14) /people/other parents
(3 14 1) /people/other parents/of disabled kids
(3 14 2) /people/other parents/of non-disabled kids
(3 15) /people/other kids
(3 15 1) /people/other kids/disabled
(3 15 2) /people/other kids/non-disabled
(3 16) /people/"other people"
(3 17) /people/all
(3 18) /people/other
(3 18 1) /people/other/bureaucrats-institutions

(4) /child
(4 1) /child/things about
(411) /child/things about/qualities of
(4111) /child/things about/qualities of/fighter
(4112) /child/things about/qualities of/survivor
(4113) /child/things about/qualities of/persistence
(4114) /child/things about/qualities of/happy nature
(4115) /child/things about/qualities of/giving quals.
(4116) /child/things about/qualities of/affectionate
(4117) /child/things about/qualities of/unselfish
(4118) /child/things about/qualities of/"normal"
(4119) /child/things about/qualities of/trusting
(41111) /child/things about/qualities of/gutsy
(41112) /child/things about/qualities of/beautiful
(41113) /child/things about/qualities of/charismatic
(41114) /child/things about/qualities of/intuitive
(41115) /child/things about/qualities of/choosey
(41116) /child/things about/qualities of/no different
(41117) /child/things about/qualities of/cheerful
(41150) /child/things about/qualities of/collected
(4115010) /child/things about/qualities of/collected/do professionals say nice things?
(412) /child/things about/appearance
(4121) /child/things about/appearance/normal
(413) /child/things about/perceptions of
(4131) /child/things about/perceptions of/failure
(4132) /child/things about/perceptions of/vegetable
(41350) /child/things about/perceptions of/collected
(4135010) /child/things about/perceptions of/collected/by professionals
(414) /child/things about/effect on others
(415) /child/things about/changed

(5) /feelings
(51) /feelings/positive
(511) /feelings/positive/pride
(512) /feelings/positive/love
(513) /feelings/positive/happiness
(514) /feelings/positive/comfortable
(515) /feelings/positive/inspired
(516) /feelings/positive/rewarded
(517) /feelings/positive/optimistic
(5150) /feelings/positive/collected
(515010) /feelings/positive/collected/influenced by professionals?
(52) /feelings/negative
(521) /feelings/negative/stupid
(522) /feelings/negative/sad
(5221) /feelings/negative/sad/chronic sorrow

249
(5 2 3) /feelings/negative/failure
(5 2 4) /feelings/negative/hurt
(5 2 5) /feelings/negative/rejection
(5 2 6) /feelings/negative/pain
(5 2 7) /feelings/negative/fear
(5 2 8) /feelings/negative/devastation
(5 2 9) /feelings/negative/guilt
(5 2 11) /feelings/negative/vulnerable
(5 2 12) /feelings/negative/powerless
(5 2 13) /feelings/negative/anger
(5 2 14) /feelings/negative/shock
(5 2 15) /feelings/negative/disbelief
(5 2 16) /feelings/negative/horrifying
(5 2 17) /feelings/negative/distressed
(5 2 18) /feelings/negative/despair-hopelessness
(5 2 19) /feelings/negative/resentment
(5 2 20) /feelings/negative/frustration
(5 2 21) /feelings/negative/not comfortable
(5 2 22) /feelings/negative/isolated
(5 2 23) /feelings/negative/debilitated-heavy
(5 2 50) /feelings/negative/collected
(5 2 50 10) /feelings/negative/collected/imposed by professionals
(5 3) /feelings/relief
(5 4) /feelings/pressured
(5 5) /feelings/why me?

(6) /values,beliefs
(6 1) /values,beliefs/re normality
(6 2) /values,beliefs/doing the right thing
(6 3) /values,beliefs/re disability
(6 3 1) /values,beliefs/re disability/positive
(6 3 2) /values,beliefs/re disability/negative
(6 3 2 7) /values,beliefs/re disability/negative/dissonant with positive attitudes re child
(6 3 3) /values,beliefs/re disability/ambiguous
(6 3 50) /values,beliefs/re disability/collected
(6 4) /values,beliefs/naive
(6 5) /values,beliefs/re socialising
(6 6) /values,beliefs/re roles
(6 7) /values,beliefs/re support
(6 8) /values,beliefs/re future
(6 9) /values,beliefs/re bringing up children
(6 10) /values,beliefs/re professionals
(6 11) /values,beliefs/re life
(6 12) /values,beliefs/prayer,religion,etc.
(6 13) /values,beliefs/death
values, beliefs / responsibility
values, beliefs / you've gotta have a good attitude
values, beliefs / other

/attitudes

/attitudes / toward mother
/attitudes / toward mother / positive
/attitudes / toward mother / positive / respect
/attitudes / toward mother / positive / collected
/attitudes / toward mother / negative
/attitudes / toward mother / negative / rejection
/attitudes / toward mother / negative / failure
/attitudes / toward mother / negative / not coping
/attitudes / toward mother / negative / patronising
/attitudes / toward mother / negative / not interested
/attitudes / toward mother / negative / collected
/attitudes / toward father
/attitudes / toward father / positive
/attitudes / toward father / negative
/attitudes / toward parents
/attitudes / toward parents / positive
/attitudes / toward parents / positive / respect
/attitudes / toward parents / positive / doing a good job
/attitudes / toward parents / negative
/attitudes / toward child
/attitudes / toward child / positive
/attitudes / toward child / positive / respect
/attitudes / toward child / positive / admiration
/attitudes / toward child / positive / hope
/attitudes / toward child / positive / pride
/attitudes / toward child / positive / protective
/attitudes / toward child / positive / collect
/attitudes / toward child / positive / collect / professionals
/attitudes / toward child / negative
/attitudes / toward child / negative / rejection
/attitudes / toward child / negative / labelling
/attitudes / toward child / negative / vegetable
/attitudes / toward child / negative / failure
/attitudes / toward child / negative / rigid
/attitudes / toward child / negative / written off
/attitudes / toward child / negative / not comfortable
/attitudes / toward child / negative / collect
/attitudes / toward child / negative / collect / professionals
/attitudes / toward professionals
/attitudes / toward professionals / positive
/attitudes / toward professionals / positive / respect
(7 10 1 2) /attitudes/toward professionals/positive/admiration
(7 10 1 4) /attitudes/toward professionals/positive/trust
(7 10 2) /attitudes/toward professionals/negative
(7 10 3) /attitudes/toward professionals/neural
(7 10 3 1) /attitudes/toward professionals/neural/off the pedestal
(7 10 3 2) /attitudes/toward professionals/neural/so there
(7 11) /attitudes/re situation
(7 12) /attitudes/re disability
(7 14) /attitudes/toward other parents
(7 15) /attitudes/towards others
(7 15 1) /attitudes/towards others/tolerance
(7 15 2) /attitudes/towards others/intolerance

(8) /behaviours
(8 1) /behaviours/mothers
(8 1 1) /behaviours/mothers/pregnancy
(8 1 2) /behaviours/mothers/caring for child
(8 1 2 1) /behaviours/mothers/caring for child/doing things
(8 1 2 2) /behaviours/mothers/caring for child/to ensure survival
(8 1 2 3) /behaviours/mothers/caring for child/comforting
(8 1 2 4) /behaviours/mothers/caring for child/discipline
(8 1 2 5) /behaviours/mothers/caring for child/protective
(8 1 2 5 0) /behaviours/mothers/caring for child/collected
(8 1 4) /behaviours/mothers/seeking information
(8 1 5) /behaviours/mothers/tactics
(8 1 5 1) /behaviours/mothers/tactics/to obtain services
(8 1 6) /behaviours/mothers/supporting others
(8 1 7) /behaviours/mothers/unexpected
(8 1 8) /behaviours/mothers/passing judgement
(8 1 8 1) /behaviours/mothers/passing judgement/not passing
judgement
(8 1 9) /behaviours/mothers/jumping to conclusions
(8 1 11) /behaviours/mothers/neglect
(8 1 1 2) /behaviours/mothers/immobilised
(8 2) /behaviours/fathers
(8 2 2) /behaviours/fathers/caring for child
(8 2 4) /behaviours/fathers/seeking information
(8 3) /behaviours/parents
(8 3 2) /behaviours/parents/caring for child
(8 3 2 1) /behaviours/parents/caring for child/doing things
(8 3 2 2) /behaviours/parents/caring for child/to ensure survival
(8 3 4) /behaviours/parents/re information
(8 3 4 2) /behaviours/parents/re information/not informing
(8 3 5) /behaviours/parents/seeking assistance
(8 3 11) /behaviours/parents/protecting
(8 4) /behaviours/child
(8 4 1) /behaviours/child/tantrums
(8 4 2) /behaviours/child/cuddling
(8 4 3) /behaviours/child/surprises
(8 5) /behaviours/siblings
(8 10) /behaviours/professionals
(8 10 1) /behaviours/professionals/passing judgement
(8 10 2) /behaviours/professionals/jumping to conclusions
(8 10 3) /behaviours/professionals/support
(8 10 3 1) /behaviours/professionals/support/practical
(8 10 3 2) /behaviours/professionals/support/emotional
(8 10 4) /behaviours/professionals/re information
(8 10 4 1) /behaviours/professionals/re information/informing
(8 10 4 2) /behaviours/professionals/re information/not informing
(8 10 4 2 1) /behaviours/professionals/re information/not informing/covering up
(8 10 4 2 2) /behaviours/professionals/re information/not informing/hiding things
(8 10 4 50) /behaviours/professionals/re information/collect
(8 10 5) /behaviours/professionals/treating differently
(8 10 6) /behaviours/professionals/obstructive
(8 10 7) /behaviours/professionals/snooping
(8 10 8) /behaviours/professionals/no great help
(8 10 9) /behaviours/professionals/labbing off
(8 10 11) /behaviours/professionals/not listening
(8 10 12) /behaviours/professionals/kicking in teeth
(8 10 13) /behaviours/professionals/non-committal
(8 16) /behaviours/others
(8 16 1) /behaviours/others/passing judgement
(8 16 2) /behaviours/others/jumping to conclusions
(8 16 3) /behaviours/others/support
(8 16 4) /behaviours/others/re information
(8 16 5) /behaviours/others/treating differently
(8 16 8) /behaviours/others/rejecting
(8 16 9) /behaviours/others/shocked
(8 16 11) /behaviours/others/celebrating
(8 16 12) /behaviours/others/no great help
(8 16 13) /behaviours/others/"normal"

(9) /expectations
(9 4) /expectations/re child
(9 4 1) /expectations/re child/development
(9 4 2) /expectations/re child/physiological condition
(9 4 50) /expectations/re child/collected
(9 10) /expectations/by professionals
(9 13) /expectations/re coping
(9 15) /expectations/re future
/expectations/re career
/expectations/changed
/expectations/other
/vacant

/relationships
/relationships/parents
/relationships/child
/relationships/with friends
/relationships/with professionals
/relationships/others
/relationships/collect

/making meanings
/making meanings/"it could be worse"

/coping
/coping/reframing
/coping/laughter

/finding out
/finding out/professionals
/finding out/professionals/literature

/maps
/maps/no maps

/fears and worries
/fears and worries/re future
/fears and worries/financial
/fears and worries/collection

/special
/special/special people
/special/special people/mothers
/special/special people/fathers
/special/special people/parents
/special/special people/child
/special/special people/special daughters
/special/special things
/special/collect

/confusion,doubts,ambiguities
/confusion,doubts,ambiguities/contributing factors
/confusion,doubts,ambiguities/contributing factors/grief
confusion, doubts, ambiguities / contributing factors / professionals

/knowing
/knowing / professionals'

/advice
/advice / helpful
/advice / helpful / professionals
/advice / not helpful
/advice / not helpful / professionals

/needs
/needs / mothers'
/needs / fathers'
/needs / parents'
/needs / child's
/needs / siblings'
/needs / professionals'

/on their own
/on their own / mothers
/on their own / parents
/on their own / collected

/meeting challenges
/meeting challenges / mothers
/meeting challenges / fathers
/meeting challenges / parents
/meeting challenges / child
/meeting challenges / collected

/out in the community

/services

/disability
/disability / advantages of
/disability / disadvantages of
/disability / people with
/disability / people with / positive attributes
/disability / collected

/medicalisation

/past experience
(28)  /past experience/of disability

(29)  /choices, decisions

(30)  /strengths
(30 1)  /strengths/What makes them strong?
(30 1 1)  /strengths/What makes them strong?/meeting challenges
(30 1 1 1)  /strengths/What makes them strong?/meeting
  challenges/yes
(30 1 2)  /strengths/What makes them strong?/hope
(30 1 2 1)  /strengths/What makes them strong?/hope/yes
(30 1 3)  /strengths/What makes them strong?/spiritual things
(30 1 3 1)  /strengths/What makes them strong?/spiritual things/yes
(30 1 3 1 1)  /strengths/What makes them strong?/spiritual
  things/yes/overlap

(31)  /"a fight"

(32)  /a death in the family

(33)  /dying
(33 1)  /dying/rituals

(34)  /spiritual things

(36)  /new perspectives
(36 1)  /new perspectives/life changes
(36 50)  /new perspectives/collected

(37)  /hard things
(37 1)  /hard things/financial
(37 2)  /hard things/worst
(37 3)  /hard things/relaying on others for help
(37 50)  /hard things/collection

(38)  /grief

(39)  /grieving love

(40)  /defiance
(40 1)  /defiance/meeting challenges
(40 2)  /defiance/caring for child
(40 3)  /defiance/tactics
(40 4)  /defiance/?resilience
(40 5)  /defiance/understanding, but defying implications
(40 6)  /defiance/because no one will do it for you (on their own)
(40 7) /defiance/reframing the reality
(40 8) /defiance/they're just having a good laugh
(40 9) /defiance/being hopeful
(40 10) /defiance/linked with professionals
(40 10 1) /defiance/linked with professionals/so there
(40 10 2) /defiance/linked with professionals/off the pedestal
(40 10 3) /defiance/linked with professionals/defying the obstructions
(40 10 4) /defiance/linked with professionals/defying them
(40 10 5) /defiance/linked with professionals/as a result of professionals
(40 10 6) /defiance/linked with professionals/expectations
(40 10 7) /defiance/linked with professionals/"a fight"
(40 16) /defiance/linked with "other people"
(40 16 1) /defiance/linked with "other people"/as a result of
treated differently
(40 16 1 1) /defiance/linked with "other people"/as a result of/being
of/rejection
(40 16 1 2) /defiance/linked with "other people"/as a result
of/judgements & conclusions

(50) /between joy and sorrow
(50 1) /between joy and sorrow/joys
(50 1 4) /between joy and sorrow/joys/child
(50 1 4 1) /between joy and sorrow/joys/child/qualities of
(50 1 5) /between joy and sorrow/joys/feeling good
(50 3) /between joy and sorrow/why are we laughing?
(50 9) /between joy and sorrow/paradoxes
(50 20) /between joy and sorrow/sorrows
(50 20 1) /between joy and sorrow/sorrows/"chronic sorrow"
(50 20 2) /between joy and sorrow/sorrows/grief
(50 20 4) /between joy and sorrow/sorrows/child
(50 20 4 1) /between joy and sorrow/sorrows/child/appearance
(50 20 4 2) /between joy and sorrow/sorrows/child/perceptions of
(50 20 4 7) /between joy and sorrow/sorrows/child/constant negativity
(50 20 4 9) /between joy and sorrow/sorrows/child/shattered
expectations
(50 20 5) /between joy and sorrow/sorrows/feeling bad
(50 20 7) /between joy and sorrow/sorrows/constant negativity

(60) /hope-despair
(60 1) /hope-despair/hope
(60 1 1) /hope-despair/hope/wishes
(60 1 2) /hope-despair/hope/shattered
(60 1 3) /hope-despair/hope/erosion
(60 1 4) /hope-despair/hope/ways to maintain

257
(60 1 50) /hope-despair/hope/collected
(60 2) /hope-despair/despair (hopelessness)
(60 2 1) /hope-despair/despair (hopelessness)/outcomes
(60 2 1 1) /hope-despair/despair (hopelessness)/outcomes/feeling stupid
(60 2 1 2) /hope-despair/despair (hopelessness)/outcomes/being a failure
(60 2 1 3) /hope-despair/despair (hopelessness)/outcomes/being resentful
(60 2 1 4) /hope-despair/despair (hopelessness)/outcomes/self-fulfilling prophecies
(60 2 1 50) /hope-despair/despair (hopelessness)/outcomes/collected

(70) /being
(80) /what's normal?

(99) /big bin

(100) /Penny's thoughts
(100 1) /Penny's thoughts/Amanda
(100 2) /Penny's thoughts/Catherine
(100 3) /Penny's thoughts/Jill
(100 4) /Penny's thoughts/John
(100 5) /Penny's thoughts/Sally
(100 6) /Penny's thoughts/Stephen

(200) /quoteables

(300) /explore with others
REFERENCES


220


Eisenberg, M. G. (1982). Disability as stigma. In M.G.Eisenberg, C.Griggs & R.J.Duval (Eds.), *Disabled people as second-class citizens* (pp. 3-12). New York: Springer.


Kearney, P. (1993a, November). Crossing boundaries: From theory to practice, to research and back... Paper presented at the CHER Conference, University of Western Sydney, Nepean.


Scholarly Inquiry for Nursing Practice: An International Journal, 
6(1), 41-42.

member with disabilities. In R. Renwick, I. Brown & M. Nagler 
(Eds), Quality of life in health promotion and rehabilitation (pp. 

ideology and services. New York: Human Sciences Press.

Mental retardation in the year 2000 (pp. 15-38). New York: 
Springer Verlag.


interviewing: Principles, techniques, analysis (2nd ed.) 
Melbourne: Longman.

Universal City Studios Inc.

Morse, J. (1994). Emerging from the data: The cognitive processes of analysis 
in qualitative inquiry. In J.M. Morse (Ed.), Critical issues in 

Sage.


Murphy, M. (1982). The family with a handicapped child: A review of the 
literature. Developmental and Behavioural Pediatrics, 3(2), 73-82.

NSW Department of Health (1996). Draft guidelines for prenatal diagnosis 


BETWEEN JOY AND SORROW:

BEING THE PARENT OF A CHILD WITH
A DEVELOPMENTAL DISABILITY

PENELOPE M. KEARNEY

A thesis submitted in fulfilment of the
requirements for the degree of
Master of Nursing (Honours)

1996

Faculty of Nursing
and Health Studies

University of Western Sydney,
Nepean
PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
CERTIFICATE

I certify that this thesis has not already been submitted for any degree and is not being submitted as part of a candidature for any other degree.

I also certify that this thesis has been written by me and that all sources have been acknowledged.

[Signature]

Penelope Kearney
ABSTRACT

This thesis explores the experiences of parents who have children with significant developmental disabilities. A dissatisfaction with the interpretive power of dominant paradigms regarding parents' responses to their children with disabilities resulted in a study in which an interpretive methodology, informed by phenomenology, was used.

The voices of six parents paint a picture which is at odds with prevalent assumptions of parental crisis and maladjustment. Whilst being conscious of their anguish and sorrow, these parents speak of hope, love, strength and joy.

An interpretation of the parents' experience is presented in light of the themes of "between joy and sorrow", "hope and no hope" and "defiance and despair". This phenomenological interpretation provides insight and understanding and has implications for nursing practice, education and research.
ACKNOWLEDGEMENTS

To Chris Atkins, my mentor - thank you for endlessly listening, questioning, debating, commenting, cajoling, supporting and finally, proof-reading. Without you, I would have given up.

To my daughters Claudia, Sophie and Madeleine - thank you for your encouragement and understanding in the midst of undertaking your own studies.

To my supervisor, Dr. Tim Griffin - thank you for your academic guidance, patience and humour, as well as for allowing my independence.

To Karen Williams, transcriber and typist - thank you for your technical expertise, as well as your helpful commentary.

To the late Dr. John Walters who endeavoured to simplify the complexity of phenomenology with me - thank you for boosting my confidence.

To Daniel Nichols - thank you for your perspectives on phenomenology.

To Andrew Fleming - thank you for your technical advice.

And to Amanda, Catherine, Jill, John, Sally and Stephen, the parents without whom this work would never have come into being - thank you for allowing me into your lives.
STYLE KEY

*Italics* - are used to indicate the words of the parents or words of others which became data.

*Bold* - used when key terms are introduced or for emphasis.

Pseudonyms are used throughout the work.
# TABLE OF CONTENTS

1. **PARENTS' EXPERIENCE OF DEVELOPMENTAL DISABILITY - INTRODUCTION and OVERVIEW**
   - INTRODUCTION
     - A Personal Context
   - OVERVIEW
   
2. **DEVELOPMENTAL DISABILITY - DENOTATION and CONNOTATION**
   - DEVELOPMENTAL DISABILITY - DENOTATION
     - Developmental Disability - Evolution of a Concept
     - Developmental Disability in New South Wales
       - Confusions with Terminology
       - Further Confusions
   - DEVELOPMENTAL DISABILITY - CONNOTATION
     - Mental Retardation - Public Definitions
     - Mental Retardation - Private Meanings
     - Mental Retardation - The Unthinkable
   
3. **RESPONSE TO DEVELOPMENTAL DISABILITY - SOME THEORETICAL PERSPECTIVES**
   - DOMINANT THEORETICAL PERSPECTIVES
     - Time-Bound Grief Models
     - Mourning and the Loss of the Perfect Child
     - Time-Bound Grief and Mourning in Relationship to the Loss of the Perfect Child
     - Chronic Sorrow

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>A Personal Context</td>
<td>2</td>
</tr>
<tr>
<td>OVERVIEW</td>
<td>3</td>
</tr>
<tr>
<td>DEVELOPMENTAL DISABILITY - DENOTATION</td>
<td>16</td>
</tr>
<tr>
<td>Developmental Disability - Evolution of a Concept</td>
<td>17</td>
</tr>
<tr>
<td>Developmental Disability in New South Wales</td>
<td>21</td>
</tr>
<tr>
<td>Confusions with Terminology</td>
<td>22</td>
</tr>
<tr>
<td>Further Confusions</td>
<td>24</td>
</tr>
<tr>
<td>DEVELOPMENTAL DISABILITY - CONNOTATION</td>
<td>27</td>
</tr>
<tr>
<td>Mental Retardation - Public Definitions</td>
<td>27</td>
</tr>
<tr>
<td>Mental Retardation - Private Meanings</td>
<td>30</td>
</tr>
<tr>
<td>Mental Retardation - The Unthinkable</td>
<td>36</td>
</tr>
<tr>
<td>DOMINANT THEORETICAL PERSPECTIVES</td>
<td>38</td>
</tr>
<tr>
<td>Time-Bound Grief Models</td>
<td>40</td>
</tr>
<tr>
<td>Mourning and the Loss of the Perfect Child</td>
<td>42</td>
</tr>
<tr>
<td>Time-Bound Grief and Mourning in Relationship to the Loss of the Perfect Child</td>
<td>43</td>
</tr>
<tr>
<td>Chronic Sorrow</td>
<td>45</td>
</tr>
</tbody>
</table>

iv
Comparison of the Concepts of Time-Bound Grief and Chronic Sorrow 50
Implications of Dominant Theoretical Perspectives 52
AN ALTERNATIVE THEORETICAL PERSPECTIVE 56
Positive Contributions 57
Cognitive Coping 58
Implications of Alternative Perspective 59
THE RESEARCH QUESTION 61

4. RESEARCH METHODOLOGY - PHILOSOPHY and APPROACH 63
   BACKGROUND 64
   PHENOMENOLOGY 67
      The Phenomenology of Edmund Husserl 69
      The Phenomenology of Martin Heidegger 71
      Comparison Between Husserlian Phenomenology and Heideggerian Phenomenology 73
   AN INTERPRETIVE APPROACH 74

5. RESEARCH METHOD - PROCEDURES 82
   TURNING TO THE PARTICIPANTS 83
      Selection of Participants 83
      Ethical Considerations 84
   GENERATING DATA 86
      Experiential Descriptions from the Parents 86
      Experiential Descriptions from Other Sources 88
   CONDUCTING ANALYSIS: TEXTUAL TRANSFORMATION 89
      NUDIST 89
6. RESEARCH PARTICIPANTS - THE PEOPLE
   THE NURSE
   THE PARENTS and THEIR CHILDREN
      Amanda and Annie
      Catherine and Charles
      Jill and John, Parents of Joel
      Sally and Stephen, Parents of Samuel

7. BETWEEN JOY and SORROW - AN OVERVIEW
   BETWEEN JOY AND SORROW

8. BETWEEN JOY and SORROW - SORROW
   SORROW
      Other People
      Sorrows
         Dying
         Finding Out
         A Death in the Family
         On Their Own
         Being Vulnerable
         Fears and Worries
         Grief
      No Hope and Despair
9. BETWEEN JOY and SORROW - JOY

   JOY
   The Child 149
   Joys 152
      Not Dying 154
      Little Things 154
      New Perspectives 156
      Becoming Stronger 162
   Hope and Defiance 164

10. BETWEEN JOY and SORROW - THE TENSIONS

   BETWEEN
   The Tensions 173
      Confusion, Doubts and Ambiguities 174
      Dissonance of Values and Beliefs 175
      Conflict of Values and Beliefs 179
      No Maps 181
      Guilt 183
      Grief 186
      Professionals 186
      Both Sides of the Rhythm 190

11. UNDERSTANDING DEVELOPMENTAL DISABILITY - DISCUSSION OF PARENTS' EXPERIENCE

   DISCUSSION
      The Research Question 197
      Sorrow 198
      Joy 201
      The Tensions 207
CONTRIBUTIONS AND LIMITATIONS OF
THE STUDY
Implications for Nursing Practice 210
Implications for Education 212
Possibilities for Further Research 215
SOME CLOSING REFLECTIONS 217

REFERENCES 220

APPENDICES
I Change in Name of Division of Mental Retardation 236
Services to Division of Developmental Disabilities
Health Commission of NSW Circular No: 81/8/
II Ethics Approval 238
III Letter to Potential Participants 239
IV Participant Information Sheet 1 240
V Consent Form 243
VI Participant Information Sheet 2 244
VII NUDIST Indexing 245
LIST OF TABLES

Table 1. Comparison of Time-Bound Grief and Chronic Sorrow 51
Table 2. Comparing and Contrasting Two Theories of Interpretation 73
Table 3. Concurrent Procedural Activities 80
Table 4. Summary of Particulars of Participants and Their Children at the Time of Initial Interview 118

LIST OF FIGURES

Figure 1. Indexing Category of “Feelings” 90
Figure 2. Between Joy and Sorrow: Being the Parent of a Child With a Developmental Disability 124
Figure 3. Between Joy and Sorrow: Sorrow 126
Figure 4. Between Joy and Sorrow: Joy 126
Figure 5. Between Joy and Sorrow: The Tensions 127